A PSYCHO-EDUCATIONAL MODEL FOR THE FACILITATION OF THE MENTAL HEALTH OF FAMILIES WHERE A CHILD IS DIAGNOSED WITH AUTISM

By

SUMARI BREETZKE

Thesis submitted in fulfilment of the requirements for the degree

PhD EDUCATIONIS

In

PSYCHOLOGY OF EDUCATION

In the

FACULTY OF EDUCATION

At the

UNIVERSITY OF JOHANNESBURG

Supervisor: Professor C.P.H Myburgh
Co-supervisor: Professor M. Poggenpoel

January 2015

ACKNOWLEDGEMENTS

I would like to thank the following people for contributing towards the completion of my study.

- Professor Chris Myburgh and Professor Marie Poggenpoel. It is very rare that two people can walk into your life and that you will forever be changed by their presence in your life. Thank you for all that you have done over the years and that you managed to keep me motivated to complete this journey. You will forever have a place in my heart.

- To all the families affected by autism that have allowed me to become part of their journey with autism. Your inner strength, love for your child and perseverance will stay with me.

- To my family, my husband, my parents and my brother and sister. You have all kept me going. Thank you for believing that I could finish this.

SUMMARY

The family is a building block in society. When the family's mental health is challenged the individual members are challenged in their contributions to society. Having a child diagnosed with autism spectrum disorder (ASD) place a unique set of challenges on the family where a child is diagnosed with ASD. Autism is a developmental disability that has a big medical component that means the children also struggle with medical issues like gut infection. When a child gets the diagnosis of ASD can be very overwhelming for a family as they have to deal with the initial shock and grieve of having a child that is medically sick and that has a range of developmental delays.

Very quickly after the diagnosis the family starts to seek educational and medical services for their child affected by ASD. A family can very easily become overwhelmed by all the information and mostly lack of information about how to best assist their child. ASD then becomes a life changing event with pervasive emotional and social effects restricting the daily living of the family as a whole. It has a 100% implication on their life. The event threatens the core family identity, requiring the family to make diverse mental, social and environmental adaptations (adjustments) in order to deal with the changing family situation. Family resilience emerges as a powerful way of coping or adaptation in a family that has to live with ASD, demonstrated by a parental perspective that "it is getting better over time".

The overall purpose of this study was to elicit the lived experiences of families with a child living with ASD. The researcher used a post-modern constructivist approach in her research design. The researcher further made use of a theory generative, qualitative, exploratory, descriptive and contextual design. Data was collected by making use of in-depth phenomenological interviews, observation, field notes, drawings and essays. The central question was asked "tell me about autism and your family and how you think it affects your everyday life". Siblings that were too young to take part in the phenomenological interviews were asked to "draw me a picture about your family".

Data was analysed by using Tesch's steps (in Creswell, 2014:154-155). Categories were developed and compared and themes emerged. A cross validation study was done as well as a literature study. Concepts were identified using criteria described by Dickoff, et al. (in Nicol 1997:552-554). From this information a model for the facilitation of mental health in a family where a child is diagnosed with ASD was developed. It is the believe of the researcher that if a family can be taught to use resilience in their family, they will be able to overcome the challenges they face due to the diagnosis of their child with ASD over the life time of the child and in doing so manage their own mental health.

TABLE OF CONTENT

CHAPTER 1

OVERVIEW AND RATIONALE

CHAPTER 2

RESEARCH DESIGN AND METHOD

CHAPTER 3

RESULTS AND DISCUSSION OF RESULTS

CHAPTER 4
CROSS VALIDATION REPORT AND LITERATURE CONTROL

CHAPTER 5

CONCEPTUALISATION CONCERNING THE CENTRAL CONCEPTS

CHAPTER 6

DESCRIPTION OF THE MODEL WHICH WILL BE THE BASIS OF THE PSYCHO-EDUCATIONAL PROGRAMME THAT WILL BE USED TO FACILITATE MENTAL HEALTH IN A FAMILY WHERE A CHILD HAS BEEN DIAGNOSED WITH ASD

CHAPTER 7

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

DIAGRAMS AND SKETCHES

FIGURES

TABLES

APPENDICES

CHAPTER 1
OVERVIEW AND RATIONALE

"to all the warriors who have come before me and to all the warriors who will come after. Just know that even though they have silenced some of our children, they will never silence us. Our voices will shake the ground of those who were responsible until all of our children are safe from harm"
(McCarthy, 2008:xiii).

1.1 RATIONALE

The family is a building block in society. When a family's mental health is challenged the individual members are challenged in their contributions to society. After the diagnosis of her son with autism spectrum disorder (ASD), McCarthy (2008:ix) stated that it was very hard receiving the diagnosis because all of a sudden people will treat you differently than they did before your child was diagnosed. She (McCarthy & Kartzinel, 2009:ix) further says that when a child gets diagnosed with cancer your neighbours will stop by your home to bring you pre-cooked meals, hugs and support, but when your child gets diagnosed with autism (ASD), families will slip down another aisle when they see you in the supermarket.

Goldstein, Naglieri, Rzepa and Williams (2012:1001) claim that autism is a biologically determined set of behaviours that occur with varying presentations and severity, which is likely caused by different causes that occur more often in boys than girls. Bradley and Caldwell (2013:8) say that there can be coexisting intellectual disabilities and other conditions that will add to the challenges of the child apart from the autism diagnosis. In a study done by Miller, Bilder, Farley, Coon, Pinborough-Zimmerman, Jenson, Rice, Fombonne, Pingree, Ritvo, Ritvo and McMahon (2013:201-2010) during the 1980's it was found that the rate of autism diagnosis was 4 in every 10 000 children, whilst during their study they show the rate of diagnosis increased to be 1 out of every 80 children. According to Lange and McDougle (2013:2-8), researchers are desperately trying to determine biological markers in the hope that this will lead to better diagnosis and more accurate treatment of autism. According to Sunita and Bilszta (2012:441), people's lack and limitations of understanding the neurobiology of autism affects the way that professionals diagnose, therefore early diagnosis is very difficult. In order for professionals to be able to diagnosis children affected by autism spectrum disorders there have been many studies over the past few years to improve our ability to screen for autism spectrum disorders and to enable us to work towards early diagnosis (Nah, Young, Brewer & Berlingeri, 2014:215-226).

It is commonly accepted that autism spectrum disorders are categorised as some of the most severe developmental delays in children (Martinez-Sanchis, Santacreu, Sancho & Domenech, 2014:17). Early research into the cause of autism left the field with many false leads into what causes autism and how society understands autism (Volkmar & Reichow, 2013:2-6). New research suggests that when a child is diagnosed with autism, one or both of the child's parents will also fall on the spectrum, and this will make it even harder for a parent to cope with the diagnosis of autism spectrum disorder in their child (Grove, Baillie, Allison, Baron-Cohen & Hoekstra, 2013:600).

Goldstein and Brooks (2011:1001) states that autism spectrum disorder is seen as a biologically determined cluster of behaviours that occur with variable appearance and severity, and which is possibly the result of many different causes. The disorder occurs more often in boys and is common across all social classes (Goldstein, Nagier, Rzepa & Williams, 2012:1001). These authors (2012:1001) further claim that it was always thought that a child diagnosed with autism spectrum disorder will have a lower than average IQ but that this has significantly changed in the last few years with most children affected by autism having a normal to above normal IQ. Over the last few years some professionals in the field have also realised that there is a need for improved training of health care providers on diagnosing and dealing with ASD (Sanita & Bilszta, 2012:438). Volkmar and Reichow (2013:2) define ASD as a group of disorders that include autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger's Disorder. The core deficits associated with ASD are impairment in social interaction and communication, as well as the presence of unusual behaviours and/or interests. The Diagnostic and Statistical Manual (DSM-V) is used to diagnose autism and related conditions such as Asperger's and Pervasive Developmental disorders (PDD) or pervasive developmental disorders not otherwise specified (PDD-NOS). After the changes to DSM-V, the criteria for diagnosing a child changed (Volkmar & Reichow, 2013:5). Even though there were a few diagnostic criteria in the new DSM-V there remains great concern over the changes to the diagnostic criteria of Asperger's, PPD and PDDN-NOS (Volkmar & Reichow, 2013:5). David, Dobrean, Mogoase and Dobrescu (2013:128) state that under the new DSM-V all of the autism spectrum disorders are now grouped under a single diagnostic label, called autism spectrum disorders (ASD).

ASD is classified as a spectrum disorder because of the different degrees of impairment in the core diagnostic areas. It occurs in all racial, socioeconomic, and ethnic groups and is four times more likely to occur in boys than girls (McCarthy & Kartzinel, 2009: 31). It is also considered to be a severe disability, secondary to the intense lifelong effects it has on the diagnosed individual and his or her family (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004:54).

Because of all the unanswered questions during the diagnosis of a child with ASD some families never get over their bitterness and hurt and never complete the grieving process in the way parents with disabled children normally grieve (Morvay, 2010:5). When families are faced with a child diagnosed with ASD the lack of information and hope can be overwhelming and can have a serious impact on their family (Renty & Roeyers, 2006:519). Mothers who have a child who is diagnosed with autism say that they suddenly find themselves having to fend for their child and their family with a diagnosis that poses questions to even trained professionals (McCarthy, 2008:10).

After receiving a diagnosis of autism spectrum disorder families may feel overwhelmed by diverse and contrasting information (Osborne, McHuhg, Saunders & Reed, 2008:1098). However, often families indicate a lack of information about their child's condition and long term outcome (Whitaker, 2002:415). Having worked with such families for many years, it is the researcher's assertion that the core family identity changes and centres around ASD. Many parents report that an outsider had to show them that they were losing focus on the rest of their lives (Montes & Halterman, 2007:255). Whitaker (2002:413) and many other professionals speak about how hard it is for a family to deal with the diagnosis of autism in their child (Adams, Edelson, Grandin, Rimland & Johnson, 2014:1). Families often speak about the fact that other people outside their family had to “pull them back to reality” after receiving their child’s diagnosis of autism (Szatmari, 2004:7).

Families have different expectations for their children. According to many parents one difficult aspect of having a child diagnosed with autism is that most often children affected by autism spectrum disorder initially starts to develop normally, and at first there isn’t anything wrong with the child. Over time, the child starts to show delays with regards to certain developmental milestones as well as certain medical problems (Johnson & Meyers, 2007:1182).

The process of facing a diagnosis of ASD spectrum disorder can be very daunting for parents and families, but medical professionals that work in the field of ASD can also at times feel overwhelmed by the lack of resources and assistance that families can lean on after the diagnosis (Siklos, 2006:921-933). Many professionals even feel as if the toolbox they have to diagnose may fail them as professionals, as they report that giving a diagnosis from the manual does not really relay what is going on with the child (Jensen, Knapp & Mrazet, 2006:ix).

With ASD being a diagnosis that presents differently, children affected and the primary cause and treatment being dissimilar, there is no single cause of action that can be taken when a child is diagnosed. This can create great levels of anxiety with parents and families, as initially no one knows the exact pathway to a treatment plan that will assist the child in reaching his/her potential, since the treatment plan for every child on the autism spectrum disorder will differ. This is due to ASD being a very individualised diagnosis with no two children having the same sets of difficulties (Bromley, Hare, Davidson & Emerson, 2004:409-423).

In many cases the diagnosis of ASD spectrum disorder will leave a family with more questions than answers and will affect the entire functioning of their family. Parents are frequently told by medical professionals that their child fits the diagnosis of ASD but more often than not, that’s all the information that is given to families (Stuart & McGrew, 2009:86-97). Parents regularly report that in the diagnosis of their child, the brief contact with a medical professional left them with more unanswered questions and emotions than they ever thought possible (McMahon, Baty & Botkin, 2006:53).

After receiving a diagnosis of autism spectrum disorder parents are so busy dealing with everyday life with autism that they forget that extended family members, such as grandparents, are also affected by the diagnosis (Woodcock & Page, 2010:109). During this time, the relationship of the parenting couple can also be strained as parents deal with feelings of grief, resentment and anger; and during this time many marriages don't survive the diagnosis of ASD in their child (Woodcock & Page, 2010:109; Blackman, 1999:190). After the diagnosis siblings are also under strain as they try to understand what is happening with their sibling and other significant people in their lives (Woodcock & Page, 2010:110). Some siblings feel that they have to grow up quicker after the diagnosis of ASD in their sibling and some may even feel like they "have lost their family" (Johnson & Rensselaer, 2010:71-92). Some siblings report that they wished their brother or sister with ASD was never a part of their lives and that they constantly felt embarrassed by their sibling with ASD (Johnson & Rensselaer, 2010:75). Specialists report that parents should spend a lot of time explaining the affected sibling's diagnosis to other children in the family in order for the siblings to deal with, and work through the diagnosis, and the changes in their home environment (Morvay, 2010:52).

Families report that after receiving their child's diagnosis of autism it was a very long and emotionally draining process. These families say that in this time they consulted many different health care professionals. Families speak about how long it took for them to simply get a formal diagnosis. For these families the first encounter with a health care professional marks the start of their journey with autism. Families report that the realisation that their child has been diagnosed with autism was an overwhelming thought, and they note that the vast differences amongst children diagnosed with autism further made it very difficult for them to know what to expect in terms of a long term prognosis and outcome for their child.

Difficulties that families face when their child has a diagnosis of autism include challenging and difficult behaviour, as well as problems with communication and social interaction. (Lord, Risi, Dilavore, Shulman, Thurm & Pickles, 2006:694-701). Professionals believe that autism is one of the most severe developmental disorders that a family can face (Martinez-Sanchis, Santacreu, Sancho & Domenech, 2014:17). Writing up different quotes from parents with newly diagnosed children with ASD may give a glimpse of what these families go through, but can never capture the raw emotion that goes with finding out that your child has a very severe developmental delay that will affect the rest of his or her life (Woodcock & Page, 2010:112).

The challenges presented to these family members include the relationship to the self, the relationship with others, and the relationship with their environment (Garbers, 1972:9). According to Patterson (2002:285) and Plant and Sanders (2007: 63), families who face ASD are challenged with feelings of isolation, worry, anger, resentment, depression, stress, marital strain, and financial stress, together with having to cope with the medical aspects of the disorder. Families become reclusive and antisocial due to the challenges they now face. As children affected with autism become older, the challenges transform into new problems as the child on the spectrum struggle to understand other people's intentions and behaviours. This creates an array of obstacles for the family (Paganini & Gaido, 2013:175). Because children with autism struggle with social situations, these children can very easily become severely socially isolated (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013:59).

Over the last few years there have been reports (O'Hara & Szakacs, 2008:42-44; Martin & Talor, 2012:91-101) of children who have an ASD that has benefited from biomedical approaches to their diagnosis. This is a very controversial field at this stage with many parents saying it has saved their children and also parents who state their children haven't benefited from the biomedical approach (Farrugia, 2013:8-12).

Children who are diagnosed with ASD have challenges that make it very hard for a family to function normally. These challenges include aspects like social interaction which is very hard for the child, thus making social interaction hard for the family as well (Woods, Mahdavi & Ryan, 2013:2-8). Because these children struggle socially, the families very easily become socially isolated along with the affected child (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013:59; Woods, Mahdavi & Ryan, 2013:4-8). Researchers have identified factors that make it hard for children with ASD to socialise (Paganini & Gaido, 2013:175).

When a child is diagnosed with ASD family roles and dynamics change. The big question that arises is how can parents help their child to the extent needed without the family suffering and having to change their core identity? Parents, grandparents and siblings get so caught up in constantly dealing with ASD that they do not realise that their family is changing. In order to cope with the emotional and physical demands of a child's diagnosis of ASD, families often don't rest until they have tried everything (Kirby, 2005:30). In the process, the family's mental health is challenged and the core family identity changes and centers around the child with ASD. Parents who have children affected by autism will at some point experience stress, anxiety and isolation, which is related to the inability of the parents to control their child. Added to this struggle, the affected child appears to be physically normal (Martinez-Pedraza & Carter, 2009:649).

When a child is diagnosed, the diagnosis and strain on the family causes a ripple effect that affects the entire family as a group, as well as the extended family and close social relations (Senator, 2005:36). In order to deal with the daily demands that ASD brings into a home, parents start to embark on this journey alone and not as a family unit. For parents the changing way in which their affected child is handled by others results in feelings of wanting to hide the child away from others (McCarthy, 2007:43).

Families who are faced with ASD are left with a lot of questions and uncertainties because of the lack of proven therapies and results. One mother spoke about her journey with her son's ASD saying that she had started on a journey of interventions so her son would be able to leave his autistic world an rejoin *her* world (McCarthy, 2007:xv).

These parents get caught up in a world where they deal actively with ASD on an ongoing basis. One mother spoke about autism being a 24/7 job where autism never goes to bed (McCarthy, 2007:xv). The uncertainty and challenges of autism in a family can be overwhelming and needs a lot of emotional and mental adjustments. Families need to start to function again as a family unit after a diagnosis without their core identity becoming ASD. This is a very difficult and strenuous process, since the initial adaption to face ASD on an individual basis is unconscious. Some families report that the hardest part of dealing with ASD is not that their child has gotten the diagnosis of ASD, but that they (the parents) could not move beyond their grief (Notbohm, 2005:97).

Even if a family realises that they need help, the magnitude of finding out where to go for help and how to go about it is too overwhelming to commence with the process. Taking into consideration that parents are seeking answers on an ongoing basis in an uncertain subject area where not even the experts are certain, can become very overwhelming. This can be a very difficult issue for families to deal with as some mothers have reported feeling maltreated by the professionals, feeling overwhelmed and surging with conflicting emotions (Maurice, 1998:55). A mother spoke about how frantic she felt after she had an encounter with a professional that left her with more questions than answers. One mother even spoke about her experiences with some professionals as being lost in a black cave called “autism” (Maurice, 1998:57).

Twoy, Connolly and Novak (2007:258) concluded that parents of children with ASD were likely to use support systems within the family’s social network as the main coping strategy. Families will mobilise their support systems directly after the diagnosis, while the affected family also struggles to cope and understand the disorder while looking for more information about the disorder (Fischer & Corcoran, 2007:413). Fischer and Corcoran (2007:413) mention that social support is a very important buffer against family crisis factors and it is a factor in family resilience that will allow a family to recover and acts as a mediator of family distress.

1.2 PROBLEM STATEMENT

During the 1940’s the term ‘refrigerator mother’ was first described for mothers who had children diagnosed with ASD (Hamilton, 2000:1-5). This term referred to the common belief that these mothers did not successfully bond with their children and thus their children showed signs of emotional and social maladaptation (Hamilton, 2000:1-15). It was not until the early 1960’s that people started to doubt the accuracy of the term ‘refrigerator mothers’. Thus, for many years the misconception meant many people grew up thinking that ASD was due to mothers not bonding with their children, and thus the blame for the problems of the child had to be placed with the parent (mother).

In the modern age, although the world has moved away from the term “refrigerator mothers”, families are still faced with more questions than answers about what causes ASD. Although professionals have learned more about ASD in the last ten years, it does not provide professionals with complete knowledge. Due to the unknown origin of ASD and because it is suspected that ASD can be brought about by different factors or combinations of factors, professionals do not have the answers parents are looking for. Professionals don’t know why many children develop ASD. When looking at treatments for ASD, professionals again are faced with admitting that they are unsure which treatment combination will assist which child.

Because many things about ASD is still not known, when a family faces a diagnosis of ASD they are bombarded with information about what treatment plan may be successful for some children. They have to navigate their way through many dead ends and at times they have to start all over again. These families not only have to confront the uncertainty surrounding ASD, but they also have to cope with the reality that even if there had been more certainty, there is still a grave shortage of supply of ASD support and service provision in both the public and private health sectors. They can rely very little on assistance from health professionals as there is not enough knowledge or services in South Africa where these families can go for all the information and services they need.

The families then start on their own journey of figuring out which of the many diets, doctors, therapies, and educational services will best assist their child. During this time the family is put under tremendous stress. Families are faced with therapies portrayed as “tested and successful” that don’t work for their child. Therapy of up to forty hours per week by strangers in their homes is often prescribed and requires many changes in their daily lives. At this point the family’s core identity starts to change. The individual family members become anxious and the family as a whole become very stressed. Most often extended family and friends are neglected. They see the family struggle, they feel helpless towards assisting the family during this challenging time, thus they too get affected by this stressful situation. Family finances also become strained during this time as the affected child's medication, education and therapy is very expensive. In some families one parent has to stop working to drive the child to appointments and manage daily life with ASD. The loss of an income in the family further aggravates the financial strain on the family.

During this very difficult time the family needs assistance from outside the family structure. This will allow the family to make peace with the diagnosis, provide some perspective and assist with the realisation that the family have to rebuild and maintain relations within the family and with the extended family structure. These families need time to accept that they did not cause ASD in their child and they need time to explain the diagnosis of their child to family and friends. They also need to get to a place where they are able to socialise in their community despite the child's diagnosis, since many families stop leisure activities for example going out to movies, dinner and being with friends after the diagnosis, as they feel that people will not understand their child's behaviour or issues. Many families find comfort in being with other families where a child has been diagnosed with ASD because they perceive them as more accepting and able to understand their situation. At times it is hard for a family to have to explain that their child cannot eat certain foods or cannot take part in certain activities. For these families it is very important that they receive assistance in finding other families with the same challenge. Many families will also realise that there is hope for their child and this hope for progress will keep them going (Kalyva, 2011:5-12).

For many families their combined lives are put on "hold" after the diagnosis of a child with autism, and this seizing of family life, according to many families, will remain for many years to come (DeGrace, 2004:543-550). This is due to the great extent of assistance and services ASD children need and the vast amount of money needed to access these services. According to DeGrace (2004:543-550), some families will even go so far as to say that their other children have to understand that their needs come after that of the child with ASD. Families also start to ensure that they are always in a position to control the behaviours of the affected child and by doing this the family makes great changes to their social network and daily schedule in order to avoid any social situation that may be too hard for the child with ASD (Robledo & Ham-Kucharski, 2005:99).

In addition to the normal challenges with marital relations, finances of the family, therapy and interventions, the family members also experience difficulties if their individual expectations of the impact of ASD and the prognosis differ from one another (Robledo & Ham-Kucharski, 2005:47).

For the ASD family the following questions all have to be dealt with (Robledo & Ham-Kucharski, 2005:40-101):

- Will our lives ever be the same?
- What should we do when we are feeling very disheartened about our child being diagnosed?
- How can we help our relatives come to terms with the diagnosis?
- I have accepted my child's diagnosis but my partner has not, what should I do?
- I sometimes feel angry at my child for being autistic, is this normal?
- Why did this happen to us?
- All the appointments with the doctors and therapists are wearing me down, how do we juggle everything?
- At times I feel that all the work we do is futile, how do we feel better about such slow progress?
- Where can we find other parents like us?
- Why is early intervention important?
- How do we manage behaviour problems?
- How do we make this up to our other children?
- How do we help our other children come to terms with this diagnosis?
- Will my affected child ever fall in love and have a normal life?
- How do we choose between all the therapies out there?

These are but a few of the questions that families battle with, but there are many more. DeGrace (2004:543-550) names the four themes that emerged in his study of the ways in which families are affected by an ASD diagnosis. He found that firstly, the whole family now revolves around autism and secondly the family feels as if they were robbed of being a normal family. Thirdly, the family gets caught in a state where their focus is to keep the affected child occupied and pacified to avoid outbreaks and meltdowns. Fourthly, he speaks about only fleeting moments of familial emotions and a lack of inner satisfaction.

According to the American Autism Spectrum Disorder Society, when a child is diagnosed with autism, every member of a family is affected (Hamilton, 2000: 278-284). They say that families are usually affected in the form of stress on marriages, other children, work, finances, personal relationships and responsibilities (Hamilton, 2000:278-284).

Then the real question arises: what can be done to assist such a family to cope with and manage the ASD diagnosis? Hamilton (2000:278-284) states that families need their extended family and friends to learn about their child's diagnosis, to listen to the family members when they speak and open up to them, to encourage and to pray for them, and they have to expect their relationships with the affected family to change. Hamilton (2000:278-284) also says that the practical aspects are important and that the family will need assistance with babysitting, housekeeping, and cooking of meals, so that the family can have time for leisure and relaxation, and especially so that the parents can have some alone time. He (Hamilton, 2000:278-284) also says that families will have a need for their friends and extended family to assist with the greater topic of autism in society, such as sending information about autism, to volunteer as friends for the affected child, to donate money for the cause, help with lesson preparations and bringing their neuro typical developing children over to play so the affected child can have social interaction.

When a child is diagnosed with ASD it is essential that the family also address the emotional and physical needs of the rest of the family because it is so easy to focus only on the needs of the child with ASD. As this is a very difficult process, it is recommended that families seek advice and guidance from an outside source that can assist them to deal with the diagnosis of ASD on an emotional and practical level. The research questions following out of this problem statement is:

- What are the lived experiences of families of a child living with ASD?
- What can be done to facilitate the mental health of families where a child is living with ASD?

1.3 RESEARCH PURPOSE AND OBJECTIVES

The overall purpose of this study is to elicit the lived experiences of families with a child living with ASD and based on the results to develop a model and guidelines to implement the model as a framework of reference to facilitate the mental health of these families.

The objectives of this study are:

- To explore and describe the lived experiences of families with children living with ASD.
- To develop a model as framework of reference to facilitate the mental health of these families.
- To describe guidelines to implement the model.

1.4 PARADIGMATIC PERSPECTIVES

Different researchers can have different paradigms and different considerations even thought their topic of exploration is the same. Taking into account that this research is a holistic approach towards individuals which involve their internal and external environment in an integrated way. The conceptualisations made by the researcher about the relationship between the researcher and the participants is important.

Neuman (2000:515) states that a paradigm is a general framework for social theory and empirical research, which includes basic assumptions, key questions that need answers, models of good research practices and theory, as well as methods for finding answers to questions. Neuman (2000:4) states that the researcher's paradigm is the window through which the world is viewed. According to Taylor, Kermode and Roberts (2007:5) a paradigm is "a broad view or perspective of something".

Additionally, Weaver and Olson (2006:460) define a paradigm as saying that "paradigms are patterns of beliefs and practices that regulate inquiry within a discipline by providing lenses, frames and processes through which investigation is accomplished". In the following section the metatheoretical assumptions, theoretic assumptions and methodological assumptions that are relevant to this study will be discussed (Burns, Grove & Gray, 2013:70-71).

1.4.1 Metatheoretical and theoretical assumptions

According to Creswell (in De Vos, Strydom, Fouche & Delport, 2011:21), social research is helpful to explain, predict and form a generalisation about how the world works. Breakwell (2004:414) says that theory is dependent upon opinion and beliefs that are present at the time that the theory is used. Breakwell (2004:414) further says that it is the role of theory to fit in with the research method that is used.

Creswell (in De Vos, Strydom, Fouche & Delport, 2011:21) states that all qualitative researchers approach their research with their own set of paradigms, world views, and a set of beliefs and assumptions that will lead their research. These have relation to:

- The nature of reality;
- the relationship of the researcher to the participants;
- the role of norms in the study;
- the process of the research or methodological aspects; and
- the role of the environment on the person.

Struwig, Struwig and Stead (2001:67) state that qualitative research theory can be used as research progresses, rather than letting theory lead the research in the early stage. Once a researcher has clarified on a paradigm, it has to be decided to what extend the current theories and literature will steer the research. In this study the researcher will make use of the educational developmental model of Garbers (1972:9) to show the theoretical aspects at the hand of three dimensions (See diagram 1.1).

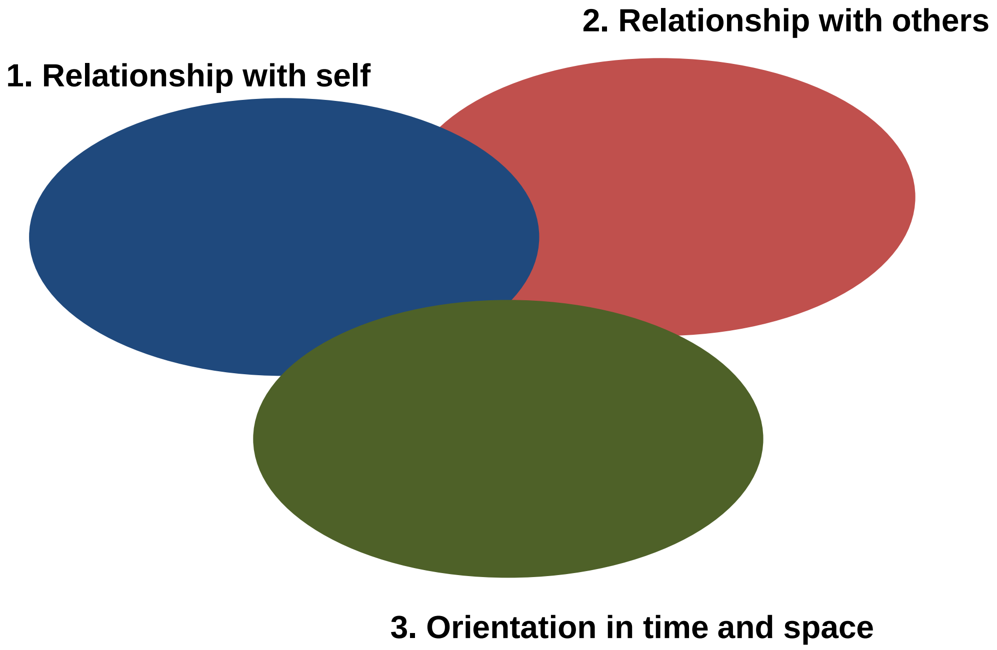


DIAGRAM 1.1: **Theoretical assumptions of the study**

1.4.1.1 Relationship with self

According to this model it is the role of the psycho-educational facilitator to support the individual in such a way that they can grow. The goal is that the person will be able to gain better knowledge of who they are as an individual and how unique they are. In this study families will be supported to find a way to maintain their mental health, despite their child's diagnosis of ASD. The researcher is of the conviction that a person's mental health can be improved by the assistance of the psycho-educational facilitator taking on this role (Garbers, 1972:9).

1.4.1.2 Relationship with others

A person is referred to as a whole being that is constantly influenced by other people. The role of the psycho-educational facilitator is to support the individual so that every person can find their unique place in relationship to other persons within the community (Garbers 1979:10).

1.4.1.3 Time and Space

Garbers (1979:10) say that nothing that an individual does, say or express can happen from nothing. Every situation has a history, a path of development and a future. Every person lives inside an orientation and a context that they find themselves in. The goal of a psycho-educational model is to facilitate every person towards their own uniqueness. Enabling each person to understand their own history better and their reason for being on earth, as well as getting some perspective about their future. This should bring contentment to their lives.

In this study the importance of the metatheoretical assumptions directly relate to the psycho-educational model with the goal to address certain aspects in order to promote mental health. In this research the chosen methods have to be functional, logical, fair and appropriate (Hadley & Mitchell, 1995:62). The researcher will give the definition of the important concepts in the table below:

TABLE 1.1: Relevant Concepts

Concept	Meaning
Model	A framework used as an example to follow or imitate (Oxford, 2014:1).
Psycho-educational model	This is aimed at the principle of a programme whereby the learning of skills is encouraged in order to promote mental health. In this study the psycho-educational model will be developed in order to facilitate mental health in a family where a child has been diagnosed with autism.
Facilitate	To make something easier or to assist with the progress of something (Colman, 2003:265).
Mental health	A person’s condition with regard to their psychological and emotional well-being (Oxford, 2014:1).
Family	A group consisting of two parents and their children living together as a unit (Oxford Dictionary, 2014:1).

Concept	Meaning
Child	A young human being below the age of puberty or below the legal age of majority (Oxford Dictionary, 2014:1).
Autism Spectrum Disorder	A pervasive developmental disorder characterized by gross and sustained impairment of social interaction and communication; restricted and stereotyped patterns of behaviour, interests, activities and abnormalities that manifests for the first time before the age of three, in social development, language acquisition or play (Colman, 2003:68).

1.4.3 Methodological assumptions

The researcher made use of the functional approach. She applied trustworthiness to ensure rigor of the research as well as the principles of postmodern research logic and justification.

1.5 RESEARCH DESIGN AND METHOD

1.5.1 Research design

A theory generative, qualitative, exploratory, descriptive and contextual research design was used.

1.5.2 Research method

The research method took place in the following four steps of theory development: Step 1: concept analysis, Step 2: relationship statements, Step 3: description of the model and Step 4: guidelines to implement the model.

1.5.2.1 Step 1 – Concept analysis

The researcher followed two phases in concept analysis, namely concept identification, and concept definition and classification.

a) Concept identification

Central concepts were identified by means of fieldwork. According to Chinn and Kramer (2011:120), it is the researcher’s responsibility to ensure that all the fieldwork that is done is carefully executed to ensure that the results are without substantial errors. A multiple-case-study-strategy sampling was done purposively. The selection criteria are data collection and analysis of data, case record study, cross-validation and literature control.

a.i) Data collection

Data will be collected by means of in-depth phenomenological interviews, observation, field notes, drawings and essays. The central question was posed to all adult participants. ‘Tell me about your family and ASD, and how you think that affects your day-to-day life’. The mother and father were interviewed. The siblings will draw a picture based on the question “can you draw me a picture about your family” before being interviewed based on the drawing.

a.ii) Analysis of data

By following the concept of field research all the data obtained from parents, siblings and grandparents were analysed. The researcher applied descriptive analysis by following the steps described by Tesch (in Creswell, 2014:154-155). As categories were developed and compared, themes emerged. This will be further discussed in Chapter Two.

a.iii) Case record study

The researcher made use of in-depth interviews. Participants were invited to answer the question: ‘tell me about your family and ASD, and how you think that affects your day-to-day life’. See table 1.2 below for the case record study.

TABLE 1.2: Case record study

Sample	Participant	Data collection Method
Purposive	Mother	In depth interviews, observation and field notes.
	Father	In depth interviews, observation and field notes.
	Sibling	Drawings: under age 6 years. Interview: sibling age 10 years and older.
	Grandparent	Interview or essay (one grandparent wrote an essay about her/his experience of her/her grandchild’s autism)

a.iv) Cross-validation report and literature control

The researcher made use of cross-validation report and a literature control. This will be discussed in greater depth in Chapter Two.

b) Defining and classification of central concepts

The central concept was identified from the results of the field study and defined. The procedure followed the three steps of Wandelt and Stewart (1975:65-67) and Copi (1987:180-196). These steps are scrutinising dictionary definitions and subject definitions for the essential criteria of the identified central concept, secondly reducing the essential criteria and thirdly, to reflect the essential criteria in a model case. The classification was done by making use of Dickoff et al.'s (in Nicol, 1997:551-562) survey list. The researcher made use of a survey list where the focus was on the agent, recipient, procedure, dynamics, context and outcome.

1.5.2.2 Step 2 – Construction of relationships between concepts

During this step of the research the concepts identified in step 1 of concept analysis were placed into relationships.

The criteria described by Dickoff, et al. (in Nicol 1997:552-554) were used for this purpose. In order to ensure that logical links with each other are formed, the researcher made use of Mouton's (2013:92-99) steps (Mouton & Marais, 1990:92-99).

When a researcher wants to link concepts it is important that the researcher understands the relationship between the logical structures. This is important as the goal of this study is model building and by using these steps the researcher can more clearly depict and express these concepts. Chinn and Kramer (2011:120) say that by employing the abovementioned, concepts can be combined to form a more meaningful whole. De Vos, Strydom, Fouche and Delport (2011:39) say that concepts should be combined so that they form a more complete whole as this allows the researcher to define the conceptual framework and will determine the function that it has.

1.5.2.3 Step 3 – Description of the model

The researcher described the model, which will be used to assist family members in facilitating the mental health of a child diagnosed with ASD. This was done according to the guidelines of Chinn and Kramer (2011:105), which is the description of the concepts, the purpose, relationships, the structure, definitions and assumptions as discussed in Mouton and Marais (1990:195-201). The evaluation of the model followed Chinn and Kramer's (2011:135-136) principles of theory evaluation. They are: how clear the theory is, how simple the theory is, how general the theory is, how accessible the theory is, and how important the theory is.

1.5.2.4 Step 4 – Guidelines to implement the model

During step 4, guidelines for implementing the model are described. Thereafter, recommendations for psycho-educational facilitators will be made.

1.6 ETHICAL MEASURES

Barlow and Durand (2005:545) call the mind a great tool through which human thought is processed and our questions answered. Psychology of education as a research field provides the researcher with a continued engagement in ethical issues relating to the research. Not all aspects in psychology of education relating to ethics have ready-made answers (Sternberg, 2001:53). Because of this the researcher has a continued responsibility to the ethical standards of the research. Ethical clearance (225/14/09/2009) has been obtained from the Faculty of Education Academic Ethics Committee and can be found in Appendix C of this study.

Barlow and Durand (2005:557) state that according to the American Psychological Association, the participant has certain rights that the researcher will adhere to, which are:

- Be informed about the purpose of the research study;
- participants have the right to privacy;
- have the right to be protected from physical and mental harm;
- have the right to participate or decide not to participate;
- the right to anonymity in the reporting of the results; and
- the right to safeguard their results.

These measures are of particular importance if taken into account that the parents, siblings and grandparents are already vulnerable and that the researcher kept this in mind at all times.

1.6.1 Informed consent

When looking at informed consent, the researcher provided the participants with enough information on how and why the study would be done to ensure that the participants have all the relevant information they need to give informed consent for themselves and their children to take part in the study (Bernard, Whitley & Kite, 2013:72). An example of the informed consent is provided in Appendix B.

1.6.2 The right to privacy

In this research project the researcher did not only guard privacy but she used anonymity. Anonymity according to Babbie and Benaquisto (2009:64) is achieved in a research project when on review “the researcher – not just the people who read about the research – cannot identify a given response with a given respondent”.

Because the researcher works closely with most of the families in the study and because the families all know each other, the researcher took great care in protecting the identity of all the families that took part in the research project. The researcher ensured that the families don’t know which other families took part in the research and the researcher ensured that she protects the identity of each participant by changing their names.

The researcher ensured that she was the only one who knew who the participants in the project were. Babbie (2005:65) states that confidentiality is guaranteed when only the researcher knows who she asked to participate and will not make this knowledge public.

The researcher was aware that she was working with vulnerable people and that she needed to take care when dealing with the participating families. The researcher obtained ethical clearance for the study (see Appendix A). She needed to ensure that she kept the privacy of all the participants confidential.

1.6.3 Misleading of participants

The researcher is confident that no participants were misled in this study. The researcher ensured that she fully explained the research to the participants.

1.6.4 Willing participation

The researcher approached many families by sending them letters (Appendix B) so that they did not feel obligated to participate in the research as most of the families knew the researcher well. All the families that chose to participate did so without any pressure from the researcher.

1.7 DIVISION OF CHAPTERS

Chapter One:	Overview and rationale
Chapter Two:	Research design and method
Chapter Three:	Results and discussion of results
Chapter Four:	Cross-validation and literature study
Chapter Five:	Conceptualization the central concepts
Chapter Six:	Description of the model which will be the basis of the psycho-educational programme that will be used to facilitate mental health in a family where a child has been diagnosed with ASD
Chapter Seven:	Conclusions, limitations and recommendations

1.8 SUMMARY

When a family is confronted with their child receiving a diagnosis of ASD, in addition to individual challenges the family as a whole and relative relationships are challenged. These families need some guidance in order to successfully deal with the diagnosis and manage their family life.

To accomplish the above, development of theory is required in order to describe a psycho-educational model that will assist families where a child is diagnosed with ASD to achieve mental health. This study aims to make use of a qualitative research design to explore the lived experiences of families where a child has been diagnosed with ASD in order to promoted mental health. Central to the study is the aim of describing a model for psycho-educational facilitators that will serve as reference for the formulation of guidelines in order for psycho-educational facilitators to assist families where a child is diagnosed with ASD to promote their mental health.

CHAPTER 2

RESEARCH DESIGN AND METHOD

"Research is best conceived as the purpose of arriving at dependable solutions to problems through the planned and systematic collection, analysis, and interpretation of data. It is a most important tool for advancing knowledge, for promoting progress, and for enabling man to relate more effectively to his environment, to accomplish his purpose, and resolve his conflicts"

(Mouly in Wilkinson, 2004:1)

2.1 INTRODUCTION

In Chapter One the researcher gave an overview and rationale of the research. In Chapter Two the focus will be on the research design and method applied to this study. The researcher will attempt to clarify how she made use of qualitative research to assist families to cope with the diagnosis of ASD in order to facilitate their mental health.

2.2 RESEARCH PURPOSE AND OBJECTIVES

The overall purpose of this study was to elicit the lived experiences of families with a child living with ASD. Based on the results a model was developed along with guidelines that can be used to implement the model to facilitate the mental health of these families. The objectives of this study were:

- To explore and describe the lived experiences of families with a child living with ASD.
- To develop a model as framework of reference to facilitate the mental health of these families.
- To describe guidelines to implement the model.

2.3 RESEARCH DESIGN

Wilkinson (2004:56) states that during the research design phase a researcher has to take the time to plan the research proposal. Smith (2007:17) states that it is during the research design phase that the parameters of the project are decided upon. The researcher utilised a post-modern constructivist approach in her research design. This means that the researcher is of the opinion that there is no neutral perspective to assess the legitimacy of methodical and ethical understanding (Smith, 2007:21). The researcher made use of a theory generative, qualitative, exploratory, descriptive and contextual design.

2.3.1 Theory generative design

In a qualitative study, theory generation serves two purposes, to outline the design of the study, as well as the data collection method. In order to generate a theory the researcher has to shape different ideas about a specific topic. Bernard, Whitley and Kite (2013:9) state that in qualitative research the researcher will work inductively. In this study theory generation was done in order to construct a psycho-educational model. The goal of this model was to describe guidelines that will assist families with children diagnosed with ASD.

According to Bernard, Whitley and Kite (2013:17), theory generation serves four purposes: to organise knowledge, to extend knowledge, as a tool guiding action, and to evaluate theories. Chinn and Kramer (2011:164) claim that theory generation is not a quick fix to a problem but rather provides knowledge that can shape understanding and practice. In this design the focus was on practice theory because of the model that was to be generated. This model is practice oriented to assist these families.

The researcher ensured that the application of the theory was done in such a way that the practice value could be assessed. The researcher did this by following the guidelines in Chinn and Kramer (2011:165). They are as follows:

- Are the theoretical goals and practice goals congruent with one another? In this study the goal was to develop a psycho-educational model to serve as a framework of reference to describe guidelines to be used when assisting families to deal with the challenges they face after the diagnoses of a child with ASD.
- Is the intended context of the theory congruent with the situation in which the theory will be applied?
- Is the explanation of the theory sufficient to be used as a basis for action?

2.3.2 Qualitative design

Miller and Dingwall (1997:19) say the quality of qualitative research can only be achieved when language is used to paint a picture of the world where society can see something of themselves and their shared humanity. Shaughnessy, Zechmeister and Zechmeister (2006:19) state that qualitative data can be seen as data about normal people going about their normal lives. Bernard, Whitley and Kite (2013:10) support this view when they say that qualitative data is concerned with the focus of how people understand their lives.

According to Struwig, Struwig and Stead (2001:226) the important aspects in qualitative research are the realisation that the information gathered will be used to build hypotheses and theories and then to gain transferability from it. Struwig, Struwig and Stead (2001:226) further state that it is the process of gathering data that is more important than the outcome, that the researcher is concerned with the meaning of how people interpret their lives. This means that the researcher used data from interviews, as well as observational notes collected from parents, siblings and grandparents, from families who have a child diagnosed with ASD.

The researcher's goal was to identify concepts that will be important to structure a psycho-educational model and to formulate guidelines for the model that will assist families to deal with the challenges they face after the diagnosis of a child with ASD. According to Babbie (2005:389), the biggest downfall for researchers working in qualitative research is influencing participants with the researcher's ideas and opinions. Babbie and Mouton (2001:204) state that the researcher must avoid imposing pre-existing knowledge on the participants. To ensure that this design is implemented successfully, the researcher made use of bracketing and intuiting processes.

According to Parahoo (2014:154) it is not possible to achieve total and absolute bracketing because it is not possible for people to either totally suspend their presuppositions or to account for all of them. Thus, bracketing refers to skill and sensitivity. Intuiting allows society more understanding of the event under inquiry (Streubert & Carpenter, 2011:32). This process allows society to make use of the process of bracketing (Babie & Benaquisto, 2009:31). In this study intuiting was used to aid in the understanding of what families described with relation to their experiences of having a child diagnosed with ASD within the family structure.

2.3.3 Exploratory design

According to Struwig, Struwig and Stead (2001:13) as well as De Vos, Strydom, Fouche and Delport (2011:124), exploratory research is research that is usually done in a unfamiliar field that has not previously been studied. Terre Blanche and Durrheim (2002:39-40) state that it is critical for research to describe the 'how' and the 'where' of the phenomenon being studied. Researchers such as Polit and Beck (2012:19) claim that the usefulness of an exploratory design is because it creates a fuller and better understanding of the phenomenon that is being studied and will allow the researcher to explore the deeper meaning of the phenomenon that is being studied.

The researcher needed to explore the lived experiences of the family members of children who had been diagnosed with ASD. At this point in the study the lived experiences were still unknown. An exploratory view was used in order to make a rigorous investigation possible during fieldwork, as well as to identify concepts for the model.

During the process the researcher remained open and proceeded cautiously towards any ideas that might come to light in order to create meaningful exploratory processes. The researcher worked from the standpoint of "not knowing" and made use of guidelines by Creswell (2014:14) when doing individual interviews and discussions. They included making use of open-ended questions and allowing participants to be the main contributors during her discussions with them. When the researcher spoke to the participants she kept in mind that the goal of the study was to generate theory that will serve as a frame of reference for constructing a model with guidelines for assisting families where a child is diagnosed with ASD. Throughout data collection and analysis, the researcher strived to maintain clarity. As previously mentioned, the researcher made use of a descriptive approach as part of generating theory.

In this unfolding process the researcher remained aware of new concepts and ideas as they emerged and in so doing facilitated the exploratory process.

2.3.4 Descriptive approach

The goal of descriptive research according to Struwig, Struwig and Stead (2001:89), is to explore and describe a specific phenomenon in a complete manner. Rosnow and Rosenthal (2005:62) mention that the goal of descriptive research is to give a precise description of the situation or set of events. Thus the aim of descriptive research is to describe, explain and interpret things that are currently going on. The goal of descriptive research is to explain a phenomenon that is unfolding during a specific time and place. Not just to answer the questions how, when and why, but rather the goal with descriptive approach is to answer the question “what”, “what is the features of the population that is being studied?” (Elliott & Timulak, 2005:147).

In this study, “descriptive” refers to describing the mental health of families where a child had been diagnosed with ASD. The descriptive approach was adopted for collecting data of families where a child has been diagnosed with ASD. A descriptive approach in data collection in qualitative research allows the researcher to collect accurate data. This will allow a clear picture to form about the data under investigation (Babbie & Mouton, 2001:43-44). In this study, the descriptive approach was appropriate because an accurate and reliable description was required of the mental health of families where a child had been diagnosed with ASD.

According to Streubert, Speziale and Carpenter (2003:22) a descriptive method in data collection in qualitative research is central to open, qualitative research interview investigations. This means that the researcher related family members' experiences of having a child diagnosed with ASD. It further allowed the entire phenomenon in the study to come to light.

Struwig, Struwig and Stead (2001:12) claim that qualitative research does not come about in a social vacuum, but that it occurs in a context of life that makes and describes the environment and social context of the participants. The reason for this is that when these aspects are not taken into account the descriptions of the experiences are not accurate. Descriptive research refers to research studies that have as their main objective the accurate interpretation of the characteristics of persons, situations or groups (Polit & Hungler, 1994:716).

The researcher described a model and guidelines to implement the model. Because every family and every individual that participated in this study had a different reality and different language, culture, history, purpose and values, this study had to be contextualised.

2.3.5 Contextual design

Heaton (2004:16) says that it is important for the research to be conducted in the environment where the phenomenon under investigation occurs to ensure that as much as possible of the context is captured. Heaton (2004:34) is further of the viewpoint that qualitative research that does not include the context in which the research was conducted cannot be seen as trustworthy. This research was conducted in the natural setting of the families, in their homes.

2.4 REASONING STRATEGIES

The researcher made use of reasoning strategies to ensure the logical reasoning that is needed in generating theory. Theory needs to be supported by logical reasoning as logical reasoning will allow logical arguments that will be able to explore and describe the mental health of families where a child has been diagnosed with ASD.

Many logical reasoning strategies were used during the theory generation process to develop a model to promote metal health in families where a child has been diagnosed with ASD (Creswell, 2014:161).

This was done in order to develop a psycho-educational model assisting families where a child had been diagnosed with ASD. The following are reasoning strategies that were used in theory building: analysis, synthesis, inductive reasoning and deductive reasoning (Thorne, 2003:55).

2.4.1 Analysis

According to Walker and Avant (2005:24) this strategy is used in theory generation to clarify and refine concepts or statements. The central concept was identified from the field study and analysed by getting essential criteria from dictionary and subject definitions.

2.4.2 Synthesis

By making use of synthesis in qualitative research individual parts can be brought together as a significant complete aspect (Walker & Avant, 2005:24). In using this aspect it enabled the researcher to understand the phenomenon as a whole because synthesis allows the researcher to bring together information from two or more sources (Terre Blanche, Durrheim & Painter, 2006:55). It was an important aspect in order to understand the information from the in-depth interviews as well as the pictures that the siblings of the children affected with ASD drew. This was a process of recreation and reconstruction. During this process the researcher combined information from many different sources such as the parents, siblings, grandparents and family friends, which allowed better insight into the phenomenon as information was added on throughout the research process as new information became available. The researcher used the process of synthesis (bringing together individual parts) to analyse (understand) the results of the in-depth interviews and pictures, thus allowing her to bring together all the information from the different families that participated in the study.

The researcher put concepts into relationships with each other by formulating a tentative model. The researcher further made use of inductive and deductive reasoning strategies as set out below.

2.4.3 Inductive reasoning

In using the inductive reasoning strategy the researcher made use of the approach repetitively as the approach enabled the researcher to identify aspects that have common features. The researcher used this approach during field interviews as well as during the literature study (Chinn & Kramer, 2011:65).

During fieldwork inductive research was used in individual interviews and for the purpose of identifying concepts that were developed into a psycho-educational model.

2.4.4 Deductive reasoning

When making use of the deductive reasoning strategy the researcher has to start off with a clear conceptual framework and then find instances to support the framework (Thorn, 2000:68-70). Thorn (2000:69-70) says that deductive reasoning strategies use observation of multiple and specific instances that have shared features. In this study the researcher made use of deductive reasoning when formulating guidelines that will be used to generate a model for managing the mental health in a family where a child has been diagnosed with ASD.

2.5 RESEARCH METHOD

The researcher made use of a theory generative approach as described in Chinn and Kramer (2011:80-108). The method was used to generate theory in order to develop a psycho-educational model for assisting families where a child had been diagnosed with ASD. This process followed from here in four steps, which are:

- Step One: Concept analysis (identification of concepts, defining concepts, and classification of these concepts)
- Step Two: Placing these concepts in relationships
- Step Three: Describing the model
- Step Four: Describing guidelines for psycho-educational professionals to implement the model.

2.5.1 Step One: Concept analysis

Concept analysis is an important aspect in theory generation. During this research process concepts that are vital to the model were used as a framework of reference to assist families to deal with the challenges they face after the diagnosis of a child with ASD. Chinn and Kramer (2011:80-108) define a concept as a multifaceted mental preparation of knowledge and say that ideas contain qualities or features that make them unique from other ideas. Concept analysis seeks to determine structure, function, attributes, and characteristics of a concept which serves to provide common understanding of the term so that future research endeavors find the concept clearly communicable and increasingly measurable. Concept analysis takes place in two phases. Phase 1: Case studies: central concept identification. Phase 2: Identified central concepts are analysed and defined.

2.5.1.1 Phase 1: Case studies: Identification of central concepts through fieldwork

Central concepts were identified by means of fieldwork. According to Chinn and Kramer (2011:120) it is the researcher’s responsibility to ensure that all the fieldwork that is done is carefully executed to ensure that the results are without substantial errors. The researcher identified the central concepts from results of case studies. A multiple-case-study-strategy sampling was done purposefully. The researcher will now discuss the population and sample, the data collection, data analysis, cross validation report and literature, as well as the identification of the central concepts.

a) Population and sample

When looking at the population and sample it refers to those persons who are approached to take part in the research. What is important to remember when it comes to sampling is representiveness (Bryman, 2012:86). In this study the researcher made use of a purposeful sampling method. Families where a child had been diagnosed with ASD were purposively included in this research. These families all live in Gauteng province in South Africa. Participants were asked if they wanted to participate by sending a letter asking families to come forward and take part in the research. Participants were only invited to take part in the research if they already had a child diagnosed with ASD. All the families who participated were families that attended a center for autism and related disorders where the researcher worked.

All the families that were invited to take part in the research either spoke Afrikaans or English at home. The reason for this is that the researcher can only effectively communicate in these two languages. The number of families that were included in the research was determined by data saturation (Singh, 2007:37), which was seen as the point where themes are being repeated and no new themes emerge. During interviews with families, as soon as there were no more new themes, interviews were halted as there was no point to pursuing further interviews (Scruggs & Mastropieri, 2006:107).

b) Data collection

Data collection deals with how relevant the data will be that is collected (Kumar, 2011:91). There are various strategies that the researcher can use to collect data in a qualitative study. Qualitative data analysis happens at the same time as data collection in qualitative studies. The researcher must collect data, organise the incoming data, and interpret the meaning of the incoming data as soon as possible after the data has been collected (Kuada, 2012:17). During phase one of this research the researcher collected data by means of phenomenological interviews as well as field notes.

Looking at phenomenological interviews the researcher made use of this in-depth interview process as it will give the richest data. Phenomenological interviews are interviews that are unstructured and can be described as a conversation with a purpose, whereby the researcher and the participant explore the research topic. One question was asked to the participants, namely: 'tell me about your family and ASD, and how you think that affects your day-to-day life'. Brothers and sisters who were too small to take part in the interviews were asked to draw a picture "Can you draw me a picture about your family".

The researcher must also look at the process of taking field notes since this enables the researcher to have a complete picture after the interviews. Field notes must consist of everything that the researcher hears and sees. The researcher must also include the activities that take place as the interviews happen, where the interviews happen, as well as all the assumptions that are made. This process will ensure that others can replicate the research, which in turn will ensure the trustworthiness of the research (Gagnon, 2010:111).

c) Data analysis

Data analysis has a primary goal to determine if a researcher's observations support his or her assumptions about behaviour and it serves to explore underlining meaning and patterns in relationships (Babbie, 2005:45). Data analysis started as soon as the interviews began. After this the individual interviews were transcribed from the recordings that were made. This was all done according to the steps described by Tecsh (in Creswell, 2014:154-155).

The researcher and independent coder made use of the following protocol of reducing data according to Creswell (2014:156-158).

- Get a feeling of the complete picture by reading through all the transcripts of interviews.
- Select one interview and read it a second time, ask what the question is that is discussed in the interview.

- Make a list of all the themes in the interviews. Group themes that go together. Sort the themes according to main themes, categories and lastly themes that don't go with the other themes. Constantly look for new themes that are emerging.
- Change the themes to descriptive categories. Condense the categories by grouping similar categories together.
- Do the data analysis.

d) Cross validation report and literature

Cross validation is often used in qualitative data analysis as several data sources are analysed to form a final consideration and explanation of a studies' results (Gagnon, 2010:113). During the cross validation all the data obtained from the interviews were compared to each other to ensure that all the themes and categories were identified. In this study the cross validation were done together with the literature control. According to Struwig, Struwig and Stead (2001:31) the literature control in a qualitative study needs to be done only after the data gathering and data analysis is completed. The reason for this is that if the literature control is done before data gathering and analysis is done, the literature may influence the research. In qualitative data the literature control serves the purpose as a guide with regards to themes and categories that are identified rather than guide the study (Willig, 2013:36).

e) Identification of the central concept

Concept selection should reflect the topic or area of greatest interest (Avant & Walker in Brush, Kirk, Gultekin & Baiardi, 2011:160-168). In order to obtain the concepts of this study the researcher made use of dictionary definitions as well as subject definitions.

The researcher reduced the abstractness of concepts. The researcher was enabled to allow the concepts to become clear as more attributes were added. During this phase of research the researcher clarified and refined the concepts on which the psycho-educational model's guidelines for operationalisation were based.

According to Chinn and Kramer (2011:58) all concepts, including the concepts for the operationalising of the model, is based on reality. The aim of this stage in the research is to ensure that the concepts are clear and easy to understand. In this study the concepts were defined in relation to promoting the mental health in a family where a child had been diagnosed with ASD. The aim will be to find a way to make the concepts operational so that they can be verified.

As mentioned, the researcher made use of dictionary definitions. This was done so that the core meaning of words could be explored and contextualised with the study at hand. Further, the researcher made use of subject definitions as these provided meaning that is specific to a certain discipline. During this process the researcher has the opportunity to ensure that the meaning that is attributed to a concept is the meaning that others will attribute to the same concept (Babbie, 2005:125).

This is a slow process and care must be taken that this is done in such a way that the meanings that is attached to the concepts will be meanings that can be put in the context of facilitating the mental health of a family where a child has been diagnosed with ASD. Terminology has to be very precise and the researcher must take every precaution that terminology is never vague.

2.5.1.2 Defining and classifying the central concept

According to Walker and Avant (in Brush, Kirk, Gultekin & Baiardi, 2011:160-168), concept analysis is used to distinguish between the defining attributes of a concept and its irrelevant structure to determine its internal structure by breaking it into simpler elements. These authors (Walker & Avant in Brush, Kirk, Gultekin & Baiardi, 2011:160-168) also claim that the concept analysis method consists of:

- Selecting a concept.
- Determine the aims or purpose of the concept.
- Identify the uses of the concept.
- Determine the defining attributes.
- Construct a model case.
- Construct borderline, related, contrary, invented, and legitimate cases.

- Identify antecedents and consequences.
- Define empirical referents.

a) Defining the central concept

In order to define the central concept the researcher made use of the following:

a.i) Determined the aims or purpose of the concept

In this section the researcher had the aim to clarify the meaning of all the concepts that were used in the model for facilitating the mental health of a family where a child had been diagnosed with ASD. As discussed in the section above, the researcher had to clarify the connotations of all the concepts used. This was best done by making use of operational definitions as this clarified any concepts within the context of the study. Additionally, the researcher had to distinguish between normal, ordinary and scientific use of terms (Avant & Walker in Brush, et al. 2011:160-168).

During the process of concept analysis the researcher remained aware of her own personal interests.

a.ii) Identified the uses of the concept

When looking at identifying all uses of the concept, dictionaries, thesauruses, colleagues and literature were consulted. The important aspect in this stage of the research process was that the researcher looked at all related fields of knowledge and not only the fields that she was working in, in order for a complete picture of the uses of the concept to emerge.

a.iii) Determine the defining attributes

When determining the defining attributes it is very important to examine the different instances of a concept as well as the different characteristics that come to light over and over again, as these characteristics will become the important defining attributes of the concept. When these defining attributes have been identified the researcher will be in a position where there will be more insight into the concepts that are used (Avant & Walker in Brush, et al. 2011:160-168).

a.iv) Construct a model case

In defining the concepts within the study the researcher made use of concepts that included all the possible critical attributes of the concept. When developing a model case the model case can either be developed together with the attributes or it can emerge after the attributes are tentatively determined (Dooley, 2002:335-354; Forrester, 2010:183).

b) Classifying the central concept

In order to do this the researcher made use of Dickoff, James and Wiedenbach's survey list (1968:435) and determined the following:

- Who is the agent? (who or what performs the activity?)
- Who is the receiver? (who or what is the recipient of the of the activity?)
- What is the framework (in which context is the activity being performed?)
- What is the procedure? (what the end part of the activity is?)
- What is the dynamics? (what the energy source for the activity is?)
- What is the terminus or the outcome? (what is the end point of the process?).

2.5.2 Step 2: Placing concepts in relationship

During this step of the research the concepts identified in step 1 of concept analysis were placed into relationships and interrelationships to facilitate a better understanding and to further elaborate on them. Concepts were also joined together to form a single concept (Chinn & Kramer, 2011:114). Chinn and Kramer (2011:114) say that concepts are placed into relationships so that no concept remains in isolation. By stringing together concepts, meaning emerged.

2.5.3 Step 3: Description and evaluation of the model

The researcher described a mental health model, which will be used to assist family members of a child diagnosed with ASD. This was done according to the guidelines of Chinn and Kramer (2011:105) which entailed describing the concepts, the purpose, relationships, the structure, definitions and assumptions.

This aspect involved a description of central concepts, classifications of statements and a description of the structure of the process as explained by Mouton and Marais (1990:195-201).

2.5.3.1 Identification of the purpose of the model

This was done by asking, “Why is it needed to generate a model?” The questions relating to this is, “Who will use this model?”, “Under what conditions will this model be used?” and “In what situations will the model be used?” (Yin, 2011:148).

2.5.3.2 Identification of concepts

This was done by asking: “Which concepts constitute the model?” “Which key ideas was used?”, and “How where they classified?”, to ensure that the concepts can be placed into a psycho-educational model (Berg, 2007: 222).

2.5.3.3 Definition of the concepts

The questions asked about the concepts were: “How are the concepts defined?”, “How clear are they?”, “Will they be comprehensible?”, and “Which of these concepts are theoretically relevant?” This was done in order to see if meaning had been shaped (Berg, 2007:332).

2.5.3.4 Establishing the nature of relationship statements

The nature of relationship statements was established by asking the question: “What was the nature of the relationship between and amongst concepts?” This is necessary in order to ensure that concepts were linked together. The nature of the relationships will reveal the theoretical purpose and assumptions on which the psycho-educational model will be based (Smith, 2007:55).

2.5.3.5 A description of the structure of the model

The structure of the model was dependent on the nature of the conceptual relationships and emerged by asking the following question: "Which of the relationships are the most central?" (Smith, 2007:60).

2.5.3.6 Assumptions of the model

It is important to ascertain the assumptions on which the model was based. The reason for this is that it reflects the values of the theory that was used. To evaluate the model the researcher made use of Chinn and Kramer's (2011:135-136) principles of theory evaluation. They are the considerations of the following questions: "How clear is the theory?", "How simple is the theory?", "How general is the theory?", "How accessible is the theory?" and "How important is the theory?"

2.5.4 Step 4: Description of guidelines

During step 4, guidelines to operationalise the model were described. The guidelines were inferred from this model so they can be applied in practical settings.

2.6 MEASURES OF TRUSTWORTHINESS

The model of Lincoln and Guba (in Krefting 1991:290-327) was used in this study to ensure trustworthiness. In order for research to be trustworthy the researcher needed to confirm that validity and reliability is maintained throughout. The researcher made use of measures of trustworthiness to indicate to others that the research was worthwhile. Lincoln and Guba (in Krefting, 1991:290-327) outline four aspects that ensure the trustworthiness in a study. These are credibility, transferability, dependability, and confirmability.

2.6.1 Truth value ensured by the strategy of credibility

Truth value is ensured by the discovery of human experience as the participants portray their lived lives. Krefting (1991:215) states that truth value is ensured by credibility. She (Krefting, 1991:215) further mentions that a study can only claim to be credible if the descriptions about human experience that is given are very concise, to such a degree that people can easily relate if they have shared that experience. According to De Vos, Strydom, Fouche and Delport, (2011:419-421) truth value can be ensured by prolonged engagement in the field, reflexivity, triangulation, member checking, peer review, structural coherence, as well as the authority of the researcher.

2.6.1.1 Prolonged engagement in the field

The researcher has been working in the field for ten years. These families are affected by ASD on a daily basis. The researcher is very closely linked to many families and spent many hours with them in private and public centers dedicated to ASD and its impact, as well as in the homes of ASD families. Taking this into account, the researcher had an inside view of what their daily living is about. The researcher is also well known in this community and parents and families have a good rapport with her. This enabled the parents to open up and trust the researcher and further allowed for good field notes. The siblings of ASD diagnosed children, as well as the extended family of the participating families, were also known to the researcher.

2.6.1.2 Reflexivity (Field journal)

Reflexivity refers to the researcher’s influence over the model (Krefting, 1991:218). According to Krefting (1991:218) the researcher’s background will dictate the framework whereby research findings are organised, studied and analysed. Heaton (2004:37) claims that when a researcher reads a field note, they have a wealth of information at their disposal. When the researcher composes the field notes it is important that she remember that the field notes must contain a chronological description of what happens in the field. At the time of being in the field, the researcher must be able to remember the aspects that will be important later in the study. De Vos, Strydom, Fouche and Delport (2011:340) state that the researcher must compile complete notes as soon as possible after returning from the field. To ensure that this important aspect was adhered to, the researcher's field notes were used so that she could reflect on her interactive patterns during the interviews.

The researcher used field notes to describe emotions, behaviour, observations and events, not only for the perspective of the researcher but also around the participants. The researcher also included questions, problems and frustrations that happened during the research process.

2.6.1.3 Triangulation

Triangulation ensures the trustworthiness of research (Struwig, Struwig & Stead, 2001:19). The researcher ensured the trustworthiness of this research by making use of multiple methods to collect data, such as in-depth interviews, observations, field notes and drawings.

2.6.1.4 Member checking

Member checking makes use of follow-up interviews with a few of the participants to ascertain their feelings and viewpoints (Tanggaard, 2009:19). The researcher made use of this if any of the themes were unclear.

2.6.1.5 Peer reviewing

This was done to ensure that the study remained focused. The researcher made use of doctoral seminars throughout her study in order to involve experts in the analysis of data (Harper & Cole, 2012:510). The researcher kept all transcripts from individual interviews.

2.6.1.6 Structural coherence

To maintain structural coherence in this study the focus was on the ability of the family to deal with the challenges they face after the diagnosis of a child with ASD. The focus of the study was to develop a psycho-educational model that will serve as a guideline that can be used to assist families in order for them to deal with the challenges they face after the diagnosis of ASD and by doing so promoting mental health.

2.6.1.7 Authority of the researcher

The researcher’s authority for conducting this study was based on her firsthand knowledge and involvement in the field of ASD in South Africa. The researcher had been actively working in the field of ASD in South Africa for the past ten years, both in special needs schools as well as in providing guidance for parents and by guiding parent support groups. The researcher is well known in South Africa with regards to ASD support centers. The researcher has been involved with both Autism South Africa as well as the Association for Autism and the Ernie Els Center for Autism. The researcher has further worked with some of the largest care providers in autism spectrum disorder in the world, such as the Center for Autism and Related Disorders, as well as Rethink Autism. Measures of trustworthiness were implemented by also applying the criterion of applicability.

2.6.2 Applicability is ensured by the strategy of transferability

Applicability refers to the degree to which the findings of this study can be applied to other contexts, groups and settings. The researcher is of the opinion that this study needed to focus on the input from participants, but it was also important to focus on the possible eventual generalisation of the study to assist as many families as possible in the field wherein she works (Sinkovics, Penz & Ghauri, 2008:689). The researcher made use of transferability by the careful selection of the sample of families.

She discussed the demographics of each participating family. Further effort was made to support applicability in this study by the use of descriptions of the results of the interviews, supported by direct quotations of the participants' interviews (Sinkovics, Penz & Ghauri, 2008:689-714). During this study the researcher made use of consistency that will further support applicability.

2.6.3 Consistency ensured by the strategy of dependability

The important aspect in this regard is the extent to which this study, when applied by others, using families who are dealing with challenges after the diagnosis of a child with ASD in a similar context, will find the same results (Krefting, 1991:26). To ensure dependability in this study, a dependability audit was done by looking at the following aspects. The researcher attempted to construct dense descriptions of the research methodology and she ensured that she made use of peer examinations as well as employed code-and-recode procedures. The researcher was also regularly in contact with, and had an independent panel of experts review the research process.

2.6.4 Neutrality ensured by the strategy of confirmability audit

During this process a chain of evidence was constructed to ensure that no bias crept into the study. The same aspects as discussed above were of importance in this regard.

2.7 CONCLUSION

All the research methods that were used in this study are outlined in this chapter. The steps taken to ensure trustworthiness are also discussed. In the next chapter, the researcher will cover the results from the in-depth interviews.

CHAPTER 3

RESULTS AND DISCUSSION OF RESULTS

“I feel life is a journey and we all have to learn to ride the storm, for some of us it can seem more like a tidal wave , but with every storm the sun eventually comes back out” - Bradley - (2014:1)

3.1 INTRODUCTION

In Chapter Two, the research design and method of this study were discussed. In Chapter Three, the focus will be on the results obtained from individual interviews with parents and siblings of children diagnosed with ASD. The overall objective of this study was to elicit the lived experiences of families with a child living with ASD, and based on the results to develop a model and guidelines to implement the model as framework of reference to facilitate the mental health of these families.

For the purpose of this study all the interviews were conducted in either Afrikaans or English and were audiotaped with the permission of the participants. Data was transcribed from the audiotaped interviews. The interviews that were conducted in Afrikaans were translated into English. All the interviews were conducted in the Gauteng province in either Pretoria or Johannesburg, South Africa.

Analysis of every transcript was conducted by making use of the data analysis steps. Follow-up interviews were conducted with one family to verify findings.

A data analysis protocol and all the transcribed interview scripts were sent to an independent doctoral graduate with knowledge and experience of qualitative research method (proof of this can be found in appendix D). Consensus was reached regarding how families can be supported where a child had been diagnosed with ASD.

3.2 DESCRIPTION OF THE REALISATION OF THE SAMPLE

Participants in this study consisted of families who had a child diagnosed with ASD. All the families that participated did so voluntarily. The children diagnosed with ASD in this study all received ABA (Applied Behaviour Analysis) therapy at the time the study was conducted (Veague, 2010:33). The researcher did not speak to the entire family simultaneously but the interviews were conducted one family member at a time as the researcher realised that the individual family members felt more at ease to be honest than when there were other members of the family present. In only two families where there was a child of less than six years of age did the parent sit in during the interview. The families that participated in this study all had children who had been diagnosed with ASD for a number of years.

Three main samples were identified for this study. These are:

- Parents of children that are diagnosed with ASD.
- Siblings of children diagnosed with ASD.
- Extended family.

3.2.1 Participants

Three families participated in this study. They consisted of:

TABLE 3.1: Participants in the study

	Family one	Family two	Family three
Mother	Yes referred to as Jane	Yes referred to as Grace	Yes referred to as Elna
Father	Yes referred to as John	Yes referred to as Fred	Yes referred to as Adam
"typical" developing children	Sister age 5 years referred to as Sally Sister age 18 months	Sister age 5 years Kate	Brother age 10 years Donavan

	Family one	Family two	Family three
Child affected by Autism	Boy age 3 years will be referred to as Ben	Boy age 4 years referred to as Elton	Sister age 5 years Helen
Unborn sibling	Mom 6 months pregnant with a boy	No	No
Grandparents	Conversed via e-mail (grandmother)	No	No

3.2.1.1 Parents

Six parents (3 families) around Gauteng province participated in the study. Informed consent was obtained from the parents (see Appendix A). Individual interviews were conducted with all the parents in their homes. During this chapter the researcher will colour mark all direct quotations from the families to easily identify the different families.

3.2.1.2 Siblings

Three siblings of the children diagnosed with ASD participated in the study. Two of the children, aged five, drew pictures after they were asked "can you draw me a picture to tell me about your family" and one sibling aged ten, was able to participate in an in-depth interview. The researcher did not have interviews with the children diagnosed with autism. The parents gave consent for the children to participate as they are all under age. The children also gave their assent. In the case of the two children of five, the mothers stayed in the room when the children drew the pictures. The one girl was able to tell me about her picture and I was also able to have a short interview with this girl when she invited me to come and join her when she played outside. The other five year old girl was able to tell me about her picture. The boy aged ten, participated in an in-depth interview with the researcher after he invited the researcher to come and watch a soccer game with him. The parents were not present during this interview.

3.2.1.3 Extended family

Grandparents were also included in the study, however the researcher could not get enough data from the grandparents as they were very concerned about what they conveyed. Because of this, only quotes from the parents regarding the impact on grandparents are included in this study.

3.3 RESULTS

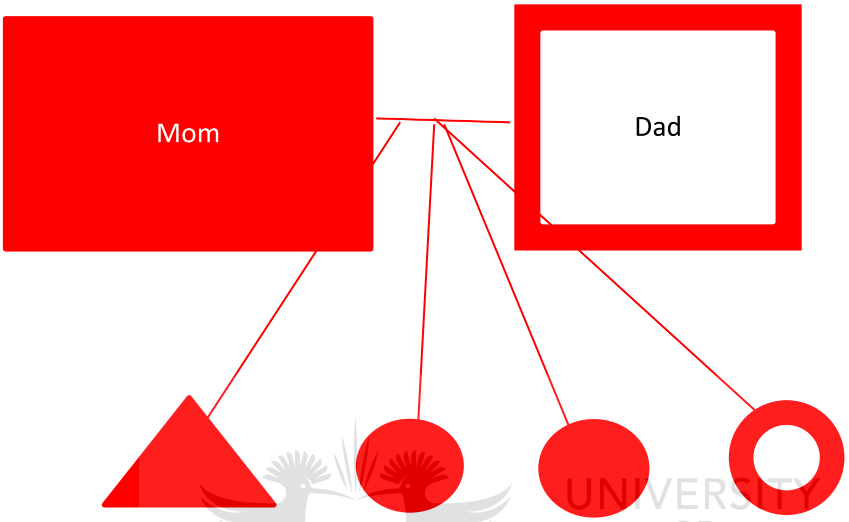
The findings from the parents and the “typical developing” siblings indicate a particular process that may be followed when assisting families where a child has been diagnosed with ASD. The results will now be discussed under their relating sections.

3.3.1 Discussion of results

All the families were very eager and excited to participate in the study. The researcher was able to speak to each member of the family individually, but it was very clear to the researcher that the mothers and fathers in each family prepared for the interview before speaking to the researcher, as the parents would all comment that; ‘I thought about what I wanted to tell you’, ‘this is what I thought to tell you’, ‘when we spoke about what we wanted to let you know’. The researcher was of the opinion that by doing this the information obtained from the families were very honest and in some families, because the family wanted the researcher to understand their situation fully, the families were able to convey raw emotion and not just facts, giving it depth. The results that are discussed below, was obtained from three families where a child had been diagnosed with ASD. Tables will be used for clarification purposes. Each family will be discussed and the cross validation report and literature control will follow in Chapter Four.

3.3.1.1 Discussion of in-depth interview: Family one

The researcher discusses the interview with family one in the following section. All direct quotations from this family are indicated by using the colour red. The names of the family members have been changed to protect their identity. See figure 3.1



Affected Child	◯	Age 3 Years - Boy
Child	●	Age 5 Years - Girl
Child	●	Age 18 months - Girl
Unborn child	▲	

FIGURE 3.1: Genogram family one

Three themes were identified in the data analysis for family one. They were:

- Experience of pervasive emotional and social effects ‘restricting’ the family as a whole.
- The experience of mental, social and environmental adaptations utilised by the family to deal with the changing family situation.
- Experience family resilience as a powerful way of coping and adapting.

3.3.1.2 Theme one: Experience of pervasive emotional and social effects 'restricting' the family as a whole

When the researcher asked the family about their family and ASD, both mom and dad started to tell the researcher about the diagnosis. For this family this was a very stressful time and when they spoke about it there was a lot of emotion around how they got to the diagnosis and how the diagnosis was conveyed to them. The family also told the researcher that it took a long time to get a diagnosis. Both mom and dad said that when Ben was diagnosed with ASD, even though they now had an answer and diagnosis, the family was left with a lot of questions.

"When we realised Ben is not your average child initially we were just worried to what degree he was affected and how it will affect our lives in the long run. Up to today we don't know for sure, there are no definite answers. The doctor said to take Ben and put him in an institution and forget about him as it would be too hard for us to deal with his needs all of the time. They gave us no hope. We did not know where to turn."

This family spoke about how they worry or fear for their affected son's future *"I worry about the future a lot. What will happen if we are no longer here or if we can't take care of him anymore? I know Jane does not want to talk about it. She doesn't think of the future. In that way she keeps positive. When we think of the future too long, we forget to live for now. There are no answers; we can't get to where we know what the answers are. My daughter asked me the other day, why her brother has autism… How can I answer her if we as the parents do not even know?"*

These parents spoke openly about the loss felt in everyday activities *"I guess you will have pros and cons but I would say the communication part, him not communicating with me in the car or where ever, I can chat to him and so, but that part puts you down a bit".* The mother of this affected child is currently expecting her fourth child. She spoke openly about the loss that she feels with her current pregnancy and about the fact that she would love to have another boy but she feels that if she knew she was expecting another boy she would be very worried and fearful as there is a bigger chance that he could be affected by ASD as well *"Then being pregnant I am fearful to* *find out the babies sex before birth. I would love to have another baby boy but I anticipate a high level of worry and stress that will spoil the pregnancy if we found out that it will be a boy. I anticipate that it will be stressful enough after the baby is born in the first 18 months. We will constantly be asking 'is he meeting his milestones? Is eye contact present? Is the pooh normal?'"*

Another aspect that the parents worried about was their son's education now that he had special needs. Both the mother and the father of this boy stated that they worry about how he would be able to receive the best education with his diagnosis. This boy's mother was raised in England and they wondered if he would be better off in South Africa or England. This placed extra stress on the family, if they would have to relocate. *"Jane started to do research about where he would receive the best (education) services, it was clear that in the UK the state would pay for everything and here (in South Africa) we would have to pay. (Jane) and her mom were both teachers for years and they were both worried that he would have to go with the teacher's assistant and would have to work in the hall all day as was standard practice in the UK. We did not want that. This made his school future look very bleak."*

The parents spoke about how they find it hard when they look at their neuro typical children's development and then compare it to Ben's development. *"What is sometimes difficult is the other kids, if you compare".*

When John spoke to the researcher he spoke about the yearning he has to have 'normal' interaction with his son who is affected by ASD. He told the researcher that he misses being able to just talk to Ben and have him understand and answer back. He spoke about the sadness for the loss of the ability to be able to have that normal interaction.

"When I go for a drive with my daughter, if we go to the shops or somewhere I can have a proper conversation with her, now the disadvantage of that is I can't really have a conversation with Ben, and that I find difficult." John said that the aspect that he feels takes away most of the moments he should have had with his son is communication, and that language is what he yearns for *"I guess you will have pros*

and cons but I would say the communication part, him not communicating with me in the car or where ever, I can chat to him and so, but that part puts you down a bit”.

John told the researcher that with the diagnosis, even though he loves and cherishes the boy that his son is today, he feels like he lost out in knowing how his boy would have been if he did not have ASD *“In ways it is fine, but I do wonder had he been a normal typical kid how he would have been, I suppose we have to take the good with the bad”.*

Both mom and dad spoke about how their son’s diagnosis has affected the rest of their family, especially their other children. How they, as the parents, feel guilty at times because they give Ben more attention, more of the financial resources *“I mean some times to a degree she feels she may not get so much attention and that may affect her behaviour. We try and share our attention span, but it is difficult to say we give her the same attention as Ben. Ben does get more attention, unfortunately that’s human; you give him more attention, the same with the baby, which makes me feel guilty. I think they, the children, are there to support each other as well as the baby. My elder daughter and the baby will keep each other company more than Ben, he will not interact with them.” “My daughter would have gone to a private school next year but she can’t, there isn’t finances for that, she has to go to a normal model C school and that makes me feel guilty, but I believe she will benefit in the long run if Ben becomes a more capable adult.” I worry that in a few years my older daughter asks why she could not go to a private school. What do we say? Will she understand why her brother is different? I sometimes wonder what she thinks. Why she thinks her brother can’t do things that the baby can do? Does she wonder, and if she does about what?”*

Jane expressed that her expectations for Ben’s sister have changed and that this makes her feel guilty, but she thinks that’s best as the children will grow up knowing that they need each other. *“I expect a lot more from her than I think I would have had Ben been normal. She knows better and I expect her to be sure that she is doing what I ask her. Like she knows that some foods he just can’t have, so I expect her not to let pieces of that food lay around the house where he can get to it.” “There are more and more days that I feel sad for her.”*

The family explained to the researcher how everyday activities have now become hard to do *"Life does not now just happen, we can't say, let's go out, we need to plan. If there was a party the poor guy would just stand there and would not be able to have anything to eat. I have avoided taking the three kids out together before because Ben has been such a handful and for safety reasons I have not been able to take him to the supermarket, or to browse around the shops at Centurion, or even the play area at Centurion because it's an open space, it's not enclosed and there is the waterfront. I have not even been able to do that with Ben as I am afraid that I will get momentarily distracted and he will wonder off into the water and I would dread to think what will happen. Life has been very distracted in what we have been able to do."*

Both the parents spoke about how hard social relationships have become for them as individuals as well as for them as a family. Another area of concern for the family was that they avoid certain social interactions. This was very important for them as a family that their entire family, especially Ben, was comfortable if they went to any social activity. Ben's mom also said that when she used to be a teacher in the UK she knows that the children who were diagnosed with ASD, often ended up sitting alone at school over lunch *"I did not want my boy to be the boy sitting alone at lunch. Nothing stays the way you plan it, as you think you understand some small piece of autism, my boy changes and we have to adjust all over again."*

A big aspect of the diagnosis according to the parents was centered on extended family and grandparents. As all the members of the particular family vastly differed in age, some members of the family did not realise the extent and prognosis of the diagnosis, which made it very hard for the parents to have Ben around his family. This was especially hard around family meals and celebrations. *"His dad's family did not see much of him because of a lack of understanding. They could not understand how much diet will affect him physically so they did not stick to the diet. So I stopped sending him to them."*

As the researcher spoke to the parents it became clear that they would do whatever it took to help their boy and that they regularly put their own needs aside to be there for their son. *"I will do whatever it takes until I feel in my heart that I have done* *enough for my family. My first priority is not myself or my new baby but it’s Ben as time is precious with him.”*

a) Experience on marital relationships

When the researcher spoke to this family they mentioned marital relationships and how they would experience their child’s diagnosis as having had an impact on their marriage. They further noted that they need different support compared to what they needed before the diagnosis of their child.

When the researcher spoke to Ben’s dad he said that he worries about his wife as she moved to South Africa and her support network and family is in the UK. *“I worry about Jane being so far away from her family. I sometimes think, does she need more support?” “Does she miss her family?” “Will she tell me if she does?” Looking after the kids is not easy, I worry about her.” “She does most of the difficult things with Ben in the week when I am at work. When I come home I can just spend quality time with them. I am grateful for that but I worry. She grew up where you raise your own kids. She never asks anyone to look after the kids, even for short times. I know she worries that when she goes to hospital, she does not want to leave Ben to be left without his language being pushed every day.”*

When the researcher spoke to Jane she noted that she thought being married helps her to be strong, but that the diagnosis does at times make things difficult. Jane also worried about what his future would be, and how they should provide for him if one day they are not there anymore.

“Telling you this has made me think, this is hard even on marriage, on every aspect, nothing is the way you plan it. I think being married to my husband helps me feel positive. If I was married to a man that was like, oh this is my first born son, my only son, and if he was, you know, what is going to become of him?, who is going to look after him, what if he can’t function , what if he never speaks? If he was that way if would affect me, but I don’t think. We are quite good for each other. If he feels that way, if he said it to you, he doesn’t say it to me; he never mentions those feeling s to me.”

b) Experience of financial worries

During the time that the researcher spoke to Jane she noted that there are many financial implications that they did not initially think of. She said that initially they thought about all the direct financial implications that they would face, like special schooling and therapies. She said that after a while they realised that there are financial implications even on everyday practical aspects, like home renovations. Jane also noted that there are financial implications like where they can afford to send their other children to school and that she might have to go back to work as they need a second income. Jane also noted that even his food is very expensive since he is on a very specific diet.

"It sounds silly but when we bought this house we had planned to knock out these walls to make the bedrooms bigger, the garage doors needs to be done and on a very practical level, there are things that needs to be done around the house; but we spend the money on his medication and education. I think parents with autistic children that are having their child treated; the financial impact is huge. Even things you have planned for now will have to wait a few years until Ben doesn't cost so much money." "Also the amount of money and time I spend preparing his food when you specifically go GFCF (Gluten free and Casein free diet) affects the family because it's a heck of a lot of money you are spending to supply that food for him."

During the session the family told the researcher that in order to afford Ben's therapy they need financial support from their extended family. As Ben's mom spoke to the researcher she mentioned that it's very hard for her to have to rely on their family for financial support and that it causes stress as some members of the family does not understand the huge amounts of money that they put towards Ben's treatment. She also mentioned that she rarely sees her own brother as he works in another country but that he sends money for Ben every month.

"The finances are not just as simple as it's hard to afford the medical and educational aspects. My family helps us in a month to afford his treatments. My mother's brother helps us and my family in the UK helps us. Only because of that can we give our son a chance".

When the researcher spoke to Ben's dad he also mentioned that managing the finances is very hard and it can affect other aspects in their lives as well. He told the researcher that he comes from a very traditional family and they don't always understand why they go to the lengths they do in order to help Ben.

"With my family it's difficult; they don't always understand why we would pay all that money every month, that's very hard."

3.3.1.3 Theme two: The experience of mental, social and environmental adaptations utilised by the family to deal with the changing family situation

In theme two the following aspects were identified:

During the interview the family spoke to the researcher and shared their viewpoint that they need to get all the information that is available since they are the only chance their son has. They had to know all there is to know in order for them to do the best for him. When the researcher spoke to the parents, this family made it clear they believe they need to keep doing research to ensure they have all the information so they can plan for his education, medical and dietary needs. This family believes they have to educate themselves so they can make the best choice for their son. John, Jane's husband said that *"Jane started to do research on where he would receive the best service. Jane decided to find out where he would be able to receive what he needed."*

Jane told the researcher that she did not have a job out of the home at that time and that she felt it was her job to do research on what would be best for Ben. She said she started to do research shortly after Ben was diagnosed and she also spoke to many different parents on how and where she could find the best and most up to date information. *"When Ben was diagnosed, my mom Ben's grandma took it hard. She kept saying that she wished that she could take that responsibility on her. She did not want me to suffer or to worry. My mom helped me do a lot of research. If I need stuff imported, I ask her. She helps where she can."*

The family made it clear they need answers. They said they know it might not mean a cure for Ben, but to make sense of the experience. During the researcher's time with the families she noted that most often the mothers of the affected children had a need to find information, so they could try to make sense of their experiences as well as what their child and family was going through.

During this time the researcher noted that the mothers of the affected children would often use different ways to change or have a positive outlook on what they were going through. Mostly the mothers would plan their affected child's therapy, schooling, socialisation, diet, as well as the activities of the rest of the family. The mothers reported that they do this so that they have complete control over every aspect of their affected child's life. The researcher further noted that the mothers would make use of positive self-talk and they would be aware of their outlook on life and would try to have a positive outlook on life when it came to their affected child.

During the time that the researcher spent with this specific family she noticed that the family made use of extensive positive self-talk. She also has a very positive outlook on their current situation as well as Ben's future. Ben's mom noted: *"But we are still hopeful and positive". "On hard days we have to remember to keep going".*

The researcher also noted that Jane, Ben's mom, did extensive planning for everyday activities, both activities that Ben had to do as well as activities where Ben would be included, such as family outings. Jane ensured that their home was a place where Ben could be comfortable. *"Even things like sofas we bought, we had to get the ones that I could wash if diarrhea got on it".* Jane also made sure she knew what and when one of Ben's siblings would have a snack or meal that Ben could not have, so that she could ensure that he wouldn't by accident get hold of that snack or meal. Jane went to a lot of trouble to ensure that she included Ben in family activities. She spoke about planning when the family has to go out. She says they try and determine beforehand what Ben will be able to handle and then work out a plan according to that *"we just have to see to what degree he can handle the situation and for the rest of the family."*

When the researcher spoke to both mom and dad they mentioned that there were many social adaptations they had to make after Ben was diagnosed. Both mom and dad spoke to the researcher about the time constrains they faced after the diagnosis. They said that time constrains were of critical importance to them. However, for mom and dad the implication of the time constrains differed. For mom the time constrains had her *"getting up very early and going to bed very early". "I was getting up at 5 am in the morning, and he Ben was very restricted with diet wise at that time, so I would prepare his food in the morning. He use to get up at 5:20 and we would have to leave our house by 6:10 and only get to Johannesburg by 7:30. That was awful, even if I look back now."*

This meant that both parents found it very hard to have time in their day where they could see each other and their other children. *"We really found it hard to spend time with his father, as he would already be asleep when his dad got home at night and we would leave our house in the morning before my husband got up".*

When Jane spoke to me she also mentioned that she spends a lot of time preparing Ben's special meals. *"The time I spend preparing his food when you specifically go GFCF (Gluten free and casein free diet) affects the family."*

With this she also said she often can't find the ingredients for Ben's meals at the normal supermarket and it even takes a lot of time to get the ingredients. Jane told the researcher that she has to be so careful when cooking for Ben; she has to be certain that she doesn't use a chopping board that has ingredients he can't have, as even a very small amount can affect Ben negatively. She also said that a huge problem is that not all the ingredients are listed or if they are, they don't say that it's made in a factory that uses gluten *"so you can't be sure that there is no gluten etc. in there".*

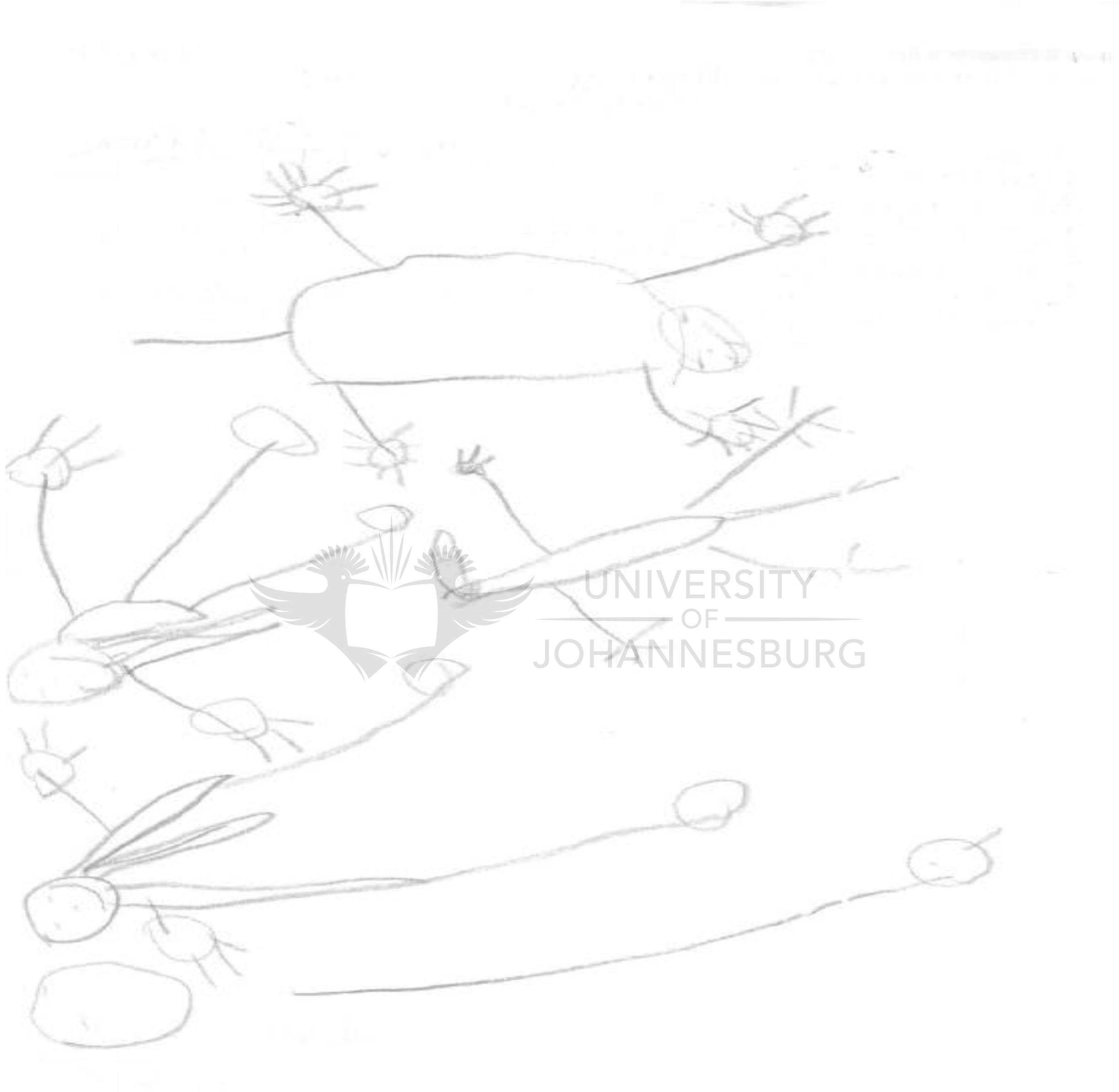
When the family spoke to the researcher they mentioned that they needed to make decisions about their finances but felt the priority of that decision needed to be centered on the needs of Ben. They explained that they decided that Jane is responsible for the children and the cooking and the finances are up to dad. Jane mentioned how that means they don't get to spend that much time with dad since he needs to work quite a lot. *"My husband has to bring in a certain amount of money to enable him Ben to have what he is having, educationally and medically. While my husband has to bring in the money I choose not to think of it too long, that's for him, he must think about it. But I don't think about it too long as it frightens me. Once the baby is born I might have to go back to work as I don't know if he can then bring in what we need. My husband has to work a lot and the kids don't always get to see him that much. So I try and give them quality time with their dad when he is at home".*

When they spoke, John said to the researcher that he has to work very long hours and does not see his family much during the week. He said he has had his own practice for a very short time and never knew that he would have to work the hours he does. He also said that it scares him to think how many patients he needs to keep his practice that busy and he can't think about what they would do if he saw a smaller number of patients. *"You have to work long hours. I want Jane here with him; then he has a chance to learn. I work. I work a lot. But that is helping my family, I will keep going. It's for Ben my family."*

The parents made it clear that both of them have a need to protect Ben from family and friends since they feel that not all their family and friends understand the unique challenges Ben faces. They told the researcher they felt that people just don't want to understand and that causes problems for Ben. When the researcher spoke to John he made it clear that he felt his family does not understand the impact of diet and medical interventions on Ben and at times it's hard for the family to understand Ben's behavioural challenges. *"My parents don't always understand."*

When the researcher spoke to Jane she said they do everything in their power for Ben and John's family doesn't understand the importance of things like Ben's diet. She said that it was very hard for her but she decided that if they did not understand Ben or make an effort to understand Ben's condition, she will not keep sending Ben to visit them. *"His John's family doesn't always get to see him that much as they don't understand, they don't understand how much diet will affect him physically so they don't stick to the diet."*

An important note on sketch 3.1 is that the sketch is very faint because it is how it was drawn by the sibling. The colours are also original as drawn by the sibling. The sizing of the sketch has also not been changed in any way. The sibling was provided with many colours that she could choose from. She chose her own colours and completed the drawing without assistance or direction from any person.



SKETCH 3.1: Drawing of “my family” done by sister of sibling with ASD

a) Drawing by sibling

The researcher spoke to all the members of the family. The oldest sibling in this family is a girl aged 5; from here the researcher will refer to her as Sally. Sally knew the researcher for two years and was comfortable to speak to her since she was in their home often during therapy sessions for her brother. She was willing to make a drawing of her family. The researcher had her mom sit in on the interview. She was able to tell the researcher about her picture and answer a few questions around her picture. The picture was independently analysed by Dr Braam Hoffman. The following information was obtained from the picture.

b) Practical aspects of the picture

The following identification of the pictures was made by Sally.

- The page orientation of the picture is landscape and a A4 page was used.
- Sally identified the following figures from the pictures: Mom is the figure on the far right, Dad is the second figure from the far right at the top. Sister (18 Months) second figure from the right at the bottom. Ben far left bottom figure. Unborn baby far left top figure and Sally second figure from the left.
- The picture was drawn in one colour, dark blue.

c) Assessment of the picture

Drawing of stick figures is normal for the age of the child. By the placement of the figures on the page, placement in the center of the page is seen to be normal. However, in the picture Sally placed herself, dad and the unborn baby above her mom, younger sister of 18 months, and Ben. This can indicate Sally's high aspiration in her family, it can show hostility, or that she wants to strive above the figures that are currently the focus figures in their home. The placement of Sally to the baby can show that she wants to be the "focus baby" in the home again. The drawing of the younger sister of 18 months has a head that is shaped differently from the rest of the family. The heads of the other figures is drawn face forward but sister, 18 months, is drawn facing towards mom and away from the self-figure. The profile view of her head suggests that there is a reluctance to communicate with her or oppositional tendencies and that Sally strives to minimise her sister of 18 months' role in the family. The drawing of the small dot eyes suggests introversive tendencies. In the picture she did not draw ears, but this is normal. Additionally, the small dot noses suggest withdrawn tendencies and are common in children. The wide upturned line affecting a smile is also normal in children. The absence of necks suggests poor adjusting in children as well as the omission or poorly defined trunks, or it could indicate feelings of inferiority. The arms in the picture are drawn as mechanical horizontal extensions at right angles to the body, which suggests affectless contact with the environment. With that, the outstretched arms and hands suggest environmental or interpersonal contact.

The drawing of the hands on the dad, with less than 5 fingers on a hand, suggests feelings of inadequacy and the mom figure has more than 5 fingers per hand and suggest ambitious and/or aggressive disposition.

After Sally drew the picture she was able to tell the researcher about it. What she told the researcher coincides with the data analysis from the picture. She told the researcher that *"Ben cannot do pottery at his school but I can at my school".* With this she illustrates that it is important to her to show that she has superior skill and abilities in comparison with Ben. It is important for her to show that she is different to her brother in terms of attending a different school. This might indicate her need to be recognised as a person in her own right, possibly because Ben gets more attention from others than she does. She also tells the researcher that *"there are lots of kids at my school, they are my friends but Ben does not have friends at his school that comes and play, only his teachers come".* Again it's important to Sally to indicate that she is socially more popular than Ben in having "lot" of friends. This may indicate her strive to be more socially acceptable than Ben and she wants to be known as the "good" child who is loved by many friends. One can merely speculate that she feels unloved by her parents.

Sally says that *"his friends at school also need to practice playing with the cooker before they can come play; my friends know how to play with the cooker so they can come".* In this sentence it is important for Sally to indicate that her friends have superior skills to Ben's friends or that she and her friends are "better" than Ben. This may indicate her striving to be recognised and acknowledged as a worthy person in her own right, possibly because Ben attracts more attention from others. Again, one can speculate that she feels unrecognised by her parents and others.

She (Sally) states that *"Ben doesn't play with my friends, he doesn't like to cook on the cooker or put his cars in the carport, he does hoover".* With this, Sally shows that she is a different person than Ben, with different friends and different likes and dislikes. It suggests that Sally is striving for individuation. She then told the researcher *"sometimes if we play he Ben gets mad, then he flaps and I say stop and he watches TV, he takes his pants off and in the holidays he vomited. If there is a lot of noise he flaps".* Looking at this statement Sally associates Ben's ASD with very negative and aversive behaviour, namely: "getting mad", "flaps", "takes off pants" and "vomits". This may be the base for her to separate her skills and friends from Ben's life, as if she is embarrassed by his life. Sally is also aware of the triggers and pacifiers for Ben's negative behaviour, indicating her ability to control their interaction to a certain extent.

"When we go to visit my auntie and my cousins Ben can't eat what we eat, if he eats what we eat he gets diarrhea then his tummy gets upset". Sally is well-aware of the allowed or non-allowed food for Ben, more so than the family members outside the nuclear family. Her use of "we" versus "he" further supports the notion of her desire to be seen as "normal" and to be regarded as a separate person in her own right. She says that *"last time when we went to my auntie's house we played cricket we were batting and throwing the ball, Ben did not want to play with us".* When she says this she suggests that Ben chooses not to play with everyone else. She places the "blame" completely on Ben for isolating himself from the others. This may be a way in which she "defends" herself against possible accusations of not wanting to play with her brother so she is the "good child" and he is the "bad" child in this situation. *"He put the soil on the leaves, all day he did not play cricket or with the Frisbee".* She indicates that Ben preferred to play alone rather than to play with the group. There also seems to be a suggestion that Ben's soil game is "weird or abnormal" when compared to their "normal" games of cricket or frisbee. This may be another approach by Sally to justify her need to be seen as "normal". Sally noted that *"I played on two places that Ben played"*. In this we can see that Sally does not completely isolate herself from her brother as it seems that sometimes they do play together. *"He Ben poured the Coke into the sand on the side of it; we only went on the slide".* However, despite her efforts to play with Ben, it seems as if she experiences that he (Ben) tends to "sabotage" their play activities.

When Sally spoke to the researcher about when they went to a restaurant, she mentioned that *“Mommy gave me a ticket and I made my own pizza, Ben did not use his ticket then I used his ticket, because that’s why, he didn’t know what to do”.* With this Sally again indicates that she has superior skill or that she is better than Ben. In this specific case she goes further than merely comparing them by actually actively using his inability to “use his ticket” for her own benefit for example “winning the competition with her brother”. This supports her striving to be recognised and acknowledged as a worthy person in her own right, possibly because Ben attracts more attention from others than her. She then said to the researcher *“…and sometimes I read the book for Ben”.* At times she exhibits prosocial behaviour towards Ben to meet one of the needs that he cannot address himself. *“…and then sometimes when we colour he just scribbles”.* Sally again indicates that she has “superior skill” above Ben and that she is better than Ben. A positive aspect in this case is that they engage in the same activity, a form of parallel play.

When the researcher spoke to Sally, she noted that there are times that her brother *“Ben does things that “is not nice”*. She said that *“He pulls his pants down and flap, and he pulled his pants down and poefed in the garden like a doggy”.* With this Sally again associates Ben’s ASD with very negative and aversive behaviours namely he “flaps” and “pulls pants down to poef”.

Sally told the researcher that *“I play with Dora the Explorer and Barbie and Ben doesn’t know how to. If I play with him then we do…. thinks for 2 minutes, we play hide and seek”.* The long time delay in her response indicates her difficulty to recall joint play activity with Ben. It confirms that they hardly engage in any positive or playful interactions. Even “hide and seek” is a game characterised by opposites and separateness, not by joint interaction. *“Then sometimes we play cricket with daddy and mommy”.* The children seem to play together only when such activities have been initiated by the parents, or at least supervised by their parents. *“Ben plays with but he just throws the ball he doesn’t see the ball when he bats like this she demonstrates how to bat daddy helps him to bat”.* It is important to note that dad is the person in the family that actually assists Ben in activities. These are the same activities that Sally seems to regularly use to isolate Ben from her and her friends due to his “lack of adequate skill”. Sally then says *“let me draw you a picture, this is* *your picture is your picture that I will give to you".* Sally seems to even use the "picture activity" to indicate to the researcher that she is a "good child" with skills, and to win the researchers' appreciation and acknowledgement.

Sally then tells the researcher that *"It's, the picture, about my family, but not the new baby yet, he is not here yet".* Her use of "my family" indicates that she has a positive "sense of belonging". She even acknowledges that her family will expand in the near future. The researcher then asked Sally if her brother is different than she is. *"Yes, he does not talk and I have to say hands down to him when he flaps if he watches TV".* With this Sally is aware of the triggers and pacifiers for Ben's negative behaviour, and it indicates her ability to control the interaction between herself and Ben to a certain extent. *"Look at my picture, do you like it?"* Sally uses this picture activity to indicate to the researcher that she is a "good child" with skills, and to win the researchers acknowledgement and seek approval. The researcher asked Sally to tell her about the picture she drew. Sally replied *"Yes, that's mommy".* What is important to know is that Sally pointed out her mom first, which indicates the dominant role that mom plays in the family. *"…she is big but not as big as daddy, there is daddy and mommy and the small one is sister of 18 months, she is a baby. The bigger one is Ben and that there is me. I love Ben, he gives me hugs like this, she gives herself a big hug".* This is the first positive comment by Sally about Ben. It seems that Ben's positive characteristics are not based in who he is or what he can do, but in terms of what Sally gets from him. *"Mommy can I go play?"* Sally's sudden urge to "escape" from the interview may be triggered by the "threat" of her positive statement about Ben on her general sense of superiority.

The researcher asked Sally if she wanted to talk to her some more? Sally then said that she would but outside at the swing. We then went outside and Sally went and played on the swing (her mom was present). Sally then said to the researcher without the researcher asking her anything *"I like playing with Ben. I teach him things like how to talk, I say, Ben say 'blue' and he says it".* With this Sally seems to revert back to her sense of superior skill and control of Ben by indicating that she likes to "play" with him in terms of teaching him to say specific words. This hardly seems like "play" characterised by mutual fun and pleasure, rather like a teacher-child relationship where one holds all the skill and power, while the other one is being taught and controlled. Sally then tells the researcher that her mommy is *"the fat one on the picture as she has the baby in her tummy".* The fact that she mentions her mom's pregnancy first indicates that it is an important aspect for Sally in her current family context. Possibly the pregnancy receives a lot of attention and focus in her family life. The researcher then asked Sally where her daddy was in her picture. She said that *"daddy is the big one, cause he looks after us" (second drawing from the top left).* With this comment it can be said that Sally views dad's main role in the family to be the "protector" and "carer" of the family. Sally then told the researcher that in the picture she is the closest to dad as she is "the biggest". She seems to identify more with her dad than with her mom.

The researcher then asked Sally why Ben is down away from the others on the picture she drew and she answered that *"cause that's where I put him".* In her answer there is a dismissive undertone that supports her earlier suggestions of her sense of superiority and "looking down" on Ben. The researcher asked why Ben does not have arms or a body and if she intended to draw him like that. Sally answered that *"I forgot",* which indicates that the content and design of the sketches are predominantly the result of subconscious processes rather than conscious decisions.

3.3.1.4 Theme three: Experience of family resilience as a powerful way of coping and adapting

When the researcher spoke to the family it was clear that the family loved Ben and he was an important part of their family. Both parents said that they would not want Ben's essence to change as he was their loveable happy boy. *"I have gentle soul for a son." They just "want him to be happy in the world that he was put in."* When the researcher spoke to the family, both mom and dad made it very clear that they are very proud of what Ben has accomplished and that they want others to see his accomplishments too *"if we are out somewhere and my son does something I will tell people that he has autism, I am proud of what he can do." "You don't know but we are quite happy with him and we have accepted what he is and we are proud of him."*

As the researcher spent many hours with the family she knew that they would celebrate every small milestone that Ben reached and every time Ben accomplished a target or was able to use words, or mastered a new task. For this family they would let all grandparents and family members know whenever Ben reached a milestone. They would let the family know whenever they worked on a big skill so they would have support, and then they would celebrate when the milestone was reached. *“We celebrate the small things; we have learned that that’s what’s important.” “… and if you think the fact that my son will run up the steps and down the slide at the age 3 years and 3 months is massive as he wasn’t doing that at 2 years 6 months.” “I don’t think we have fared too badly as I think some other families have, I feel at peace.”* Both parents had a very positive outlook and did not only dread the future; they were working hard on the present and was willing to take the future as it came*. “It (autism) also has had a positive effect on our lives, and I don’t want to change the essence of my boy as he is a lovely boy… I feel fortunate…”.*

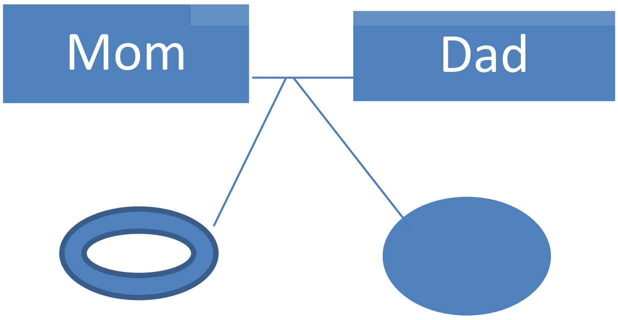
When the researcher spoke to this family both mom and dad was very positive about where the family was at that time. They told her that they enjoyed having Ben in an ASD specific programme as it also helped them to be in a community where they felt there were parents with similar experiences. The parents said that they could speak to other parents about things that *“you just wouldn’t understand if you had never been in such a situation. I find it helpful to speak to people who have been there, who know what they are talking about. Professionals and family members want to help but they have not been there, they are only saying what they think but they have not been there”.*

During the time that the researcher spent with the family, they mentioned more than once that they believe they should find out as much as possible so that they could take control of their situation. For this family resourcefulness is an important aspect as they feel they will have more input and control over the education of their child. Both parents report that they have grown closer to God and have their trust in him. The researcher realised that the parents in this family was very committed to the wellbeing of their family *“It’s also has a positive effect on our lives, and I don’t want to change the essence of my boy as he is a lovely boy.”*

The family acknowledged how far they have come and that they feel everything is getting better with time. *"We are more flexible in doing things than we were 6 months ago."* They do their best as a family to support one another. *"I think being married to my husband helps me to feel positive as I think he is also very positive."* As a family they are trying to grow from the diagnosis and they don't see the diagnosis as bad as they feel it could have been. *"For us it has also been an opportunity to grow and to see Ben grow every day. You don't know but we are quite happy with him and we have accepted what he is and we are proud of him. We are grateful as Ben could have been much worse off. I don't think that we have fared too badly as I think some other families has. I am so proud of him. What I am saying is that it's not that bad, I am not finding it so bad."*

3.3.2 Discussion of in-depth interview family two

The researcher will give a discussion of the interview with family two in the following section. All direct quotations from this family will be indicted by using the colour blue. The names of the family members have been changed to protect their identity. See figure 3.2 below.



Affected child ◎ Age 4 Years – Boy
Girl Child ● Age 5 Years – Girl

FIGURE 3.2: Genogram family two

The second family consisted of a father, mother and two children. The oldest child is a girl aged 5 years, a typically developing child, the second child is a boy age 4 years, child affected by ASD. To ensure that the family member's identity remained private, the researcher named them as follows: Mom will be called Grace, dad will be called Fred, boy affected by ASD will be called Elton, and his sister will be called Kate.

From the data analysis three themes were highlighted by this family. They are as follows:

- Experience pervasive emotional and social effects 'restricting' the family as a whole.
- Experience of mental, social and environmental adaptations utilised by the family to deal with the changing family situation.
- Experience family resilience as a powerful way of coping and adapting.

3.3.2.1 Theme one: Experience of pervasive emotional and social effects "restricting" the daily living of the family as a whole

When the researcher visited the family it was clear that for them the diagnosis was still fresh in their minds and on an emotional level it had a great impact on them. A few years ago when this family received the diagnosis of ASD, they were busy moving from another province to Gauteng. Shortly after the family moved to Gauteng, the dad needed to go away on business for quite some time. The dad, Fred, reported that during this time it seemed to him that he had left his family when they needed him most. This family did the interview with the researcher in Afrikaans and it was then translated into English.

As the researcher arrived, both parents started to talk about the day they received the diagnosis and how they felt during this time. They said they had just heard that they had to move to Gauteng. They had seen a doctor where they lived and he said that they needed to see a neurologist in Gauteng. They arrived at the neurologist and mom said that up to that point they had not even heard of ASD spectrum disorder, ever. The doctor told them that their son had ASD and that there was nothing they could do for him. *"Die dag toe Elton gediagnoseer is, ons het niks van outisme geweet nie, en die manier waarop die dokter vir ons gesê het, het vir my* *soos ‘n doodsfonnis geklink. Die klein seuntjie wat in my kop was wat rugby sou speel en saam met sy pa sou visvang; als is op daai oomblik daai dag dood. Ek kan onthou, in die kar oppad huis-toe het ek my man gevra of dit soos Down Sindroom was, of ons vir altyd ‘n kind in die huis sou hê”.* (“We did not know anything about autism, when Elton was diagnosed, the way in which the doctor told us and gave us the diagnosis; it sounded to me like a death sentence. The little boy that I had in my head, that was going to play rugby, and go fish with his dad; all of that died for me that day. I remember in the car on our way back from the doctor I asked Fred if it’s like down syndrome, are we going to have a child in the house forever?”).

The researcher asked the parents if she could speak to each parent separately. They agreed and the researcher then spoke to mom, Grace. Grace told me that she felt overwhelmed after speaking to the doctor who gave them the diagnosis. She said that he did not tell them what ASD meant, just that their son will never speak or be able to learn. She said that getting the diagnosis did not answer any questions that she or her husband had and it left them feeling very bewildered. *“Die dokter het ons absoliet geen hoop gegee nie, en dan die hele… ek weet nie, ons het deur ‘n baie moeilike tyd gegaan, ons gaan steeds deur ‘n baie moeilike tyd. Ek dink nie dit gaan ooit weg nie”.* (“The doctor gave us absolutely no hope, and then the whole….; I don’t know, we went through a very difficult time, we are still going through a very difficult time. I don’t think it ever goes away”). As the researcher spoke to both parents it was clear that this family was going through a very hard time with regards to dealing with the diagnosis. Both parents spoke openly and said that initially the worst was the uncertainty of what was going to happen and what should happen next. *“Dit was ‘n baie groot skok en die onsekerheid oor wat gaan gebeur en wat moes gebeur. Ons het glad nie enige iets van dit geweet nie en die onsekerheid was oorweldigend”.* (“It was a very big shock and the uncertainty of what now needed to happen or was going to happen. We absolutely did not know anything about it and the uncertainty around it was horrific”). When the researcher arrived at their home dad said that the time around the diagnosis was the most difficult for him and that he wishes he could have taken that time and the memories of it away from his wife and children.

The family spoke about how they struggle to make sense of what has happened to their family, that they feel like they keep going through a very hard time emotionally, and that they find it very hard to move past the initial diagnosis. Dad mentioned that *"Dit het 'n honderd present impak op ons lewe gehad, op ons lewens en ons familie s'n. Aanvanklik is dit skok en rou oor drome wat nooit sal wees nie, en dan gaan dit oor die drome en verwagting wat jy gehad het en jy wonder of dit ooit sal kan wees".* ("It had a one hundred percent impact on our lives, on your live and your families live, initially its shock and grief of dreams that will not be realised, and then it's about these dreams and expectations that you had and then you wonder if they will now ever be realised").

When the researcher spoke to Grace she made it clear that the diagnosis affected her entire family. She did say that because she is the mother she can't *"Ek kan nie uitmekaar val nie", "ek het ander goed wat my pla as wat my man het".* ("I can't fall apart", "I have different issues than my husband") in relation to the diagnosis. Grace then explained that she had to worry about the everyday things that have to happen in her household, *"Ek moet aangaan, verstaan, ek kan nie opgee en op 'n hopie gaan sit en jammer voel vir myself nie, ek het 'n gesin, ek moet aangaan en omsien na almal".* ("I have to go on, understand, I cannot give up and sit and be sorry for myself, I have a family, I have to go on and take care of everyone"). In this family mom stopped working after they received the diagnosis and dad has to work very long hours so he can financially support his family. Grace mentioned that they have a lot of extra expenses that they need to cover as there is medical, educational and food bills that differ greatly because of their son's diagnosis.

In this family both mom and dad spoke openly to the researcher about the worries and fears they had for their son's future. Both parents said the future is an overwhelming aspect. They told the researcher they felt overwhelmed when the thought about what Elton's future could be. *"Jy probeer altyd dink, hoe gaan ek in die toekoms na hom kyk? Wat as ons nie langer daar is om goed vir hom te doen nie? Jy raak bang en selfs 'n eenvoudige besluit soos maak jou bang want jy weet nie hoe jou besluit hom in die toekoms gaan affekteer nie. Ek probeer om nie oor die toekoms te dink nie want ek glo as jy aan die toekoms dink gaan jy sukkel om positief te bly en ek moet positief bly".* ("You try and think all the time, how will I look after him in the future? What if we are no longer there to do it for him? You get scared to make even a simple decision as you don't know how your decision now will affect him in the future. I try not to think about the future as I believe if you think about the future you will struggle to stay positive and I have to stay positive").

Grace told the researcher that she feels very guilty that she has to be the one who stays home while her husband has to work, but they have decided that she must be at home so she can be there for Elton. *"Fred hou aan om vir my te sê dat dit meer belangrik is vir my om op die stadium by die huis te wees. Ek wou werk omdat die diagnose baie finansiële druk op ons plaas. Dit plaas baie finansiële druk op ons soos, waar gaan die geld vandaan kom?"* ("Fred keeps telling me that it is more important for me to be at home at this point. I wanted to work as the diagnosis has placed a lot of financial burdens on us. "It put a lot of financial stress on us, like where will the money come from?")

Both parents noted that they wished they knew that a big part of ASD is the medical aspects. They said they never knew their son had pain. Both mom and dad have feelings of guilt about not treating the medical side at first. They say they only found out about the medical side a few months after Elton was diagnosed. Since then they have been working very hard on addressing Elton's many medical challenges but they say that it can be very hard. As the researcher knew the family for quite some time, she knows that Elton can become very ill if he eats even the smallest amount of the wrong foods. Grace said she was feeling very guilty that she never knew Elton was in pain and that she would have done something if she knew *"Die feit da thy siek was ook, hy het altyd met sy boudjies in die lug gelê, ek bedoel ek het nooit geweet hy is in pyn nie. Die skuldgevoel wat daarmee saam gaan, die feit dat jou kind vir jare in pyn was en jy het nie geweet nie, ja dit is baie moeilik".* ("The fact that he was sick as well, he was always laying with his bum in the air, I mean I never realised that he was in pain. The guilt that goes with that, the fact that for years your child was in pain and you did not know that, yes that is very hard").

When the researcher spoke to Fred she noted that for this dad it was very hard to accept that the dreams he had for his son will be very hard to obtain. He explained that the diagnosis was very hard to accept and now they find it hard to go on as if nothing is wrong. He said there are times you are very aware that what you had hoped for will never be obtainable. He also said there are things that a family is supposed to be able to do together that they just can’t do. He said that as a family *“Jy verloor baie”* (“you lose a lot”), and that makes you very aware that things did not go as they should have. *“Enige tyd wat jy van hom af weg is maak jou skuldig voel. Ek het nooit so gevoel met ons dogter nie, want indien jy weg is vir ‘n aand of ‘n naweek dan voel jy nie asof die tyd wat jy weg is ‘n impak gehad het op jou tipiese kind se ontwikkeling nie. Omdat Elton nie leer nie soos ‘n gewone kind nie wonder ek altyd of die uur, dag of week wat mens weg was nie tyd was wat jy saam met hom moes spandeer om hom te help leer nie. Dit sit baie druk op ‘n mens ne maak ‘n mens baie skuldig voel”.* (“Any time that you spend away from him you feel guilty. I never felt it with our daughter, because if you are away for a night or a weekend then you don’t feel like the time you spent away had an impact on your typical child’s development, but because Elton does not learn like a typical child I always wonder if the hour, day or week you were away isn’t time you should have spent with him helping him learn. It puts a lot of pressure on you and you feel very guilty”).

While speaking with this family the researcher could sense the amount of personal loss they dealt with*, “in die huis, die gewone goed soos om jou kleintjie te kry om in sy eie bed te slap, dinge soos dit kan jy nou nie hê nie”.* (“in the home, normal things like seeing your little one sleeping in their own bed, little things like that you can now not have”). The family told the researcher that they don’t have the opportunity as other families to go away and get out of the house. Both mom and dad said that when they had their first child they had time to go away for a weekend or an hour knowing she was safe and happy with granny or so, but now they can’t go anywhere as they feel that Elton doesn’t cope with change and it’s too hard to prepare his food away from home. Grace then mentioned that she does a great amount of planning before they can go somewhere outside their home. *“Jy kan nie net meer jou goed pak en gaan nie, want Elton het dadelik met die dieet begin, so nou moet jy eerste aan kos dink, dit is nie net meer oor in die kar klim en gaan nie, dit is net nie meer so maklik nie. Dit is nogsteeds so, jy kan nie net nie.., dit is baie beplanning waar ook al jy gaan. Ek weet nie, eenvoudige goed soos vakansies, jy kan nie net ‘n vakansie beplan nie. “n Mens moet altyd eers dink hoe dit hom sal affekteer en of daar ‘n plek is waar ‘n mens sy etes kan voorberei. Daar is niks wat normal kan gebeur met* *sosiale goed nie. Ons kom nie uit nie, ons gaan nêrens nie".* ("You can't just pack up and go anymore, because Elton started on the diet straight away, so now you have to think about food, it's not just about getting in the car and going anymore, it's just not that easy anymore. It still the same, you just can't, it's a lot of planning where ever you go. I don't know, simple things like holidays, you just can't plan a holiday. One always have to think how it is going to affect him and if there is a place where we can prepare his meals. There is nothing that can happen normally that is related to social." "We don't get out, we go nowhere").

When the researcher spoke to both mom and dad it was clear that they found the diagnosis very challenging and it created intense sadness for them. During the time that the researcher was in the interview with mom and then dad, they both cried. Dad especially sobbed as he told me that *"enige tyd wat jy weg spandeer van Elton af laat jou skuldig voel, dit plaas baie emosionele druk en spanning op jou",* ("any time that you send away from Elton you feel guilty, it places a lot of stress on you and emotional pressure"). For the researcher the intense sadness was very evident in this family. They became progressively more distressed as they spoke about their unique family situation. *"Ek dink nie aan die toekoms nie, die vêrste wat ek kan dink is of hy sal kan skool toe gaan en of die kinders by die skool wreed sal wees met hom en of hy sal inpas by die skool, di hoe vêr ek dink".* ("I don't think of the future, the furthest that I will think is if he will be able to go to school and if the children at school will be cruel to him and if he will fit in, that's how far I think").

During the time that the researcher was with the family Grace said she worries about Elton's education. She noted they are working very hard to ensure he gets the type of education he needs, but it's very hard to know what exactly they need to do about his education. Even though they speak to other parents who have children with ASD they never know, since children differ in what they need. Grace said that you have to pray that what you are doing is what your child needs. *"Ons het 'n vriendin, haar kind is twee jaar ouer as Elton, haar kind praat ook nie. Ons het haar twee weke gelede weer gesien, ek het toe vir Fred gesê, ons weet nog nie wat vir ons voorlê nie. Hy is nou nog 'n baba, ons het nog nie regtig met die skool ding gesukkel nie. Hoe ouer hy word hoe moeiliker gaan dit word".* ("We have a friend whose child is two years older than Elton. Her child also doesn't speak. We saw her again two weeks back and then I said to Fred we don't yet know what is coming for us. He is still a baby, we have really had to do such difficult things with the school thing, but I know that it is coming. The older he gets the harder it's going to get").

Both parents told the researcher that one aspect which is very hard is Elton's education. Even though Elton has ASD his mother is still hoping for him to be able to go to school. *Selfs nou as mense my vra wat gaan gebeur met sy skool, sê ek vir hulle hy gaan skool toe, selfs al is dit met 'n skadu, maar hy sal skool toe gaan".* ("Even now if people ask me what is going to happen with school, I tell them, he is going to go to school even if he needs a shadow but he will go to school").

The researcher was fortunate to spend a bit of time with the family and during this time the parents felt they wanted to say all they felt was needed so that other parents had the opportunity to learn from them. They spoke about how they really longed for interaction with their son and that this aspect was very difficult for them and remains one of the hardest challenges they are faced with. *"Vir my is die groot vraag wat ek Elton wil vra is of hy alleen en geïsoleerd voel, voel hy deel van die gesin? Wat dink hy as hy so babble. Ek wil graag insig hê in sy wêreld. Ek wil graag weet wat hy voel en hoe hy die lewe ervaar,… maar ek kan nie".* ("For me the one big question that I want to ask to Elton is if he feels isolated, does he feel part of the family? What does he think if he babbel, I would like insight into him? I would like to know what he feels and how he experiences life, but I can't").

When the researcher spoke to Grace she said that due to the fact that Elton can't speak, she will "stand up" for him if he plays with other children. Mom also said she feels like she needs to protect Elton against other people and that she finds herself reacting differently in social situations than she did with her other child who is not on the ASD. *"Ek weet dat dit 'n ma-ding is maar ek voel asof ek Elton moet beskerm. As ons na 'n parkie of so gaan. Ek laat hom nie onder my oë uit nie,dis oor hoe ander kinders reageer teenoor hom. Party kinders sal hom by die glyplank afstoot en hy kan niks sê nie, so hy sal net opstaan, glimlag en aangaan. Dit is wanneer ek nader staan en vir hulle sê dat hulle dit nie kan doen nie. Dit is dalk oorbeskermend maar ek is fanaties oor goed soos dit. Mense moet dink dat ek baie streng is maar ek dink nie twee keer oor sulke goed nie. Dis dalk verkeerd maar dit is hoe ek is. Hy* *kan nie opstaan vir himself nie so ek moet”.* (“I know that it is a mother thing but I feel like I have to protect Elton. If we go to a park or something, I don’t allow him to go out of my sight. It’s because of how other children react to him. Some of them will push him down a slide and he can’t say anything, so he will just get up smiling and go around again. That’s when I will stand closer and tell them that they cannot do that. It might be over protective but I am fanatic about things like that. People must think that I am very strict but I don’t think twice about things like that. It might be wrong but that is how I am. He cannot stand up for himself so I have too”).

For this family in particular there are a lot of emotional effects with relation to their extended family as they see their family often and have a lot of interaction with them. Both mom and dad found this aspect very hard as they want interaction with their family but they told the researcher these relationships changed quite a lot after they received the diagnosis. They spoke about how the family does not always understand Elton’s developmental delays or the huge difficulty around Elton’s diet and related medical conditions. They also discussed how difficult they find socialising with their family as they feel they can’t socialise like other families by going out for a meal or so. “*Vir my,.. hulle verstaan nie ons situasie nie want hulle is nie in dit nie, maar hulle moet some redelik wees, met wat hulle van ons verwag as ek dit so kan sê. Ook met wat ons kan en nie kan doen nie. Ek bedoel, ons kan nie soos ‘n gewone gesin na ‘n restaurant toe gaan en iets eet nie, di twerk net nie so nie. So in ons familie voel ons baie sosiaal geïsoleer omdat jou familie net nie verstaan waardeur jy gaan nie.* (“And for me, they don’t understand our situation, because they are not in it, but they have to be reasonable sometimes, if I can say it in that way. With what they expect from us, and what we can and can’t do with them. I mean we cannot go to a restaurant like a normal family, and have a meal; it just does not work like that. So in the family you feel very socially isolated because they don’t get what you are going through”).

When the researcher spoke to Grace she also mentioned that it’s very hard for her to see other children in her family who are developing in a typical manner, as she then realises how bad their situation is and how much Elton differs from other kids his age. *“Baie van ons familie se kinders is rondom Elton se ouderdom en dit is vir my baie moeilik om te sien hoe hulle normal ontwikkel terwyl Elton nie ontwikkel nie. As* *ek hulle sien is dit vir my baie moeilik om te besef hoe Elton moes wees”.* (“A lot of our family has a child around Elton’s age and it is difficult for me to see how they are developing normally and Elton is not. If I see them I find it hard to see and think how Elton should have been”).

Grace then noted that a big aspect for them is not if people treat their son correctly or even treat them like they are aware of his challenges. Instead, for this family it was important that their friends and family try to understand the situation they were in as a family. *“DIt gaan nie vir my so erg oor hoe ons familie hom (Elton) hanteer eerder as wat dit daaroor gaan hoe hulle ons situasie verstaan”.* (“It’s not about how our family handle him as much as it is how they understand our situation”). The parents told the researcher it is not only hard around family but also around friends. They spoke about their need for people not only to understand their son but to understand their family situation in terms of understanding that they want to spend time with them but that it’s not always possible for them to do ‘normal’ things like have a meal in a restaurant and how their relationship with their friends changed after the diagnosis *Vir my het dit daaroor gegaan oor hoe ons vriende op daardie tyd die diagnose hanteer het, hulle het dit of hanteer of hulle is nie langer vriende nie, het het bande gebreek met baie mense. Hulle het dit of korrek hanteer in my oë of nie, hulle was of daar om ons te ondersteun of hulle was nie. So ons het baie vriende op daai stadium verloor, die vriende wat gebly het is mense wat werklik omgee vir ons situasie. Dis nie net oor Elton nie, dit is oor of hull ons situasie verstaan”.* (“For me it was about how our friends at that time handled the diagnosis, they either did or they are no longer my friends, I really broke ties with a lot of people. Either they handled it correctly in my eyes or they did not, they were either there to support us or they were not. So we lost a lot of friends at that time, the friends that remained is people that really care for our situation. It isn’t only about Elton it’s about how they understand our situation”). Both the mother and the father found it very hard after the diagnosis to go outside the home and socialise. *“Aan die begin het ek baie geïsoleerd gevoel en ek het myself in die huis geïsoleer, ek wou nêrens gaan nie. Jy begin jou sosiale patrone verander en jy sonder jouself van die buite wêreld af en jy moet begin moeite doen om nie geïsoleerd te word nie”.* (“At the beginning I felt isolated and I isolated myself in my home, I did not want to go anywhere, you start to change your social pattern and seclude yourself from the outside world and you have to start and go to trouble to ensure that you don’t isolate yourself”). The parents spoke about how easy it is to change the way you relate to yourself and in changing the way you relate to yourself you can easily change the outlook you have on the diagnosis and living with it. For these parents socializing, which was always something they enjoyed, now became something that was difficult and that they had to do for the sake of doing it.

When the researcher spoke to the parents they both spoke about how the demands they faced had an impact on their social relationships. For this family their social relationships had taken strain and they were aware as a couple that this could easily happen to their marital relationship as well.

In the first week after the diagnosis the family made contact with an organisation that made them aware that the divorce rate in families where a child was diagnosed with ASD was eighty present. In their individual interviews both the mother and father discussed their marital relationship. *“Waaroor ek baie bly is, is dat Fred so ondersteunend is en dat ons huwelik stabiel is. Ek dink regtig dit het ‘n groot verskil gemaak dat ons daai eerste week wat Elton gediagnoseer is gehoor het dat tagtig present van huwelike nie hou nie. So ons is baie bewus daarvan. Ons weet dit kan gebeur so ons waak daar teen. Ons porobeer tyd maak vir mekaar. Ons is gelukkig dat my ma en pa baie naby aan ons bly so hulle kan baie maklik na die kinders kyk. Ek kan seker op my een hand tel hoeveel keer ons uitgegaan het en tyd gemaak het vir mekaar. Dis al waaraan ek kan dink”.* (“What I am very happy about is that Fred is so supportive and that our marriage is stable. I really think it made a difference that we heard the week that Elton was diagnosed that eighty present of marriages don’t survive. So we are weary about that. I know it can happen so we work on our marriage.” We try and make time for one another. We are lucky that my mom and dad live close by so they can watch the children. I can probably count on my one hand how many times we have gone out but we try and make time for us. That’s all I can think off”).

The parents spoke about the practical effects that the diagnosis had on their marriage. *“Na Elton se diagnose was hy baie siek gewees, ons het op daardie tyd besluit om hom uit sy kot te haal en by ons in die bed te sit. Hy is toe by my in die* *bed in en nog nooit weer daaruit nie. So in daai verband is ek en my man van bed geskei. Ten minste weet ons dit is as gevolg van Elton, dis anders as wanneer ons ander verskonings gehad het, maar ons weet dis todat ons hom uitgesorteer het. Alles het verander, selfs ons huwelik".* (*"*Elton was very sick at that stage, few weeks after he was diagnosed and we decided to take him out of his crib and put him in bed with us. He then went in the bed with me and hasn't left ever since. So in that regard, my husband and I are separated from our bed. At least we know why we are separated from bed, it would have been different if we had excuses but we know it's because of Elton until we can have him sorted. Everything changed, even our marriage").

The mother was very worried about the impact that their son's diagnosis has on his older sister, aged five. She spoke about how his sister always used to think that her brother could not talk but that she now is starting to realise that there is more wrong with him. *"Dit is vir haar 'n baie moeilike tyd, dis amper asof sy nou eers vir die eerste keer besef dat daar iets verkeerd is. Tot nou toe het sy net gedink haar boetie praat nie, maar nou besef sy".* ("She is having a very hard time; it is almost as if she is now only realising for the first time that there is something wrong. Up to this point she just thought her brother does not talk, but now she is realising"). Grace told the researcher since the diagnosis she has started to expect more from Elton's older sister. She says that because she can understand things, Grace needs her to take responsibility for things like not letting food be around the house that Elton can't have. *"Sy moet weet dat as sy iets eet en hy kan dit nie hê nie sy dit moet weghou van hom af, selfs die papiertjies moet weggehou word van hom, anders kan hy iets inkry wat hy nie mag nie. Dis moeilik vir sy sussie. Ek verwag meer van haar, ek weet dit is verkeerd maar ek verwag meer van haar want sy is my normale kind".* ("She has to know that if she has a snack and he can't have it to keep it away from him, even the wrappers have to be kept away or he can get something in that he shouldn't have. It's very hard for his sister. I expect more off her, I know that it's wrong, but I do expect much more off her as she is my 'normal' child").

Grace also expressed that as Elton's mom, she felt tired. She said that she never knows if what she is doing is what she should be doing. Grace admitted that it's been a very hard road for them. *"Ek lees nie meer boeke oor outisme nie; Ek wil nie* *meer lees oor ander mense se hartseer nie ek het genoeg hartseer in my eie lewe”.* (“I don’t read books about autism anymore; I don’t want to read about other people’s heartache anymore, I have enough heartache in my own life”).

When the researcher interviewed both mom and dad she was aware of the profound feelings of loss and sadness that both parents had around their son’s diagnosis and his life with ASD. Both parents also mentioned that they feel very sorry for their normal developing child, as they feel that she has to face things and deal with things because of her brother’s diagnosis that she would have never had to face and deal with. When the researcher spoke to Elton’s parents they said they felt *“jammer”* (“sorry”) for Kate as they feel that their *“verwagting vir haar is anders”* (“expectations are different”) for her than it would have been if not for Elton’s diagnosis.

3.3.2.2 Theme two: The experience of mental, social and environmental adaptations utilised by the family to deal with the changing family situation

During the time that the researcher met with the family she realised that this family had a great need to understand their son’s condition as they wanted to know what they could do that would have a positive impact on him. Both parents mentioned that they wanted to find as much information about their son’s condition as was available.

For this family they felt that there weren’t enough places they could go to receive education and correct current information about ASD and managing life for their son. When the researcher spoke to Grace she mentioned that she isn’t only trying to find a cure for her son but she would very much like to make sense of the experience. Grace told the researcher that she has to be positive in order for her to find the strength to keep going for her family *“Ek moet positief bly vir my gesin”.* (“I have to be positive for my family”).

When the researcher spoke to Fred he told her *“Jy kan nie meer net gewone goed doen nie”.* (“you can’t just do normal things anymore”). He said everything that people take as normal daily activities now becomes a huge logistical operation.

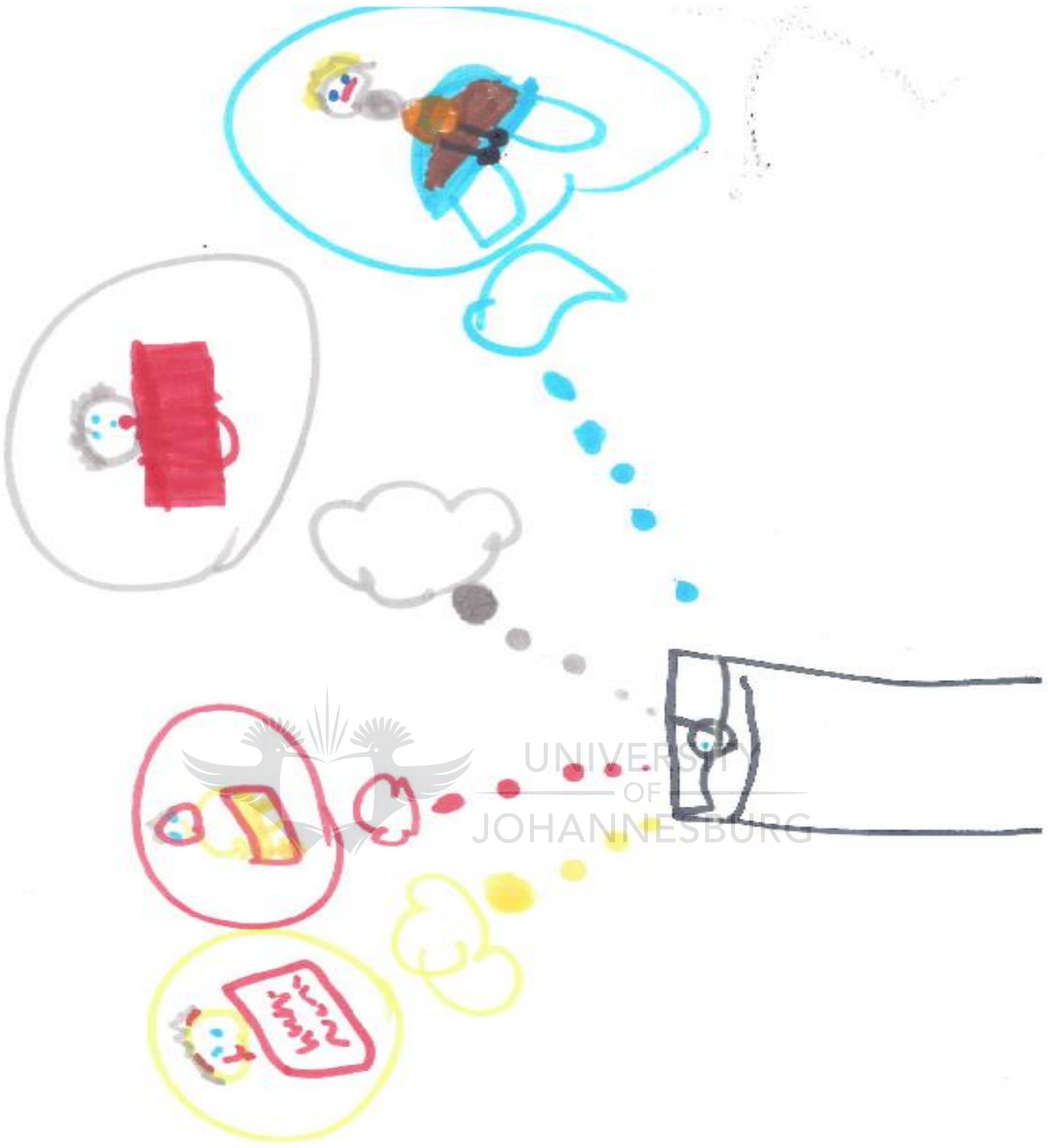
Both parents spoke to the researcher about how they remember events around the time that Elton was diagnosed. While Grace spoke about this time in their lives she was very emotional. *"Drie weke na ons die diagnose gekry het moes Fred weggaan van die huis af vir drie maande van opleiding in Stellenbosch, so ek was absuliet in die diepkant ingegooi. Ek moet terapeute kry en Elton was baie siek op daai stadium".* ("Three weeks later after receiving the diagnosis Fred had to go away from home for three months for a training he had to do in Stellenbosch, so I was absolutely thrown into the deep-end. I had to find therapists and Elton was quite ill at that time").

Even though this family was very concerned about the diagnosis of their son with ASD, they were very aware that having a brother diagnosed with ASD would have a great amount of implications for his typically developing sister. During our discussion Grace made it known that she felt there was a very hard time ahead for Kate and she knew that life would be very different for her because of her brothers' diagnosis. *"Dit is baie moeilik vir Kate. Sy het 'n baie harde tyd",* ("It is very hard for Kate". She is having a real hard time").

Both parents consented that the researcher could ask Kate to draw a picture about her family. The picture was independently analysed. She was told ahead of time that the researcher would come to talk about Elton. The researcher asked her "Kate can you draw me a picture about your family"? See sketch 3.2.

a) Drawing by sibling

The researcher spoke to all the members of the family. The oldest sibling in this family is a girl aged 5 years. From here I will refer to her as Kate. Kate has seen the researcher a few times before but she doesn't know the researcher very well. Both parents agreed that Kate could draw the researcher a picture but they were very anxious for the researcher to ask Kate questions about her picture. The researcher was not able to get much information from Kate. The picture was independently analysed by Dr Braam Hoffman.



SKETCH 3.2: Sibling of child diagnosed with ASD (age 5 years)

b) Practical aspects of the picture

- Sketch 3.2: Participant in bed thinking about Elton.
- Note 1: Page orientation of the picture is landscape, page size A4 was used.

- Note 2: The participant identified the various figures as follows: Self-figure (in bed), Elton all the figures at the top of the sketch. The activities in the top figures (from left to right) are the following:

1. Elton jumps trampoline
2. Elton reading a book
3. Elton is climbing
4. Elton watches TV

These activities represent the activities that Elton can do.

c) Assessment of the picture

Note 3: The participant was requested to draw her family. The fact that she only drew her brother represents the fact that he is the focus of the family, as well as in her own mind. It may also indicate Elton's lack/avoidance of social/peer interactions within his family.

Note 4: Koki-pen drawing; various colours used
The researcher has included the assessment of the picture as this reflects the impact that Elton's diagnosis has on the way that his older sister views her family's life. The quality of the male figures is approximately between 4th and 21st percentile rank. The quality of the human figures places the participant in the lower quarter of a theoretical group of 100 children. Note that the standard score and percentile rank is based on a study of American children of the participant's age.

The small size of the top figures, together with the use of Koki-pens to make the drawings, make it almost impossible to analyse any detail on the respective figures. Therefore, only a few general remarks are given. The self-figure low on the page suggests feelings of inadequacy that can be as a result of having to compete with her brothers' diagnosis on a constant daily level. The self-figures' inactivity, for example lying in the bed, is in contrast to the figures of Elton activities. This may indicate her experience of Elton's high activity level in comparison to her own low activity level.

The use of various “thought bubbles” to indicate Elton’s activities indicates that the participant relies to a certain extend on fantasy to make sense of her own world that may at times feel very out of control due to her brother’s diagnosis. Also, note that the head, for example the only body part of the participant in the sketch, is considered the site of intellectual and fantasy activity. The absence of the rest of her body suggests feelings of inferiority and a denial of emotionality.

All of Elton’s activities are performed alone without the presence or participation of any other person. This may indicate his lack/avoidance of social/peer interactions, as well as his possible stereotyped behaviour patterns.   This is further emphasised by the clear compartmentalisation of his respective activities. Note that in three of the four Elton figures the body below the head is covered by various physical objects. This suggests some form of denial/repression of thoughts regarding Elton’s body functions. One can only wonder if he does not expose himself in some inappropriate way at times, causing embarrassment/shame for the participant.

After Kate finished her picture she said that she wants to draw another picture about her brother. The picture is also included in this section to show how she has drawn her brother. During the time that the researcher spent with this family for the interviews, both parents asked the researcher more than once if she would be able to let them know if she thought that their daughter was struggling with her brothers diagnosis.

In the time that the researcher was in this family’s home she was able to realise that this family was very aware of the possible implications that their son’s diagnosis could possibly have for their daughter. The researcher was aware that the family felt their daughter had a burden that other children don’t often need to face due to her brothers diagnosis of ASD. It was evident for the researcher that this family was functioning under very stressful circumstances and having their son diagnosed with ASD was a very big emotional burden that caused them a lot of anxiety and trauma.

d) Drawing by sibling

The researcher asked Elton's sibling Kate to draw her a picture about her family. She drew two pictures (Sketch 3.2 and 3.3) with this picture being the second one (Sketch 3.3). Her mother was also present when she drew this picture. As with the previous picture, the researcher could not ask her about her picture.

e) Practical aspects of the picture

The following identification of the picture was made: Sketch 3.3.

Note1: The page orientation: Portrait, Page size: A4
Note 2: The participant identified the figure as Elton her autistic brother
Note 3: The participant was requested to draw her family. The fact that she only drew her brother indicates that he is the focus of the family, as well as in her own mind.
Note4: Koki-pen drawing; various colours used
Note 5: Keep in mind that this sketch represents the participant's projection/view of Elton unless otherwise stated in the various explanations.

f) Assessment of the picture

Overall quality of the assessment: The quality of the male figure is approximately between the 53rd and 84th percentile rank. This means that the overall quality of the figure places the participant in the upper half of a theoretical group of 100 children. Note that the standard score and percentile rank is based on a study of American children of the participants' age. The general placement of the human figure in the center of the page suggests that the participant is a normal, reasonably secure person. This is the most common placement at all ages.

SKETCH 3.3: **Sketch of brother affected by ASD drawn by sibling age 5 years sketch B**

The presence of a butterfly on the left side of the human figure suggests that the participant rely to a certain extend on fantasy to make sense of her world. This notion may further be strengthened if the figure on the lower right side of the human figure presents a flower. A flower may also serve as a symbol of growth and love. Note the tendency of the participant to project feminine symbols for example butterfly and flower onto the figure of her brother.

The presence of a prominent ground line suggests that Elton experiences strong security needs or insecurity. Also, it indicates the need for stability or a feeling of personal instability. The sun in the top right hand corner suggests that Elton presents feelings of inadequacy, as well as a need for warmth and love. The relatively large head in comparison to the rest of the body can be considered normal for children below the age of seven. The dot-eyes suggest childish tendencies, although it is common and normal in sketches of young children. The small ears suggest that Elton presents impaired communication and minimal environmental contact/awareness. However, note that ears are frequently omitted by children. The nose with nostril indicated may suggest aggressive tendencies. However, note that any form of nose may be normal for children. The wide upturned line effecting smile is normal with children. The relatively “normal” neck suggests adequate balance between intellect and affect. The narrow trunk may suggest inferiority feelings and/or poor adjustment. The relatively narrow shoulders suggest that Elton presents inferiority feelings. The relatively low and tight waistline suggests that Elton presents blocking/conflict regarding emotional control of body impulses.

Looking at the sides of the figure the stiff arms suggest that Elton presents rigid, compulsive and inhibited personality. The mitten-type hands obscuring fingers suggests that Elton presents with suppressed aggressive tendencies where the aggression may be expressed in emotional outbursts. The legs pressed closely together suggest that Elton presents with rigidity and tension. In combination with the arms pressed to the body it suggests a tendency to ward of the environment and rigid defenses. The feet being left out from the picture suggests that Elton’s is viewed as shy or aggressive, with possible emotional instability. The stiff posture of the whole figure suggests tension, possibly with attempted rigid control of impulses and fantasies.

3.3.2.3 Theme three: Experience family resilience as a powerful way of coping or adapting

When the researcher spoke to the family it was very clear that the diagnosis of ASD had a very big impact for them on all aspects of their lives. However, they also acknowledged the things that have gone right since they received the diagnosis.

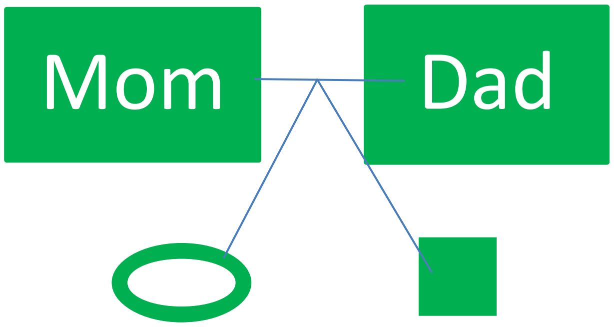
Fred said that *"Dit help om met ander gesinne te praat wat 'n kind het wat met outisme gediagnoseer is, veral op die biomediese kant, 'n mens kan amper sien hoe hulle gesond word. Die belangrike ding is dat jy 'n ondersteuningsnetwerk moet kry by mense wat al was waar jy is, want 'n mens voel dat net hulle werklik kan verstaan waardeur 'n mens gaan. Ek wens daar was 'n boek met riglyne wat mens kan leer oor die biomediese kant want 'n mens kan sien dat dit baie help. As die kinders beter is en nie in pyn is nie kan 'n mens beter voel oor jou situasie want as jou kind regtig siek is, is dit baie moeilik om te hanteer".* ("It helps to speak to other families that have had a diagnosis of autism, especially on the biomedical side as you can almost see the kids getting healthier. The important thing is that you have to get a support network in people that have been where you are, because I feel that they are the only people that can really understand what you are going through. I wish that there was a guide about the biomedical side or something that can teach parents about the biomedical side because you can see that it helps a lot. When the kids are healthy and not in pain then at least you feel better about your situation, because if your child is really sick, it's very hard to deal with").

The family said that they will always be hopeful and they love their child dearly. They mentioned the value of support systems and that they feel it's important to stay positive. Grace said she knows that *"Enige iets kan verkeerd gaan maar ek sal aanhou hoop,… ek is lief vir hom*". ("Anything can go wrong but I will keep hoping…,I love him"). As with dad, mom mentioned the importance of having a good support systems as she said that this gives you hope to hold onto**.** *"Ons was baie gelukkig dan ons Louise en Jenny die eerste week na sy diagnose ontmoet het, ons het dadelik begin antwoorde kry en dit het ons hoop gegee".* ("We were very lucky in that we met Louise and Jenny in the first week after the diagnosis. We started to immediately get answers and that gave us hope"). Grace said she thinks that *"As* *iemand met die ouers en die familie kan werk sodat hulle hul denke kan positief hou".* ("If someone can work with the parents and the families to help them keep their mind positive"). She (Grace) said she feels as the mom she has a very important role in her family as she has to keep her family going *"Ek moet aangaan, verstaan, ek kan nie opgee nie, ek het 'n gesin".* ("I have to go on, understand; I can't give up I have a family").

Even though it was very clear to the researcher that the diagnosis of ASD was a life changing event for all the members of this family, she could also see that as a family they were still finding ways to move forward and to cope with their lives, even with ASD.

3.3.4 Discussion of in-depth interview family three

The researcher will give a discussion of the interview with family three in the following section. All direct quotations from this family will be indicted by using the colour green. The names of the family members have been changed to protect their identity. See figure 3.3.



Affected Child ○ Age 5 years- Girl
Boy child ■ Age 1- Years- Boy

FIGURE 3.3: Genogram family three

During the interviews with this family three themes were identified. These were as follows:

- Experience pervasive emotional and social effects 'restricting' the family as a whole.
- Experience of mental, social and environmental adaptations utilized by the family to deal with the changing family situation.
- Experience family resilience as a powerful way of coping and adapting.

3.3.4.1 Theme one: Experience of pervasive emotional and social effects 'restricting' the family as a whole

As this family invited the researcher into their home, both mom and dad said that they spent a lot of time trying to decide what they wanted to tell the researcher. Both parents gave their consent for participating in the research as well as their consent for their older child, aged ten years, to participate in the research. The researcher used other names to ensure that the families' identity remained private. Mom will be called Elna, Dad will be called Andre, girl child aged five years affected by ASD will be called Helen, and her brother aged ten years will be called Donavan. They said that they don't really know what impact their daughter's diagnosis of ASD had on their family as they cannot remember the time before the diagnosis. They said they felt that what they wanted the researcher to know was hard to say so they said they would use a lot of examples to tell their story.

When the researcher asked the family to tell her about their journey with ASD, Elna started to say that *"the hardest time for us was when we got the diagnosis. They tell you to take her and put her away and forget about her".* Elna asked the researcher *"how can a parent do that?"* According to Helen's father, the diagnosis caused big changes in their family but he said that they knew there was something wrong when she did not meet her milestones. They said their other child also has some cerebral palsy issues but it doesn't affect him with regards to developmental milestones.

Their daughter was diagnosed at about age two (she is now age five). They told the researcher that when she was diagnosed, there were very little services available both medically and educationally but this has changed in the last two years and they feel they now have access to good services for their daughter. They said that knowing and seeing that there can be improvement have changed how they view their daughter's ASD diagnosis.

Both mom Elna and dad Andre spoke about how the diagnosis meant that their family *"changed dramatically"* from that moment. They said it takes time to *"hear"* that your child has got a diagnosis, and that it's the hardest thing to hear. *"Around the (diagnosis) I suppose you go through a denial phase, an angry phase and then acceptance".*

During the time the researcher worked with Helen (daughter with ASD), she got to know the family well. The family was always very proud of their daughter and did everything they could for her. As the researcher spent time with this family during interviews she realised that even though it seemed as if this family was "taking ASD in their stride", there were things she only realised after the interviews for both mom Elna, dad Andre, and brother Donavan, the diagnosis meant *'loss'.*

Elna and Andre both spoke about personal moments that they should have been able to have with their daughter as well as social moments and interactions they feel they have lost out on. As Helen was the only daughter and only had a brother, Elna said she feels there are moments both socially and emotionally that a mother and daughter should be able to share together. Elna told the researcher that until a few weeks ago there has never been something that they did as a mother and daughter could do together even though Helen was five years old already. She said that even though it may sound silly, the first time she felt they did something as a mother and daughter was when Helen was potty trained a few weeks ago and they took a trip to the beach. She said they stopped at a One Stop and for the first time they could go to the restroom as a mother and daughter. Elna said she missed "normal" things.

"You just can't do normal things. At this age you should have been able to take her to things, talk to her, see her whole world open up and be able to converse with her about things and we can't, we don't have that. So in a way the world becomes a whole lot more narrow, the normal chain of development is not happening to the

same extend so that impacts on us". "We don't get to do the things we should have been able to do. I would just love to connect with her; I would love to do things with her that you would do with a child, like build puzzles and things. I would just love to be with her more, not like now where I just take care of her; but mother and daughter thing like baking and painting".

The researcher spent a lot of time with this family as she worked with Helen inside their home. Both mom and dad had a great sense of loss as they felt that when Helen was diagnosed there were no services in South Africa that was at a standard where they made any improvement to Helen's life. They felt that in some way because of this *"they failed her"* since they could not provide what she needed. Both mom and dad felt they had lost time they could never get back for her.

The family told the researcher that there are dreams and hopes that they had for their child that after the diagnosis of ASD has to change. They said there are small things that you wish for that baby when it's born that just doesn't exist anymore and your hopes and dreams change to "normal" things that you take for granted with other children, like going to school. Elna said that *"I was just thinking of her the other day and thinking that she is close to the age where Donavan started school, the year before grade one. But I think, I mean that's like worlds apart. It's just very different. You adjust your expectations, as well and you are incredibly proud of what they achieve in their world and that is the thing; and that is what you must do… the minute you start expecting her to be like other children her age you are set up for disappointment, frustration and all that type of stuff. So it's about scaling down and adjusting your expectations and then you value what she achieves."* Andre mentioned that she is still his little girl even though she has ASD and that it's hard for him to see her struggle through life. He said *"I love her. I just wish I could talk to her more. I know she understands what I am saying but I want to take her out and walk with her and have a conversation. I want to know that she wants to talk to me."* Dad said that he hopes that one day she will be able to go to school but that it's something that he can't worry about now, *"that's for one day."*

When the researcher spoke to mom she said there have been definite changes in their social interactions since they found out that Helen has ASD. She said there just are things that someone can only understand in Helen's behaviour if they know and understand ASD. She relayed that this makes it very hard for them to go somewhere where people don't know or understand Helen. Mom said that overall Helen behaves very well but that there can be things that trigger her and can cause a huge meltdown. She mentions that people don't understand that if they make comments or don't even try to understand Helen, we can't go there. She said the problems come in when *"you try to have a conversation with someone or when you try and keep her busy so you can have a meal".* When Elna spoke to the researcher about their social interactions she said that *"you do to a certain extend become isolated from people, friends and stuff like that because they don't always understand. For me being with (center) now has just been so wonderful; having people who are in similar situations with kids in similar problems and so because there is a connection, whereas a lot of other people just don't understand it."* Elna said that both her and her husband have decided that it's easier if they only try to do an activity with one of their children at a time. She said it makes the planning and logistics around an outing easier and then they feel that their son also has an opportunity to do something that he will enjoy. She said that *"you tend to keep them separate generally, do one thing with one and another with the other."*

After thinking for some time, Elna said that their friends and family do try to understand their situation but that it's not always so easy for someone that's not living with ASD every day to understand what they are going through. *"They want to understand but they just don't quite get that we can't do what we use to do. We can't just go hunting for a weekend, the more we keep her in routine the better it is. Take her out of routine, you pay the price. It's all about routine." "We spend more time as a family at home than I think other families do, just because it's more easy dealing with her here at home."*

The family said that they have a lot of frustration with people who think Helen is slow or incapable *"She understands that she struggles to learn, that's it, and she is not stupid or slow. People need to realise it. Autism spectrum disorder is not a death sentence. It means that she has a different style of learning than other children her age. If we had the opportunity and, service provider, came to South Africa sooner she would have not been so far behind. She is catching up now, and yes, it's hard* *for us, but it must be very hard for her. She looks at other children talking and you can see she know she is different. I don't want her to think she is not good enough."* When the researcher spoke to dad he noted that he also feels that friends and family try to understand their situation after the diagnosis but they just don't understand the daily things that go hand in hand with having a child diagnosed with ASD. *"Friends and family is hard, even at the best of times. They want to understand but they just don't quite get what we can't do what we used to do."*

During the interview both Elna and Andre said they felt very frustrated with regards to medical personnel and the treatment their daughter receives. They said the contact they had with doctors left them feeling *"powerless"*. They also told the researcher that they took Helen back to the specialist that diagnosed her as they had paperwork he needed to complete, and they wanted him to see how much skill she had gained.

They were very excited to show the doctor that even though he diagnosed her and said that she would be unable to learn, she had gained speech and a lot of cognitive development in the last year due to intensive therapy. They said that they just wanted him to see that. But they said that after that visit they will never go back to that doctor as they felt he just doesn't get it. *"He just humiliated Helen and us."*

Elna told the researcher about the visit to the specialist's office the week before. She said that the entire visit was really hard for them and for Helen, and the visit brought back feelings of helplessness that they haven't had since she was first diagnosed. She said that over the last year she showed so much progress that they haven't felt like this in quite some time. She said that *"he showed her a bowl of fruit, took the bananas out where she saw him take it out, then he put the bananas in his drawer. He asked her to give him the bananas. She knew it wasn't in the bowl anymore, she saw him put it in his drawer. She got up to get it from the drawer; he did not allow her to go behind his desk so she could get them. "He jumped up and said in front of Helen 'see she is not capable'. He made me feel helpless all over again. That afternoon Helen wanted to sit with us. She knew the visit upset us and she was upset too".*

When speaking to dad he kept saying how upset they were about the visit to the specialists offices the week before *"last week I really got upset; we took Helen back to the guy that gave us the diagnosis, only for the tax forms. He was the biggest bastard, sorry for my language but that is how mad I am that I have ever met. He ignored me and only spoke to Elna. We told him how much she has improved; he did not even listen. Then he did what I saw as mocked Helen I took her and the two of us waited for Elna in the car."*

The parents spoke about how they felt that doctors who did their degrees more than ten years ago don't realise that things are not the same as it was back then. *"They don't understand how much each milestone she meets means to us, they don't realise that that's the most important thing in our lives right now."*

Elna and Andre said they feel after their daughter's diagnosis there is an element of sadness in their lives. *"I think there is an element of sadness, as you don't know what the future holds"* they said it's something that they think will never go away or get better. They also said they worry about what will become of her if they are no longer there *"what happens if we are not there any longer?"*

As the researcher spoke to Andre he said there are things he wished he could change about the diagnosis. That if he could he would want to take ASD out of his family's life; but if he can't do that he wishes that he could understand his daughters' ASD more. He said he wishes he could know what gave her ASD as he thinks it would be easier if he could understand the *"why"* *"I will always wonder what gave her autism, if it was something we did wrong. …you just never know what the blow was that resulted in autism, we will never know… and that is the big thing we have to make peace with. We will never know if it was something we did or didn't do, so we don't think about it anymore, it's just too hard you know."*

But for them the guilt that they feel is not only related to their diagnosed child but also their 'normal' developing child. *"It's hard for him, I feel bad about that".* The family said that their son wants to understand his sister (diagnosed) but it's hard for him because he is at an age where he gets friends over and then the ASD doesn't exactly *"fit in."*

Financially the family said it is very hard for them. Elna said that she has to work at the moment for them to be able to afford the therapy at the center that they are at now. *"I have to work for us to be able to afford the therapy that she is getting at this point. That's something that I sometimes wish could be different".* When the researcher spoke to Elna she said that her work is something that at times she feels very guilty about as she says that the amount of time she spends away from the home is a lot. She says she feels guilty at times that she works a lot as she sees it at times as a way to get away from ASD. She said that spending every day at home with Helen would be too much for her. *"I don't spend a lot of time with her in the evenings; I think there is a part of me that is escaping from it. I sometimes think work is a type of escape. I don't actually think I could deal with the entire afternoon and evening and so on".*

Elna then said that they don't have the extra support system that many other families have as her parents are deceased and Andre's parents are ill and live far away. She said that they realised very early on that her husband is her support system and that she is his support system. Elna then spoke about her marriage and their personal lives. She said that *"Helen really put a strain on us. I don't want to say on our marriage but on personally".* Elna then went further and told the researcher that because they have heard of all the families that have marriages fall apart after a diagnosis, they are weary about working on their marriage. She told the researcher that she really has someone, her husband, that helps her and that he does his fair share. She believes the diagnosis brought her and her husband closer. *"We have decided we both have to deal with this issue autism together, it's not one person's responsibility but it's both ours".* When the researcher spoke to Andre he said that their marriage was strong but that at times he worries about Elna. *"Elna is more stressed I think. Easy things like dressing Helen and so on are difficult if she is in a bad mood. I know Elna wants to do more mother and daughter things with her but I think they will in the future."*

Andre then also said that it's sometimes hard to know what will be best for Helen and that Elna might want to do things different than he thinks would be right and then they can have a moment where they disagree, but that is it for them.

3.3.4.2 Theme two: Experience of mental, social and environmental adaptations utilised by the family to deal with the changing family situation

When the researcher spoke to this family they said that one thing that they will always have to live with is the unknown. They said they will never know why Helen got ASD and that they need to make peace with *"We will never know"* why she got autism. They said that they will need to make peace with the fact that at this time she can't talk and that there will always be things they just can't do with her because of her diagnosis of autism.

They also said they need to make sure they do the little they can do as a family; things that Helen can take part in and that they must make peace with the fact that they don't know if she will be able to live independently one day and even if she will be able to go to school one day. Dad said that *"…we still hope that one day she will go to school, but that's for then, and then things like will she be able to live by herself when she is 30 years old? I don't know, I hope so for her"*. When the researcher spoke to mom, she said that *"typical normal things that others might do like go out to play, you can't…"*. She said that you *"do to a certain extend become isolated from people"* and that they will rather socialise with other families who have children who are diagnosed with ASD, as those families *"understand our unique situation".*

As the researcher spoke to the family it was clear that they make decisions for their family based on Helen's needs. *"We don't go out that much anymore as its easier handling her here at home than somewhere else".*

In this family both parents work in order to afford the services that their child needs. The parents told the researcher that Helen needs someone to be with her *"twenty four seven"* and that those demands were very hard for them as it is physically tiring. This family, as with the other families that the researcher spoke to, said that in social situations they feel the need to protect her. They said that their goal is to ensure that she catches up in the milestones that she is behind in and that they are confident that she will.

For them a big aspect is the impact the diagnosis had on their 'normal' developing child. They spoke quite a lot about how it impacts him. Their son also reported that he finds the diagnosis and what comes with it, very hard. According to his parents he is at an age where friends are important in his life and he finds it hard to have friends over to the house because they don't always understand Helen. *"Well, at this point I only worry about Donavan. For him it is very hard. He wants to understand but he is also at the friend point where they are important to him. His friends mock Helen a lot when they play. What can you do? It's just how boys are."* They also said that it's not just the emotional things but physical things as well. *"We can't give Donavan everything we would have been able to give him if Helen was not diagnosed but that is how it is."* Both parents said to the researcher that their son ends up feeling like the victim all the time as he doesn't understand if Helen does something, like destroy his room. *"It's been very hard for Donavan our son. Our biggest issue is the sibling, how he relates to her so that he doesn't feel like the victim all of the time."* They also spoke about how hard they feel it is when they don't always know how to discipline Helen. *"I am not always sure what is normal sibling behavior and what is particular autistic and problematic. She gives her older brother quite a hard time, so that is probably one of our biggest adjustments, is coping with the two of them together."*

For her sibling Donovan, it has been very hard to understand and deal with the diagnosis. The researcher was able to do an individual interview with him. At the time the researcher spoke to Donavan, he was aged ten. Donavan spoke to the researcher and said that he thinks Helen just does things to make him mad. *"Helen has autism, autism spectrum disorder means like she doesn't know what to do and that she is simply brain dead cause she was born that way. She doesn't know what sharing and kindness is. It all depends on what mood she is in, if she is in a bad mood she screams, that makes studying hard".* Even though the relationship between his sister and himself is difficult for Donavan, he told the researcher that he thinks its even harder for him because he has to come home after school. *"It's hard for my mom and dad but they don't have to spend half the day with her, because they are at work."* Healso felt that he needs alone time with his parents away from Helen so that they can do 'normal' things. *"Then my dad is always busy with her and if it's not my dad it's my mom. She can never be alone. She put her dolls and* *everything everywhere. She doesn't tell you what she wants, you always need to guess. When my dad and I went camping last time, she and my mom came too. One day then they came with us to the field, then when I wanted to shoot she yelled and the buck got away. I said to my dad I will not go if she goes again."*

Social interaction with his family away from home also proved to be problematic for Donavan. *"I don't like it when everyone looks at us."* He struggled to understand the different ways of discipline that there is for him and his sister, and he struggled to understand that she doesn't always know when she is doing something wrong. *"She makes me mad; she needs to understand something like rules. She doesn't want to because she knows she can get away with it. If she screams hard enough she can get away with it. If she screams hard enough she can get anything."*

For Donovan his sister's diagnosis has been very hard to understand and deal with it. When he spoke to the researcher he said that he thinks his sister *"just does things as she knows that it will make him mad".* Even though the relationship between Donovan and his sister was very hard for him, he still told the researcher that he *"did not want to lose her anywhere".*

Donovan said that it was harder for him as he is at home with his sister after school and that his parents only came home after work. He said that at times he feels like he needs alone time with his parents. When he spoke about social interaction with his family outside of his home, he said that this was also a very difficult aspect for him. For Donovan it was very hard to understand that his parents had to discipline his sister in a different way than they discipline him.

3.3.4.3 Theme three: Experience of family resilience as a powerful way of coping or adapting

The parents, as well as Donavan, expressed their love and affection towards Helen. They spoke about how over time things are getting better and that they are able to be more positive about the future. They talked about the value of support systems when they said that they like getting together with the (service providers) families since they have things in common. They keep in mind that she can understand when people speak about her and the family says that they don't want her to think she isn't good enough. *"I don't want her to think she is not good enough".* For this family there are moments that they did not have before but that they have recently started to have. *"Helen came with me and we both went to the bathroom together, that was our first mother and daughter moment."* As with any father and daughter, for this dad she is the apple of his eye. *"It is hard but I will never trade her for another child. I love her. She is my princess".* Both parents love her dearly *"You adjust your expectations as well and you are incredibly proud of what they achieve in their world and that's the thing".* And just like only a big brother can, Helen's brother told the researcher *"I love her. She is not great but I don't want us to loose her anywhere".* As the researcher gets ready to leave, Helen's father remarks "I would not recommend it to anyone as a sport or anything like that but she is wonderful…"

3.4 CONCLUSION

It's very clear for the researcher that ASD is a lifelong changing event with pervasive emotional and social effects that restrict the daily living of the family as a whole. The event threatens the core family identity, requiring the family to make diverse mental, social and environmental adaptations in order to deal with their situation. Resilience emerges as a powerful way of coping/adaptation in a family that has to live with ASD, demonstrated by a parental perspective that 'it's getting better over time'.

In Chapter Four the researcher will discuss the cross validation report and literature study.

CHAPTER 4

CROSS VALIDATION REPORT AND LITERATURE CONTROL

“Imagine that you are trying to reach a young prince locked inside a huge castle. First, you must cross the wide moat, which is filled with hungry alligators. Once across, you must find a way into the castle. Arriving inside you see armed guards everywhere. You must find your way past the guards as you look for the secret stairway up to the highest tower in the castle. Should you find the way up, you must search for the correct key to open the lock. With key in hand, you may open the heavy door. Inside you see the child looking out the window. He does not turn to greet you. You may walk over, and being ever so careful not to speak to the child or even touch him you may stand beside him and look out of the window. After a while you may in quiet tones speak about what you see when you look out the window. If you have been careful and respectful enough and have noticed the ‘right’ things as you looked out the window, the child may turn to acknowledge that he is no longer totally alone. You will spend a long time in the tower, often longer than you imagined. Then a day may come when the child notices the door and leads you to it. You open the door. The child lets you hold his hand as you creep down the castle stairways, past the guards, out the door, across the moat and into the outside world. You will spend a long time exploring together. Maybe the day will come when the child, who has now grown older, say, ‘farewell I am ready to explore with others and by myself’.

- Shore (2003) p.ix-x

In this chapter the researcher will conduct a cross validation study as well as the literature control. The researcher will make use of colour to indicate the data by the different families.

• Family one:	Red
• Family two:	Blue
• Family three:	Green

4.1 CROSS-VALIDATION ACCOUNT OF THREE FAMILIES EXPERIENCES OF LIVING WITH ASD

Central storyline/core category: ASD is a **life changing event** with **pervasive emotional and social effects *"restricting"* the daily living of the family as a whole** *("it has a 100% implication in your life")*. The event threatens the **core family identity**, requiring the family to make **diverse mental**, **social** and **environmental adaptations** (adjustments) in order to deal with the changing family situation. **Family resilience** emerges as a resource of coping/adaptation in a family that has to live with ASD, demonstrated by a parental perspective that ***"it is getting better over time"***. See table 4.1 below.

TABLE 4.1: Cross-validation account

Themes	Categories
1. **Experience of pervasive emotional** and **social effects** *"restricting"* the daily living of the family as a whole	1.1 **Experience of emotional effects** in the **parental-sub system** resulting from being confronted with ASD as a life changing event • **Emotional turmoil** • **Position of not knowing** • **Yearning for interaction with the child with ASD and "***normal***" engagement** • **Mourning personal losses and loss of daily activities** 1.2 **Experience of emotional effect on siblings** 1.3 Experience of e**motional effects on extended family and friends** 1.4 **Experience of the demands of taking care of an autistic child on social interactions**

Themes	Categories
	- **Marital relationship** - **Relationship with self** - **Sibling identity and expectations** - **Relationships with extended family** - **Social relationships**
2. **Experience of mental, social and environmental adaptations** utilized by the family to deal with the changing family situation	2.1 **Experience of mental adaptations** 2.2 **Experience of social adaptations** - **Experience of parental role changes** - **Experience of sibling adaptation** - **Experience of “socializing wise”** 2.3 **Experience of environmental adaptations**
3. **Experience of family resilience** as a powerful way of coping and adapting.	3.1 **Experience of positive emotions** associated with the child with ASD within the family system 3.2 **Experience of the child with ASD described in positive terms** . 3.3 Experience of acknowledging the value of **support systems** 3.4 Experience of being **resourceful as a person**

The researcher will discuss each theme and provide the literature control in the following section.

4.2 THEME ONE: THE EXPERIENCE OF PERVASIVE EMOTIONAL AND SOCIAL EFFECTS ‘RESTRICTING’ THE DAILY LIVING OF THE FAMILY AS A WHOLE

With the families experiencing pervasive emotional and social effects that ‘restrict’ them in their daily living, there were a few categories identified that the researcher will discuss below.

4.2.1 Category 1.1: Experience of emotional effects in the parent-sub system as a result of being confronted with ASD as a life changing event

As the researcher spoke to the families, it was clear that for all of them the diagnosis of their child with ASD resulted in an experience of pervasive emotional and social effects on them as a family, which restricted the daily activities of the family. It was clear that for all the families there was an experience of emotional effects in the parent-sub system that resulted from being confronted with ASD as a life changing event. When the researcher spoke to the families they spoke about how they **experienced emotional turmoil** that was linked to initial shock and disbelief.

The family told the researcher about the time when they got the diagnosis of ASD for their at that time only son. For this family initially it was a very stressful time and when they spoke about when they got the diagnosis they exhibited a lot of emotion related to how they got to the diagnosis and how the diagnosis was conveyed to them. This family found this a very trying and emotionally draining time as they did not get a diagnosis right away when they noticed that something was different with their son. They said they had to go to many doctors and tell their story over and over before Ben was diagnosed. Mom said she felt that this took time away from them being able to start helping Ben and it was very traumatic to keep having to see different doctors and keep telling your story over and over just so they could refer you to someone else. Mom also said to the researcher that even after the diagnosis they were sent for genetic tests as one doctor thought that “ASD could not be the only thing that was wrong”. She said that this made the whole process even more traumatising for them.

Both mom and dad said that when Ben was diagnosed with ASD, even though they now had an answer and diagnosis, the family was left with a lot of questions. According to Shore and Rastelli (2006:68) a diagnosis of ASD can be seen by parents as a 'kind of death'. According to these authors parents must go through a time where they grieve after the diagnosis, as their life will never be the same again (White, McMorris, Weiss & Lunsky, 2012:457-465). Skellern, McDowell and Schluter (2005:413-418) composed a study to determine why so many parents have to struggle for a very long time before they receive a diagnosis. In their study they found that many clinicians, like pediatricians, do not have sufficient training on identifying a range of different developmental challenges that children may face. Weiss and Lunsky (2011:521) say that there will be many stressors in the lives of families where a child is diagnosed with ASD. Ben-Sasson, Soto, Martinez-Pedraza and Carter (2013:846-853) convey that these stressors can also include sensory aspects that can be very hard to deal with and understand. Smith and Elder (2010:189) claims that a diagnosis of ASD is very taxing for families and according to Karst and Van Hecke (2012:247-277), raising a child with ASD can be an overwhelming experience for a parent.

During the time that the researcher spoke to this family both parents said that for them their first encounter with the word 'autism' left them feeling cold and alone as they were told "your son has autism" but they say they were not told what autism spectrum disorder meant. They said they weren't sure what their son had and they were unsure where to turn for the answers they needed. They felt that the doctor who diagnosed their son should have told them what he meant with 'autism' or should have told them where to go to find out. The family spoke about their first encounter with the diagnosis and said that they did not receive any hope. Both parent's spoke openly and said that initially the worst was the uncertainty of what was going to happen and what should happen next. The family spoke about how they struggle to make sense of what has happened to their family, that they feel like they keep going through a very hard time emotionally and that they find it very hard to move past the initial diagnosis.

Robledo and Ham-Kucharski (2005:44) say that after having a child diagnosed with ASD, parents should allow themselves time to mourn for the child that was diagnosed as there will now be hope and dreams that will have to change and this will allow the parents to ‘move on’ and find new hopes and dreams for their affected child.

When the researcher spoke to the third family they said that it’s very hard to go through all the stages of grieving as you easily get stuck in a denial phase. They spoke about how the diagnosis for them meant that their family **“changed dramatically”** from that moment and they knew they went through a denial phase, an angry phase, and then acceptance. Kapp and Brown (2011:459) state that having a child diagnosed with ASD presents many challenges to the parents and other family members as ASD affects almost all areas of the families’ functioning. These authors (2011:460) further state that there is a unique emotional burden on parents that they need to cope with as well as a burden with regards to managing challenges like the child’s behaviour (Hodgetts, Nicholas, Zwaigenbaum, & McConell, 2013:166-169).

Eisenhower et al. (in Kenny & Corkin, 2011:16) found that parents with a child diagnosed with ASD experience significantly higher levels of stress than parents of children diagnosed with other disabilities. They claim that this is in part due to the impact of the diagnosis and the continuing psychosocial development and behavioural demands of raising a child diagnosed with ASD. It was clear for the researcher that parents face emotional turmoil after the diagnosis (Collins & Fauser in Kenny & Corkin 2011:1). Carbone, Behl, Azor and Murphy (2010:317) also say that parents who have children diagnosed with ASD have less satisfaction with their child’s health care providers than parents with children with other disabilities. Carbone, Behl, Azor and Murphy (2010:317) further claims that parents of children with ASD feel that health care providers do not have enough knowledge of ASD or the treatment of ASD, and struggle to make the diagnosis of ASD.

The three families all spoke about how they **worry or fear for the future** after the diagnosis. The families disscussed their **impaired future outlook,** which is related to the well-being of their child, as well as significant others. During the time that the researcher spent with family one mom, Jane, said to the researcher that she just can’t think about the future as she will then be overwhelmed. Her husband said that he is the one who thinks about the future but it scares him at times. This family said they need to get their son to a point where one day, he doesn't need to be a burden on his siblings. Solomon and Chung (2012:257) as well as Weiss and Lunsky (2011:521-528) state that a parent can only move forward from worry and fear after their child has been diagnosed with ASD if such a family has a comprehensive treatment plan. This will allow a parent to move from crisis to coping as many families can "over focus" on aspects like the long term outcome and forget to focus on their current family coping skills.

In this family both mom and dad spoke freely to the researcher about how much they worry and fear for their son's future. They both said the future is an aspect that they feel is overwhelming. This mother said to the researcher that she feels she cannot think about the future as she is the one who has to be positive and carry her family through this. She said that when she thinks about the future she gets very nervous and feels overwhelmed, and she then struggles to stay positive. Mom said that she feels guilty to have to say so but she feels its dad's job to think about and plan for the future. When the researcher spoke to dad he said that someone needs to think about the future, and that he has to, but that if he could choose he wouldn't want to be the one who has to think about it as he doesn't know what and how to plan for his son's future.

Woods, Mahdavi and Ryan (2013:1-2) speak about how the fear for their child's future can overwhelm parents after the diagnosis, to the extent that they are unable to focus on the present. During all the interviews that the researcher conducted with the families, this remained a very sensitive topic for them and it was clear for the researcher that for these families the uncertainty about their child's future remained a huge stressor (Maljaars, Boonen, Lambrechts, Noens & van Leeuwen, 2014:501-508). Bradley and Caldwell (2013:9-12) say that due to the differences of manifestation of ASD in different children it can be very hard for parents to determine what the long term outcome can be, thus affecting parents as they struggle to know how to plan for the future.

When the researcher spoke to family three, both parents said they worry about what will become of their daughter if they are no longer here. During the interview dad said that he thinks about the future but doesn't want his wife to worry about it. When the researcher spoke to the mother, she said you adjust your future expectations and you have to value what they do achieve in the present, even if that's different than what you hope for in your heart. Carpenter (2005, in Kenny & Corkin, 2011:16) states that family's change their outlook on the lives of their children's after the diagnosis and that the family experiences many conflicting emotions which is especially true with regards to their child's future.

All the families the researcher interviewed said that **financial worries** put a strain on them and that it had a lot of implications for their family. In a study done by Meadan, Halle and Ebata (2010:21), they stated that the family's financial situation is one aspect that causes stress in families where a child has been diagnosed with ASD. According to Viecili, Robinson, Weiss, Lunsky and Sloman (2012:303-305), it's very important that after a diagnosis a family receives proper intervention but they also claim that it can be very costly to provide all the interventions that a child will need.

When the researcher spoke to this family they said they can only afford the therapy their son is doing by taking funds away from other areas of their household, as well as by relying on family to assist them financially. This mother told the researcher that she worries about where the money will come from. Dad also spoke about how he doesn't get to see his family very often as he has to work very long hours so they can afford therapy for their son. This family had to have extra funds so their affected son could have schooling but he also needed a lot of medical interventions that's very costly, as well as a very restricted and costly diet. During the time that the researcher spent with this family, both mom and dad often said how the diagnosis of their son with ASD had placed a huge financial burden on them as a family. When the researcher spoke to mom she said that there are times when she feels very guilty as she doesn't work and she knows how hard her husband has to work so they can afford therapy and biomedical interventions for their son. She said that her husband say that she needs to be home as their son will need her during the day and that its more important than for her to have a job. This family said that it's a huge financial burden on them and the treatments and schooling is very expensive. They confirmed that finances place a lot of stress on you as you don't always know where the money will come from. Kirby (2005:11) say that even though many parents will treat a child's medical conditions associated with ASD, many children will never make a full recovery to full health.

When the researcher spoke to mom she said that due to financial obligations she needs to work as well as her husband, otherwise they can't afford therapy for their daughter. Mom spoke to the researcher and said that she wanted to be home with her daughter but there is no way they can get by on one salary. Dad said that he feels guilty that his wife needs to work as hard as she does, but that they don't have a choice. Both parents spoke about how they should have been able to give their son other things financially but that they can't as their available finances needs to be allocated to her therapy. They also spoke about things that they have planned for financially that they just can't do now. They explained that there are things that have to wait for in life that they thought they will be able to do, small things like painting their home or holidays. Shore and Rastelli (2006:342) claim that parents need to investigate sources of financial aid so that this burden can be eased, as well as that parents need to consider major lifestyle changes as treating ASD can be extremely draining on finances. In all of the families that took part in the research it was clear to the researcher that they all had to make big changes with regards to their finances after the diagnosis of their child with ASD. In most cases they have to take finances away from family activities and even family needs (Ouyang, Grosse, Riley, Bolen, Bishop, Raspa & Bailey, 2014:1518-1527). They cut back on holidays and maintenance and repairs to their homes and other basic family activities. Shore (2003:27) said that often one parent will work late leaving the other parent frustrated at home.

As the families told the researcher about **worries and concerns over educational and professional resources,** the researcher realised that these families would do whatever they could in order to help their children. Estrella (2013:24-25) say that it's very common for parents to struggle to find the correct interventions for their children after being diagnosed with ASD. Tongerloo, Bor and Lagro-Janssen (2012:1531-1538) say that practitioners need more training so they can diagnose more effectively. Estrella (2013:24-25) further writes that it's very hard for people from outside the family to understand what the family needs as each family has such unique needs. Adding to the problem of finding services for a diagnosed child is that many of the available therapies have not been proven to be effective in treating children diagnosed with ASD (Farrugia, 2013:8-14). Weiss and Lunsky (2013:303-304) claim that providing parents with interventions and professional resources gives parents the ability to become a part of a group where they feel that there are people who completely understand their day to day challenges. Cridland, Jones, Magee and Caputi (2014:213-222) say that when looking at interventions, family focused intervention should be considered as a very high priority.

When speaking to family one, they told the researcher that their extended family assisted them with researching the best interventions that were available at that point. The researcher was told that Ben's mom and grandmother worked in the UK where they knew that Ben would be left sitting in the hall all day with a classroom assistant, and that they did not want that for him. When the researcher spoke to mom she made it clear that it's now her full-time job to ensure that she knows about the best research that is available. Nadesan (2005:219) say that families need to find out what educational resources they have access to so that they can make informed decisions, and according to Shore and Rastelli (2006:34) parents should start to read as much as possible about their child's condition, so when they have to take decisions with regards to interventions, they understand and know their child's needs, since nobody knows the child better than their parents.

When the researcher spoke to family two, Grace (mom) said that she worries about Elton's education a lot. Even though Elton has ASD his mother is still hoping for him to be able to go to school. She said that she realises as he gets older things like school will get harder to manage and she fears that when they reach that point she will not know what to do. When the researcher spoke to dad he said that every moment is important to spend with Elton as he only learns when they are there, actively teaching. He feels that there aren't many people that can teach him so dad feels they can never be away from him as he will lose out on learning time. They feel that they have to continuously be researching so they know about every therapy or possible way to help Elton live a better life.

Estrella (2013:25) says that at the time of the diagnosis of a child with ASD, parents have a need to receive positive information and by giving them information on treatments that's available it allows them some hope. McMorris, Cox, Hudson, Xudong and Bebko (2013:42-49) speak about the importance of accurate early diagnosis. Perumal, Veeraraghavan and Lekhra (2014:791-797) also state that there are many things to consider when looking at interventions for the child affected, that can give the family some quality of life.

Family two spoke to the researcher and said that when their daughter was younger they did not have appropriate educational services available in South Africa, and they feel like they have lost time, and needed her to catch up now they have found appropriate educational services. They said that it's very important for them to know what is out there and what they can use to assist their daughter. In a study done by Meadan, Halle and Ebata (2010:26) families who have access and knowledge about which educational services they have access to experience less stress than families that don't know what services they have access to. Bradley and Caldwell (2013:11) and McMorris, Cox, Hudson, Xudong and Bebko (2013:42-49) state that taken into account that each child has their unique challenges, it's important to find a programme for each child that will match the needs of the child and in doing so it will support the parents. Siller, Reyes, Hotez, Hutman and Sigman (2014:433-446) further supports the idea that what the family's needs are should be taken into account before services are undertaken.

The researcher realised that the families all **experienced helplessness and guilt related to the child with ASD** as well as **the siblings,** not only about the diagnosis but related to everyday family life. During the time that the researcher spent with these families she was able to see that they had a lot of emotions about their child's diagnosis that was difficult for them to deal with, such as feeling that they did something that caused their child's ASD. For most families this was one aspect they felt they wished they had known; why their child was the one who got ASD.

Then there were some parents who had so much guilt about having to spend all the families' available resources on one child. They felt guilty for not being able to provide specific luxury things for their "normal" children and on the other hand they felt guilty if they did spend money on any luxury activities because that money took away from their child's therapy. The families also spoke about how they felt their "typical developing" children had to grow up quicker than they would have if they did not have a sibling with ASD. The "typical developing" sibling(s) had to "parent" the child with ASD at times by knowing what the affected child can eat or play and so on. When the researcher spoke to family one, both parents said that at times they feel guilty as Ben gets more attention from them and they want their other "typical developing" children to know that he needs more attention as they can do things for themselves and Ben can't. They said that more of their available finances in the family go towards Ben's schooling, therapies, food and medication. Jane spoke about how her expectations for Ben's sister have changed quite a lot. She said that she is older and can understand more so they expect more from her, and this makes her feel guilty. Mom told the researcher that her oldest daughter will go to school in the next year and they would have put her in a private school but because Ben will still need a lot of therapy in the next 3 years, they will not be able to afford it and she will have to go to a public school. During the researchers' time with this family, she could see that this aspect was really hard for them to handle. Slifirczyk, Krajewska-Kulak, Brayer and Maciorkowska (2013:128) say that many parents need to change their life plans and objectives after they have a child who is diagnosed with ASD. This has a "multidimensional" impact on a family where a child is diagnosed with ASD. They (Slifirczyk, et al. 2013:128) claim that these aspects can lead to feelings of frustration and depression in parents. Seymour, Wood, Giallo and Jellett (2013:1547-1554) reports that parents can have many overwhelming feelings after the diagnosis of a child with ASD.

When the researcher spoke to family two, Grace (mom) told the researcher that she feels very guilty that she has to be the one that stays home, while her husband has to work, but they have decided that she must be at home to assist Elton with what he needs. She spoke about how she would protect Elton in public places and she feels he can't stand up for himself so she has to stand up for him. Slifirczyk, et al. (2013:128) state that there are many families that after the diagnosis of ASD has one parent that takes over the role of primary caregiver and the caregiver may at times keep other people at a "distance", which can cause conflict between the caregiver and others. She spoke about how she was feeling very guilty that she never knew that Elton was in pain and that she would have done something if she knew. Farrugia (2013:8-14) states that many children have a clear medical base for some of the challenges that they face and if addressed, the child will come out feeling much healthier, but this is something that is very hard to scientifically prove and most research done on medical interventions come out proving that it's not very effective. However, the researcher could see that after starting the medical intervention, this specific child felt much better physically which made mom and dad feel much less guilty. Dad then spoke about how they feel very guilty every time they spend some time away from Elton. He said that the reason for this is that when they are away they feel that Elton isn't getting the intensive one-on-one that he would get if they were there. He said that they never felt guilty when they left their "typical developing" daughter with granny or a friend, but they feel this is not the same for Elton as he doesn't learn when they are away. Shore and Rastelli (2006:95) say that many children can greatly benefit from medical interventions for some conditions associated with ASD. Both mom and dad said that they feel very guilty about why Elton got ASD as they will never know if it was something that they did wrong that gave him ASD. Tuteur (2013:1) says that it's better to be powerful and wrong than to be completely powerless when it comes to managing a child's destinies. Tuteur (2013:1) made this statement after she realised that many mothers would blame themselves for their child's diagnosis of ASD, even if they knew they are probably wrong in their thinking of what gave their child ASD. Lange and McDougle (2013:2) say that researchers are currently desperately trying to find out what causes ASD so that this can improve the accuracy of diagnosis as well as lead to the future development of better treatments. Sunita and Bilszta (2012:41) speak about the importance of early diagnosis and how children with risk factors should be screened for possible diagnosis of ASD early on, making it very frustrating for parents when they struggle to get a diagnosis for their child. Mayes, Calhoun, Murray, Morrow, Yurich, Mahr, Cothren, Purichia, Bouder and Petersen (2009:1682) say that there is an urgent need for children to be diagnosed at an early age. They (Mayes, Calhoun, Murray, Morrow, Yurich, Mahr, Cothren, Purichia, Bouder & Petersen, 2009:1682) further state that early diagnosis can reduce the overall cost of ASD on a family and community as these children will need less intervention in the long run due to the early diagnosis.

During the interview, guilt was identified as one of the aspects that this family struggled with after the diagnosis of their child with ASD. Tongerloo, Bor, Antoine and Largo-Janssen (2011:1531) state that because of the hardships that parents face after the diagnosis of their child with ASD, a lot of these parents struggle with depression and related diagnosis. They said that they will always wonder what gave their daughter ASD, and if it could have been something that they did wrong. They also felt a huge amount of guilt as they feel that they had waited very long before they received a diagnosis for their daughter and doctors and nurses did not understand when they told them there was something wrong with their child. Tongerloo, Bor, Antoine and Lagro-Janssen (2011:1532) say the younger the child at the age of diagnosis, the better chance there is for regaining skill. But for them the guilt that they feel is not only related to their diagnosed child but also their 'normal' developing child. The family said that it was hard for their normal developing sibling and they feel guilty about that. Schuntermann (2009:298) states that it's very hard for a typical sibling who has to grow up with a sibling that has certain development delays and such a sibling will face many different obstacles. The family said that their son wants to understand his sister (diagnosed) but it's hard for him because he is at an age where he gets friends over and then the ASD doesn't exactly 'fit in'. They also spoke about the guilt that they felt because of their financial situation, they said there are things they should have been able to give their "typical" developing son that they now just can't give him because of how expensive their daughters therapies and schooling are. Kurtzer-White and Luterman (2003:234) report that a parent with a disabled child does not only experience grief once but that it must be seen as a process over the child's developmental life.

These families also **experienced anger (directed to doctors), frustration and a great amount of sadness**. When the researcher spoke to all three families they made it clear that they felt angry about the care they receive from medical doctors, both during and after the diagnosis of their child. Even though all of the families who participated in the study received the diagnosis that their child had ASD more than two years ago, they all still, years later found it very hard to even speak to the researcher about the diagnosis. According to Olivie (2012:742) primary care pediatricians will need to have enough knowledge and understanding of ASD as they are usually the first point of contact and play an important role in early detection.

Tonerloo, et al. (2012:1531-1532) state that children with ASD often visit their general practitioners' office much more often than other children since they have more medical challenges than other children. Tonerloo, et al. (2012:1531-1532) state that because these medical professionals have so much contact with these children, they play an important part in early diagnosis but unfortunately they are not trained to diagnose ASD, thus many children go undiagnosed for a very long time and it becomes a very long road for parents to have their child diagnosed. Tonerloo, et al. (2012:1531-1532) say that general practitioners should be trained so they can assist with early diagnosis and a more positive experience for families with a child that may be diagnosed with ASD.

When the researcher spoke to this family both parents said that the time surrounding the diagnosis of their son was very hard. They explained that it took a very long time for them to receive the diagnosis for their son and this put a lot of emotional pressure on them. They said that even after they received the diagnosis of ASD, their ordeal wasn't over. The doctor who diagnosed Ben kept saying that he gives them the diagnosis of ASD but that it's not to say that there isn't more wrong with Ben. Mom said this caused them a lot of uncertainty and the tests that needed to be done to rule out other disorders, had to be done 3 times as they kept making mistakes with the blood work. She said it should have taken 3 months but ended up taking 9 months to get the results. She said that the tests came back saying that he only has ASD.

Both mom and dad said that during the time they got the diagnosis they did not feel like any medical personnel was supporting them in a time of great uncertainty. The researcher could see when they spoke about the diagnosis they were very emotional. Both mom and dad said that when Ben was diagnosed, even though they now had an answer and diagnosis, the family was left with a lot of questions.

They told the researcher how they got to the diagnosis and how the diagnosis was conveyed to them. According to them the doctor told them to take Ben and put him in an institution and forget about him as he felt it would be too hard for the family to deal with his needs all the time. The family said they did not receive any hope and did not know where to turn. There has been a lot of research conducted in the past 5 years that look at how parents and physicians interact, as many parents will have primary contact with a primary health care provider. According to Carbone, Behl, Azor and Murphy (2009:317) primary health care providers do not accurately advocate for parents when it comes to accessing adequate services. Olivié (2012:741-749) say that many parents feel that they did not receive the level of care from their primary health care provider and that primary health care providers need to be adequately trained to deal with both giving parents the diagnosis of ASD, and being able to direct the family to trained service providers. Sari (2014:65-80) says that when families consider therapy, professionals should look at using play-based home support as this will cause minimum disruptions to the family's already disrupted routine.

The parents of family two first spoke about how they felt the doctor told them about the diagnosis, and how even having a diagnosis from an 'expert' in the field it did not answer any of their questions. Mom said that when the specialist told them that their son had ASD he did not show any compassion or empathy, nor even explain what ASD was so that they could understand what he said. When the researcher spoke to the mother she made it clear that the diagnosis affected her entire family but she mentioned that when they received the diagnosis they did not know anything about ASD. Slifirczyk, et al. (2013:123) says that the diagnosis of ASD places a great amount of stress on a parent that is accompanied by social and behavioural difficulties and feelings of guilt. Sakai and Smith Myles (2005:47) states that parents can feel like they have failed if others say things like, behaviours in the child affected by ASD is due to bad parenting or spoiling the child.

Grace said to the researcher that the way in which the doctor gave them the diagnosis sounded like a death sentence to her and the little boy that she had in her mind, that little boy who was supposed to go fishing with his dad and play rugby. All her hopes and dreams for her child died that day. Grace told the researcher that she asked her husband in the car on the way back from the doctor if ASD was like Down syndrome and if they were going to have a child in the house for ever. This dad said that they could not even receive therapy from a psychologist as they just don't 'get' their situation. Viecili, Robinson, Wiess, Lunsky and Solman (2013:304) say that parents need to be put in touch with other parents who have a child diagnosed with

ASD. These parents will then have a way to speak to other parents that have similar situations, difficulties which will give the parents a way to process their feelings within an acceptable environment. When parents get together they can learn from each other and address their negative emotions.

Viecili et al. (2013:304) further say that if parents speak to other parents with the same chronic difficulties, they will be able to tolerate and accept their frustration and life situations. This will increase their ability to practice healthy psychological acceptance. All of the families that took part in the research said at one stage they either wished they had other parents to speak to, or that they were very happy they had a support network in other parents. They also said that only other parents who had a child diagnosed with ASD could fully understand their situation. When the researcher spoke to family three, they said that they feel better about their daughter's diagnosis of ASD after they have managed to put her in a school where she gets all the therapy and education that she needs. They said it was very hard to find educational and therapy interventions that she (daughter) needed as there isn't many places that a child and families can go to get assistance after the diagnosis. Solomon and Chung (2012:257) as well as Smith and Anderson (2014:114-122) state that creating an all-inclusive treatment plan for their child is part of what helps parents move on from crisis to coping. During the time that the researcher spent with the families she identified this as one aspect that allows a family to feel like they are in control of their lives and that they will be okay. Once the child receives appropriate interventions, parents and families start to manage with daily activities. Both parents spoke to the researcher about how frustrated they felt about doctors at that point.

The parents told the researcher that they took Helen back to the specialist who diagnosed her as they had paperwork that he needed to complete and they wanted him to see how much skill she had gained. Both parents said that after that visit they will never go back to that doctor as they felt he just doesn't get it. The doctor said in front of Helen 'see she is not capable'. The parents said this made them feel helpless all over again and that even Helen realised that the visit upset them and that it upset her as well. Andre went as far as to say that to him the doctor was a "bastard" for the way he acted. Andre said that they told him how much gains their daughter had made but that he did not even listen to them.

The parents spoke about how they felt that doctors who did their degrees more than ten years ago don't realise that things are not the same as it was back then. According to this family, doctors don't realise how much each milestone means to them and that it's the most important things in their lives now. Sicile-Kira (2003:58) state that many parents as part of the grieving proses will get to the point where they are angry and many doctors still think (incorrectly) that ASD is incurable and parents vent their anger towards doctors or medical personnel. Solomon and Chung (2012:253) say that many parents have a long journey to get to the stage where they have a diagnosis and when they reach the diagnosis at long last, they may have developed a feeling of mistrust in the helping-professionals as they may feel the amount of time it took for their child to get the diagnosis, only cost them time.

These families spoke about an **intense sadness** and **loss** they felt after the diagnosis. At the time that the researcher spoke to the family, mom was expecting a new baby. She said she felt the probability of the baby being a boy makes her worry and she feels sad that she struggles to enjoy the pregnancy. John told the researcher that with the diagnosis, even though he loves and cherishes the boy who his son is today, he feels like he lost out in knowing how his boy would have been if he did not have ASD. Both parents spoke about how they long to be able to communicate with their son, especially dad, who had a great desire to have a conversation with his son. The family also spoke about the loss of activities and relationships with people outside of their family and in some instances even the loss of family that didn't understand their son's unique needs. They also spoke about activities and outings that because of the diagnosis they now can't do anymore. Before the researcher left, mom also added that they had to make peace with a lot of dreams and plans that they had for their son and their family that now would never happen or had to change dramatically. Ariel and Naseef (2010:1) says that the sadness that you feel from grief never goes away. That grief will always make you feel sadness and emptiness created by significant losses. Ariel and Naseef (2010:1) claims that having a child diagnosed with ASD and losing the dreams you had for that child, is considered a significant loss. Wakefield and McCarthy (2010:iii), a mother with a son diagnosed with ASD, said that the doctor should not judge her but if she dies she will take her son with her as she is all he has. She (Wakefield & McCarthy, 2010:iii) says that she is the only person who loves him.

While speaking with this family the overwhelming and intense amount of grief and sadness that crippled them was very evident for the researcher. They said that with the diagnosis came a tremendous feeling of sadness and they don't think it ever goes away; "you just get use to that feeling". For the researcher the intense sadness was very evident in both mom and dad, and became progressively more open as the day went on, and they allowed the researcher to see the emotions they experience. When the researcher spoke to Elton's little sister, even she was distressed when speaking about her brother and their daily activities and routines.

When the researcher spoke to dad he said that he only has one desire: to ask his son if he is happy and to have his son answer and even though his son can't answer he said that he longs for the day that he can. When dad told this to the researcher he was very emotional. He said that not knowing if his son is happy or if he is in pain is one aspect of the ASD diagnosis that he doesn't think he will ever be able to handle. Mom then told the researcher that she knows this is extremely hard for dad but that she struggles with the knowledge that her son was in pain and they never knew. This family told the researcher that you have to make peace with the dreams that you had that will now never be. Mom told the researcher that the dreams she mourns for mostly is the "daily things" like having your baby sleep in his own bed, having your child eat with the family and then things like playing rugby and going fishing with his dad and being able to have a conversation with your child.

They spoke about how hard it is when people around you, like family and friends, don't recognise what your family needs from them in this very hard time and this can increase the feeling of losing everything. She also said that it's very hard to see family and friends who are the same age as Elton as you then become acutely aware of how far behind Elton is and how much developmental milestones you are losing out on. She said that at times she doesn't want to see family and friends with children of Elton's age as it causes her too much pain. She also spoke about how hard it is to see other children on playgrounds that will talk to Elton and then he can't talk back or play with them and then at times she has to "jump in and keep him safe" from the questions of other children. Zaidman-Zait, Mirenda, Zumbo, Wellington, Dua and Kalynchuk (2010:1269) say that a lot of parental stress after the diagnosis of ASD of a child is due to a lack of social support and ineffective coping strategies.

While speaking to this family the researcher became aware that both mom and dad had a really hard time relating to the diagnosis of their daughter with ASD. This family had said those personal moments that they should have been able to have with their daughter they feel are things that they may never have with her. They spoke about things like being able to speak with your child and to converse with them, as well as small things like reading a book together. These are all things they now feel they might never have with her. They also felt like daily activities that they should have been able to do with her, like going to birthday parties and on holidays, are all moments that now are so different or can't even happen. During the researchers time with this family it became more evident that for them the diagnosis meant 'loss'. They felt that they had lost out previously when there weren't services in South Africa and they now have to make up for that time. At one stage dad asked the researcher "how does a parent make up for lost time"? He felt each moment that they have lost would have been a teaching moment that she could have been learning. The family did not only speak about the loss of activities but also the loss of their own dreams. Mom told the researcher about very personal mother daughter moments that she felt they have lost out on and that she feels they might in time have some of those moments together. Mom further revealed not being able to come from work in the evenings and have special time with her daughter as most of the time getting the daily things done at night, like having a bath, takes a lot of energy and fighting and that this means they don't get a lot of time just to be together as a family. Both parents spoke about friends and acquaintances that they have lost contact with as there are times when it's too hard to go out with their daughter. Cashin and Woodgate (in Kenny & Corkin, 2011:16) state that parents grieve for the loss of an idealised child, the loss of 'normal' parenting, and the loss of a 'normal' family. They also speak about a loss of self-image, family-image and a way of life, which according to them implies a different parenting journey with different hopes and dreams for the family and the child. During the many hours that the researcher spent with these three families she realised that all of them had to manage the feelings associated with "loss" in different areas and aspects of their lives. For all of them there were aspects associated with loss that they could manage but there were also aspects within their "loss" that was very hard for them to manage every day. Paradiz (2005:x) said that the only way she could foster self-respect during a time of intense loss after her son was diagnosed with ASD was to start to write literature and poems as it made her feel less alone.

All the families spoke about the **frustration** that they experienced since the diagnosis of their child with ASD. Their frustration was mainly around others that did not understand their unique and different situation as well as frustration with struggling to find their way around the diagnosis. Skellern, McDowell and Schluter (2005) say that many parents will first seek medical advice when they realise that their child is behind in certain developmental areas. They (Skellern, et al. 2005:413-418) say that more and more there will be a responsibility for the primary healthcare provider to know where to refer such patients so that families can get assistance sooner so that families don't spend so much time struggling to get their children diagnosed. When the researcher spoke to this family she realised that they were very frustrated with people who made comments and judgments when they did go out in public. They then started to tell people when they were out in public that their son had ASD. They said they find it very frustrating to have to explain, especially to family, that their son has different needs than other children, over and over again. Mom said that the older people in the family just couldn't understand and that she felt they did not want to understand. She said that she feels it's extremely frustrating when you try a new diet or when you read up on something new and then the product isn't available in South Africa. Both parents said that they felt frustrated that there isn't more they can do for their son. With mom being very far away from her family (she is from the UK) she felt especially frustrated about struggling with her husband's family that did not understand Ben's diagnosis. For this family it was important to tell people that their son has ASD if they went somewhere and he did something inappropriate. They said that people were very ignorant and they found that hard. When the researcher spoke to the mother she said that she finds it very frustrating that she needs to explain her son to the family over and over again.

When the researcher spoke to this family they said their frustration was around family and friends who didn't understand their situation and they made the decision that they will then cut all ties with these friends and family. They further felt very frustrated with how hard it is to find appropriate medical and educational services for their son, and doctors and medical personnel that they have encountered, saying that they don’t show the necessary empathy with parents and they felt frustrated struggling to find information and support from the doctor after the diagnosis of their son.

The family said that they have a lot of frustration with people who think Helen is slow or incapable. They said that she understands everything, and she is not stupid or slow and they want people to realise that. They said they know she looks at other children and she knows that she is different but they don’t want her to think that she is not good enough. The family further noted that they felt quite frustrated with how difficult it was to initially find services for their daughter. Her brother was also very frustrated as he did not understand why rules differed for his sister and why she could get away with things he couldn’t. He further felt that when he brought his friends home she ruined their play-interaction as she wanted to join them but did not have the skill she needed to have appropriate interaction with him.

Looking at how frustrated the families were when they spoke to the researcher it was clear that this was a big aspect for the families during the time that their families live dealing with the diagnosis of a child with ASD. During the conversations as the researcher spoke to the families, it was clear that all three families yearned for some interaction with their child affected with ASD. All three children diagnosed with ASD had very little verbal speech and all the parents had a yearning to spend time with the child in communication. All of the children further had challenges with behaviour that made this yearning of the parents to communicate (verbally) with their child very difficult. Interaction with the child remains the biggest yearning that the families have and they all said to the researcher that interaction is the one thing that if they have, they will be okay. These families all spoke about an **experience of yearning for interaction with their child** who is diagnosed with ASD.

When John talked to the researcher he spoke about the yearning he has to have ‘normal’ interaction with his son who is affected by ASD. He said that he misses being able to just talk to Ben and have him understand and answer back. He spoke about sadness for the loss of the ability to be able to have that normal conversation. John said that the aspect that he feels takes away most of the moments he should have had with his son is communication, and language is what he yearns for. They spoke about how they really longed for interaction with their son and that this aspect was very difficult for them and remains to be one of the hardest challenges they are faced with. Elton's dad said that it's extremely hard for him to not be able to ask his son if he is happy. For mom the hardest aspect is not being able to know when he is feeling sick and that causes a lot of guilt. When dad spoke to the researcher he said that they want that interaction with her, but they feel like they can't have the interaction at this point, but he hopes there will be a time where they can have proper interaction with her. Shore and Rastelli (2006:186) state that the most difficult part of the ASD diagnosis for a parent is the communication aspect.

The researcher was able to see that dad especially really had a need to speak to his son verbally about everyday activities and he found it very hard not to be able to speak to his son. The dad of the second family also had a great need to speak to his son. Mom wanted communication with him but not to the extent that dad needed interaction. It was evident that when the researcher had spoken to the third family that, as in the previous two families, dad again had a great desire to have functional spoken communication with his daughter. In all of the families the mothers also hoped for communication but time and again it was the dads who spoke about their yearning for interaction and communication with their children. Szatmari (2004:7) said that for many parents the lack of social reciprocity is a very hard aspect of an ASD diagnosis.

The families told the researcher they felt that after the diagnosis they **experienced a position of not knowing** what the outcome of the diagnosis will be. While speaking to all three families the researcher noticed that thoughts of the future were very intimidating and most of the mothers felt that this was an aspect that the dads needed to focus on. The families all thought they would give this aspect attention when the children were older and they knew how their long term future would be. For the immediate future the parents were all worried if the children would be able to attend school and if they would be able to cope with school and the demands that this would place on them with regards to academics and friends. All of the families told the researcher that they just don't know what the outcome for their child will be and this makes planning for anything related to the future very difficult. These parents also didn't know if their children would someday be able to speak or even live independently. Kogan, Blumberg, Schieve, Boyle, Perrin, Ghandour, Singh, Strickland, Travat and van Dyck (2009:1395-1403) say that when parents are in a position where they don't know what their child's long term outcome will be, it can be very distressing for them.

This family told the researcher that there just aren't any answers and they feel the answers stay out of their reach. When the researcher spoke to mom she said that it's dads work to worry about the future as she doesn't have the emotional capacity to worry about that as well. Mom said that nobody knows what the future will hold and they have to live with the knowledge that they don't have all the answers. They also said that they never know what therapies exactly will work for their child, so "you have to try everything so you know you have done all that you can". The family said to the researcher that they get scared to even make a simple decision as they don't know how their choices will affect their son in the future as they don't know what the future will hold for their child. In this family dad said to mom that it's his job to worry about the future and that she just has to worry about the everyday activities. Mom said that she hopes one day her son will be able to attend school and she worries about whether other children will be cruel to him or what the outcome will be. When the parents spoke to the researcher, dad said that since the diagnosis there is an element of sadness in their lives as well as when they think of their daughter's future. Dad told the researcher that they don't know what the future holds for their daughter and they worry about what will one day become of her if they are no longer there. They further spoke about how you just have to let go of everything you hoped for your child and you have to celebrate all the small things. They said they have to make peace with the fact that there will always be things they just don't know what the outcome will be, but they have learned to live with that knowledge.

4.2.2 Category 1.2: The experience of emotional effects on the siblings

When the researcher approached the families the parents were all very eager to participate, as well as the brothers and sisters. In this study the siblings were all 5 years and under except for one brother who was aged 10 years. The siblings all spoke to the researcher on a daily basis and knew her well as their brothers and sister attended the center were the researcher worked. The researcher did home sessions for all of the families and thus the siblings felt at ease speaking to her. This sibling, aged 5 years, drew a picture and spoke to the researcher. According to Chan and Goh (2014:145) there is an emotional effect on the siblings of the child affected with ASD. Chan and Goh (2014:144) say that parents need to recognise that the diagnosis of ASD will have a big effect on the other siblings. Atkin and Tozer (2014:225-242) agree with this when they say that even adult siblings struggle when they have a sibling diagnosed with ASD. When the researcher spoke to mom and dad as well as the sibling, and from data gathered from the drawing she made, it was clear that the sibling experienced feelings of embarrassment, frustration, and anger. Data suggested that at times she (sister age 5 years) feels like a victim due to the challenges that the family face after her brothers' diagnosis of ASD, and she craves attention from her parents at times. For the older sister (age 5 years) in this family, data indicated that she wanted to feel recognised and acknowledged as a person in her own right and that she strives for individuation. Some of the data indicates that she feels embarrassed by her sibling who is on the spectrum at times. Further interaction with the data revealed that she wants people to know that she is different from him (the affected sibling) and that she wants to be seen as 'normal'. She has a sense of having superior skill and control over the affected sibling and sees herself as the one who holds all the skill and control over the affected sibling. She places the blame completely on Ben for isolating himself from others. She wants to be seen as the 'good' child and her affected sibling as the 'bad' child. Data does indicate that she has a positive sense of belonging and that mom is the dominant figure in the family. The data suggested that according to the drawing that Sally drew about Ben on the spectrum was that Ben was the focus in the family as well as in her own mind. The data suggested that Sally had feelings of insecurity and inadequacy and she relied to a certain extend on fantasy to make sense of her world.

When the researcher spoke to family two she realised that both mom and dad are very worried about Elton's sister as they felt she was vulnerable and they were very aware that she would face many different challenges due to her brothers' diagnosis of ASD. Both mom and dad also said that she missed out on quite a lot of things because she had to grow up much quicker than she would have if her brother didn't have ASD. They were very worried about how different her future would be now that she had a brother with ASD. For this family analysis of a drawing of Elton's sibling

Kate, suggested that she might have feelings of inferiority. There were also signs that suggested that denial of emotionality as well as some form of denial/repression of thoughts regarding her brothers' body functions (like voiding in his pants). Some data suggests that she sees her brother as presenting feelings of inadequacy as well as his need for warmth and love. All indications are that her drawing suggests tension, possibly with attempted rigid control of impulses and fantasies.

When the researcher spoke to Helen's brother (Donavan age 10 years) he said that it has been very hard for him having a sister diagnosed with ASD. His parents reported that it has been very hard for him to understand and deal with the diagnosis. Donavan spoke to the researcher and said that he thinks Helen just does things to make him mad. He believes that she can get away with things he is not allowed to do. He felt that his sister does not understand kindness and sharing. He also said that his sister was "brain dead" and that she was born that way. It's very important that she is in a good mood otherwise she is very difficult to manage and when she is screaming he struggles to study for school tests. Even though the relationship between his sister and himself is difficult for Donavan, he told the researcher that he thinks it's even harder for him because he has to come home after school and can't stay at work like his parents. Donavan also felt that he needs alone time with his parents away from Helen so they can do 'normal' things as he feels that someone always has to watch his sister and she can never be alone. He was also very unhappy that his sister went along with the hunting trip and that she ruined his trip by her actions that weekend. Social interaction with his family away from home also proved to be problematic for Donavan. He also said to the researcher that he finds it hard that his sister gets to spend more time with his parents than he does.

Donavan struggled to understand the different ways of discipline that there is for him and his sister, and to understand that she doesn't always know when she is doing something wrong. He felt that his sister knew that she could get away with more things so she used it. So she can scream and then get what she wants.

4.2.3 Category 1.3: Experience of emotional effects on extended family and friends

This was a big part of the diagnosis for families. When the researcher spoke to all three families it was clear that there were many emotional effects on the extended family and also on friends after the diagnosis of a child with ASD. When the researcher initially contacted the families she wanted to speak to the grandparents as well. Emotionally it was very hard for the grandparents to even speak to the researcher about how they experienced the diagnosis of a grandchild with ASD. They, the grandparents, were very concerned about the well-being of their own children and said to the researcher that they wished they, as the grandparents, could take on the “burden” of ASD for their children to spare them the pain that they can see they are going through. The grandparents initially struggled to be honest about how overwhelmed they felt about the things they saw their children struggle with and the overwhelming feeling that there was nothing they could do to help their own children cope and manage better after the diagnosis of their grandchildren with ASD (Sullivan, Winograd, Verkuilen & Fish, 2012:484-494). Many of the families also made a conscious decision only to surround themselves with people who would understand their situation. According to Doheny (2014:1-15) it’s very important that a family maintain their social relationships with their friends after the diagnosis of their child with ASD.

When the researcher asked this family if she could contact the grandparents, they gave their permission. The grandparents on the mother’s side lived in London at the time of the interview and the researcher contacted them via e-mail. This grandmother was very worried about the diagnosis as she did not want her own daughter and her family to have to cope with the demands that the diagnosis brings. She said that as the grandmother she wanted to take Ben and raise him herself so that she can spare her daughter the pain. She also struggled to know that she was so far away from them and that all she could do was provide financial assistance.

During the conversation the researcher had with this family they said that it is important that their family and friends understand their situation, not only their son and his special needs, but also what this experience meant for them as a family.

They said that they wanted them to understand that if they say they can't go with the rest of the extended family on holiday or even just for a meal, they would understand why it would be hard for them.

This family made it clear that they did not have any family as a support system. When the researcher spoke to them they said their family, who wants to be a part of their support network, is unable to assist them as the grandmother is not healthy and lives far away. This family said they have made friends with other families who have a child diagnosed with ASD and they choose to use them as a support system. They said that this makes them feel like for the first time they have friends who understand their situation and who will not talk about them when they leave, but they find it hard at times not to have family who can help out. Suppo and Floyd (2012:12-26) as well as Hall (2012:111-122), say that it's very important for families to have a support network that they can rely on.

4.2.4 Category 1.4: Experience of the demands of taking care of an autistic child on social interactions.

When the researcher spoke to the families, they said there were many aspects of their **marital relationships** that changed after their child's diagnosis. All the parents said they are very aware of the high divorce rates amongst parents who have a child diagnosed with ASD. For the researcher it was clear that there were a big difference between the aspects that the mothers spoke and worried about and the aspects that the dads spoke and worried about (Estrella, 2013:24-28). Viecili, Robinson, Weiss, Lunsky and Sloman (2012:303-304); Slifirczyk, Krajewska-Kulak, Brayer and Maciorkowska (2013:123); Estrella (2013:24-25); Andreica-Sandica, Patca, Panaete and Andreica (2011:479) all state that when a child is diagnosed with ASD there are many demands placed on parents affecting most of their life, including marital relationships and relationships with themselves and others.

When referring to their spouses, the dads were all worried about the fact that their wives had to take on a lot of the daily struggles with their affected child and that the moms still all needed to be there for their families. The dads mainly worried if the moms were coping and if they were overwhelmed. The mothers spoke to the researcher and said they will do the daily struggles that they face but the dads had to work very long hours and they (as a family but also as a marital couple) did not see the fathers very often as they only got home from work very late. Johnson (2012:555-565) says having a child diagnosed with ASD can affect couples in many different ways. During the time that the researcher spent with this family the mother and father both said that all aspects of their marriage changed after the diagnosis of their son with ASD. The families all said that aspects in their marriages changed after the diagnosis. This family said that the diagnosis is very hard on everything, even on a marriage. Dad said that nothing (not even your marriage) stays the way you have planned it, because as soon as you think you understand one aspect of your son's diagnosis, things change all over again and you start at the beginning.

They said they are grateful as they can support each other through this. When the researcher spoke to mom she said that she is lucky to be married to her husband since he is the one helping her get through this. Dad said that there are times he worries about his wife, because she has to take on a lot during the day when he is at work. He also worries as she is very far from her family and her support system. They said that they don't often have a chance of having alone time as mom isn't used to having someone else look after her kids because of where she grew up. Tuniali and Power (2002 in Lin, Tsai and Chang 2008:2733) states that after a child receives a diagnosis of ASD there are many family stressors that will include poor marital relationships. Page and Woodcock (2010:109) say that after their son's diagnosis they heard that statistically more marriages fail where a child is diagnosed with ASD. LaSalle (2004:55) said that after her child's ASD she and her husband had decided that he should move out of their family home as they were lost as a couple.

When the researcher spoke to the second family they were very emotional and they spoke openly about their marriage. Dad said that he feels after the diagnosis he and his wife started to do more things apart than they had done previously as it is sometimes easier if one goes somewhere, like church, and the other one stays home with Elton. Mom said that she and dad can no longer share a bed as it's not practically possible, but that they know what the reason for it is and they work with what they have. They said that after their son was diagnosed they were told it can be very hard on a marriage and that they constantly work on their marriage and sometimes try to do things together as a couple.

Both mom and dad said that they support each other quite a bit and they feel this has brought them closer as a married couple. Mom confirmed this when she said to the researcher that she thinks the diagnosis of their son with ASD brought them closer together. Mom then said that it is sometimes hard as dad has to work long hours but that it’s okay. When the researcher spoke to dad he said that their marriage was strong but at times he worries about Grace as he thinks she is more stressed.

During the researcher’s conversation with the first family they told her that because they did not have any family and a big support system, they only have each other and this has made their marriage stronger. Dad said that they have built a social relationship between himself and his wife. Mom told the researcher that if she isn’t coping dad will step in and she will again step in for him when he is not coping. Dad said that it’s hard when he and his wife disagree about things regarding Helen. Dad also spoke about how he worries about the tremendous stress that his wife is under and say that he wished he could take it away for Elna or make it easier.

.

The families spoke about their **relationship with themselves** and said they all felt very isolated socially in many different areas of their lives. Parents spoke about how they struggled with social situations with friends and family and how that left them feeling isolated. The researcher also saw that the parents will put their own needs aside to address the needs of the child. Andreica-Sandica, Patca, Panaete and Andreica (2011:479) say that many parents with a child diagnosed with ASD feel alone, isolated and their emotions may fluctuate between relief of finally knowing what is wrong with their child, and despair that the child suffers from a disability with no known cure. LaSalle (2004:55) said that after her son was in preschool for two years they had not received a single invitation to a child’s birthday party. The parents spoke about how easy it is to change the way you relate to yourself and in changing the way you relate to yourself you can easily change the outlook you have on the diagnosis and living with ASD. Both mom and dad spoke about how they will always wonder what gave their son ASD and if it was something they did or did not do.

The family spoke to the researcher about how easy it is for you as parents to keep feeling guilty about your child begin diagnosed with ASD. Both parents said that as a parent they will always wonder if they could have done anything differently or if there was something they could have done to keep their child safe from ASD. They said not knowing what gave their daughter ASD will always remain to be something they carry with them for the rest of their lives.

The family told the researcher that it's physically trying because someone is attending to Ben's needs all the time. They also explained that it's hard when they compare Ben to his siblings and other children his age, as they are then confronted with the normal development of the children. They said that there are times that they feel guilty about their son being diagnosed with ASD as they will always wonder if their son got ASD because of something they did.

According to Shore and Rastelli (2006:344) it is very important for parents with a child diagnosed with ASD to get out and do something to relax and recharge. Athari, Ghaedi and Kosnin (2013:102) state that there is a very real relationship between the severity of a child's ASD and a mother's degree of suffering from depression.

When the researcher spoke to the families she realised that there is a big change in the **experience in relation to the sibling identity and expectations** in families where a child is diagnosed with ASD. In two of the families there were 2 children in the family with one being diagnosed with ASD and in the third family there where three children with one diagnosed with ASD. When the researcher spoke to family one, mom said that her other children play together but they don't play with Ben. Mom mentioned that she expects more from her oldest daughter than she might have before the diagnosis as she 'knows better' and she is the "normal child". Both mom and dad spoke about how they see their son's diagnosis has affected the rest of their family, especially their other children. They say that their child with ASD needs more attention than their other children and this means their other children might get less attention than they perhaps should get. This family spoke about how they feel their normal developing eldest child had to grow up quickly and that they feel sorry for her. Both mom and dad think that all the extra things their normal daughter need to do has changed her behaviour and they feel that at times she will misbehave to get their attention.

When the researcher spoke to this family, mom said she expected more from her “normal” developing daughter, and feels guilty about that at times. She feels her daughter is only now starting to realise that her brother is different and she feels very sorry for her. The researcher realised that it was very painful for mom to realise that their daughter now knows that there is something wrong with her brother. Both parents said there are times they wonder what their “normal” daughter’s life will be like having a brother diagnosed with ASD.

The third family told the researcher that the diagnosis has had a big impact on their oldest son as he has to deal with situations that a typical 10 year old will not have to deal with. Both parents spoke about how they expect more from him than they think they would have expected of a 10 year old under normal conditions.   The parents told the researcher that at times their “normal” developing son feels very frustrated with things regarding his sister’s behaviour and this sometimes causes him to act out as well.

All the families that the researcher spent time with reported **that experience with relationships with their extended family** had become very difficult and how they **experienced the change in their social relationships** after the diagnosis. For some of the families this meant making a conscious decision to change their ways of interacting socially. Slifirczyk, et al. (2013:123) say that many parents will hide their children with ASD in their homes, because they want to keep their children away from other people. Both parents spoke about how hard social relationships have become for them after their son’s diagnosis with ASD. They spoke about how they avoid most social situations as they feel they can only go out if their son will be able to cope with the social situation. They said that it’s really difficult for them to find things they can do as a family where all the members of the family can participate. They said they found interaction with family and grandparents very hard as they don’t always understand their situation. Mom said that at a point they could not have their son affected by ASD go and visit his grandparents as they did not understand what a big impact his diet would have on his overall health.

When the researcher spoke to this family in particular there are a lot of emotional effects with relation to their extended family as they see their family often and have a lot of interaction with them. The family said that they felt isolated in the family as their family doesn't always understand what they are going through. Both mom and dad found this aspect very hard as they want interaction with their family but they told the researcher that these relationships changed quite a lot after they received the diagnosis. The family said that it's difficult for them to be around friends and family who have children the same age as their child since watching those children develop normally is hard. The parents told the researcher that it is not only hard around family but also around friends. They spoke about their need for people not only to understand their son but to understand their family situation. They said that after receiving their son's diagnosis they decided that if they had friends who would not understand their unique situation they would cut all ties with them and not see them anymore. Mom said that this made their social circle very small and left them feeling very isolated socially.

Family three spoke about the social impact that the diagnosis has had on their family. They told the researcher they feel like they have made friends now with the parents of the children that attend the service provider. When they go over to visit one of those families they understand their situation and they don't feel threatened to hide away their diagnosed child. They said they don't feel when they leave after a visit that people speak behind their backs about them. The parents then spoke to the researcher about their extended families. Both parents said that they don't have a big family network but "that's fine", and in general their family have been "good about it". Elna said that not having that extended family network does sometimes make things hard. Grinker (2007:234) state that families where a child is diagnosed with ASD very often stop being a part of the social setting as they try to keep their family situation hidden from people that 'just don't understand their situation'.

4.3 THEME TWO: THE EXPERIENCE OF MENTAL, SOCIAL AND ENVIRONMENTAL ADAPTATIONS UTILISED BY THE FAMILY TO DEAL WITH THE CHANGING FAMILY SITUATION

When the researcher spoke to the families it was clear that for of them there were many mental, social and environmental adaptations that they had to make after the diagnosis of their child with ASD.

4.3.1 Category 2.1: The experience of mental adaptations

The parents spoke to the researcher about the mental adaptations they feel they had to make as a family after the diagnosis of their child with ASD. They said that initially they struggled to even understand what ASD was and then, as time went on, they realised that it would be very hard to find specific ways in which to help their child. They said that there were so many options and different things that worked for different children that it was very hard to understand what do. All the parents felt that it was very hard to find out what the best options would be for them to help their child and they felt that since few professionals knew how to help their child, they need to do so themselves. Carbone, Behl, Azor and Murphy (2010:317) said that there aren't enough primary healthcare providers that know enough about ASD.

During the time that the researcher spent with the families she was able to realise that mostly the **mother's need information** to make sense of what is happening to their family. The researcher noticed that the families made use of **extensive positive self-talk** throughout the time that she spent with them. All the families made use of **extensive planning** for everyday activities. They spoke about how their **outlook on life** changed and how their **decision-making** has changed and how they **avoid curtain activities.**

In a study done by Meadan, Halle and Ebata (2010:24) they speak about the need to seek more information as a coping strategy used by a family.

When the researcher spoke to the parents this family made it clear that they believe they need to keep doing research to ensure that they do whatever is best for their son. This family believes they have to educate themselves so they can make the best choice for their son. They made it clear they feel they need answers, not only to cure their son, but to make sense of the experience. When mom spoke to the researcher she said that she plans extensively for every single thing that has to do with her son: education, medical, outings and finances. She said they have to take a lot of aspects into consideration before they can make a decision on even everyday activities. She also told the researcher that after the diagnosis they don't get to do the things she always thought she would be able to do with her family as she doesn't do things that her son wouldn't enjoy.

The family said that they did not know what caused Elton's ASD and they needed to know where it went wrong to make sense of the experience. The family found it hard to accept and move past the diagnosis as they said they will never know what caused his ASD. In making sense of the experience this mother told the researcher that the impact of the diagnosis on them as parents differ, as moms think differently about things than dads and it's been much harder for her husband to be positive after the diagnosis. The family spoke about their struggle with these questions and how ASD changed their outlook on life. They said they have a great need to find out and be educated on their son's condition. Not only to find a cure but to make sense of the experience. The family told the researcher that even 'easy' everyday decisions have been affected and have become challenging for them after the diagnosis of their son. The family said they make use of positive self-talk, and do extensive planning. They report that the diagnosis affects their decision making.

The family spoke to the researcher about their journey to find the answers as they say they feel that's the only way they will ever make sense of the experience. This mother told the researcher that she knows and has done all the research but she hasn't yet implemented it in every regard as it is a huge undertaking. She said that she needs to do a lot of planning to ensure that everything goes according to plan every day. Both mom and dad said they need to be positive as that's the only way they know how to support each other. This family said that you have to readjust your outlook on life in order to go on and they can no longer go anywhere or just do anything as they have to take their daughter into consideration and it takes a lot of planning.

4.3.2 Category 2.2: The experience of social adaptations

The families spoke to the researcher about the social adaptations that they feel they have made. They said that the **parental roles** changed, that they face **excessive time demands** and that they have a **need to protect** their child. They spoke about **managing practical aspects** and that the **family context differs**. In most of the families the mother was the sole caretaker and the father had to work long hours. Solomon and Chung (2012:251) say that there are many domains that will change in a family after a diagnosis of ASD is made.

In this family the mother felt that she must protect her son. She said to the researcher that protecting her son meant two things; she needed to ensure that people understood his specific condition so that they would know how to best manage and protect him and on the other hand she needed to educate people about ASD. Both parents also expressed their desire to see his sibling assist and stand up for their brother. After the researcher spoke to this family she realised that because of the diagnosis of their son, both mom and dad's roles in the family have changed significantly. Both parents said that mom has to stay home; she takes care of their son's needs, like cooking, driving to therapies and assisting with therapies, as well as dealing with all medical aspects that her son has to face, like blood tests and scans. Since the diagnosis, dad has to work very long hours for them to be able to afford the therapy. In this family the finances are up to dad. This family also said that on a practical level nothing is as they expected it to be and every small thing that happens in their family needs to be planned for extensively. Mom said that this even includes small things like a quick outing for groceries.

This family also mentioned that dad has to work very long hours so that mom can be at home taking care of the cooking and Elton's education and needs. In this family dad has to manage the financial aspects and mom takes care of the daily activities like cooking, therapies and educational plans. Having dad work long hours and mom having to stay home with the kids is just one of the many social adaptations this family had to make. Both parents spoke about their need to protect Elton, not only from people but also from being sick and getting sick as this is a big problem for the family. This family spoke about the practical aspect that for them means things like mother and father cannot sleep in the same bed. They also spoke about how much the family has to pre plan every small thing that they want to do and how much time this takes on a daily basis.

The family told the researcher that as a family they avoid certain place and people after the diagnosis of their daughter with ASD as they want to protect their daughter, since she knows when people treat her strangely. The context in their home differs as the parents feel that they now can't do normal family things with their daughter and they mainly just take care of her. They spoke about how they now have to manage practical aspects that before they would have just been able to do without thinking about it. They spoke about how the diagnosis affects even smaller things like getting ready to go out, and how they have to keep in mind that things take a lot of time with their daughter, like getting her dressed, and they have to plan for that too. Kenny and Corkin (2011:17) state that in most families where a child has been diagnosed with ASD the father will assume the role of main provider of income. They also say that the perception of the mother and father can differ dramatically. They say that the mother often suffer extreme psychological stress as they experience loss of their own social activity and feel a disregard for their own career and autonomy. All of these families told the researcher that one of the hardest parts of managing the diagnosis is that there are many time demands that place a lot of pressure on families as they have to spend the extra time with the child, as well as still having to do all normal activities within the household.

All of the families that the researcher spoke to had a great need to protect the affected child from outsiders and people who do not understand their child's diagnosis and unique struggles. This was evident for the parents as well as for all of the siblings. One of the siblings said to the researcher that even though he doesn't always get along with his (affected) sister he does not want loose her anywhere.

These families also spoke about their **experience of sibling adaptation**. They **acknowledge differences** as a way of **making sense/comparing** with self and wishing for a **sense of control.**

Pilowsky, Yirmiya, Doppelt, Gross-Tsur and Shalev (2004:855) say that when there is a sibling who is diagnosed with ASD, other siblings in the home will face great social and emotional adjustments. They (Pilowsky, Yirmiya, Doppelt, Gross-Tsur and Shalev) state that siblings have to adapt to different family roles, structure and activities, feelings of guilt and shame, and loss of parental attention. They say that all of these aspects can affect the functioning of the home and the well-being of their own functioning, as well as their functioning as a family in their home. Solomon and Chung (2012:258) say that siblings who have another sibling diagnosed with ASD have a greater possibility that they will themselves (typical sibling) develop emotional and behavioural issues. Schuntermann (2009:298) state that even though having a brother or sister diagnosed with ASD creates a set of unique challenges to a typical developing sibling, it also creates unique opportunities for such a typical developing sibling. Johnson and Rensselaer (2010:64) say that it is important for parents to help typical developing siblings deal with frustrations related to having a sibling diagnosed with ASD, and Koutsis, de Clercq and Galbraith (2006:17) claim that it can be very hard for typical developing siblings to have to explain to their friends that their sibling has a diagnosis of ASD. Morvay (2010:52) say that when there is a sibling diagnosed with ASD it will affect the family as a whole.

During the analysis of the sketches and the interview with the older brother the following things were addressed by the siblings. In this family the sibling was a few years older than the child affected by ASD. She was able to draw a picture and speak to the researcher. For the older sister (age 5 years) in this family, data indicated that she wanted to feel recognised and acknowledged as a person in her own right and she strives for individuation. Some of the data indicates that she feels embarrassed at times by her sibling diagnosed with ASD. Further interaction with the data revealed that she wants people to know that she is different from him (the affected sibling) and that she wants to be seen as ‘normal’. She has a sense of having superior skill and control over the affected sibling and she sees herself as the one that holds all the skill and control over the affected sibling. She places the blame completely on Ben for isolating himself from others. She wants to be seen as the ‘good’ child and her affected sibling as the ‘bad’ child. Data does indicate that she has a positive sense of belonging and that mom is the dominant figure in the family.

This sibling was able to interact with the researcher and she spoke openly about her brother. Both mom and dad said that there are times when they wonder how she perceives the diagnosis and if there is something she could change if that was possible. In this family mom and dad was aware of the fact that they had other expectations for her because of her brothers' diagnosis. Both mom and dad said that they would one day expect her to be there for her brother, but they don't know what that means yet.

When the researcher met this family they were very weary to have their daughter take part in the study as they said they struggle at times with the knowledge that she has to go through so much extra things because of her brother's diagnosis. They also feel that there are times they wish she didn't have to know that her brother is different. The researcher gave them some time to decide and they said that they want her to take part as she has only recently started to notice that her brother is different. The data suggested that according to the drawing of Kate, Elton (ASD) was the focus in the family as well as in her own mind. The data suggested that Kate had feelings of insecurity and inadequacy and she relied to a certain extent on fantasy to make sense of her world. Further analysis suggested that she might have feelings of inferiority and denial of emotionality as well as some form of denial/repression of thoughts regarding her brothers' (on the spectrum) body functions. Some data suggests that she sees her brother as presenting feelings of inadequacy as well as his need for warmth and love. For her, her brother represents impaired communication and minimal environmental contact/awareness. He also represents rigid, compulsive and inhibited personality. She views her brother as shy. All indications are that her drawing suggests tension, possibly with attempted rigid control of impulses and fantasies. The researcher could see that in this family both parents had a great need to protect their "normal" developing daughter from her brother's diagnosis of ASD. They were trying to give her as normal a life as possible. Both mom and dad said they could see that in the last few months their "normal" daughter started to notice that there was something wrong with her brother and that up to that point she just thought he doesn't speak. Both parents were clearly saddened by the fact that she now knows her brother is different. These parents also said that they put more pressure on her than would be the case if her brother was normal, as they expect her to know things like not letting food lay around the home.

For Donavan (typical sibling) it has been very hard understanding and dealing with the diagnosis. The researcher was able to do an individual interview with him. At the time the researcher spoke to Donavan he was aged ten. Donavan spoke to the researcher and said that he thinks Helen just does things to make him mad. Even though the relationship between his sister and himself is difficult for him, he told the researcher that he thinks it's even harder for him because he has to come home after school. Donavan also felt that he needs alone time with his parents away from Helen so that they can do 'normal' things. Social interaction with his family away from home also proved to be problematic for Donavan. He struggled to understand the different ways of discipline that there is for him and his sister, and he struggled to understand that she doesn't always know when she is doing something wrong. When the researcher spoke to Donovan she could see that there were many things that he found very difficult about his sister's diagnosis. Because Donovan was older than the other siblings who participated, there are unique struggles that he faces, like having time to study for tests and then also things such as seeing how much his parents struggle with daily activities surrounding his sister's diagnosis and not feeling like he is able to help them cope better.

4.3.3 Category 2.3: The experience of environmental adaptations

Slifirczyk, et al. (2013:123) says that there are many families who struggled with activities of daily life as there are so many things that change after the diagnosis of ASD. The families spoke to the researcher about how they have to **manage disruptions in family activities.** When the researcher spoke to the families they all said that since the diagnosis of their child with ASD there where many times where they had to manage extreme disruptions in their family's activities and that is something that was very hard. They spoke about this aspect and said that they feel this makes a big difference in the coping skills they as a family use. All the families spoke about adaptions they as a family had to make. Bradley and Caldwell (2013:9-13) say that there are many physical adaptions families need to make after having a child diagnosed with ASD.

When the researcher spoke to this family they told her that because they had three other children besides the child affected by ASD, there are many times that it's hard to manage their family activities. When mom spoke to the researcher she said that she feels they need to plan extensively before they go out as a family. She said that she needs to plan so that Ben can take part in the activity and that it's an activity that the other children can also enjoy. Mom said that the problem with that is that there aren't many such activities or places where they can go. Mom said that it's hard to go out mainly because of Ben's strict diet. She said that she will go to great trouble to ensure that the activities she plans are activities that everyone in their family can enjoy.

Mom also said that there are other disruptions, such as numerous therapy activities that her son needs to go to and even though she doesn't work, she can't drive her other children as she needs to be there driving Ben. Also, mom said that there are many times when there is either a therapist in their home working with Ben or the family, or there will be a therapist with them as a family when they go on a family outing.   When the researcher spoke to this family it was clear to her that there were many disruptions in their daily activities. The researcher could see that in this home it was mom's job to ensure that they are able to go out as a family and that she had the responsibility to manage all of the disruptions.

During the time that the researcher knew this family she noticed that mom did not go anywhere without ensuring that the outing or activity would be something where Elton could manage with the environment as well as the food. Mom told the researcher more than once that they hardly go anywhere after they received the diagnosis of ASD. For this family the most important aspect was that they could only go somewhere if they were very sure that there would not be any food that Elton would be able to get to as he can get extremely sick from eating the wrong foods. To the researcher it was quite alarming that this family will not go out of their home much and it was clear to her that they were very socially isolated.

Mom also spoke about the many hours of therapy that her son has and she said this together with the extensive amount of planning for his dietary and medical needs, takes up most of their time as a family. Mom said that they don't really go out and dad said that if they have to go out they will go one parent at a time so that someone is always home with Elton. Dad told the researcher that this means as a family they end up doing most things alone (each member of the family by themselves) that they would have done as a family. Both parents said that they no longer go to “braai’s” with friends and family as activities like this are now too hard to manage.

During the researcher’s discussion with mom she said that in terms of changes and disruptions in their family activities, there has been many. She told the researcher that before their daughters’ diagnosis of ASD they liked to go hunting at times but that this is no longer possible. She said they did take their daughter hunting once but there were too many things that she struggled to cope with during the long drives in the car, and their son felt like she “ruined” the hunting weekend. Mom said now she and her daughter will rather stay home. This was just one example of many things that they, after the diagnosis, either don’t do at all or that they do alone. Mom said that their daughter doesn’t cope well in small spaces and they arrange things so that they don’t take her where she will not cope. Mom and dad spoke about how many small things in their home has changed since the diagnosis and dad spoke about bedtime and morning dressing routines that changed quite drastically. Both parents said that it’s the small things every day that makes things hard over time.

4.4 THEME THREE: THE EXPERIENCE OF FAMILY RESILIENCE AS A POWERFUL WAY OF COPING OR ADAPTING

When looking at having a child diagnosed with ASD it is a very traumatic experience for a family and it has a big impact them (Andreica-Sandica, Patca, Panaete & Andreica, 2011:478). However, it seems that after speaking to the families she realised that even though they were facing extreme hardships, there was something that kept them going. These families showed the researcher that even in the face of extreme emotional turmoil and hardships they managed to get up every day and even say at times that “it’s not so bad” or “it could have been much worse”. Most families agreed that after getting the diagnosis they could start working on the problem and that this made it possible to give a name to what their children struggled with (van Tongerloo, Bor & Lagro-Janssen, 2012:1531). They told the researcher time and time again that they felt blessed with their child and that they feel that as time goes by they are able to manage the demands of having a child who is diagnosed with ASD. One family told the researcher that they feel “blessed” to have their son since he is such a blessing in their lives.

Many of the parents said they feel having a child diagnosed with ASD has allowed them to learn that sometimes in life you need to “adjust your expectations”. All of these families said that having a social support system in a school or therapy center has enabled them to speak to people who would be able to understand their unique situation.

One mother said that just because her daughter has ASD, it doesn’t mean that they love her any less. Another mother said the same when she said that she wouldn’t want to change her son as he has a great personality. Another dad told the researcher that even though he wouldn’t “recommend having an autistic child as a sport”, his daughter is wonderful and that she is his “princess”.

When reading all the struggles that these families face, the researcher did not expect to find that they would feel that they manage, but it became clear to her that each family had a way in which they looked at and focused on the positive aspects that keeps them functioning as a family.

4.4.1 Category 3.1: The experience of positive emotions associated with the child with ASD within the family system

During the interviews with the families there where many times that they referred to the child diagnosed with ASD with overwhelming positive feelings. The researcher felt overwhelmed by the families describing the children in such positive ways despite the hardships they have been subjected to because of the child’s diagnosis of ASD.

Karst and Van Hecke (2012:257) state that it’s very hard to determine what makes parents feel positive about their child diagnosed with ASD as they are vulnerable, but when parents receive appropriate interventions with their affected child, the outcome will be more positive. Whittingham, Sofronoff, Sheffield and Sanders (2009:469-480) say that when professionals train parents to manage things, like their affected child’s behaviour, those parents will be much more positive and there will be a more positive outcome (Cebula, 2012:847-849). Tiba, Johnson and Vadineanu (2012:209) say that if parents are shown how to use positive coping mechanisms and positive resilience, those parents would be less likely to have negative metacognitive believes and irrational believes. According to Kayfitz, Gragg and Orr (2010:337), parents report less parental stress if they report more positive experiences in the process of raising their child affected by ASD.

When the researcher spoke to the family it was clear that they loved Ben and he was an important part of their family. Both parents said that they would not want Ben's "essence" to change as he was their loveable happy boy. They made it very clear that they are very proud of what Ben has accomplished and they want others to see his accomplishments. According to this family the diagnosis also had a positive effect on their lives. The family acknowledges how far they have come since first receiving their son's diagnosis of ASD and that they feel as time goes on, things are getting better.

They do their best as a family to support one another. As a family they are trying to grow from the diagnosis and they don't see the diagnosis as being as bad as it could have been. Mom said that there are many families they know of who are much worse off than they are and she sees them as doing well with comparison to other families trying to cope with the diagnosis of a child with ASD.

As the researcher spent many hours with this family in their home, she was able to see that Ben was a very important part of his family and they thought of him in a very positive and loving manner. They went out of their way to ensure that whereever they went they would educate people about ASD if a situation arose. Mom said that they did this as they were very proud of their son and they would like people to know how hard he fights even for the smallest of things.

When the researcher spoke to the family they spoke about Elton with longing for the 'normal' boy that they have 'lost' but they also spoke about him as a child very dear to them that might, because of his diagnosis, need them as parents more than children usually need their parents. This family made it very clear that they will do whatever it takes to assist their child in living a life where he is happy and fulfilled. They said that even though their diagnosis was two years ago they still get emotional but they think that's healthy. They spoke about taking it day by day and that their little boy has already come so far. The family said that they will always be hopeful and love their child dearly. When the researcher spoke to the family she noticed that they had an overwhelming sense of love for their child affected with ASD and they would do whatever they could to assist him.

The parents, as well as Donavan, expressed their love and affection towards Helen. They said they will never trade her for another child. When the researcher spoke to Helen's brother Donavan, he told the researcher that even though she at times irritates him he wouldn't want to lose her anywhere. This wording from her ten year old brother showed the researcher that even though daily things were very hard for Helen's brother, he still had this overwhelming love for her and he did not try to hide it. Kenny and Corkin (2011:17) state that the parents of a child diagnosed with ASD can find that their child affected by ASD can be a source of much personal growth, strength, fulfillment and above all, happiness.

4.4.2 Category 3.2: The experience of the child with ASD described in positive terms

When the researcher spoke to all of the families she noted that they described their child affected by ASD in very positive terms time and time again. All of them said that they have learned they needed to let go of the dreams they had for their child before the diagnosis of ASD and they need to celebrate the small things their child makes progress on. All of the families said that "you can't live in the future too much" and that they must "take each day as it comes". Kidshealth.org (2014:1) states that when parents have a child who is diagnosed with ASD get enough positive support, they will be able to "see" the positive in their child and in their situation.

When the researcher spoke to this family they said they celebrate the small skills that Ben gains as these are the things that make it all worth it. Both parents had a very positive outlook and did not only dread the future; they were working hard on the present and were willing to take the future as it came. The family said that they would not want to change the essence of their son and that each milestone that he reaches means so much more for them than just “another” milestone as with a normal child, since there is a lot of hours very hard work and dedication involved in every milestone he reaches. They said that holding on to dreams that will not be after the diagnosis just wears you down so they don’t focus on it anymore. They just celebrate each small bit of progress that their child makes.

When the researcher spoke to family two, she was able to see that this family wasn’t as far along in accepting their child’s diagnosis and the changes that will go with that as the other families were. They spoke about taking it day by day and that their little boy has already come so far. They said they are very proud of their son and he is a lovely child. During the time that the researcher spent with family two she was able to see that they were struggling a little more than the other two families to find the positive in their son’s diagnosis. This family’s son was also diagnosed a few years ago but they were struggling a lot with many aspects surrounding the diagnosis. For them the positive was that they were now in a new therapy center and around likeminded parents who would understand their situation.

Both parents love her dearly and say that the key is you just have to adjust your expectations and you have to celebrate the small things. As with any father and daughter, for this dad she is his princess. He said that it is hard but he will never trade her for another child. Even in this family her brother was able to tell the researcher that he will protect her if it’s needed and he really loves her. Helen was really cherished and loved by her family even though there was a sense of sadness and loss. Dealing with this family day by day the researcher never felt that their interaction with Helen was centered on sadness and loss but the researcher could see that they loved her tremendously and that she really was “daddy’s princess”.

4.4.3 Category 3.3: The experience of acknowledging the value of support systems

When the researcher embarked on this study she realised very early on that parents have a great need to be a part of some or other support system. During the researcher’s time working at the center she realised that the parents who had a big support network where the parents that would often seem to function better. As the research data became more evident, the researcher was made aware that these three families all said that having a support network changes the hardship of the diagnosis (Kenny &Corkin, 2011:18). Most families said it's great when you have access to trained professionals who assist your family but that those professionals sometimes have "no idea" how it is to have a child diagnosed with ASD with you 24/7.

The parents said that the best support networks are when you can speak to other parents and families who "have been there" or who have had the diagnosis for longer periods of times. The parents said that if you speak to other parents who have a child who is also diagnosed with ASD, those parents will not only understand what you are saying but they will understand how it is or how it feels and they will not judge you and your family like others might (Kenny & Corkin, 2011:18).

Slifirczyk, et al. (2013:123) says that parents can suffer from "burnout" if they don't have sufficient support systems. Viecili, Robinson, Weiss, Lunsky and Sloman (2012:304) also say that its of very high importance for a family where a child is diagnosed with ASD that they should have a "venue" where they can speak their mind in an environment where other people will fully understand the hardships they face.

They said that they find it helpful to speak to people who have 'been there'. For this family, resourcefulness is an important aspect as they feel they will have more input and control over the education of their child. When the researcher spoke to mom she said there are times when you can speak to other parents and they "get" what you say. She also said that other parents have resources that you are struggling with, like they might have recipes that are gluten free and so on. Dad said that it's easy to speak to other dads in a social environment as the dads don't often pick up or drop off the kids. This family told the researcher that it's 'nice' to be around other families.

A big aspect for this family is the hope that it will come to a point where there can be more support for the entire family who is involved after the diagnosis. They said they felt that you as a newly diagnosed parent need information from someone who knows ASD, because traditional psychologist did not realise what they were going through. The family also spoke about their need for bio-medical assistance as they said it's hard enough to have a child diagnosed on the ASD spectrum, but that it becomes very hard if your child has pain as well. Currently, there are many different views on the accuracy and reliability of bio-medical interventions for children affected by ASD (Farrugia, 2013:8-13).

The family acknowledged that they were privileged that they got in contact with professionals the week that Elton was diagnosed and because of that, they felt they will be okay. They say that even a few answers about his condition gives you hope. They also spoke about the fact that they are privileged to have grandparents who stay close enough so that they can have an evening away and have the grandparents watch their children. They think the most important thing is that you surround yourself with people who "get our situation", people who understand what you are going through and will not judge you on what you do right or wrong in their eyes. Kenny and Corkin (2011:17) state that it is important for families to surround themselves with people who are in the same situation. As mentioned above, all the families in this study had a great need to interact socially with other families who have a child that is diagnosed with ASD.

This family spoke to the researcher about the value of support systems when they said that they like getting together with the (service providers) families as they have things in common. They expressed that it's nice to know that when you go home from visiting with the other families from the center you know they will not be talking behind your back. Both parents said that they always keep in mind that Helen can understand when people speak about her and they don't want her to think that she isn't good enough. For this family there are moments that they did not have before but that they have recently started to have.

When looking at the feedback from the parents of all three families, having a support group or just people in the same situation that will understand your child's specific needs were invaluable. All three families told the researcher that it's so nice to sometimes be able to get out of the house and knowing that you are going somewhere where others will understand and take your child into consideration.

4.4.4 Category 3.4: The experience of being resourceful as a person

When the researcher spoke to these families they discussed being more resourceful as a family after the diagnosis of a child with ASD. They talked about how they felt that over time their situation was getting better. These families all said they feel positive about their lives. Some of them spoke about how their faith keeps them going and they feel that there is a higher hand at work in their time of trouble. Estrella (2013:24) as well as Solomon and Chung (2012:257) say that when families manage to get enough information about how to manage and be resourceful, they will do very well.

During the years that the researcher knew this family she was very aware of the fact that they made it their focus to manage and cope with their son's diagnosis of ASD to the best of their knowledge. They went out of their way to ensure that their son was healthy and happy. When the researcher spoke to them they said that it is their main focus to have a healthy and happy family. They said that their son is making progress as time goes on and they feel it's not that bad as it is getting better with time. They spoke about how they, as a family, where trying to stay positive about their family's future as well as their son's future. When the researcher spoke to mom she said that because her son has ASD she felt even prouder of the things he achieved and she will easily tell people how proud she is of him and how much she felt that he added love to their lives and their home as he is a very lovable boy. The researcher was very aware of the hardships that all the families faced on a daily basis and she realised that despite all the hardships and the hours that the families spend trying to overcome the challenges of the ASD diagnosis, they were in a way much closer and more in tune with the needs of every member of the family than families who never face any hardships. During the time that the researcher spend with family two she was told by mom that for them the diagnosis of ASD meant that their son is medically ill and doesn't speak. They said that they still believe he will be able to go to school and they do all they can to stay positive. This family said to the researcher that they feel they were very grateful that in the first few days after the diagnosis that they got good advice and that there were a few pitfalls that they could look out for and stay away from. This family knew that the future would be very uncertain but they said that they were in it together. The researcher was aware of the fact that for some families, even though there was a lot of progress that their child made, the family struggled to get past the diagnosis and everything that this meant to them. Family three said that for them it is now starting to get better and they are having their first special moments with their daughter. They said that they are looking forward to the future in seeing her develop and grow. This family said that they had a very special daughter and they all loved her very dearly. She is daddy's little princess and she is a very important part of the family. They revealed that having their child have ASD isn't a sport that they would tell anybody to take up but that they wouldn't change their daughter for anything in the world. They said that what she has been able to achieve means the world to them and that they are grateful for their lives with her.

During the time that the researcher spent with these families she noted that the families made use of a number of resilience factors such as, family time and routines, family hardiness, family support, spousal relationships, family activities such as, togetherness and family routines, gaining knowledge and skills relating to having a child diagnosed with ASD, accepting the diagnosis and reframing circumstances, having hope and optimism and perseverance, family organization, and looking at the health and well-being of all the family members, as well as looking at the individual needs of family members (Kapp & Brown, 2011:460-462). Kapp and Brown (2011:462) say that families who have a child diagnosed with ASD are able to make use of a number of resilience factors that will enable them to meet the demands of having a child that is diagnosed with ASD. These families will be able to meet the challenges of life and return to previous levels of functioning (Kapp & Brown, 2011:462; Poso, 2014:442-458).

Bayat (2007:702) say that family resilience includes aspects such as family connectedness and closeness, positive meaning-making of the disability, and spiritual and personal growth. He claims that when families make use of resilience, these families do much better over the long term and have a more positive outcome.

The researcher could see that all of these families where making use of resilience and she is of meaning that when families are trained to use resilience in full they will benefit from the knowledge of how resilience can assist them in everyday managing of the struggles regarding having a child diagnosed with ASD.

4.5 CONCLUSION

During the time that the researcher spent with these three families it became increasingly clear to her that having a child diagnosed with ASD brought a unique set of circumstances in the way these families function. She also realised that these families were able to cope and function even under these very extreme unique circumstances. In Chapter Five the researcher will discuss the conceptualisation concerning the central concepts.

CHAPTER 5

CONCEPTUALIZATION CONCERNING THE CENTRAL CONCEPTS

One's first step in wisdom is to question everything – And one's last is to come to terms with everything (George Lichtenberg in Sicile-Kira, 2003:244).

5.1 INTRODUCTION

In the previous chapter the researcher discussed the results of the interviews of parents with children diagnosed with ASD by making use of a literature study. In this chapter the researcher will start to develop a model as the basis for the psycho-educational programme. The researcher will focus on concepts, and links between concepts.

5.2 DEFINITION OF CONCEPTS

The researcher identified the concepts from data originating from interviews with parents siblings and grandparents in families where a child has been diagnosed with ASD. The researcher used the steps in Wandelt and Steward (1975:64-69) as well as Chinn and Kramer (2008:84) and Copi (1987:169) to define the relevant concepts.

5.2.1 Identification of the main concepts

During the data analyses in both Chapters Three and Four, the researcher realised that these families can be assisted in maintaining psychological health despite the changing family situation after the diagnosis of their child with ASD. In this study the central concept was identified as **the facilitation of resilience in a family**. The researcher will follow the theory of Walker and Avant (2005:26-27) where they state that a theory is built around concepts and concepts are conveyed by making use of language.

5.3 DEFINING THE CENTRAL CONCEPTS

During concept definition the goal is to ensure that the meaning of all the relevant concepts is clear. Another important aspect is that the theoretical explanation should clearly influence the meaning of the relevant concepts (Copi, 1987:138-143). Humans attach different meanings to the same concept, therefore it is very important according to Babbie (2005:125), that any concept should have a meaning that was "agreed-on meaning" so that there is no uncertainty about what the meaning of the concepts is referring to. During this process the researcher has the opportunity to ensure that the meaning she attributes to the relevant concepts is the meaning that others will also attribute to the same concept.

In this study the central concept is the **facilitation of resilience in a family** where a child has been diagnosed with ASD. This has a pervasive emotional and social effect on the family and 'restricts' the family as a whole. When the researcher spoke to these families, it was clear that for them the event of having a child diagnosed with ASD threatens the core family identity and that requires the family to make diverse mental, social and environmental adaptations (adjustments) in order for them to deal with the changing family situation. In this process the researcher noticed that family resilience emerges as a powerful way of coping in a family where a child has been diagnosed with ASD. This is demonstrated by the parental perspective that 'it gets better over time'.

5.3.1 The central concept of 'facilitating resilience in a family'

The researcher will define the central concept of **facilitation of resilience in a family** by using general dictionaries as well as subject specific dictionaries. The central concepts that the researcher will use to describe the meaning of facilitation will be underlined in the text and a summary will be provided in Table 5.1.

5.3.1.1 'Facilitation' dictionary definitions

According to The Pocket Oxford Dictionary (1992:309) 'facilitate' is a process that is 'eased' or whereby a process is made easier. According to Dictionary.com (http://dictionary.reference.com/brows/facilitate?s=st), to facilitate a process means to make something easier or less difficult, to help forward or to assist the progress (of a person). The New Thesaurus (1995:372) states that facilitation is when something is made less difficult.

According to Colman (2006:265), facilitation refers to the act or process of assisting the progress of something or to make it easier. The term facilitation is broadly used to describe any activity which makes tasks easy for others, or tasks that are assisted.

5.3.1.2 Subject definitions ‘facilitation’

At heart, facilitation is about the process of helping people to explore, learn and change. Schwartz (2002:5) explains what he sees facilitation as: facilitation must be done in such a way that the families are empowered by the process. Heron (1999:2) state that facilitation must be a spiritually, energetically and physically endowed experience, encompassing feeling and emotion, intuition and imaging, reflection and discrimination, intention and action.

Rogers (1967:304-311) believes that people increasingly trust others when they feel at a deep level that their experiences are respected and understood (Rogers, 1967:304-311). Based on this he argued that there are three 'core conditions' for facilitative practice – realness, acceptance and empathy. Rogers (1967:304-311) named three essential aspects to facilitation: people’s needs to be real in the facilitation of learning, caring for the learner and then empathic understanding. When these three aspects are present, Rogers (1967:304-311) claims that it will be possible to facilitate an environment where the family can strive towards mental health.

Evans (2007:131) speaks about the importance in the facilitation process of enabling participants to engage in conversation and to be able to develop an understanding of their situation as time goes by. Schwarz (2002:61) refers to facilitation as a process where a facilitator has decision-making power or an authority that can help a group improve the way that it identifies and solves problems as well as how they, as a group, make decisions. Bens (2005:117) speak about a facilitator as being able to provide structure and process to interactions so that groups are able to function effectively, and in doing so they can make high quality decisions.

She (Bens, 2005:117) also talks about a facilitator as a helper who has the goal to support others so that they can achieve remarkable performance. Heron (in Jarvis, 2006:99) say that it's important that during the process of facilitation individuals are guided to get in touch with their internal capacities to learn and make sense of their experiences.

The University of Johannesburg (2002:6) state that facilitation is a **dynamic and interactive process** that promotes health through positive environment, **mobilisation of resources** as well as the identification and overcoming of problems in the search for health.

During this process families are initially **assisted** to reach their goals by an outside party (Parsons, 1996:13). In this study **"Interactive and dynamic process"** will show towards a process where all parties are actively participating and where there is a constant **process of interaction** between all parties, where they are working towards a common goal (Ryan & Deci, 2000:69-74). **Assistance** will show towards the fact that family members will constantly be supported by an outsider during facilitation (Ryan & Deci, 2000: 72). The **mobilisation of resources** will refer to the internal and external resources and opportunities that are identified. These resources and opportunities are used in such a way that it can lead to self-exploration. Self-exploration is done so that barriers can be identified and overcome, and conscious decisions can be made to move past the barriers and to develop and grow as a person (Ryan & Deciu 2000: 70).

As Schwarz (2002:14) has commented, 'facilitation is challenging work that calls forth a range of emotions'. It also involves certain values and ways of treating people. Each person has his or her own style and approach – and it is that uniqueness, that realness, that makes a contribution possible. The central concepts that will be used to describe facilitation will be summarised in Table 5.1.

TABLE 5.1: Central concepts of ‘facilitation’

Essential criteria	Related criteria
- **Interactive and dynamic process**	- This shows towards a process where all parties is actively participating and where there is a constant process of interaction between all parties where they are working towards a common goal.
- **Assistance**	- During this process of facilitation the family members are constantly supported by an outside party to reach their goals.
- **Mobilisation of resources**	- During facilitation Internal and external resources are identified. These resources and opportunities are used in such a way that it can lead to self-exploration. Self-exploration is done so that barriers can be identified and overcome, and that a conscious decision can be made to move pass the barriers and to develop and grow as a person.

5.3.1.3 Defining ‘facilitation’

Facilitation is **interactive and dynamic processes** where families are **assisted** by a psycho-educator to **mobilise resources** in order to overcome barriers, develop and grow as a person, and reach their goals.

5.3.1.4 ‘Resilience’ dictionary definitions

According to Dictionary.com (http://dictionary.com.reference.com/brows/resilience?s=st), resilience refers to the ability to recover readily from illness, depression, adversity or the like. The Pocket Oxford dictionary (1992:773) states taht resilience refers to the ability to recover from a setback. The New Thesaurus (1995:830) states that resilience refers to the capability to withstand stress without injury. The Concise Oxford dictionary (2001:1218) indicates that resilience is the process whereby a human can withstand or recover quickly from difficult conditions. According to Wikipedia (en.wikepedia.org /wiki/Resilience) resilience in psychology refers to the idea of an individual's tendency to cope with stress and adversity. This coping may result in the individual **"bouncing back"** to a previous state of normal functioning, or using the experience of exposure to adversity to produce a "steeling effect" and function better than expected. Resilience is most commonly understood as a process, and not a trait of an individual.

5.3.1.5 Subject definitions ‘resilience’

According to Clarke and Clarke (2003:23), resilience “is apparent when, against common expectancies, children maintain development within, or accelerate markedly after, adverse situations”. Machin (2009:41) states that resilience is an innate self-righting mechanism that assists people in redirecting their lives after detrimental or stressful circumstances. She further notes that the three important aspects of resilience are personal resourcefulness, a positive life perspective, and social embeddedness. Carr (2004:188) state that a resilient individual shows positive adjustment.

According to Bayat (2007:703) several key factors which contribute to a family becoming resilient are: (1) making meaning of adversity, (2) affirming strength and keeping a positive outlook, and (3) having spirituality and a belief system. In addition, for a family to recover in the face of a challenging situation, the family needs to possess certain organisational qualities, such as flexibility, connectedness, communication and being able to utilise resources.

Chesnay and Anderson (2005:405) state that “resilience is a measure of the individuals’ strengths, which depends on the physical and social capital of the family and the larger community”. Brooks and Goldstein (2011:4) say that resilience embraces the ability of a person to deal with stress and pressure effectively; to cope with everyday challenges; to **bounce back** from disappointment, adversity and trauma; to develop clear and realistic goals. Simon, Murphy and Smith (2005:430) relate that resilience is “the ability of a family to respond positively to an adverse situation and emerge from the situation feeling strengthened, more resourceful, and more confident than its prior state”.

According to many studies, resilience is an important tool that can assist families in coping during times of hardship, but it is unfortunately underused (Luthar, Cicchetti & Becker, 2000:546). In the face of challenges, some families were shown to get stronger despite dealing with adversity (Bayat, 2007:702). In a study done by Bayat (2007:702) it was found that if a family was utilising resilience after they had a child diagnosed with ASD, these families showed clear signs of family connectedness and closeness, positive meaning-making of the disability, and personal and spiritual growth. This study provides evidence that, despite extraordinary challenges faced by families of children with ASD, a number of these families show evidence of resilience.

Looking at the above, families who made use of resilience were able to grow individually and as a family. These families become stronger as a unit and even showed spiritual growth and could make positive meaning out of the challenges they face (Harvey & Delfabbro, 2004:4; Ungar, 2004:24; Bayat, 2007:1). These studies show that this is due to the families becoming more resilient (McCubbin, Thompson & McCubbin, 2001:366). Resilience in a family can also give existence to healthy growth and development in the family (Bernard, 2006:198), as well as causing positive adaptations in the family despite the challenges they face, with good outcomes as the end result (Luthar, et al. 2000:543; Masten, 2001:228). According to Masten and Wright (2010:213-237) resilience-promoting interactions were embedded in basic protective systems, including positive attachment, self-regulation processes, opportunities for agency mastery, reasoning and problem solving, supported by effective executive functioning, making meaning, and culture and religion.

In many of Walsh's (2003:1-7) studies he suggests that parents tend to become 'advocates' for their child affected by a disability (such as ASD) or that the parents report that the affected child is a source of pride and honour for them despite the disability (Walsh, 2003:1-7). He (Walsh, 2003:1-7) further claims that these components, including positive attachment, self-regulation processes, opportunities for agency mastery, reasoning, and problem solving, supported by effective executive functioning, making meaning, and culture and religion, are components of resilient families and that there can thus be positive contributions of disability on families. Bayat (2007:702-703) states that resilient families often "change for the better" by having "learned important lessons" which might have life-altering consequences for them.

Walsh (2003:5-7) calls resilience the "ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful". The concept of family resilience with its focus on factors leading to a family's well-functioning in view of a crisis, is part of a movement in positive psychology towards identifying factors of health as opposed to factors of pathology (Seligman & Csikszentmihalyi, 2000:5-14). According to Patterson (2002:349), most researchers view resilience as a process in which risk and protective factors interact, relative to a specified outcome.

Ungar (2004:342-343) describes resilience as the outcome of negotiations between an individual and their environment that enables the individual to remain healthy despite conditions that are collectively viewed as adverse. Ungar (2004: 342-343) explains that researchers of resilience continuously try to conduct studies in the hope of finding ways to protect children against a person, family, and the environment's acute and chronic stressors. He further says that resilience should focus on factors that are unique to each individual and their specific social group.

When looking at resilience, researchers state that humans live in social communities that are influenced by the larger social context and that this impacts families' belief systems which are an integral part of resilience in families, as these include family values, attitudes, biases, assumptions and concerns (Walsh, 2003:1-7; Greene, 2006:58). By attaching meaning to unexpected or unanticipated life events that the family would not see as typical, they can make the event manageable and meaningful (Walsh, 2003:1-7).

Walsh (1998:24) asserts that families need to organise themselves, particularly during challenging times. This **organisational patterns** often provides a level of stability and comfort, establishing a foundation of trust that allows connections with outside resources and supports. Resilient families often have family rules that are age appropriate, acknowledged, and predictable (Black & Lobo, 2008). Walsh (1998: 24) notes that the family relationships change over the course of the life cycle, emphasising that families must continually assess their current level of connectedness to ensure that each family member's needs are being met. While Olson and DeFrain (2000:48) acknowledge that families tend to prefer stable and orderly patterns, they often function best when a balance is achieved between moderate amounts of structure and flexibility. Other important components of family organisational patterns include social and economic resources. During times of adversity, resilient families are able to tap into their social and professional networks for concrete financial, educational, and therapeutic resources.

Clear **communication** is vital to family resilience (Walsh, 2003:12). Families who are able to share feelings with one another and empathise with each other's unique experiences are able to overcome challenges. Positive interactions and feelings of connectedness provide strength for coping, and resilient families demonstrate the ability to brainstorm and **problem solve,** and this allows them to feel that their situation is **getting better over time** (Walsh, 2002:130).

According to Masten, Monn and Supkoff (2011:103-119) and Rutter (2005:338), the rational for resilience research has always been a positive support ethic: a deeper understanding of the processes that encourage people towards healthy functioning, despite circumstances that predict unhealthy functioning. Family resilience-promoting-factors include a sense of hope, religion and spirituality, family hardiness, support networks, and a sense of coherence. Those coping pathways have been referred to as adaption to adversity or bonadaptation (Bayat, 2007 in Kapp & Brown, 2011:1).

Overall, the adaptation phase aims to restore harmony and balance to the family system, with specific reference to its interpersonal relationships, the development, well-being, and spirituality of the unit and the individual within the community and nature (McCubbin, et al. 2001:366). Dale, Jahoda and Knott (2006:465) speaks about the psychological characteristics of families including; perceived self-efficacy, one's ability to positively handle stress, and coping strategies are attributes that assist in the developing a string sense of accomplishment and over all family well-being. According to Fischer and Corcora (2007:413), social support has been found in a number of studies to be an important buffer against family recovery and as a mediator of family stress. The concept of resilience entails the discussions between an individual and their environment that over time will enable the individual to remain healthy despite their circumstances, thus enabling the individual to rebound from adversity and become more strengthened and resourceful.

Resilient **families** are able to use their **belief systems** to help them make sense of a crisis or event. These families are further able to **organise** themselves in terms of trust, resources, support, family rules that are age appropriate, acknowledged and predictable. They have a moderate amount of structure and flexibility. Resilient families are able to **communicate** by sharing feelings, empathise with each other, and can brainstorm together. As the family becomes more resilient they can even thrive during times of adversity. They use their **problem-solving** resources and thus the family builds "on the development of a competence-base and strength-orientated family paradigm". A clear description of the central concepts of resilience will be set out in table 5.2.

TABLE 5.2: The central concepts and definitions of 'resilience'

Essential Criteria	Defining the related Criteria
• The individual "**bouncing back**"	• to rebound after a setback
• **Family belief systems**	• make meaning out of diversity, to have a positive outlook or hope, transcendence and spiruality (Walsh, 1998:7).

Essential Criteria	Defining the related Criteria
Organisational patterns	Flexibility, connectedness, social support (Walsh, 1998:7).
Communication and problem solving	Clarity, open emotional express, collaborative problem solving (Walsh, 1998:7).
Getting better over time	Being more skilled and managing difficulties with more ease.

5.3.1.6 Defining 'resilience'

Resilience refers to the process whereby an individual or family has the ability to **bounce back** after a setback by making use of the core aspects of resilience that will enable them to develop their **organisational patterns**, their **communication** and **problem solving skills,** as well as their **family belief system** driven by a realisation that their situation is **'getting better over time'**. In table 5.3 the essential criteria for facilitation of resilience is presented.

TABLE 5.3: Defining the concept of 'facilitation of resilience'

Central Concept	Essential criteria
Facilitation	• Interactive and dynamic process • Assistance • Mobilisation of resources
Resilience	• Bouncing back • Family belief system • Organisational patterns • Communication and problem solving • Getting better over time

5.4 DEFINITION OF FACILITATION OF RESILIENCE IN A FAMILY

Facilitation of resilience in a family is an **interactive and dynamic process** that is used by the psycho-educational facilitator to **assist** families where a child has been diagnosed with ASD to enable them to **mobilise resources** and overcome barriers. Enabling the family to **bounce back** after the diagnosis and to become aware of their **families' belief system**, **organisational patterns** as well as **communication and problem solving skills** with the realisation that their situation is **getting better over time**.

5.5 A MODEL CASE DEMONSTRATING THE ESSENTIAL CRITERIA OF CENTRAL CONCEPT: FACILITATION OF RESILIENCE

For families where a child is diagnosed with ASD in South Africa there aren't many places the family go in order to gain access to information about the diagnosis of ASD or the long term outcome for their child affected with ASD. Initially the researcher found that families reported that they did not even know where to find out what ASD is. For these families, from the moment of diagnosis they feel very alone and isolated due to a lack of knowledge, not only on their part but more importantly on the part of the professionals that deal with them. The researcher found that for these families the most important aspect after the diagnosis is how they can assist their child diagnosed with ASD and that in the process the rest of the families' emotional and physical needs gets moved to the back 'until they can sort out their affected child'. These families have socially isolating lives as they start to isolate their family from activities that may be challenging to manage.

During the time the researcher worked in centres where children with ASD came for intervention, she noted that the parents, siblings, grandparents and extended family where in need of a way to manage the emotional and physical aspects of the diagnosis. During the researcher's work at the center (unnamed center to protect the identity of the participants) she realised that the children diagnosed with ASD were receiving the interventions that they needed but that the families of these children were struggling.

The researcher started to speak informally to parents, siblings and extended family in asking them what their needs where as a family. The researcher was astounded that all the families replied that in some way they were worried about their family life, social life, finances, siblings, and extended family. That they were making very big sacrifices to ensure that their child diagnosed with ASD received the very best. The researcher realised that because they were so busy with the child affected with ASD, the rest of their family and family life was strained.

The researcher conducted interviews with families and an overwhelming response from all the families indicated that after the diagnosis of ASD they went through a life changing event that caused pervasive emotional and social effects that restricted the family as a whole and that affected the core family identity that caused diverse mental, social and environmental adaptations.

The advanced psycho-educational practitioner had several meetings with parents and siblings. During these times of **interaction** they got to know the psycho-educator and started to accept her **assistance** and a **dynamic process** began. In turn this **mobilised resources** and facilitated a productive environment and started the process where the families can move towards resilience. The advanced psycho-educational practitioner ensured this by talking to the families about **bouncing back** after a setback, looking at the **families' belief system,** ensuring that they could make meaning out of their adversity, to have a positive outlook or hope, and looking at the family's spiruality and transcendence. The researcher assisted the families to look at their organisational patterns to consider their flexibility, connectedness and social support. The researcher and the families spoke about their **communication and problem solving** abilities looking at the clarity of their communication, open emotional express, and their collaborative problem solving skills. Moving towards resilience where the family can feel that their situation is **'getting better over time'**.

5.6 CLASSIFICATION OF CONCEPTS

The researcher decided to make use of Dickoff, et al. (1968:432) to identify the central and related concepts in the study. According to Dickoff, et al. (1968:432) the following aspects are of importance when identifying the central and related concepts, the agent, receiver, the context, dynamics, procedure and goal setting. In the next section I will describe these by making use of the concepts.

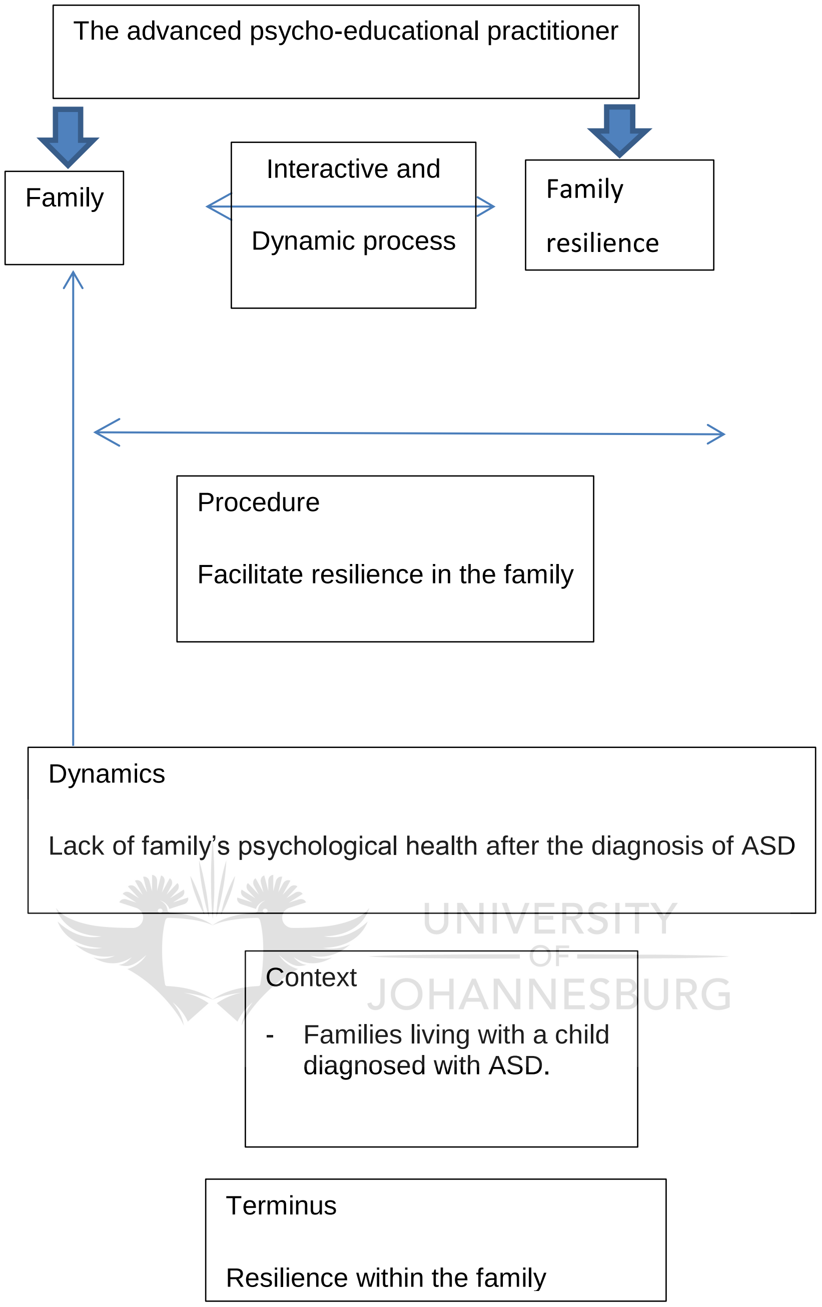


FIGURE 5.1: Thinking map

5.6.1 Facilitator

In this study the facilitator is an advanced psycho-educational practitioner. It is the role of the advanced psycho-educational practitioner to ensure that he or she lead the participants through their education journey. The advanced psycho-educational practitioner should assist the participants to explore their own experiences and the experiences of others. The advanced psycho-educational practitioner should share their knowledge in such a way that the participants can learn from them in order to enable the participants to identify their own strengths and weaknesses (Schwarz, 2002:71).

5.6.2 Parents, siblings and extended family or the participants

In this model the researcher has used the term 'participant' to refer to parents, siblings, as well as extended family, which included the grandparents. The participants in this study were the parents, siblings and extended family in a family unit where a child has been diagnosed with ASD. Because of the extreme and invasive changes a family has to make after a child has been diagnosed with ASD, it was clear after this study that the family needs skills that they can utilise to overcome the impact of the diagnosis in order to maintain mental health in the affected family.

5.6.3 Context

The context of this model is families living with a child with autism. This is the context and the framework of the model of resilience. The families are based within two big cities, Johannesburg and Pretoria.

The diagnosis of a child with ASD is a life changing event with pervasive emotional and social effects, "restricting" the daily living of the family as a whole. The event threatens the core family identity, requiring the family to make diverse mental, social and environmental adaptations (adjustments) in order to deal with the changing family situation. Family resilience emerges as a resource of coping/adapting in a family that has to live with ASD, demonstrated by a parental perspective that "its getting better over time". These families need to be supported so that they can develop their own resources as they have the capacity to use resilience to overcome the barriers they face.

The model for the facilitation of resilience is a family where a child has been diagnosed with ASD. During the process of facilitation families will be enabled to overcome barriers by making use of the process of resilience. Theoretical definitions serve the purpose of creating clarity on the context of the model.

5.6.4 Procedure: facilitation of resilience

A facilitator will be used to guide the families through the process of becoming more resilient. The goal with teaching families how to facilitate resilience in their own family will be implemented as this will allow the family to manage future barriers that they may face.

5.6.5 Dynamics

The families had an initial experience where their family life was very disrupted by the diagnosis of ASD, which had a big influence on their mental health. This was because ASD is a life changing event with pervasive emotional and social effects that restrict the daily living of the family as a whole. The event threatens the core family identity that requires the family to make diverse mental, social and environmental adaptation in order to deal with the changing situation. During the process family resilience emerged as a powerful way of coping or adaptation in a family that has to live with ASD. This is demonstrated by the parental perspective that ‘it is getting better over time’.

5.6.6 Terminus

Facilitation of resilience in the family is an interactive and dynamic process that is used by the psycho-educational practitioner to assist the families where a child has been diagnosed with ASD to enable them to bounce back after the diagnosis and to be aware of their families’ belief system, organisational patterns, as well as communication and problem solving, steering the family towards an outcome where they feel that their situation is ‘getting better over time’.

5.7 RELATIONSHIP STATEMENTS

The concepts that were discussed, defined and classified in Chapter Five is considered or identified against one another to identify the patterns. The possible relationships between concepts are explored. The explanations of the statements are as follows:

- The psycho-educational facilitator assists families through a dynamic and interactive process where a child has been diagnosed with ASD by mobilising resources.
- Resources are mobilised and that mental, social and environmental adaptations are made.
- By using the process of resilience there will be positive changes in the families belief systems, organisational patterns as well as their communication and problem solving abilities.
- With the above changes the family will be able to overcome barriers; they will be more flexible, creative and adaptive in their daily life as well as in their problem solving abilities.
- This will mean that the family can use resilience in their daily life without the assistance of an outside party or facilitator.
- By teaching families to use resilience when facing barriers, families will be able to develop the realization that their situation is getting “better over time”.

5.8 CONCLUSION

Families where a child is diagnosed with ASD can manage the challenges their family faces by making use of resilience. It is on these abovementioned assumptions that a model to mobilise resilience in a family is proposed in Chapter Six.

CHAPTER 6

DESCRIPTION OF THE MODEL WHICH WILL BE THE BASIS OF THE PSYCHO-EDUCATIONAL PROGRAMME THAT WILL BE USED TO FACILITATE MENTAL HEALTH IN A FAMILY WHERE A CHILD HAS BEEN DIAGNOSED WITH ASD

> *"Through the blur, I wondered if I was alone or if other parents felt the same way I did - that everything involving our children was painful in some way. The emotions, whether they were joy, sorrow, love or pride, were so deep and sharp that in the end they left you raw, exposed and yes, in pain. The human heart was not designed to beat outside the human body and yet, each child represented just that - a parent's heart bared, beating forever outside its chest."*
>
> *Debra Ginsberg*
>
> *(http://www.goodreads.com/quotes/tag/autism)*

6.1 INTRODUCTION

In the previous chapter the concepts of the model was identified and defined. In this chapter the model is illustrated visually and described with regards to the structure and processes. The researcher will also describe the model that will be the basis of the psycho-educational programme that can be used to facilitate mental health in a family where a child is diagnosed with ASD.

6.2 STRUCTURE OF THE MODEL

The structure of the model for the psycho-educational programme consists of the following:

- Overview of the model
- Purpose of the model
- Assumptions of the model
- Context of the model
- Conceptual framework

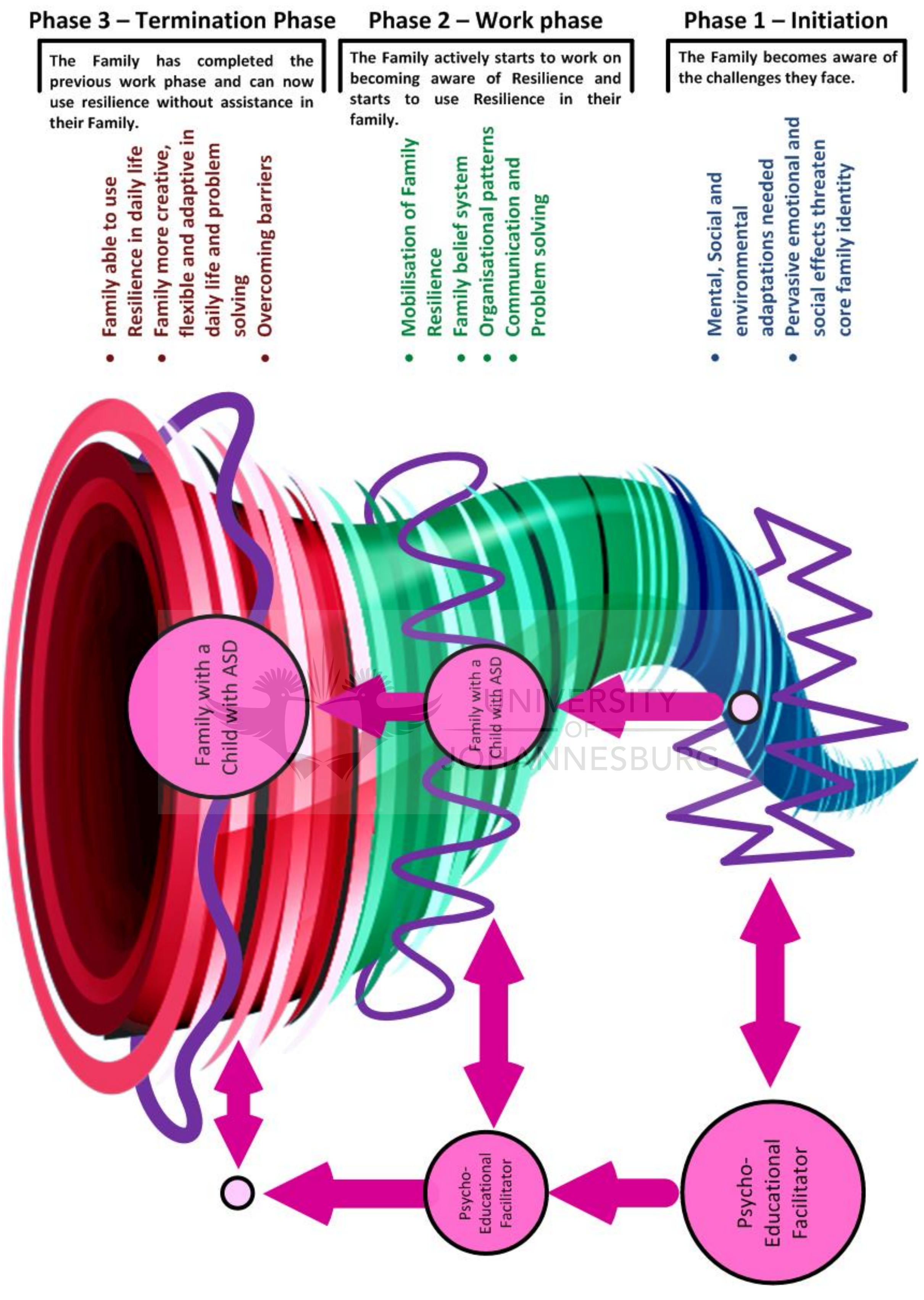
- Structural description of the model
- Process description of the model
- Guidelines for the operationalization of the model
- Evaluation of the model

6.2.1 Overview of the model

The goal of the model is to facilitate resilience in a family where a child has been diagnosed with ASD. (See figure 6.1). The model states that a family must be made aware of resilience, the family must then be thought to facilitate the process resilience in their own family in order to cope with challenging situations that may arise in the future. The model as framework of reference assists the advanced psycho educational practitioner to initiate facilitation and mobilisation of resources. It is visualised that the psycho-educational model for facilitating resilience in a family where a child has been diagnosed with ASD will be effectively used by the advanced psycho-educational facilitator to mobilise resources. In this regard, families will be able over time, to take responsibility for the resilience of their family. Resilience relies on a family's ability to be aware of their own resourcefulness and previous ways of dealing with adversity. Being aware of their own ability to become (more) resilient, a family can continue with a lifelong process of resilience, causing them to feel that their situation is 'getting better over time'.

Having families participate in the process of facilitating resilience is processes where they will be empowered to be able to develop their families' belief system, organisational patterns, and their communication and problem solving capabilities, allowing the family to become more creative, flexible and adaptive in daily life and in problem solving. Thus justifying a family where a child has been diagnosed with ASD to be able to adapt and cope during the different phases of the affected child's life.

Being able to facilitate their own (over time) resilience will allow the affected family to effectively deal with daily challenges relating to having a child affected by ASD, as well as long term challenges that their family may face due to the diagnosis.



Phase 3 – Termination Phase

The Family has completed the previous work phase and can now use resilience without assistance in their Family.

- Family able to use Resilience in daily life
- Family more creative, flexible and adaptive in daily life and problem solving
- Overcoming barriers

Phase 2 – Work phase

The Family actively starts to work on becoming aware of Resilience and starts to use Resilience in their family.

- Mobilisation of Family Resilience
- Family belief system
- Organisational patterns
- Communication and Problem solving

Phase 1 – Initiation

The Family becomes aware of the challenges they face.

- Mental, Social and environmental adaptations needed
- Pervasive emotional and social effects threaten core family identity

FIGURE 6.1: Model for the facilitation of resilience in a family where a child has been diagnosed with ASD

Resilience will assist the family to feel that their situation does get better with time. Resilience is a long term process where the family will initially need the psycho-educational practitioner to guide them to become aware of the aspects of resilience. Over time the family will take more responsibility as they become aware of the aspects of resilience. This will allow the family to develop and use the aspects of resilience without any input from outside the family structures.

The psycho-educational facilitator has the goal to facilitate resilience in a family where the child is diagnosed with ASD. Facilitation of the process of resilience will be used in the psycho-educational programme. The process is illustrated in figure 6.1.

6.2.2 Assumptions of the model

In the following section the researcher will describe the assumptions that are based on the model. These assumptions will include both meta-theoretical and theoretical assumptions as described in Chapter One.

Assumptions of the Theory of Health Promotion in Nursing (University of Johannesburg, 2010:5-9) will be used in the following section. Assumptions related to the model will be ASD, the environment, as well as mental health.

6.2.2.1 Autism spectrum disorder (ASD)

A pervasive developmental disorder characterised by gross and sustained impairment of social interaction and communication; restricted and stereotyped patterns of behaviour, interests, and activities, and abnormalities manifests before the age of three years in social development, language acquisition and/or play (Colman, 2006:68). In this model the researcher assumes that a diagnosis of ASD will provide the child with some developmental challenges that will challenge existing family structures.

6.2.2.2 Environment

According to the paradigm of the Department of Nursing of the University of Johannesburg (2010:5-9) the environment consists of external and internal components.

When looking at the external environment, it consists of family values, norms, methods of worship, attitudes and all forms of expressions. A family will also interconnect with their extended family as well as the community they live in. By this measure the external friends and family and community all contribute to make up the environment for the family, contributing to their mental health.

Taking into consideration each person that is part of the family's inner resources that is made up of physical, social, psychological and spiritual needs provides these members of the family with the ability to sort out their experiences. The facilitation process initiated by the advanced psycho-educational facilitator promotes the environment by mobilising resilience.

6.2.2.3 Mental health

Mental health is the emotional, social and psychological well-being of a person or a network of people. Mental health refers to a person that is functioning at a satisfactory level of emotional and behavioural adjustment (World Health Organization, 2013:1). When a family is assisted by the advanced psycho-educational facilitator to become more resilient as a family, it will allow the family to become mentally healthy as it will address their emotional, social and psychological well-being.

The discussion will now focus on the context of the model.

6.2.3 Context of the model

The context of this model resides within the family as a group at home, as well as the family within their community with regards to the interaction of the family with the community.

When a child is diagnosed with ASD the impact on the family and family unit is great. When a family unit is struggling, the individual members of the family struggle. When a child is diagnosed with ASD there it is a life changing event with pervasive emotional and social effects on all members of the family. This in turn affects the core family identity that requires the family to make diverse mental, social and environmental adaptations in order to deal with the changing family situation. By facilitating resilience, the family is able to cope and adapt to the new situations they face. The family can then, in their environment adapt better, be more flexible and have better ways to problem solve in everyday situations, enabling the family to function in their environment.

6.2.4 Definition of concepts

Theoretical definitions that will be defined and contextualised here are resilience and its attributes. These are facilitation and family. The following concepts are important in the model of resilience and they too will be defined: mental health, promoting mental health and the psycho-educational facilitator.

6.2.4.1 Definition of the central concept: facilitation of resilience in the family

Facilitation of resilience in a family is an **interactive and dynamic process** that is used by the psycho-educational facilitator to **assist** families where a child has been diagnosed with ASD to enable the family to **mobilise resources** and overcome barriers. Enabling the family to **bounce back** after the diagnosis and to become aware of their **families' belief system**, **organisational patterns** as well as **communication and problem solving skills** with the realisation that their situation is **getting better over time**.

6.2.4.2 Definition of related concepts

a) Facilitation

Facilitation can be defined as an **interactive and dynamic process** where families are **assisted** by an outside party, psycho-educator, to **mobilise resources** in order to overcome barriers, develop and grow as a person and reach their goals. The first related and essential criteria from facilitation is facilitation as an interactive and dynamic process. This shows towards a process where all parties are actively participating and where there is a constant process of interaction between all parties where they are working towards a common goal. Secondly, related criteria from facilitation is assistance: during this process of facilitation families are constantly supported by an psycho-educator to reach their goals. During facilitation internal and external resources are identified. The last related criteria of facilitation is mobilisation of resources.

b) Resilience

Resilience refers to the process whereby an individual or family has the ability to bounce back after a setback by making use of the core aspects of resilience that will enable them to develop their **organisational patterns** their **communication** and **problem solving skills,** as well as their **family belief system** driven by a realisation that their situation is **"getting better over time".** The essential and related criteria of resilience are as follows. The first essential criteria is the ability of the individual to bounce back, which means that the individual is able to rebound after a setback. Secondly, the family's belief systems that will enable them to make meaning out of diversity, to have a positive outlook or hope, transcendence and spirituality (Walsh, 1998:7). Thirdly, the organisational patterns that refers to flexibility, connectedness and social support (Walsh, 1998:7). The next important essential criteria are communication and problem solving. Here it is important to look at clarity of communication, open emotional express and collaborative problem solving (Walsh, 1998:7). The last essential criteria of resilience is that for the families their situation is getting better over time because they are more skilled and managing difficulties with more ease.

6.3 STRUCTURAL FORM OF THE MODEL

The structure of the model is represented by a tornado. As the family enters the tornado and gets picked up, they get drawn upwards by the winds inside the tornado towards the last phase that is the termination phase. Initially at the bottom of the tornado the family still moves around erratically, but as they move upwards the winds get more stable and they don't get thrown around so much anymore. During this process where the family moves upwards inside the tornado, the psycho-educational facilitator is initially very involved but becomes less involved as the family moves up.

The process moves in an upward direction indicated by the arrow in the middle of the tornado as to mobilise resilience. As the role of the psycho-educational facilitator becomes smaller, the role of the family gets bigger as indicated by the circle of the psycho-educational facilitator that gets smaller and loses colour and the families' circle that becomes bigger and darker in colour.

The essential structure that makes up the model of resilience in families where a child is diagnosed with ASD is the parents, siblings and extended family. In this model the context is the family. The focus of the model is on improving mental health in families where a child is diagnosed with ASD by making use of the principles of resilience. By making use of facilitation of resilience the families will be able to over time move towards self-sustained process that they themselves can manage.

Participants are able to move at their pace through the different levels of the model. If the family needs to, they can be in one level for a longer amount of time than another family so that they have time to process the information at each level. The facilitator will take into consideration that different families will move through the different levels at their own pace. In the model there are three phases and each phase has different levels.

On the flowing pages the researcher will discuss the phases as well as give sketches to illustrate the different phases of the model.

6.3.1 Phase one

Phase one constitutes the initiation of the model as well as the relationship phase (See Figure 6.2). During phase one there is pervasive emotional and social effects that threaten the core family identity. During this phase the family becomes aware of the challenges they face as well as the mental, social and environmental adaptations they need to make. The colour is indicated as a dark blue that shows towards healing, trust, faith and power. The dark pink circle of the psycho-educational facilitator shows towards the compassion, understanding, nurturing and insightfulness that the psycho-educational facilitator has towards the family and the process of mobilisation of resilience. The family is represented by a smaller pink circle that indicates that they are only starting to become aware of the process of resilience. There is an arrow between the psycho-educational facilitator and the family to indicate that there is an interactive facilitation process between the family and the psycho-educational facilitator.

FIGURE 6.2: Phase one – Initiation phase

6.3.2 Phase two

Phase two constitutes the facilitation of the model or the work phase (as described in Figure 6.3). During this phase the family actively starts to work on become aware of resilience and start to use resilience in the family. As resilience is mobilised the family's belief system, organisational patterns, communication and their problem solving abilities increases. The colour green is used in this phase as it represents growth and renewal in the family structures. During this phase the winds in the tornado become more stable and the family (due to resilience that is starting) is not being thrown around by their circumstances as much as they were in phase one. The family's pink circles gets larger and darker in colour as they become more familiar with the process of resilience and the pink circle of the psycho-educational facilitator becomes smaller and the colour fades as the family starts to use resilience more on their own and the psycho-educational facilitator starts to fade out.

FIGURE 6.3: Phase two – Work phase

6.3.3 Phase three

Phase three is the termination or closure phase (see Figure 6.4). The family has completed the previous work phases and they can now use resilience in their family unaided. During this phase the family is more creative, flexible and adaptive in their daily life and in their problem solving. The colour used during this phase is red as red symbolises energy, passion and action. The skill of being resilient is now transferred to the family where they are able to use resilience in the future for any challenges that they might face. The pink circle of the family is now at its biggest and darkest in colour as the family have learned the skill of resilience from the psycho-educational facilitator. The circle of the psycho-educational facilitator has now faded out as she (he) is no longer needed to facilitate the process as the family can manage by themselves. During this phase the winds in the tornado is at its most stable. Since the family has become resilient they will not be as affected as before by challenges that they might face.

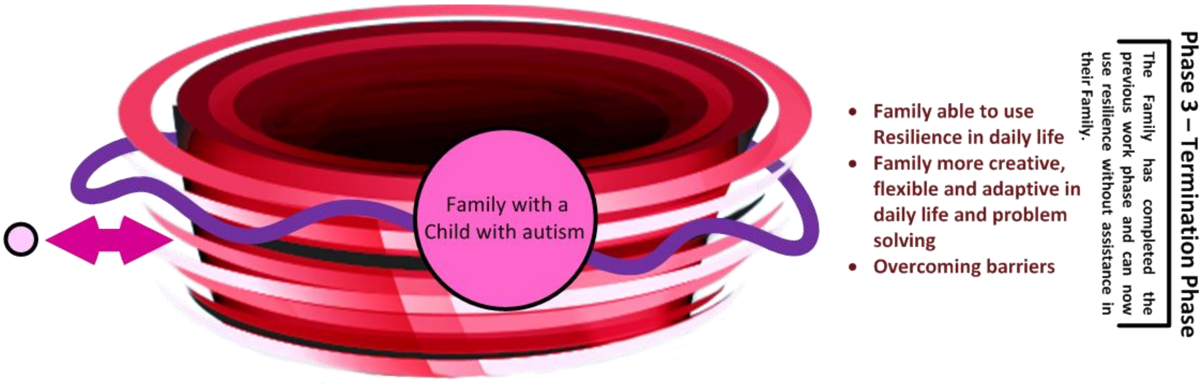


FIGURE 6.4: Phase three – Termination phase

6.4 PROCESS DESCRIPTION OF THE MODEL

During the process of facilitating resilience the psycho-educational facilitator is able to guide families towards mental health. The process of resilience is therefore designed to give families the ability to adapt or bounce back after a diagnosis of ASD in their family. This will enable the family to overcome barriers and move towards mental health. Initially the family will work closely with the psycho-educational facilitator in the process of mobilisation of resilience but as the family become more accustomed to using resilience they will be able to take on more of an active role, thus fading out the psycho-educational facilitator. Using resilience in their family will become a lifelong process that the family will have to manage throughout their lives as the affected child enters each new developmental phase or educational, social and medical challenge. As with each phase of development and each new challenge, the family must consciously be aware of the process of resilience and draw on past experiences in order for them to successfully take on the new challenges.

During the implementation of this model it is important that the psycho-educational facilitator takes into consideration that there are many human factors present in relation to the processing of the model. Due to the uniqueness the diagnosis of ASD in each child, it must be remembered that each family will face different challenges to a different extent. It is therefore said that each family's development with resilience will take place under a unique set of circumstances.

The model of resilience has three interrelated dimensions that will be operationalised at the same time. The three dimensions are: initiation phase, work phase and finally, the termination phase. It is very important that resilience is a lifelong process with the abovementioned dimensions all working together to facilitate the family towards resilience and mental health.

6.4.1 Phase one: Initiation phase

The initiation phase will form the initial facilitation point of the model. During this dimension the psycho-educational facilitator will get to know the family where a child has been diagnosed with ASD. Access to the families will be gained through diagnosticians and families seeking first line of contact services at a service provider, as well as through support groups at the center where the researcher works.

Initially the psycho-educational practitioner will meet with the family in an interactive and dynamic process to get to know them and their unique set of circumstances due to the diagnosis of ASD in one (or more) of their children. The psycho-educational facilitator will work with the family, assist them, in order for them to be able to identify the emotional and social effects that will become a barrier in their lives. The psycho-educational practitioner will then be able to identify the aspects that can threaten the families' core identity.

Together with the psycho-educational facilitator the family will mobilise resources to identify the mental, social and environmental adaptations that they need to make in order to become aware of their families' changed needs.

6.4.2 Phase two: Work phase

Facilitation of resilience - the work phase - will be addressed through personal contact sessions with the family, one family at a time. The goal with this phase is for the families to become aware of using resilience in their family and to start to use resilience in their family. During this phase the families will be supported by the psycho-educational facilitator. When using resilience the families will mobilise resilience in their family and will have positive changes in their family belief systems, organisational patterns, as well as in their communication and problem solving abilities.

During phase two the facilitation process will focus on:

- Mobilisation of resilience.
- Clarify family belief systems.
- Work on family organisational patterns.
- Improving communication and problem solving abilities.
- Getting better over time.

When working with the families the psycho-educational facilitator will make use of direct strategies such as questioning, time for reflection as well as step by step guidance through the process of resilience.

6.4.3 Phase three: The termination phase

During phase three, the termination phase, the psycho-educational facilitator will make use of less direct strategies as the family starts to take responsibility for their own resilience from this point. As the family moves from the work phase to the termination phase, the psycho-educational facilitator will slowly step back to allow the family to take responsibility for their own mental health. As the family reaches phase three, the psycho-educational facilitator can be assured that they will be able to manage resilience in their family on their own.

During the termination phase the family will be more creative, flexible and adaptive in their daily lives as well as in their abilities to problem solve. The family will be able to overcome barriers by using resilience. This will in turn allow the family to be mentally healthy. Even though the process takes time, the end result will leave the families with the idea that their situation will get ‘easier with time’, and this will allow them to cope and to set new dreams and hopes for every member of their family.

During the termination phase the family is left with new knowledge and insight into their lives. The psycho-educational facilitator will know that the family has reached this point when the family is more flexible, adaptive in their daily life and their problem solving. The family will be more resilient, making them more positive, and they will be able to have future hopes and dreams with an all-round feeling that life has meaning.

6.5 GUIDELINES FOR OPERATIONALISING THE MODEL OF RESILIENCE IN FAMILIES WHERE A CHILD HAS BEEN DIAGNOSED WITH ASD

6.5.1 Guideline 1: Initiation phase

Objectives:

The objectives in the initiation phase are that resilience in a family where a child is diagnosed with ASD is a process that will continue over the lifespan of the child diagnosed with ASD.

Actions:

A dynamic and interactive process through assistance. It is a process whereby the family becomes aware of the mental, social and environmental adaptations they need to make because of pervasive emotional and social effects that threatens the family’s core family identity. The family will be able to start to become aware of the mental, social and environmental adaptations that they will need to make by working with the psycho-educational facilitator. It requires mobilisation of resources.

6.5.2 Guideline 2: Work phase

Objectives: Facilitation of resilience

During this phase the action is that the psycho-educational facilitator will facilitate the process of resilience with the family. This will allow them to become aware of the barriers they face and will start the family in the process to become more resilient. During the process the family will initially work very closely together with the psycho-educational facilitator as the facilitator will initially teach the family how to understand and use resilience in their family.

Actions:

- Mobilisation of resilience.
- Clarify family belief systems.
- Work on family organizational patterns.
- Improving communication and problem solving capabilities – getting better over time.

During the mobilisation of resilience families will be taught how to understand and work on their family belief systems, their families' organisational patterns, as well as on their families' communication and problem solving abilities. During this process the psycho-educational facilitator will become less involved as time goes by, carrying over the skill to the family. During this phase the action will be that the family starts to take responsibility for developing resilience and the facilitator will become less and less involved as time goes by.

6.5.3 Guideline 3: Termination phase

During this phase the objective will be for the facilitator to remove themselves from the facilitation process as the family is now able to use resilience unaided in their family. The skill of being resilient is now been mobilised to the family. The family can now use resilience in the future for any challenges that they may face. The actions that the family will use during this phase are being able to use their belief systems, their organisational patterns, as well as their communication and problem solving abilities.

Each family's unique situation should be taken into account when the family is guided by the psycho-educational facilitator.

6.6 EVALUATION OF THE MODEL

The model has been evaluated during a doctoral seminar and consisted of eleven academics and researchers with previous knowledge and experience of model construction. The assessors were academics and researchers at the University of Johannesburg. Direct quotations of the assessors are placed within the assessment. The feedback that was received during this session will be discussed in the following section.

Several consultations and revisions between the researcher and her programme leaders were made before the model became clear and workable. The researcher made use of Chinn and Kramer's (2008:237) criteria to describe the model. The criteria that is important in the process to describe the model includes that all the aspects of the model needs to be clearly defined, it needs to be simple and understandable. The model needs to adhere to generality as well as empirical applicability. All the consequences need to be understood. There needs to be meaning and logic adequacy. There needs to be operational adequacy as well as predictability. Paradigmatic adequacy also needs to be taken into consideration.

6.6.1 Clarity

Initial definitions and concepts had to be written in a clear and simple manner in order for the meaning of the relationships to be clear and understandable. During the initial phases of model development the researcher had to shorten some of the definitions and concepts as they were too long. During this process the researcher had to link applicable definitions and concepts in order for the relationships to be understandable. The researcher will place the comments of the assessors in purple.

During the seminar there was consensus that the model is clear and easy to understand. *"I like it that I can understand the model easily", "In your model it's easy to identify the different phases and it's easy to understand them" , "I like the idea of using a tornado to illustrate the families progress through the different phases", "When you look at the model you can understand the model right away".* The feedback suggested that some of the colours in the model were too vibrant and needed some adjustment *“Should the colours in the model be a bit ‘duller’? It’s a bit distracting”, “The colours can be a bit less vibrant”.* This alteration was made and after discussion with the study leaders it was decided that the new colours was correct.

6.6.2 Simplicity

The model is not complex. The core concepts support the purpose of the model. The concepts of the model fit well into psycho-educational practice *“Your way of describing the concepts in the model makes it easy to understand the concepts, “The concepts are clear and easy to understand”, “The concepts are clearly defined and understandable”, “I see that this model will work well in practice”.* Their meanings have been retained by guarding against adding new and unimportant concepts.

During the seminar it was said that the model is simple and understandable. According to the seminar panel it is easy to identify the concepts used in the model.

6.6.3 Generality

The model is intended for use in facilitating resilience in families where a child is diagnosed with ASD. The goal of the model is to assist families to facilitate mental health in their family where a child is diagnosed with ASD. Parents, siblings and extended family constitute the context for this model. This model can be utilised in the promotion of mental health in families where a child has been diagnosed with ASD.

The model was developed for families where a child has been diagnosed with ASD, and according to the seminar panel this model could have a broader application as it shows signs for other populations that has similarities with this target population. The seminar panel further reported that the model can be applied in general to facilitate mental health. *“I think that possibly this model can be used in broader applications”, “Have you thought about using this model to tech resilience in families with other challenges than autism?, “I think that this model can be used to facilitate mental health in general”.*

6.6.4 Empirical applicability

The empirical applicability of this model is encouraged by the clarity of its concepts, including its identified purposes. This is promoted by adequately defined concepts and the provision of meaningful conceptual relationships. *"It's easy to understand your model and to identify how to use and for what to use your model", "The purpose of your model is clear", "The empirical applicability of you model is overall done well".*

During the seminar there was consensus that the empirical applicability of this study is sound and easily identified and understood.

6.6.5 Consequences

The consequence for this theory is that it will contribute to promoting mental health in families where a child has been diagnosed with ASD. The guidelines based on this theory are open to new ideas and further exploration.

During the seminar the panel was very excited about the models consequences in other possible applications. *"I am excited to think that there are other applications for your model", "I would love to use your model to see if it would work in other applications".*

6.6.6 Meaning and logical adequacy

Meaning and logical adequacy is retained by persistently working within the stated assumptions, definitions, and its conceptual relationships over and above working within the frame of the selected theoretical model (University of Johannesburg, 2005:5-9).

Throughout the seminar the panel reported that the assumptions, definitions and conceptual relationships of the model was easy to understand and that it was easy to identify the conceptual relationships within the model. *"It's not hard to understand where you got your assumptions from, I can see where your conceptual relationships* *and definitions come in", "The meaning and logical adequacy in your model is done well".*

6.6.7 Operational adequacy

The researcher strived to achieve operational adequacy for this model by ensuring that concepts were operationally defined in relation to the theoretical concepts. *"I think that you managed to achieve operational adequacy".* This was ensured when the study leaders confirmed that the process had been achieved.

6.6.8 Contribution to understanding

This model contributes to the understanding of mental health in families where a child has been diagnosed with ASD. It introduces a way in which an advanced psycho-educational facilitator can facilitate and mobilise resilience in families where a child has been diagnosed with ASD. Simple explanations have been used to explain the reasoning behind the model. *"I have never thought about the families of the children that are diagnosed as we always just think of the children. I can see how helping the family cope directly will also help the child", "This is an aspect that is neglected, I am so glad that someone thought too look at the family", "I have never thought about how the families cope, I just look at the affected child", "I think your model can help families cope that have a child affected with any long term illness or disability".*

During the seminar there was excitement about the models impact on facilitation of resilience in many different fields.

6.6.9 Predictability

For this model the theory generated has a specific purpose as the theory serves as a reference for the operationalisation of psycho-educational guidelines in promoting the mental health of families where a child has been diagnosed with ASD. With this in mind, the theory is a situation-relating theory. *"I think the predictability of your study is accurate".*

6.6.10 Pragmatic adequacy

The theory generated is useful and will contribute to mental health. Further, the theory is practice orientated. The great contribution of this model is that families can take responsibility for their own mental health and the mental health of their family. Families will be able to use resilience as a lifelong tool and will be able to manage their own resilience without the aid of an outside party. They will be able handle all future adaptations they need to make before it can threaten their families' core identity. They will be able to manage their families' belief systems, organisational patterns, as well as their communication and problem solving abilities. *"Your study is very useful and I am sure that this study will be able to be used in any practice where there is families and children with autism", "I like the fact that families can help themselves and don't need to be subjected to years of therapy from an outside the family source", "I like it that your model can be used over the life span of the family so they can manage future challenges they may face".*

6.7 SUMMARY

This chapter covered the discussion of the model of resilience in a family where a child has been diagnosed with ASD. Guidelines for the implementation of the model by the psycho-educational facilitator were given.

In the next chapter the researcher will discuss the evaluation, the limitations, as well as the recommendations of the study.

CHAPTER 7

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

"When living with a neurological condition, or with a loved one that has one, it can be very easy to focus on the challenges and limitations. But in my life, I have found that focusing on abilities, finding new ways to adapt, have been crucial to my successes in life. Seeking those solutions can even be seen as a form of creativity. Although, like anyone, I have my moments of discouragement, I've moments of discouragement, I've learned to use my challenges to push me forward. I believe what Dr. Sacks says is very important. There is much more to life on the spectrum than just "deficiencies and deficits" can be strengths in certain circumstances."

-S. Borgman-

7.1 INTRODUCTION

In the previous chapter the researcher described the facilitation of mental health in a family where a child has been diagnosed with ASD. In this chapter the researcher will assess if the objectives of the study was reached. The researcher will further discuss the limitations of the study as well as give recommendations with regards to the operationalisation in the educational filed as well as in practice and research.

7.2 EVALUATION AND CONCLUSION

In this study the goal was to develop a psycho-educational model that will give guidelines to the psycho-educational facilitator to assist them to facilitate the mental health of a family where a child has been diagnosed with ASD. The method was thus to facilitate the mental health in a family where a child has been diagnosed with ASD spectrum disorder, thus moving the family towards mental health.

The researcher strove to meet these goals by making use of a theory generative, qualitative, exploratory, descriptive and contextual design. The researcher made use of field work to collect information from families and this was done by using in-depth interviews with family members where a child has been diagnosed with ASD. The data obtained from these interviews was analysed in terms of themes and categorised. Thereafter the researcher made use of cross validation report and a literature study; all findings were validated. In Chapter Two the researcher discussed the research methodology and in Chapter Three the researcher gave the results of the in-depth interviews as well as the discussion of the results.

The results from the in-depth interviews indicated that having a child diagnosed with ASD spectrum disorder is a life changing event with pervasive emotional and social effects on the family, restricting the daily living of the family as a whole. The event threatens the core family identity, requiring the family to make diverse mental, social and environmental adaptations in order to deal with the changing family situation. Family resilience emerges as a powerful way to cope or adapt in a family that has to live with ASD, demonstrated by the parental perspective that ‘it’s getting better over time’.

During the discussion of the results in Chapter Three and the cross validation and literature control of Chapter Four, the researcher was of the conviction that the families where a child had been diagnosed with ASD spectrum disorder all loved their affected child very much. What seemed to affect the families most was that they were not aware there would be so many changes in their daily lives after the diagnosis.

The families also felt very overwhelmed with the practical aspects that came with the diagnosis, such as driving to therapies and needing extra income to manage the financial burden that was placed on them with the diagnosis. The siblings of the affected child also had a very hard time understanding why their sibling was different and why the rules in their home differed for the affected sibling. Extended family members also indicated that they did not always know how to assist the affected family and that they felt helpless.

Data stated that the families had to face lots of emotional effects in the parental-sub system that was as a result from being confronted with ASD spectrum disorder as a life changing event. The families had to face emotional turmoil, and they stated that they were in a position of not knowing. They yearned for interaction with the affected child and had to mourn personal losses and daily activities. The families stated that there were a lot of emotional effects on the siblings of the affected child as well as on extended family and friends.

The families further said that they experienced great demands in taking care of the affected child, as well as many demands on their social interactions. There were demands on their marital relationships, their relationships with themselves, their extended family, as well as their social relationships. The families also claimed that the sibling identity and expectations changed a lot after the diagnosis of a sibling with ASD.

The families added that they also had experiences of mental, social and environmental adaptations that the families utilised to deal with the changing family situation. There are mental adaptations needed to educate the self, experiences of social adaptations with included parental roles that changed as there are financial changes and burdens, excessive time and practical demands, as well as a strong need from the parents to protect the affected child. The families further experienced sibling adaptation in the ways that the siblings made sense of their affected brother or sister's diagnosis. They spoke about socialising and how they had to make a lot of environmental adaptations like family outings in order for them to deal with the diagnosis of ASD.

Facilitation of resilience then emerged from the data as a powerful way for the families to cope or adapt to their situation. This was as a result of the families associating a lot of positive emotions around the child affected by ASD. The families also spoke about the affected child in positive terms. They recognised the importance of having support systems in place, as well as being resourceful as a person. All the families acknowledged that over time their situation gets better.

As resilience emerged as a powerful way to cope or adapt for the family members, this was further explored in Chapter Five, where the conceptualisation of the central concepts were presented. The central concept that was identified is **facilitation** of **resilience**. The model serves as a frame of reference for the facilitation of resilience to enhance the mental health in a family where a child is diagnosed with ASD. A unique aspect of the model is that over time the family will be able to manage the process of resilience themselves and thus take control over their own mental health.

Chapter Six consists of a description of the psycho-educational model which can be used as a framework of reference to facilitate mental health in a family where a child is diagnosed with ASD. Guidelines were formulated in Chapter Six for the operationalisation of the psycho-educational model that serves the purpose of promoting mental health in a family where a child is diagnosed with ASD. It is important that families are given the tools to assist them to develop resilience as a family and to be able to promote their own mental health. Thus, having a family that is managing well and who is mentally healthy will enable the family to thrive in their community.

7.3 LIMITATIONS OF THE STUDY

In the initial planning the researcher wanted to have one-to-one interviews with the grandparents of the affected families. Some of the grandparents initially agreed to be interviewed. Only later did they say they would rather communicate via e-mail, as they felt it's not their place to say how they see their own children coping with their affected child. One of the grandparents said that even though they felt their own children weren't coping, they did not want to say how they as grandparents feel as their children already had enough to deal with. At a later stage the researcher did manage to speak to some of the grandparents but never felt that they said all that they needed to say.

7.4 ORIGINAL CONTRIBUTION

This study contributes a unique model and a psycho-education programme to the field of psycho-educational facilitations. The research and contribution is unique as this study did not only focus on the child with ASD but also on the family as a whole that is affected when another member of the family receives a diagnosis of ASD. By taking part in the facilitation process, families are given skills that will allow them to manage the barriers that they face at any time of the affected child's life. This psycho-educational model thus allows the family to manage their mental health on their own, without needing outside intervention.

7.5 RECOMMENDATIONS

The recommendations stated in this section are based on the usefulness in a psycho-educational setting where families are assisted after the diagnosis of a child with ASD spectrum disorder, as well as for future psycho-educational research. Using reflection, the limitations as well as the conclusion and recommendations will be listed below as follows:

7.5.1 Recommendations with regards to research

The researcher suggests that further research needs to be done with regards to supporting families where a child is diagnosed with ASD. There are not enough emphasis on the impact of a diagnosis on the family, extended family and friends. When a child is diagnosed with an illness like cancer, there is a specific starting point and end for the family involved, but when a child is diagnosed with ASD, a family is mostly left with more questions than answers. Families start to only 'live' ASD spectrum disorder and this poses a lot of difficulties and hardship on the path of the family. The families are constantly faced with a new aspect involving ASD; an example is that first a child can struggle with language like speaking. When they then start to speak, what they say can be very inappropriate as they don't always understand what is socially acceptable to say and what is not. Every milestone the child doesn't reach, each comment from a member of the public such as "why don't you just discipline your child" poses the family with new challenges. Extended family and friends need to navigate their way through what the family need and doesn't need while they also struggle to deal with the diagnosis.

When a child gets diagnosed there are so many different things that the child needs in terms of therapies, schooling and medically, that the family gets "lost" and professionals easily forget about the individual members of the family and how the diagnosis affects them.

The researcher is excited about the prospect that other researchers will do more research on the topic as well as apply the model to other relevant fields. In many countries there is a new emphasis on supporting families but in South Africa we are still struggling to get basic services to the affected child, that we don't have any resources left to assist family members.

7.5.2 Recommendations in practice

Professionals tend to focus on the problem at hand, for example the child is not talking, so professionals put in place speech therapy. However, professionals are inclined to forget what the impact of the issue at hand is on the family as a whole. Professionals forget to ask parents if they are coping and how the siblings or grandparents are doing. Professionals forget to ask if the parents are coping with their child's disability and if the parents are still functioning in society.

As multi-disciplinary teams it is the psycho-educational facilitator that will see to it that the model is implemented to facilitate the mental health of the family, in families where a child has been diagnosed with ASD.

7.5.3 Recommendations in education

The psycho-educational facilitator is in a unique position when a child is diagnosed with ASD or a related disorder. As the psycho-educational facilitator they will be able to meet the family and work with that family so that the family become aware of the barriers that they might face. The psycho-educational facilitator has the responsibility to support the family in gaining the skills that they will need. The psycho-educational facilitator has to support the family in such a way that the family's needs are met.

7.6 SUMMARY

The discussion in this chapter concludes the understanding of the concept of facilitating mental health in a family where a child is diagnosed with ASD.

BIBLIOGRAPHY

Adams, J.B., Edelson, M., Grandin, T., Rimland, B. & Johnson, J. (2012). *Advice for parents of young autistic children*. Part 1. Page 1-60.

Andreica-Suandicua, B., Patca, S., Panaete, A., & Andreica, S. (2011). The impact of autism diagnosis on the family. *Acta Medica Transilvanica, 16*(3).

Ariel, C.N. & Naseef, R.A. (2010). *Voices from the spectrum: Parents, Grandparents, Siblings, People with autism, and professionals share their wisdom*. Jessica Kingsley Publishers: London.

Athari, P., Ghaedi, L. & Kosnin, A.b.M. (2013). Mothers' Depression and Stress, Severity of Autism among Children and Family Income. *International Journal of Psychological Research, 6*(2):110-108.

Atkin, K.M. & Tozer, R.J. (2014). Personalisation, family relationships and autism: Conceptualising the role of adult siblings. *Journal of Social Work*, 14(3):225-224.

Babbie, E. (2005). Improving the Measurement of Public Opinion. *The Illusion of Public Opinion: Fact and Artifact in American Public Opinion Polls*, 187.

Babbie, E. (2005). The basics of social research. 3rd edition. *Belmont, CA: Wadsworth*.

Babbie, E.R. & Benaquisto, L. (2009). *Fundamentals of social research.* 2nd edition. Toronto: Nelson Education Limited.

Babbie, E.R. & Mouton, J. (2001). *The practice of social research.* London: Oxford University Press.

Barlow, D. & Durand, V. (2005). Abnormal Psychology: An Integrative Approach Thomson Wadsworth. *Belmont, CA*.

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research,* 51(9):702-714.

Ben-Sasson, A., Soto, T.W., Martinez-Pedraza, F. & Carter, A.S. (2013). Early sensory over-responsivity in toddlers with autism spectrum disorder as a predictor of family impairment and parenting stress. *Journal of child Psychiatry*, S4(8):846-853.

Bens, I. (2005). *Facilitating with ease! Core skills for facilitators, team leaders and members, managers, consultants and trainers.* San Francisco: Jossey-Bass.

Berg, B.L. (2007). *Qualatative reseach methods for the social sciences.* Pearson/Allyn & Bacon.

Bernard, B. (2006). *Resilience: What we have learned*. Library of congress: Boston.

Bernard, E., Witley, J.R. & Kite, M.E. (2013). *Principles of research in behavioral science*. 3rd edition. New York: Routledge.

Black, K. & Lobo, M. (2008). A conceptual review of family resilience factors. *Journal of Family Nursing,* 14(1):33-55.

Blackman, J.A. (1999). Attention-deficit/hyperactivity disorder in preschoolers: does it exist and should we treat it? *Pediatric Clinics of North America,* 46(5):1011-1025.

Bradley, A. (2014). www.Researchautism.net/autism/personal/-accounts-living-with-autism/Alyson-bradley.

Bradley, E. & Caldwell, P. (2013). Mental Health and Autism: Promoting Autism FaVourable Environments (PAVE). *Journal on Developmental Disabilities,* 19(1).

Breakwell, G.M. (editor). (2004) *Doing social psychology research.* Blackwell Publishing: Australia.

Bromley, J., Hare, D.J., Davison, K. & Emerson, E. (2004) Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism SAGE Journals,* 8(4):409-423.

Brooks, R. & Goldstein, S. (2011). *The power of resilience*. McGraw Hill Professional: New York.

Brush, B.L., Kirk, K., Gultekin, L. & Baiardi, J.M. (2011). Overcoming: a concept analysis. *Nursing forum*, 46:160-168.

Bryman, A. (2012). *Social research methods.* New York: Oxford University Press.

Burns, N., Grove, S.K. & Gray, J.R. (2013). *The practice of nursing research: Appraisal, synthesis, and generation of evidence.* 7th edition. Sounders: New York.

Carbone, P.S., Behl, D.D., Azor, V. & Murphy, N.A. (2010). The medical home for children with autism spectrum disorders: Parent and pediatrician perspectives. *Journal of autism and developmental disorders,* 40(3):317-324.

Carr, A. (2004). *Positive Psychology: The Science of Happiness and Human Strengths.* Brunner-Routledge.

Cebula, K. (2012, May). Applied Behavior Analysis Programs for Autism: Sibling Psycholosocial Adjustment During and Following Intervention Use. *Journal of Autism & Developmental Disorders,* 42(5):847-862.

Chan, W.L. & Goh, E.C.L. (2014). ‘My Parents told us that they will always Treat my Brother Differently Because he is Autistic’ – Are Siblings of Autistic Children the Forgotten Ones? *Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community,* 28(2).

Chesnay, M. & Anderson, B. (2005). *Caring for the vulnerable: Perspectives in nursing theory, practice and research.* Jones and Bartlett publishers: Sudbury.

Chinn, P. & Kramer, M. (2008). Integrated Theory and Knowledge Development in Nursing Mosby. *Integrated Theory and Knowledge Development in Nursing Mosby*. Elsevier, St. Louis, MO.

Chinn, P.L. & Kramer, M.K. (2011). *Integrated theory and knowledge development in nursing*. 8th edition. Mosby Elsevier: St Louis.

Clarke, A.M. & Clarke, A.D.B. (2003). *Human Resilience: A fifty year quest.* Jessica Kingsley: London.

Colman, A. (2006). *A dictionary of psychology.* Oxford University Press.

Colman, A.M. (2003). *Oxford Dictionary of Psychology*. Oxford university press: New York.

Copi, I.M. (1987). *Informal logic*. Macmillan: New York.

Creswell, J.W. (2014). *Research: Qualitative, Quantitative, and Mixed Methods Approaches*. 4th edition. London: SAGE.

Cridland, E.K., Caputi, P., Jones, S.C. & Magee, C.A. (2014). Understanding high-functioning autism during adolescence: A personal construct theory approach. *Journal of Intellectual and developmental disability volume,* 39(1).

Dale, E., Jahoda, A. & Knott, F. (2006). Mothers' attributions following their child's diagnosis of autistic spectrum disorder Exploring links with maternal levels of stress, depression and expectations about their child's future. *Autism,* 10(5), 463-479.

David, D.D., Dobrean, A., Mogoase, C. & Dobrescu, I. (2013). Screening for Autism in Romanian Population: An Initial Study Investigating the Clinical Utility of the Screening Questionnaire for Autism Spectrum Disorders. *Transylvanian Journal of Psychology,* 14(2):127.

De Vos, A.S., Strydom, H., Fouche C.B. & Delport, C.S.L. (2011). *Research at grass roots: for the social sciences and human service professionals.* 4th edition. Van Schaik: Pretoria.

DeGrace, B.W. (2004). The everyday occupation of families with children with autism. *The American journal of occupational therapy,* 58(5):543-550.

Dickoff, J., James, P. & Wiedenbach, E. (1968). Theory in a practice discipline: Part I. Practice oriented theory. *Nursing Research,* 17(5):415-434.

Dictionary.com. (n.d.). '*Facilitate'.* Available from: www.dictionary.reference.com.

Dingwall, R. & Miller, G. (1997). *Cotext and method in qualitative research.* London: SAGE publications.

Doheny, K. (2014). *Autism and Family Relationships*. Retrieved from Web MD: www.webmd.com/brain/autism/features/autism-and-family-relationships?

Dooley, L.M. (2002). Case study research and theory building. *Advances in developing human resources,* 4(3):335-354.

Dyches, T.T., Wilder, L.K., Sudweeks, R.R., Obiakor, F.E., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders,* 34(2):211-222.

Elliott, R. & Timulak, L. (2005). *Descriptive and Interpretative approaches to qualitative research.* Available from: Nideffer.net/classes/GCT_ RPI_s14/readings/ interpretive.pdf.

Estrella, C. (2013, November). Parental perspectives on the care of children with autism. *Learning Disability Practice,* 16(9):24-28.

Evans, L. (2007). *Inclusion.* Taylor Francis publishers: London.

Farrugia, J.M. (2013). The use or misuse of biomedical treatment approaches to autism. *Malta Medical Journal,* 25(1).

Fischer, J. & Corcoran, K. (2007). *Measures for Clinical Practice and Research: A Sourcebook Volume 2: Adults.* Oxford University Press, USA.

Fischer, J. & Corcoran, K.J. (2007). *Measures for Clinical Practice and Research: A Sourcebook*. Volume 1: Couples, Families, and Children.

Forrester, M.A. (2010). *Doing Qualitative Research in Psychology.* SAGE.

Gagnon, Y.Z. (2010). *The case study research method: A practical handbook.* Quebec: Book publishings Industry Development Program.

Garbers, J.G. (1972). *Ordening tot 'n opvoedkundige ontwikkelingsmodel.* Johannesburg: RAU.

Goldstein, S. & Brooks, R.B. (2011). *Handbook of Resilience in Children.* Springer.

Goldstein, S., Naglieri, J.A., Rzepa, S. & Williams, K.M. (2012). A National Study of Autistic Symptoms in the General Population of School-Age Children and Those Diagnosed with Autism Spectrum Disorders. *Psychology in the Schools,* 49(10):1001-1016.

Greene, R. (2006). *Social Work Practice: A Risk And Resilience Perspective.* Thomson Brooks/Cole.

Grinker, R.R. (2007). *Unstranged minds: remapping the world and autism*. Basic books: Philadelphia.

Grove, R., Baillie, A., Allison, C., Baron-Cohen, S. & Hoekstra, R.A. (2013). Empathizing, systemizing, and autistic traits: Latent structure in individuals with autism, their parents, and general population controls. *Journal of abnormal psychology,* 122(2):600.

Hadley, R.G. & Mitchell, L.K. (1995). *Counselling research and program evaluation*. Cenage learning: London.

Hamilton, L.M. (2000). *Facing autism*. Colorado Springs, Colorado.

Harper, M. & Cole, P. (2012). Member checking: Can benefits be gained similar to group therapy. *The Qualitative Report,* 17(2):510-517.

Harvey, J. & Delfabbro, P.H. (2004). Psychological resilience in disadvantaged youth: A critical overview. *Australian Psychologist,* 39(1):3-13.

Heaton, J. (2004). *Reworking Qualitative data*. SAGE publications: London.

Heron, J. (1999). *The Complete Facilitator's Handbook.* Kogan Page.

Hodgetts, S., Nicholas, D., Zwaigenbaum, L. & McConnell, D. (2013). Parents' and professionals' perceptions of family-centered care for children with autism spectrum disorder across service sectors. *Social Science & Medicine,* 96*:*138-146.

Jarvis, P. (Ed.). (2006). *The Theory and Practice of Teaching*. 2nd edition. Routledge.

Jensen, P.S., Knapp, P. & Mrazek, D. (2006). *Toward a new diagnostic system for child psychopathology: Moving beyond the DSM*.

Johnson, J. (December 2012). Treating Couples Raising Children on the Autism Spectrum: A Marriage-Friendly Approach. *Contemporary Family Therapy: An International Journal,* 34(4):555-565.

Johnson, C.P. & Meyers, S.M. (2007). *Identification and Evaluation of children with autism spectrum disorders,* 120(5):1183-1215.

Johnson, J. & Renssalaer. (2010). *Siblings: The Autism Spectrum through our eyes*. Jessica Kingsley Publishers: London.

Kalyva, E. (2011). *Autism:* Educational and therapeutic approaches.

Kapp, L. & Brown, O. (2011). Resilience in Families Adapting to Autism Spectrum Disorder. *Journal of Psychology in Africa,* 21(3).

Kapp, S.K., Gillespie-Lynch, K., Sherman, L.E. & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental psychology,* 49(1):59.

Karst, J.S. & Van Hecke, A.V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical child and family psychology review,* 15(3):247-277.

Kayfitz, A.D., Gragg, M.N. & Orr, R. (2010). Positive experiences of mothers and fathers of children with autism. *Journal of Applied Research in Intellectual Disabilities,* 23(4):337-343.

Kenny, J. & Corkin, D. (2011). The challenges of caring for an exceptional child: The qualities and support parents need to maintain family bonds while bringing up a child diagnosed with an autism spectrum condition are discussed by Jodie Kenny and Doris Corkin. *Learning Disability Practice,* 14(9):14-18.

Kidshealth. (2014). Kidshealth.org/parent/medical/learning/pervasive_ development_disorders_html.

Kirby, D. (2005). *Evidence of Harm: Mercury in Vaccines and the Autism Epidemic: A Medical Controversy*. Macmillan.

Kogan, M.D., Blumberg, S.J., Schieve, L.A., Boyle, C.A., Perrin, J.M., Ghandour, R.M., Strickland, B.B., Singh, G.K., Travat & van Dyck, P.C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US. *Pediatrics,* 124(5):1395-1403.

Kogan, M.D., Strickland, B.B., Blumberg, S.J., Singh, G.K., Perrin, J.M. & van Dyck, P.C. (2009). A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005-2006. *Paediatrics,* 122(6).

Koutsis, A., De Clercq, G. & Galbraith, R. (2006). *What about Me?: The Autism Survival Guide for Kids, a Book for the Brothers and Sisters of a Child with Autism.* Wantirna Heights School.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy,* 45(3):214-222.

Kuada, J. (2012). *Research Methodology: A project guide for University students.* Frederiksberg: Samfundsliterature.

Kumar, R. (2011). *Research methodology: A step by step guide.* London: SAGE.

Kurtzer-White, E. & Luterman, D. (2003). Families and children with hearing loss: grief and coping. *Mental Retard Dev Disability Res Rev,* 9(4):232-5.

Lange, N. & McDougle, C.J. (2013). Help for the Ch{\i}ld with Autism. *Scientific American,* 309(4):72-77.

LaSalle, B. (2004). *Finding Ben: A Mother's Journey Through the Maze of Asperges.* McGraw-Hill Education.

Lin, C.R., Tsai, Y.F. & Chang, H.L. (2008). Coping mechanisms of parents of children recently diagnosed with autism in Taiwan: a qualitative study. *Journal of Clinical Nursing,* 17(20):2733-2740.

Lord, C., Risi, S., DiLavore, P.S., Shulman, C., Thurm, A. & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of general psychiatry,* 63(6):694-701.

Luthar, S.S., Cicchetti, D. & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child development,* 71(3):543-562.

Machin, L. (2009). *Working with loss and grief*. SAGE: London.

Maljaars, J., Boonen, H., Lambrechts, G., Van Leeuwen, K. & Noens, I. (2014). Maternal parenting behavior and child behavior problems in families of children and adolescents with autism spectrum disorder. *Journal of autism development disorder*, 3(44):501-512.

Martin, J. & Taylor, T. (2012). *Fighting autism and win: Biomedical therapies that actually work.* JRT Publishing: London.

Martinez-Sanchis, S., Santacreu, M.C., Sancho, R. & Domenech, M. (2014). Language laterality, handedness and empathy in a sample of parents of children with autism spectrum disorder. *Psicothema,* 26(1).

Martinez-Pedraza, F. & Carter, A.S. (2009). Autism Spectrum Disorders in young children . *Early childhood mental health*, 18(3):645-663.

Masten, A.S. (2001). Ordinary magic: Resilience processes in development. *American psychologist,* 56(3):227.

Masten, A.S. & Wright, M.O. (2010). Resilience over the lifespan: Developmental perspectives on resistance, recovery, and transformation. In Reich, JW., Zautra, A.J., Hall, J,S. (eds) *Handbook of adult resilience.* Page 213-237. NY: Guilford: New York.

Masten, A.S., Monn, A.R. & Supkoff, L.M. (2011). *Resilience in children and adolescents.* Cambridge University Press: London.

Maurice, C. (1998). *Let me hear you voice: a families' triumph over autism.* Fawcett books: Toronto.

Mayes, S.D., Calhoun, S.L., Murray, M.J., Morrow, J.D., Yurich, K.K. & Mahr, F.. (2009). Comparison of scores on the Checklist for Autism Spectrum Disorder, Childhood Autism Rating Scale, and Gilliam Asperger's Disorder Scale for children with low functioning autism, high functioning autism, Asperger's disorder, ADHD, and typical development. *Journal of Autism and Developmental Disorders,* 39(12):1682-1693.

McCarthy, J. (2007). *Louder than words: A mother's journey in healing autism*.

McCarthy, J. (2008). *Mother warriors: A nation of parents healing autism against all odds.*

McCarthy, J. & Kartzinel, J. (2009). *Healing and preventing autism: A complete guide.*

McCubbin, H.I., Thompson, A.I. & McCubbin, M.A. (2001). *Family Measures: Stress, Coping and Resliency: Inventories for Research.* Kamehameha Schools.

McMahon, W.M., Baty, B.J. & Botkin, J. (2006). Genetic counselling and Ethical issues for autism. *American Journal of Medical Genetics*, 142(1):52-57.

McMorris, C.A., Cox, E., Hudson, M., Xiudong, L. & Bebko, J.M. (2013). Parents perceptions of obtaining a diagnosis of childhood cancer can included experiences of disputes and delays. *Journal of cognitive and behavioural psychotherapies,* 13(1):42-49.

Meadan, H., Halle, J.W. & Ebata, A.T. (2010). FamiliesWith Children Who Have Autism Spectrum Disorders: Stress and Support. *Exceptional Children,* 77(1):7-36.

Miller, G. & Dingwall, R. (1997). *Context and method in qualitative research.* Sage.

Miller, J.S., Bilder, D., Farley, M., Coon, H., Pinborough-Zimmerman, J. & Jenson, W. (2013). Autism spectrum disorder reclassified: A second look at the 1980s Utah/UCLA autism epidemiologic study. *Journal of autism and developmental disorders,* 43(1):200-210.

Montes, G. & Halterman, J.S. (2007). Bullying among children with autism and the influence of comorbidity with ADHD. *A population-based study*, 7(3):253-257.

Morvay, B. (2010). *My brother is different: A siblings guide to coping with autism.* Bookmasters INC: Ashland.

Mouton, J. (2013). *Understanding social research.* Van Schaik Publishers.

Mouton, J. & Marais, H. (1990). Basic concepts in methodology for the human sciences. *Basic concepts in methodology for the human sciences*. Pretoria: Human Sciences Research Council.

Nadesan, M.H. (2005). *Constructing autism: unravelling the 'truth' and understanding the social*. Routledge: London.

Nah, Y.H., Young, R.L., Brewer, N. & Berlingeri, G. (2014). Autism Detection in Early Childhood (ADEC): Reliability and validity data for a level 2 screening tool for autistic disorder. *Psychological assessment,* 26(1):215.

Neuman, W.L. (2000). *Social research Methods: Qualitative and Quantitative approaches*. 7th edition. SAGE: New York.

Nicol, D.J. (1997). *Research on learning and higher education teaching.* UCoSDA.

Notbohm, E. (2005). *Ten things every child with autism wishes you knew.*

O’Hare, N.H. & Szakacs, G.M. (2008). The recovery of a child with autism spectrum disorder through biomedical interventions. *Alter Health Med*, 14(6):42-44.

Olivie, H. (2012). Clinical practice. *European journal of pediatrics,* 171(5):741-749.

Olson, D.H. & DeFrain, J. (2000). *Marriage and the family: Diversity and strengths .* Mayfield Publishing Co.

Osborne, L.A., McHugh, L., Saunders, J. & Reed, P. (2008). *Parenting stress reduces the effectiveness of early interventions for autistic spectrum disorders*, 38(6):1092-1103.

Ouyang, L., Grosse, S.D., Riley, C., Bolen, B., Bishop, E., Raspa, M. & Bailey, D.B. Jr. (2014). A comparison of family financial and employment impacts of fragile X syndrome, autism spectrum disorders, and intellectual disability. *Research in Developmental Disabilities*, 35(7):1518-27. Epub ahead of print Apr 20, 2014.

Oxford dictionary (2014). *‘Family’*. Available from: www.oxforddictionary.com/family.

Oxford dictionary (2014). ‘*Model’*. Available from: www.oxforddictionary/model.

Poso, E.S. (May 2014). Family quality o flife and psychological well-being in parents of children with autism spectrum disorders: a double ABCX model. *Journal of Intellectual Disability Research,* 56(5):442-458.

Paganini, C. & Gaido, D. (2013). Perception in autism: An interactive global research between folk psychology and folk physics. *Journal of Social, Evolutionary, and Cultural Psychology,* 7(2):175.

Paradiz, V. (2005). *Elijah's Cup: A Family's Journey Into the Community and Culture of High-Functioning Autism and Asperger's Syndrome.* Jessica Kingsley Limited.

Parahoo, K. (2014). *Nursing research, Principles, process and issues*. 3rd edition. London: Palgrave Macmillan.

Parson, D.W. (1996). P*ublic Policy: An introduction to the Theory and Practice of Policy Analysis.* Edward Elgar Publishers: Philadelphia.

Patterson, J.M. (2002). Understanding family resilience. *Journal of clinical psychology,* 58(3):233-246.

Perumal, V., Veeraraghavan, V. & Lekhra, P. (2014). Quality of life in families of children with autism spectrum disorders in India. *Journal of Pharmacy Research,* 8(6):791-797.

Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V. & Shalev, R.S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry,* 45(4):855-865.

Plant, K.M. & Sanders, M.R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research,* 51(2):109-124.

Polit, D.F. & Beck, C.T. (2012). *Nursing research: Generating and assessing evidence for nursing practice*. 9th edition. LWW: New York.

Polit, D. & Hungler, B. (1994). Essentials of Nursing Research: Methods, Appraisal, asid Utilization. *Essentials of Nursing Research: Methods, Appraisal, asid Utilization*.

Renty, J.O. & Roeyers, H. (2006). Quality of life in high functioning adults with autism spectrum disorder: *The predictive value of disability and support characteristics,* 10(5):511-524.

Robledo, S.J. & Ham-Kucharski, D. (2005). *The autism book: Answers to your most pressing questions.*

Rogers, C.R. (1967). *Person to person: The problem of being human. Real people press.* London.

Rosnow, R.L. & Rosnthal, R. (2005). *Beginning behavioral research: a conceptual primer*. 5th edition. Pearson/Prentice Hall.

Rutter, M. (2005). *Resilience as a dynamic concept development and psychopathology*, 24(2012):335-344.

Ryan, R.M. & Deci, E.L. (2000). Intrinsic and Extrinsic Motivations: Classic Definitions and New Directions. *Contemporary Educational Psychology*, 25:54-67.

Sakai, K. & Smith Myles, P. (2005). *Finding Our Way: Practical Solutions for Creating a Supportive Home And Community for the Asperger Syndrome Family.* Autism Asperger Publishing Company.

Sari, O.T. (2014). Outcomes of Play-Based Home Support for Children with Autism Spectrum Disorder. *Social Behavior & Personality: an international journal,* 42:65-80.

Schuntermann, P. (2009). Growing up with a developmentally challenged brother or sister: A model for engaging siblings based on mentalizing. *Harvard review of psychiatry,* 17(5):297-314.

Schwarz, R.M. (2002). *The Skilled Facilitator: A Comprehensice Resource.* New York: Jossey-Bass.

Scruggs, T.E. & Mastropieri, M.A. (2006). *Applications of Research Methodology.* JAI Press: Kidlington, 19.

Seligman, M.E. & Csikszentmihalyi, M. (2000). *Positive psychology: An introduction.* (Vol. 55). American Psychological Association.

Senator, S. (2005). *Making Peace with Autism: One Family's Story of Struggle, Discovery, and Unexpected Gifts.*

Seymour, M., Wood, C., Giallo, R. & Jellett, R. (2013). Fatigue, stress and coping in mothers of children with an autism spectrum disorder. *J Autism Dev Discord*, 43(7):1547-54. doi: 10.1007/s10803-012-1701-y.

Shore, S. (2003). *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome.* Autism Asperger Pub.

Shore, S. & Rastelli, L.G. (2006). *Understanding autism for dummies.* For dummies publishers: London.

Sicile-Kira, C. (2003). *Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and Other ASDs*. Perigee Trade: New York.

Siklos, S. (2006). *Assessing the need for social support in parents of children with autism and down syndrome.* 36:921-933.

Siller, M., Reyes, N., Holtez, E., Hutman, T. & Sigman, M. (2014). Longitudinal change in the use of services in Autism spectrum disorder: Understanding the role of child characteristics, family, demographics and parent cognitions. *Autism,* 18(4):433-446.

Simon, J.B., Murphy, J.J. & Smith, S.M. (2005). Understanding and fostering family resilience. *The Family Journal,* 13(4):427-436.

Singh, Y. (2007). *Research Methodology.* Darya Ganj: APH Publishing Corporation.

Sinkovics, R., Penz, E. & Ghauri, P. (2008). Enhancing the trustworthiness of interview based qualitative research. *Management International Review*, 6:689-714.

Skellern, C., McDowell, M., & Schluter, P. (2005). Diagnosis of autistic spectrum disorders in Queensland: Variations in practice. *Journal of paediatrics and child health,* 41(8):413-418.

Slifirczyk, A., Krajewska-Kulak, E., Brayer, A. & Maciorkowska, E. (2013). The impact of the disease on functioning of a family with an autistic child. *Progress in health Sciences*, 3(2):122-128.

Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology,* 1(1):39-54.

Smith, J.A. (Ed.). (2007). *Qualatative Psychology: A Practical Guide to Research Methods.* SAGE.

Smith, L.E. & Anderson, K.A. (2014). The Roles and Needs of Families of Adolescents With ASD. *Remedial and special education,* 35(2):114-122.

Smith, L.O. & Elder, J.H. (2010). Siblings and family environments of persons with autism spectrum disorder: a review of the literature. *Journal of Child and Adolescent Psychiatric Nursing,* 23(3):189-195.

Solomon, A.H. & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family process,* 51(2):250-264.

Sternberg, R.J. (2001). Why schools should teach for wisdom: The balance theory of wisdom in educational settings. *Educational psychologist,* 36(4):227-245.

Streubert, Speziale, H. & Carpenter, D. (2003). Qualitative research in nursing. *Advancing the Humanistic Imperative.* 3rd edition. Lippincott Williams \& Wilkins.

Streubert, H.J. & Carpenter, D.R. (2011). *Qualitative research in nursing*. 5th edition. Philladelphia: Library of congress.

Streubert, H. & Carpenter, D. (1995). Qualitative Research in Nursing: Advancing the Humanistic Paradigm. *Qualitative Research in Nursing: Advancing the Humanistic Paradigm*. JB Lippincott, Philadelphia, PA.

Stuart, M. & McGrew, J.H. (2009). Caregiver burden after receiving a diagnosis of Autism Spectrum Disorder. *Research in Autism Spectrum disorders*, 3(1):86-97.

Struwig, M., Struwig, F. & Stead, G. (2001). *Planning, Reporting & Designing Research.* Pearson South Africa.

Sullivan, A., Winograd, G., Verkuilen, J. & Fish, M.C. (2012). Children on the autism spectrum: grandmother involvement and family functioning. *J Appl Res Intellect Disability,* 25(5):484-94.

Sunita, S. & Bilszta, J.L. (2012). Early Identification of Autism: A comparison of the checklist for autism in toddlers and the modified checklist for autism in toddlers: *Journal of Paediatrics and Child health*, 49(6):438-444.

Suppo, J. & Floyd, K. (2012). Parent Training for Families Who Have Children with Autism: A Review of the Literature. *Academic journal article Rural Special Education Quarterly*, 31(2).

Szatmari, P. (2004). *A Mind Apart: Understanding Children with Autism and Asperger Syndrome.* Guilford Press.

Tanggaard, L. (2009). The research interview as a dialogical context for the production of social life and personal narratives. *Qualitative Inquiry,* 15(9):1498-1515.

Taylor, B., Kermode, S. & Roberts, K. (2007). *Research in nursing and health care: evidence for practice*. 3rd edition. Thompson: Australia.

Terre Blanche, M. & Durrheim, K. (1999). Histories of the present: Social science research in context. *Research in practice: Applied methods for the social sciences, 2*:1-17.

Terreblanche, K.M., Durrheim, K. & Painter, D. (2006). *Research in practice: Applied methods for the social sciences.* 2nd edition. Rondebosch: University of Cape Town.

The Pocket Oxford Dictionary. (1992). American Press: New York.

The New Thesaurus. (1995). Berkley Publishing Group: London.

Thorne, S. (2003). data analysis in qualitative research. *data analysis in qualitative research*, 3:68-70.

Tiba, A., Johnson, C. & Vuadineanu, A. (2012). Cognitive vulnerability and adjustment to having a child with a disability in parents of children with autistic spectrum disorder. *Journal of Cognitive & Behavioral Psychotherapies,* 12(2).

Tuteur, A. (2013). Available from: www.thinkingmomsrevolution.com/tag/amy/-tutuer.

Twoy, R., Connolly, P.M. & Novak, J.M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners,* 19(5):251-260.

Ungar, M. (2004). *Nurturing hidden resilience in troubled youth.* University of Toronto Press.

University of Johannesburg. (2002). *Theory of Health promotion in nursing*. Faculty of Health Science. Johannesburg: University of Johannesburg.

University of Johannesburg. (2010). *Theory of Health promotion in nursing*. Faculty of Health Science. Johannesburg: University of Johannesburg.

Perumal, V., Veeranaghavan, P. & Lekhra, O.P. (2014, June). Quality of Life in families of children with autism spectrum disorder in India. *Journal of Pharmacy Research,* 8(6):791-797.

van Tongerloo, M.A., Bor, H.H. & Lagro-Janssen, A.L. (2012). Detecting autism spectrum disorders in the general practitioner's practice. *Journal of autism and developmental disorders,* 42(8):1531-1538.

Veague, H.B. (2010). www. Scribd.com/doc/184100104/heather-barnett-veague-autism2010-pdf#scribd.

Viecili, M.A., Robinson, S., Weiss J.A., Lunsky, Y. & Sloman, L. (2012). *Direct and indirect changes in children with autism spectrum disorders and their parents after social skills intervention.* Department of Psychology, York University, Toronto, ON, Canada, (2)York University, Toronto, ON, Canada, (3)Centre for Addiction and Mental Health, Toronto, ON, Canada.

Volkmar, F.R. & Reichow, B. (2013). Autism in DSM-5: progress and challenges. *Molecular autism,* 4(1):13.

Wakefield, A. & McCarthy, J. (2010). *Callous Disregard: Autism and Vaccines -- the Truth Behind a Tragedy.* Skyhorse Pub.

Walker, L.O. & Avant, K.C. (2005). *Strategies for theory construction in nursing*.

Walsh, F. (1998). *Strengthening Family Resilience.* Guilford Press.

Walsh, F. (2002). A family resilience framework: Innovative practice applications. *Family relations,* 51(2):130-137.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family process,* 42(1):1-18.

Wandelt, M. & Stewart, D. (1975). *Slater nursing competencies rating scale.* Appleton-Century-Crofts.

Weaver, K. & Olson, J.K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing,* 53(4):459-469.

Weiss, J.A. & Lunsky, Y. (2011). The brief family distress scale: A measure of crisis in caregivers of individuals with autism spectrum disorders. *Journal of child and family studies,* 20(4):521-528.

Whitaker, P. (2002). *Supporting families of pre-school children with autism: what parents want and what helps*, 6(4):411-426.

White, S.E., McMorris, C., Weiss, J.A. & Lunsky, Y. (2012). The experience of crisis in families of individuals with autism spectrum disorder across the lifespan. *Journal of child and family studies,* 21(3):457-465.

Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M. R. (2009). Stepping Stones Triple P: an RCT of a parenting program with parents of a child diagnosed with an autism spectrum disorder. *Journal of Abnormal Child Psychology*, 37(4):469-480.

Wikipedia. http://en.wikepedia.org/wiki/facilitation.

Wilkinson, S. (2004). 10 Focus group reseach. *Qualitative research: Theory, method and practice*, 177.

Willig, C. (2013). *Introducing qualitative research in psychology.* 3rd edition. Open university Press: England.

Woodcock, L. & Page, A. (2010). *Managing family meltdown: the low arousal approach and autism.* Kingsley publishers: Philadelphia.

Woods, A.G., Mahdavi, E. & Ryan, J.P. (2013). Treating clients with Asperger's syndrome and autism. *Child Adolesc Psychiatr Ment Health,* 7(1):32.

World-Health organization (2013). Available from: www.who.int/nmh/en/.

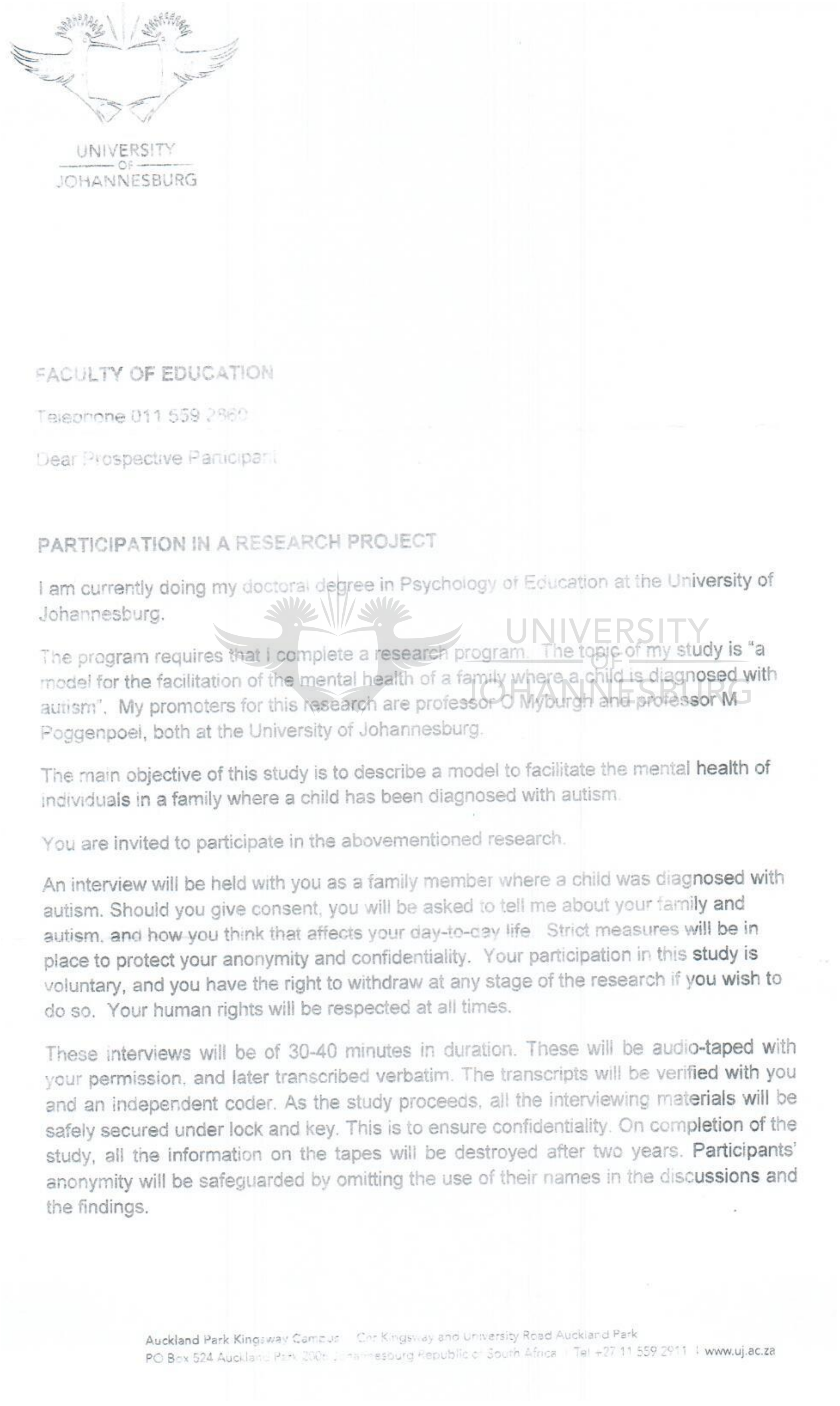
Yin, R.K. (2011). *Qualitative Research from Start to Finnish.* Guilf.

Zaidman-Zait, A., Mirenda, P., Zumbo, B.D., Wellington, S., Dua, V. & Kalynchuk, K. (2010). An item response theory analysis of the Parenting Stress Index-Short Form with parents of children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry,* 51(11):1269-1277.

Zechmeister, E.B., Zechmeister, J.S. & Shaughnessy, J. (2006). *Research methods in psychology.* McGraw-Hill Higher Education.

APPENDIX A

Participation in a research project



UNIVERSITY
OF
JOHANNESBURG

FACULTY OF EDUCATION

Telephone 011 559 2860

Dear Prospective Participant

PARTICIPATION IN A RESEARCH PROJECT

I am currently doing my doctoral degree in Psychology of Education at the University of Johannesburg.

The program requires that I complete a research program. The topic of my study is "a model for the facilitation of the mental health of a family where a child is diagnosed with autism". My promoters for this research are professor C Myburgh and professor M Poggenpoel, both at the University of Johannesburg.

The main objective of this study is to describe a model to facilitate the mental health of individuals in a family where a child has been diagnosed with autism.

You are invited to participate in the abovementioned research.

An interview will be held with you as a family member where a child was diagnosed with autism. Should you give consent, you will be asked to tell me about your family and autism, and how you think that affects your day-to-day life. Strict measures will be in place to protect your anonymity and confidentiality. Your participation in this study is voluntary, and you have the right to withdraw at any stage of the research if you wish to do so. Your human rights will be respected at all times.

These interviews will be of 30-40 minutes in duration. These will be audio-taped with your permission, and later transcribed verbatim. The transcripts will be verified with you and an independent coder. As the study proceeds, all the interviewing materials will be safely secured under lock and key. This is to ensure confidentiality. On completion of the study, all the information on the tapes will be destroyed after two years. Participants' anonymity will be safeguarded by omitting the use of their names in the discussions and the findings.

Auckland Park Kingsway Campus | Cnr Kingsway and University Road Auckland Park
PO Box 524 Auckland Park 2006 Johannesburg Republic of South Africa | Tel +27 11 559 2911 | www.uj.ac.za

The benefits of your participation are that you have the opportunity to share your experience and in doing so help to support other involved family members. Should you require debriefing after the interview, facilities will be made available to you. The research results will be made available to you on request.

……………………………………… 20/8/2009……………………

Prof CPH Myburgh Date

H.Ed; B.S.c. (Hons); M.Com; B.Ed; M.Ed; D.Ed

Supervisor

……………………………………… ……………………………

Prof. M. Poggenpoel Date

Co-Supervisor

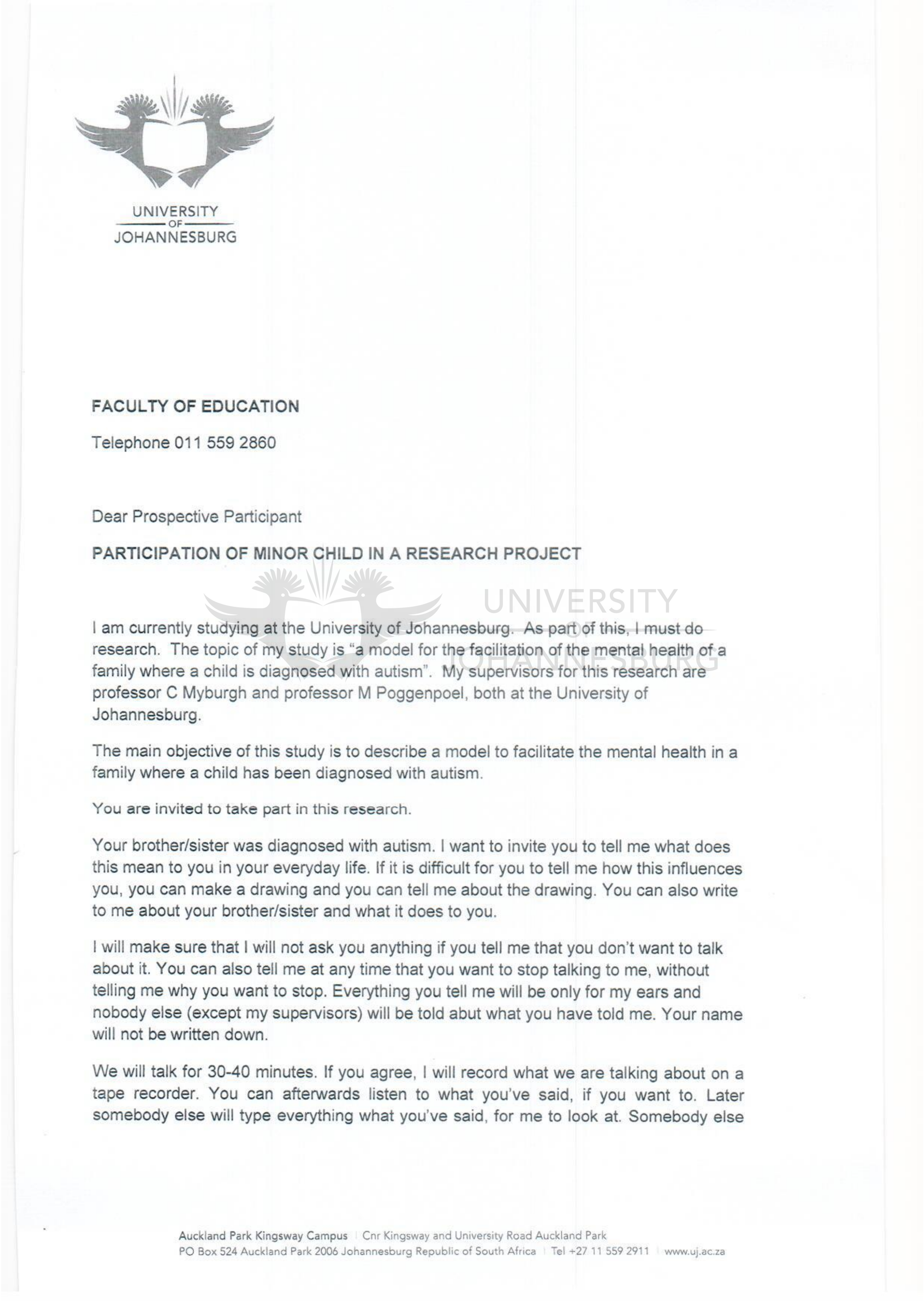
Mari Poggenpoel………

S. Breetzke (Tel. 082 326 9225)

D. Ed student researcher

APPENDIX B

Participation of a minor child in a research project



UNIVERSITY
OF
JOHANNESBURG

FACULTY OF EDUCATION

Telephone 011 559 2860

Dear Prospective Participant

PARTICIPATION OF MINOR CHILD IN A RESEARCH PROJECT

I am currently studying at the University of Johannesburg. As part of this, I must do research. The topic of my study is "a model for the facilitation of the mental health of a family where a child is diagnosed with autism". My supervisors for this research are professor C Myburgh and professor M Poggenpoel, both at the University of Johannesburg.

The main objective of this study is to describe a model to facilitate the mental health in a family where a child has been diagnosed with autism.

You are invited to take part in this research.

Your brother/sister was diagnosed with autism. I want to invite you to tell me what does this mean to you in your everyday life. If it is difficult for you to tell me how this influences you, you can make a drawing and you can tell me about the drawing. You can also write to me about your brother/sister and what it does to you.

I will make sure that I will not ask you anything if you tell me that you don't want to talk about it. You can also tell me at any time that you want to stop talking to me, without telling me why you want to stop. Everything you tell me will be only for my ears and nobody else (except my supervisors) will be told abut what you have told me. Your name will not be written down.

We will talk for 30-40 minutes. If you agree, I will record what we are talking about on a tape recorder. You can afterwards listen to what you've said, if you want to. Later somebody else will type everything what you've said, for me to look at. Somebody else

Auckland Park Kingsway Campus | Cnr Kingsway and University Road Auckland Park
PO Box 524 Auckland Park 2006 Johannesburg Republic of South Africa | Tel +27 11 559 2911 | www.uj.ac.za

will also look at what was said to make sure that we say precisely what you've said. I will make sure that nobody else sees what you've said, except I and my supervisors. After two years we will destroy the tapes.

Talking to me will make sure that I hear what you say. Through this you might be able to better understand what is happening to you, and your brother/sister, and family. If you feel that you must talk to somebody after talking to me, just tell me. Someone who learned to help other people will then listen and talk to you.

…………………………………… …20/8/2009……………………

Prof CPH Myburgh Date

H.Ed; B.S.c. (Hons); M.Com; B.Ed; M.Ed; D.Ed

Supervisor

……Marie Poggenpoel…………… …20/08/09……………………

Prof. M. Poggenpoel Date

Co-Supervisor

……………………………………………………

S. Breetzke (Tel. 082 326 9225)

D. Ed student researcher

Participant's declaration (assent)

I …………………………………………… have read this letter to assent and voluntarily agree to participate in this study, and be interviewed.

…………………………………………… ……………………………………………

Participant's signature Date

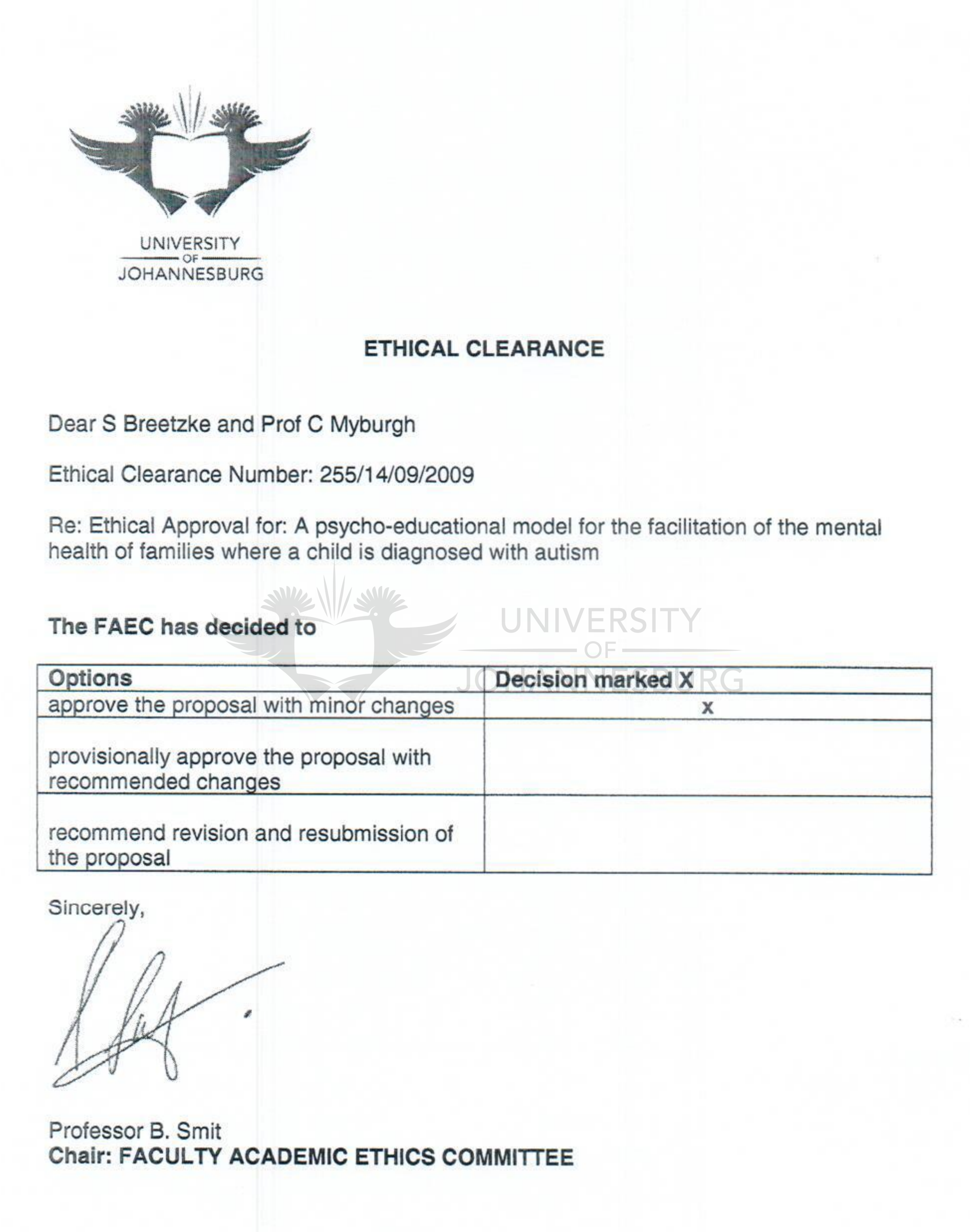
I assent voluntarily that the interviews be audio-taped.

…………………………………………… ……………………………………………

Participant's signature Date

APPENDIX C

Ethical Clearance



UNIVERSITY
OF
JOHANNESBURG

ETHICAL CLEARANCE

Dear S Breetzke and Prof C Myburgh

Ethical Clearance Number: 255/14/09/2009

Re: Ethical Approval for: A psycho-educational model for the facilitation of the mental health of families where a child is diagnosed with autism

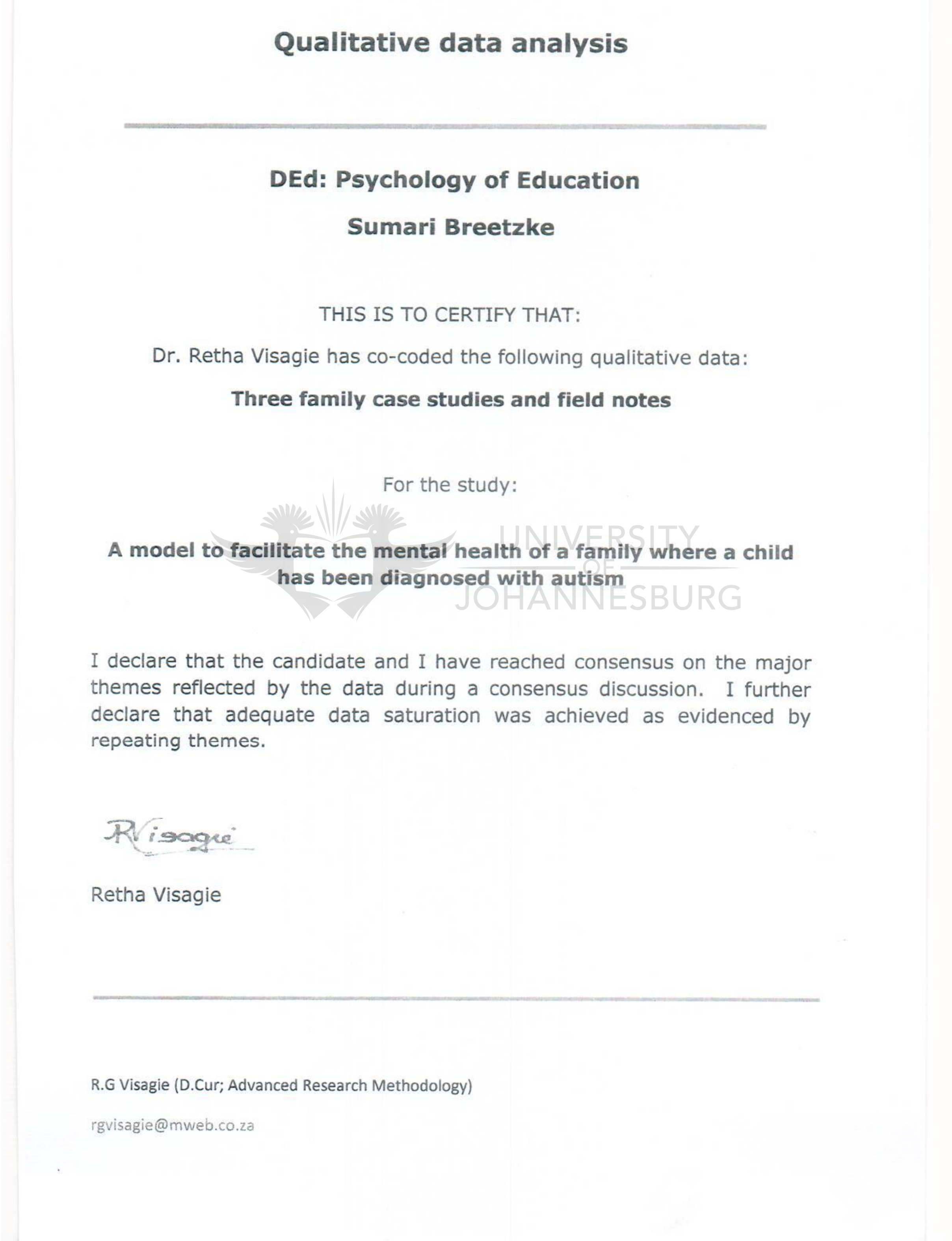
The FAEC has decided to

Options	**Decision marked X**
approve the proposal with minor changes	x
provisionally approve the proposal with recommended changes	
recommend revision and resubmission of the proposal	

Sincerely,

Professor B. Smit
Chair: FACULTY ACADEMIC ETHICS COMMITTEE

APPENDIX D
Qualitative data analysis



Qualitative data analysis

DEd: Psychology of Education

Sumari Breetzke

THIS IS TO CERTIFY THAT:

Dr. Retha Visagie has co-coded the following qualitative data:

Three family case studies and field notes

For the study:

A model to facilitate the mental health of a family where a child has been diagnosed with autism

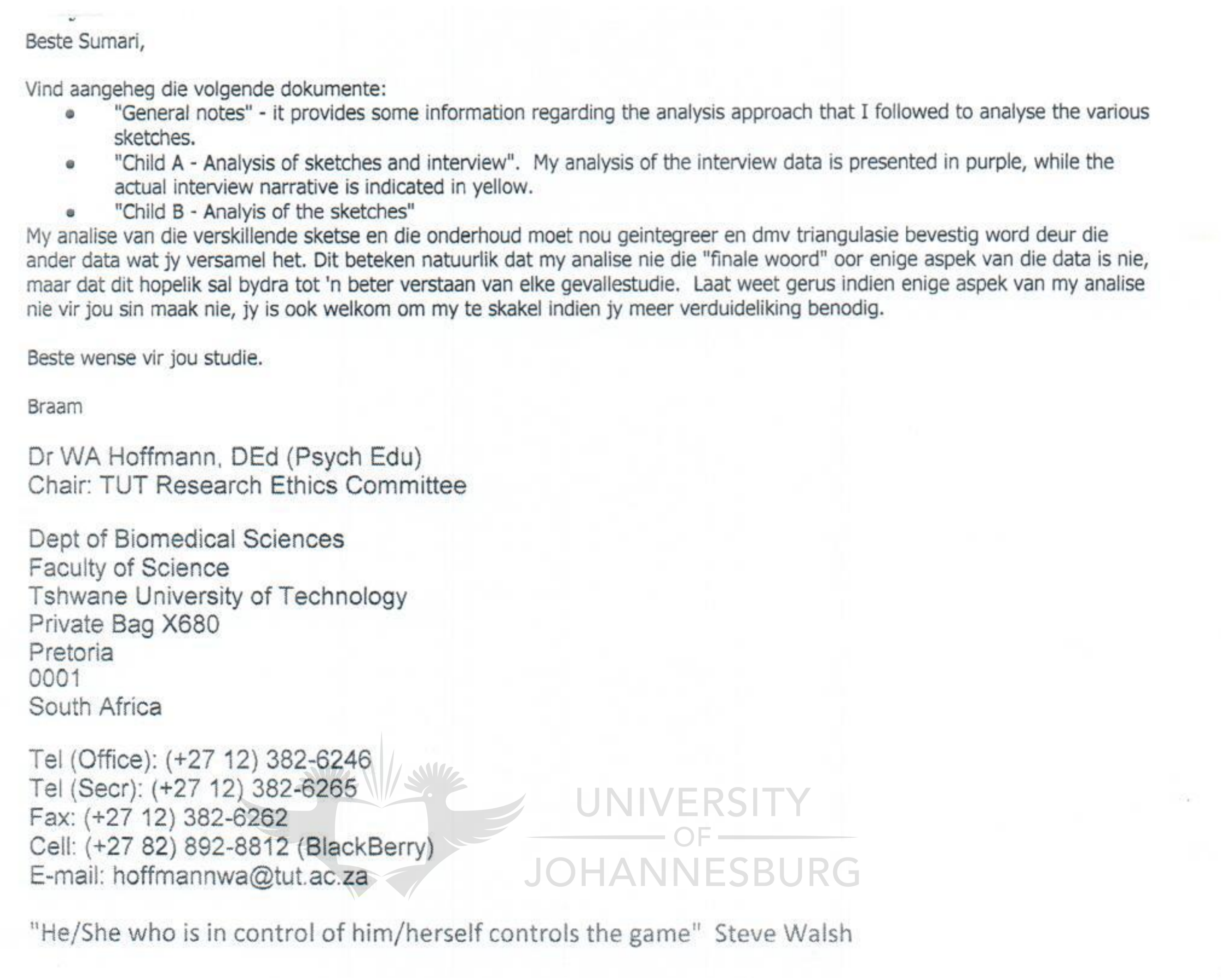
I declare that the candidate and I have reached consensus on the major themes reflected by the data during a consensus discussion. I further declare that adequate data saturation was achieved as evidenced by repeating themes.

RVisagie

Retha Visagie

R.G Visagie (D.Cur; Advanced Research Methodology)

rgvisagie@mweb.co.za



Beste Sumari,

Vind aangeheg die volgende dokumente:

- "General notes" - it provides some information regarding the analysis approach that I followed to analyse the various sketches.
- "Child A - Analysis of sketches and interview". My analysis of the interview data is presented in purple, while the actual interview narrative is indicated in yellow.
- "Child B - Analyis of the sketches"

My analise van die verskillende sketse en die onderhoud moet nou geintegreer en dmv triangulasie bevestig word deur die ander data wat jy versamel het. Dit beteken natuurlik dat my analise nie die "finale woord" oor enige aspek van die data is nie, maar dat dit hopelik sal bydra tot 'n beter verstaan van elke gevallestudie. Laat weet gerus indien enige aspek van my analise nie vir jou sin maak nie, jy is ook welkom om my te skakel indien jy meer verduideliking benodig.

Beste wense vir jou studie.

Braam

Dr WA Hoffmann, DEd (Psych Edu)
Chair: TUT Research Ethics Committee

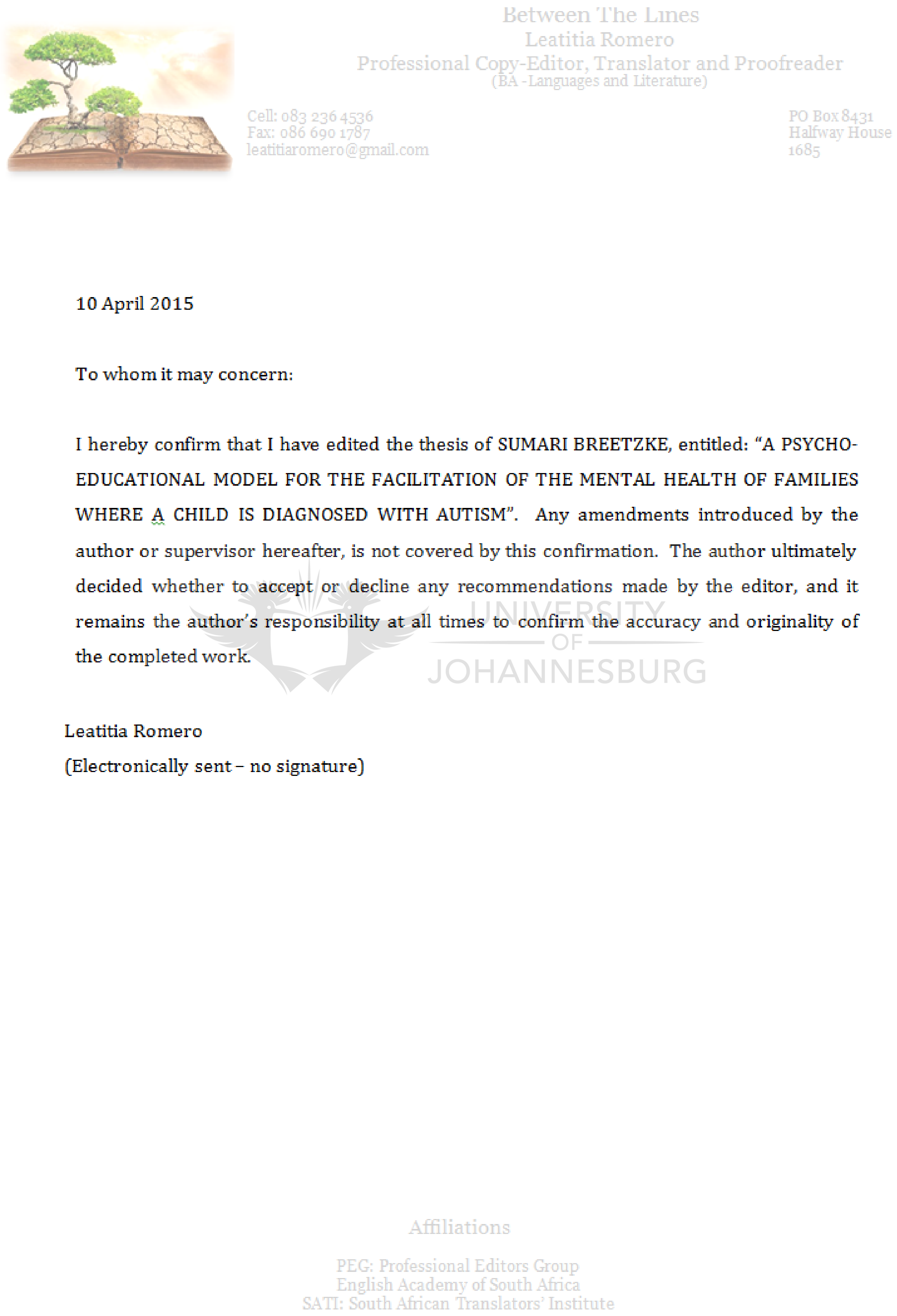
Dept of Biomedical Sciences
Faculty of Science
Tshwane University of Technology
Private Bag X680
Pretoria
0001
South Africa

Tel (Office): (+27 12) 382-6246
Tel (Secr): (+27 12) 382-6265
Fax: (+27 12) 382-6262
Cell: (+27 82) 892-8812 (BlackBerry)
E-mail: hoffmannwa@tut.ac.za

"He/She who is in control of him/herself controls the game" Steve Walsh

APPENDIX E

Language Edit Certificate



Between The Lines
Leatitia Romero
Professional Copy-Editor, Translator and Proofreader
(BA - Languages and Literature)

Cell: 083 236 4536
Fax: 086 690 1787
leatitiaromero@gmail.com

PO Box 8431
Halfway House
1685

10 April 2015

To whom it may concern:

I hereby confirm that I have edited the thesis of SUMARI BREETZKE, entitled: "A PSYCHO-EDUCATIONAL MODEL FOR THE FACILITATION OF THE MENTAL HEALTH OF FAMILIES WHERE A CHILD IS DIAGNOSED WITH AUTISM". Any amendments introduced by the author or supervisor hereafter, is not covered by this confirmation. The author ultimately decided whether to accept or decline any recommendations made by the editor, and it remains the author's responsibility at all times to confirm the accuracy and originality of the completed work.

Leatitia Romero
(Electronically sent – no signature)

Affiliations

PEG: Professional Editors Group
English Academy of South Africa
SATI: South African Translators' Institute