

UNIVERSITY OF CAPE TOWN
DEPARTMENT OF SOCIAL DEVELOPMENT

**EXPLORING THE PERCEIVED CHALLENGES OF SINGLE MOTHERS WITH
CHILDREN DIAGNOSED WITH AUTISM DISORDER IN THE JUNIOR PHASE AT
VERA SCHOOL**

By

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(MNRNTH001)

A dissertation submitted in partial fulfilment of the requirements

for the award of the degree of

Masters of Social Science Specialising in Clinical Social Work Practice.

Faculty of Humanities

University of Cape Town

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February 2015

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DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

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ACKNOWLEDGEMENTS

My first and foremost gratitude goes to my almighty God, my saviour. “I can do all things through CHRIST who strengthens me” (Philippians 4:13).

Special thanks to my Supervisor, Ms Fatima Williams for supervising this dissertation. Your unconditional encouragement and support you have shown throughout the duration of this process are invaluable. You have enabled me to grow in so many ways as a more competent researcher.

The Western Cape Department of Education, for granting permission for me to conduct this study at Vera School, Rondebosch East, Cape Town and the staff of Vera School for granting me permission to enter into their organisation. The single mothers of junior phase learners at Vera School for their consent to participate as participants and be interviewed for this study.

Thanks to Mr Samuel Lubega who spent an enormous time mentoring and supporting me in writing this dissertation. It is also with great thanks to Dr Marc Roffey for taking time to read and edit my work. My friend Thembakazi Makwakwa who has supported me throughout the journey of writing this dissertation. A special thanks to Mrs Elizabeth Trew for editing this dissertation.

My mother, Nomsa, fiancé Zophi, Lerato, Neo and Dineo, thank you for your unconditional support and for having faith in me throughout this journey. I would also like to acknowledge Valkenberg Hospital for granting me permission to study, and to my friends and colleagues for their on-going encouragement and guidance during this time.

Finally, many thanks to the Department of Social Development at the University of Cape Town for the on-going support throughout this dissertation.

DEDICATION

This dissertation is dedicated to my loving son Neo Monare who was diagnosed with Autism before the age of two years;

to all the single mothers of children with Autism who take enormous strides, perseverance and dedication to raise their children with special needs abilities; and

to my family for all their support and encouragement they have shown me throughout the development of my academic career.

ABSTRACT

This study aimed to explore the perceived challenges of single mothers with children diagnosed with Autism who are in the junior phase at Vera School, focussing on key struggles which they face in caring for their children. Emphasis was on parental stresses during their children's diagnostic processes as well as lack of availability and accessibility of resources about Autism Spectrum Disorder. A qualitative research design was used to carry out the research, and purposive sampling was utilised to select the sample for this study. The sample comprised of 15 single mothers. A semi-structured interview schedule and a voice recorder were used to conduct the interviews. The research was conducted at Vera School, Rondebosch in Cape Town.

Findings were drawn from the responses of the participants and compared with literature from previous studies. These findings indicated that single mothers of children diagnosed with Autism lack support to cope with the demands of caring for their children. This was highlighted in the early stages of assessment, making a diagnosis, and during early intervention of their children in a special needs school. Multiple roles, financial constraints and stigma were primary sources of parental stress, as pointed out in this study. Limited resources such as long waiting lists for admissions at special schools and aftercare facilities were highlighted as a great need.

It is recommended that relevant stakeholders such as non-governmental organisations and special schools should collaborate in providing supportive structures for single mothers of children with Autism. There is a great need for public and professional awareness about early identification of Autism Spectrum Disorder so that the stress associated with lengthy diagnostic processes can be minimised. Special needs schools should implement interventions and support structures for single mothers of children with Autism, as highlighted in the study.

GLOSSARY

CWD - Children with Disability

PCWD - Parents of Children with Disability

WHO - World Health Organisation

SAG - South African Government

WCPA - Western Cape Provincial Authority

WCED - Western Cape Education Department

UNICEF - United Nations International Children's Emergency Fund

ASD - Autism Spectrum Disorder

PECS - Picture Exchange Communication System

IEDA - Individuals with Disability and Education Act

DSM-1V- TM- Diagnostic and Statistical Manual of Mental Disorders

DOBE - Department of Basic Education

CDCP - Centre for Disease Control and Prevention

PDD-NOS- Pervasive Developmental Disorders not otherwise specified

IEP- Individualized Education Program

SAFOD - South African Federation of the Disabled

SAHRC -South African Human Rights Commission

NCSNT - National Commission in Special Needs and Training

NCSE - National Council for Special Education Support

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Chapter 1 PROBLEM FORMULATION

1.1 INTRODUCTION

This chapter introduces the background to the study, the rationale and the research site. The research questions and objectives, and clarification of concepts are examined. Ethical considerations and reflexivity are also discussed. The structure of the dissertation is then explained and finally some concluding remarks complete the chapter.

1.2 BACKGROUND TO THE PROBLEM

Disability can be viewed as a major public health problem worldwide. It is estimated that 15% of the world's population live with various types of disabilities (World Health Organisation, 2011:29). The burden of childhood disability as a public health problem in developing countries remains relatively unrecognised (Shawky, Abalkhail and Soliman, 2002: 61). This is because figures vary from country to country. "Country-specific information suggests that between 5 and 10 percent of all children in Africa grow up with disabilities" (United Nations International Children's Emergency Fund, 2012:1), but it is clear that there is much work to be done if all disabled children are to have access to all the services they need to grow up healthily and live up to their potential. One of the various forms of physical, mental and developmental disability concerns about Autism and its challenges are emerging, especially in Africa where parents of children with Autism face enormous challenges (Hutton and Caron, 2005:188).

Autism was first described by Leo Kanner in 1943 more than half a century ago (Siklos and Kerns, 2006:9). He reported that it is a disorder characterised by the inability to relate to other people, delayed speech, language abnormalities, and obsessive desire for sameness at an early part of infancy. Due to changes in technology and the advance in research in the twenty first century, Autism is understood as a neurological disorder that changes the way the brain functions causing delays or problems in many different skills from infancy to adulthood (Bailey, Le Couteur, Gottesman, Bolton, Bolton, Simonoff, Yudza, and Rutter 1995:63).

Autism research is considered to be well established and it has found to have a genetic component, although that component is not well known. Environmental factors might contribute to the cause of Autism (Rutter et al., 1995:63).

The prevalence of people affected with Autism has increased and it is the fastest growing developmental disability disorder (Luther, Darly, Canham and Cureton, 2005:40). Although there is concern about the radical increase of Autism among children worldwide, the World Health Organization (WHO) does not maintain accurate global statistics on the prevalence of Autism. Available information shows that Autism in children has increased significantly in the past 15 years (Luther, Darly, Canham, and Cureton, 2005:40).

Approximately 67 million people around the world are impacted by Autism. The increase could be as a result of more research being done in this field and better assessment tools being used to identify symptoms at an early stage. The prevalence of the diagnosis of Autism has increasingly been reported in developed countries such as the United States of America and United Kingdom (Centre for Disease Control and Prevention, 2014:1). In countries such as in Asia, Europe and North America, one in every thousand children is diagnosed with Autism, with South Korea showing an estimate of two coma six per cent (Centre for Disease Control and Prevention, 2014:1). Thus four out of every thousand individuals are affected with this illness, which suggests that this developmental disability is highly prevalent (DSM -IV-TR, American Psychiatry Association, 2005: 69). This increase is also experienced in South Africa in that every hour a child is born with a potential to develop Autism (Taylor, 2011:1).

Studies show that Autism is a severe developmental disability that begins at birth or within the first three years of life (Hutton and Caron, 2005:187). Children with Autism experience difficulties in social interaction and communication. These difficulties are often demonstrated through their behavioural patterns. The nature of these difficulties can be overwhelming for their parents (Jardine, 2008:1). The symptoms of Autism in children vary from child to child but the core symptoms are language delay, poor social skills and unwanted patterns of behaviour (Gaspar de Alba and Bodfish, 2011:634). These authors highlighted that these characteristics were helpful in diagnosing this disorder. However, such symptoms do not necessary lead to an accurate diagnosis because these symptoms are not predominant to each child who has the condition.

There is also a problem of diagnosing children at an early age, which leads to delays in seeking interventions for these children. Historically, parents kept precise notes and often diagnosed their children by stating the symptoms. They noted observations such as observing something

different with the child, especially when professionals were unfamiliar with the symptoms (Fernandez, 2007:1). This information from parents of children with Autism was used as a primary source of research (Fernandez, 2007:1). In addition, low-income parents are often faced with the problems of accessing resources and sometimes not knowing what to do. This could indicate that there may be many children at home who are suffering from Autism but parents are not aware of what to do or who to approach for assistance. This difficulty in accessing information and support by single parents often causes them to place their children in the care of grandparents or crèches which are not equipped to look after the child with special needs (Huws, Jones and Engledew, 2001:569). This has been reported to trigger judgment and discrimination of children because their disability is not understood by others (Goodenough, 2001).

1.3 RATIONALE

In South Africa, there is not enough information with regards to the issues of children with disability (CWD) such as educational support and guidance, because previously they were regarded as health and welfare issues (Integrated National Strategy White Paper, 1997:5). Parents need assistance from other experts to help them work together and raise these children, which experts can be found at special needs schools. Parents need to be involved in their child's education program interventions at these schools (Lall, Campbell and Gillborn, 2005: i). It is important to explore the problems experienced by single mothers in their struggle towards placing these children in the special needs schools such as Autism schools. In these schools all learners at the junior phase need to make a transition before moving to the senior phase. This transition requires skills' development hence a substantial effort between the parents and teachers is important. In addition, there are long waiting lists for children with Autism to be placed at special schools, as these schools for learners with Autism are fewer in South Africa as a whole (Bozalek ,2011: 10).

For many centuries, Autism has been researched, when there have been many strides in research to understand its management. However, the research outputs are not yet understood by society, and the condition continues to be a complex disorder to treat with no known cure (Silkos and Kerns, 2006:9). The lack of clear and comprehensive information about the condition, in addition to a lack of resources on Autism creates a challenge to parents in care of the children with Autism. Despite the fact that information about the diagnosis is a crucial factor for parents in

order to understand their child's disability, this remains a problem in South Africa among single mothers (Mackintosh, Myers and Goin-Kochel, 2005:49).

There is limited research that examines the challenges that single mothers who are raising children with Autism face. It affects many families in South Africa and while a number of studies done have only focused on the diagnosis of Autism and the impact it has on the child, very little research focuses on parental experiences and challenges. Parents play a crucial role with regards to their involvement in early interventions of their children. Furthermore, the school finds it difficult to work with the learners without parental involvement (Lall, Campbell and Gillborn, 2005:3). These skills learnt at school by these children should be incorporated at the learner's home environment as well, which requires the mother's participation (Bronfenbrenner, 1986:732).

Lall, Campbell and Gillborn (2005:4) stated that many parents, especially single parents, struggle to be involved in their children's education and activities due to economic problems, such as intensified work. It is documented that many parents are struggling with special needs schools due to the fact that the teachers or staff members may not have time or information to give to parents (Lall, Campbell and Gillborn, 2005:9). There is limited research in this area to explore challenges facing single mothers in South Africa when their children are identified to have Autism.

The caring of a child continues to be viewed in society as a woman's responsibility with the assumption that mothers will be available to provide this care (Gottlieb, 2001:5). Single parenting has unique challenges even before you add the demands of raising a child with special needs, such as daily roles of taking care of other children, making sacrifices in their own lives and having full time employment in order to promote and provide interventions for their children with Autism (McCabe, 2009:1). Mothers also have to spend more time looking for work in order to afford the cost of intervention programmes of their children. These mothers also have to provide for emotional and financial needs of other family members, while coping with the challenges associated with caring of a child with special needs. The balancing of multiple roles might be a difficult task for single mothers (Koulouglioti, Cole and Moskow, 2011:151). A child with Autism is an extra task for a single mother without enough support from the family or the community (Gottlieb, 2001: 5). Furthermore, Blackledge and Hayes, (2006:1) stressed that single

mothers of children with Autism with these enormous challenges could have an impact on their psychological well-being.

The researcher explored parental challenges in placing children at the special needs schools, and further gained a better understanding with regards to lack of participation of parents in school activities and programmes. This research has also explored issues in relation to accessing support, information, knowledge and the availability of resources to parents and teachers. The findings of the research will assist Vera school in understanding parental needs and possibly start programs that will provide support to parents. This study has focused on single mothers of children in the junior phase with a special school (Vera School). The research setting is now discussed.

1.4 RESEARCH SETTING – VERA SCHOOL

The study was conducted at Vera School, which was established in 1970. It is the oldest of only five Autism-specific government schools in South Africa, making provision for learners with Autism Spectrum Disorder. The school is situated in the residential suburb of Rondebosch East. It was the first school in the world custom built for learners on the Autism spectrum as there is a hostel for 35 learners on the same premises. The school is a public school functioning under the auspices of the Western Cape Education Department (WCED). The school receives an annual state subsidy and 145 learners pay school fees. As the education and treatment of learners with Autism are regarded internationally as the most demanding, the high teacher - learner ratio is essential (Charity SA, 2012).

The full staff complement at Vera is 74. The Department of Education acknowledges the need for high staff - learner ratio and allocates more staff to Vera in relation to other schools. However, this is not enough, and Vera has to spend the largest part of the budget on salaries in order to maintain the present effective staff complement. There are no funds for Autism specific staff training or for developing the facilities at the school. The school relies on fundraising to attain these goals (Vera School, 2012c).

The admission criteria for the school are that the child has Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder. The child would need to be seen by the professional in the field of health, education or social service before being considered for

admission at the school. The learners are allocated to a school according to a geographical area in which they stay. The following schools cater for Autism Spectrum Disorder (ASD) learners: Ligstraal (Paarl), Cherel Botha (Bellville), Noluthando (Khayelitsha), Beacon (Mitchell's Plain), Glenbridge (Plumstead), Vera (Rondebosch East), and Alpha (Cape Town). (Vera School, 2012a).

Parents are intimately involved in the formulation of Individualised Educational and Development Programmes (IEDP's) for their children. They are welcome to observe and experience the curriculum delivery to their children in the classroom from time to time. Parents are also invited to attend formal staff training projects and to make the use of training in Autism specific approaches that the school offers for example the Picture Exchange Communication System (PECS) in the family. The psychologist is available to parents for guidance and counselling. A policy of informed parental consent is adhered to when implementing interventions (Vera School, 2012b). The junior phase learners in a special needs school are usually between the ages of 6 years to 11 years.

1.5 RESEARCH TOPIC

Exploring perceived challenges of single mothers with children diagnosed with Autism Disorder in the junior phase at Vera School.

1.6 RESEARCH QUESTIONS

The following research questions are listed below:

- What are the perceived challenges facing single mothers before their child is placed at Vera School?
- What are the perceived challenges facing single mothers after their child has been placed at Vera School?
- What types of support services are single mothers aware of in order to assist them in caring for their child with Autism?
- What are the single mothers' perceptions of the support they are receiving from the school?
- What recommendations would single mothers like to make to the school in terms of support offered to parents?

1.7 RESEARCH OBJECTIVES

The following research objectives are identified and studied:

- To explore the perceived challenges of single mothers before their child has been placed at Vera School;
- To establish the perceived challenges facing single mothers after their child has been at Vera School;
- To examine the types of support services single mothers are aware of in order to assist them in caring for their child;
- To explore single mothers' perceptions of the support they are receiving from the school; and
- To establish the recommendation single mothers would like to make to the school in terms of support offered to parents.

1.8 CLARIFICATION OF CONCEPTS

AUTISM

DSM-IV-TR, American Psychiatry Association, (2005:73) highlights the essential features of autistic disorder that includes the presence of markedly abnormal or impaired development in social interaction, impairments in communication and a restricted repertoire of activity and interests. These symptoms in the impairment of social interaction may be in the use of non-verbal behaviours such as eye to eye gaze, facial expression, body posture and gestures to regulate social interaction. In the impairment in communication, the symptoms may be a delay in communication or total lack of communication in the development of spoken language. In a marked restricted, repertoire of activities and interests there may be pre-occupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus. The disturbance must be manifested by delays or abnormal functioning in at least one of the above areas prior the age of 3 years for a child to be diagnosed with Autism disorder (DSM -IV-TR, American Psychiatry Association, 2005:73). The DSM-IV underwent a revision in 2013 and DSM-5 has been adopted into local use since the beginning of this year (2015). Autism spectrum disorder is a broader diagnostic category, the essential features of which are: persistent impairment in reciprocal social communication and interaction, and restrictive, repetitive patterns of behaviour, interests or activities. Specifiers are used to provide more detailed clinical descriptions and in this way the manual includes conditions that in DSM-IV were considered

separate illnesses e.g. Asperger's disorder. As DSM-IV (including its diagnostic entities and language, for example Asperger's, which the researcher makes frequent references to in the study) was the version in use when the study was conceptualised and executed, and the researcher was comfortable and familiar with the terminology, a decision was made to continue using the DSM-IV term 'autistic disorder'.

CHILD

A child is a person under the age of 18 years (Children's Amendment Act, No. 41 of 2007).

JUNIOR PHASE

A junior phase is defined as a foundation phase that lays the groundwork for all formal schooling during the Grade 1, Grade 2 and Grade 3 years. The aim is to ensure that each child is taught in literacy, numeracy and life skills (South African College Junior, 2013:1).

SPECIAL NEEDS EDUCATION

Special needs education refers to needs and priorities which the individual person or the system may have which must be addressed in order to enable the system to respond to differences (diversity) in the learner population, remove barriers to learning, and promote affective learning among all learners (United Nations Educational Scientific and Cultural Organisations, 2011:19).

LEARNER

A learner is any person receiving education or obliged to receive education in terms of the South African Schools Act (South African Schools Act No.84 of 1996:12).

SPECIAL SCHOOL

A special school is a school that is resourced to deliver education to learners requiring high-intensity education and other support on either a full- time or a part- time basis (Department of Basic Education, 2010:50).

CHALLENGE

A challenge is defined as something that needs a lot of skill, energy and determination to deal with (Oxford Advanced Learners Dictionary, 2010:238).

PERCEPTION

A perception is an individual view or interpretation of something (Oxford Advanced Learners Dictionary, 2010:515).

SINGLE MOTHER

Single mother in this study refers to a parent who has most of the daily responsibilities in raising a child diagnosed with Autism. Single mothers have become an accepted norm in the world and there is no single definition of single mothers (Nurek, 2006:10). Single mothers include divorced and widowed women and those not in a relationship; although these women may live alone the term could include women who live within extended families and who are directly involved in the day to day responsibilities of raising a child (Cohen, 2002:451).

1.9 ETHICAL CONSIDERATIONS

When conducting research of any nature all researchers have a responsibility towards their participants in the study, and researchers must follow ethical guidelines which serve as standard, and basis upon which researchers ought to evaluate their conduct (De Vos, Fouche and Strydom, 2011:114). For the purpose of this research the following ethical issues were considered:

1.10 AVOIDANCE OF HARM

The fundamental ethical rule of research is that it must not bring harm to participants (Babbie and Mouton, 2007:27). It is important that participants are not harmed physically or emotionally during the course of the study. The researcher has an ethical obligation to protect the participants from any harm of any nature, for example, emotional or physical harm, within all possible reasonable limits, from any form of physical discomfort that may emerge from research (Creswell, 2003:64). In this qualitative study the harm could have been of an emotional nature. The participants were informed beforehand about the nature of the study and that they may withdraw at any time. The researcher is well trained who used her skills in a sensible and caring manner when conducting the interviews. The researcher informed the participants that she was available for debriefing should such need arise. None of the participants contacted the researcher for debriefing after the interviews.

1.11 VOLUNTARY PARTICIPATION

Rubin and Babbie (2005:71) state that participation should be, at all times, voluntary, and no one should be forced to participate. The researcher explained to the participants that the study is of a voluntary nature.

1.11.1 INFORMED CONSENT

Grinnell and Unrau (2008:5) explain that respect for persons that will participate in research requires that the subjects be given the opportunity to choose what shall or shall not happen to them. Informed consent allows for participants to give voluntary legal consent to participate in the study, that they have an understanding of the details of the research as well as what the study would entail. Its purpose was explained verbally to all the participants, who had all the information about the study. Its possible impact was presented to them in an unbiased way so that they made a voluntary and thoughtful decision about their participation in the study. They were informed about the purpose and the content of the study, what the results would be used for, and what the impact would be for them. They were also informed that the study is voluntary and that they could withdraw from the interview at any stage if they wished. There were no participants who wanted to withdraw from the interviews.

1.11.2 DECEPTION OF SUBJECTS AND / OR PARTICIPANTS

Deception refers to misleading participants, deliberately misrepresenting facts or withholding information from participants (Struwing and Stead, 2001:69). Deception also occurs when the researcher intentionally misleads subjects by way of written or verbal instructions, the actions of other people or certain aspects of the setting (Neuman, 2000:229). The researcher cannot intentionally or unintentionally mislead the participants in any way. The participants are not intentionally misinformed or deceived by the researcher in any way. It is seen as unethical in research to use the participants under false pretences. Deception of subjects and /or participants is seen as unethical in research as one which uses the participants under false pretences. In this study the researcher informed the participants both verbally and in writing with regard to the purpose and content of this study as well as their role within the research. The written consent was signed by each respondent in agreement that they were clearly informed in order to ensure the prevention of subject deception.

1.11.3 VIOLATION OF PRIVACY/ ANONYMITY / CONFIDENTIALITY.

According to De Vos, Fouche and Strydom (2011:119), “every individual has a right to privacy and it is his or her right to decide when, where, to whom, to what extent his or her attitude, beliefs and behaviour will be revealed.” These authors further explain that this principle can be violated in a variety of ways and it is imperative that researchers be reminded of the importance of safe guarding the privacy and identity of participants. In this study the participants were assured that their real names were not used in the study and pseudonyms were used and the information was destroyed after the research. The participants were also made aware that the findings of the study would be shared with the school as it might assist in making future recommendations for the parents at the school.

1.11.4 DEBRIEFING OF PARTICIPANTS

Debriefing sessions are gatherings during which subjects get the opportunity after the study to work through their experience and its aftermath, and where they can have their questions answered and misconceptions removed (De Vos, Strydom, Fouche and Delpont, (2011:122). Given the nature and sensitivity of the study, each participant, after the interview had been conducted, was given an opportunity off the record to say how they felt during the interview process. The researcher, for the purpose of research, had offered an opportunity to each participant for debriefing.

1.11.5 ACTIONS AND COMPETENCE OF RESEARCHER

Researchers are ethically obliged to ensure that they are competent, honest and adequately skilled to undertake the proposed investigation (De Vos, Strydom, Fouche and Delpont, 2011:123). Actions and competence of the researcher entails that researchers are adequately skilled and experienced to conduct the research. This includes conducting research, collecting the data, analysing the data, and reporting on it, which must be done ethically and adequately by the researcher. The researcher is an experienced social worker and was confident in her ability to conduct this research.

1.11.6 PUBLICATIONS OF THE FINDINGS

It is the researcher's duty to ensure that the findings of the study must be introduced to the reading public in written form or it will mean very little and will not be viewed as research (De Vos, Fouche and Strydom, 2011:126). The data and outcomes of the study were compiled and any limitations of the research are disclosed. The participants from this study will be informed of outcomes via a written report that will be provided to Vera School that contain the findings and recommendations which emerged through the study.

1.11.7 REFLEXIVITY

The nature of some research topics can evoke emotions that may affect the researcher's objectivity. De Vos, Fouche, Strydom and Delpont (2002:369) describe reflexivity "as the ability to formulate an integrated understanding of one's own cognitive world, especially understanding one's own influence or role in a set of human relations. It is a quality of metacognitions, thinking about one's perceptions and ideas". These characteristics are related to the widely supported social work qualities of self-awareness (De Vos, Fouche, Strydom and Delpont, 2002:369).

Tripodi and Tripodi (1999:89) describe reflexive practice as "a practice that is capable of learning from and adapting itself to the lessons learned. The practitioners who bring certain advantages to the research task also need to overcome certain difficulties (Tripodi and Tripodi, 1999:89). They state that the advantages include an overlap in professional skills, and argue that research minded practitioners are well placed to inform research agendas as they know better than most what questions could be addressed to increase understanding of the circumstances and problems of communities and service users, and improve the effectiveness of services.

During the research process the researcher had to be aware of her role as a researcher and a practitioner. She could relate to participants' experiences and challenges of caring for a child diagnosed with Autism. This shared understanding made it difficult at times, due to the nature of the practitioner's scope of practice in psychiatry, to change from the role of a practitioner to that of the researcher. In order to maintain this boundary the researcher applied the social work principles and skills such as empathy, non-judgmental and self-awareness. Her role as a researcher was also not influenced by the participants' experiences because she was being supervised.

1.12 STRUCTURE OF THE RESEARCH REPORT

The research report will follow the following structure:

CHAPTER ONE

The problem formulation explores the nature of the problem that this study aims to investigate.

CHAPTER TWO

The literature review in this study is linked with previous research that has been conducted in this area of work.

CHAPTER THREE

The methodology chapter closely analyses the research method used in executing the study.

CHAPTER FOUR

The findings chapter presented the research findings by first providing the demographic profile of the participants, framework of analysis and then discussing the findings using the research objectives as headings, which relate to the main themes and categories in the framework of analysis.

CHAPTER FIVE

This chapter uses the research objectives to discuss the conclusions that came from the findings. It also presents the recommendations of the researcher based on the findings.

1.13 CONCLUSION

This chapter discusses the background to the problem, the rationale for choosing this topic, the main research questions and main research objectives. Clarifications of concepts, explanations of the ethical considerations of this study, reflexivity as well as structure of this dissertation are discussed. The following chapter presents the literature review.

Chapter 2 LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents literature pertaining to the study. The theories that underpin the study are Ecological Systems Theory, Hepworth, Rooney, Rooney, Gottfried and Larsen (2006:17) and Erikson's (1968:122) Psychosocial Theory of Development. For the purpose of this study the researcher examines literature on parental challenges, focusing on single mothers, looking at parental stresses, and the availability and accessibility of resources. A range of international literature and South African studies are explored. There is a challenge to find literature in the South African context regarding single mothers with autistic children.

2.2 THEORETICAL FRAMEWORKS

2.2.1 Ecological Systems Theory

The Ecological systems theory originated from biology. This theory makes a close conceptual fit with the 'persons in environment', a perspective that dominated social work until the mid-1970s. Social work adopts both system theories and ecological theories (Hepworth, Rooney, Rooney, Gottfried and Larsen, 2006:16). The National Association of Social Workers, (2012:9) defines the ecological perspective for school social workers as the interaction between the child, family, and their environment. According to this theory, school social work practice should not only be focused on the individual, rather it should include all interrelated systems that affect a child's development (Clancy, 1995:40). A child's environment includes many systems that interact and affect one another at different levels. The ecosystems perspective helps social workers recognise that one cannot understand the functioning of an individual without examining his or her environment (Sheafor and Horejsi, 2006: 87). Therefore, Ecological Systems Theory defines effective practices as interventions that take place in microsystems, mesosystems, and macrosystems.

According to Hepworth, Rooney, Rooney, Gotfreid and Larsen (2006:17), "Ecological Systems Theory suggests that individuals constantly engage in transitions with other humans and systems in the environment and that these individuals and systems reciprocally influence each other." The authors further highlight, in the context of disability that the importance of an ecological

framework of a disabled person exists by the interaction through which society engages with a disability. In this context these are: the child with a disability, the parent who is the caregiver, and the school, which is the environment. Disability is thus minimised by maximising the goodness fit between the needs of people with physical or mental limitations, and the environmental resources that correspond to their special needs (Hepworth et al., 2006:17).

Ecological Systems Theory is suitable for describing the environment experienced by parents, and the various subsystems can also be extended to include additional experiences and settings experienced by these parents of children with development disabilities. Therefore the effects on parents who are caring for a child with a disability can be influenced by the social environment. For example, the extended family and community attitudes towards single parents with disabled children can influence the outcome of the child with disability (Hornby, 1994:26). In addition to the above, attitudes and assistance from medical and health care workers, and help from other parents can also influence the outcome of a child with disability (Seligman and Darling, 2009: 68).

Ecological Systems Theory in this study gives a theoretical base in understanding how systems influence each other. Furthermore, this theory is important in the context of this study because of the way it understands the importance of environmental factors and the ways in which people interact with their environment (Hepworth et al., 2006:16). It is clear from the ecological system's perspective that the satisfaction of human needs and mastery of developmental tasks require adequate resources in the environment and positive transitions between people and their environment. Hepworth et al. (2006:16) further state that any gaps in the environmental resources may provide limitations to parents who need to utilise these resources. This can cause dysfunctional transitions between individuals and the environmental systems which therefore threaten to block the fulfilment of the child's needs, which this can lead to stress and impaired functioning. Hepworth, et al. (2006:17) further highlight that to reduce or remove this stress requires coping efforts from parents aimed at gratifying the needs of their children, that is, achieving adaptive fit between the child and the school. However, with no access to adequate resources of the child, parents may lack effective coping methods. The quality and availability of government services and support groups can be a significant factor in determining how well

parents cope as parents who have increased levels of formal and social support, and who may have more skills to handle any situations that may arise (Hornby, 1994:167).

Bronfenbrenner's model (1979:3) uses four subsystems to describe how families interact with external environments. This author viewed the ecological environment as a set of nested structures, each inside the next. The innermost level is the microsystem which consists of environments containing the developing person, such as the immediate family. The microsystem of families of children with a disability includes the family that is the parents, child and other siblings. How well the family is able to function depends on factors associated with each member, for example, the type of disability, and birth order of the child, personality of the child and any siblings, and closeness of the parental relationship and employment and health status (Hornby, 1994:31).

According to Bronfenbrenner (1979:209) the next level is the mesosystem which consists of a range of settings within which the family participates, as well as the relationships between the settings. The school can help such parents to meet their child's needs by linking them with or developing essential resources (Gupta and Singhal, 2005:64).

From an ecological perspective the assessment at the school requires knowledge of the diverse systems involved in the interaction between people and their environment (Hepworth et al., 2006:17). This includes interpersonal systems like the parent-child, family, friends, social networks, organisations, physical environment and communities. Parents who have established good relationships with their neighbours, work mates, friends and professionals are all positive contacts that can promote healthy relationship family functioning (Hornby, 1994:212). The levels of support and assistance from each of these levels can have an effect on the family's perceptions of their environment and on how well they may be able to cope with any additional stressors that may arise.

The third level suggested by Bronfenbrenner (1979:237) is an external setting called the exosystem, which includes financial and government supports, the availability of health care that may be required if their child has severe impairments, and the accessibility of an appropriate education for their child (Seligman and Darling, 2009:68). Gupta and Singhal, (2005:66) reported on the challenges of inadequate resources for parents. Adequate resources are very essential with regards to early intervention, especially when the child is in a junior phase at a

special school. This is a critical period with regards to obtaining skills development of the child, as literature supports that early intervention has a better prognosis of the child with Autism (Silkos and Kerns, 2005: 11). Accessing environmental resources such as finances have hindered parents with providing the required assistance to raise their children. This is because the child might need more than one intervention programme which might not be catered for from a single school and parents might need to access them in other community areas (Gupta and Singhal, 2005:66). By not having enough resources the special schools and the community tend to block the transition needs of the child's development.

The fourth level is the macrosystem, which consists of society and cultural beliefs and laws (Bronfenbrenner, 1979:258). The macrosystem also includes economic and political elements as policies will largely determine what level of professional support and programmes will be available for a child with a disability (Seligman and Darling, 2009: 21). The developing person is not immediately present in this subsystem; however, events occurring at this level can have an effect on their development. All these systems influence each other. Government policies are also highly important as this can determine the levels of professional support parents are able to receive (Evaslage, 2012:37). Governments who put a large amount of money into providing therapy and practical assistance will be more beneficial to the immediate family environment than a government that is not able or does not provide much financial assistance.

The Ecological Systems Theory is important for this study as the main aim is to examine the parent's environment of families who have children with developmental disabilities. As parents report the levels of support received and their perceptions of the family environment, external aspects of the environment can be examined in order to determine the effects this may be having on the immediate family environment, especially a single mother's psychological well-being in raising the child with a disability. According to Bronfenbrenner (1979:244), these interactions can be explained within the microsystem, mesosystem, exosystem and macrosystem. In light of the above discussion, the next discussion is on Erikson's psychosocial development in understanding how the child with Autism needs to enhance skills development in the junior phase.

2.2.2 Erikson's psychosocial theory

Erikson's theory is based on the study of human growth and development with a conflict or crisis to be resolved at each stage. This theory consists of eight major stages, with each stage posing a unique development task that individuals will meet and resolve (Erikson, 1968:122). The junior phase learners in a special needs school are usually between the ages of 6 years to 11 years, which pertains to school-aged children. According to Erikson's theory (1959:83), the junior phase learner falls into the developmental stage four, which is Industry versus Inferiority.

In this stage a child is learning new skills and develops a sense of pride of what she / he has accomplished. When a child is encouraged, rewarded, praised and acknowledged for his or her skills, the child develops confidence in them. When the child lacks the praise, encouragement, and acknowledgement of the skills he /she is proud of, the child will doubt him/ herself, and lack confidence in them. At this stage in a child's life, it is very important to have his or her parents' positive feedback and to always encourage the child to explore and develop new skills (Erikson, 1959:86). The role of the single mother in this stage is to support the child in life skills learnt at school such as social skills, communication skills and homework and incorporate these skills daily in their home environment so that the child can be industrious and master the skills of life.

Erikson (1968:122) believed that the fourth psychosocial crisis is handled, for better or for worse, during what he calls the "school age" presumably up to and possibly including some of junior high school. Erikson (1968:123) mentions that the child learns to master the formal skills of life (1) relating to peers according to rules (2) progressing from free play to play that may be elaborately structured by rules and may demand formal team work (3) mastering social studies, when reading and homework becomes a necessity. Therefore, the need for self-discipline increases yearly. This author emphasises that the child who, because of his successive and successful resolutions of earlier psychosocial crisis, develops trust, becomes autonomous and full of initiative and will learn easily enough to be industrious. However, the mistrusting child will doubt the future. The shame- and the guilt-filled child will experience defeat and inferiority (Erikson, 1968:124).

An autistic child develops in different ways from than a non-autistic child. However, an autistic child does have his or her own interests, skills, and strengths. Allowing an autistic child to polish and strengthen his or her interests will help them become successful and confident about him or

herself (National Dissemination Centre for Children with Disabilities n.d). This is a critical period of development where children are curious about how things work and develop a sense of mastery and competence (Erikson, 1959:85).

Many scholars such as Ungerer and Sigman, (1981:348); Kanner, (1943:513), Rutter, (1983: 256); Baron-Cohen, Tager-Flunberg and Cohen, (1993:138), argue that autistic children are characterised with some sort of a delay in their developmental milestones resulting in them needing great assistance from educators and parents in developing their skills. This is the time when parents and educators need to work hand in hand to enhance the skills development of the child.

Lall, Campbell and Gillborn (2005:3) are in agreement with stated scholars, suggesting that parental involvement, particularly in providing support at home and being interested in education contributes significantly to improving learner's progress and achievement at school. Early research suggests that in children with Autism, the earlier the intervention received the better chances of adapting to society (Rutter, Greenfield and Lockyer, 1967; Kanner Rodriguez and Ashenden, 1972; Dawson, Newson and Everard, 1984; and Paul, 1987). These authors highlighted that the greater the intervention received on how things work the better the chances of skills development and higher functioning as individuals in society. This theory is relevant to the study because the theory explains how the child learns new skills at a school going age. Because of autistic children's developmental delays associated with their condition early intervention is essential in their skills development. This is a critical stage of development with mastering and enhancing the skills development of an autistic child for better chances of higher functioning as individuals of society. The following discussion explains policies related to children with disabilities.

2.2.3 Policies related to children with disabilities

Disability is a human rights and development issue, and understanding this leads to a recognition and acknowledgment that People with Disability (PWD) are equal citizens and therefore enjoy equal rights and responsibilities. Chapter 2 of the 1996 South African Constitution guarantees fundamental rights to all citizens. It includes, in section 9, the equality clause, and the right to freedom from discrimination based on disabilities. Specifically mentioned disabled people are

therefore guaranteed the right to be treated equally and enjoy the same rights as all other citizens Constitution of the Republic of South Africa, 1996: chapter 2).

The South African Human Rights Commission (SAHRC, 2012) stipulates that the special needs schools need to make all the necessary arrangements in order to accommodate children with severe and complex impairment. This is consistent with the Education White Paper-6 of 2001, to ensure all the necessary facilities and equipment availability, to accommodate all learners with disabilities. In South Africa the South African Federation of the Disabled (SAFOD, 2014:1) also promotes the rights of all people with disabilities, ensuring that children with disabilities are promoted through the adoption of strategies, training and awareness raising to enhance lives of people living with disabilities. Furthermore, according to the Education White Paper-6 of 2001, special needs education can also exist outside classroom such as support for the children and their mothers in life skills. The latter are legal boards responsible for foreseeing the educational rights of children with disability, so mothers with children with disability (CWD) have an obligation to fulfill this. However, it is not clear whether these single mothers understand the parent responsibility as stipulated in the White Paper in explaining the role of parents' participation and involvement towards their children's education. In the next section the researcher provides an explanation of Autism.

2.3 AUTISM

Autism is one of several related developmental disorders which are referred to as Autism Spectrum Disorders. Due to advancing research, it is now understood as a lifelong neurodevelopmental disorder characterised by significant impairments in social relatedness and communication and repetitive and restricted interests or behaviours (American Psychiatric Association, 2005:59). However, due to difficulty in accurately diagnosing Autism Spectrum Disorders it is difficult to determine what proportion of the children has Autism.

Elder, Dawson, Toth, Fein and Munson (2008: 17) also mention that other children seem to develop normally at first, only to present symptoms when they are 18 months to 36 months old. Autism is usually diagnosed around the ages of 2 or 3 although some signs emerge earlier. Children with Autism have trouble communicating. They have trouble understanding what other people are thinking and feeling. This makes it very hard for them to express themselves either in words or gestures, facial expression, and touch (Camarata, 2014:7). Autism knows no racial,

ethnic, or social boundaries. Family income, lifestyle, or educational levels do not affect a child's chance of being autistic (Autism Society of America n.d).

2.3.1 Types of Autism

There is such a wide variety of types of Autism spectrums that it can be difficult to group a child's symptoms together. Autism is a spectrum disorder which means that one person can be highly functioning and mildly affected by Autism and another can be low functioning and severely affected. Symptoms that affect communication, social interaction, and behaviour can be mild to severe. Depending on the severity, people with Autism may also have sensitivity to light, sounds or touch, and mental retardation. It is also known in research that many people with Autism are highly intellectually capable individuals but due to Autism they may not be able to express themselves. The Diagnostic and Statistical Manual of Mental Disorders DSM IV-TR, (2005:61) describes a class of five disorders, which will be discussed.

2.3.1.1 Autistic Disorder

This disorder is often referred to as the hallmark of Autism and is the disorder that most people think of when hearing the word Autism (Volkmar and Pauls, 2003:1133; Exkorn, 2005:6; Simmons et al, 2006; CDCP, 2008:2). Individuals with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviours and interests (American Psychiatric Association, 2005; Volkmar, Chawarska and Klin, 2005:42). Individuals with this disorder can have intellectual disabilities, but this is not a requirement for diagnosis (American Psychiatric Association, 2005:67). Many children with Autistic Disorder can appear to have little or no interest in making friends or establishing relationships with others and appear more interested in objects than people (American Psychiatric Association, 2005). It is a common misconception that children with Autism Spectrum Disorders do not desire establishing friendships when many do, particularly children with Asperger's Disorder; they appear this way because they have difficulties sustaining friendships, (Chan, Quan and Wood, 2012: 1). Their play can be noticeably different than other children as they do not engage in pretend play, are often seen playing alone, and they use toys differently (Adams, Green, Gilchrist, and Cox, 2002: 681; Exkorn, 2005:38 and Simmons, 2006:59).

2.3.1.2 Pervasive Developmental Disorder (PDD- NOS)

Pervasive Developmental Disorder are commonly referred to as atypical Autism because children with this diagnosis show some but not all of the criteria for the other disorders (American Psychiatric Association, 2005:59). A child with PDD-NOS has severe impairment in verbal or non-verbal communication skills or displays unusual behaviours, interests, and activities; they do not meet criteria for a specific pervasive developmental disorder (American Psychiatric Association, 2005:64). For example, this would include a child who does not meet criteria for Autistic Disorder because of late age of onset or atypical symptoms (American Psychiatric Association, 2005:64). This is a milder form of Autism, usually diagnosed between ages 2 and 6.

2.3.1.3 Asperger's Disorder

Asperger's Disorder is characterised by highly impaired social skills, difficulty relating to others, a lack of imaginative play, and a preoccupation with a highly specific topic (American Psychiatric Association, 2005:63; Van Bergeijk and Shtayermman, 2005:23). It is often referred to as high functioning Autism because an individual with this disorder shares behaviours and difficulties like someone with Autistic Disorder, but they tend to have average or above average intelligence and typical or advanced language skills American (American Psychiatric Association, 2005:64; Exkorn, 2005:6; Simmons et al., 2009:2705). It is distinguished from Autistic Disorder because the severities of symptoms are milder, and there is an absence of language and cognitive delay (American Psychiatric Association, 2005:64; Simmons et al., 2006; CDCP, 2008). Children with Asperger's develop typical communication skills in the first few years of life and present strong verbal skills that are not a component of diagnosis for a child with Autistic Disorder (American Psychiatric Association, 2005:64). A child with Asperger's Disorder might appear different from other children because they do not understand social rules and might lack empathy for others. They can appear socially awkward, but usually want to fit in and have social interaction, unlike some children with Autistic Disorder (Simmons et al, 2006). Asperger's is often not diagnosed until the child is in school because it is difficult to recognise at an early age (Van Bergeijk and Shtayermman, 2005:23; Exkorn, 2005:282).

2.3.1.4 Childhood Disintegrative Disorder

A very rare disorder in which normally developing children lose motor, language, social, and potty skills around ages 2 to 4. This disorder is marked by the loss of skills previously acquired. The areas of significant loss may be expressive and receptive language, social skills and adaptive behaviour, bowel or bladder control, play, or motor skills. Many parents see this disorder quickly and lead to a diagnosis of Autism (American Psychiatry Association, 2005, DSM -1V–TR: 62).

2.3.1.5 Rett's Disorder

This is an extremely rare disorder, diagnosed only in females, whereas Autistic Disorder occurs much more frequently in males. This disorder has the symptoms that match up closely with Pervasive Developmental Disorder. Children with this disorder have one major difference: there is a characteristic of head growth deceleration, loss of previously acquired purposeful hand skills, and the appearance of poorly coordinated gait or trunk movements. Particularly during the preschool years, individuals with Rett's Disorder may exhibit difficulties in social interaction similar to those observed in Autistic Disorder, but these tend to be transient (American Psychiatry Association, 2005, DSM -1V–TR: 61).

2.3.2 Causes of Autism

There is a lot of debate and research about the causes of Autism. Bailey, Le Couteur, Gotterman, Bolton, Simonoff, Yudza and Rutter (1995:63) consider the cause of Autism to have a genetic component and environmental factor, which might contribute to the causes of Autism. Clifford, Dissanayake, Bui, Huggins, Taylor and Loesch (2006:745) in their research show that there is fragile X syndrome in children with Autism and further suggests more investigations still needs to be done in understanding the causes of Autism. The exact cause of Autism is still unknown and at present no cure exists (Levy et al., 2009:9). There is a variety of therapeutic and educational approaches are known to Autism interventions (Levy et al., 2009:9). However, such therapeutic and educational contribution benefits some, but not all children with Autism.

2.3.3 Treatment of Autism

The number of treatments proposed for children with Autism have grown suddenly with the increase of identified cases of Autism Spectrum Disorders (Volkmar, Chawarska and Klin, 2004:

328), but at present there is no treatment to improve all symptoms of Autism Spectrum Disorders available (Levy et al., 2009: 9). A web-based survey conducted by Green and colleagues (2006:962) found that speech therapy is the most common treatment followed by visual schedules, sensory integration, applied behaviour analysis and social stories. In addition, 52% of parents were using at least one medication to treat their child. Despite the number of treatments available it is still unknown which treatments or combinations of treatments will be most effective and whom they will be effective for (Rogers and Vismara, 2008:8).

The main source of treatment for children with Autism is the family or educational system (Lord et al., 2005:696). Treatment often involves a comprehensive approach and includes combinations of specialised educational services, developmental therapies, behaviourally based treatments, and intensive parent training that is in the home, community or school setting (Rogers and Vismara, 2008:8; Volkmar and Pauls, 2003:1137). Interventions are targeted at core symptoms of socialisation, communication, and behaviour (Levy, Mandell, and Schultz, 2009:7). Targeting core symptoms might be more effective when treatment is initiated in early childhood, making early screening and diagnosis important (Lord et al., 2005:695). Behavioural or developmental manifestations of core symptoms are most obvious, and are therefore the main focus of treatment (Levy, Mandell, and Schultz, 2009:7).

There are different treatment models that have a role depending on a child's development (Coplan, 2010). There are also specialists who are experts in targeting the symptoms of Autism such as an occupational therapist who focuses on sensory integration, a behaviour analyst who focuses on shaping behaviour and a speech therapist who focuses on language (Coplan, 2010). However, these treatment models cannot be successfully implemented without parental involvement.

2.3.3.1 Interventions with parents

There is increasing evidence that early intervention improves outcomes for children with Autism Spectrum Disorders (Rogers and Vismara, 2008:8). Furthermore, in contrast to interventions for pre-school and older children with Autism, there is a consensus that parents should be involved in interventions designed for infants and toddlers (Beadion, Sebire and Couture, 2014:1). This view is consistent with early intervention, which involves working with children in their natural environments (Dunst, Hamby, Trivette, Raab and Masiello, 2008:3).

Parent-mediated interventions have been shown to be an important aspect of intervention for children with disabilities (Levy et al., 2009:8). When parents are trained in highly structured behavioural methods improvement in generalisation and maintenance of behaviour change in children with Autism Spectrum Disorders have been demonstrated (Steiner, Koegel, Koegel and Ence, 2012:3). When these strategies were taught to parents they found they were easier to use in the home, needed less hours of training, increased leisure and teaching time, and improved their satisfaction and enjoyment of the treatment. Parents are now thought to be important collaborators at all stages from assessment through to goal development and treatment (Levy et al., 2009:8).

2.3.3.2 Educational interventions

Children with an Autism Spectrum Disorder have opportunities to learn through a variety of settings. The Individuals with Disabilities Education Act (IDEA) in the United States ensures that all children with disabilities receive free, appropriate public education in the least restrictive environment that are tailored to each child's individual needs. However, in South Africa children with disabilities do not receive free education. Parents still need to pay school fees for their children with disabilities. Parents also have an option to apply for a state disability grant. Assessment is done by the state organisation such as Department Social Development. The assessment is based on the parents' financial income and expenditure on whether they qualify to receive the state disability grant.

A child with an Autism Spectrum Disorder attends school in one of the following ways: in a regular educational environment with support services; in a special education classroom with or without mainstreaming within the school; or in a school for children with special needs (Creedon et al., 2006: 2705; Levy et al., 2009:3). The setting chosen depends on the needs of the individual student (Creedon et al., 2006: 2705). An Individualised Education Program (IEP) must be developed for any student receiving special education services (Kurt and Mastergeorge, 2010:147).

In addition, an Individualised Educational Plan (IEP) covers what support services will be necessary for the child and any adaptations include where the student sits in the classroom, the use of visuals to help him communicate, extending school days or the programme to home (Creedon et al., 2006: 2705). A special education setting is highly structured with a low student

teacher ratio and has accommodations available to address core characteristics of Autism Spectrum Disorders. These accommodations may include the use of visual or communication devices to address communication problems and supportive therapies to help with sensory processing difficulties (Creedon et al., 2006:2705). The same applies in South African special education settings.

2.4 MULTIPLE ROLES OF SINGLE MOTHERS

According to Gottlieb (2001:11), single mothers are faced with enormous challenges of having multiple roles in their lives. They have the roles of providing financial assistance to their families, and daily roles of caring for the child at home as well as having a full time job. Single mothers with multiple roles tend to exhibit role imbalance and role overload as they may also experience role conflict and lack of control over their lives (Gottlieb, 2001:11). The need for these mothers to support their child with the disability may be in conflict with their need to care for their families (Gottlieb, 2001). Balancing these multiple role responsibilities is a difficult task for single mothers. This has not been examined extensively in research studies on single mothers of children with Autism (Luther, Darly, Canham and Cureton, 2005:46).

The impact of having a child with Autism on single mothers can be very significant, because of having to adapt to a family schedule and structure at home, including having to plan ahead for simple trips, not having free time to relax thus making family vacations and time for fun virtually impossible. It is clear from available studies (Gupta and Singhal, 2005:64) that the impact of the disability on single mothers is tremendous. Furthermore, what happens when a single mother has other children who are siblings to the child who has Autism and carries all the responsibilities of caring for her children without spousal support? Intuitively we would expect that the multiple challenges facing these single mothers would leave them increasingly vulnerable to negative consequences such as stress and psychological issues. There is very little research to understand how single mothers financially and emotionally manage a family that includes a child with Autism.

In general, children are expected to have a consistent daily routine at home, especially when they attend school. Consistent daily routines have been associated with children's well-being but single mothers with pre-school aged children are less likely to engage in regular family meals or bedtime routines, which could be the result of multiple roles they face on a daily basis in their

homes (Koulouglioti, Cole and Moskow, 2011:144). Single parent families are less likely to maintain daily meals, naps, and bedtimes for their children when compared to two parent families (Koulouglioti, Cole and Moskow, 2011:144). Children of single parent families who are living in low income and poverty situations are less likely to have a bedtime routine and are less likely to be part of a parent child interactive routine. (Hale, Berger, Le Bourgeris and Brooks-Gunn, 2009). Research has failed to focus on single mothers with special care-giving functions on how the daily routines impact on the mental state of the mother and on the mother and child interaction at home (Gottlieb, 2001:3).

It is also important to understand how employment affects single mother families of children with developmental disabilities. There is also increasing societal pressure for single mothers of school aged children to be employed rather than rely on public welfare (Ellwood and Jencks, 2002:32). There is little research done on how single mothers of children with Autism cope financially with their school-aged children who need intervention programmes at schools, as literature suggests early intervention and better prognosis of the child to adapt to society (Gottlieb, 2001:3; Gupta and Singhal, 2005: 66).

Mothers who are primarily working full-time on top of their family responsibilities may feel they have little time for or are unable to afford extra child care needed for outside activities. This may create more pressures for these mothers leaving them vulnerable to stress; it would be important for service providers to link these mothers to low cost or free support groups or intervention programmes, which is a problem in South Africa (Mackintosh, Myers and Goin-Kochel, 2005:49). Furthermore, parents experience stigma from society (Gray, 1993:105) with regards to these challenges and have concerns about their children's uneven developmental progress (Schuntermann, 2002). The following discussion will be on challenges experienced by single mothers with autistic children.

2.4.1 Challenges of single mothers with autistic children

Single mothers with autistic children face enormous challenges, but very little attention has been paid to their psychological needs (Blackledge and Hayes, 2006:1). Challenges experienced by these mothers start when they realise their child is different, then they seek professional help from doctors such as paediatricians in order to gain a better understanding of what is happening to their child (Hutton and Caron, 2005:187).

Parents, especially mothers, are the first ones to realise that something is different about their child's development. According to Hutton and Caron (2005:180), research findings have shown that parents recognise the problems with their child before the age of 2 years. There are also research studies done which show that symptoms of Autism can be detected as early as infancy (Osterling, Dawson and Munson, 2002:245).

Single mothers also experience difficulties with acquiring appropriate diagnosis, obtaining necessary services, and learning to balance these issues present serious coping challenges to the most capable parents. These parents' perceptions about the system for diagnosing their children results in many months of waiting, numerous referrals and in some cases very late and inaccurate diagnosis (Hutton and Caron, 2005:180). These challenges cause a lot of stress for single mothers, which pose a high risk to their psychological well-being (Gupta and Singhal, 2005:62).

Phetrasuwan and Miles (2009:158) in their report also included challenges such as difficulties in communication and learning facing children with Autism. This is due to issues related to emotional expression and language impairments, which raise a need for single mothers to manage such behaviours. This extra care giving required from single parents is due to the child's lack of self-care skills, on-going dependency needs, and the need for these mothers to advocate on behalf of the child at school, mental health and social agencies. Counselling services or referrals for services like support groups might be very effective in helping to meet the emotional needs of these single mothers while they wait for intervention services to be implemented (Hutton and Caron, 2005:188). The following section will discuss the lack of resources as one of the challenges faced by single mothers in caring for their child with Autism.

2.4.2 Lack of adequate resources

In the case of Autism there is still a challenge of adequate resources, which results in a lack of effective coping methods of parents (Gupta and Singhal, 2005:66). Adequate resources, such as occupational therapy and speech therapy are very essential with regards to early intervention, especially when the child is in a junior phase at a special school. This is a critical period with regards to obtaining skills development of the child as literature also supports early intervention for a better prognosis of the child with Autism (Silkos and Kerns, 2005: 11). Single mothers face a major challenge in accessing resources with regards to intervention of the child and have financial implications, which serves as a limitation for the child to receive intervention

programmes at school because the child might need more than one intervention programme. These are speech therapy sessions, music therapy, more occupational therapy, and art therapy, which might be catered by the school. However, these are limited, and parents might need to access them in the community or in private organisations (Gupta and Singhal, 2005:66).

The special schools and the community, by not having enough resources, tend to block the transition between the individual, which is the child, parent and environment in fulfilment of the child's needs, which leads to a deprivation of the child's development. Research has shown that single mothers of children with emotional and behavioural disorders lack appropriate community-based services and resources needed to support work and family obligations (Montes and Halterman, 2008:825). These authors further mention that lack of resources that fit the special needs of the child can have a significant impact on work and family functioning, leading to a significant difficulty in establishing a work-family balance.

In South Africa there are not enough resources for parents of children with Autism, which poses a lot of challenges in how single mothers cope with their children. Difficulties include placement on long waiting lists, not obtaining services in schools or not being able to obtain any services in the community (Hutton and Caron, 2005:180). The authors also highlight that more challenges are experienced by single mothers when the child is placed in a special school as there are serious financial implications for these mothers as they try to seek additional interventions for their child, like more access to speech therapy, occupational therapy and other interventions to assist with the developmental skills of the child. Despite all these challenges and lack of resources experienced by single mothers there are also additional challenges faced by them such as having multiple roles. Environmental stigma will be discussed as the next challenge for single mothers.

2.4.3 Environmental stigma

Studies conducted by Wahl and Harman (1989); Spaniol et al. (2003) and Cooney et al. (2006:327) showed that people with Autism Disorders experience stigma. Mothers and the parents of severely disabled children are more likely to perceive themselves as being stigmatised (Gray, 1993:116). There are unusual aspects of Autism that make normal social interaction difficult and that are significant in terms of stigma. Autism is often accompanied by extremely disruptive behaviour such as antisocial behaviours. Although problems with language, for

example, are common characteristics of the disorder, more troublesome symptoms such as tantrums, self-destructive acts and other forms of inappropriate public behaviour are also frequent and parents of children with Autism feel stigmatised because of child's disorder (Gray,2002:741).

Serious challenges are experienced by mothers of individuals diagnosed with chronic illnesses such as Autism (Gray, 1993:102). Mothers as primary care givers are more vulnerable to stigma than fathers because they assume the primary responsibility of caring for the child (Gray, 1993: 118). This means that the mother as a primary caregiver will be the parent taking more responsibility for the daily management of her child and will be the parent that may most likely deal with the child in ordinary public activities such as social activities and shopping. Mothers of autistic children may encounter more negative reactions from outsiders. For parents, these behaviours can lead to humiliation, social exclusion and isolation (Gray, 1993: 119).

It is important to provide short term and long term programmes that are geared to empower mothers against stigma (Dehnavi, Malekpour, Faramarzi, and Talebi, 2011:251) Public education and exposure to Autism Disorder is needed to increase society awareness. There is a strong relationship between stigma and mental health of mothers, especially stress, which is associated with caring of a child with a disability (Gray, 1993:119). In light of the above discussion it is not a surprise why single mothers are more vulnerable to stress.

2.4.4 Parental stress

Research findings reported by Gray (1993:103) found that parents of children with Autism experience higher levels of emotional stress as well as other feelings like anxiety and depression. Caring for the child with Autism has fallen predominantly on the mother, who may as a result experience low parenting competence, significant levels of chronic stress and fatigue (Gupta and Singhal, 2005:64). In some families, single mothers have shown to suffer higher levels of anxiety and depression than fathers of children with Autism (Civic, 2008:44). The reason for this is not clear; one can speculate that mothers tend to assume primary responsibility for day to day care of the child. Raising a child with a disability is a life changing experience for any parent, especially single mothers who have to raise a child with a disability without the support of another parent. Another concern for the mothers is their children's dependency on the care of others and that the most stressful factors associated with a child with Autism is the concern over the future and the

permanency of the condition (Pisula, 2007:4). One of the experiences reported in recent studies by parents included feelings of isolation and stress (Jadine, 2008:42).

Single mothers of children with Autism often feel a sense of isolation, especially when there is lack of support in their lives. Studies conducted from interviews with parents from sixteen families concerning their lived experiences of having a child with Autism revealed that these parents experienced a sense of living in a world of their own. This essentially reflects a sense of isolation which was identified by these parents as stemming from the society's lack of understanding about the disorder, missing a 'normal way of life, feeling disconnected from family, and an unsupportive system' (Woodgate and Secco, 2008:1078). This risk appears to be especially true for those unmarried mothers who are truly single, without a supportive partner and who are either unemployed or are working full-time (Gottlieb, 2001:10). This forces the single parent to withdraw from society, and limits the mother's choices of social support, which can reduce stress. Some of these challenges start when parents try to seek a diagnosis. Parents of children with Autism can become increasingly socially isolated at the time of diagnosis (Huws, Jones and Ingledew, 2001:571). One of the factors that have been shown to increase the isolation in parents of children with disabilities is when the child has behavioural problems.

2.4.5 Behavioural and cognitive problems in autistic children

Single mothers who are raising children with developmental disability face enormous challenges, especially when there are serious behavioural problems that accompany the disability (Ekas and Whitman 2010:1202). These behavioural problems might include tantrums, self-stimulation, inappropriate use of their bodies through flapping, feeling through smelling and uttering objects, showing signs of improper forms of social interactions, which characteristics lead to stereotyped and common prejudice in society (Mak and Kwok, 2010: 2045). These behaviours are associated with causing a lot of stress for single mothers. Boyd (2002:213) suggests that both parent and child characteristics play a role in parents' decisions to seek social support, and highlights two of the most significant characteristics of the child that lead mothers to seek social support, namely the child's cognitive limitations and behavioural problems (Barker, 2003:217).

Cognitive limitations place a greater degree of stress on mothers because of the potential long-term dependency that comes with it. Baker (2003:217) also highlight that even with interventions, mothers of children with significant cognitive limitations were more stressed than

mothers of children with less severe cognitive impairments. The behavioural issues may present more of a challenge to mothers than cognitive ones because of the potential scrutiny parents face from society, and perhaps from friends and family (Boyd, 2002:213). These dramatic situations often lead to higher levels of stress and depression in mothers. The role of social support is now discussed.

2.6 THE ROLE OF SOCIAL SUPPORT

Dunst, Trivette and Cross (1986:403) defined social support as being a multidimensional construct that includes physical and instrumental assistance, sharing of information and resources, which provide emotional and psychological support. The term may also refer to formal services received by professional organisations and less formal organisations, such as social clubs or churches, which the family feel is important to their lifestyle (Dunst, Trivette and Cross 1986:403). These definitions can be summed to define social support as a network of individuals who are able to provide information, resources, and emotional and psychological support through either formal, professional services, or through less formal mutual involvement within a family, friendship or social group.

Social support is able to act to facilitate coping with crisis and adaptation to change (Cobb, 1976: 300), and may act as a mediator of stress by influencing how well parents are able to cope with the demands of raising a child with a disability, as families who report higher levels of social support generally report lower levels of stress (Boyd, 2002:214). Parents who do not have effective support networks may have few people to provide respite care, and thus will have very few breaks from the continual pressure of caring for their child, which leads to increased pessimism, exhaustion and risk of burnout (Perry, Factor and Freeman, 1990:139). There are few studies that have examined parents' own perception of needs and whether they felt their needs were met. Parents of children with Autism frequently turn to Autism services providers to access support designed to help with the adaptation to the challenges of having children with a life-long impairment (Siklos and Kerns, 2006:932).

Siklos and Kerns (2006:933) in their study conducted in India reported that the availability of professional help, leisure in which one can engage in recreational activities, as well as support from community programmes geared towards families of children with Autism enhanced social support. However, this is not always possible with regards to availability of services and

resources geared towards families with autistic children in South Africa. There are few community programmes and recreational activities for autistic children. Due to this lack of social support in the community, parents find themselves struggling with their child and not knowing what to do. This challenge creates more stress and places parents at a risk of psychological well-being.

The presence of social support may lead to more positive perceptions of the family environment as it is linked to more stable functioning, a more positive perception of the child, and can enhance the parent-child relationship (Meral and Cavkaytar, 2012:125). In a study conducted by Dunst, Trivette, Hamby and Pollock (1990:167) they reported that parents with increased supportive social networks felt less of a necessity to overcompensate by being overprotective of their child regardless of the child's disability. This study also found that parents who had increased supportive social networks their children were likely to have made more developmental progress. These findings suggest that positive social support received by the parents, the less stress associated with raising a child with a disability and the more positive relationship established with their child. As parents with increased social support may be more willing to allow their child to try out new things with their skills and provide them with more independence, which may explain why these children made greater developmental progress.

The effectiveness of support networks has been found to have a more positive effect on the parental self-esteem than the size of the network (Seybold, Fritz and MacPhee, 1991:29) thus a small, actively helpful family or group of friends is more effective at increasing a parent's self-esteem than a larger, less active support group. Social support enriches the parent's quality of life and can improve parental attitudes towards their children (Meral and Cavkaytar, 2012:21). While it is acknowledged that social support is an important factor in reducing the stress of parents with children with disabilities, research has found that families of children with disabilities have less social support available to them than families of typically developing children (Dunst et al., 1986:167).

There are two different types of support which research studies have been proven to be the most effective coping method for parents of children with disabilities, namely formal support and informal support. According to Gottlieb (2001:10), informal support includes support that is received from one's spouse and family. Formal support includes parent support groups which

provide a means of social support within the framework of an educational or community setting and provides a space where the mothers feel free to discuss their concerns about rearing a child with Autism (Luther, Daryl, Canham, and Cureton, 2005:40).

2.6.1 INFORMAL SUPPORT

Research studies done on single mothers of children with disabilities has shown that mothers who had support from their male partners experienced greater psychological well-being and less depression than those with a non-supportive partner or no partner (Gottlieb, 2001:10). Partners in these relationships might serve as a source of emotional support as having someone to talk to and listen to their difficulties about the child is experienced as a positive factor in reducing their stress. These partners could also share daily roles of child care at home. However, it has been proven that mothers who are unemployed and do not have a partner may feel especially isolated and experience substantial role imbalance (Gottlieb, 2001:11). The reality is that in South Africa there is still a lack of resources about services that are geared towards assisting families with children who have Autism (Gupta and Singhal, 2005:79). For single mothers who have no spousal support, intervention programmes need to be available for the coping of such parents, and one of these interventions is formal support. In this study the majority of the fathers had no role to play in their child's life. In the instances where participants were staying with extended families, the family members provided supportive roles with respect to sharing the daily responsibilities of child care.

2.6.2 FORMAL SUPPORT

Formal support groups are regarded as parent support groups which provide means of social support within the framework of educational or community setting (Luther, Daryl, Canham, and Cureton, 2005:40) and provide a space where the mothers feel free to discuss their concerns about rearing a child with Autism. The support groups provide a platform whereby the parents can relate to other parents who are facing the same difficulties. Research studies have shown that support groups have been proven to be an effective method in reducing stress and provide healthy adaptation for parents of children with disabilities (Boyd, 2002:214). However, support groups for parents with children who have Autism are few because of limitations of resources in this field.

Given the challenges that face single mothers of children with Autism, more support groups are needed in the communities. Service providers should create more services that will be easily accessible to parents; this is the area which needs development in order to promote good mental health and wellbeing of single mothers (Bromley, Davison, Hare, and Emerson, 2004:409). This expansion of this social support can help parents build a strong social support network to facilitate effective coping mechanisms for single mothers so that they don't feel alone in their challenges (Huws, Jones and Engeldew, 2001:570).

Another form of support needed are training and information support groups. These groups provide mothers with information on how to manage difficult behavioural problems associated with the characteristics of the disability (Gupta and Singhal, 2005:70). The authors further highlight that these forms of groups and interventions which focus on parents' coping skills have reported positive results. Future studies and research are needed to establish the availability of support groups, the types of services parents have been utilising and parents' knowledge about the types of services available to them. This information is important to determine accessibility of resources and determine changes in the service delivery system.

2.5 CONCLUSION

This chapter presented the literature review and provided background information on the challenges experienced by single mothers of children with Autism. The following chapter discusses the methodology used in this study.

Chapter 3 METHODOLOGY

3.1 INTRODUCTION

This chapter presents details of how this study was conducted. It includes the research design, sampling, data collection, data analysis, data verification and the limitations of the study.

3.2 RESEARCH DESIGN

An explorative, qualitative research design approach was adopted for this study. This kind of research design can describe and create understanding of the problem at hand (Babbie and Mouton, 2001:270). The key objective of qualitative research design is of “describing and understanding” (Babbie and Mouton, 2001:270). This was illustrated in this study, which explored the perceived challenges of single mothers with children diagnosed with Autism at a junior phase at Vera School. Babbie and Mouton, (2001:270) further outline a number of significant elements pertinent to qualitative research design, which are “naturalism, process, insider perspective, description and understanding, contextual interest, inductive approach and inter subjectivity”. De Vos et al. (2011:308) state that a qualitative research design is conducted to produce more in-depth, comprehensive information from its participants using subjective information and participant observation to describe the context or the natural setting of the variables under consideration, as well as the interactions of the different variables in the context of gaining a wide understanding of the entire situation.

Qualitative research emphasises the importance of looking at variables in their natural setting in which they are found in order to describe and understand actions and/ or events being researched. The interaction between the variables is important in this approach, and detailed data is gathered through open-ended questions that provide direct quotations where the interviewer is an integral part of the investigation. Qualitative research is not designed to generalise its findings, but rather to contextualise the findings (Babbie and Mouton, 2001: 270).

In the context of this study it was imperative that the data gathered was a personal and detailed account of the perceived challenges of the participants. The reason for this was that the aim of the study was to explore single mothers’ views on the challenges experienced with autistic

children; a qualitative research approach therefore was more preferable as opposed to using a quantitative approach.

3.3 RESEARCH TYPE

The research type selected for the study was phenomenological research. Phenomenological research aims to describe the psychological meaning of several individuals of their lived experiences of a particular phenomenon (Creswell, 2007:60). The researcher has become more interested in developing a greater understanding of people's lived experiences of certain phenomena which are the experiences of single mothers with children diagnosed with Autism. Babbie and Mouton (2001:271) also add that Phenomenological research attempts to view human behaviour as a product of how people interpret their world, and the task of the researcher in this study was to capture that process of understanding the person's point of view by putting themselves in the shoes of the participant.

3.4 SAMPLING

Babbie and Mouton (2001: 164) describe sampling in qualitative research as the selection of individuals to be studied making use of individuals or units with characteristics relevant to the research question which are not statistically determined. Non-probability sampling is the most commonly used sampling technique in qualitative studies. In non-probability sampling the odds of selecting a particular individual are not known because the researcher does not know the population size or the members of the population (De Vos et al., 2011:231 cited Salkind 2000; Gravetter and Forzano 2003).

A non-probability, purposive method was used in this study. The single mothers of the learners with Autism were purposively selected. In purposive sampling a particular case is chosen because it illustrates some feature or characteristics, representative or typical attributes of the population that serve the purpose of the study (De Vos, et al., 2011:232). Creswell, (2007:125) argues that this form of sampling is used in qualitative research and that the participants and sites are selected that can purposefully inform an understanding of the research problem of the study. The search for data must be guided by processes that will provide rich detail to maximise the range of specific information to be obtained from and about the context. In this study a particular site has been chosen, which is Vera School. Purposive sampling selects participants that are most

representative of the respective group of people that will provide the most informative responses in relation to the area of interest of the study (Babbie and Mouton, 2001: 277).

The sample of the study consisted of single mothers of learners from the junior phase of Vera school. Before the researcher began with the research, the researcher approached the school, in order to receive permission to conduct the research study. The processes of getting permission also involved submitting a written proposal of the study to the Western Cape Education Department. Following the receipt and consideration of the proposal a permission letter was sent to the researcher giving permission to conduct the study (See Appendix F). The researcher approached the school again and was referred to the school psychologist. The researcher provided all the information about the study to the school psychologist. The school psychologist and the researcher then discussed the selection criteria to be followed and the information sheets (see Appendix B) were given by the researcher to the psychologist. The psychologist approached the potential participants informing them about the study and asking the participants permission to give their contact details to the researcher. After the participants gave permission to the psychologist to provide the researcher with their contact details, a list of 25 single mothers who were comfortable to participate in the study was provided to the researcher by the psychologist. However, only 15 single mothers were able participate in the study and this was due to their work commitments. Although this was a small sample, a qualitative research generally selects a relatively small sampling group (De Vos et al., 2011:308).

3.5 PILOTING

According to Kelley, Clark, Brown and Sitza (2003:263), the purpose of the pilot study is to conduct the research design for a probable study in an attempt to evaluate its feasibility. The pilot study enabled the researcher to identify areas that may have been previously overlooked. In qualitative research the pilot study is usually informal, and the few parties who have the characteristics of the main investigation can be involved in the study. The purpose is to determine whether the relevant data can be obtained from the participants (Royse, 1995:172). In addition, it allows the researcher to focus on specific areas that have may have been unclear previously or to test certain questions. A small number of participants, characteristically similar to those that have been used in a main investigation, were selected for a pilot study. Two

participants - two single mothers, were interviewed to test the semi-structured interview, the questionnaire, and the digital voice recorder.

3.6 DATA COLLECTION

3.6.1 Data collection method

De Vos et al. (2011:342) express the use of interviewing as a valuable data collection method in that it allows the participants to express their experiences that engage both the participants and researcher as well as having the potential to open up interaction. The process of qualitative interviewing allows the participants to mostly guide the interview, yet allows the researcher to explore relevant areas. Bryan (2012: 477) adds that semi-structured interviewing is a beneficial data collection method when the research relies on personal accounts and/ or experiences as the main source of data. The nature of this research was dependent on the experiences of the challenges of single mothers at Vera School. One-to-one semi-structured interviews focus on the respondent's perceptions, and semi-structured interviews guide the direction of the interview yet allow for flexibility of the semi-structured interview schedule. Semi-structured interviews allow for the participants to be seen as professionals as they predominantly guide the direction of the interview through their responses (Babbie and Mouton, 2001:503).

In this study a qualitative design technique of one-to-one semi-structured interviewing was used to explore the perceived challenges of single mothers with children diagnosed with Autism. In-depth interviews are best used to explore these objectives as interviews allow participants the opportunity to relay their detailed interviews, experiences and feelings around issues. In this way the researcher obtains richer data which provides him or her with a better understanding of the problem (Sarantakos, 2012:278). The sequence of the semi-structured interview in addition to the literature review aids the researcher in the direction that the interview schedule should take (De Vos et al., 2011:351). Fifteen semi-structured interviews were conducted with single mothers of children with Autism at Vera School. These were conducted at the venue of the participant's choice; some interviews were held in the participant's workplace during their lunch hour, others in the researcher's office, while others in their homes after working hours and even weekends when child-care arrangements were made with family members or relatives. Each interview was about 40-60 minutes long as single mothers had limited time due to their work constraints and

responsibilities. After obtaining ethical clearance from the University of Cape Town, Vera School and Western Cape Department of Education authorities (see Appendix F), the researcher approached the participants. Prior to the commencement of the study, written information about the study (see Appendix B), its aim as well as a consent form (see Appendix C) was given to participants. Those who participated in the study were asked to provide a signed informed consent and contact detail sheet (see Appendix D).

3.6.2 Data collection instrument

A semi-structured interview schedule guide (see Appendix E) was also developed. The semi-structured interview schedule provides the researcher with present questions that allows for the participants to expand by providing more detailed accounts of subjective experiences (De Vos et al., 2011:340). It is useful for the researcher to become acquainted with the relevant literature around the topic that is being researched in order to assist in assessing which areas or issues that arise during the interview are relevant to explore and that will ultimately aid in gaining new data (De Vos et al., 2011:340). This enabled the development of the outline for the semi-structured interview schedule. From the literature review the researcher was able to identify key areas essential to the research study. These were identified as pertinent to exploring and understanding the relevance of the study. This semi-structured interview guide provides the researcher with a set of predetermined questions that were used as an appropriate instrument to engage the participant and designate the narrative terrain (Holstein and Gubrium 1995:76; Monettee, 2005:178). The participants in this study were given a choice about the venue where the interviews were to be conducted. The researcher also handed the interview schedule to the participant. She could then choose which particular question she wished to answer at a specific stage. This allows the participant to play a role in determining how the interview will proceed. If the interview moves away from the questions on the schedule, the decision was taken by the researcher on how much deviation is acceptable.

3.6.3 Data collection apparatus

A digital recording device was used with the permission of the participant to record the face-to-face interview. De Vos et al. (2011:350) explain that a data recording device allows for a more detailed and accurate account of recording the interviews. This improves the reliability and validity of data gathered. The digital recording device was chosen as the preferred method of

data collection apparatus for this study. The advantage of using a digital recording device was that the researcher was able to focus on non-verbal cues of the participant rather than focusing on writing notes. This improves the reliability and validity of the data being gathered. This type of data collection apparatus enabled the researcher to obtain all of the data from the interviews and to be able to replay them in an attempt to improve reliability of the transcriptions and furthermore provide adequate data analysis (De Vos et al., 2011:402).

3.6.4 Data analysis

Schwandt, (2007:6) describe data analysis as a process of bringing together, structuring and making meaning of the mass of collected data. De Vos et al., (2011:397) state that it involves reducing the volume of raw data information, shifting significance from trivia, identifying significant patterns and constructing a framework for communicating the essence of what the data reveals. Once all the interviews had been conducted the recorded interviews were transcribed and then analysed according to the steps for analysing qualitative data devised by Tesch (1990). Transcribing interviews involves converting spoken words of the recorded interview into written words. The interviews were transcribed by the researcher and arranged into themes, categories and subcategories according to Tesch's (1990) eight steps for data analysis as follows:

The researcher familiarised herself with the transcriptions and paid close attention to patterns and similarities across the interviews.

The researcher went through each transcription and made notes of the interview in relation to emerging themes.

The researcher then repeated steps 1 and 2 for all the transcripts. She then listed the topics, themes, categories and sub-categories.

The listed topics were coded and divided up categorically. Additional categories that emerged were added into the existing structure.

The researcher selected the most appropriate description for each theme, category and sub-category that most accurately described what each section contained.

The researcher made decisions regarding the categories and arranged them alphabetically.

All the data applied to a particular category was collated and analysed. This was done for every category and ultimately created the initial analysis.

The researcher had to recode any existing data where it was necessary.

3.7 DATA VERIFICATION

Lincoln and Guba (1985) describe a series of techniques that can be used to conduct a sound qualitative research, which consists of four concepts that are: credibility, transparency, dependability and conformability. These concepts are discussed below:

Credibility refers to compatibility between the researcher's reconstruction of the participants' views, and the views of the participants themselves (Schurink, Fouche and De Vos et.al., 2011:310) A prolonged engagement in the field is recommended in order to increase the credibility of the research (Lincon and Guba, 1985). The researcher spent 40-60 minutes interviewing each participant in order to have time to establish rapport and gain a fuller understanding of the participants' perceived challenges of raising a child with Autism. Referential Adequacy is another recommended procedure for achieving credibility, which refers to material used to document the findings. Transferability refers to whether the findings are applicable in other situations or with other participants. The researcher recorded and transcribed all the interviews in order to capture the content of the interviews correctly. While qualitative research does not claim that data from one context will be necessary for another context (Babbie and Mouton, 2001:270), the researcher attempted to provide the readers with a detailed description of the research collected. The readers are more able to judge whether the findings are transferable if the descriptions of the data collected and the findings reported are sufficiently detailed (Babbie and Mouton, 2001: 270).

Dependability involves the reader with evidence that similar findings would be discovered if the study were repeated in the same or similar context or with similar participants (Babbie and Mouton, 2001: 270). The researcher explored literature on single mothers raising children diagnosed with Autism. Giallo, Wood, Jellett and Potter, (2011:80) indicate that caring of the child with Autism is associated with high levels of parental stress, fatigue and stigma.

It is also well documented in research internationally that many parents of children with Autism face multiple and demanding roles in their lives (Gottlieb, 2001:11). Researcher found that social support may lead to more positive perceptions of the child diagnosed with Autism, and can enhance the parent-child relationship (Meral and Cavkaytar, 2012:125). Dehnavi, Malekpour, Faramarzi and Talebi, (2011: 257) also indicate that public education and exposure to Autism minimises stigma experience by single mothers in raising a child diagnosed with Autism. The literature provided the researcher with evidence that similar findings have been discovered internationally, and this suggests dependability of the research study.

Confirmability refers to whether the findings can be confirmed by somebody else (Shurink et al., 2011). Sufficient evidence should therefore be left to trace the findings and interpretations of their sources (Babbie and Mouton, 2001). The researcher has physical evidence of the process of data analysis, which illustrates the concrete manipulation of the data into themes. Confirmability also relates to the extent to which the findings are the result of the focus of the research rather than researcher bias. The researcher had regular discussions with her supervisor regarding the methodology and research findings, which helped reduce researcher bias.

3.8 LIMITATIONS

The limitations of this study pertain to:

3.8.1 Research design

A qualitative research design was chosen for this study as the subjective experiences of the participants were necessary to explore of the problem being researched. According to De Vos et al. (2011), a limitation of qualitative research is where the findings from that research cannot be generalised in a larger population. For this particular research the findings did not need to reflect that of the general population, but rather the subjective experiences of the participants.

3.8.2 Data collection approach

The data collection approach used here was that of one-to-one semi structured interviews. De Vos et al. (2011: 328) describe how interviewing provides rich, in-depth data. The limitations of this data approach is that interviews are time consuming, not only for the researcher but also for the participants who agreed to participate in the interviews during their lunch time at work,

sometimes after working hours and even at weekends. Despite this limitation the participants were to be present for the duration of the interview. The participants who worked on a full-time basis were available weekends.

3.8.3 Data collection instrument

According to De Vos et al. (2011: 328), the limitation of using a semi-structured schedule is related to the reliability of this data collection instrument. In this way the researchers may focus too rigidly on the semi-structured schedule thus overlooking important issues being raised by the participants. The researcher followed the semi-structured schedule as a guide and remained flexible to explore relevant topics raised by the participants.

3.8.4 Data collection apparatus

The researcher used a digital recording device to record all the interviews. A limitation of a digital recording device is that some participants may feel uncomfortable being recorded and even the participants that consented to being recorded may continue to feel uncomfortable thus impacting on their responses (De Vos et al., 2011:328). The researcher ensured that the recording device was placed close to the respondent without making her feel uncomfortable. In addition, the researcher also reminded each respondent about continuing to adhere to confidentiality during the interview.

3.8.5 Data analysis

De Vos et al. (2011: 397) explain the limitations of data analysis in that it is largely time consuming and needs to be done correctly to ensure the outcomes of accurate results. The researcher began transcribing the interviews as soon as they had been completed and adhered to the appropriate steps of data analysis outlined by Tesch (1990).

3.8.6 Researcher bias

Researcher bias is a limitation on the part of the researcher within which a conducted study has a potential to alter the results and outcomes of the research being conducted (De Vos et al., 2011:397). The researcher had supervision and maintained an open- mind and non-judgemental attitude to the study as well as to the participants who controlled for researcher bias throughout this study.

3.9 CONCLUSION

This chapter discussed the methodology of this study, which comprised the research design, sampling, data collection, data analysis and possible limitations. The penultimate chapter presents the findings of the study.

Chapter 4 FINDINGS

4.1 INTRODUCTION

This chapter presents the findings of the study. A demographic profile of the participants is provided followed by a framework of the analysis and a discussion of the findings using the research objectives as headings. Lastly, some concluding remarks complete the chapter.

4.2 DEMOGRAPHIC PROFILE OF PARTICIPANTS

Table 1- Demographic Profile of Participants

| PARTICIPANTS | AGES | HOME LANGUAGES | AREA OF RESIDENCE | HOUSEHOLD MEMBERS | NUMBER OF CHILDREN | EMPLOYMENT STATUS | HOUSEHOLD INCOME |
|--------------|------|----------------|-------------------|------------------------------|--------------------|-------------------|------------------|
| 1 | 27 | English | Heideveld | Self, Son, mother and father | 1 | Employed | R7,000pm |
| 2 | 29 | English | Observatory | Self and son | 1 | Employed | R6,600pm |
| 3 | 32 | English | Rondebosch | Self ,son and mother | 1 | Employed | R,7000pm |
| 4 | 35 | English | Wynberg | Self and son | 1 | Employed | R8,000 pm. |
| 5 | 36 | English | Bonteheuwel | Self, son and 3 siblings | 4 | Employed | R9,000pm. |
| 6 | 35 | English | Elsies River | Self, son and mother | 1 | Employed | R6,500pm |
| 7 | 37 | English/ Xhosa | Gugulethu | Self and son | 1 | Employed | R6,500pm |
| 8 | 33 | English | Rondebosch | Self and son | 1 | Employed | R14,000pm. |
| 9 | 32 | English | Strand | Self and son | 1 | Employed | R7,500pm |
| 10 | 35 | English | Rondebosch | Self and son | 1 | Employed | R29,000pm. |
| 11 | 33 | English | Heideveld | Self and son | 1 | Employed | R7,000pm. |
| 12 | 36 | English | Rondebosch | Self and two daughters | 2 | Employed | R30,000pm |
| 13 | 37 | English | Wynberg | Self and son | 1 | Employed | R7,000pm |
| 14 | 36 | English | Observatory | Self and son | 1 | Employed | R20,000pm |
| 15 | 33 | English | Hanover park | Self, son and 3 siblings | 4 | Employed | R17,000pm |

4.3FRAMEWORK OF ANALYSIS

Table 2- Framework of analysis

| OBJECTIVES | THEMES | CATEGORIES AND SUB-CATEGORIES |
|--|---|--|
| 4.4.1 Objective: 1 Challenges facing single mothers before their children were placed at the school. | 4.4.1.1 Challenges prior to the diagnosis of Autism | 4.4.1.1.1 Understanding the symptoms of Autism. 4.4.1.1.2 Numerous referrals of consultations. 4.4.1.1.3 Limited information about Autism 4.4.1.1.4 Reliance on Media 4.4.1.1.5 Receiving the diagnosis. |
| | 4.4.1.2 Challenges experienced after the diagnosis of Autism | 4.4.1.2.1 Taking time off at work. 4.4.1.2.2 Limited resources 4.4.1.2.3 Financial problems 4.4.1.2.4 Long waiting list for admission to special school |
| 4.4.2 Objective: 2 Perceived Challenges facing single mothers after their children were placed at school | 4.4.2.1 Stress related to parenting | 4.4.2.1.1 Stress of Multiple roles. 4.4.2.1.2 Financial stress of being the breadwinners 4.4.2.1.3 Public Stigma 4.4.2.1.4 Social Isolation. |
| 4.4.3 Objective: 3 Support services that single mothers are aware of in assisting them in caring for their child with Autism | 4.4.3.1 Support services for parents | 4.4.3.1.1 Support from staff 4.4.3.1.2 School's Transport support 4.4.3.1.3 Aftercare support services |
| 4.4.4 Objective: 4 Single mother's perceptions of support they are receiving from the school | 4.4.4.1 Teacher support | |
| 4.4.5 Objective: 5 Recommendations single mothers made in terms of support offered to parents | 4.4.5.1 Parent support group. 4.4.5.2 Educational workshops. | |

4.4 DISCUSSION OF FINDINGS.

The findings of this research have been presented in relation to the research objectives:

4.4.1 OBJECTIVE 1. CHALLENGES FACING SINGLE MOTHERS BEFORE THEIR CHILDREN WERE PLACED AT VERA SCHOOL

4.4.1.1 Challenges prior to the diagnosis of Autism

All the participants in this study expressed that they experienced challenges with their children before the children were admitted to a special school. These problems were first experienced before their children were diagnosed with the condition. The participants reflected a wide range of concerns. These included areas such as understanding their child's symptoms, numerous medical consultations, limited information about Autism, reliance on media for information about Autism, taking time off work and finally receiving the diagnosis. This section explores the challenges experienced by the participants before their children were diagnosed with Autism. The first challenge to be explored is that of understanding of the symptoms of Autism.

4.4.1.2 Understanding the symptoms of Autism

The majority of the participants described a wide range of experiences associated with understanding the symptoms of Autism in their children. Findings from the participants also revealed that they felt frustrated because they could not make sense of what was happening to their children. These participants described a time of uncertainty in their lives. This was characterised by difficult emotions such as sadness and doubts, which in some cases led to the participants questioning their parenting skills as they become desperate for answers as to why their child was different. The following statements reflect these experiences.

“I was really concerned about my son, there was something different about him, but I did not know what it was, I thought it was me that I was not coping, but when he was one year and eight months, I was really worried. He would cry a lot and bang his head and hurt himself, he was not feeling any pain, and I became more worried. There was a lot going on with him, mmm I could not connect with him, I tried everything”. (Participant: 5)

“I was concerned about her since the age of six months. She would, cry, cry, and cry....and I was not able to comfort her, and she would not stop crying for hours, Oh....., I tried everything. It was terrible, I tried to bond with her, it was extremely hard and I felt inadequate as a mother. Eventually, I had depression”. (Participant: 3)

“I could tell there was something wrong with him since he was a baby, but I did not know what it was. My mother kept on saying there is nothing wrong with him he looks normal I’m over reacting, all babies are different. I was just not bonding with him, I could not tell what he wants, he was not maintaining eye contact, and I thought he was deaf. It was really frustrating. There was a lot going on. I thought it was me. I just did not understand my baby”. (Participant: 15)

Findings in this study indicate that all of the participants were aware of early abnormalities in their children’s development. This finding concurs with research by De Giacomo and Fombonne (1998:1) which indicates that about ninety per cent of parents of autistic children recognise these symptoms in their children before the age of twenty four months. Blackledge and Hayes (2006:1) also indicate that in making sense of these symptoms parents of autistic children are vulnerable, and this poses a risk to their mental health. The researcher observed that the participants were struggling with their emotions such as sadness and grief and could recall with clarity how difficult it was for them to understand their children’s symptoms. Some of the participants were noted by the observer to feel relief at finally knowing what was different about their children. Numerous medical consultations were also perceived as another challenge facing the participants.

4.4.1.3 Numerous medical consultations

The majority of the participants felt frustrated with the numerous medical consultations they had to experience to establish what was wrong with their children. This frustration was particularly felt around being referred from one clinician to another and yet nobody could really tell them what was wrong with their children. The statements below reflect some of the participants’ frustrations with the numerous referrals.

“I was concerned about my son, speech was a problem, and he was not doing what other children were doing, so I took him to see a normal doctor (General Practitioner). The doctor

referred me first for the scan and blood test. I was then referred to the state hospital for hearing tests, speech therapy and occupational therapy. Speech therapy said there were some concerns about my son and she (speech therapist) referred me to the Developmental clinic at the state hospital where again I saw another doctor and they finally made the diagnoses of Autism; by that time he was about one year and eight months. It was a very long process, but what can I do? Except to be patient". (Participant: 1)

"My real concern at first was that he was deaf, because he was not responding to his name, and then he just stopped talking, he was babbling, so I took him to a paediatrician. He (the paediatrician) referred him for a scan and some blood tests. Then he told me he suspects Autism, but he was too young to confirm the diagnosis. So..... he referred me to the state hospital, for hearing tests, speech therapy and occupational therapy. I was told there is nothing wrong with his hearing. There were some concerns from the speech therapy and occupational therapy, so again I was referred to the developmental clinic which was in a state hospital. I saw the doctor and he said my son has Autism. By that time, he was one year and eight months. It was a long and frustrating process". (Participant: 2)

Siklos and Kerns (2005:922) in their study indicate that parents of children with Autism experience hardships in attempting to obtain a diagnosis for their child. The findings are also consistent with that of Hutton and Caron (2005:187) who found that parents' perceptions about the system of diagnosis results in months of waiting, numerous referrals and in some cases very late and inaccurate diagnosis. These findings also indicate that problems with these numerous referrals present serious coping challenges for the participants. After many months of consultations with doctors and clinicians additional challenges were experienced by the participants who had limited information about Autism.

4.4.1.4 Limited information about Autism

All of the participants expressed that they were not given a clear explanation of what Autism entails and what the causes are. They all expressed that the diagnosing professionals were vague in their explanations of what Autism is. In order for the participants to understand this limited information about the diagnosis, the participants were encouraged to research the information themselves using media.

“I did not know or understand what Autism is; I thought it was Down’s Syndrome because nobody could give me a clear explanation of what it is or what’s causing it. The doctor just told me to watch the movie called ‘Rain man’ so that I could understand.” (Participant: 4)

“I was just told that my son has a disability called Autism. I asked what caused it and he (doctor) gave me a vague explanation and said they are not sure what’s causing it. I needed more information about this condition and they did not have any readings on it. The doctor then suggested that I can Google it on the internet and read up on it so that I can understand about the disability.” (Participant: 7)

This finding is consistent with research by Volkmar, Chawarska, and Klin (2004: 315) who reveals that information on Autism in infants and very young children is limited in South Africa. It has become clear to the researcher that the diagnosing professionals need to make the information on Autism more accessible to parents. With such limited information about Autism, the participants relied on the media to access more information about the condition.

4.4.1.5 Reliance on the media for information

The majority of the participants in the study indicated that they relied on the media such as the internet and television programmes to access information about Autism. The participants expressed that they could relate to the symptoms explained in the media because those symptoms resembled those of their children. This was shown to have a positive effect in their understanding of the disability. The statements below reflect the positive impact the media had in understanding Autism.

“My mother was watching TV, there was this “Oprah” programme which was playing and she called me to come and listen. I was just amazed at what they were saying, like the head banging, rocking himself, they were talking about what my son was doing. He had all those things. Then, I started to google it more, but there was too much information on the internet about Autism and it was confusing. I just focussed on the symptoms my son was having. At least then I could understand it”. (Participant: 5)

“I relied on books from the library, internet and magazines to understand the diagnosis of Autism”. All I could do was just to read....read ...read”. (Participant: 2)

This finding concurs with Huws, Jones, and Ingledew (2001:569) who found in their study that parents of children with Autism have difficulties obtaining adequate information about Autism disorder. However, with the growth of technology there are opportunities for parents to access information about Autism. Data captured from participant number two also reveals that the participants can be overwhelmed by information obtained from technology. These findings concur with literature by Mackintosh, Myers and Goin-Koshel, (2005:41) that parents of children with Autism are starved of information about the disorder but in the process can be swamped in obtaining what's most accurate about it. It became clear to the researcher that it is problematic to obtain accurate information about Autism diagnosis in children, which creates serious challenges for the mothers to understand their child. The following section presents emotional challenges faced by the participants when their children are finally diagnosed with Autism Disorder.

4.4.1.6 Receiving the diagnosis of Autism

All of the participants clearly remembered what it was like for them when receiving the diagnosis of Autism. It is clear in this study that the participants' experiences about their children's diagnosis was a defining moment in their lives, which many of them still recall with great clarity. The biggest concern was that around the permanency of the disability. These experiences from the participants reflected a sense of enormity and loss, which they described feeling when their children were diagnosed with this condition. The diagnosis meant a sudden loss of an imagined future for their children, which parents take for granted, like the child getting married, living independently, and many more. The following expressions reveal the impact of these experiences.

“Mmm.....I would never forget that moment....mmm ...when the doctor told me that my son has Autism, I was in a state”. (Participant: 3)

“I was shocked and upset... When I was told that my child has Autism disability...then I cried”. (Participant: 8)

“It's so devastating when you are told the news.....about the diagnosis, that your child has a lifelong disability called Autism. It's really like somebody had ripped your heart out of your chest”. (Participant: 11)

“He is my only son..... I had a lot of dreams of what he would become as an adult; the thought of him not able to have the same things like other people is devastating. I don’t know what the future holds for him”. (Participant: 13)

This reaction was particularly felt when the participants received the diagnosis of Autism, which impacted on the participants’ emotional state. This finding supports that of Siklos and Kerns (2005:20) that parents of children with Autism react to the diagnosis of Autism with high stress levels. Hutton and Caron (2005:180) in their research also found that the way in which diagnostic information is conveyed to the family can have a long-term influence on parents’ attitude, parents’ levels of stress and coping strategies. It was clear from these participants that receiving this diagnosis presented serious coping challenges. Additional challenges were also experienced by the participants after the diagnosis.

4.4.1.7 Challenges experienced after the diagnosis

Additional challenges were also experienced by single working mothers after their children have been diagnosed as it caused problems in their work place. These challenges involved taking time off at work to attend their child’s therapy sessions.

4.4.1.7.1 Taking time off work

All of the participants in this study are single working mothers. The majority of the participants had to take time off work to take their child to different therapy sessions. They regarded this experience as very time consuming, especially because sessions were only available in the week. Some of the participants took their children to private occupational therapy and speech therapy but also felt they had to be absent from work to attend these sessions, which was also time consuming. The following quotes illustrate this:

“I had to take him first for occupational therapy at a state hospital; he also had to attend speech therapy. I had to take a day off at work each time because at outpatients at the state hospital, you can sit there the whole day and I was running out of family responsibility leave because I had to go there every month.” (Participant: 10)

“I had to take him to a state hospital every week for speech therapy and occupational therapy. I was really worried of being absent from work all the time.” (Participant: 7)

“I had to leave my full-time job so that I can take my son for speech therapy, occupational therapy. I would not have been able to do that if I was employed full-time. He needed the sessions regularly. I am now working part-time.” (Participant: 5)

Literature on families of children with a serious disability indicates that parents of children with disabilities seeking interventions for their child can have a significant impact on their work (Montes and Halterman 2008:e825). Data captured above corroborates the research finding that mothers of children with Autism pay the price of absenteeism at their workplace due to the demands associated with seeking interventions for their child (Cidav, Marcus and Mandell, 2012:618). Dehnavi, Malekpour, Faramaz, and Talebi, (2011: 256) state that many mothers of children with Autism had to give up their careers to take care of their children.

4.4.1.7.2 Limited resources

The majority of the participants expressed their frustration at access to limited resources such as occupational therapy and speech therapy to assist them with their child. The participants felt that due to the nature of their child’s disability their children needed to attend more therapies such as occupational therapy, speech therapy and many more recommended by the doctors. Participants who were referred to a state hospital expressed that they had to attend sessions once a month, which they felt was not sufficient. Some of the participants resorted to private services because they felt their children needed more than one session per week. Financial constraints emerged as a subcategory of limited resources. Due to state hospitals having limited resources some participants in the study felt they needed to take their children for additional interventions which are available in private services. These private services were regarded as very expensive. Participants who are earning higher salaries also expressed that they experienced financial strains, as reflected in the demographic profile table (table 1). These financial strains felt by the participants were due to the fact that the majority of the participants are the sole breadwinners in their families.

“My son had to attend speech therapy and occupational therapy at a state hospital once a month, I felt that was not enough.” (Participant: 13)

“Because speech was a problem, the doctor referred me to a state hospital because I did not have a medical aid. Then I should take him for speech therapy and occupational therapy

because he was delayed in his milestones. I went there once a month and I felt he needed more.” (Participant: 11)

“Raising a child with Autism is expensive, I had to take my son to private therapies and it was very expensive, it really puts a toll on your finances.” (Participant: 5)

The findings concur with research by Montes and Halterman, (2008:821) that families of children with Autism face substantial health care expenses related to their child’s care.

4.4.1.7.3 Long waiting list for admissions at the school

Ten out of fifteen participants expressed their dissatisfaction with long waiting lists for placements at special need schools for Autism. The main concern for the participants was the negative impact they felt their children were experiencing at normal day care crèches while waiting for placement. Their concerns were that their children were not receiving adequate care at these day care facilities and they highlighted that these day care centres were not equipped to look after special needs children. The participants also reflected that lack of communication from the school about the admission of their children was perceived as another challenge. This lack of communication from the school was perceived as a frustrating process.

“They told me there was a long waiting list for the admission at the school, they will give me a call when the space is available but they don’t tell you how long.” (Participant: 6)

“I kept on phoning to find out about the admission date for my son at the school, the school receptionist kept on telling me I will be contacted, she does not know when. And that they have a long waiting list. It took 2 and half years for my son to be admitted at the school.” (Participant: 14)

“I had no choice but to leave my child in a normal day care. I’m a single mother without support and I have to work to support us. The staff at the day care kept on complaining that my child needs constantly to be watched and they don’t have the staff capacity to look after him.” (Participant: 11)

This challenge is consistent with the findings of Lall, Campbell and Gillborn, (2004:9) in their study on parental involvement in education; where parents feel frustrated at the nature of their relationship with schools, especially parents of special needs children. There are limited special

schools for Autism in South Africa, which impacts on the admissions' waiting list at the schools. The long waiting list creates frustration for parents of children with disabilities.

In summary, participants in this study expressed that they struggle alone with the challenges of raising their children with Autism even before their children attend a special school. The challenges included the lack of early identification of Autism symptoms by the diagnosing professionals, which results in months of consultations, numerous referrals, and limited access to information about the condition. Seeking interventions for their children also impacts on finances and work. All these struggles mentioned above by the participants reflect a lack of supportive structures for parents of children with Autism in their communities.

4.4.2 OBJECTIVE 2. PERCEIVED CHALLENGES FACING SINGLE MOTHERS AFTER THEIR CHILD HAS BEEN PLACED AT A SPECIAL SCHOOL

The results reflect the negative impact of the challenges experienced by participants even after their child has been placed in a special school as an emerging theme. Results indicate that due to these challenges a high proportion of the participants in this study experience high stress levels. These stressors have been individually explored. The first stressor to be explored is that of stress related to parenting.

4.4.2.1 Stress related to parenting

All of the participants in this study experienced stress related to the behavioural issues and the demands of raising their children. The participants who lived alone with their child without any family support experienced the most stress. Fatigue emerged as a key part of parental stress and all of the participants expressed struggling with fatigue in their lives. They expressed that balancing their daily duties as well as constantly monitoring their children was the major reason for feeling fatigued.

This experience of feeling fatigue was associated with the daily demands of caring for their child with Autism.

“He is the only one, but it feels like I’m having ten children. He needs a lot of attention and can throw a huge tantrum when he cannot have his way. I have to constantly watch him all

the time because if I don't, he can cause a lot of damage in the house like opening taps.”
(Participant: 15)

“My son needs to be watched all the time; he just cannot sit still, and causes a lot of mess in the house. I just leave things as they are. I'm constantly tired.” (Participant: 13)

“He is so..... busy, everyone in the house has a role to play, my mother and my sister take turns watching him, he just moves from one thing to another. It's tiring, that is why all of us must keep an eye on him. I don't know what to do at times, I just cannot manage him.”(Participant: 9)

“He gets aggressive with me at home, at school he is fine, I receive no complaints, and they (the school) must show me how they do it with him, so that I can do it too. It's really hard.”
(Participant: 10)

This finding is supported by Giallo, Wood, Jellett and Potter, (2011:80) who indicate that factors associated with high levels of fatigue are associated with stress-related demands of caring of the child with Autism. Research shows that the level of parenting stress is higher in parents of children with developmental problems than in parents of typically developing children (Baker, McIntyre, Blacher, Crnic, Edelbrock and Low, 2003:226). In addition to this stress and fatigue experienced by the participants there is an additional stress of multiple roles.

4.4.2.1.1 Stress of multiple roles

All the participants in this study were employed in a full-time or part-time basis as reflected in the table one. The participants in this study reflected experiencing high levels of stress in managing their multiple roles in their daily lives. This stress of multiple roles was that of being the breadwinners, with limited support from biological fathers of the child in their households as well as managing their daily duties of a child with a disability. Balancing all these multiple roles was perceived as more stressful especially by the participants who do not have support. The stress of multiple roles was reflected as having no one to assist with the daily duties of their children. Additionally, three of the participants had more than one child to look after in their household which added extra stress because they also had other children to care for.

“During the week, I have to be at home in the afternoon to look after my son when he comes from school, I have no time to relax at all. When I'm off at work, I had to see to my household

duties. It's endless there are so many things to do. I don't remember the last time we spent as a family together". (Participant: 8)

"I had to work part-time; there is no one to look after my son in the afternoon when he comes back from school. I have to see to everything in the house, I have no support I live alone with my son". (Participant: 11)

This finding is supported by Gottlieb (2001:11) who posits that single mothers who are employed without any spousal support are vulnerable to the stress of role imbalance and role overload in their lives. It is also well documented in research internationally that many parents of children with Autism face multiple and demanding roles in their lives. Such roles also include serving as a teacher, an advocate for their child as well as a loving parent and family member (National Research Council, 2001:32). Only three participants in this study were with their parents and they had a role to play involving child care when the mother is at work. Financial stress emerged as a core concern. This will now be discussed below.

4.2.2.1.2 Financial stress of being the breadwinners

All of the participants in this study expressed that they were experiencing financial stress because of their children's special needs, for example, their dietary needs. Only one participant had little support financially from the biological fathers of the child. Others received little financial support from the grand-parents and other extended family members. The majority of the participants in this study reflected that their major financial stressors were the concerns of being the only breadwinners at home or not earning enough.

"An autistic child is expensive, you have to buy certain food that he eats, which is recommended by the school, and I really don't know how I cope." (Participant: 12)

"My father works and caters financially in the house, my salary is only for my son but still it's not enough because he has to eat certain things. I just get by with what I have." (Participant: 8)

"I have no one to assist financially with my child. I do what I can with my salary." (Participant: 15)

“I am a single mother and I have other children to support besides my son, it’s really hard. My salary does not cater for everyone. I just do what I can.” (Participant: 10)

There is very little research in South Africa and internationally that documents the experiences of single mothers who financially manage a family which includes a child with Autism. Literature by Gottlieb (2001:10) concurs with this finding that more research is needed to understand how single mothers manage financially in supporting a family that includes a child with Autism.

4.4.2.1.3 Public stigma

The participants expressed having been negatively affected by the stigma in public places and identified shopping malls as being the place that they experienced the most stigmas. Participants were very emotional when they expressed how the stigma affected them and expressed a range of feelings such as anger when sharing their experiences. The anger felt by the participants was particularly around the negative reactions they encountered from the public because of the symptoms associated with their child’s disability. These negative reactions were experienced as an embarrassment to the participants. Four participants expressed that they sometimes tried to explain to people that their child has a disability but that sometimes this did not help either. However, some of the participants expressed that they cope with the stigma by ignoring the negative reactions from people.

“People look at you funny or make comments when your child cries and throws a tantrum in the shop when he wants something and he cannot get it. At first it used to affect me, but now I do not care anymore. My parents are more affected, they respond back to the people.” (Participant: 4)

“I remember when we went to a restaurant, my son went to other person’s table and he just started eating. Whew. I was so embarrassed. I explained to them that my son has a disability called Autism and that sometimes [it] seems to help.” (Participant: 5)

“There was this one lady, we were in a crowded space in the aquarium, my son touched this lady, and she shouted that my son must back off. When I try to explain he has Autism, she shouted again, “I don’t care what’s wrong with your son...just control him”. “I don’t think she understood what I was talking about.” (Participants: 1)

Findings concur with Gray (1993: 119) who indicates that mothers of autistic children encounter more stigma and negative reactions from ordinary public places such as shopping places. The researcher also found that despite the negative reactions encountered by the participants in public places, the participants seem to be resilient and have found a way to cope with this stigma by sometimes explaining to the public about their child's disability. Findings by Dehnavi, Malekpour, Faramarzi and Talebi, (2011: 257) have supported the notion that public education and exposure to Autism Disorder is needed to increase society awareness. The following section discusses social isolation as another challenge experienced by single mothers.

4.4.2.1.4 Social isolation

All the participants in this study experience social isolation in their lives. This was particularly so for the participants who live alone with their children without family support. The participants expressed that their experience of isolation was related to having lost friendships because of the demands of caring for their child.

“I don't visit my friends anymore; I have lost touch with them. Every time they invite me to come for coffee or going out to a restaurant, I am not able to go. I have to look after my son, I have no one to look after him.” (Participant: 5)

“We are on a world of our own, you know! Nobody understands what we are going through as mothers in raising autistic children! Even your family at times they don't understand. I remember we were having a family get together, my aunt was telling me I'm a drama queen because I was upset and they don't understand what it's like.....you know, so I no longer go to family functions. It's only me and my son now.” (Participant: 6)

“I just don't go anywhere, I stay inside the house. I do not even visit people anymore, I know my son will act out and they won't understand.” (Participant: 12)

Literature on single mothers without support indicate that single mothers face isolation in their lives (Gottlieb, 2001:5) and for mothers of children with Autism the behaviours of their children can lead to isolation (Gray1993,2002). According to Erikson's (1968:122) Psychosocial Theory of Development the child needs to develop and master the skills of life; the role of the mother at this stage is to support the child in developing social skills by teaching the child life skills on how to behave in society and in that way the mother cannot isolate herself from friends and

family members. The participants of this study are single mothers, who are employed, without spousal support and have a child with Autism in a special school. All these participants experienced challenges in caring for their children with special needs. Parental stress was perceived as a major challenge in caring of a child with Autism. The parental stress included the multiple roles the participants play in their lives. Financial stress of being the sole breadwinner was also a challenge facing the participants. Additionally, participants faced public stigma and social isolation in their lives. Single mothers of children with Autism experience psychological problems due to not having support with the daily demands of caring for their children. The findings related to the third objective will now be discussed.

4.4.3 OBJECTIVE 3. SUPPORT SERVICES THAT SINGLE MOTHERS ARE AWARE OF IN ASSISTING THEM TO CARE FOR THEIR CHILD WITH AUTISM

4.4.3.1 Support services for parents

Only a few participants were able to list a small number of support services that are available in their communities for parents of children with Autism. These support services were mostly private services that required payment for services. The majority of the participants in this study expressed that there are no support services that they are aware of in their community for parents of children with Autism. The only support comes from the school. The school was perceived as providing good support for the participants and their children. The fact that their children were admitted at the school was perceived as support in itself. The following services were identified by the participants as support services:

4.4.3.1.1 Support from staff

The school has professional staff members such as teachers, occupational therapists, psychologists, and speech therapists that are trained in providing specialised interventions that are suitable for the children's skills and developmental needs. The staff at the school were regarded as very friendly and provided a good service with educational interventions of their children. Some of these interventions included PECS (Picture exchange communication system).

“My son’s teacher is very good and supportive, she encourages me to use the PECS (Picture exchange Communication System) at home, and my son has shown improvements since I

started the PECS (Picture Exchange Communication System) with him. I can understand him now when he wants something.” (Participant: 14)

“The speech therapist is very good with my son. He has shown a lot of improvement since he was admitted at the school. He can talk now. The PECS (Picture Exchange Communication System) program is amazing.” (Participant: 5)

Bronfenbrenner’s Ecological Systems Theory describes different aspects of the child’s environment, which includes many systems that interact and affect one another at different levels (Bronfenbrenner, 1979). Based on this theory it could be assumed that parents who receive more support from the mesosystem will have closer relationships within the microsystem. Data captured above indicate the finding that parents who are able to engage in positive relationships with their child’s teacher can have a positive perception of support from their school environment. Research studies by Carr and Felce (2007:780) have reported that autistic children have developed speech after receiving training from school interventions such as PECS (Picture Exchange Communication System).

4.4.3.1.2 School’s transport support

The participants who were using the schools transport for their children felt that this was a very good support provided by the school. One of the participants who were using the school transport revealed this support in her statement:

“The school transport is a great support to parents like me who do not have a car.” (Participant: 7)

“My son uses the school transport, it really helps a lot. I don’t think I would have coped in using public transport to take him to school.” (Participant: 11)

In South Africa it also highlighted in the Department of Education (2007: 18) that a special school must provide transport for all the learners who require transport in order to be able to access the school. This finding is also supported by the Integral National Disability Strategy White Paper (1997:33) that children with disabilities should be supported and provided with the necessary transportation in order to access education. In the context of a child with a disability, the ecological framework of the child exists by the interaction through which the society engages with the disability by understanding the importance of having environmental resources that

correspond to the child's special needs (Hepworth, Rooney, Rooney, Gottfried and Larsen, 2006: 17).

4.4.3.1.3 Aftercare support service

Participants highlighted some concerns with access to aftercare services at the school. They expressed that there is a long waiting list for aftercare services at the school.

“I struggle with my son after school; there is a long waiting list with aftercare at the school.”

(Participant: 9)

“I work part-time now because I have no one to look after my son after school, there is a long waiting list at the school for aftercare.” (Participant: 15)

The Disability Rights Charter of South Africa promotes equal opportunities for all disabled people (Integral National Disability Strategy White Paper, 2007:3). In South Africa it is a challenge for parents of children with disabilities to access aftercare facilities for their children. Aftercare support at the school was highlighted as a great need for the participants due to these mothers being employed and having difficulties accessing aftercare facilities for children with special needs. Children with disabilities have the right to access resources such as day care centres (Integral National Disability Strategy White Paper, 2007:17).

Findings indicated that the majority of the participants identified the school as their only support service available to their children due to the limited support services in their communities. Only a small number of participants identified private services. The school was identified as providing good support services such as teaching their children social skills such as communication skills. School transport was also identified as a positive. Aftercare support was identified as a great need for the participant's children.

4.4.4 OBJECTIVE 4. SINGLE MOTHERS' PERCEPTIONS OF SUPPORT THEY RECEIVE FROM THE SCHOOL

One of the key factors that emerged from the theme support from staff also emerged from the theme 'teacher support':

4.4.4.1 Teacher support

The majority of the participants felt they are receiving good support from their child's teacher at the school. This teacher support included communication in the child's diary, guiding and giving advice on what to do with the child at home, advice on diet and difficult behaviour.

The support expressed by the participants was the satisfaction of receiving feedback in their child's diary about how the child was during the day and homework for the child at home. Communication between teachers and parents takes a range of forms. Findings in this study indicate that the school has developed fora where teachers and parents communicate by using a diary. The following expressions reveal this support.

“My son's teacher is amazing, she gives me support on what to with my son; (she) sometimes advises me on how to handle him at home.” (Participant: 13)

“She writes in my son's diary and gives me feedback about how my son was doing during the day. Sometimes she would send me reminders about things of the school.” (Participant: 10)

This finding concurs with Lall, Campbell and Gillborn, (2004: 4) who indicate that some schools are developing new fora and modes of communication in an attempt to ensure improved parental involvement. Parental involvement in special schools is viewed as one of the most important factors that contribute to achievement of skills development of the children with special needs (Lall, Campbell and Gillborn, 2004:1). The findings linked to the final objective will now be discussed.

4.4.5 OBJECTIVE 5. RECOMMENDATIONS SINGLE MOTHERS MADE IN TERMS OF SUPPORT OFFERED TO PARENTS AT THE SCHOOL

Participants made the following recommendations in terms of support offered to parents at the school: the need for parent support groups, educational and training groups and information sessions with class teacher. The need for a parent support group is first presented.

4.4.5.1 Parent support groups

All the participants expressed the need for a support group to be available for parents. The need to connect with other parents at the school was strong. The participants felt that this would help

in terms of coping with their stress. They also expressed that by having support groups they get an opportunity to meet other parents and possibly learn and share experiences. They expressed that this kind of support is limited available in their communities.

“We are so isolated we don’t even know each other. We need parent support groups. Places where you can share with other parents about the same problems and for coping, you know?”

(Participant: 7)

“We are in a world of our own; nobody understands what we are going through in caring for our children especially being a single parent. It would be really nice to have the support groups at the school so that you meet other parents who share these experiences with you.”

(Respondent: 15)

“It would be so nice to go to a place where you feel understood, to hear from other mothers how they cope with their children. It would be also nice to have support groups at the school then you get an opportunity to meet other parents from your child’s class.” (Respondent: 8)

Mandell and Salzer (2007:120) support this finding and state that the advantages of a support group for mothers of children with Autism are opportunities to receive support, to create chances of interaction with others and to increase information about where appropriate resources may be accessed. The desire of having the support group at the school was perceived as decreasing social isolation, reducing stress and increasing the access to information about appropriate care of their children.

4.4.5.2 Education and training workshops

The majority of the participants felt they would benefit from workshops that provide education about Autism and also that train them on how to use the educational interventions used at the school with their children. These participants expressed that they need to be trained on how to manage their child’s behaviour at home.

“It would be nice you know if they can give us information on how they do things with the children in class because my child at home is completely different; even if they meet us once a month.” (Participant: 13)

“It would be nice if the school can organise some education and training on what they actually do with the children in the classroom, so that I can do the same at home.”

(Participant: 12)

“It would be really great if the school can provide some updated information on interventions used overseas would be nice so that we can keep with the current trends in education of our children.” (Participant: 8)

Lall, Campbell and Gillborn (2004: 1) confirm that parent’s involvement in the education of their children has been identified nationally as a major contributing factor in overall levels of attainment in school. The Integral National Disability Strategy White Paper (1997: 39) also supports this finding that there should be parent empowerment programmes to encourage parent involvement in education of their children with special needs. The participants made the recommendation that there is a great need for parental support programmes to be implemented at a special school. These parental support programmes should include the support groups, educational workshops and information sessions on skills development of their children. Participants felt they would benefit more in terms of support if such services can be implemented at the school. The next section provides a summary of findings on challenges experienced by single mothers before and after their children attend a special school.

Findings indicated that single mothers of children with Autism face challenges even before their children attend a special school. These challenges start when they realise that something is different with their children, followed by a lengthy and complicated diagnostic processes, their struggle with limited resources, making sacrifices in their lives such as taking time off at work and long waiting lists for admissions at the special school. All these challenges have proven to have a negative impact on their well-being and leave them vulnerable to stress. The predisposition of such stress was the lack of support services for single mothers of children with Autism in their communities. When the children are finally placed at a special school, findings indicate that there are additional challenges that single mothers experience such as stress related to parenting, stress of multiple roles in their daily lives, stress of being the sole bread winners in their households, public stigma and social isolation. Although the findings indicated that the school and its resources was perceived as a great source of support to the participants, limited

resources such as aftercare at the school was highlighted as a great need due to the participants being employed.

The participants stated that they struggle alone with these challenges as single mothers and proposed that there is a great need for the development of parental support programmes for single mothers of children with Autism at school. The parental support programmes can assist the mothers in understanding their children's condition by providing effective education; provide necessary support on skills development of the children, and provide guidance on how to raise their children with Autism before their child attends a special school. The participants proposed that the government needs to play a more active role in creating such services for single mothers of children with Autism. The government needs to work together with non-governmental organisations like Autism South Africa in creating such services and make funds available for the implementations of such services in communities and train staff in the area of Autism.

4.5 CONCLUSION

This chapter presented the research findings. These were discussed using the research objectives as headings. The final chapter presents conclusions and recommendations pertaining to the study and for future research.

Chapter 5 CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The final chapter presents conclusions with regards to the objectives of the study. The chapter also offers recommendations directed at relevant stake holders and for future research.

5.2 CONCLUSIONS

The conclusions are discussed using the research objectives as headings.

5.2.1 OBJECTIVE 1: CHALLENGES OF SINGLE MOTHERS BEFORE THEIR CHILDREN WERE PLACED AT THE SPECIAL SCHOOL

Single mothers of children with Autism experience enormous challenges with the demands of raising their children. These challenges are experienced from the beginning when their children start showing symptoms of Autism, the process of understanding these symptoms, their experience of diagnostic process which involves numerous referrals, limited information, work constraints and finally on receiving the diagnosis. Symptoms of Autism became evident from the ages of six months to one year eight months and participants experienced a range of emotions in trying to understand the symptoms. This concurs with other researchers who state that parents experience a range of emotions associated with caring for their children with Autism (Gottlieb, 2001:10 cited Crosby, 1991). Apart from the parental stress, mixed emotions and financial challenges parents also have to deal with lengthy and very complicated diagnostic processes adding to the problems they face (Hutton and Caron, 2005:108).

Challenges go beyond commonly-reported problems such as financial problems associated with demands for caring of the child with Autism regardless of the participants' differences in their salaries. Challenges within service delivery of assessments and early diagnosis of the children were also experienced. Data collected indicates that all the participants in this study were experiencing difficulties while they waited for the school to finalise and communicate the decision about admission processes.

5.2.2 OBJECTIVE 2: THE PERCEIVED CHALLENGES FACING SINGLE MOTHERS AFTER THEIR CHILDREN ARE PLACED AT VERA SCHOOL

The majority of the participants were vulnerable to stress associated with demands of caring for their children. Some of the challenges single mothers faced were assuming multiple roles with regards to caring of their children with Autism. Data from the National Research Council (2001:3) show that parents of children with Autism play multiple roles, which are demanding in their children's lives, such as serving as a teacher, carers and loving mothers, which adds more stress in their lives. They also made sacrifices to serve the needs of their children. The mentioned challenges indicate a greater need for support to help single mothers care for their children with Autism.

Some of the perceived challenges experienced by the participants were associated with stigma in public places and public stigma had a negative impact on the single mothers' daily lives. Some coped with stigma by isolating themselves from friends and family. Single mothers are therefore confronted with the problem of limiting their exposure to public places and develop techniques for protecting themselves and their children from stigmatising environments, for example, selecting friends and family that have consideration for their child's disability (Gray, 2002: 736).

5.2.3 OBJECTIVE 3: SUPPORT SERVICES SINGLE MOTHERS ARE AWARE OF TO ASSIST THEM IN CARING FOR THEIR CHILD

There are very limited services to support mothers in caring for their children in communities. The majority seems not to know of any support services available in the community. Private services were indicated by a few as support services in the community; however, these private services were said to be expensive. It is safe to assume that there is a great need for the development and access to parental support services in the area of Autism. Dabrowska and Pisula (2010:267) in their research in assessing the association between parenting stresses and coping style found that there are very few professionals specialising in therapy and developmental support for children with Autism. They also add that there are no governmental programmes for early interventions and diagnostic programmes for these children. As a result only a very limited group of parents and children receive appropriate support, if any.

Government and special needs schools may have to consider creating support services in the community that parents of children with Autism can easily access.

5.2.4 OBJECTIVE 4: SINGLE MOTHERS' PERCEPTIONS OF SUPPORT THEY ARE RECEIVING FROM THE SCHOOL

The school was perceived as a positive support in areas such as providing transport and aftercare for the child. The school provides an effective transport system whereby the children are collected at home and then dropped off at school. This is very beneficial for parents and their children because they are not exposed to public stigma due to using public transport. Some of the perceived challenges for single mothers are exposure to stigma in public places therefore utilising the schools transport limits their children to exposure to public stigma. Although the children are taken back to their homes by the school transport after school some of the children attend aftercare. It has been highlighted by the participants that the aftercare service has a long waiting list and extra aftercare facilities were expressed as a great need. All the participants in the current study were working mothers who verbalised the importance of sufficient after-care facilities for their children while they are at work. If the school can provide extra aftercare facilities the parents would feel more supported by the school.

5.2.5 OBJECTIVE 5: RECOMMENDATIONS SINGLE MOTHERS MADE REGARDING SUPPORT OF PARENTS AT THE SCHOOL

Three suggestions were considered to be important, which are: the provision of support groups, educational workshops, and information sessions with teachers. The research results indicated that the majority of the participants would like more opportunities to connect with other parents. Educational workshops were reflected as a great need in keeping the parents updated with current trends and treatment of Autism. It is also evident that the participants would benefit if the school provided more resources and information about Autism Spectrum Disorder. Lastly, open communication channels from teacher to parent, especially about the progress of their children in the classroom were deemed essential. The overall recommendations of the study are discussed below.

5.3 RECOMMENDATIONS

5.3.1 RECOMMENDATIONS TO VERA SCHOOL

5.3.1.1 The need for increased public and professional awareness about Autism Disorder

Findings from the study have indicated that there are challenges faced by single mothers even before their children are placed in special schools. A key identified area is that there is a great need for increased awareness in the area of Autism in public and professional sectors. This can be achieved if, during the Autism month in April of each year, the Vera School can be involved in an awareness drive campaign by creating public awareness in the community. This can be achieved by approaching a radio station to get airtime in order to raise awareness about Autism Spectrum Disorder. Radio broadcasts can target everyone, including people in the rural areas, so that they can be educated about the symptoms of Autism. This awareness drive campaign might help parents to identify the symptoms of Autism in their children and prompt them to seek interventions earlier. The school can further create awareness in public places like shopping malls by having information stalls about Autism and distributing pamphlets to the public. These awareness campaigns can assist in alleviating stigma faced by parents of children with Autism.

5.3.1.2 Training about Autism Disorder

Vera School can then provide further training on Autism that is accredited by the South African Qualifications Authority (SAQA) at a reasonable fee. This training can be offered to the health professionals in public and non-governmental organisations so that knowledge of Autism becomes accessible to everyone in the health field. The funds generated from the training can be used to employ an additional staff member like a school social worker who they can train in the area of Autism. This social worker can also be involved in providing the training.

The school can also use some of the money generated from these trainings to make pamphlets that markets Autism and increase knowledge about the condition. These pamphlets can also be sold at a reasonable fee to the interested organisations such as non-governmental organisations. The dissemination of these pamphlets is to create awareness about Autism, complement the existing services and minimise public stigma.

5.3.1.3 Support services for single mothers

It may be important to note that although the school is viewed as providing good support services for these mothers raising children with Autism, there is still a need for more support services to be implemented to complement the existing services. Very little attention is paid to the development of parental empowerment programmes such as early intervention supportive programmes to encourage parent involvement in special needs schools. The development of support services for single mothers can include the school social worker, as stated earlier, to work in different areas that can support single mothers. These areas include:

Liaising with organisations like Autism Western Cape to be involved in special schools by giving talks to parents at the school at least once a year, empowering parents with knowledge about Autism Spectrum Disorder and keeping up-to-date with information on Autism Spectrum Disorder.

Linking single mothers to organisations like Parent Centre, and focusing on those mothers who are struggling to cope with the daily demands of their children. Furthermore, counselling and support services can also be provided by the school the social worker or other organisations like FAMSA (Family and Marriage Society of South Africa) when necessary.

Lastly, the social worker can be involved in the initiation of a support group at the school. The support group can encourage and empower single mothers with skills to cope better with the daily demands of caring for their children diagnosed with Autism.

5.3.1.4 Aftercare support services

Findings from the participants indicated that there is a need to address the long waiting list for aftercare services at the school. This waiting list can be managed through raising funds by charging fees for aftercare and use the funds to build extra classrooms and hire staff needed for aftercare. In this way the school is able to provide much needed support for working single mothers who are faced with the challenges of balancing work and caring for their child diagnosed with Autism.

5.3.1.5 Addressing the long waiting lists for admission at the school

The long waiting lists for admissions at special schools have been highlighted in this study as a struggle for parents while they wait for their children to be placed at these schools. To manage

these waiting lists, the researcher suggests that special schools for Autism in the Western Cape work together and compile a proposal requesting funding to organisations like the National Lotteries Board and others. These funds can be utilised to open a pre-school foundation phase and hire staff for children who are on the waiting lists for admissions at the schools. The funds can also be used to pay hired staff who will teach in the pre-school foundation phase. The hiring of teachers for the pre-school foundation phase and extra classes may minimise the long waiting list at special schools.

5.3.2 RECOMMENDATIONS FOR FUTURE RESEARCH

There is a need for further research using a bigger sample of single mothers in all the five schools of Autism in the Western Cape. Additional research on this topic would add to the findings of this study. Further research can explore experiences of raising a child with Autism in South Africa, for married couples as the current study only focused on single mothers. This knowledge will help in understanding the challenges of parents in raising a child with a disability such as Autism in South Africa. The findings of the current study on challenges experienced by single-mothers indicate the need for further research on parental involvement in raising a child with Autism Spectrum Disorder. Furthermore, future research can focus on rural areas as the current study was conducted in urban areas because this will equip parents or care givers with knowledge to manage better in carrying for their child diagnosed with Autism in South Africa.

5.4 CONCLUSION

The final chapter of the dissertation has concluded that single mothers with children diagnosed with Autism face enormous challenges. These challenges are experienced even before their children start school, and struggles are experienced from when children start showing the symptoms of Autism, when difficulties with very lengthy and complicated numerous referrals, problems with limited information about the disorder and limited resources arise. For this reason, more attention should be paid to the development of services for single mothers of children with disabilities such as Autism. It is recommended that more attention should be paid in the development of early intervention services for Autism such as education and training, support services to alleviate parental stress. Additional resources are also needed in a special needs school, such as a pre-school foundation phase to address the problems of long waiting lists for admissions at special schools, aftercare facilities for working single mothers at the school and

social workers working in the field of Autism who will provide support services for single mothers.

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APPENDIX A - Research Invitation Letter

Dear Parent

I am a Social Work Clinical Masters Student at the University of Cape Town, and as part of my training I have to undertake a research study. Permission to conduct this study has been obtained from the Department of Education and Vera school. I am keen to carry out my research in the field of Autism. In particular, I am interested in exploring the challenges of Single mothers with children diagnosed with Autism in the junior phase.

As a parent of a child with Autism, I would like to invite you to take part in this research. If you agree to take part you will be asked to meet with me for one interview to discuss your experiences. This interview is likely to last for around an hour. Enclosed with this letter is an information sheet for you to read, which will tell you more about what the research involves. .If, after reading the information sheet, you are interested in taking part please complete the contact detail sheet to know the best way to contact you (i.e. phone, e mail, post) so that I can have up-to- date details. As soon as I know you would like to take part I will contact you to organise a suitable time and location for us to meet and discuss the interview further. If you are still happy to take part we can go ahead and do the interview at this meeting, or if, you prefer we can arrange another meeting.

Please do not hesitate to contact me if you have any questions or would like to discuss things further before making a decision.

Yours Sincerely

Ms Nthabiseng Monare

Supervisor: Ms Fatima Williams

Social Work Clinical Masters Student

Contact number: 021 650 3485

Work - 021- 4403134/0825363230

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E mail- Fatima.Williams@uct.ac.za

APPENDIX B - Information Sheet

Exploring the Perceived challenges of single mothers of children diagnosed with Autism in the junior phase at Vera School.

Researcher: Ms Nthabiseng Monare

You are invited to take part in a research study. Before you decide if you would like to participate it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with anyone you choose. Please do not hesitate to contact me if there is anything that is not clear or if you would like to more information. Thank you for reading this.

What is the purpose of the study?

I would like to find out more about your challenges as a single mother in raising a child with Autism. To help me do this I would like to meet with you and ask you some questions about your challenges.

Why have I been chosen?

I have asked you to participate because you have a child who has been diagnosed with Autism. I am interested in understanding the challenges of single mothers who have children with this condition.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part, you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and do not have to give a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any care or services that you receive.

What will happen if I agree to take part?

If you agree to take part I would like to meet with you to ask you some questions. The meeting will take place either at my office or at your home and should not last no longer than a 1 hour. I will only need to meet you once for the interview. The interview will be recorded so that I can transcribe it later. The recording will be kept in a secure place and when I transcribe it I will

ensure that any information that might identify you is removed. The original recording will be destroyed once the research project has been fully written up. (Approximately by December 2013). Once I have analysed your interview and summarized my findings I would like to ask you for some feedback to make sure that I have accurately understood what you told me. Either we meet again to discuss this, or you can write feedback down and send it to me. If you would like a summary of the results from the study once it is complete, this can also be arranged.

What are the possible disadvantages of taking part?

Some people can find it upsetting to talk about their challenges.

What are the possible benefits of taking part?

It is not expected that there will be any direct benefits to you of participating in this research, although some people find it helpful to have an opportunity to talk about their experiences. I do hope the study will provide a general benefit to services and parents continuing our understanding of what it is like to have challenges associated with caring of a child with Autism.

Will my taking part in this study kept confidential?

All information, which is collected during the course of the research, will be kept strictly confidential. Any information about you, which is used in the final written report, will be made anonymous so that you cannot be recognized from it.

Is there any assistance if I am available if I am negatively affected by participating in this study?

The researcher is an experienced Social Worker by profession and debriefing will be offered to participants who need it after the session. Should a participant request assistance with a mental health issue or request further in-depth debriefing session, the participant will be referred to an appropriate experienced counsellor.

What will happen to the results of the study?

The findings could potentially be used to educate teachers about what it is like to have challenges to a single mother with a child with Autism. This information could then be passed on to other parents whose children are diagnosed with Autism. If parents know about other parents challenges they may find it easier to adjust to their own child's diagnosis. The results could also

be used to increase social awareness to teach people about what it actually means to be a parent to a child with Autism

Who has reviewed the study?

The research study has been reviewed by the University of Cape Town, Department of Social Development. It has also been approved by Ethics committee of University of Cape Town and the Department of Education.

Contact for further information

If you would like to talk a bit more about the study before deciding whether to take part, you can contact me (Nthabiseng Monare) on Mondays to Thursdays from 13h00-16H00. Alternatively you might like to e mail me at Ntmonare@westerncape.gov.za, Tel: 021 4403 134/ 0825363230

My supervisor's details is contactable on (021 650 3485) Ms Fatima Williams.

If you would like to take part in the study

If you like to take part please complete the enclosed sheet with your contact details and give it to Ms Joana (Psychologist at Vera school) she will give it to me so that I know you are interested. I will then get in touch with you to organize a meeting.

Thank you for taking time to read this

APPENDIX C - CONSENT FORM

Exploring the perceived challenges of single mothers with children diagnosed with Autism disorder at the junior phase in Alpha School.

Researcher: Ms Nthabiseng Monare

Please read the following statements carefully and then tick the box alongside to show that you agree. Please ask if you have any questions.

I confirm that I have read and understand the information sheet for the above study.

I have the opportunity to consider the information and ask questions. I have had any questions answered satisfactory.

I understand that my participation is voluntary and that I am free to withdraw anytime without giving any reason. A decision to withdraw will not affect my medical care or legal rights.

I understand that my interview will be audio recorded and agree to this. I am aware recording will be destroyed once the research is complete (approximately by December 2013).

I agree to take part in the above study.

Name of participant

Signature

Date

Name of researcher

Signature

Date

Thank you for your help

APPENDIX D - CONTACT DETAIL SHEET

Exploring the perceived challenges of single mothers of children diagnosed with Autism disorder at the junior phase at Vera school.

Researcher: Nthabiseng Monare

If you are interested in taking part please complete this slip with your preferred contact details.

Name (s):

Telephone No.:

Email:

Address:

Thank you for your help

APPENDIX E - Semi-Structured Interview Guide

Thank you for participating in this research study. This interview will take up an hour of your time. With your permission, the researcher will use a tape recorder to record the interview. The information obtained from you will be used for research purposes. This information will be kept confidential. Your name will be kept anonymous. This information will be recorded, transcribed and analysed for research purposes only. The tapes will be kept in a locked place and will be destroyed after the research is completed.

Research Topic: Exploring the perceived challenges of single mothers with children diagnosed with Autism disorder in the junior phase at Vera school.

Section A: demographics

Choose a name for yourself.

Age?

Home language?

Where do you live?

Who lives with you?

Is your child the eldest, middle child or youngest?

How many children do you have?

How do you earn a living?

What is your household income?

Section B: Perceived challenges of facing single mothers before their child is placed at special school

At what age did you notice that there were concerns about your child?

What were those concerns?, (can you elaborate more on this concern)

What did you do to address these concerns?

Tell me more about the process you went through to address these concerns about your child?

What recommendations would you make about this process?

How old was your child when diagnosed with this condition?

5. How did you feel about the diagnosis? (Can you elaborate?)

6. What do you know about the condition after your child was diagnosed?

7. What kind of support have you received in terms of information about Autism?

9. Who is assisting you with your child care duties?
10. What level of care does your child need at home?
11. How are you coping financially? , (elaborate)
12. Who is assisting you financially to cater for the needs of the child?

Section C: Perceived Challenges facing single mothers after their child has been placed at a special school

How did you know about Vera school?

Who referred you to Vera school?

How did you obtain placement of your child at the school?

How long did you have to wait before your child was placed at the school?

How old was your child when you receive placement at the school?

What was your experience about the admission process of placing your child at the school?

What recommendations would make about the admission process at the school?

What do you think or feel about the information given on the condition once your child was placed at the school? eg. Library, special schools, internet, Department of education, Doctors etc.

What are your experiences after your child was placed at the school?

Have you experienced stigma in the community since your child has been placed at the special school. If yes, (elaborate)

How has the stigma affected you? (Elaborate)

Section D: Single mother's perceptions of the support received from the school.

What support has the school provided you with regards to your child?

What do you feel about the support you are receiving at the school?

What are your own perceptions of support you are receiving from the school?

What are the support services for parents that you are aware of at the school?

What is your experience of the support service for parents at the school?

How has this support service for parents assisted you?

Section E: What suggestions would single mothers make in terms of support offered to the parents?

What kind of further support do you need with regards to your child at the school?

What are your own perceptions of support should parents receive at the school?

What recommendations would you make to the school with regards to support for parents?

Section F: Closing the process of interviewing

How did you find the interview? , (explore).

What feelings are you left with after the interview? (Debrief if necessary or needed)

Is there anything you would like to say after this interview?

Thank you so much, will be analysing this information you have given to me and others, I will organize a copy and send it to you.