A Needs Assessment of Parents on How to Raise an Autistic Child

By

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Dedicated to all parents raising children with autism.

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SUMMARY

A Needs Assessment of Parents on How to Raise an Autistic Child

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**DEGREE: MASTER OF DIACONIOLOGY
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The motivation of the study was to explore the problems of families in South Africa who struggle to manage their children with autism and to find out whether they were receiving appropriate assistance. This was done by assessing the needs of the parents of children with autism by means of semi-structured interviews.

Through these interviews, the parents were given the opportunity to express what information or recommendations they would like to have available to them. How the parents view their experience, their feelings about these experiences, and the strategies and actions that they take in order to cope with raising their child with autism, is important information. The aim of the study was to explore the problems South African families have so that this may form the base of information supplied to professionals such as psychologists, social workers, and educators thereby assisting in improving service delivery to parents of children with autism.

Key terms:

Autism, Pervasive Developmental Disorder, Parent, Gestalt, Qualitative study, Semi-structured interviews, Needs assessment

I declare that "**A Needs Assessment of Parents on How to Raise an Autistic Child**" is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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1.1 INTRODUCTION

Autism is a neuro-developmental disorder defined behaviourally by a triad of impairments (Mandelbaum, Stevens, Rosenberg, Wiznitzer, Steinschneider, Filipek & Rapin, 2006: 33). The triad of impairments are: social development, communication, and repetitive behaviour (Baron-Cohen, 2005: 398). Autism is differentiated from mental retardation, another neuro-developmental condition, by the distinct impairment of social and communication development (Bregman, 2005: 3).

In the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) (American Psychiatric Association, 1994), autism is classified in the category of Pervasive Developmental Disorders. Pervasive developmental disorders are disorders where many areas of infant and child development are severely affected simultaneously (American Psychiatric Association, 1994). Bregman (2005: 7) uses the terms Pervasive Developmental Disorders and Autism Spectrum Disorders interchangeably, suggesting that they mean the same thing. The word spectrum is defined as "*an entire range of related qualities*" (The Oxford Paperback Dictionary, 1994, u.w. 'spectrum'). Autism Spectrum Disorders have communication, socialisation and empathy problems in common (Kutscher, 2005:92). Disorders that fall under the Autism Spectrum are Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorders – not otherwise specified, Rett's Disorder, and Childhood Disintegrative Disorder (Kutscher, 2005: 93).

Autism goes beyond gender and cultural barriers; it affects children of all creeds, colours and races. Males have been found to be affected four times more frequently than females (Taylor, 2006: 511). Children are usually diagnosed with autism before the age of three. According to Adams, Edelson, Grandin and Rimland (2004: 1), the diagnosis of autism can be devastating to parents as their child has been diagnosed with a developmental disability and

is not like, nor will be like, other typical children. These parents experience grief for and loss of the child they had hoped they would have had and the life they would have led with a typical child. The diagnosis can be devastating, however, some parents experience relief as they have a label for their child's unusual behaviour and problems.

Autism is surrounded by much controversy, as the cause of autism is not clear. Adams *et al.* (2004: 1-13) discuss the speculated causes in their paper. They state that some people believe vaccinations have a causative role. However, genetics also seem to play a role in causing some incidences of autism. In twin studies, it was found that identical twins both had autism, but in fraternal twins, if the one twin is autistic, the other is seldom autistic. Bregman (2005:5) agrees that there is a strong genetic influence in the cause of autism. Scientists have not found a single gene responsible for causing autism; currently, more than 20 genes appear to be associated with autism (Adams *et al.*, 2004: 1-13). Autism is not a condition with a single cause, but is a "*group of related conditions that share many clinical features and underlying social-communicative impairments*" (Bregman, 2005: 14).

In California, from 2001 to 2002, a 31% increase in the number of children diagnosed with severe autism was recorded. In 1994 there were 5 108 cases of autism in California. In 2003 there were 20 377 cases (The Center for the Study of Autism, 2007). It is not known why there has been such a rapid increase in autism. Given that there is more than one possible cause for autism, there may be more than one reason for the increase. Autism affects one in 158 children under the age of six in South Africa (Autism Western Cape, 2007). Gillberg and Coleman (2000: 96) estimate, reasonably and conservatively, that one in 1 000 children is diagnosed as having autism (excluding other disorders on the autism spectrum). Rinehart, Tonge, Bradshaw, Iansek, Enticott & Johnson (2006: 272) agree with this estimate of autism's prevalence.

Children with autism are different to typical children in many ways. Autism causes many dysfunctional behaviours such as self-stimulating, repetitive

behaviours like rocking or hand flapping, self-injurious behaviours like hand biting and head banging, sleeping and eating problems, as well as poor eye-contact, hyper- or hypo activity, attention deficits, perseverative behaviour, and insisting on sameness (Edelson, 1999). The child with autism displays obsessive behaviours that are repetitive and lead to unimaginative and uncreative play (Baron-Cohen & Bolton, 1993: 50). In addition to these behaviours, the child with autism has difficulty expressing needs, has difficulty interacting with others, has tantrums, is unresponsive to normal teaching methods, is unresponsive to verbal cues, has obsessive attachment to objects, has no fear of danger, has uneven gross or fine motor skills, prefers to be alone, has sustained odd play, laughs or cries for no reason, and shows distress for no reason (Autism Society of America. 2007). Many children with autism have sensory integration problems, which according to Piek and Dyck (2004: 475-488), provides insights into the social difficulties experienced by children with autism. Children with autism experience problems with multi-modality sensory integration (Minshew, Sung, Jones & Furman, 2004: 2056-2061) and sensory processing failure (Frith, 2003: 149-166).

From the behavioural characteristics listed above, it can be deduced that parents of a child with autism commonly experience stress. At the time of diagnosis, parents are faced with assessing their child's health problems as well as sensory, educational and behavioural needs. This is an extremely stressful time (Edelson, 2003). These parents may not be receiving any form of support in raising their child with autism and, therefore, may have many needs unmet. "*It is important to find effective services, treatments and education for autistic children as soon as possible. The earlier these children receive appropriate treatment, the better their prognosis*" (Adams *et al.*, 2004:1). Bregman (2005: 14) agrees that early identification or diagnosis of autism allows for the implementation of educational and treatment interventions and states that early interventions would also provide the family with education, support and resources, which may reduce stress and anxiety. Adams *et al.* (2004) proposes adequate treatment and services for children with autism. If parents are not receiving appropriate support in raising their

child with autism, they may not be providing their child with these adequate treatment and services.

Hecimovic and Gregory (2005: 112-113) define a family as "*a unique and complex system of relationships, experiences, values, and expectations*", and view the family as very important in the life of the child with autism. The family is seen as an important partner to the professionals working with the child, and it is thought that the family should establish a relationship with these professionals.

> *It is this relationship, and the sensitivity, skills, and information with which professionals approach the relationship that define how much support families receive from the professionals with whom they will interact, simply because they happen to have a family member who experiences autism* (Hecimovic & Gregory, 2005: 113).

These authors further discuss the assumptions that professionals made of parents in the past. These assumptions were:
- the doctor knows best,
- parents need professionals to solve their problems,
- parents contribute to their child's problem,
- parents are unrealistic, and
- parents need counselling.

According to Hecimovic and Gregory (2005: 113-115), these old, negative assumptions hindered the parent – professional relationship. There has been a change in the assumptions made of parents of children with autism. It is now thought that:
- children are better off in families,
- families are best viewed as a system,
- parents know their children better than anyone else,
- the family is the best advocate for their autistic child,
- families want to be involved in the child's intervention,

- parents should question professionals,
- autism need not be viewed as negative, and
- parents and professionals share concern for the long term development of their child.

This study focuses on assessing the needs of parents raising a child with autism, whereas current literature focuses on parents managing their child and communicating with their child with autism. This study differs in that it provided the parents with the opportunity to express what information or recommendations they would like to have available to them.

The researcher selected five aspects of raising a child with autism. The researcher speculated that these were the main issues that parents had to deal with when raising a child with autism. As indicated in this introduction, the child with autism has many developmental difficulties that lead to the child with autism being a challenge to his or her parents.

The following assumptions of the researcher are conceded by literature.

Firstly, the researcher speculated that parents of children with autism had had interactions with health professionals both leading up to and following the diagnosis of autism. The researcher focused on the parents' perceptions of their interactions with health professionals and their child with autism's use of medication. Hecimovic and Gregory (2005: 116-119) discuss the parents' difficulties in dealing with medical doctors and psychologists and the doctor's difficulty in diagnosing the child.

Secondly, the researcher speculated that, as the child with autism has developmental difficulties, education of the child may be a challenge and may differ from the education received by a typical child. The researcher narrowed the focus to the parents' perceptions of the school experience of their child with autism. Education is seen as an important intervention in the development of the child with autism and is discussed by Shamow and Zager

(2005:295-326). Bloch, Weinstein and Seitz (2005: 229-230) affirm that there needs to be collaboration between the responsibilities at home and at school.

Thirdly, the researcher shows, in the introduction, that children with autism have dysfunctional behaviour, difficulty communicating and lack social skills. This led the researcher to speculate that the home life of a family with a child with autism may be difficult and challenging. The researcher focused on parents' perceptions of the effects of autism on family life. Bloch, Weinstein and Seitz (2005: 229 –265) focus on the gap between the parents' expectations of family life and the reality of family life when a child with autism is part of the family. These authors state that parents are not prepared for the impact and changes that come with having a child with autism.

Fourthly, the researcher speculated that, as the child with autism requires significant and ongoing care, parents may have concerns for the future care of their child with autism. The researcher focused on parents' concerns and hopes for their child with autism. Hecimovic and Gregory (2005: 130-131) discuss the constant concern that parents have for the future of their child with autism. They discuss transition planning and estate and financial planning as two ways of easing this concern.

Lastly, the researcher speculated that parents of a child with autism have many difficulties in their daily lives due to the amount of care required by the child with autism. The researcher focused on the parents' perceptions of getting through the day. The researcher assumed that this information would be of use to other parents with children diagnosed with autism and that it may ease their sense of isolation. This notion is supported by Hecimovic and Gregory's (2005: 123) statement that "*it is helpful to hear stories of other families to put into perspective that feeling of 'Are we the only ones who ever had something like this happen to them?' …having access to common questions can often be helpful*". The tools and aids that parents use to get through the day may become useful tips and ideas for other parents dealing with similar problems with their child with autism.

How parents view their experiences, their feelings about these experiences, and the strategies and actions that they take to cope with raising their child with autism, will be important information for both professionals working with children with autism and other parents of children with autism.

These are the common themes that have arisen from studying the literature indicated above. This will be discussed further in the problem formulation. The study has not excluded other aspects that have arisen in the course of interviewing parents.

1.2. PROBLEM AND RATIONALE FOR STUDY

1.2.1 Motivation for choice of research

The researcher's motivation for the choice of this research was both personal and professional. The researcher's interest was piqued after watching a documentary about a family with a child with autism and their struggle to find assistance and treatment (I Want my Little Boy Back, 1997). The family's struggle made the researcher realize that there may be many families in South Africa struggling to manage their child with autism and that they may not be receiving the appropriate assistance.

The professional motivation for this research was to assess the needs of the parents of children with autism in South Africa in order to provide information to professionals such as social workers, psychologists, child therapists and teachers as well as other parents of children with autism. This information might assist these professionals to form a helping partnership with parents to improve service delivery, assistance and the support given to parents. The information might also assist parents of children with autism to feel less isolated in their experience of raising a child with autism and give recommendations from other parents who have experienced similar difficulties.

Personally, the researcher has an interest in working with children with autism and their families as working therapeutically with the child with autism holds

many challenges for the therapist. Parents of children with autism face greater challenges than other parents and the researcher would like to be of assistance to these parents. The researcher would like to use this research process as a tool to gain knowledge about autism and the experiences of parents of children with autism. This research may become a pilot study for the researcher's doctoral thesis.

Throughout this study, the child with autism will be referred to as "he" for practical purposes and it is not intended to be a gender bias.

1.2.2 Problem formulation

According to Fouché (2005a: 116), problem formulation is the point of departure of the research proposal, whereby the research problem must be clearly defined in order for the reader to understand what the proposed research will include. The research problem is the foundation of the research study and in this study the research problem is centred on autism and the particular needs parents have in raising children with autism.

In The United States of America autism is diagnosed in one in every 166 births (Autism Society of America, 2007). In the 1990s, in the United States of America, the autism increase was 172% (Autism Society of America, 2007). In the United Kingdom 38.9 in every 10 000 children are diagnosed with autism. Simplified, this is a ratio of 1 in 257. (The National Autistic Society, 2007). In the last four decades there has been a vast increase in the number of children diagnosed with autism in the United Kingdom. In 1966 4.5 children in 10 000 were diagnosed with autism. In 1979, 13 years later, the figure was nearly five children in 10 000. In 2006, 27 years later, 38.9 children in 10 000 were diagnosed with autism in the United Kingdom (The National Autistic Society, 2006). Autism affects one in 158 children under the age of six in South Africa (Autism Western Cape, 2007).

The increase in children with autism in the United Kingdom and the United States of America resonates with the figure in South Africa where one in 158 children under the age of 6 is diagnosed with autism. This increase in the

number of children with autism indicates that there are now more parents dealing with children with autism in South Africa than ever before. Therefore, the researcher speculates that there may not be enough support or assistance for parents of children with autism in South Africa and that the parents' needs are not being met.

The lack of support and assistance given to parents of children with autism may lead to poor parenting of the child with autism, poor education of the child, little or no social, emotional and cognitive development of the child, parental stress, emotional and psychological distress, strain on the marital relationship and strain on relationships within the family.

The problems ensuing from the lack of support for the parents of children with autism are significant and indicate the necessity for a needs assessment in order to establish what these needs are and to gain a better understanding of them.

There is very little academic literature on parents raising a child with autism. However, there appears to be a number of non-fictional books on the topic. These are typically written by parents for other parents raising a child with autism. In addition, there seem to be many web sites and web logs (blogs) devoted to sharing experiences of parenting children with autism. These non-academic texts deal with many issues. For example, web sites such as www.lucasworks.org and www.autism-resources.com discuss the emotions experienced by parents when they are given the diagnosis of autism. According to parents who have contributed to these sites, the emotions are: shock, grief, terror, hurt, blame and loss, among others. The web sites also refer to parents' struggles with medical diagnoses, care and testing (Padgett, 2007 & Wobus, 2007). Others discuss parents' concerns for their child's future as well as their hopes and expectations (Russell, 2007). Another prominent theme on these web sites is the parents' experiences and concerns about their child's schooling (Padgett, 2007 and Wobus, 2007). Two sites make specific mention of the means parents use to get through the day. Some suggestions are: extended family support, joining a support group, linking with

organizations (Wobus, 2007) and making sure there is order and safety in the home (Padgett, 2007).

The issues discussed in these electronic texts confirm the researcher's speculations that there are specific issues regarding raising a child with autism that are significant to parents. However, as it is not academic in nature, the researcher approached this information with caution. Nevertheless, the information should not be overlooked. These web sites offer insight into the world of parents raising a child with autism and provide valuable information directly from parents of children with autism. These texts aided the researcher in deciding on the five main areas of focus for this research.

1.2.3 The research question

The research question is a workable plan that leads to the goals and objectives of the study (Strydom, 2002: 282). The research question in this study is: "What are the needs of parents raising a child with autism?"

1.2.4 Aim and objectives of the research

An aim is the same as a goal, which Fouché (2005: 104) describes as "*the end toward which effort or ambition is directed*". The aim of the research is to conduct a needs assessment of parents of children with autism in order to provide professionals with information that will assist in improving service delivery to parents of children with autism.

An objective is described by Fouché and De Vos (2005: 104) as the steps taken within a time span in order to reach the goal or aim. According to Babbie and Mouton (2001:79), there are three common objectives in research: exploration, explanation and description. Fouché and De Vos (2005: 106) agrees with Babbie and Mouton (2001: 79) in that exploration, description and explanation can be regarded as research objectives.

Exploratory research "*is conducted to gain insight into a situation, phenomenon, community or individual*" (Fouché & De Vos, 2005: 106).

Exploratory research answers the "what" question of the research. Descriptive research "*presents a picture of the specific details of a situation, social setting or relationship*" (Fouché & De Vos, 2005: 106). Descriptive research answers the "how" and the "why" question of the research. Descriptive studies overlap somewhat with exploratory studies. "*Descriptive research presents a picture of the specific details of a situation, social setting, or relationship*" (Neuman, 2003: 30). This study is descriptive in nature, as it describes the needs and perceptions of parents raising a child with autism, and, in so doing, presents a picture of the day-to-day life of a parent of a child with autism.

The objectives of this research study are exploratory and descriptive. These objectives are:

- to explore literature by way of a preliminary literature review, which will be done before interviewing parents of children with autism,

- to explore, through semi-structured interviews with parents of children with autism, the parents' needs and perceptions of raising a child with autism,

- to describe the needs of the parents of children with autism, and

- to make recommendations, based on the outcomes of the study, to parents of children with autism and to professionals who work with children with autism.

1.3   RESEARCH APPROACH

There are two main research approaches, namely, quantitative and qualitative. These two approaches can also be conducted as combined research. The quantitative approach takes a scientific explanation and aims to measure, test, and predict phenomena. The qualitative approach is interpretive and holistic; it aims to understand meaning, experience and perception (Delport & Fouché, 2005: 74). Qualitative research uses an inductive approach, which has an emphasis on developing insights and

generalizations from the collected data (Neuman, 2003: 137), while quantitative research uses a deductive approach, which emphasizes detailed planning.

The research approach in this study is the inductive, qualitative approach. The researcher's aim was to understand the needs and perceptions of the respondents and make meaning of it.

1.4 TYPE OF RESEARCH

This study is applied research. Applied research is generally a short study in which practical results are found that people can use. "*Applied researchers conduct a study to address a specific concern or to offer solutions to a problem*" (Neuman, 2003: 22). This particular study was conducted to address the concern that parents of children with autism in South Africa may not be receiving the assistance and support that they require.

As mentioned under the aim, this study is exploratory and descriptive in nature. Exploratory studies are usually the first of a sequence of studies and are often the stepping-stone to later research on the topic. Exploratory studies enable the researcher to become familiar with the topic, develop a mental picture of the conditions, formulate questions for future research and generate new ideas (Neuman, 2003: 29). This is true for this study as the researcher has little knowledge on parenting a child with autism. In this study, the researcher explored the needs of parents with a child with autism.

1.5 RESEARCH STRATEGY

The research strategy is the way in which the researcher goes about collecting the data. Fouché (2005b: 268) prefers the term research design, as do Babbie and Mouton (2001: 278) and Neuman (2003: 121). Neuman (2003: 121) refers to research designs both within qualitative and quantitative research. For this research study the researcher will use Fouché's (2005b: 268) terminology of research design.

The research design used in this research study is the case study. Case studies, according to Babbie and Mouton (2001: 281), "*take multiple perspectives into account and attempt to understand the influences of multilevel social systems on subjects' perspectives and behaviours*". Fouché (2005b: 272) states that the case study consists of detailed and in-depth data collection methods such as interviews, observations, and documents from multiple sources of information that are rich in context. There are three types of case studies: the intrinsic case study, the instrumental case study and the collective case study. The intrinsic case study focuses on gaining an understanding of the individual case. The instrumental case study focuses on elaborating on a theory and gaining knowledge of a social issue. The collective case study's focus is to advance the researcher's knowledge of the population being studied. The individual case studies are a means to gaining information about the group of cases.

This research study used the instrumental case study research strategy, as the researcher interviewed many parents of children with autism in order to gain knowledge of the social issue, which is the experience of parenting a child with autism.

1.6 RESEARCH METHODOLOGY

According to Neuman (2003: 69), there are three approaches to research: positivism, interpretive social science and critical social science. In this study the researcher used the interpretive social science approach. Interpretive social science views research as a means to understand and describe social action. It views people as social beings who create meaning and are always trying to understand their reality or life (Neuman, 2003: 91).

1.6.1 Research procedure and work method

1.6.1.1 Literature review

"*A literature review is based on the assumption that knowledge accumulates and that people learn from and build on what others have done*" (Neuman, 2003: 96). The literature review in qualitative studies can be conducted either before or after the data collection, according to the type of study conducted. The researcher conducted a case study which, according to Fouché and Delport (2005: 265), is in the middle of the continuum and can either have a literature review to "*guide the study in an explanatory way*" before the data collection or, after the data is collected, to compare and contrast the data with the literature. The researcher conducted a preliminary literature review before collecting the data in order to gather background information on autism and parents raising a child with autism. The researcher then gathered information by conducting interviews with parents of children with autism. Once the data had been collected, the outcome was described against an in-depth literature review, which acted as a control.

1.6.1.2 Paradigm of researcher

A paradigm, stated in Neuman (2003: 70), is a "*whole system of thinking*" which includes assumptions, questions and techniques to be used. A paradigm is one's basic orientation or point of reference.

The researcher's paradigm is that of a middle-class, English-speaking, white South African social worker. The researcher has the worldview that people are ultimately good and people in the world should help and care for each other in any way possible. The researcher chose social work as a profession as she believes in helping people to help themselves and in making a difference in a person's life. The researcher has a philosophy of care and service delivery to improve society.

The researcher has a particular interest in children and in providing services that improve the lives of children. The researcher has an affinity for working with children, as she believes that children are valuable and vulnerable and

require love, attention and care. Children grow to become adults and the more appreciated, respected and protected the child, the better adjusted he or she will be as an adult. The researcher believes strongly in the importance of well-adjusted parents and families. This is because the researcher comes from a close, nuclear family with an extended family that is very involved in her life. The researcher is fortunate to have loving, supportive parents who come from a service delivery position as they are both in the medical profession, one as a doctor and the other as a nurse.

As a trained clinical social worker, the researcher has a systems-theory background but has integrated this with the knowledge of Gestalt Theory, acquired during her more recent masters training. The researcher believes that each person has to be viewed within his or her environment, as the environment is very much an important part of what makes a person who he or she is. Being a middle-class, white South African, the researcher comes from a privileged background. Due to apartheid in South Africa's history, the researcher has a strong belief in equality and has grown up with a caring, accepting, non-judgmental and liberal outlook. With this liberal viewpoint, the researcher finds it difficult to subscribe to one religion, but rather, has an interest in many different religious philosophies. This, again, is due to the researcher's family members who are broadminded and have more than one religious affiliation.

The researcher has a healthy lifestyle and an interest in the lifestyles of others. The researcher views the topic of autism and of parents raising children with autism as an exciting, but compassionate, venture into the lives of those who require caring assistance from professionals such as social workers and play therapists, both of which are the researcher's areas of skill or study. The researcher's interest in working with children, and the belief in the importance of families, is intertwined in this study.

The theoretical background of the researcher is clinical social work. However, the researcher was recently introduced to Gestalt Theory and this research study will be based on Gestalt Theory.

1.6.1.2.1 Gestalt Theory

Gestalt Theory is a phenomenological-existential theory (Yontef, 1993:1), which means that Gestalt Theory is about existing in the present. Gestalt is a German word that means form. In the case of therapy, the word form stands for wholeness. The Gestalt view is that the whole is more than the sum of its parts, as a client's distress is holistically evident in the way he feels, thinks and behaves. The researcher believes that one should take a holistic approach to viewing a person and their problem and even more so when viewing the child with autism and his family, as the child has to be viewed in the environment of his family and in the context of autism. Gestalt's holistic approach and paradigm of thinking that the whole is more than the sum of the parts therefore fits with the researcher's belief in holism.

The researcher views Gestalt Theory as having a focus on all aspects of the present and not very much interest in the past, as the here-and-now and awareness of oneself in the here-and-now, is what is important in Gestalt Therapy. Yontef (1993: 1) explains that in Gestalt Therapy one focuses more on the process of the session than on the content since what is happening is thought to be more important than what is being said, as the awareness of the here-and-now is the key.

Gestalt Theory states that the client should become responsible for him or herself and become self-supportive. It provides the client with the means to be aware of him or herself. Jacobs (1978, Cited in Yontef, 1993: 3) explained it as: "…*a way of being authentic and meaningfully responsible for oneself. By becoming aware, one becomes able to choose and/or organize one's own existence in a meaningful manner*".

According to Gestalt Theory, self-realization is brought about through focusing awareness on the present situation. In Gestalt, the client takes on responsibility and becomes a co-worker in the therapeutic process, learning how to heal him or herself, thus, the experience of the client is seen as more reliable than the interpretation by the therapist. Gestalt is about the here-and-

now, not about the past. People are always rediscovering and renewing themselves so there will always be new problems and new opportunities that come to the foreground and create a new *gestalt* (Yontef, 1993: 1-6).

1.6.1.3 Data collection

"*Interviewing is the predominant mode of data or information collection in qualitative research*" (Greeff, 2005: 287). Semi-structured interviews were conducted with parents of children with autism. Semi-structured interviews are defined as interviews "*organized around areas of particular interest, while still allowing considerable flexibility in scope and depth*" (Greeff, 2005: 292). The areas of interest that were focused on in the interviews were:

- the interactions with health professionals,
- the school experience,
- the effect on family life,
- concerns and hopes for the future, and
- coping strategies used to get through each day.

The researcher did not have a list of questions to ask but rather used the areas of interest as a guide. Allowing flexibility in the interview enabled the inclusion of other areas the parents wished to discuss. These interviews were tape recorded and the researcher wrote notes on areas of particular importance or interest whilst conducting the interview. These notes and tape recordings were used in the data analysis process.

1.6.1.4 Data analysis

In qualitative research, there is an inseparable relationship between data collection and data analysis, because as data is collected it is analysed and the analysed data can suggest a need to make changes to the data collection procedures (De Vos, 2005: 335).

Data analysis involves collecting and recording data, managing data, reading and memo-ing, generating categories, themes and patterns, and finally, coding the data (De Vos, 2005: 334). The data was managed by organizing

the collected data into files, thus making it easily retrievable. These data files were converted into text, that is, a transcription was made. The researcher read the transcripts many times to get a sense of the interview and to become familiar with the data. While reading the data, the researcher made notes of any ideas or key concepts that came to mind. Generating categories, themes and patterns from the data is the most difficult phase of the data analysis (De Vos, 2005:337). This phase is an analytic process whereby the researcher will make comparisons, look for categories and identify themes, ideas and belief patterns (De Vos, 2005: 338). The themes and categories were further broken down into sub-categories. The researcher carried out a first interview and analysed the data collected, as mentioned above. A second interview was conducted and the data was analysed. The new themes and categories that arose from the second interview were added to the themes and categories from the first interview. This process was repeated until no new themes or categories were found. The researcher then interpreted the data by making sense of it all. Lastly, the data was presented in text.

1.6.2 Sample and sampling

1.6.2.1 The universe

The universe refers to "*all potential subjects who possess the attributes in which the researcher is interested*" (Strydom, 2005b: 193). The universe in this study is parents of children with autism in South Africa, Western Cape Province.

1.6.2.2 The population

The population refers to "*individuals in the universe who possess specific characteristics*" (Strydom, 2005b: 193). The population sets boundaries on the universe. The population in this study is the parents of children with autism in the Southern and Northern Suburbs of Cape Town in the Western Cape.

1.6.2.3. Demarcation of the sample

A sample is the part of the population that is considered for the study (Strydom, 2005b: 193). The sample came from parents who had children of school-going age with autism. The researcher collected data from parents until saturation of data took place.

1.6.2.4 Sampling technique

This study used non-probability, purposive sampling. In qualitative research non-probability sampling is used as the researcher seeks individuals or groups where the specific process being studied is likely to occur (Delport & Strydom, 2005: 328). Qualitative researchers are interested in the sample of respondents that will increase the researchers' understanding of the topic. The respondents are therefore chosen based on their relevance to the research topic and ability to provide the information needed. This often means that the researcher selects the respondents or cases gradually with attention given to the specific content of such case (Neuman, 2003: 211).

Purposive sampling is selective sampling of cases that fit the specific purpose of the study. This type of sampling is used in studies such as this one where particular types of cases are needed for an in-depth investigation (Neuman, 2003: 213). Strydom (2005b: 202) states that purposive sampling is based on the judgement of the researcher, that the researcher specifically chooses those respondents that are most characteristic or representative of the population. For this study the sample included parents of children with autism who attend school in Cape Town, Western Cape, South Africa. Parents may or may not have more than one child with autism and may have a typical child not diagnosed with autism. The parents must have at least one school (includes play/nursery school) age child with autism. The sample was originally going to come from parents of children who attend the Alpha School or the Vera School. Unfortunately, due to strike action at departmental schools at the time of data collection, it was not possible for the researcher to access parents through those schools. The sample was, therefore, identified by the researcher's professional colleagues, who supplied the researcher with

contact details of parents of children with autism who were willing to partake in the study.

1.7 ETHICAL ASPECTS

1.7.1 Harm to respondents

According to Strydom (2005a: 58), research respondents may be harmed physically or emotionally during data collection. The researcher has an ethical obligation to protect the respondents from any form of harm. In the social sciences, emotional harm is more likely than physical harm, although physical harm is possible. Emotional harm is more difficult to predict than physical harm and has consequences that are more extensive. The best way to protect the respondents from harm is to inform them of all the possible consequences of the research. The respondents should have the option to withdraw from the research after receiving this information or at any time during the course of the research. It is the researcher's responsibility to identify vulnerable respondents and to exclude them from the research.

Neuman (2003: 120) discusses psychological abuse and whether it is unethical to place respondents in stressful, embarrassing or anxiety-provoking situations, as often social science research requires the respondent to be placed in a stressful position. It is argued that the results of the study often outweigh the harm to the respondents, but this is still a debate and Neuman (2003: 122) concludes that "*only experienced researchers who take precautions before inducing anxiety or discomfort should consider conducting experiments that induce significant stress or anxiety*" and that unnecessary stress should never be caused.

In this study there was the possibility of causing emotional harm or stress to the respondents as the subject matter is of a personal nature, emotional and a possible cause of sadness. On the other hand, the study may have been experienced by the respondents as a stress reliever as it may have given the respondents a verbal outlet where they could express their feelings, needs, concerns and wishes. The study could have provoked a hope of change in

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service delivery to the respondents, which may have been a false hope. The researcher was responsible for making it clear to the respondents that there would be a possibility that the research could bring about change but that there would be no guarantee that change would occur.

1.7.2 Informed consent

Informed consent refers to

> *all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher, be rendered to potential subjects or their legal representatives* (Williams, Tutty & Grinnell, 1995: 30 cited in De Vos, 2005: 59).

Respondents must be given accurate information so that they can make informed and voluntary decisions on whether to participate in the research. Only legally and psychologically competent participants may give consent to become respondents. Respondents should be advised that they are entitled to withdraw from the research at any time. An informed consent statement contains a brief description of the purpose of the research and the procedures taken, a statement of any risks involved in participating in the research, a guarantee of confidentiality, information about the researcher and about where to find information about rights of the respondents, a statement that participation is voluntary and can be ended at any time if the respondent so wishes, a statement of alternative procedures, a statement of any compensation provided to the respondents and an offer to provide the respondent with a summary of the findings (Neuman, 2003: 124). Written consent was obtained from the respondents.

1.7.3 Deception of respondents

Deception of respondents occurs in a number of ways. Deliberately withholding information and misrepresenting the truth in order to get

respondents to participate in the research, where, if they had had the correct information they may not have agreed to participate, is one form of deception (Strydom, 2005a: 60). The most common deception occurs where the researcher disguises the goal of the study as he or she suspects the respondent may need to hide information (Babbie & Mouton, 2001: 525). This deliberate deception of respondents should be disclosed to the respondents immediately after conducting the experiment or study; however, there is still a debate about whether this is ethical or not (Neuman, 2003: 123).

There are, however, two types of deception, One is deliberate, as described above. The other is unintentional, following an unpredicted development during the research. If this were to occur, the development would be discussed with the respondents and rectified immediately after their interview to ensure that there had been no deliberate deception (Strydom, 2005a: 61).

In this study, the respondents were fully informed of the goal of the study. As the researcher believes that the ultimate goal of the study is to improve the lives of the parents, there would be no need for the respondents to hide information and consequently, no need for the researcher to disguise the goal of the study. Informed consent prevented deception of the respondents in this study.

1.7.4 Anonymity and confidentiality

It can be said that the main ethical concern in the research process is the protection of the respondent's identity. Anonymity is different to confidentiality although they are often used interchangeably. Anonymity refers to the case where the researcher is unable to pair a response with a specific respondent. If anonymity is a criterion, it is impossible to do an interview, as the researcher collects the information directly from the respondent. On the other hand, if confidentiality is the criterion, the researcher declares not to identify the respondents publicly but can match a response to a respondent. In practice this is done by replacing all names and address on the data collected with identification numbers. These numbers are only meaningful to the

researchers. It is unethical to violate a respondent's right to privacy. (Babbie & Mouton, 2003: 523)

In this study the respondents were interviewed, therefore, anonymity was not an option. The researcher knows which respondent gave what information but the respondents' names have been removed from the collected data to ensure confidentiality.

1.7.5 Actions and competence of researcher

Ethically, researchers have to be adequately skilled and competent enough to conduct research This is very important in research of a sensitive nature. Furthermore, adequate supervision of the research is important. A characteristic of being a competent researcher is the ability to be objective and to refrain from making value judgments of the respondents. (Strydom, 2005a: 63-64). Another aspect of being a competent researcher is the ability to respect the respondents, their customs and the communities they live in.

This researcher is a qualified Social Worker and is enrolled in the Masters in Play Therapy programme at The Huguenot College, which is affiliated to The University of South Africa. The researcher has had training in the master's degree programme and is working under supervision. The Research Committee at The Huguenot College has approved the research. Consequently, the researcher could be considered competent and adequately skilled to have undertaken this research.

1.7.6 Release of findings

The research findings must be released to the public in written form as a clear, accurate and objective report. This includes avoiding bias, as a bias in reporting is unethical. All sources must be referenced to avoid plagiarism (Strydom, 2005a: 65).   Babbie and Mouton (2001: 526) refer to the release of findings as analysis and reporting. They go on to say that the researcher must honestly report unexpected findings as being unexpected and not create fictitious hypotheses that mislead the reader into believing that the findings were pre-planned. Babbie and Mouton (2001: 526) and Strydom (2005: 66)

agree that negative findings must be reported with the positive findings and that the researcher must admit to any errors or shortcomings in the research. Any constraints arising from the methodology should be included in the report. Lastly, the researcher should not make changes to the data collected or to their observations (Babbie & Mouton, 2001: 526). In other words, the research and the findings must be reported accurately and honestly by the researcher; anything other than this is considered unethical. The findings of this study are released as a Master's dissertation to the University of South Africa.

1.7.7 Debriefing of respondents

According to Strydom (2005a: 66), debriefing the respondents after the interview is a method of decreasing or minimizing any harm done to the respondents. Debriefing gives the respondents the opportunity to express their feelings about the study and about participating in the study and also affords the researcher the opportunity to rectify any misunderstandings or incorrect perceptions that the respondents may have had. The debriefing can sometimes include a termination session with the respondent to avoid causing the respondent harm resulting from the completion of the study (Strydom, 2005a: 67). Debriefing should be done in a therapeutic mode and not in a research mode.

The respondents in this study were given the opportunity, after taking part in the interview, to have a debriefing session with the researcher if the respondent felt it to be necessary. As the topic under discussion may have caused an emotional response in the respondent, the researcher felt it was important to offer debriefing and encouraged the respondents to have such a debriefing.

1.8 DEFINITIONS OF MAIN CONCEPTS

Pervasive Developmental Disorder

Pervasive Developmental Disorders (PDD) is a category of disorders characterized by impairment in social interaction, imaginative activity,

communication skills and a limited number of interests (National Dissemination Centre for Children with Disabilities, 2003:1). There are five disorders that fall under the category of Pervasive Developmental Disorders. These are: Autistic Disorder; Rett's Disorder; Childhood Disintegrative Disorder; Asperger's Disorder; and Pervasive Developmental Disorder Not Otherwise Specified (National Dissemination Centre for Children with Disabilities, 2003:1).

The researcher understands pervasive developmental disorders to be the umbrella term for developmental disorders that is all-encompassing and, therefore, affects more than one area of development.

Autism

According to the Diagnostic and Statistical Manual of Mental Disorders (4th edition) (American Psychiatric Association, 1994), autism is a pervasive developmental disorder. This is a category of disorders in which basic areas of infant and child psychological development are affected at the same time. The three major characteristics of Autistic Disorder are: qualitative impairment in social interaction, qualitative impairment in communication and restricted, repetitive and stereotypical patterns of behaviour, interests and activities. The onset is before the age of three years.

Adams *et al.* (2004:1) describe autism as

> *… a developmental disability that typically involves delays and impairment in social skills, language and behavior. Autism is a spectrum disorder, meaning that it affects people differently. Some children may have speech, whereas others may have little or no speech. Less severe cases may be diagnosed with Pervasive Developmental Disorder (PDD) or with Asperger's Syndrome.*

The researcher describes autism as a pervasive developmental disorder that has a spectrum of severity. Autism is on the severe end of the spectrum while

Asperger's Syndrome is on the mild end of the autism spectrum. Autism is a life-long disability that affects social skills, communication and behaviour.

Parent

The Dictionary (1994, u.w. 'parent') defines a parent as "*a person who has a child; a father or a mother*".

The researcher defines a parent as the person or people who are the legal guardians of the child and provide care to the child. A parent influences and teaches the child through behaviour control and supervision and emotionally and psychologically supports the child through warmth, responsiveness and love. A parent's role is to love and protect their child and to provide education and healthcare.

For this research study, a parent will be the legal guardian who cares for and raises the child with autism. The parent may or may not have more than one autistic child and may or may not have other children not diagnosed with autism. The parent will have at least one school-aged autistic child.

1.9 OUTLINE OF RESEARCH REPORT

- **Chapter 1**
  Introduction and rationale for the study
  Chapter one includes a brief description of autism and the study to be conducted. The research problem, methodology, goals and objectives and sampling strategy are discussed. The main concepts are defined in chapter one.

- **Chapter 2**
  Autism
  The literature review maps out the main issues in the field of autism that are being studied. The literature review indicates how this research will fit into the issues in the field. This literature review is a preliminary

review in order to provide background information on autism and on parents raising autistic children. A more in-depth literature review is carried out in chapter four.

- **Chapter 3**

  Data collection and analysis

  In chapter three, the data collection procedure is described comprehensively, clearly explaining the context and purpose of the data collection and describing the respondents, the research design, the sampling plan, as well as the data collection procedures and the steps followed. The process, analysis and interpretation of data are also included in this chapter.

- **Chapter 4**

  Parents raising a child with autism

  A second, more in-depth literature review is conducted as a control to compare the empirical findings with the reviewed literature.

- **Chapter 5**

  Conclusions and recommendations

  In chapter five, the conclusions, recommendations and further interpretations of the findings are presented. A summary of the study is included here.

1.10 CONCLUSION

This chapter described the research problem and rationale for this study. The researcher described the research approach, strategy and methodology and set out the procedure and work method that was carried out. The sampling, as well as ethical aspects, were discussed. This chapter includes definitions of the main concepts in this study. A literature review in chapter two provides information on autism. This review indicates how the research will fit in with the issues in the field.

Chapter Two
AUTISM

2.1 INTRODUCTION

This literature review is a preliminary review of the literature on autism and on parents raising a child with autism. Chapter four will review literature in more depth so as to describe literature according to the findings of this study. This preliminary literature review will begin by explaining autism and the features associated with autism. The prevalence of autism is discussed as well as causes and treatment. Finally, literature on parenting the child with autism is looked at. These aspects of the child with autism are focused on in order to understand the world of the child with autism better and to gain insight into the life of parents raising a child with autism. This understanding and insight will increase the researcher's ability to conduct the interviews of the parents of children with autism.

2.2 AUTISM

Autism is a neuro-developmental disorder defined behaviourally by a triad of impairments (Mandelbaum et al, 2006: 33). The triad of impairments are: social development, communication and repetitive behaviour (Baron-Cohen, 2005: 398). The diagnostic criteria for autism, as laid out by Gillberg and Coleman (2000: 6), are agreed upon by most authorities. There are four criteria, namely, severe abnormality of reciprocal social relatedness; severe abnormality of communication development; restricted, repetitive behaviour, interests, activities and imagination; as well as early onset of signs and symptoms.

The first three criteria are referred to as the triad of impairments. These three impairments lie in social, communication and behavioural areas. Gillberg and Coleman (2000: 7) state that many authors would include a fifth criterion for diagnosis. This fifth criterion would be abnormal responses to sensory stimuli. According to Mandelbaum *et al.* (2006: 33), children with autism have a variety of sensory-motor deficits such as low muscle tone, clumsiness and

stereotypies. In a study conducted by Mandelbaum *et al.* (2006: 38), children with autism were sharply discriminated from children with mental retardation or low IQ by their willingness or inability to perform a sensory motor task. Children with autism would not or could not perform the tasks possibly due to severe mental retardation or the deficits in comprehension of language, impaired perception of rewards for cooperation, or severe impaired attention.

Early onset of autism is widely accepted as before two and a half to three years of age (Gillberg & Coleman, 2000: 10). Males have been found to be affected four times more frequently than females (Taylor, 2006:511). Learning difficulties are reported in 70% of children with autism (Taylor, 2006: 511). Gillberg and Coleman (2000:10) concur by stating that the majority of children with autism are mentally retarded and, therefore, a minority of children with autism function in the normal to near-normal IQ range.

Baird, Robinson, Boyd and Charman (2006: 604) state that usually abnormalities become clear in children with autism before the age of two years, even though diagnosis may only occur later. A pattern of normal behaviour followed by a cessation in development with loss of existing language and behaviour skills in the second year of life is labelled autistic regression. This type of autism has a poorer outcome, with the child having a lower IQ, lower language level and lower adaptive level. Autistic regression occurs in 15 - 40 % of autistic children.

The possible cause of autistic regression is thought to be sub-clinical epilepsy. However, in the study carried out by Baird *et al.* (2006: 607), no evidence was found that epileptiform discharges in the sleep of autistic children is the cause of autism or autistic regression. They do, however, state the importance of awareness of epilepsy complicating autism and vice versa.

Gillberg and Coleman (2000: 4) view autism not as a disease but as a comprehensive diagnosis in the same way as mental retardation, cerebral palsy or epilepsy. Autism is just one variant on the autism spectrum. Disorders that fall under the autism spectrum are Autistic Disorder, Asperger's

Syndrome, Pervasive Developmental Disorders (PDD)–not otherwise specified (NOS), Rett's Disorder and Childhood Disintegrative Disorder (Kutscher, 2005:93). Autism spectrum disorders are referred to as childhood autism, infantile autism, autism, autistic disorder, autistic continuum and pervasive developmental disorder (Gillberg & Coleman, 2000: 5 - 6). In this study, the researcher will refer to the term autism.

2.2.1 Autism profile

There are low and high functioning children with autism. Low and high functioning children with autism are the same in their core deficits (Prior & Ozonoff, 1998: 64); their IQ determines their level of functioning. Approximately one quarter of people with autism function in the intellectually normal range. It has been found that females with autism score lower in intellectual tests than males and that there are fewer high functioning females with autism than males with autism. (Prior & Ozonof, 1998: 71).

The following profile of people with autism is generalized across the levels of functioning.

2.2.1.1 Severe restriction of the ability to engage in reciprocal social interaction

Gillberg and Coleman (2000: 12) describe the severe restriction of reciprocal interaction as a markedly decreased capacity for reciprocity in social interactions, extreme egocentricity and failure to recognize the uniqueness of other people. According to Tuchman (2006: 38-39) this is demonstrated by "*gaze avoidance, failure to respond when called, failure to participate in group activities, lack of awareness of others, indifference to affection or inappropriate affection and lack of social or emotional empathy*".

The child with autism has a reduced capacity for shared attention and fails to develop skills to attract other people's attention. This is presented in the failure to develop normal peer-relationships, the avoidance of visual or physical contact and the behaviour of the child with autism towards people as if they were objects. (Gillberg & Coleman, 2000: 12-13).

2.2.1.2 Severe restriction of the ability to communicate reciprocally

There is often language delay in children with autism and the language that does develop is deficient in conversational use, especially non-verbal language (Rapin, 2006: 54-59). The child with autism fails to grasp the meaning of communication and has difficulty comprehending gestures and speech. The child makes little social use of communication skills and has a deficit in the use of social imitation. Coupled with this difficulty, is the child's misinterpretation of facial expressions. The child with autism usually has a delayed development of speech, or normal development until the age of two years when it ceases. The speech that the child with autism does develop tends to have an oddity in vocal volume and pitch (Gillberg & Coleman, 2000: 13-16).

2.2.1.3 Severe restriction of imaginative abilities with a small and rigid behavioural range.

There are categories of rigid behaviours displayed by people with autism. These categories are: stereotypy, self-injury, compulsion, ritual, sameness and restriction (Mink & Mandelbaum, 2006: 68). These authors explain these behaviours as the following:

- Stereotypies are involuntary movements that are rhythmic, repetitive and purposeless. These may include rocking, head nodding and/or hand flapping to name a few;
- Self-injurious behaviours are also stereotyped and repetitive behaviours but differ in that they have the potential to cause harm to the child. These may include: hitting, biting, scratching etc;
- Compulsions are purposeful behaviours that are repetitive and performed according to rules. These include ordering, checking, hoarding and so forth;
- Rituals differ from compulsions in that they are routines of daily activities, however, they have to be carried out in a rigid, repetitive manner and they often include following rules;

- Sameness overlaps somewhat with rituals, but sameness is characterized by the resistance to change;
- Finally, restrictions can be explained as a limited range of behaviour or interests and leads to a limited behaviour range.

Gillberg and Coleman (2000: 16 –19) suggest that the severe restriction of behaviour range is due to only being able to learn through rote copying of what other people have done. This is presented by the child with autism as displaying attachments to objects or parts of objects and a fascination with objects that have a particular quality.

2.2.2 Common symptoms not amongst diagnostic criteria

Gillberg and Coleman (2000: 19-21) and Doo and Wing (2006: 650) discuss the many common symptoms that are associated with autism. These symptoms are not listed in the DSM-IV, but are commonly found in children with autism.

- Abnormal responses to stimuli:
  An abnormal response to sounds is most distinctive in children with autism. This is coupled with an extreme variability in the reactions to sound. The child displays abnormal responses to visual stimuli and has difficulty recognizing things. The abnormal responses to visual stimuli include oddities of the child's gaze and an extreme fascination with contrasts of light. Another abnormal response to stimuli is the child's abnormal sensitivity or often in-sensitivity to pain, heat or cold (Gillberg and Coleman, 2000: 19).
- Abnormal activity levels:
  The child with autism is most often either hyperactive or hypoactive with only a few children having normal activity levels. In the preschool years hyperactivity is common, early school years are characterized by normal active behaviour and then hypo activity is common in adolescence (Gillberg & Coleman, 2000: 20).

- Abnormal eating behaviours:

  Children with autism often refuse particular foods, they become obsessed with a particular food fad, are found to hoard food or to overeat. Various degrees of anorectic behaviours have also been reported (Gillberg & Coleman, 2000: 21).

- Abnormal sleep patterns:

  Children with autism tend to require less sleep and often wake at night, disrupting the sleep of family members. This is most striking in infancy but can continue into adulthood. Sleep disturbance is a common feature of pervasive developmental disorders. Sleep disturbances in children with pervasive developmental disorders (PDD) are characterized by "*problems with sleep onset, night waking, irregular sleep-wake pattern, early waking and poor sleep routines*" The cause of the sleep disturbances have not been found, however, there is a hypothesis that the unique features of PDD such as social-communication deficit and brain pathology are associated with the sleep disturbances. (Doo & Wing, 2006: 650).

- Aggression and self-injury;

  Aggression presents particularly in adolescents and young adults. Self-injury, however, is present in children with a combination of autism and mental retardation and is in the form of head-banging, wrist or knuckle biting, chin-knocking, cheek-smacking, eye-poking, hair-tearing and clawing (Gillberg & Coleman, 2000: 21).

2.3 DEVELOPMENT OF THE CHILD WITH AUTISM

2.3.1 Cognitive profile

The cognitive functioning of the child with autism is of particular interest as many children with autism are mentally retarded; however, the cognitive profile of a child with autism differs from that of a solely mentally retarded child in many ways (Gillberg & Coleman, 2000: 22). The cognitive profile of the child with autism, as it differs from the mentally retarded child, is discussed.

Gillberg and Coleman (2000: 22) describe the cognitive functioning of the child with autism. As previously mentioned, commonly the child with autism is mentally retarded. However, there are often islets of special ability displayed, even in the mentally retarded child with autism. These islets of ability are distinguished by the fact that they are of little use or assistance in other cognitive areas of the person's life (Prior & Ozonoff, 1998: 75). The child with autism makes use of concrete interpreting and problem solving and has superior visuo-spatial skills. The child does, however, have low language ability, a lack in intuition and empathy and an impaired memory in terms of recalling past activities when asked open questions (this may, however, be due to lack of comprehension of the question).

2.3.2 Clinical course

The manifestations of autism change over time and often improve (Tuchman & Rapin, 2006: 13). Autism presents in different ways throughout the development and the life span of a person with autism. How autism is presented from infancy to adulthood is illustrated below.

Infancy: In infancy non-specific symptoms are recognized, such as the lack of initiative, hyperactivity and sleeping and feeding problems. Children may develop normal speech until the age of two and then stop. Fifteen percent of children with autism develop seizures in the first few years of life and these spasms or seizures are thought, in some case, to cause autistic withdrawal (Gillberg & Coleman, 2000: 63-64).

Preschool: At this age typical autistic behaviour becomes evident. A diagnosis of autism can be made when the child is 30 months or older. Temper tantrums regarding insistence of sameness and routine, hyperactivity, destructiveness and engaging in repetitive activities are common. The child with autism fails to communicate with spoken language and does not show an interest in other children. He shows active avoidance of other children (Gillberg & Coleman, 2000: 64-65).

Early school years: Children with autism in this stage of development gradually become less difficult to manage, social aloofness subsides and they become more cooperative. The majority of children with autism at this age no longer avoid other children entirely. The development of spoken language is very different from child to child. Some children develop useful speech and appear less deviant than they were in preschool, but others could remain as they were at age three. Hyperactivity and temper tantrums become less frequent. Fewer problems with sleep are experienced, as the child may be able to occupy himself at night when he has less need for sleep and, therefore, may not disturb others. This is seen as a somewhat calmer period. (Gillberg & Coleman, 2000: 65-66.)

Gillberg and Coleman (2000: 66) qualify their statement that the early school years is a calmer period by stating that, in their experience, it will depend to some extent on whether or not the child has been correctly diagnosed as suffering from autism at the earlier age.

Adolescence: Many complications of the autistic disorder manifest themselves in adolescence. Many children with autism develop epilepsy in adolescence. Twelve to 32% of autistic children display cognitive and behavioural deterioration in adolescence. This deterioration is accompanied by regression and the emergence of behaviours associated with the preschool aged autistic child. (Gillberg & Coleman, 2000: 67).

Puberty aggravates the symptoms in many children with autism. Commonly, these symptoms are aggression, self-destructiveness, hyperactivity and restlessness. These perceived aggravated symptoms may be due to the physical growth and strength of the adolescent with autism and because these symptoms stand out as inappropriate far more in adolescence than they did when the person with autism was a younger child. (Gillberg & Coleman, 2000: 68).

A minority of children with autism improve in adolescence. These are usually the high functioning children with autism and many go through adolescence

with little disturbance or change other than the normal behavioural problems that are associated with normal functioning adolescents (Gillberg & Coleman, 2000: 66).

Adulthood: The majority of children with autism will display deviancies and experience psychiatric impairments throughout life, however, some improve enough to lead an independent life (Gillberg & Coleman, 2000: 76). Often there is an improvement in social isolation even though social skills and the ability to make friends are still impaired. The communication and language deficits often continue into adulthood and there are permanent inadequacies in conversational skills. Stereotypical behaviour, however, may decrease, but abnormalities of gait and posture persist (Tuchman & Rapin, 2006: 13).

2.4 PREVALENCE

The prevalence of autism has significantly increased in recent years, which, according to Taylor (2006: 511), is a sign of greater awareness, changes in diagnostics with broadening diagnostic criteria, more trained diagnosticians and a greater acceptance of the label of autism. Tuchman and Rapin (2006: 25) agree with this statement by saying that the diagnostic criteria have changed over time and, with greater awareness of autism, more diagnoses are being made. Taylor (2006: 512-513) debates whether the increase in the prevalence of autism is due to more incidences of autism or to diagnostic substitution, previous under-diagnosis of autism and/or greater awareness and acceptance.

Baron-Cohen (2005: 398) states that the increase in the prevalence of autism is viewed by critics as due to the widening of the diagnostic category to include Asperger's Syndrome and other syndromes on the autism spectrum and an increased awareness of autism among the medical profession and the public in general. Gillberg and Coleman (2000: 94-96) agree that the diagnostic categories used to diagnose autism have changed over time and are less strict than the original Kanner's criteria and that there is a greater awareness of autism. Gillberg and Coleman (2000: 96) estimate, reasonably and conservatively, that 1 in 1,000 children is diagnosed as having autism

(excluding other disorders on the autism spectrum). Rinehart, Tonge, Bradshaw, Lansek, Enticott and Johnson (2006: 272) agree with this estimate of autism's prevalence.

2.5 CAUSES OF AUTISM

Unravelling the causes of autism proves to be a difficult task as autism is a condition with many manifestations that change with age (Trevarthen, Aitken, Papoudi & Robarts, 1998: 50). There are strong genetic factors as well as prenatal biological determinants. Recently, vaccines have been incriminated as a cause of autism, however, Taylor (2006: 514) states that no definite post-natal environmental causes have been identified.

The researcher discusses all the possible causes of autism.

2.5.1 Psychological causes

Gillberg and Coleman (2000: 102) state that there are three psychological concepts involved in autism. These are mentalizing, central coherence and executive function. People with autism have been found to fail tests for mentalizing and central coherence. Not all people with autism are impaired in all three areas; however, it is generally accepted that there are many neuropsychological impairments in people with autism.

There are four psychological theories explaining autism. They are Mindblindness Theory, Empathizing-Systemizing Theory, Executive Dysfunction Theory and Central Coherence Theory.

2.5.1.1 Mindblindness Theory / mentalizing

Baron-Cohen (2005: 398) discusses the theory of mindblindness as a psychological cause of autism. Mindblindness is explained as a deficit in the processing of empathy. Empathy involves two elements: the first is the ability to attribute mental states to oneself and others, which the author sees as the natural way of making sense of people and the second is displaying an appropriate emotional reaction to another person's mental state. Most of the tests done on mindblindness revealed profound impairment in the

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empathizing ability of people with autism, manifested in reduced shared attention, reduced use of mental state terms, reduced use of and grasp of social pretence, difficulty appreciating other people's beliefs and trouble understanding subtle emotions.

The theory of mindblindness can also be explained as the ability to understand that other people have thoughts and intentions. This requires the ability to interpret emotional expressions and behaviours (Tuchman, 2006: 39). The presence of mindblindness is illustrated in the child's failure to develop normal peer-relationships, the avoidance of visual or physical contact, and the child's behaviour towards people is as if they were objects (Gillberg & Coleman, 2000: 13).

Gillberg and Coleman (2000: 105) similarly discuss the Affective Theory that states that people with autism have a dysfunction in the ability to perceive the mental state of others as evidenced by their facial expressions. This dysfunction is said to underlie the social and communication problems experienced by people with autism. They go on to say that a disorder of empathy underlies the behavioural symptoms of autism, as without being able to conceive the mental states of other people and the thoughts and feelings behind what people say and do, the person with autism will not comprehend most of what people do and say. "*Not having a well-developed theory of mind will lead to extreme deficits in reciprocal social interaction, in communication and in "creative" imagination*" (Gillberg & Coleman, 2000: 106).

2.5.1.2 Empathizing-Systemizing Theory
This theory states that people with autism have an intact or superior ability to systemize while at the same time they have a deficit in empathizing. Systemizing is the ability or drive to analyse and build systems (natural, technical, social or abstract) in order to understand events and to predict behaviour, in terms of rules and regularities. The impairments in empathizing cause people with autism to have difficulties with social skills, communication and imagining other's minds. The strength of systemizing leads to islets of ability, obsessions with systems and repetitive behaviour (Baron-Cohen,

2005: 398-399). An interesting observation by Baron-Cohen (2005: 399) is that, in the general population, females tend to be stronger in empathizing, while males tend to be stronger at systemizing. Autism is more common in males and may represent an "*extreme of the male brain*".

2.5.1.3 Executive Dysfunction Theory

Executive Dysfunction Theory attempts to explain the repetitive behaviour and need for routine and sameness of people with autism. This theory views this repetitive behaviour as negative and as a "*form of frontal lobe perseveration*". However, due to the fact that some people with Asperger's Syndrome have no executive dysfunction, but still have strengths in systematizing and deficits in empathizing, demonstrates that executive dysfunction cannot be a central part or core cause of Autism Spectrum Conditions. (Baron-Cohen, 2005: 399-400). Executive function is explained by Gillberg and Coleman (2000: 108) as the faculties that enable people to be motivated to work toward a goal that may take time to reach. These faculties are motivation, focusing skills, sequential skills and time concept. These qualities are most often poor in people with autism. Specific impairments in executive function in people with autism are: working memory, ability to inhibit, plan, organize and shift from one cognitive set to another.

2.5.1.4 Central Coherence Theory

Central coherence refers to global processing, in other words, processing whole systems. People with autism demonstrate weak central coherence as there is a superior attention to detail. This links with systemizing as systemizing requires excellent attention to detail; however, the Central Coherence Theory differs from the Empathizing-Systemizing Theory when it comes to the whole. The Empathizing-Systemizing Theory predicts that the autistic person will display a strong desire to understand the whole system, while the Central Coherence Theory predicts that the person with autism will fail to grasp the whole system or the relationships between parts of the system (Baron-Cohen, 2005: 400). Gillberg and Coleman (2000: 108) explain the person with autism's weak drive for central coherence as a preference for processing information at an analytical level rather than a global level. People

with autism also struggle with switching from detail to the whole and back again.

2.5.1.5   Gestalt Theory

Gestalt Theory is explained in chapter one as a phenomenological-existential theory (Yontef, 1993: 1), which means that the Gestalt Theory is about existing in the present. Gestalt Theory is a useful theory from which to view the child with autism. The researcher finds the philosophy and certain concepts of *gestalt* particularly pertinent to viewing the child with autism. These particular concepts are the phenomenological perspective, the field, the here-and-now and holism. A great concept of Gestalt Theory is that the whole is seen to be more than the sum of the parts, that is, the whole is more important than the parts. A client's distress is holistically evident in the way they feel, think and behave. The researcher believes that one should take a holistic approach to viewing a person and their problem, as a person cannot be separated from their environment. The environment plays a part in their problem and, therefore, in the solution to the problem.

The researcher views holism as important when viewing the child with autism and his family, as the child with autism is very dependant on the environment to fulfil his needs. The environment can have a significant impact on the development of the child with autism, whether it be emotional, social or intellectual. The environment, known as the field in Gestalt Theory, is, therefore, of great importance especially when viewing the child with autism, as the field is significant to understanding who the child with autism is and why he is the way he is. Yontef (1993: 3) states that one needs to explore the environment that the event, in this case, autism, is part of, and to acknowledge that each part of the environment or field is influenced by this event. The child with autism has to be viewed in the environment of his family, school and therapy sessions and in the environment of the syndrome of autism. It is important to take note of the field of the child with autism and how this field impacts on the child and those around him, such as his parents, in order to understand the different influences in the child's life and decipher which influences are positive and which are negative.

The researcher views Gestalt Theory as focussing on all aspects of the present and with little emphasis on the past, as the here-and-now and awareness of oneself in the here-and-now is what is important in Gestalt therapy. The past is incorporated into Gestalt Theory by the way the client deals with the past in the here-and-now. Yontef (1993: 5-6) states that what exists here-and-now is more valuable than any interpretation of the client. The researcher agrees with this statement and believes that this is a positive way to view the child with autism, as the child with autism, as mentioned before, has difficulty understanding language and social cues and struggles to communicate, thus remaining in the here-and-now. "*Gestalt therapy treats what is subjectively felt in the present, as well as what is objectively observed, as real and important data*" (Yontef, 1993: 2).

2.5.2 Neurological causes

According to Brothers (1990), social intelligence is a function of three regions of the brain: the amygdala, the orbitofrontal cortex and superior temporal sulus and gyrus, together called the social brain. The amygdala is "*activated when decoding signals of social importance, such as gaze, expression-recognition, and body movements*" (Baron-Cohen, 2005:400). Patients with lesions in the amygdala have impairments to social judgement similar to autism. Abnormalities of the amygdala have been found in people with autism. Such abnormalities are: increased cell density in the amygdala, reduced amygdala volume and less amygdala activation during an empathizing task. As the amygdala is linked to autism, it is likely that there are other areas of neural abnormality possibly linked to autism (Baron-Cohen, 2005: 400-401).

Cerebellar dysfunction (Rinehart, Tonge, Iansek, McGinley, Brereton, Enticott, & Bradshaw, 2006: 822) is indicated by difficulty walking in a straight line, reduced stride regularity with increased variability in velocity and the coexistence of variable stride lengths and duration. Children with autism have been found to be less coordinated and more variable and inconsistent than other children.

2.5.3 Genetic causes

In early research of autism there was said to be no genetic link. Today, autism is thought to be one of the most heritable psychiatric conditions (Szatmari & Jones, 1998: 109), however, there is "*no consensus on the mode of transmission of autism*" (Szatmari & Jones, 1998: 125). According to Gillberg and Coleman (2000: 232), there is a consensus that the autism spectrum is mainly composed of underlying genetic diseases. This consensus is not proven and cannot be proven until each person diagnosed with autism has a specific diagnosis. They have said that twin studies have shown that there is a hereditary factor to autism and that the genetic element has been found to be unusually strong.

Badawi *et al.* (2006: 85) state that the best supported hypothesis in the cause of autism is a genetic predisposition. However, they state that there are multiple interacting genes that contribute to autism. Insults or damage to the foetus early in prenatal development can increase the risk of autism. In the study conducted by Wier, Yoshida, Odouli, Grether, and Groen (2006: 506), it was found that there is a link between congenital anomalies and autism spectrum disorder. This may indicate that there is a shared gene and/or an environmental insult that occurred during pregnancy that led to the congenital anomaly and autism. They also suggest that congenital anomalies are on the causal pathway to autism spectrum disorders.

2.5.4 Environmental causes

It has been found that prenatal exposure to particular teratogens (Definition: an environmental agent that can cause abnormalities in a developing organism, e.g., the rubella virus) is a risk factor associated with autism and indicates that foetus mal-development is a likely path to autism (Fombonne, 2006: 84). Wier et al. (2006: 500) describes a study of Swedish patients where prenatal exposure to a teratogen occurred which resulted in a greater proportion of autism. They suggest that first-trimester injury may impair brain development, which potentially leads to autism. Insults occurring during gestation in the foetus lead to neuro-developmental disorders, particularly autism spectrum disorders (Fombonne, 2006: 84). According to a study by

Badawi et al. (2006: 85), children who have experienced encephalopathy are 5.9 times more likely to be diagnosed with autism spectrum disorder, and a strong association was found between encephalopathy and the development of autism.

2.5.5 Medical conditions commonly associated with autism

Cass, Sekaran and Baird (2006: 523) list a number of medical conditions that have been found to be commonly associated with autism. These medical conditions can be separated into genetic/chromosomal disorders and neurological disorders.

Genetic/chromosomal disorders:

Fragile X

Tuberous sclerosis

Phenylketonuria

Neurofibromatosis

Down's Syndrome

Williams Syndrome

Duchenne muscular dystrophy

Non-specific dysmorphic syndromes

Other neurological disorders:

West Syndrome

Landau Kleffner Syndrome

Hydrocephalus

Cerebral palsy

Sensory deficits

Pre-/peri-/post-natal:

      Congenital infection

      Encephalitis

      Hypothyroidism

      Foetal alcohol syndrome

2.6 TREATMENT

There is no specific medication for the treatment of autism. Early identification is thought to be most desirable and special education has been found to be beneficial (Baron-Cohen, 2005: 401).

> The importance of early detection of autistic deviation in the development of young children has been emphasized in the last 15 years as new intensive intervention programs for children with autistic symptoms have shown that the earlier and more intensive the intervention, the better the outcome (Fombonne, 2006: 84).

Behavioural interventions appear to be the most popular therapies and treatments for children with autism. Romanczyk and Gillis (2005: 533) state that applied behaviour analysis is the treatment of choice and is one treatment that has clear and substantial research support. According to Harris (1998:196) behavioural assessment or therapy sees each person with autism as a unique individual and examines his biological factors, learning history and current environment. The assessment focuses on which situations bring about maladaptive behaviour and whether it is possible to change the environmental cues that trigger the behaviour. It is also important to assess which skills exist and whether these skills can assist the person with autism to learn a new skill. The aim of behavioural therapy is for the person with autism to be able to generalize the newly-learned skill to every appropriate setting and to maintain this skill over time.

Teaching language and social skills is part of behavioural therapy. It has been found that teaching language skills in a natural setting and reinforcing any attempts made by the child results in more speech and better generalization of the skills. Social skills are best taught in groups and by using role-play, peer-modelling and rehearsals of behaviours. Peer-modelling has been found to be a powerful tool for teaching social skills. (Harris,1998: 199).

Decreasing maladaptive behaviour is an important aspect of behavioural therapy and, as mentioned previously, requires an assessment of the individual's needs.

> …research shows that, if one does a careful assessment, teaches the client alternative ways to communicate needs and alters controlling environmental variables, it is possible to reduce the frequency of many intrusive behaviours such as aggression, self-injury and stereotyped behaviour (Harris, 1998: 200).

Harris (1998: 201-202) states that in some cases, early interventions can alter the developmental course of autism. Individualized, comprehensive programmes, with a systematic approach to teaching the child to interact with peers and to function in their natural environment, are said to be the most effective interventions. Gillberg and Coleman (2000:66) state that families receiving an early diagnosis and adequate educational programmes involving the parents, report better coping strategies and fewer problems than those who were given the diagnosis later.

2.7 PARENTING THE CHILD WITH AUTISM

There is little academic literature and research on parents' needs and perceptions of raising a child with autism. However, there is a fair amount of lay literature that touches on aspects of raising a child with autism, *"…being the parent of a child with a PDD is inherently stressful. As a result, parents may require considerable formal and informal support in dealing with the demands imposed on them by their child's unusual needs*" (Harris, 1998:204). Trevarthen *et al.* (1998: 52) too acknowledge that the child with autism will be a strain on parents and will affect the emotions of the parents and, therefore, threaten the emotional health of the family. "*Parental anxiety can aggravate an autistic child's problem of development, reducing his or her ability to cope, leading to ineffective attempts to control the child*".

Doo and Wing (2006: 650-654) state that parents of children with autism experience higher stress levels than parents of children without disabilities.

Parents of PDD children are particularly concerned about their child's future. Their study on sleep disturbances demonstrated that sleep problems lead to increased parental stress. The sleep disturbances experienced by children with autism are an added burden on the parents. Sleep disturbances lead to daytime problems such as sleepiness and the interference with educational and behavioural development. These sleep problems have an early onset, are chronic and persist as the child grows. The authors go on to say that parental stress may be a cause or a result of the child's sleep disturbances. Changes to the care of the child, due to the stress levels of the parents, may contribute to sleep problems.

Raising a child with a disability can be a life-changing experience that prompts families to examine their beliefs and world-views. Changing their world-views, values and priorities about their child, their parental role and the family's role, can enable the parents to gain a sense of control (King, Zwaigenbaum, King, Baxter, Rosenbaum & Bates, 2006: 353). Parents raising a child with a chronic condition such as autism face many stressors and they have to adapt to their new situation. Adaptation is a life-long process and the family belief system is seen as pivotal to the adaptation and resilience of the family. Belief systems are made up of world-views, values and priorities. King *et al.* (2006: 353-354) describe a world-view as assumptions about the social and cultural environment and one's place in the world. Values refer to the organizing principles that the family lives by and priorities are the roles and activities the families view as important.

Resilience relies on the family's ability to reframe events and experiences adaptively. A sense of coherence is a crucial factor in successful adaptation. Beliefs play a protective role in reducing the risk of poorer outcomes. Family belief systems are said to make up the family's resilience. The belief system acts as an anchor and provides stability. The belief system also acts as a guide for their choices and actions (King *et al.*, 2006: 353-354).

Reframing experiences and attributing positive meaning to these experiences defines the experience as manageable and enables the family to cope (King

et al., 2006: 369). Support given to families of children with intellectual disabilities may prevent the child being placed in residential care (McGill, Papachristoforou & Cooper, 2006: 159). McGill *et al.* (2006: 164) found there to be a poor fit between advice or treatment provided to parents of intellectually disabled and seriously challenging children and the parents' situations and beliefs. The implication of this is that parents are often not receiving helpful support, advice and treatment. The absence of this support may lead to the child being placed in a residential care facility; limit the development of the child and increase stress and costs to the parents.

The parents' support of behavioural interventions is important. The parents can learn and master the necessary behavioural skills and become part of teaching their autistic child. This is said to be highly effective when the family is provided with ongoing support (Harris, 1998: 204).

This study differs somewhat from the lay literature and information available. This study focuses on understanding the difficulties and challenges faced by parents raising an autistic child and discovers what the needs of these parents are. This study provides parents with the opportunity to have their voices heard.

2.8 CONCLUSION

This literature review has described autism as a neurological developmental disorder distinguished by a deficit in social reciprocity, language and communication and behaviour. It has been estimated that there is 1 in 1 000 children who is diagnosed as having autism. It has not yet been established what the cause of autism is, however, there are many thoughts and theories on this. The causes can be separated into psychological, neurological, genetic and environmental. As there is seen to be more than one cause of autism, there is more than one treatment. Behavioural and educational interventions coupled with early intervention are seen to be effective. Parents are thought to play an important part in the treatment of the autistic child. Parents of autistic children have been found to experience more stress than parents of other children and this stress may lead to difficulties in assisting with their

child's treatment and may cause more maladaptive behaviour in the child. It can be determined from the literature reviewed that parents raising an autistic child, require support.

The information in this chapter aided the researcher's understanding of the world of the child with autism and his parents and enabled the researcher to conduct interviews with parents of autistic children, with some insight into the aspects that are a part of their daily lives.

Chapter three describes the data collection procedure comprehensively, clearly explains the context and purpose of the data collection and describes the respondents, the research design, the sampling plan, as well as the data collection procedures and the steps followed. The process, analysis and interpretation of data are also included in the following chapter.

Chapter Three
DATA COLLECTION AND ANALYSIS

3.1 INTRODUCTION

In this chapter, the data collection procedure is described comprehensively, clearly explaining the context and purpose of the data collection. Furthermore, a description is given of the respondents, the research design, the sampling plan, as well as the data collection procedures and the steps that were followed. The analysis and interpretation of data are also included in this chapter.

3.2 DATA COLLECTION PROCEDURE

3.2.1 Context and purpose of the data collection

The purpose of the data collection was to explore and describe the needs of the parents of children with autism in South Africa, in order to provide information to professionals such as social workers, psychologists, child therapists and teachers, as well as to other parents of children with autism. This information might enable these professionals to form a helping partnership with the parents to improve service delivery, assistance and the support provided to the parents. This information provided to parents of children with autism may enable them to feel less isolated in their experience of raising a child with autism and they may be able to use recommendations from other parents who have or are experiencing similar difficulties.

3.2.2 Research design

The research design is the way in which the researcher will go about collecting the data (Fouché, 2005b: 268). The research design used in this research study was the case study method. Case studies take into account numerous viewpoints and the influences that the society has on the way the research respondents live their lives (Babbie & Mouton, 2001: 281). Fouché (2005b: 272) states that the case study consists of detailed and in-depth data collection methods such as interviews, observations and documents from multiple sources of information that are rich in context. In this research study,

the instrumental case study was used, as the researcher interviewed many parents of children with autism in order to gain knowledge of the social issue, which is their experience of parenting a child with autism.

3.2.3 Sampling plan

3.2.3.1The universe and population
The universe in this study was parents of children with autism in South Africa. The population in this study was the parents of children with autism in the Southern and Northern Suburbs of Cape Town in the Western Cape.

3.2.3.2 Demarcation of the sample
The sample was originally set out to come from parents whose children attend schools for children with autism in Cape Town, The Vera School and Alpha School. However, due to strike action, the sample could not be drawn from the schools for children with autism. Instead, the sample was identified by the researcher's professional colleagues, who supplied the researcher with contact details of parents of children with autism who were willing to partake in the study.

3.2.3.3 Sampling technique
This study used non-probability, purposive sampling. The respondents were chosen due to their relevance to the research topic and their ability to provide the information needed. The researcher selected the respondents gradually, with attention given to the specific content of each case. Strydom (2005b: 202) states that purposive sampling is based on the judgment of the researcher, that the researcher specifically chooses those respondents that are most characteristic or representative of the population.

For this study, the sample included parents of children with autism in Cape Town, Western Cape, South Africa. Parents may or may not have more than one child with autism and they may have a typical child, not diagnosed with autism. The parents had to have at least one school-aged (including play/nursery school) child with autism. The parents were all Caucasian

women, all of whom spoke English; however, one of the women had Afrikaans as a first language. The mothers were all voluntary research respondents who had been identified through colleagues of the researcher as likely to be willing to participate as research respondents in this study. The researcher approached the mothers telephonically and provided them with an informative email.

3.2.4. Respondents

The respondents in this study were five mothers of children diagnosed with autism, living in the Cape Town area of the Western Cape, South Africa. The ages of the children ranged from 5 to 14 years old and included males and females.

The respondents' ages were not obtained, however, the researcher speculates that their ages ranged from 35 to 45 years old. Two of the five respondents were stay-at-home mothers, another two worked in the field of autism and the fifth respondent worked in the field of science. One of the five respondents was divorced. The other four were married. Of the four married respondents, only one received less support from her husband than the other three who received more support from their husbands. The majority (4) of the respondents had only one child diagnosed with autism; one respondent had three children with autism. Three of the respondents had more than two children. Four of the five respondents had their child or children involved in the remediation programme called REACH.

Table 1. Summary of participant information

Participant	Marital status	Number of children	Age of child	Gender	Age at diagnosis
Mother A	Married	3	14	Female	5 years
Mother B	Married	1	5	Male	2
Mother C	Divorced	4	12	Male	3
Mother D	Married	2	5	Female	3
Mother E	Married	3	6	Male	3 and 6 months

There were participants with more than one child with autism, but due to confidentiality this is not in the scope of this dissertation to specify.

All five research respondents have been given pseudonyms to protect their anonymity. During the interviews, the respondents mentioned names of doctors, psychologists, speech therapists and schools. The researcher has omitted these names.

3.2.5 Semi-structured interviews

"*Interviewing is the predominant mode of data or information collection in qualitative research*" (Greeff, 2005: 287).   Semi-structured interviews were conducted with parents of autistic children. Semi-structured interviews are defined as interviews "*organized around areas of particular interest, while still allowing considerable flexibility in scope and depth*" (Greeff, 2005: 292). The areas of interest that were focused on in the interviews were: the interactions with health professionals; the school experience; the effect on family life; concerns and hopes for the future and coping strategies used to get through each day.

The researcher made use of these areas of interest as a guide to asking questions. Allowing there to be flexibility in the interview enabled the inclusion of other areas the parents may have wished to discuss, such as financial strain. The interviews were between 40 and 60 minutes in duration and were tape-recorded. These tape recordings were then transcribed to convert the audio data into text. These transcripts were used in the data analysis process.

3.3 DATA ANALYSIS

In qualitative research, there is an inseparable relationship between data collection and data analysis, because as data is collected it is analysed and the analysed data can suggest a need to make changes to the data collection procedures (De Vos, 2005: 335). Data analysis involves collecting and recording data, managing data, reading and memo-ing, generating categories, themes and patterns and finally coding the data (De Vos, 2005: 334). The procedure of data collection has been described above. The data obtained from the interviews was managed by organizing the collected data into electronic audio files, which were easily retrievable from the researcher's computer. These audio data files were converted into text, known as a

transcription. The researcher read the transcripts many times to get a sense of the interview and to become familiar with the data. While reading the data, the researcher made notes of any ideas or key concepts that came to mind. The next step was to generate categories, themes and patterns from the data. These steps are described below.

3.3.1 The process

Generating categories, themes and patterns in the data is the most difficult phase of the data analysis (De Vos, 2005: 337). This phase is an analytic process whereby the researcher makes comparisons, looks for categories and identifies themes, ideas and belief patterns (De Vos, 2005: 338). The researcher did identify themes, which were broken down into categories. Where applicable, sub-categories were identified. The researcher carried out an interview and then analysed the collected data as mentioned above. A second interview was then conducted and the data was again analysed. Any new themes and categories that arose were added to the themes and categories from the first interview. This was repeated until no new themes or categories were found. The researcher then interpreted the data. Finally, the data was presented in text form.

3.3.2 Analysis

Before interviewing, the researcher identified five themes as the main areas of interest that the interview was to be guided by. These themes were:
- health professionals,
- school experience,
- family life,
- getting through the day, and
- the future.

Two new themes came from the interview process. These were:
- challenges, and
- gaps in service.

3.4 INTERPRETATION

3.4.1 Health professionals

The mothers all had had interactions with health professionals in order to find a diagnosis for their children's abnormality. The interactions were experienced as extensive, inconclusive and frustrating. From this theme, the following categories were identified:

3.4.1.1 Search for diagnosis

The majority (4) of the mothers viewed the assessment process by the health professionals as frustrating and time consuming. Mother A felt that "*the more assessments you do, the more you split hairs*". Mother D experienced going from one health professional to another "*not really getting any answers*". The search for an answer was experienced as a slow process; it took a long time before the diagnosis was made. Mother C, for example, had *"absolutely no information"* and *"nobody to help [her]."* She described the diagnostic process as going *"from pillar to post for a good year"*. All the mothers had had their children's hearing tested, as the children had appeared to be deaf. The mothers had all sought assistance from speech therapists and educational or developmental psychologists, many of whom were fully booked for months in advance and, therefore, could only see the mothers after months of waiting. This may explain the time it took to receive a diagnosis.

3.4.1.2 Doctors interaction with the parents

A doctor told Mother C that her children *"are going to be institutionalised"*. Mother D's experience of the health professionals was frustrating as her child was ill very often and she did not get any answers. Mother D "*was so fed up of seeing doctors and having antibiotics thrust down [her] child's throat. [She] was just not getting anywhere with anything.*" Her feeling was "*I was beyond the system, I don't want to know any of you, I will find out what is going on with her and do this on my own.*" This mother experienced a particular doctor to be dismissive of one of her concerns.

3.4.1.3 Summary

The interactions with the health professionals were experienced as frustrating as the diagnosis took a long time due to many assessments and many long waiting periods between the assessments. The doctors were viewed as unable to assist the mothers to understand what was wrong with their child or with a diagnosis. The attitudes of the doctors were experienced as unhelpful and dismissive.

3.4.2 School experience

Schools that enrolled autistic children were experienced as few and not adequately suited to the children with autism. From this theme the following categories were identified:

3.4.2.1 Mainstream education

Mother A moved her child to a different school each time her educational needs changed. Her child started at a school for the hearing impaired then moved to a Montessori school for a short while before attending a school for autistic children. Next, she moved her child to a special-needs class at a mainstream school. The child is now at another mainstream school, but with a facilitator in attendance. This mother experienced the current school as "*stunning*" and "*absolutely lovely*" and views the progression of schools as "*stepping stones*" to reaching mainstream education. Mother A views special-needs schools as "*cocooned*" and not able to equip the child with the skills necessary to go out into society. A mainstream school will, according to this mother, give her child a better chance of fitting into society as she will learn social norms and what is and isn't acceptable and that this will help to integrate the child into society.

Mother B agrees with this and does not want her child to attend a school for autism as she would "*like his life to be . . . pretty much as normal as possible*" and she would like to keep him in a mainstream school with a facilitator. This mother is of the opinion that "*as long as your child can cope in a mainstream environment that will still be the best bet. You want normal. Our goal is*

normal. So, surely, your goal then would be to place him in the most normal setting as possible."

Mother D has decided to send her child to a mainstream school. However, this mother says that there are not many options of mainstream schools in her area. The school that she had planned to send her child to "*has awareness of learning issues and has tolerance towards it and with guidance.*" However, they have to close due to a new law passed by the Department of Education. This mother feels that her "*options for sending [her child to a mainstream school] are back to square one.*" She had visited a school on the day of the interview but felt that she could not send her child there as they "*had no inkling*" about autism. This mother feels that "*there are very few options*" available to her. Mother D has decided that she will not put her child in a school for autism, as she does not believe her child will develop there. She feels she will be failing as a mother if she did not do what was best for her child's potential. She says: "*I will home school her before I take that step, I cannot.*"

3.4.2.2 Special education

Mother E is of a different opinion about mainstream schooling. She had been advised that her child would cope in a mainstream school, but this mother does not want to send him to a mainstream school. She feels that "*he's going to be a little bit different and, perhaps, he won't have friends there . . .*" and "*he will feel different and I thought it would be nicer for him to go to a special school where he could feel successful . . . [where] everybody's, perhaps, got special needs and he won't feel like he's the odd child.*" Mother E is concerned about her child's emotional and social well being at a mainstream school, but she also believes that he is not at the level to cope in Grade One. She wants to send him to a special-needs school, but not a school for autism, as he is not severely autistic. Mother E believes that the special-needs schools "*tend to want to mainstream the children*" once they had attended a special-needs school. Nevertheless, she is willing to monitor her child's progress and "*if he is flying, then we won't hold him back.*"

3.4.2.3 Summary

All the mothers discussed mainstream schools, but they did not view mainstream schooling as the perfect solution to their problems. The view was that the education was/is lacking. Some of the feelings were that no school catered for these children's needs, as they did not fit a certain category. Some children attended special schools, but no school had catered for their specific needs. It was felt that, in terms of schooling, there were not many options. Although some children on the autistic spectrum attended special-needs schools, the mothers felt that they attended these schools because there was nowhere else for them to go. They perceived the education that was available to children with autism as elitist, unaffordable and unsuitable.

3.4.3 Family life

Having a child with autism affected the families of these children in many ways. From this theme, the researcher identified the following categories:

3.4.3.1 Impact on family life

Mothers C and D felt that the child with autism had a significant impact on family life. Mother C perceived her children with autism as controlling. She viewed autism not only as a disability, but also as a "*very controlling thing in our home environment*". She described it as "[a character] *who controls what we do, no matter how well disciplined* [he is]." They are inflexible and this inflexibility is seen as "*really, really dysfunctional*". Mother D said it took the family a very long time to "*get back to normal*" after an outing. The family could not take the child with autism out in public because "*if anyone looked at her she would scream. Heaven forbid [that] they touched her or came into her space; she would scream.*" This mother experienced this as "*an absolute nightmare.*" The child's behaviour began to split the family, as the mother had to stay at home with the child when the father took the sibling on an outing.

Mother A viewed her child with autism as part of the family just as her other children were part of the family. She felt that her child with autism had just as much right to be there as the other children.

3.4.3.2 Siblings

The four mothers who have typical children, observed that there was an effect on the sibling/s of the child with autism. Mother A believed it had a positive impact, as having a sibling with autism had improved her [typical] son's emotional intelligence. However, she acknowledged that there would have been some negative impact on the siblings, for example, by witnessing the difficult behaviour and the disciplining of the child with autism. However, this mother feels that the siblings had learnt to cope with it. Mother C's concern was: "*Is my [typical] child learning these [autistic] behaviours?*" She imagines that the years after the diagnosis were difficult for her typical child because he needed more from her than she was able to give him. However, this mother also believed that being a sibling to children with autism, *"hasn't taken away from his life".* Her typical child "*went through a very difficult year last year, depression, has dietary issues, all kinds of issues and I just realized I needed to get him away from this constant impact.*" This mother felt that it was her ex-husband's turn to look after their children with autism. She had devoted the past year to her typical child and has seen a marked improvement in him, which she believes is due to him having his own space and having his mother to talk to without interruptions.

Mother D believed her typical child resented the child with autism for dictating where the family could go. She believed that this was "*more than the usual sibling rivalry.*" Mother E said that the relationship between her eldest daughter and her son with autism as difficult. The eldest daughter often resented that her sibling "got away with things" that she could not and that, at times, she would be asked to "give in" to her sibling with autism. The mother maintained that she and her husband "*were very aware of trying to balance it out and explain it nicely to her [so] that she never felt that he used to just get his own way all the time.*" It was difficult for their eldest daughter. Nevertheless, she was very protective of her autistic sibling, which this mother believed had developed due to his special needs.

3.4.3.3 Remediation

Four of the five mothers had employed an outside tutor for home remediation of their autistic children. Three of the mothers found the presence of tutors in the home difficult to adjust to. Mother B described it as a *"big adjustment"* and "*very hard . . . because I wanted the control and I wanted to be able to see what was going on but there was something appealing about dropping him off somewhere and still having my personal space*". This mother adjusted and subsequently coped with having the tutors in her home, but "*that took getting used to*". Mother E said that the presence of the tutors in the home affected family life. She described it as "*quite an overwhelming time where it kind of felt like we lost control over what was happening. Something started taking over, you know. He was in this programme and there were people coming and going and things were happening. So, that wasn't very nice. That was quite a hectic time for us… for me specifically.*"

3.4.3.4 Marital relationship

One of the five marriages failed due to the difficulties of raising a child with autism. Mother C experienced it as a confusing time that affected the marital relationship. She believed that the strain on the relationship was due to both her and her husband "*constantly trying new things*" because nothing was working with the children, "*and eventually you lose faith in each other's . . . ability . . . you just don't stand with each other . . . It just becomes chaos really.*" These parents are now divorced, but are still very involved in each other's lives. Mother C believed that "*We just didn't have what it took to see our way through this journey.*" She felt that her husband was very resentful as "*he just lost me to planet autism*". Mothers A and B had support from their husbands. Mother A saw her husband as very supportive and viewed him as her partner in coping with their child with autism. They are "*in it together*".

Mother B said her husband trusted her to make the decisions concerning their child and that she was happy to take on this role. Mother B felt that having a child with autism has brought her and her husband closer together and strengthened the marriage as they viewed the demands of raising an autistic child as a shared experience. Mother B acknowledged that it could place

stress on some marriages. Mothers D and E had husbands who were somewhat removed from it all. Mother D said that her husband resented her sleeping in her child's bed for half the night. She did this to get her child to sleep and to get some sleep herself. This mother was involved in her child's remediation without her husband's participation. She found this isolation difficult to handle. Mother E maintained that her relationship with her husband had remained the same**.** Her husband "*didn't get too emotional about the whole thing*"; however, she would have liked him to be more emotional. She felt that this would indicate that he was experiencing the same thing as her.

3.4.3.5 Summary
The presence of a child with autism affected family life as the child with autism is controlling and dictates what the family could do and where they could go. Siblings of a child with autism were affected in both positive and negative ways. The positive impact was that they learned to cope with a sibling that has special needs and that their general understanding of people increased. The negative impact was that the siblings resented the child with autism because of the difficult behaviour. In addition, the parents did not discipline the child with autism in the same way they would discipline a typical child. Mothers found the remediation process to be intrusive as they had tutors in their homes and they found it difficult to hand control of their children to these outsiders. A child with autism put the marital relationship under stress. This stress could pull the relationship apart, due to strain and resentment by the husband, or it could bring the parents closer together.

3.4.4 Getting through the day
The mothers had many different ways of getting through the day. These were broken into the categories and sub-categories below.

3.4.4.1 Coping strategies
The mothers had different coping strategies to enable them to get through each day. These coping strategies were (1) information, (2) the process of the child and (3) relaxation.

Three of the five mothers said that gathering information was their coping strategy. Mother A said that educating herself by attending courses and reading extensively had helped her cope on a day-to-day basis. Mother B proactively addressed her concerns. This helped to control her anxiety levels. She involved herself by staying in contact with a professional working in the field of autism and by attending the group meetings of professionals interested in autism. She found the Internet and books to be good sources of information. She accessed the Internet often and read a lot.

Mother C felt that, in the beginning, she was losing time and everyday she was losing her children more. She began reading, researching and educating herself. Subsequently, she taught other people and started a "*mini clinic*" at her home with six tutors. She said she "*researched and trained twenty four seven*". This mother experienced information as her "*absolute saving grace*" and she believes it is "*the core thing*" for every mother with a child with autism. **"***Information helps you deal with your child, it helps you make informed decisions for the future, it helps you with everything.*"

3.4.4.1.2 The process of the child

Mothers D and E found that knowing their children and reading the warning signs were their way of getting through the day. Mother D has learned how to deal with her child. Consequently, she knows that, if she wants to introduce something new or out of the ordinary, she has to prepare her child for the change. Being conscious of her actions has helped this mom get through the day. Since she has become better at reading her child's warning signs, the family are able to do things together. Mother E said that it helped to know when her child was "*going to fall apart*" and then being prepared to manage it. She said that he could be unpredictable and have bad days, but that his behaviour has improved as he has become older. This mother commented on the incomparable joy of hearing her child say, "I love you, Mom" "*unsolicited and unprompted*". Mother C said that, initially, witnessing the progress her children were making was what had enabled her to get through the day. For

mother C, the challenge was trying to reach her children. However, the methods she had used had not accomplished this. She found this heart breaking and exhausting. Furthermore, she commented on the "*immense frustration of not being able to reach your [her] child, not being able to control the tantrum, being helpless in solving the situation*". She viewed this frustration as a key aspect of having a child with autism.

3.4.4.1.3 Relaxation

For relaxation, Mother D had started yoga. She found this was "*extremely calming, centring, [and] a very good thing to do*". Unfortunately, she had to stop going to yoga because her husband was unable to get the children to bed on his own.

3.4.4.2 Support

The majority (4) of the mothers maintained that the support they had received had helped them get through the day. Forms of support were classified as (1) family and friends, (2) faith or belief and (3) positive attitude and acceptance.

3.4.4.2.1 Family and friends

Four of the five mothers had a support system in place.

Mother A's support system consisted of the family, the speech therapist, the facilitator and the remedial teacher. She felt that she could not have coped with her child without the support system. This mother also had a very understanding husband to whom she could talk when she was frustrated or "*down*". She said that her husband was the only other person who understood the responsibility of raising their child and the emotions she feels. They were "*in it together*". Her mother also played a supportive role by helping with the child's homework.

Mother B said that trust and the freedom to make decisions about her son was the support that she had received from her husband. She was the one most affected by these decisions because she spent the most time with her

son. This mother said that the experience of having a child with autism had strengthened the relationship that she had with her husband.

Mother E experienced people as very supportive. The REACH programme was a support for her as it had helped her to make contact with other families and had helped her find a school for her child. As her parents lived in the area, they were able to support and help the family. The paternal grandmother also provided a "*fair bit of support*". This mother thought that it helped to have the support of her faith and her family and believed that coping would be much harder without them.

Mother D believed that she did have a support structure in place unlike some other people. Her mother had supported her from the beginning. Although her father was supportive, he had less understanding of autism than her mother. Until recently, her husband had not been involved with their child or any of the issues regarding their child. This was very difficult for the mother. The father and grandfather were "*extremely offended that this child screamed at them*". They blamed the child for this behaviour, as they had no understanding that there was something wrong. It caused friction when the grandmother questioned Mother D when she disciplined her autistic child differently to her other child. However, the mother knew that her child could not understand her and, therefore, could not be disciplined in the same way as her other child.

Mother C, who did not have support with raising her children with autism, felt very lonely. "*There was no one to really understand or talk to*". She found people, including her family, to be ignorant about autism. What was important for this mother to note was that there had been no one to help her raise her children with autism. She believed that "*obviously [you need] a support system if you want to get through this functionally*". This mother said that the lack of a support system was "*probably one of the hardest things that I had to work through in the last three years of my life*". She was proud that she did not depend on others but believed that it made things dysfunctional. Her parents were not supportive and told her "*God knows who to give it to, so best you take this burden and don't make it ours.*" She has good friends who support

her now. However, she had created an environment where she did not ask her friends for assistance with her children. Her ex-husband supported her in this respect. Two of the mothers mentioned the support of friends as a way of coping.

<u>3.4.4.2.2 Faith or belief</u>
For four of the five mothers, a belief system or faith played an important role in coping with their experiences of raising a child with autism and provided them with extra support.

Mother A had the outlook or belief that you have to believe in yourself and believe in what you are doing. She felt it was also important for a mother to believe in her child. This mother believed in energies that had directed her and her child in the right direction and that things had worked out when they were the right things to have done.

Mother B believed her "*biggest strength*" came from her faith and said it was "*where my peace and my joy and everything would come from*". Mother B said her faith and religion were her main ways of getting through the day and coping. "*I actually went into a place where I was very happy, for the most part and it's only because of my faith."* She commented on her ability to be joyful despite her circumstances.

Mother C saw her faith as an aid to manage raising her children. She repeatedly said that she did not know how she had done it, how she had managed, but that she "*just had faith, absolute faith*". She said that she prayed and that people prayed for her and, "*by the grace of God*", she had made it through. She has "*had the energy*" to cope and lived her life with the attitude that "*today is going to be good".*

<u>3.4.4.2.3 Positive attitude and acceptance</u>
All the mothers were positive. They seemed to have come to terms with the diagnosis and have accepted it.

Mother A viewed the experience of raising a child with autism as a positive experience and as a gift. She believed it was her duty to make the most of her child's life. Her outlook was that her child with autism was part of her family and had as much right as her typical children to be part of the family. She felt that this view had had a positive effect on her younger children who had to learn that "*life hasn't only been for . . ."* them. She and her husband were "*in it together*" and viewed their experience simply as "*this is what we have been given*". This mother viewed this experience as providing her with personal growth and that what she has learnt and accepted was "*enormous*". She believed in confronting the problem and trying her best with what she had. "*I would say you have to find the positives in this because, if you keep looking at the negatives, you are not going to get out of it. You have to find the positives and hold onto those positives otherwise you are going to bring the child down with you*".

Mother C viewed her life as being "*filled with miracles*" and that "*so much of my life is filled with things that I wouldn't have had if it wasn't for . . ."* this experience*.

For Mother E, "*understanding that [he] is exactly who he's meant to be*" and accepting that it was not a mistake, helped her get through the day. She viewed autism as "*not such a big problem*". She acknowledged that "*his moments that he falls apart are terrible*" but generally views him as a likeable, easy child. The fact that she did not struggle with her son daily seemed to have contributed to her positive attitude towards autism. This mother said that it came as a surprise to her to find how positive and rewarding this experience has been for her. She accepted that there are things that she could not predict and that she doesn't know how her child's life would unfold, but her view was to take things as they came and make decisions at that time. Her child had made progress and exceeded their expectations of where they thought he would be. This made it more of a positive experience for this mother.

For Mother B, acceptance of the diagnosis and the treatment process was very important. She believed she had to trust the process and the diagnosis of

autism in order to cope with the treatment, as the treatment could be very hard to bear. "*If you don't buy into autism and you don't buy into how they are going to treat your child, you won't survive. You won't survive that period.*"

Mother D had a positive outlook and believed that "*every step you take is another door to hope*". She was willing to try new things and to see where it led them. She felt that she had "*learnt so much about so many things, that it's quite awesome.*" This mother also believed that a coping tool that she needed to develop was a "thick skin", but that she had not yet done so. This coping mechanism had been suggested to her had experienced critical looks from the public when her child behaved badly.

Mother C said it was difficult for her that "*people just think your kids are naughty because they look normal*" and "*the harder you are trying, the less you are achieving, the more criticism you are getting for being a shocking mom*".

Mother E had also received critical comments about her parenting skills and, before the diagnosis was made, people would blame her and her husband for their child's behaviour.

3.4.4.3 Summary
The mothers got through each day with their child with autism in many ways. Coping strategies for the mothers included providing themselves with knowledge and information about autism. This enabled the mothers to feel proactive and gave them a sense that something could be done. Getting to know their children with autism was a coping mechanism that enabled the mothers to be aware of the stimuli that would trigger their children's aberrant behaviour and how to avoid these stimuli. Additionally, it allowed them to cope with the difficult behaviour when it did take place. The support given to these mothers was significant in getting them through the day. Their families played a large role in the emotional and practical support of the mothers. The mothers' beliefs or faiths gave them strength to get through each day and enabled them to feel that they had been doing the correct thing for their child.

A positive attitude and acceptance of the autism diagnosis were important aspects of getting through the day for these mothers. Acceptance of the diagnosis enabled them to find appropriate interventions and education for their children. A positive outlook urged them forward in their journey to help their children.

3.4.5 The future

The hopes and dreams the mothers had for their children changed after they received the diagnosis of autism. The following categories were identified in this section:

3.4.5.1 Concerns

Three of the mothers were concerned about the future of their autistic children after they had died. Mother D described it as *"fighting the clock"*. Mothers B and E were concerned about their children being stigmatised for being different and that their self-esteem would be affected by this. Mother A's most significant concern about the future of her child was what would happen to her when she leaves school. Two of the mothers had concerns about the immediate future. Mother C was "*absolutely terrified*" by what she had read about the actions of older children with autism, such as masturbating in public or smearing faeces on shop windows. She feared that these *"horrendous things"* would happen as her child got older. Mother E worried about the immediate future. She worried that her child would lose the skills he had acquired and regress from the progress he had made, as "*that would be terrible*". Mother C said one of her biggest fears concerned her typical child; she feared that "*something I have done left him lacking*", because she had focused so much on her children with autism.

3.4.5.2 Hopes

Mother A said she had tried not to have hopes for the future of her child, as they may not materialize. One hope that the mother did reveal was to move into the country with her child to live on a horse farm as the child loved horses. Another hope would be for her other children to take care of the child with autism when she and her husband were deceased . Mother C had the

opposite hope. She said her typical child would *"certainly not look after them [siblings with autism], never ever. That's what we work for."* This mother felt very strongly that her typical child should not have to take care of his siblings with autism if something were to happen to his parents. Her hopes for her children with autism were: "*protected employment, functional group homes where their dignity and their self-esteem and their independence can be maintained and that they can be who they are, but that they are supported.*" Mother C said her children would not live with her as adults because "*no kids should live with their parents*". Mother E was happy for her child to live with her when he was an adult, but she would like him to be able to "*hold down a job, get married . . . I would love to see him thrive as an adult. It would be nice to see that he could live independently and I think that, perhaps, there is a chance that he will*". This mother said she would "*be quite happy to set up a granny flat for him here and he can cook his own meals and I can go and check he turned the stove off*". This mother's hope for her child was for him to know God and serve God. She looked forward to seeing her other children as adults, coping on their own, but for her child with autism, "*I don't have that anymore . . . I don't envision him one day going off and doing his own thing*". Mother E was aware that her child may never live independently without support. This mother had no expectations of her child, she did not "*feel that pressure for him*" but she would like him to reach his potential, whatever it may be. She experiences this viewpoint as "*a nice sort of freedom*". She does not want him to struggle at school and be picked on, therefore, she would rather home school him and have him be happy. Her opinion was that "*it's better that he's happy than that he's well educated*".

Mother B's hope for the future of her child was that the autism would be cured, ". . . *you always wish someone will tell you its over, you know. I think that desire never goes away*". She hoped that his language usage would be on par with that of his peers and that his socialising skills would improve. This mother was concerned about his skills and would "*really like his skills, the very specific skills, language, social skills and academic skills to really stay, at least, kind of, in that range of where he should be*". She wanted him to have good self-esteem and to accept the autism. She wanted him to know that he

is more than the autism and that the autism is just one part of him. The mother acknowledged that building self-esteem is a difficult task for a typical child and accepted that she and her husband had extra work to do. The mother viewed the future as challenging and believed they should take it one step at a time. In the long term, she would like him to be able to study and get a job and to have significant relationships with people.

Mother D wanted her child to be able to cope despite the autism. Her greatest dream was for her daughter to experience love in a family and have her own children. In general, this mother did not look far ahead because she felt that if she had set her hopes too high, she "*set[s] [herself] up for a fall*". Mother D's first priority was to help her child develop her language skills, as her daughter would then be able to communicate her needs. Her next aim was to educate her child "*so she can have a life . . . where she can not be frustrated, embarrassed, shamed by living in the society we live in that expects everyone to meet their stipulation of normality*".

3.4.5.3 Summary

These mothers had similar hopes and fears. They tried not to hope for too much in case they are disappointed and yet, they hoped their children would lead lives where they would be happy, experience love and be secure in who they are. The main hopes were those for employment, independence and relationships. They hoped that their children would be able to cope as adults. The fears and concerns were linked to the hopes that may not materialize. The mothers worried about what would happen to their adult children when they, the mothers, were no longer alive. They were concerned about where their children would get care from when they were adults. Another concern was that society would stigmatize their children.

3.4.6 Challenges

The mothers had experienced many challenges in raising their children with autism. The following categories were identified:

3.4.6.1 Assessment /diagnosis

<u>*3.4.6.1.1 Experience*</u>

The assessment and diagnostic process was challenging for all the mothers. For Mother A, it was a stressful and frustrating time. Mother B found the process challenging as it took time for the diagnosis to be made and for her to become involved in and accept the diagnosis.

Mother D described the experience of the time of diagnosis as "*traumatic*" and said she "*sort of put it back*" in her mind, in a way, repressing the experience. This mother did experience denial during the diagnostic process. She described her experience as "*one of the many times I was sitting in the waiting room of some doctor waiting to be seen with [my child]. I was paging through a magazine and there was this thing about autism and there was this check list - if your child has any of these then maybe you should consider . . . I remember going through that checklist and go 'Oh, that's too close to home', closed it and put it away. I didn't want to think about it.*"

<u>*3.4.6.1.2 Response*</u>

Mother B experienced many emotions in response to the diagnostic process. "*You go from denial to I don't know. The sadness and the anger is all mixed up*". She experienced disbelief, irritation, denial, anger and then acceptance. She said it was reading a book on autism that had helped her to accept the diagnosis. The book was 'Overcoming Autism' (Koegel,L.K. & Lazebnik,C.) and it helped her to start accepting the diagnosis as a reality. When she was willing to "*see the connection*" she said, "*things started to fit*". The acceptance of the diagnosis brought about a mourning period. "*You really do mourn. It's the only way to describe it. You mourn the loss of this idea you had for your child. It's a loss of potential, all these things it's going to mean or might mean for him for the rest of his life and you know that's gone".*

One of Mother C's responses to the diagnosis of autism was to seek information. She became preoccupied with the need to learn about this

disorder. "*There were days I would get in my car and I hadn't driven for, like, three weeks. Just absolutely removed from society, just lived in this little cocoon.*" She thought that this was difficult for her husband and that it affected their relationship. They still discuss it and "*threaten to go for counselling and work through it, because neither of us have gotten over it. We haven't been able to move on.*" She believed that she "*bush whacked my way through my kids for the first three years, I didn't see them, I just was so determined to try and change things for them*". This mother's grieving period started a lot later than that of the others "*because your child looks normal so the grieving process is different*" and her experience was that most mothers felt that if they start to cry, they would not be able to stop. She did not understand the treatment techniques and had *to "be cold and removed because otherwise I was just going to go and fall apart quietly"*. Consequently, she cut off her emotions.

Once the diagnosis had been made, Mother D felt "*shell shocked*" and felt that the information she was getting about autism "*went in only so far*". However, she was glad to receive some information and felt that there was something that she could do. She said she had always been a proactive person and her response was to say, "*tell me what to do and I will move heaven and earth to do it*". It was very important to this mother to know how her child would be treated. The mother felt that her child "*needs to know that you respect her and she needs to be treated like a person equal to you and me. I will not have you treat her as an animal*".

The diagnosis devastated Mother E. She "numbed it out" and took a long time to accept it. This mother had a lot to cope with, as she had a new baby and an older child whom she was home schooling; consequently, she couldn't allow herself to be overwhelmed. She felt she had to keep everything going smoothly otherwise *"the other kids feel it too, they suffer"*. She could not allow herself to fall apart. Mother E struggled for a long time with a sense of loss for the child she thought she was raising. She did not want to look at his baby photos or watch videos of him as a baby because he seemed like a different child to her. It had taken this mother a long time to "*get to the point where*

autism isn't a yucky dreadful word that I can't even say. I think, for a good while, I didn't even want to say the word autistic or autism because these were just such heavy words, big words and they carried such a lot of, they were loaded with fear and whatever else came with it". Mother B also experienced the word autistic to have a horrible connotation and preferred to say she has a son with autism rather than an autistic son. She felt that labelling him as autistic was to say that autistic was all he was.

3.4.6.2 Financial strain

All five mothers agreed that there was financial strain when raising a child with autism. It was described as "*extremely expensive*" and viewed as "*financially . . . a huge burden, it is massive*". Mother C had struggled and had had the feeling of "*how on earth am I going to do this.*"

3.4.6.3 Summary

Receiving the diagnosis that their children have autism was an emotional experience for the mothers. The mothers experienced an array of emotions in response to the diagnosis. They all went through a process of denial and then a mourning or grieving period before they accepted the diagnosis. It was a challenge for the mothers to cope with their children with autism in their lives. The financial strain of raising their children with autism was another challenge experienced by the mothers.

3.4.7 Gaps in service

Each mother had experienced a gap in the service she was provided with while raising her child with autism. The following categories have been identified:

3.4.7.1 Personal needs of parents

Three mothers mentioned the lack of support for parents. Mother B was considering starting a support group as she felt that mothers sometimes needed to talk about what was hard for them.

The lack of government funding for special needs was a burden all these parents experienced as raising a child with autism was financially draining. Mother C believed that "*you either have the financial resources to do it or you don't and for the people that don't have the financial resources, there are no options*". She thought that it would be good if there were more state-provided options.

Mother B mentioned the gap between the number of people trained to work with children with autism and the number available. She viewed this as one of her biggest issues. She had been without a tutor for her child for six months, as there were insufficient trained people. She felt there was a need for someone to be in charge of providing parents with tutors.

Mothers C and D commented on the differences of opinion about autism held by professionals and medical doctors. Both these mothers felt that the medical profession did not listen to parents. Mother C perceived the doctors as "*so scared to tell you this and you actually know there is something wrong and they just don't go, this is what it is.*" She felt that it was best for the medical profession to be open with parents about what was wrong with their child so that time was not wasted. Mother D agreed and felt it was better for the professionals to be up-front about the diagnosis.

Mother E said that insufficient treatment options were available to her. She would have liked to have had the option of choosing a programme that suited her. She viewed herself as "*quite a nurturing kind of mommy*" and had found it difficult to witness the applied behavioural treatment because the therapists had forced her child to do things while he screamed. The mother believed that there was a lack of choice in remediation programmes in this country.

3.4.7.2 Parents' needs for their children with autism
The respondents said that the education available to children with autism was elitist unaffordable. There were very few choices of schools for children with autism as mainstream schools were not suitable for most children with autism. "*Schooling is a massive issue*" for four of the five mothers. These mothers felt

that "*if they are remediated and they have the potential, they need something between [a school for autism] and a regular school, there needs to be something . . . where they can learn in a different way and if they want to transition to mainstream school, cool. They can't go straight from remediation into mainstream school. There needs to be some sort of bridging school*."

Another concern of the mothers was the lack of options available to adults with autism. Mother C wanted there to be a place where "*children who do not have a supportive family, when they are adults, are able to be cared for in an environment that doesn't threaten them, that doesn't send them round the bend with expectations*." Mother C said there were no options for children with autism when they became adults, but that she would get involved and create something for her children and those that follow.

3.4.7.3 Summary
According to the mothers, there were gaps in the services available to them in this country. There was little support for parents of children with autism and there was no government funding available to support those parents who were not able to cope financially. The treatment options and number of people trained to work with children with autism were limited. The parents found that very few schools were appropriate for their children with autism and the options available to these children when they become adults were very limited if not non-existent.

3.5. CONCLUSION
This chapter describes the data collection procedure by explaining the context and purpose of the data collection. The research design, sampling plan and the research respondents are described. The chapter goes on to describe the data collection procedures and the steps followed. The data analysis process, the analysis and the interpretation of the data are included in this chapter. In chapter four, a literature control is conducted in order to review the literature on parents raising a child with autism in more depth to compare the literature with the findings of this chapter.

Chapter Four

PARENTS RAISING A CHILD WITH AUTISM – LITERATURE CONTROL

4.1 INTRODUCTION

The data that was collected are presented and analysed in chapter three. In this chapter, a literature control is conducted in order to review current literature on parents raising a child with autism in more depth to compare the literature with the findings of chapter three.

This literature control is done according to the themes and categories that arise from Chapter three, namely, (1) health professionals, (2) school experience, (3) family life, (4) getting through the day, (5) the future, (6) challenges and (7) gaps in service.

4.2 HEALTH PROFESSIONALS

4.2.1 Search for diagnosis

In this study, the search for a diagnosis by the respondents was experienced as frustrating as the diagnosis took a long time due to many assessments and many long waiting periods between the assessments. A study in Belgium found that parents waited more than two years for a diagnosis and this was thought to be too long. These parents were dissatisfied with the diagnostic process (Renty & Roeyers, 2006: 382). Cosser (2005: 116) found that parents experienced a period of uncertainty before the diagnosis was made; there were many years between the initial visit to a health professional and the formal diagnosis being made. The time between the initial visit and the formal diagnosis ranged from 2 years to 9 years. In Cosser's (2005: 118-119) study, it was found that parents were frustrated by having to see many health professionals, spending money and then the professionals could not help. Siklos and Kerns (2007:11) stated that *"During the long and stressful diagnostic process, parents typically see several professionals and are often told to 'wait and see' whether the child is going through a phase, or is truly developmentally* delayed" (Siklos & Kerns, 2007: 11). Most parents were dissatisfied with the diagnostic process, reported high levels of stress

associated with the diagnosis and were significantly dissatisfied with the services they had received, as there had been long waiting lists and specific criteria required for eligibility of services (Siklos & Kerns, 2007: 19).

Siklos and Kerns (2007: 10) attribute the delay in obtaining an early diagnosis to: (1) the variability of autism in different children, (2) the limitations of the assessment, which includes the lack of assessment measures for preschool children, the limited time available for assessment, no assessment taking place across time or in a range of environments, and reliance on parent reports, (3) insufficient specialized training of professionals to recognize the early signs of autism and (4) a shortage of specialized services. It was found that "*parents of children with ASD* [Autism Spectrum Disorder] *experience significant hardships in attempting to obtain a diagnosis for their child*".

Rahi, Manaras, Tuomainen and Hundt (2004: 477) list the following needs of parents during the diagnostic process: (1) the need for information in general, (2) the need for information about education and social services, (3) the need for emotional support from professionals, (4) the need for social networks, and (5) the need for support groups. They recommend key workers to assist parents with these needs.

4.2.2 Doctors interactions with parents

In *this study*, the doctors were viewed as unable to assist the mothers with an understanding of what was wrong with their child or to give a diagnosis. The attitudes of the doctors were interpreted as unhelpful and dismissive. In Cosser's (2005: 116) study, some parents felt that doctors implied that the child's problems were due to poor parenting. Parents took offence to the attitude of the health professionals (Cosser, 2005: 118-119).

Family physicians, general practitioners and pediatricians are often the first point of contact when parents have concerns about their child (American Academy of Pediatrics, 2001:1221). *"The family physician can play an important role in detecting autism early, coordinating its assessment and treatment, counseling the parents and classroom teacher, and monitoring the*

child's progress on a long term basis" (Karande, 2006: 205). Early diagnosis is important, as it has been found that there are improved outcomes with early implementation of consistent and appropriate intervention (American Academy of Pediatrics, 2001: 1224).

> The need for early intervention also speaks to the importance of knowledge of the behaviours associated with the condition to better recognize a threat of a child potentially being diagnosed with autism. Waiting six months or a year before obtaining awareness and engaging in a treatment behaviour could seriously hinder the development of the child. (Fortunato, Sigafoos & Morsillo-Searls, 2007: 95).

4.3 SCHOOL EXPERIENCE

In this study, the parents found schools available to the children with autism were few and not particularly suited to their children with autism. Education that was available to children with autism was perceived as elitist, unaffordable and unsuitable. In Renty and Roeyers' (2006: 382) study, many parents experienced difficulties obtaining support, information and education for their children. Generally, the choice of education for a child with autism is home schooling, special schools, or inclusive or mainstream schooling. It is suggested that the choice of schooling depends on the child's functioning and the parent's aspirations. (Narayan, Chakravarti, David & Kanniappan, 2005: 365). It was found that the majority of parents want to send their children to suitable schools instead of home schooling them, but they were dissatisfied with the existing schools. Home schooling was found to improve the children with autism, but it caused stress to the parents. Many parents send their children to private schools, as the class sizes are smaller (Cosser, 2005: 157).

4.3.1 Mainstream education

Mainstream schooling was discussed by all the mothers in this study but they did not view mainstream schooling as the perfect solution. The view was that the education available to their children was inadequate. Some feelings were

that there was no school that catered for these children's needs, as they did not fit a specific category.

Chamberlain, Kasari and Rotheram-Fuller (2007: 239) found that children with autism in mainstream schools are less accepted by their peers and have fewer reciprocal friendships. However, children with autism reported similar levels of closeness, security and conflict as their peers and did not experience greater loneliness. Despite being less accepted, they are not seen as isolated. It appears that active efforts by teachers and parents can improve social networking.

4.3.2 Special education
In this study, some children had attended different special schools, but no school had catered for their specific needs. It was felt that, in terms of schooling, there were not many options. Although some children on the autistic spectrum attended special-needs schools, the mothers felt that they attended these schools because there was nowhere else for them to go.

Renty and Roeyers (2006: 382-383) found that parents were dissatisfied with the accessibility of appropriate support and education. The parents experienced long waiting lists and limited special schools. However, parents were more satisfied with the support and services received at special schools than mainstream schools, as many mainstream schools were found to be ignorant about autism.

In Cosser's (2005: 159) study, it was found that some parents were against placing their child in a special-needs school as it may highlight their problem and, once placed in a special school, they may never move to a mainstream school.

Nachshen and Minnes (2005: 901) suggest a family-centred service delivery, which encourages empowerment.

In the education system, this means providing parents with clear messages regarding the school goals, clarifying the parents rights and responsibilities, including the parent in planning and decision making, respecting their knowledge as caregivers and supporting their hopes for their child.

4.4 FAMILY LIFE

Parents' roles have expanded to include the jobs of information seeker, problem solver, committee member, public educator, political activist and, most importantly, spokesperson for the needs of a child who may be unable to communicate his or her own needs to those in power (Nachshen & Minnes, 2005: 899).

Families with a child with a developmental disability cannot be assumed to be maladaptive simply due to increased parental demands (Nachsen & Minnes, 2005: 901).

4.4.1 Impact on family life

The child with autism has an impact on the family. Faux and Nehring (2007: 91) state that *"there is a long-held popular belief that having a child with an I/DD* [Intellectual and developmental disabilities] *is a universally negative event, leading to long-term parental suffering (i.e., chronic sorrow) and negative emotional and psychological sequelae for other family members"*.

Cosser (2005: 121) found that the family's daily routine needs to be adapted, as a child with a disability takes up more time than a child without a disability. This was experienced in *this study* by Mother C who perceived her children with autism as controlling.

"Raising a child with ASD [Autism Spectrum Disorder] *can impose a great deal of stress on the entire family"* (American Academy of Pediatrics, 2001: 1224). Parents of children with autism reported high levels of stress and

aggravation, markedly higher than parents of children without special needs. Parents of children with autism face unique stressors and may benefit from family-centred treatment (Schrieve, Blumberg, Rice, Visser & Boyle, 2007: 120-121). Mothers of children with an intellectual disability experience psychological distress and social disruption due to social deprivation and the child's emotional and behavioural difficulties (Emerson, 2003: 397).

Mothers experience many demands, including time demands and lack of time for social and recreational activities (Van Riper, 2007: 124). Working mothers raising a child with a disability have less time for personal care and leisure than mothers raising a typical child (Brandon, 2007: 677). Mother D experienced this in *this study* when she was no longer able to attend yoga classes due the needs of her child with autism. Potential health consequences caused by the lack of time for recreation and physical activities are hypertension, coronary heart disease and depression. Decrease in personal care time and time for socializing and leisure directly affects the mother's sense of control over her life (Brandon, 2007: 669).

The child with autism sometimes splits the families up; the child "*acts as another wedge separating these families from normal family life*". (Glass, 2001: 130) Family activities have to be carefully planned around the child with a disability (Cosser, 2005: 121). In *this study,* Mother D said it took the family a very long time to "*get back to normal*". The child's behaviour began to split the family, as Mother D had to stay at home with the child when the father took the sibling out.

It was found in Glass's (2001: 132) study that families viewed their child with autism as different to the family, as an extension of the family rather than part of the family, while in this study*,* Mother A viewed her child with autism as part of the family.

4.4.2 Impact on siblings
In this study*,* it was found that the siblings of a child with autism were impacted in both a positive and a negative way. The positive impact was that

they learned to cope with a sibling who has special needs and their general understanding of people was increased. The negative impact was that the siblings resent the child with autism.

Having a brother or sister with a disability does not inevitably lead to poor adjustment in siblings (Cuskelly & Gunn, 2006: 924). In a study of siblings of Down Syndrome children, the following was found:

> Being the sibling of a child with Down Syndrome does not appear to have a negative impact on either problem behaviours or self-perceptions of competence and these brothers and sisters of a child with Down Syndrome do not seem to be penalized in their opportunities to participate in a normal childhood (Cuskelly & Gunn, 2006: 924).

In contrast, a study by Giallo and Gavidia-Payne (2006: 942-945) found adjustment difficulties, emotional symptoms and peer problems in the siblings of children with a disability. Positive family experiences play a more significant role in sibling adjustment than the sibling's own experience of stress. Parental stress was found to be a strong predictor of sibling adjustment difficulties and there is a relationship between parental emotional functioning and sibling adjustment. It is suggested that better adjustment can be fostered by the use of routines, family activities and positive experiences and effective communication and problem solving.

There are pressures on the parents' time that lead to less time to spend with their spouses and other children, which has an impact on the siblings of the child with autism (Williams & Wishart, 2003: 295-296). Parents of children with a disability feel as if they have to be two different people. They have to respond differently to their child with a disability than to their typical child (Cosser, 2005: 122-123). Parents feel that they have to treat their child with a disability differently to their typical child and this can sometimes cause sibling rivalry and have an impact on the siblings. However, the parents have also

experienced their typical child being protective of their sibling with a disability (Cosser, 2005: 150-157).

4.4.3 Remediation

In this study, it was found that the remediation process was difficult for the mothers as they had tutors in their homes and had to hand their children and the control of the children over to these tutors.

> In applied behaviour analysis interventions, students are active participants in their learning. Procedures within the applied behaviour analysis approach include the use of response prompts to evoke target behaviours in the presence of relevant stimuli. Correct responses by the child are reinforced with preferred objects or activities, so as to increase the behaviour. Applied behaviour analysis treatments often involve structuring the learning environment to create frequent opportunities for the child to respond (Fortunato *et al.*, 2007: 93).

Applied Behaviour Analysis is found to be most effective when it (1) begins early, from the age of 2 or 3 years old, (2) is intensive [40 hours per week] and continues for 3 to 4 years, (3) encompasses most of the child's day, and (4) addresses the child's entire behavioural range (Fortunato *et al.*, 2007: 94).

Schwichtenberg and Poehlmann (2007: 603) found that the intensity of Applied Behaviour Analysis (ABA) related to maternal depression and strain. Families participating in ABA were found to experience elevated depressive symptoms much like any family with a child with autism. Mothers reported fewer depressive symptoms when their child with autism had more hours of ABA therapy per week. However, those mothers who themselves spent more hours per week involved in the ABA programme reported higher personal strain levels. These findings imply that intense programmes for children with autism that do not rely on mothers as therapists are superior to those that involve the mother as a therapist.

The drawback of the programme was found to be the pressure on the parent's time, but the benefits were that the parents felt more positive emotionally, the family life was happier and "positive family experiences of involvement were found to be related to a high level of perceived efficacy of the programme" (Williams & Wishart, 2003: 295 - 297).

4.4.4 Marital relationship

In this study, it was found that the marital relationship was put under stress and could be pulled apart due to strain and resentment by the husband. Alternatively, the experience of raising a child with autism could bring the parents closer together.

It was found by Kersh, Hedvat, Hauser-Cram and Warfield (2006: 883) that the marital relationship is important to parental well-being and parental well-being is important to a positive family climate. Marital quality is said to predict the mental health of the parents and parenting stress levels (Kersh *et al.*, 2006: 889-890). The child's behaviour is a critical predictor of parental well-being and behaviour problems are associated with parental stress and efficacy. The findings suggest that "*mothers derive self-evaluations of their parenting, in part, from a supportive marital relationship*". Glass (2001: 123) states that spousal support plays a large role in the stability of the family.

> The sharing of parental duties, spousal communication about their feelings concerning their autistic child, a mutual respect for one another, and the acknowledgement of each other's daily accomplishments clearly allow a pathway for proper family development. (Glass, 2001: 126)

In Cosser's (2005: 147-149) study, it was found that there was conflict between spouses, due to frustration about the one parent not being as involved with the child with a disability as the other parent. One parent felt that he or she had to deal with the situation alone. This was expressed in this study as well. Some mothers expressed the opinion that having a child with a disability was very difficult for a marriage and put a marriage under 'extreme

pressure'. In this study, it was also said that the experience could bring parents closer together.

4.5 GETTING THROUGH THE DAY

4.5.1 Coping strategies

Quality of life is relevant to conditions such as autism where the level of autism is chronic and impairs the lives of the child and the family (Mungo, Ruta, D'Arrigo & Mazzone, 2007: 2). Quality of life is defined by the World Health Organisation as:

> Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad concept incorporating the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment. (Mungo *et al.*, 2007: 2)

Parents of children with pervasive developmental disorders were found to have had significant impairment of quality of life compared to parents of children with mental retardation or cerebral palsy. It is thought that the lower quality of life is due to the greater stress and burden of having a child with a severe developmental disorder who displays difficult behaviours and the strain of not being able to understand the child. Parents were found to experience heightened stress, impaired mental health, self-blame, weakened physical functioning, and tiredness. There are financial strains, difficulties in obtaining a diagnosis, stressful experiences with professionals, problems associated with school, ineffective services, unmet needs and concerns for the future. These stressors can be moderated by factors such as socio-economic status, social support, parental and child characteristics and coping strategies (Mungo *et al.*, 2007: 2-6).

Dunn, Burbine, Bowers and Tantleff-Dunn (2001: 49-50) agree that social support and coping style moderate stressors. The most effective styles of coping are said to be positive reappraisal and confrontive coping. Positive reappraisal involves personal growth, finding new faith and rediscovering important things in life. Confrontive coping involves fighting for what one wants and expressing emotions in appropriate ways.

4.5.1.1 Information

In this study, a coping strategy for the mothers was providing themselves with knowledge and information about autism This enabled the mothers to feel proactive and gave them the sense that something could be done.

A coping strategy for some parents, in Cosser's (2005: 117) study, was to gather information, read and learn about their child's disability. *" . . . Some parents may be coping with the challenge of parenting a child with autism by seeking knowledge about the disorder*" (Kuhn & Carter, 2006: 569). Mothers who were more active in their child's development were found to have a greater knowledge of autism, which suggests that seeking information and being proactive in the treatment of the child may go hand-in-hand. The mothers who reported being more active in their child's development experienced the feeling of higher maternal self-efficacy. *"Active coping strategies are generally thought to be more positive ways of dealing with stressful events as an individual attempts to change the nature of the stressor or how one perceives the stressor"* (Tway, Connolly & Novak, 2007: 258). Later in this chapter, the way the mothers perceived stressors will be discussed further.

4.5.1.2 The child's process

In this study, mothers found that getting to know their children with autism was a coping mechanism. This coping mechanism enabled the mothers to be aware of the stimuli that would trigger their children's behaviour and how to prevent difficult behaviour from happening, as well as coping with the difficult behaviour when it took place. Nothing was found in the literature about

parents knowing their children and making use of this as a coping mechanism, so this can be viewed as a new finding for coping mechanisms.

4.5.1.3 Relaxation

One mother in this study mentioned relaxation, in the form of doing yoga, as a coping mechanism. However, a mother raising a child with a disability has less time for personal care and leisure than a mother raising a typical child. There are potential health consequences to the lack of time for recreation and physical activities (Brandon, 2007: 669). The mother in the study was unable to continue with yoga due to the need to care fore her child with autism. No other literature has found that indicates that parents use relaxation as a coping mechanism, but the literature does support the health benefits of recreation and physical activity (Brandon, 2007: 667-669).

4.5.2 Support

In this study, the support the mothers received was a significant contributor to getting through the day. Family played a large role in providing emotional and practical support. Support of caregivers to children with autism is essential as the stress on families with a child with autism is significant and chronic (Tway et al. 2007: 257).

4.5.2.1 Family and friends

It has been found that parents of children with autism are resilient and adapt to raising a child with autism. Van Riper (2007: 124) agrees that many families are able to respond to the challenge of raising a child with a disability. With resilience and adaptive functioning, *"they are able to endure, survive, and even thrive in the face of ongoing challenges associated with raising a child"* with disabilities. Social support received from family and friends was found to be a large part of coping strategies. (Tway *et al.* 2007: 257) Dunn *et al.* (2001: 48) found that higher levels of social support resulted in fewer marital problems.

In Cosser's (2005: 187) study, a parent said, *"Having a support system is vital"*. Some parents found that the relationship with their spouses was a good

support system and stated, "*you have to have a very strong relationship to live through this*" (Cosser, 2005: 148).

Some experienced the extended family as supportive; others said it was stressful when the extended family was critical of the parents' parenting skills (Cosser, 2005: 152-153). Glass (2001: 127-128) found that the extended family more often than not did not provide respite support and were uncomfortable around the child with autism. The parents felt that they were imposing on the extended family.

It was found that the severity of the child's symptoms coupled with the parent's perceived social support and self-esteem predict the stress levels of the parents. The stigma attached to autism and the lack of understanding by the public also put parents under stress (Ming, 2006: 47-49).

4.5.2.2 Faith or belief

In this study, the mothers' beliefs or faith gave them strength to get through each day and enabled them to feel that they were doing the correct thing for their child. In a longitudinal study of coping over time, it was found that, for many parents, their faith or beliefs and emotion-focused strategies helped them cope. Their coping with autism changed over time; there was a shift away from problem-focused coping to emotion-focused coping. The reliance on service providers declined and the importance of faith or belief and strategies, such as appreciating the positive qualities of their child, increased. (Gray, 2006: 970). King et al.,(2006: 359) found that parents' faith or beliefs adapted over time and some parents found their values and priorities changed frequently. The experience of having a child with a disability spurred these parents on to examine their beliefs.

> It is important for parents to be clear about their values because these are linked to their priorities for their child and thereby to (i) the supports and opportunities they provide or seek for their child; and (ii) the goals they have with respect to therapeutic intervention (King *et al.*, 2006: 359).

Values and priorities help parents to feel in control of the choices they have made and provide a rationale for the decisions they are required to make. Parents have found that having a child with a disability has strengthened their values and broadened their world-views. The parents feel that their understanding of societal issues has increased and the experience of raising a child with a disability has strengthened their values (King *et al.*, 2006: 359-361).

4.5.2.3 Positive attitude and acceptance
In this study*,* a positive attitude and acceptance of the diagnosis of autism proved to be an important aspect of getting through the day for the mothers. Accepting the diagnosis enabled them to find appropriate intervention and education for their children and a positive outlook was what urged them on in their journey to help their children.

It was found by Ming (2006: 50-54) that parents' self esteem had a significant impact on their level of stress and natural and genuine positive emotions predicted more psychological well-being. Positive emotions are necessary for improving social competence and increasing interpersonal benefits such as relationship satisfaction. It was found that the parents' ability to cope with chronic stressors rely on the ability to experience positive emotions. Positive emotions build psychological resilience. *"When one experiences more pleasure amidst pain, frustration and long term demand, they find more meaning for the struggle. In turn it can sustain their morale and shore up their continued coping"* (Ming, 2006: 53). Tway *et al.* (2007: 257) agree that maintaining a positive outlook is key to resilience.

Van Riper (2007: 124) found that most parents expressed positive responses regarding coping and expressed positive consequences of raising a child with a disability. This may be linked with redefining or reframing how they view their lives. Tunali and Power (2002: 32) found that *"mothers respond to the uncontrollable stress of raising a child with autism by redefining what constitutes the fulfilment of various human needs and/or finding alternative ways to fulfil them".* Less emphasis is placed on having a career and more on

parenting. Less emphasis is placed on the opinions that others have of their children's behaviour, and more emphasis is placed on parental roles and support from their spouse. This reframing of what is important in life has lead to greater life satisfaction. According to Tway *et al.* (2007: 257), reframing the stressors in a positive way can help with finding solutions.

4.6 THE FUTURE

4.6.1 Concerns

The fears and concerns found in this study were that the mothers worried about what would happen to their adult children when the mothers were no longer alive. They were concerned about the care their children would receive as adults and they worried that their children would be stigmatized by society. Ethier (1999: 109-112) found that parents are concerned about the peer relationships that their child will have and Cosser (2005: 178-179) found that parents are concerned about their child having self-esteem problems.

Parents experience thinking about the future as difficult as they have many concerns. The parents are concerned about what will happen when they are no longer able to care for their child, as they see the future as involving some form of care for their child (Glass, 2001: 123) and are concerned about their child not receiving support (Ethier, 1999: 109-112). The parents are concerned about the quality of life of the child with autism. The parents also have financial concerns and concerns regarding the siblings of their child with autism; they worry about them being resentful (Glass, 2001: 123). Other parents are concerned for their child being on their own without a caring environment around them (Cosser, 2005: 178-179) and the risks associated with their child being independent (Ethier, 1999: 109-112).

4.6.2 Hopes

It was found in this study that the mothers' hopes and dreams changed for their children when they received the diagnosis of autism. The mothers tried not to hope, as they feared disappointment. Their hopes were that their

children would lead lives where they were happy, that they would experience love and would be secure in who they are.

Hope is important for families with a child with autism. "*Hope involves having a vision of the future, which provides the family with a sense of direction in terms of the steps that can be taken to move towards that possibility*". New dreams are needed to replace the lost dreams (King *et al.*, 2006: 359). Ethier (1999:109-111) found that the parent's hope for their child with a disability is far less than it was before the diagnosis was made. Parents hope that their child will learn to read and no longer hope for their child to go to university. They hope that their child will move towards independence as far as he is capable. Some parents have hope for love, marriage and children for their child with autism, but it is seen as a dim hope (Glass, 2001:121). Some parents hope that their child will have an education and find a job, but most parents seem to want their child to be happy and be loved (Cosser, 2005: 180-183).

4.7 CHALLENGES

4.7.1 Assessment and diagnosis
In this study, the mothers experienced receiving the diagnosis that their children have autism as an emotional experience. The mothers experienced an array of emotions in response to the diagnosis and all went through a process of denial and then mourning, or a grieving period, before they accepted the diagnosis. It was a challenge for the mothers to cope with their children with autism within their lives.

In the study done by King *et al.* (2006: 358), the initial reaction of parents to their child's diagnosis was that it was life changing, unplanned and it meant that the parents had to give up the hopes and dreams that they had had for their child. They felt that they needed to grieve the lost dreams. Parents experience grief and loss, which can lead to depression or trigger personal growth. The parents describe it as mourning for the hopes and dreams for the child (Glass, 2001: 121). It was experienced as the loss of the ideal child, the

person that he could have been (Cosser, 2005: 130). The grieving process was explained as mourning for that child that one thought one was going to have (Cosser, 2005: 140).

"*Hearing and dealing with the diagnosis was still emotionally and intellectually difficult*". It was described as a shock, overwhelming and the end of the world. Others had a sense of relief and sense that something could be done now that they knew what it is (Cosser, 2005: 117).

Parents experienced conflicting emotions such as joy and sadness. Parents need to embrace this paradox for psychological well-being, as it provides parents with hope, optimism and personal growth (Van Riper, 2007: 124). Parents experienced personal growth, which involved greater understanding of their self and acquiring new skills or virtues. Part of the personal growth was learning what the important things in life are and finding joy in small things. The parents' priorities changed from wanting and needing to 'fix' their child, to focusing on what their child was able to do and accepting him for who he is (King et al, 2006: 361-362).

The parents sometimes felt that others were blaming them for their child's difficult behaviour, or perceived the child's behaviour as a reflection of their parenting abilities (Glass, 2001: 133). Cosser (2005: 124-126) also found that parents felt people blamed them for their child's behaviour and some parents even blamed themselves before receiving the diagnosis. A parent of a child with a disability said that she resented her child, because nothing she did made a difference (Cosser, 2005: 127). Some parents expressed feeling very alone and isolated. They had difficulty taking their children out of the home because of their difficult behaviour and some parents experienced being ostracised (Cosser, 2005: 128-130).

The response of some parents to the daily challenges associated with the diagnosis was anger.

Obtaining services for their child is a daily struggle. Rejection by society, the school system, their neighbourhood and in some cases, their families fuel their anger. For the most part their anger is directed toward the doctors who offer no treatment, the school system that offers no services, autism itself, or other people (Glass, 2001: 130-131).

4.7.2 Financial strain

In this study, it was found that having a child with a disability required more monetary resources than a typical child and some families could not afford everything on offer for their child with a disability. The disability is experienced as a financial burden and "extremely expensive" (Cosser, 2005: 121-122). It was found that families with an intellectually disabled child were significantly economically disadvantaged in comparison to those families with a child who did not have an intellectual disability (Emerson, 2003:385).

Socio-economic deprivation is associated with poorer psychological outcomes for mothers with children with a disability. The association between the child's emotional and behavioural difficulties and maternal distress appeared to be moderated by socio-economic status (Emerson, 2003: 397). This implies that families who are struggling financially, will have higher stress levels and families who cope with the financial strain due to a higher socio-economic status, will have lower levels of stress.

Some families experience the cost of the applied behaviour analysis programme as a financial burden and some have mortgaged their homes and borrowed money in order to alleviate the financial strain. Some parents have struggled to place their child in a suitable school and have had to place their child in a private school, which adds to financial pressure (Glass, 2001: 126-132).

4.8 GAPS IN SERVICE

In this study, it was found that there were gaps in the services available to parents of children with autism in this country. There was little support for

parents of children with autism and there was no government funding available to support those parents who were not able to cope financially. The treatment options and number of people trained to work with children with autism was found to be limited and the parents found that there were very few schools that were appropriate for their children with autism to attend. The residential or care options available to these children when they become adults was very limited, if not non-existent.

In the literature, is was found that many parents experience dissatisfaction with the diagnostic process and with their interactions with the professionals (Cosser, 2005: 118-119; Renty & Roeyers, 2006: 382; Siklos & Kerns, 2007: 11). The diagnostic process is thought to take too long and professionals do not have sufficient training to enable them to identify the early signs of autism.

The literature identified a gap in service that confirms one of the gaps found in this study, that is, the lack of appropriate schooling for children with autism. The services and support provided by schools was seen as inadequate and insufficient (Cosser, 2005: 159; Narayan et al., 2005: 365; Renty & Roeyers, 2006: 382).

4.9 CONCLUSION

This chapter compared the literature on parent's raising a child with autism with the collected data presented in chapter three. The findings in chapter three, for the most part, are confirmed by the literature quoted in the literature control in this chapter. There are some findings in chapter three that are neither confirmed nor denied by the literature because no information was found to compare it to. The following chapter will discuss the overall findings of this study and the implications these findings have for further research and implementation in the field.

Chapter Five
RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

In this chapter, the researcher once again highlights the aim and objectives of this study, discussing whether they were attained and relevant. The researcher will also draw conclusions from the research into parents raising a child with autism and provide relevant recommendations.

5.2 SUMMARY OF RESEARCH

The mothers of children with autism discussed seven areas. The areas were: (1) Health professionals, (2) School experience, (3) Family life, (4) Getting through the day, (5) The future, (6) Challenges and (7) Gaps in service.

The mothers experienced the interactions with the health professionals as frustrating because the diagnosis took a long time. This was due to the many assessments and the long waiting periods between the assessments. The mothers' experiences of the doctors were that the doctors were unable to assist with an understanding of what was wrong with their child, or to provide a diagnosis. The attitudes of the doctors were perceived to be unhelpful and dismissive.

When questioned about schooling for the child with autism, all the mothers discussed mainstream schooling, but they did not view mainstream schooling as the perfect solution. The view was that the education available to their children was lacking and it was felt that, in terms of schooling, few options were available. Education that was available to children with autism was perceived as elitist, unaffordable and unsuitable.

The presence of a child with autism affected family life as the family experienced him as a controlling force within the family. The siblings of a child with autism were affected, positively, by learning to cope with a sibling that has special needs and thereby increasing their general understanding of

people and negatively, in that the siblings resented the child with autism because of the difficult behaviour they presented. Mothers found it difficult to cope with the remediation process and the presence of tutors in their homes. In some families, the autistic child put the marital relationship under stress or the relationship was pulled apart due to strain and resentment by the husband. In other families, the parents were brought closer together.

When questioned about ways of getting through the day, the mothers had many different notions. Information and the acquisition of knowledge about autism were used as a coping strategy that enabled the mothers to feel proactive and to have a sense that something could be done. A second coping strategy was getting to know their child with autism. This enabled the mothers to be aware of the stimuli that would trigger their child's behaviour, how to prevent difficult behaviour from happening and coping with the difficult behaviour when it did take place. Support, belief or faith and a positive attitude were all significant tools used by these mothers for getting through the day.

When discussing the future, the mothers had similar hopes and fears. The hopes were for employment, independence and relationships. The fears were regarding the child with autism as an adult. They were concerned about who would care for their children when they are adults. Another concern was that society would stigmatize their children.

The challenges experienced by the mothers were many. Receiving the diagnoses that their children were autistic were emotional experiences for the mothers; they experienced an array of emotions in response to the diagnoses. They all went through a process of denial and then a grieving period before they accepted the diagnoses. It was a challenge for the mothers to cope with their children with autism within their lives. The financial strain of raising their children with autism was another challenge experienced by the mothers.

The identified gaps in service were: little support for parents of children with autism; no available government funding to support those parents that were

not able to cope financially; limited treatment options and number of people trained to work with children with autism; very few schools that were appropriate for their children with autism to attend; and, the options available to these children when they become adults were very limited if not nonexistent.

For the researcher, the value of this research lies in the parents' voices being heard. These parents were given the opportunity to express their needs and these needs will be relayed to those interested in working with children with autism and their parents.

5.3 AIM AND OBJECTIVES

5.3.1 Aim

As stated in chapter one, the aim of the research was to conduct a needs assessment of parents of children with autism to give professionals information that will help in improving service delivery to parents. This needs assessment was conducted by means of semi-structured interviews and the findings of the needs assessment are presented in Chapter three. The needs assessment offers professionals, working with children with autism, a glimpse into the lives of the parents raising these children and the difficulties they face. This aim was reached by focusing on various objectives.

5.3.2 Objectives

The objectives of this research study were exploratory and descriptive. The researcher used the objectives to gain an understanding of autism, parents' experiences of raising a child with autism and to identify what was lacking. These objectives and the way they were reached are discussed below.

Objective 1

A preliminary literature review will be conducted before interviewing parents of autistic children.

The researcher carried out a literature study that served as a conceptual framework on autism and parents' experiences of raising a child with autism. In conducting this literature study, the researcher found there to be extensive literature on autism, but limited academic or scientific literature on parents' experiences of raising a child with autism.

Objective 2

To explore, through semi-structured interviews of parents of children with autism, the parents' needs and perceptions of raising a child with autism.

The researcher conducted five interviews of mothers of children with autism. The interviews were semi-structured, revolving around five areas: (1) health professionals, (2) school experience, (3) family life, (4) getting through the day, and (5) the future. Two new areas of significance arose from the interviews. These were (1) challenges, and (2) gaps in service. Through these semi-structured interviews, the researcher was able to gain an understanding of the needs and perceptions of parents raising a child with autism.

Objective 3

To describe the needs of the parents of children with autism.

The researcher analysed each semi-structured interview and presents the findings in Chapter three. To analyse the semi-structured interviews, themes, categories and subcategories were identified. The researcher compared these themes, categories and subcategories extracted from each semi-structured interview and summarized the findings. These findings describe the needs of parents raising a child with autism.

Objective 4

Based on the outcomes of the study, the researcher will make recommendations to parents of children with autism and to professionals who work with children with autism.

Recommendations that have arisen from this study are discussed under 5.4.2.

5.4 SHORTCOMMINGS AND RECOMMENDATIONS

5.4.1 Shortcomings of the study

A small sample (five mothers) was interviewed. Saturation took place in this sample, but different information may have been found in a larger sample or if the universe differed. Four of the five mothers interviewed had been involved in the REACH programme. If mothers involved in other remediation or treatment programmes had been interviewed, there may have been an increase in the number of different experiences found.

Each mother was interviewed once for an average of 50 minutes. If the interview had been longer, more information may have been gathered. The fathers could have been interviewed to get another perspective on raising a child with autism. It appeared that the mothers became the research respondents, as they were the primary care givers.

This research has scratched the surface of parents' experiences of raising a child with autism. The researcher is of the opinion that there is a need for further research on specific topics within this research topic.

5.4.2 Recommendations

The researcher recommends that research be undertaken into the process of diagnosing autism to create a more effective and efficient process. This increased efficiency will enable the child to receive appropriate intervention far quicker than is currently reported. Perhaps, there is a need for general medical practitioners and paediatricians to improve their knowledge of autism thereby enabling them to identify the early symptoms of autism and to refer the parents directly to a specialist for a possible diagnosis.

In South Africa and particularly in the Western Cape, where this study was conducted, there is a need for affordable and accessible schooling for children with autism who are functioning at a level high enough that they do not need to attend a school for autism, but who are not able to integrate into

mainstream schooling with ease. The school would need to be a middle-ground between mainstream schooling and a school for autism.

In South Africa, there is a lack of funds, a lack of remediation or intervention options and a lack of options available to adults with autism. The researcher recommends that these areas be given attention, as action is needed in order to provide opportunities for children with autism and for their parents.

There is a need for support for parents immediately after the diagnosis of autism and while raising their autistic child. Perhaps, a service could be offered to parents immediately after the diagnosis. Such a service could be a consultation with a professional able to provide information, a range of resources and a debriefing. The availability of support groups throughout the child's life is another need of the parents. REACH provides a compulsory support group for parents who have enrolled their child in the REACH programme. There is a need for more similar support groups.

Each of the seven themes, their categories and sub-categories could become a research topic, as these areas could be explored in more depth. In particular, the category of siblings is one that would be useful to research to find out how a child with autism affects the life of his or her siblings; another would be the impact of the child with autism on the marital relationship.

5.5 CONCLUSION

This chapter indicated that raising a child with autism is a challenge for parents. The parents who participated in this study were given the opportunity to tell their story of raising a child with autism. The parents gave their opinions and expressed their needs. Many of the needs were not met. For most of the parents, the time when the need existed has passed. Most of their needs arose when they were seeking a diagnosis, seeking intervention or treatment for their child and seeking appropriate schooling for their child. However, the ongoing needs are those of support in coping with the day-to-day challenges of raising a child with autism, managing the impact that the child with autism

has on the family, the lack of available opportunities for their child in the future and the gaps in the services provided.

This study has achieved what it set out to do. It has assessed the needs of parents raising a child with autism, giving the parents themselves the opportunity to express their needs. This study will serve as important information for professionals working with children with autism and their families.

APPENDIX A

LETTER OF CONSENT

A NEEDS ASSESSMENT OF PARENTS ON HOW TO RAISE AN AUTISTIC CHILD

INFORMED CONSENT FORM

I _____ the research respondent in the study "A Needs Assessment of Parents on How to Raise an Autistic Child" through The University of South Africa, give the researcher, Lara Balfour, permission to interview me and audio record the interview for transcription purposes. The audio recordings may only be used for transcription by Lara Balfour and is strictly confidential. All documentation regarding myself as research respondent in this study will be treated as strictly confidential. A therapeutic debriefing session will be available to me after the interview. The debriefing session will not be recorded or used in anyway as part of the research.

Signed: _____

Date: _____

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