

# Exploring the experiences of mothers on their daily occupations while having a child on the spectrum of autism

by  
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**DECLARATION**

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

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## **ABSTRACT**

Prior to the commencement of this study, an abundance of information on the topic of autism spectrum disorders and its symptoms, its prevalence and the effect on the family's psychosocial- and emotional well-being were available. However, studies to describe the impact of a child with autism spectrum disorder on the occupations of families were limited, especially within the South-African context, and the researcher could find no information describing the impact of such a child specifically relating to the daily occupations of their mothers. This qualitative study used a phenomenological approach to explore how mothers with children on the spectrum of autism experience the impact of the child on their own daily occupations, and the meaning they derive from these experiences.

Purposive sampling was used in selecting eleven mothers whose children attended therapeutic and medical follow up at one of the tertiary public hospitals in the Western Cape. In-depth semi-structured interviews following an interview guideline were conducted with each of the participants. The interviews were audio taped, and thereafter transcribed verbatim. A process of open coding was used to analyze the transcribed interviews. The findings emerging from the data-analysis process, uncovered three themes, namely 'mothering as an identity', mothering as an occupation', and 'making sense and moving forward'. These themes emphasized the immense changes the mothers had to face with regards to their occupational engagement, as well as on a personal level due their children's diagnosis of autism spectrum disorder. It also brought to light the factors influencing the experiences and actions of mothers, shaping their mothering identities, as well as their needs and barriers in terms of successful participation in their everyday occupations. The study reported on the occupational risk factors these mothers face, as well as the enabling elements with regards to successful and meaningful occupational engagement.

Occupational therapists working with children should be especially conscious of the inseparable relationship between the occupations of the child they are treating, and the occupations of the primary caregiver when implementing therapy programs. Only through ensuring the successful and meaningful participation in occupations of both the mother and the child, the occupational therapist will be able to improve the health and well-being in the one or the other. Careful selection and collaborative goal setting when planning therapy programs are therefore essential.

## OPSOMMING

Verskeie studies het in die verlede rapporteer oor die diagnose, simptome en prevalensie van outisme spektrum steurnisse. Studies wat die impak van hierdie toestand op die emosionele en psigo-sosiale welstand van families ondersoek het, was ook volop. Beperkte inligting, veral binne die Suid-Afrikaanse konteks, was egter beskikbaar om die impak van 'n kind op die spektrum van outisme op families se deelname in alledaagse aktiwiteite te ondersoek. Met die aanvang van hierdie studie, kon die navorser geen inligting vind wat spesifiek na die impak van 'n kind met outisme op hulle moeder se deelname in alledaagse aktiwiteite ondersoek ingestel het nie. Hierdie kwalitatiewe studie het gebruik gemaak van 'n fenomenologiese benadering om die ervarings van moeders, met 'n kind op die spektrum van outisme, te ondersoek rakende die impak van hierdie kind op die deelname van hulle eie alledaagse aktiwiteite, asook die betekenis wat die moeders aan hierdie ervarings kon heg.

Doelgerigte steekproeftrekking is gebruik in die seleksie van elf moeders wie se kinders terapieë en medies opgevolg word by 'n tersiêre publieke hospitaal in die Wes-Kaap. In-diepte, semi-gestruktureerde onderhoude is gevoer met elk van die deelnemers aan die hand van 'n onderhoud riglyn. Die onderhoude is op band opgeneem, waarna dit verbatim getranskribeer is. 'n Proses van oop kodering is gebruik om die getranskribeerde onderhoude te analiseer. Die resultate wat verkry is gedurende die data-analise proses, het die volgende temas uitgelig, naamlik 'moederskap as identiteit', 'moederskap as beroep', en 'om sin maak en aan te beweeg'. Hierdie temas het die geweldige veranderinge vir die moeders in terme van deelname aan hulle alledaagse aktiwiteite, sowel as op persoonlike vlak, beklemtoon. Die faktore wat die deelnemers se ervarings en aksies, en dus hulle identiteit as moeders beïnvloed het, was ook geïdentifiseer. Die resultate het ook die struikelblokke en behoeftes van hierdie moeders in terme van suksesvolle deelname aan hulle alledaagse aktiwiteite, aangedui. Die studie het die risiko faktore, sowel as die elemente wat benodig word vir suksesvolle deelname aan alledaagse aktiwiteite, uitgelig.

Arbeidsterapeute werksaam in die veld van pediatrie, behoort bewus te wees van die onafskeidbare verhouding tussen die deelname aan alledaagse aktiwiteite van die kind wat hulle behandel, en dié van die primêre versorger. Slegs wanneer suksesvolle deelname aan aktiwiteite deur beide die kind én die moeder verseker word, kan die welstand en gesondheid in die een of die ander bevorder word. Die seleksie van terapie doelwitte in samewerking met die familie en primêre versorger, is dus kardinaal.

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## LIST OF TABLES

	<b>Page</b>
Table 4.1 Profile of research participants	29

## LIST OF FIGURES

	<b>Page</b>
Figure 4.1: Summary of findings	31

## LIST OF APPENDICES

	<b>Page</b>
Appendix A: Approval from Health Research Ethical Committee, Stellenbosch University	91
Appendix B: Permission from tertiary public hospital	92
Appendix C1: Participant Information Leaflet and Consent form	93
Appendix C2: Deelnemer Inligtingstuk en toestemmingsvorm	99
Appendix D: Biographical Information of participants	104
Appendix E: Interview Guideline	108
Appendix F: Introduction of participants	116
Appendix G: Interview transcriptions	121

**LIST OF CONTENTS**

	<b>Page</b>
Declaration	i
Abstract	ii
Opsomming	iii
Acknowledgements	iv
List of tables	v
List of figures	vi
List of Appendices	vii
Chapter 1: Introduction	1
1.1 Background and Problem Statement	1
1.2 Purpose of the Study	2
1.2.1 Study Aim	3
1.2.2 Objectives	3
1.3 Terminology	3
1.3.1 Autism spectrum disorders	3
1.3.2 Experiences	4
1.3.3 Impact	4
1.3.4 Occupation	4
1.3.5 Daily Occupations	4
1.4 Delineation of the Study	4
1.5 Chapter Overview	4
Chapter 2: Literature Review	5
2.1 Autism	5
2.1.1 Definition	5
2.1.2 Diagnostic criteria	5
2.2 Motherhood	7
2.3 Mothering as an Occupation	8
2.3.1 Occupation	8
2.3.2 Mothering roles	9
2.3.3 Occupational change with the transition into motherhood	10
2.3.4 Mothering occupations with a child on the spectrum of autism	10
2.3.4.1 Mothering a child with a chronic disability	10

2.3.4.2 Mothering a child with autism	11
2.3.5 Occupation and health/ well-being	12
2.4 Family-centred therapy	12
2.5 Measuring the experiences of the participants	13
2.5.1 Participant observation	13
2.5.2 Document Study	13
2.5.3 Interviewing	13
2.5.3.1 One-to-one interviews	14
2.5.3.2 Focus group interviews	15
2.5.3.3 Interview order	16
Chapter 3: Research Methodology	17
3.1 Introduction	17
3.2 Research Design	17
3.3 Target population and Sampling	18
3.3.1 Type of sampling	18
3.3.1.1 Selection Criteria	18
3.3.2 Sampling method	19
3.3.3 Study Population	19
3.4 Data Collection	19
3.4.1 Semi-structured Interviews	19
3.5 Data Analysis	21
3.6 Quality Assurance	22
3.6.1 Credibility	23
3.6.2 Transferability	24
3.6.3 Dependability	24
3.6.4 Confirmability	24
3.7 Ethical Considerations	25
3.7.1 Autonomy	25
3.7.2 Beneficence	25
3.7.3 Non-maleficence	26
3.7.4 Justice	26
3.8 Limitations of the Study	26

Chapter 4: Findings	28
4.1 Introducing the participants	28
4.2 Analysing the findings	30
4.2.1 Theme 1: Mothering as an Identity	34
4.2.1.1 Category 1: Experiences of being pregnant and giving birth	34
4.2.1.2 Category 2: Magnitude of being a mother	38
4.2.1.3 Category 3: Change in identity when mothering a child with autism spectrum disorder	42
4.2.2 Theme 2: Mothering as an occupation	48
4.2.2.1 Category 1: Views on typical mothering roles	48
4.2.2.2 Category 2: Change in occupations when mothering a child with autism spectrum disorder	50
4.2.2.3 Category 3: Change in time spent when mothering a child with autism spectrum disorder	58
4.2.3 Theme 3: Making sense and moving forward	60
4.2.3.1 Category 1: Barriers and Needs	60
4.2.3.2 Category 2: Coping and Adjusting	62
4.3 Summary	64
Chapter 5: Discussion	65
5.1 Introduction	65
5.2 Mothers' everyday occupations and health	65
5.2.1 Occupational Risk Factors	66
5.2.1.1 Occupational Imbalance	66
5.2.1.2 Occupational Deprivation	67
5.2.1.3 Occupational Alienation	70
5.2.1.4 Occupational Marginalization	71
5.2.1.5 Occupational Injustice	71
5.2.2 Mediators for occupational health	71
5.2.2.1 Occupational Identity	72
5.2.2.2 Occupational Competency	77
5.2.2.3 Coping and Adjusting	78
5.2.2.4 Meaning	79

Chapter 6: Conclusions and Recommendations	81
6.1 Summary	81
6.2 Strengths and Limitations	81
6.3 Implications for practice	81
6.4 Recommendations for further studies	83
6.5 Conclusion	83
Reference list	85
Appendices	91

## CHAPTER 1: INTRODUCTION

### 1.1 Background and Problem statement

In 2002 the Western Cape Department of Health produced a strategic plan for future public health care services in the Western Cape. This initiative, originally known as Healthcare 2010, has been reshaped into Healthcare 2020, and is based on the 1995 Health Plan<sup>1</sup> and the 2010 Comprehensive Service Plan<sup>2</sup>. In line with national and provincial policy frameworks (the “green paper” on National Health Insurance, the national Human Resources for Health framework and the provincial strategic plan)<sup>3</sup>, Healthcare 2020 is directed at the prevention of disease and the promotion of well-being<sup>3</sup>. While still incorporating the primary healthcare approach as introduced by Healthcare 2010, a strong emphasis on the patient experience and quality of care is incorporated into the Healthcare 2020 plan<sup>3</sup>.

The researcher is currently working as an occupational therapist at a tertiary hospital within the public health sector, and has the responsibility of managing the paediatric occupational therapy in- and outpatient service. Healthcare 2020 guides the strategic planning of this Occupational Therapy department when setting goals concerning service delivery by aiming at early intervention and preventative care. Using their knowledge concerning occupational performance, the impact of the context in which these occupations are performed, and the importance of occupation to enable a healthy lifestyle, occupational therapists assist their clients in identifying barriers and making adjustments in order to promote successful participation in meaningful activities.

The paediatric occupational therapy service at the hospital where the researcher is currently employed is faced with numerous barriers in terms of the efficiency of service delivery. These barriers include a shortage of staff, huge patient load, and a lack of resources. Transport- and financial problems on the patient's side are also impacting significantly on the regularity of follow up appointments. Due to these barriers, the researcher's personal experience is not having the opportunity to deliver regular direct intervention programmes to the patient, and compensates by rather working with families/ caregivers and by means of home programmes.

Prior to the commencement of this research project, the researcher became aware of an increase in the number of outpatients diagnosed with autism spectrum disorders (ASD) referred to occupational therapy since 2007. Departmental statistics indicated an increase of 180, 5 % since 2007 until December 2011. The increase in patients diagnosed with ASD is in line with the increase of these patients seen worldwide<sup>4,5,6</sup>, as well as nationally<sup>7</sup>.

A component of the service offered to families with children on the autistic spectrum, is a support group run by a speech therapist, occupational therapist (the researcher) and a social worker. Information shared by families in the support group revealed the significance of having a child on the autistic spectrum in the family.

No information could be found to specifically describe the impact of a child on the spectrum of autism on the mother's daily occupations, especially within the South-African context. Prior studies done, reported on the normal process of change in occupations when women enter motherhood<sup>8,10</sup>, and the effect thereof on the mother<sup>9</sup>. Numerous studies investigated the relationship issues between mothers and children on the spectrum of autism<sup>11,12</sup>, as well as the emotional and psychological burden of having a child on the spectrum of autism on the mother<sup>13</sup>. Studies done on the impact of children with other chronic disabilities, such as neuro-muscular disorders, meylodysplasia, global developmental delay and cognitive impairments, on their mother's occupations indicated an increased amount of time spent on child-related activities, as well as a change in the type of activities these mothers engage in<sup>14</sup>. The study done by Werner DeGrace<sup>15</sup> were the only study reporting on the impact of the child on the spectrum of autism on family occupations, but again this study was not investigating the impact of such a child on the daily occupations of the mothers specifically. Werner DeGrace<sup>15</sup> found that fulfilling the needs of the child with autism takes up the major part of the family's day and that they require fulltime attention and supervision of a family member.

The day to day barriers with regards to service delivery experienced by the researcher, the emphasis on the prevention of disease and promotion of well-being in the Healthcare 2020 plan, together with the researcher's knowledge with regards to the importance of occupation in the health and well-being of human beings, inspired the need to better understand the phenomena related to the experiences of mothers on their everyday occupations while having a child on the spectrum of autism. The lack of literature describing these experiences from the perspective of the mothers, further supported the relevance of research regarding this topic.

Therefore the research question states the following: How do mothers with children on the spectrum of autism experience the impact of the child on their everyday occupations?

## **1.2 Purpose of the Study**

Research to determine how mothers with children on the spectrum of autism experience the impact of the child on their daily occupations, may be valuable to the field of occupational therapy, as literature highlights the importance of therapists being aware of the increased amount of demands on mother's with children with disabilities, and how this awareness may impact on the intervention that therapists plan for these families, especially when implementing home programmes<sup>14,16</sup>. This may be even more relevant and important within

the public health sector in South Africa, where additional strains such as finances, unemployment, extended families and lack of resources and support, may contribute to families having extra burdens to carry. The fact that therapists often need to make use of family intervention and home programmes in terms of service delivery to these children and their families, contributes to the relevance of having this information. The knowledge of the occupational therapist with regards to day planning and the analysis of activities will enable them to assist the mothers in matching their daily activities to the time they have available and the time they need to address the needs of their children, while taking the mother's own needs and interests into account. The researcher therefore identified the following aim and objectives to answer to the research question.

### **1.2.1 Study Aim**

This study aimed to explore the experiences of mothers on the engagement with their daily occupations while having a child on the spectrum of autism.

### **1.2.2 Objectives were:**

- To investigate the subjective experiences of mothers regarding the fulfilling their daily occupations while having a child on the spectrum of autism
- To explore what these mothers view as typical roles and tasks involved with being a mother
- To explore how mothers had to adapt in fulfilling of their daily occupations to the needs of a child on the spectrum of autism
- To explore what needs these mothers have in order to fulfil their daily occupations successfully and satisfactory

## **1.3 Terminology**

### **1.3.1 Autism Spectrum Disorders**

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), 2000, defines autism as a pervasive developmental disorder characterised by abnormal or impaired development in social interaction and communication, along with restricted, repetitive and stereotyped patterns of behaviour, interests and activities. Abnormal functioning in at least one of the described areas must be evident by the age of three years old<sup>17</sup>.

### **1.3.2 Experiences**

Experiences can be defined as an event or a series of events that a person has participated in or lived through, and the totality of such events in the past of the individual or group. In this study experiences will include particular feelings and/or actions that mothers undergo in the attempt to execute the roles of motherhood, their direct personal participation and perceptions on the situation<sup>18</sup>.

### **1.3.3 Impact**

The term impact is defined as the measure of the tangible and intangible effects or consequences of one thing or entity's action or influence upon another<sup>19</sup>.

### **1.3.4 Occupation**

Within the field of occupational therapy, occupation can be defined as follows: "The term occupation embraces all self-care, productive, and leisure pursuits. The concepts of activities, tasks, and occupations are viewed as nested within each other. Activities are considered to be the basic units of tasks; tasks are sets of purposeful, related activities; and occupations are groups of self-directed, functional tasks and activities in which a person engages over a life span"<sup>20</sup>

### **1.3.5 Daily occupations**

Everyday occupations, for the purpose of this study, will include all the activities and tasks the participants need to execute in order to fulfil their respective roles during the course of the day.

## **1.4 Delineation of the Study**

The study was conducted over a period of four years as part of the requirements for completion of the Masters Degree in Occupational Therapy (Paediatrics) at the University of Stellenbosch. The participants were mothers of children diagnosed with autism spectrum disorder attending the occupational therapy out-patient service at the tertiary institution where the researcher is currently employed. The data collection process was also concluded at the occupational therapy department where the researcher is working.

## **1.5 Chapter Overview**

In the following chapters, the researcher will give an overview on the literature relating to the topic of enquiry prior to the commencement of the study (Chapter 2). She will also report in depth on the methodology used to conduct the study (Chapter 3) and the findings derived from the investigation (Chapter 4). The researcher will aim to interpret the findings in terms of the significance to the field of occupational therapy (Chapter 5) and will make suggestions on the implementation of the findings within clinical practice (Chapter 6). The researcher will also make recommendations for future research related to the findings (Chapter 6).

## **CHAPTER 2: LITERATURE REVIEW**

According to Mouton<sup>21</sup>, the results of the literature review can be structured in a number of ways. The researcher chose to structure this review by means of topic and concepts. The main topics/ concepts that will be discussed, is the following: autism (the diagnosis), motherhood (the concept), mothering as an occupation, family-centred therapy and method of inquiry. These concepts will be discussed using the above order in the following paragraphs.

### **2.1 Autism**

#### **2.1.1 Definition**

In order to understand the impact of an autistic child on motherhood, and how mothers experience this, it is necessary to understand the diagnosis of autism and how it manifests within the child.

Dodd<sup>22</sup> uses the following definition of the Diagnostic and Statistical Manual of Mental Disorders 1994 (DSM-IV): "Autism may be defined as a pervasive developmental disorder, characterised by impairments in communication and social interaction, and restricted, repetitive and stereotypic patterns of behaviour, interests and activities". Kanner used the term "autism" for the first time in 1943, when he described a group of children who seemed to be absorbed in their own world and uninterested in other people<sup>22</sup>. In 1979, Wing and Gould<sup>22</sup> introduced the term 'triad of impairments' when describing the impact of the disorder on children's social interaction, communication and social imagination. Wing discovered a group of children in 1988 who did not meet the original criteria of Kanner's Syndrome, and the broader term of 'autism continuum' was then introduced for children showing the triad of impairments. The term 'autistic spectrum' has been used since 1996, as the characteristics may present in many different combinations, and the severity of how the child has been impacted by the disorder, ranges from mild to severe<sup>22</sup>. The triad of impairments currently describe the three areas that are impacted by the disorder, and includes communication, social relating, and restricted interests and repetitive behaviours<sup>22</sup>.

#### **2.1.2 Diagnostic Criteria**

The literature describes a number of methods to identify early symptoms of autism spectrum disorders in children<sup>23</sup>. Although the assessment tools used to identify the symptoms might vary, the literature all confirms the importance of identifying the condition before the age of three<sup>23,25</sup>. Primary care paediatricians, as well as other health care professionals, have an important role in identifying the possibility of a diagnosis such as autism spectrum disorder<sup>23,25</sup> but the condition is most commonly only formally diagnosed by experienced paediatricians or psychiatrists using autism specific measurement tools<sup>23,25</sup>.

A formal diagnosis of autism spectrum disorder is made using clinical observations based on the following criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), 2000<sup>17</sup>. The researcher slightly adapted the layout of the criteria from the original source to allow for an easier read.

Firstly, the patient should present with a total of six (or more) symptoms from categories one to three. There should also be at least two symptoms from category one and one symptom each in categories two and three.

Category One: Qualitative impairment in social interaction, as manifested by at least two of the following:

- Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
- Failure to develop peer relationships appropriate to typical developmental level
- A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
- Lack of social or emotional reciprocity

Category Two: Qualitative impairments in communication as manifested by at least one of the following:

- Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- Stereotyped and repetitive use of language or idiosyncratic language
- Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level

Category Three: Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- Apparently inflexible adherence to specific, non-functional routines or rituals
- Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
- Persistent preoccupation with parts or objects

A second criterion for making a diagnosis of autism spectrum disorder, the patient should present with delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

- Social interaction
- Language as used in social communication
- Symbolic or imaginative play.

Lastly, in order to confirm a diagnosis of autism spectrum disorder, the disturbance should not be better accounted for by Rett's disorder or childhood disintegrative disorder.

In addition to the above mentioned assessment criteria, the paediatric neurologists also use a standardised assessment tool, such as the Autism Diagnostic Observation Schedule (ADOS-2) to confirm the diagnosis<sup>26</sup>.

The second concept/ topic to be discussed in relation to the research question and –aims, is motherhood.

## **2.2 Motherhood**

Francis-Connolly<sup>8</sup> captures the complexity of what motherhood entails by describing motherhood as “an intricate phenomenon”. Nelson<sup>16</sup> confirms and elaborated on this statement when describing motherhood as a role that is forever fluctuating according to personal, social and environmental influences on both mother and child.

In Horne, Corr & Earle<sup>9</sup>, Letherby describes motherhood as “an identity, an experience, and an institution”. According to Arendell<sup>27</sup>, the definitions of motherhood share a theme of taking care and fostering for their children, while Boulton<sup>16</sup> also included the impact of the broader social connotation of having children. Motherhood is based on the specific relationship that exists between the mother and the infant<sup>9</sup>, and depends both on the mother's personal beliefs, values and experiences, as well as the social context she functions within<sup>16</sup>. Motherhood evolves as children grow older and as the beliefs of the society changes<sup>16</sup>. For the researcher, motherhood entails the roles that mothers fulfil in taking care and rearing their children from birth until adulthood, and it depends on the mother's personal value systems, her culture and background, as well as the beliefs and expectations from the community she functions within.

The social construct of motherhood is widely described in literature. Apple and Golden in Francis-Connolly<sup>8</sup>, states that “social construction refers to the process of how motherhood (and mothering) is culturally defined within social, economic, and historical contexts”. Ambert<sup>28</sup> supports this statement when saying that parenting are determined by the current historical era, as well as aspects such as culture, ethnicity, socio-economic status. According to Francis-Connolly<sup>8</sup>, social changes such as the second-wave feminist movement, the entry of woman to the paid workforce and a decrease in family size, encouraged research in the field of parenthood, and specifically motherhood.

Motherhood are strongly influenced by the demands set by the social context in which the mother finds herself, and she constantly needs to negotiate between her own personal perceptions on mothering and that of the social group<sup>8</sup>. According to Thompson and Walker<sup>16</sup>, the societal perceptions of motherhood include aspects such as the mother enjoying her child, instinctively knowing the needs of her child, unconditional love and caring, and total devotion to the needs and wishes of the child. Zaatari<sup>29</sup> highlights the importance of the shift in the meaning of motherhood along with the various changes within the political context. The existing gender belief system within a society, determines the performance of motherhood within a specific society at a specific time<sup>27</sup>. Therefore, while the term motherhood captures the broader concept of being a mother in the light of the current political, historical, social and cultural expectations, mothering refers to the roles and tasks involved in taking care of their children.

## **2.3 Mothering as an Occupation**

As the research topic states, the researcher is interested in how mothers experience the impact of a child on the spectrum of autism on the performance of their everyday occupations. As an occupational therapist, the importance of occupation in relation to health and well-being is integral to our clinical frame of reference.

### **2.3.1 Occupation**

The term “occupation” has been widely defined in the literature. Stewart, Letts, Law, Cooper, Strong and Rigby state that “the term occupation embraces all self-care, productive, and leisure pursuits. The concepts of activities, tasks, and occupations are viewed as nested within each other. Activities are considered to be the basic units of tasks; tasks are sets of purposeful, related activities; and occupations are groups of self-directed, functional tasks and activities in which a person engages over a life span”<sup>20</sup>. De Witt<sup>30</sup> uses the influences of Wilcox and Kielhofner when defining occupation as “all purposeful human activity”, and “the doing of work, play or activities of daily living within the temporal, physical and socio-cultural contexts that characterise most of human life”. Hinojosa, Kramer, Brasic Royeen and Luebben<sup>31</sup> compile their definition on occupation from authors such as Clark, Yerxa and Krishnagiri by stating that occupation entails the tasks and activities people engage in which has personal meaning, purpose and value to the individual. They too believe that the engagement of occupations by an individual is determined by each individual’s cultural background, as well their personal interests, values and meaning derived from the activities they engage in. Law and Baum<sup>32</sup> describe occupation as “everything we do in life, including actions, tasks, activities, thinking and being”.

Wilcock<sup>33</sup> strengthens the argument that occupation is not merely the “doing” of tasks and activities, but is entangled in the personal attributes that each individual contributes when engaging in occupations. She adds another element to the term occupation, by valuing personal growth, development and meaning as a result of the successful participation in occupations.

### 2.3.2 Mothering roles

While it is clear from the literature above, that the everyday occupations of mothers will constitute of a variety of roles and tasks, each determined by the individual's context and personal attributes, the basic roles of motherhood are described in the literature.

Crowe<sup>34</sup> describes the daily occupations of mothers as the tasks involved with taking care of their children, managing of the household, personal care, participation in social and leisure activities, working, education, as well as rest and sleep. Hasselkus<sup>35</sup> adds to this by describing everyday occupation as "the phenomenology or lived experiences of day-to-day life". She adds by stating that everyday occupation provides the structure and routines by which we organize our lives.

Glenn, as cited in Francis-Connolly<sup>8</sup>, describes mothering as the tasks involved in taking care and nurturing their children. In the same article, Ruddick argues that mothers are responsible for protecting and defending their children, as well as to promote their children's growth and development<sup>8</sup>.

Mothering is viewed as a lifelong occupation, although the tasks involved during the different mothering stages may differ<sup>8</sup>. The stages referred to by Francis-Connolly imply the mothering of preschool children (newborn to five years of age) versus the mothering of young adults (nineteen to twenty-nine years of age)<sup>8</sup>. Olsen<sup>36</sup> identifies feeding/ eating; getting settled for sleep/ sleeping, and comforting/ self-comforting as three of the major co-occupations of mothers and their young children. Esdaile & Olsen<sup>37</sup> uses the elaborate description of Pierce and Marshall to explain the role of mothers in their children's play:

"..., mothers act as the stage managers and choreographers behind the play scenes of the home. They choose, maintain, and provide play objects to match the child's evolving developmental capacities. They manage the child's access to the spaces of the home and the immediate outdoor surroundings. They furnish spaces with childcare equipment and monitor those spaces for safety. They manage the child's day within the complex priorities of the needs of the child's development and safety, the need for order in the home, the mother's need for peace of mind, and multiple schedules of family members. They support the child's efforts to maintain play sequences and defend the child's play from common disruptions. They work to establish temporal routines within the child for feeding, sleeping, and playing".

None of the above mentioned mothering roles can be performed successfully without having the unique intimate and affectionate relationship which mothers have with their children.

### **2.3.3 Occupational change with the transition into motherhood**

Many studies describe the normal process of occupational change that takes place during and after becoming a mother<sup>8,9,10</sup> and the effect thereof on the parent<sup>9</sup>. These changes include the following:

- A decrease in time spent on self care- and leisure time activities<sup>8,9</sup>
- A change in the type of leisure time activities that they could participate in<sup>8,9</sup>
- Loss of sleep<sup>10</sup>
- A decrease of marital satisfaction<sup>8</sup>
- Occupational engagement were restricted to the home environment<sup>9</sup>

Although parents still engaged in occupations which they perceived as meaningful and goal-directed, these were often performed at the expense of other activities which they engaged in prior to parenthood<sup>9</sup>. Feelings of inadequacy, a change in identity and being “shell-shocked”, accompanied the initial transition into parenthood<sup>9</sup>. The change in occupational demands and imbalance in occupational participation, contributes to the magnitude of the change experienced by parents<sup>9</sup>. The researcher was of opinion that these changes in roles, as well as the mothers’ experiences of these changes in roles, will be even more significant when having a child with a disability. However, mothers with typical developing children, experience these disruptions in occupational engagement as temporary, and with enough support the situation resolves itself<sup>9</sup>. Again, the research speculated that this process of adaptation, after the birth of an infant, might not take place, or may take much longer, when having a child with a disability.

### **2.3.4 Mothering occupations with a child on the spectrum of autism**

Literature to uphold the above speculations in relation to being a mother to a child on the spectrum of autism, were not commonly available prior to the commencement of this study. However, other chronic conditions which impacts on the behavioural status of the child, as well as the impact of a child on the spectrum of autism on the occupations of the family, were also viewed as relevant.

#### ***2.3.4.1 Mothering a child with a chronic disability***

In Crowe’s<sup>14</sup> article, Joosten, Johnson and Deitz, Erickson and Upshur and Harris and McHale, all indicated that mothers with children with disabilities spent significantly more time on child-related activities than mothers of typically developing children. Breslau<sup>14,38</sup>, however, differed with these findings in that she found in her studies that mothers of children with disabilities spent significantly more time on doing housework than mothers of typically developing children, but that there were no differences in the amount of time spent on child-care.

Research also found that mothers of children with chronic disabilities engage in different activities than those of typical developing children. Crowe<sup>14</sup> found that mothers of typical developing children participated in more socialization activities than those of children with multiple disabilities or those of children with Down syndrome, while the type of leisure time activities that mothers with children with disabilities engage in, became more sedentary. Llewellyn, Thompson and Whybrow<sup>39</sup> highlighted the fact that when mothering a child with a disability, mothers are faced with additional social demands to that of the gendered expectations of women as carers. These authors also discuss the added role of activism that mothers of children with disabilities often need to take on in order to “remove the social restrictions, disadvantages, and discriminations levelled against their children”. Mothers of children with disabilities also often need to take on roles such as researcher with regards to their child’s condition, act as mediator between health professionals and schools, therapists when implementing home programmes designed by therapists, and teacher in trying to teach their children new skills<sup>39</sup>. Mothering a child with a chronic impairment adds to the occupational demands on these mothers, as they now need to accommodate the specialised needs of that child<sup>16</sup>.

Meyerowitz & Kaplan, Burton and Satterwhite<sup>38</sup> suggest that the care of severely disabled or chronically ill children restricts mothers’ extra-domestic activities, including employment, and increases their burden of daily routines. These authors found that the participants in their studies spend an estimated 4 hours a week in home therapy and 30 hours a year in accompanying their children to doctors’ visits – duration of six times higher than the amount of time spent on the above activities by parents with typical development younger than 18 years<sup>38</sup>. In disorders where the behaviour of the child is impacted, mothers are often so busy with the managing of the child’s behaviour, that there is little time left to participate in more “normal” day-to-day activities. Activities such as shaving their legs were viewed as a luxury, and the mothers often had to choose between satisfying their own or their child’s needs<sup>16</sup>.

#### **2.3.4.2 Mothering a child with autism**

In the case of families with a child on the spectrum of autism, Werner DeGrace<sup>15</sup> found that a considerable amount of time during the day revolves around the needs of the child. The child on the spectrum of autism requires full-time attention from a family member<sup>15</sup>. Family activities often revolve around the child with autism and these families are often unable to participate in activities families normally do together<sup>15</sup>. Families with children on the spectrum of autism felt “robbed” of doing the activities that would shape the feeling of “belonging as a family”<sup>15</sup>, and felt isolated from a “normal life”<sup>40</sup>. The families experienced the monotony of their daily activities as overwhelming and stressful<sup>15</sup>. The study done by Werner DeGrace<sup>15</sup> indicates that families with children with severe autism may experience difficulty in engaging in daily activities that hold positive meaning and rely on stringent patterns of routines that revolve around the child with autism to meet the demands of daily life. Joyful activities such as family holidays are experienced as “totally impractical and

not enjoyable". Parenting a child on the spectrum of autism, have added responsibilities such as having to protect the child from their environment, preparing them for new situations and implementing treatment programs<sup>40</sup>. The emotional and psychological impact of parenting a child with a disability has been well documented in the past<sup>13,41,42,43</sup>. Parents of children on the spectrum of autism report higher incidences of stress<sup>13</sup> and mood disorders such as depression<sup>41</sup>. Taking these effects into consideration highlights the significance of meaningful and satisfactory occupational engagement for this group of mothers.

### **2.3.5 Occupation and health/ well-being**

Within the profession of occupational therapy, the value of successful and meaningful participation in occupations is seen as empirical to well-being and health. Erlandsson and Eklund<sup>44</sup> use the statements from Wilcock and Meyer when claiming that in order to maintain their health, humans need to participate in a balanced variety of occupations on a daily basis. As early as 1998, Wilcock<sup>45</sup> emphasised the unique relationship between occupation and health by stating that humans "prompt occupation to overcome physiological, psychological or social discomfort, and to maintain the well-working of the organism through use". She elaborates on the above statements by adding that engagement in occupation contributes to health and wellbeing when it "..., provide optimal opportunity for desired growth in individuals or groups, and be flexible enough to develop and change according to context and choice". When working with children, the occupations of the child and the primary caregiver, most commonly the mother, are intertwined and cannot be separated from each other. It therefore becomes important to ensure the healthy participation of occupation in both the mother and the child, when aiming to improve health and wellbeing in the one or the other<sup>35,46</sup>.

### **2.4 Family-centred therapy**

"Sensitivity to the demands and needs of the family should enable the occupational therapist to have a more client-centred focus"<sup>16</sup>. Professionals sometimes unintentionally overwhelm a family with advice, treatment, suggestions and management ideas that show minimal understanding of their effects on the family's daily schedule"<sup>13</sup>. Health professionals need to be constantly aware of the needs of the family as such, and need to plan and develop services in collaboration with the family unit<sup>13</sup>. Additional activities, such as home programmes needs to be considered only after careful examination of the mother's existing commitments. Pierce and Frank, as cited in Esdaile and Olsen<sup>16</sup> emphasise the importance for therapists working with children to understand the role of the mother in facilitation of the child's play and development within the home environment. Understanding this unique relationship between the mother and child, will contribute to reinforcement of therapy goals at home.

The last concept to be discussed is the method chosen to measure the experiences of mothers with children on the spectrum of autism with regards to the impact of this child on their own daily occupations.

## **2.5 Measuring the experiences of the participants**

With qualitative research designs, the researcher typically use techniques such as participant observation, in-depth interviewing and document study to collect the data required<sup>47,49</sup>. The researcher will discuss these methods in the sections to follow.

### **2.5.1 Participant observation**

Participant observation is a technique where the researcher becomes actively emerged in the world of participants or a situation over an extended time by making use of observations and comprehensive field notes in order to describe the phenomena under investigation<sup>47,48,50</sup>. This technique enables the researcher to experience the world and realities of their participants first hand. Participant observation provides the researcher with the added information of learning directly from his/ her own experiences while being part of the world of the participants or situation. The personal involvement by the researcher allows for a more objective and comprehensive experience of the matter under investigation<sup>50</sup>. On the other hand, the researcher's direct involvement may cause participants to act differently, therefore resulting in an untrue reflection of the matter being investigated<sup>50</sup>. This method is also criticised for its poor scientific value, and the reliability and validity of this method is often questionable<sup>50</sup>. Participant observation is a time-, as well as labour intensive data collection method, and often has large financial implications as well<sup>50</sup>.

### **2.5.2 Document Study**

Another method of data collection within qualitative research is the use of documents and artefacts. Personal documents (diaries, letters, memoirs and autobiographies), official documents (minutes of meetings, agendas, files and statistics), media directed documents (news papers, magazines, newsletters) and artefacts (material objects and symbols such as photographs, posters, pictures) are often used to provide additional information with regards to the topic being studied<sup>47,48,50</sup>, as well as to validate findings derived from other methods<sup>51</sup>. Document study is also particularly useful in concept analysis and historical studies<sup>47</sup>. Document study is usually not an expensive method of data-collection, and is a valuable method of data collection where it is difficult to have direct access to participants<sup>51</sup>. On the negative side, document studies are often influenced by biased by the author, and are also often incomplete as a result of them not being originally intended for research purposes<sup>51</sup>.

### **2.5.3 Interviewing**

Interviewing is the primary method used in qualitative research to collect data<sup>52</sup>. This method is used when the researcher is interested in creating meaning from the "stories" of participants in relation to a specific topic or experience.

### **2.5.3.1 One-to one Interviews**

Individual interviewing is the most commonly used method of data collection in qualitative research. It entails having an open discussion with the participant to speak for him-/her- or itself in relation to a specific topic, without having the restrictions of predetermined questions<sup>48</sup>. During this form of interviewing, the researcher can make use of two methods of interviewing, namely unstructured and semi-structured interviewing<sup>48</sup>. During unstructured, or in- depth interviewing, the researcher use open-response questions to obtain data regarding the meaning, experiences and perceptions of the participants with regards to a specific topic<sup>47,48,52</sup>. Semi-structured one-to-one interviewing makes use of predetermined questions to gain insight into a specific matter of interest, but at the same time allowing the researcher to expand on the comments of the participant as the interview progresses<sup>48,52</sup>. One-to-one interviewing can take form in different formats, depending on the nature of enquiry. These may include some of the following:

#### ***Computer-Assisted Interviews***

This form of interviewing implies the use of technology, such as the telephone or computer, to conduct interviews<sup>53</sup>. This method is useful when wanting to interview participants living in remote or dangerous areas, and can be conducted via e-mail correspondence or through chat interviews<sup>53</sup>. E-mail conversation will imply a time-lapse between the question asked by the interviewer and receipt of an answer from the participant, while chat interviews allows for interviews to happen more or less at the same time<sup>53</sup>. Another benefit of this form of interviewing is that the written text between the researcher and participant is self-transcribing, and therefore allows for immediate analysis once the conversation took place<sup>53</sup>. While it is difficult to make observations such as body-language and the environment with this form of interviewing, it provides a more comfortable and less threatening platform to address intimate issues, or for participants who struggles with body-image concerns<sup>53</sup>. In order to use this form of interviewing, it is necessary that both the researcher and participant should be skilled in written communication<sup>53</sup>, and of course both have access to the medium of conversation.

#### ***Factual Interviews***

Factual interviewing is used when reliable factual information is required about a topic, instead of the perceptions and meanings of individuals<sup>53</sup>. In order to gain the most valid information during this form of interviewing, the way in which questions are worded, is extremely important<sup>53</sup>.

#### ***Conceptual Interviews***

When interested in the views, opinions and meaning attached to conceptual frameworks between participants, conceptual interviewing is commonly used<sup>53</sup>. It also provides for contrasting the practical and theoretical viewpoints of participants in relation to a specific concept<sup>53</sup>.

### ***Narrative Interviews***

During narrative interviewing, the researcher is interested in the stories, plots and accounts of the participants relating to the subject of enquiry<sup>53</sup>. Using this form of interviewing, it is possible to elicit the temporal, social and meaning components which participants attach to the information provided<sup>53</sup>.

### ***Discursive Interviews***

Discourse analysis aims to discover the way conversation or text is used to direct action and identities<sup>53</sup>. It focuses on how “knowledge and truth are created within discourses, and on the power relations of discourses”<sup>53</sup>.

### ***Ethnographic Interviews***

During this form of interviewing, the researcher uses a series of formal or informal interviewing questions when trying to obtain and validate the participants’ knowledge and observations with regards to cultural matters from their own perspective<sup>52</sup>. Three main types of question may be incorporated<sup>52</sup>:

- Descriptive questions to collect a sample of the participants’ language
- Structural question to discover the basic units of the participants’ cultural knowledge
- Contrast questions to provide meaning of the various terms in the participants’ language

### ***Phenomenological interviews***

Phenomenological interviewing is a specific way of interviewing when wanting to investigate the meaning of a lived experience among a specific group of participants<sup>47</sup>. It aims to investigate what was experienced, how it was experienced and the meaning attached to the experiences which had a significant impact on the participants<sup>47</sup>.

### ***Confrontational Interviews***

Confrontational interviewing is an active interviewing method, contrasting with the traditional empathic and consensus-seeking interviewing methods<sup>53</sup>. This method entails actively engaging and confronting participants during the interview process to elicit power and conflicts<sup>53</sup>.

### ***2.5.3.2 Focus Group Interviews***

Focus group interviews are done in a group of six to ten participants, where the researcher facilitates a conversation amongst the participants to gain a variety of viewpoints on a specific topic<sup>48,53</sup>. The interactive conversation between the participants, allows them to stimulate each others’ thinking about the matter at hand, and may illicit information that would otherwise not be available to the researcher<sup>48</sup>. This method is often seen as a way to save time and money, but according to Bobbie and Mouton<sup>48</sup> it results in the loss of valuable

information on both individual- and group level. The nature of this interview format also makes it very difficult for the researcher to control the interview process, and analysing the interview transcripts are very difficult<sup>53</sup>.

### **2.5.3.3 Interview order**

Literature suggests scaffolding of qualitative interview guides in the following order<sup>53</sup>:

- General to more specific questions – the researcher would typically start with broader, generalised questions relating to a specific topic, before targeting focus areas of enquiry.
- Positive questions before negative questions – the researcher will aim to get both negative and positive perspectives from participants during the interview process, but will usually explore positive feelings/ experiences first in order to allow the participant to be more comfortable to share negative thoughts.
- Unaided questions before aided questions – the researcher will encourage participants to answer question in their own words, before following up with specific questions to explore the responses of the participants in more depth.
- Behavioural related questions before feeling related questions – the researcher will usually target questions at how participants responded or acted on specific situations, before moving on to questions on how they feel about their experiences or situations.

The above information with regards to the topic of enquiry, as well as methods of data-collection, guided the researcher in the choice of research methodology as will be described in depth in the following chapter. The researcher considered document study and semi-structured interviewing as the most effective data collection methods applicable to this study.

## **CHAPTER 3: RESEARCH METHODOLOGY**

### **3.1 Introduction**

By aiming to explore the experiences of mothers on the fulfilment of their everyday occupations while having a child diagnosed on the spectrum of autism, the researcher needed to obtain a better understanding of the participants' views on typical roles and tasks involved with being a mother, and how they had to adapt in fulfilling their everyday occupations while having a child on the spectrum of autism. The researcher also wanted to explore the subjective experiences that mothers of children on the spectrum of autism have in terms of fulfilling their everyday occupations, the needs they have in order to fulfil their everyday occupations satisfactory and the meaning they derive from these experiences. Detail with regards to the specific research design –and approach used in this study, the data collection process, instruments used, quality assurance and ethical consideration will accordingly be discussed to provide a solid foundation for the subsequent findings.

### **3.2 Research Design**

A qualitative research design using a phenomenological approach seemed appropriate as qualitative research can be defined as “the study of people and events in their natural setting”<sup>54</sup>. It allowed the researcher to “delve into questions of meaning, examine institutional and social practices and processes, identify barriers and facilitators to change, and discover the reasons for the success or failure of interventions”<sup>55</sup>. The researcher chose to use a phenomenological approach, as phenomenological studies aim to understand and interpret the meaning that subjects give to their everyday lives<sup>49</sup>. Denscombe<sup>56</sup> highlights the fact that phenomenological research deals with people's perceptions or meanings, their attitudes and beliefs, as well as their feelings and emotions in relation to specific phenomena. In this study, the previous statements implied the investigation of the participants' experiences of having a child on the spectrum of autism in relation to their own daily occupations, and how they had to change these daily occupations to accommodate the child with autism spectrum disorder. The researcher also wanted to investigate the participants' views on what their needs, as well as the barriers were which prevented them from successful participation in their everyday occupations.

### 3.3 Target population and Sampling

Next, the researcher will describe and motivate how the participants for this study were selected.

#### 3.3.1 Type of sampling

Based on the description of Strydom and Delpont<sup>57</sup>, a purposive sampling technique was used. Strydom and Delpont describe purposive sampling as a method where “a particular case is chosen because it illustrates some feature or process that is of interest for a particular study”<sup>57</sup>. Purposive sampling was used because of the descriptive nature of the study, and because the aim of the study was not to generalize the findings, but rather to understand specific phenomena related to the subjects and the research question at hand<sup>47</sup>. The method was a quick, inexpensive and convenient way of sampling. Strydom and Delpont<sup>57</sup> suggest that researchers using a purposive sampling method should “think critically about the parameters of the populations and then choose the sample case accordingly”. Therefore the researcher chose participants which were accessible, who were thought to share the same experiences, and who would be able to provide in-depth information with regards to the research topic. The following selection criteria were implemented:

##### 3.3.1.1 Selection Criteria

- The mothers of children formally diagnosed on the spectrum of autism (typical or a-typical), as well as a diagnosis of pervasive developmental disorder not otherwise specified, referred to the researcher during the time of the study and willing to participate.
- The study did not include mothers of children diagnosed with developmental disorders such as Asperger Syndrome, Rett’s Syndrome and Childhood Disintegrative Disorder.
- Mothers were included in the study irrespective of when the child’s diagnosis was made.
- Mothers of children, who had additional disabilities or medical problems to that of the diagnosis of autism, were excluded from the study.
- The child had to be receiving some form of therapeutic input at the facility where the researcher is employed, as well as regular medical follow up appointments at the Paediatric neurology department during the time of the study. This was to ensure that all participants shared the same exposure in terms of expectations set by therapists with regards to the implementation of therapeutic programmes, waiting times at clinics and travelling with an autistic child.
- Mothers from various cultural- as well as socio-economic groups could participate.
- The mothers participating in the study had to be 18 years and older in order to sign the consent form as required by law.

### **3.3.2 Sampling method**

Participants were recruited after ethical approval to conduct the study was obtained by the Health Research Ethics Committee at Stellenbosch University (Appendix A) and the Medical Superintendent at the tertiary hospital where the study was conducted (Appendix B). Mothers who fitted the selection criteria were approached to participate in the study during one of the child's occupational therapy appointments. Potential participants were informed about the nature of the study, and how the data-collection process would unfold. Once the mothers agreed to participate, separate appointments were made for data collection. Mothers were given the option of having the appointments at a venue of their convenience, but all of them chose to attend the appointments at the Occupational Therapy department in the hospital where the researcher is employed.

### **3.3.3 Study Population**

Thirteen mothers gave informed consent to participate in the study initially, of which two mothers never attended the interview appointment thereafter. Therefore the study population consisted of eleven mothers in total. The mothers included in the study, were between the ages 24 to 38 years, all of which had a child on the spectrum of autism. Participants were all attending therapeutic and medical services at a tertiary public hospital in the Western Cape during the time of the study.

## **3.4 Data Collection**

After agreeing to participate in the study, an appointment date was agreed upon between the researcher and the participant. At this appointment, the participants received the participant information leaflet. The participant information leaflet was offered in the language of preference of the participant and the researcher explained the information in the leaflet to participants. Once the researcher received confirmation from the participant that she understood the information, the participant was asked to sign the consent form (Appendix C). A questionnaire on biographical information (Appendix D) was then completed. The researcher was available to assist with the completion of this questionnaire and to answer any questions pertaining to the content. Information obtained from this questionnaire were used to introduce the participants in Chapter 4, and included information such as the mothers' age, level of education, occupation, marital status, number of children, socio-economic status, residential context and support structures in the community.

### **3.4.1 Semi-structured Interviews**

The next step in the data-collection process was to conduct the semi-structured interviews. The reason for using semi-structured interviews was to ensure that the researcher remained focussed with regards to the topic of enquiry while interviewing the participants, but at the same time gather in depth information with regards to the participants' beliefs, perceptions and experiences, and the meaning they attach to these

experiences<sup>52</sup>. Semi-structured interviews were a time-effective way of gathering in depth data, while at the same time allowing for flexibility to investigate interesting avenues that emerged from the interview<sup>52</sup>.

Prior to the interview process, the researcher incorporated a process of bracketing or epoch as introduced originally by Husserl<sup>58,59</sup>. This step was incorporated to set aside the researcher's assumptions and ideas with regards to the topic of enquiry to allow her to investigate the phenomena from a fresh and new perspective. The researcher assumed, for instance, that mothers with a child on the spectrum of autism would have difficulty to continue with prior occupations, and that the mother would have to spent more time on certain daily activities. The researcher also believed that caring for a child on the spectrum of autism, would consume a lot of the mothers' time during the day. Another assumption from the researcher was that engaging in their daily occupations, would be very difficult, stressful and demanding for mothers while having a child on the spectrum of autism. The questions that were included in the interview guideline were based on the issues that proved to be relevant through the literature search in order to eliminate bias from the researcher. These issues included the following:

- Occupational change when having a child with a disability<sup>9,14,15</sup>
- A change in the time spent on certain activities when having a child with a disability<sup>14,15</sup>
- Adapting or coping in the way that mothers are performing their roles in order to accommodate their child with a disability<sup>15</sup>
- The meaning that mothers derive from these experiences<sup>15,16,60</sup>.

The researcher made use of open-ended questions, documented on an interview guideline (Appendix E) to guide the interview process. Each interview was audio taped and the recordings were then transcribed verbatim. The researcher recorded her own reflections, feelings and observations in field notes after each interview<sup>52</sup>. The interview duration varied between 20 – 90 minutes. The interviews were all conducted in the therapy room where the participants would usually bring their children to attend their occupational therapy treatment sessions.

With the first four participants, the researcher asked the mothers to bring along artefacts (photo's, objects, pictures, drawings) which reflected their experiences on the impact their child with autism spectrum disorder had on the performance of their everyday occupations. The researcher aimed to use this step as a catalyser to stimulate the mothers' thoughts on the research question at hand, but due to the abstract nature of this request and poor compliance with attendance of the appointments, this step was later incorporated as an additional question during the interview process.

The interviews were initially conducted on a second appointment date, but due to the mothers having difficulty with transport, interviewing was incorporated within the first appointment, and often on the same day of the child's therapy appointment. This adjustment urged the researcher to make alternative arrangements, such as asking the mother to bring along somebody who could look after the child, while conducting the interview with the mother. The researcher found that the participants were more relaxed and focussed once they were not distracted by their children, although one of the participants appeared slightly anxious about having her child in the care of somebody else. With some of the participants, the interview process was conducted over three appointment dates, and the researcher also had informal member checking interviews with nine of the participants. Next, the researcher will describe how the data collected, were analysed.

### **3.5 Data Analysis**

The recorded interviews were transcribed verbatim by an experienced transcriber. The transcriptions were delivered back to the researcher in computer file format. Each interview was marked with a number to insure confidentiality. Once the researcher received the transcriptions, they were printed, and she then compared them with the original audio taped interviews. This allowed the researcher to make corrections if necessary or to add qualitative information, such as a change in the tone of voice or a participant crying or laughing.

According to Creswell and De Vos, as cited in De Vos, Strydom, Fouché and Delport<sup>61</sup>, the process of data collection and data analysis in qualitative studies cannot be separated, and that it is a continuous process of refining the data until the richest and in-depth interpretation of the data can be portrayed.

The data was analyzed according to fourteen stages as described by Burnard<sup>62</sup>:

Stage 1: After each interview, the researcher made notes with regards to the topics which were addressed during that interview. During this stage the researcher also made notes/ wrote memo's on the categorising of the data, and theories and ideas the researcher developed as she worked with the data. The researcher also reflected on her own feelings and thoughts that were evoked during each interview.

Stage 2: During stage two of the data analysis process, the researcher read through the transcripts and made notes on the general themes that emerge. This process allowed the researcher to become "immersed" in the data and to become "fully aware of the 'life world' of the respondent".

Stage 3: A process of open coding was used during this stage to analyse the data. Data was broken down and coded according to themes related to the phenomenon under investigation. The researcher used the research sub-aims to guide her in coding the data related to the research question.

Stage 4: Categories/ themes were grouped together to unite similar themes.

Stage 5: The new list of categories/ themes and sub-headings were worked through and similar headings or ones that repeat themselves were removed to compile a final list.

Stage 6: Stage six involved peer checking by one of the lecturers at the university, not involved in supervising the researcher. She generated her own codes from the data, and this list was then compared with that of the researcher. Consensus between the parties with regards to the codes and categories identified was reached after the first four interviews. This step enhanced the validity of the categorising method and assisted in preventing researcher bias. At this point the two parties also agreed that data saturation was reached after the first four interviews, although all seven interviews were transcribed and coded. Data saturation is the “point in the study where the researcher begins to hear the same information repeatedly being reported and no longer hears anything new”<sup>52</sup>.

Stage 7: Transcripts were re-read and compared with the final list of categories and sub-headings to ensure that all aspects of the interviews were covered.

Stage 8 to 10: Transcripts were worked through in relation to the list of categories and sub-headings and “coded” according to the list of category headings. Coded sections were then grouped together under each category. The process of coding data and grouping data under relevant categories was done by using the Weft QDA computer software programme.

Stage 11: During this stage mothers who participated in the interviews were asked to check whether the content of their quotation of their interview corresponds with the category it was allocated to. This step assisted in maintaining the validity of the categorising process. Two of the mothers who participated in the original interviewing process could not be reached.

Stage 12: All sections were filed together for direct reference during the writing up of the findings. Copies of the complete interviews, as well as the tape recordings were kept close by to allow the researcher to refer back if anything was unclear during the analysis of the data. The researcher at all times ensured that the information were stored where it could not be viewed by external parties in order to protect the confidentiality of the participants.

Stage 13 & 14: These stages involved the writing up of the data as in the chapters to follow.

### **3.6 Quality Assurance**

Proving rigour and trustworthiness in qualitative research is very important. “The researcher must have some way of demonstrating that their findings are ‘true’ otherwise there are no good grounds for anyone to believe them”<sup>56</sup>. Lincoln and Guba, as described in De Vos et al<sup>61</sup> and Babbie and Mouton<sup>48</sup>, introduced four concepts as alternatives to the traditional terms of internal validity, external validity, reliability and objectivity, to use in qualitative research. These terms are credibility, transferability, dependability and conformability and will be discussed in the following paragraphs.

### 3.6.1 Credibility (“Does it ‘ring true’?”)<sup>48</sup>

Credibility refers to the researcher’s confidence that the findings reported in the study are accurate, appropriate, compatible and a true reflection of the experiences of the participants<sup>48,61</sup>. In this study, credibility was ensured by the implementation of the following steps:

- Reflexivity: The researcher made use of the process of bracketing prior to the interview process to set aside her own presumptions with regards to the experiences of the mothers, and to ensure that she could enter into the interviews unbiased. Field notes on the observations made during the interview process, the researcher’s own feelings and difficulties/ challenges experienced during the interview process were made after each interview. Reflection in the form of field notes, enable the researcher to keep her own feelings and thoughts separate to that of the participants. The recording of field notes also assisted the researcher to note inconsistencies with regards to the response of the participant and the observations that were made during the interview. Comparing the field notes with the printed transcriptions and the original audio-tapes, allowed the researcher to add qualitative information to the transcriptions, such as a mother being tearful.
- Triangulation: Theoretical triangulation<sup>63</sup> was incorporated by reviewing the most recent literature confirming or contradicting to the categories and themes that emerged from the data analysis
- Interview technique: Credibility was further enhanced by incorporating interview questions around themes which were constituted by literature supporting to the topic of enquiry. Semi-structured interviews allowed the researcher to probe into each answer to explore the variables, complexities and differences that each of the participants might add to the topic. It also allowed the researcher to probe for answers until she was sure that a point of saturation on that specific topic was reached. Questions were reframed and repeated when the researcher needed clarity on what was meant by the participants’ responses. Tape recordings of the interviews ensured an exact fit between the responses of the interviewees and the representation of the researcher on these responses.
- Peer reviews: Peer review was done during the coding phase by one of the lecturers at the university not involved with supervising the researcher, who generated her own code list, which was then compared with that of the researcher. These codes were discussed and altered until consensus between the two parties was reached. Discussions with the research study leaders and feedback from peers attending the research support group, was incorporated.
- Member checks: Member checking was done with five of the participants, as the other two mothers could not be reached. This was done with each of the mothers individually, by presenting the codes, categories and themes the researcher allocated to their transcribed interviews, and asking them for feedback in order to reach consensus.

### 3.6.2 Transferability

Transferability refers to “the extent to which the findings can be applied in other contexts or with other respondents”<sup>48</sup>. As the aim of this study, as with qualitative research in general, was not to generalize the findings, but rather to give a detailed description of the experiences of mothers with a child on the spectrum of autism on her daily occupations, it remains the responsibility of the reader to judge the applicability of the findings to a different context<sup>48,63,64</sup>. However, the researcher incorporated the following steps to enhance transferability of this study:

- Thick description: Denzin, as cited in Mouton<sup>21</sup>, defines the term “thick description” as follows: “A ‘thick description’ does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion and the web of social relationships that join persons to one another. Thick descriptions evoke emotionality and self-feelings. It inserts history into experience. It establishes the significance of an experience, or the sequence of events, for the person or persons in question. In thick description, the voices, feelings, actions, and meanings of interacting individuals are heard”. By giving a detailed description of the participants, their context, the research methodology and -setting, the reader will be able to determine applicability to a different setting.
- Purposive sampling: The researcher made use of purposive sampling to select a group of participants she thought to share the same experiences and who would be able to provide in-depth information with regards to the research topic.

### 3.6.3 Dependability

Dependability refers to the accuracy and consistency of the research process. Dependability was achieved by the following:

- Audit trail: The researcher kept record of all raw data, personal notes and notes on the research method to ensure dependability.
- Thick description: A detailed description of the data collection- and analysing process has been provided.
- Peer checking: Regular discussions with the study leaders were held. Feedback from these meetings, as well as feedback from peers attending the research support group, was incorporated. Coding was peer checked by a lecturer not involved in the supervising of the student.

### 3.6.4 Confirmability

Confirmability is the “degree to which the findings are the product of the focus of inquiry and not of the biases of the researcher”<sup>48</sup>. To ensure conformability the researcher kept record of all raw data such as the audio-taped interviews, written field notes and verbatim transcriptions of the interviews. The researcher will also

record all original themes and categories derived from the data. Existing literature were used to support the findings.

### **3.7 Ethical Considerations**

Ethical approval to conduct this study was obtained from the internal Ethical Committee of Stellenbosch University before the study commenced (Reference number: N09/10/283) on 14 November 2011 Appendix A). Permission from the medical superintendent at the tertiary hospital where the study was conducted, were also obtained to execute the study and access records of participants (Appendix B).

Ethical standards were ensured by applying the following ethical principles:

#### **3.7.1 Autonomy**

- Participants were provided with an information leaflet (Appendix C1 and C2) to explain the purpose and process of the study. The information in the leaflet pertaining to the study was also verbally explained to the participants.
- The participants were informed that their participation in the study was voluntary, and that they could withdraw from the study at any time.
- Once the participants were clear with the aim and process involved in participating in the study, written informed consent was gained by completing the consent forms (Appendix C1 and C2).
- Interview transcriptions were provided with a numerical number, and pseudonyms were used at all times during discussions and in the research report to protect the identity of the participants, their children and other members of their families.
- The identity of the hospital where the study was conducted was also kept anonymous.
- All audio tapes and interview transcriptions were kept under lock and key during the data-analysis process.
- Confidentiality will further be ensured by storing all audio tapes and transcriptions at the Division of Occupational Therapy, Stellenbosch University, for a three year period and it will thereafter be destroyed.

#### **3.7.2 Beneficence**

- The participants were made aware that there would be no direct gain for themselves or their children through participation in the study, but that the researcher would be willing to re-imburse them with transport fees if they had to attend additional appointments to those of the child's therapy appointments.

- Family members, who had to accompany the mother for interview appointments, also received transport money.
- The researcher made it clear that participation in the study will not have any implications with regards to their child's therapy.

### **3.7.3 Non-maleficence**

- The nature of this study did not inflict any direct danger or harm to the participants, however non-maleficence was insured by the awareness that the participants might experience some distress when discussing sensitive matters.
- The researcher therefore established good rapport with the participants before delving into more sensitive matters, and allowed the participants to stop their interviews when they felt that the discussion were becoming too emotional.
- On two occasions, referral to other health professionals were offered to participants who the researcher felt might need further support and assistance.

### **3.7.4 Justice**

- The participants were informed that their participation in the study would not have any impact on future occupational therapy to their children.
- It would also not inflict on any other form of intervention necessary to themselves or their families.

## **3.8 Limitations of the Study**

The research method allows for a rich description on how the participants experienced the impact of their children on the spectrum of autism on the performance of their daily occupations. The findings of the study can however not be directly generalised to a different setting, and the readers will have to judge transferability to their own setting when viewing the description and the reporting of the findings as presented. The information derived from the participants may be influenced by their willingness to share sensitive information with the researcher, especially as she is also the therapist involved in the treatment of their children, but on the other hand it could also added to them being more comfortable in sharing sensitive matters. The participants' responses might also have been impacted by their cognitive level of functioning, and with some of the interviews, very concrete information was shared, and it was difficult to delve into more depth into the experiences of the participants. The stage of mourning in which the participants were during the time of the interview also impacted on the content of their responses. The researcher chose to include participants of whom the child on the spectrum of autism were not formally placed in a special school setting, and therefore the findings do not reflect the opinions of mothers with children in school settings.

The above chapter provided a detailed description on the method of data collection in this study. The findings acquired will be discussed in the next chapter by making use of themes, categories and sub-categories which became evident during the data analysis process.

## **CHAPTER 4: FINDINGS**

In the next chapter, the researcher will report in detail on the findings obtained from the data-collection and -analysis process as described in Chapter 3.

### **4.1 Introducing the participants**

A summary of the participant information is reflected in table 4.1 for easy reference. A detailed introduction of the participants is provided in Appendix F, including some relevant information obtained during the member checking process. Confidentiality was ensured by the use of pseudonyms to protect the identity of the participants and their families.

Table 4.1 Profile of research participants

Participant	Age	Ethnic Group	Language	Level of education	Current Occupation	Marital status	Number of children	Ages of children	Position of child with ASD in family	Socio-economic status	Number of people living in the house	Participants with psychiatric symptoms/ history
Nadia	37	Coloured	English	Gr 12	House wife	Married	2	9 5	2	Average	4	Post-natal depression
Anne	29	Coloured	Afrikaans	Gr 10	Domestic worker 3x/ week	Married	2	7 3	1	Low	4	
Candice	38	Caucasian	English	HDE Senior Primary Teaching	Self – employed (Music teacher)	Married	2	6 5	1	High	4	Post-natal depression
Lea	24	Coloured	English	Gr 11	Unemployed	Single	1	6	Only child	Low	6	
Sharron	33	Coloured	English	National Diploma in Retail Business Management	Unemployed	Married	1	4	Only child	Low	4	Depression
Olga	35	Coloured	Afrikaans	Gr 9	Unemployed	Single	2	9 5	2	Low	3	Depression
Desiree	26	Coloured	English	Gr 11	General worker at cleaning company (contract)	Married	1	3	Only child	Low	3	
Carmen	38	Coloured	Afrikaans	Gr 12	Unemployed	Married	3	15 9 5	3	Low	5	
Jane	31	Coloured	Afrikaans	Gr 12	Personnel assistant at Shoprite/ Checkers	Married	1	6	Only child	Average	3	Depression
Delia	39	Coloured	Afrikaans	Gr 9	Unemployed	Not married	2	15 5	2	Average	4	
Maria	23	Coloured	Afrikaans	Gr 10	Unemployed	Single	1	4	Only child	Low	5	

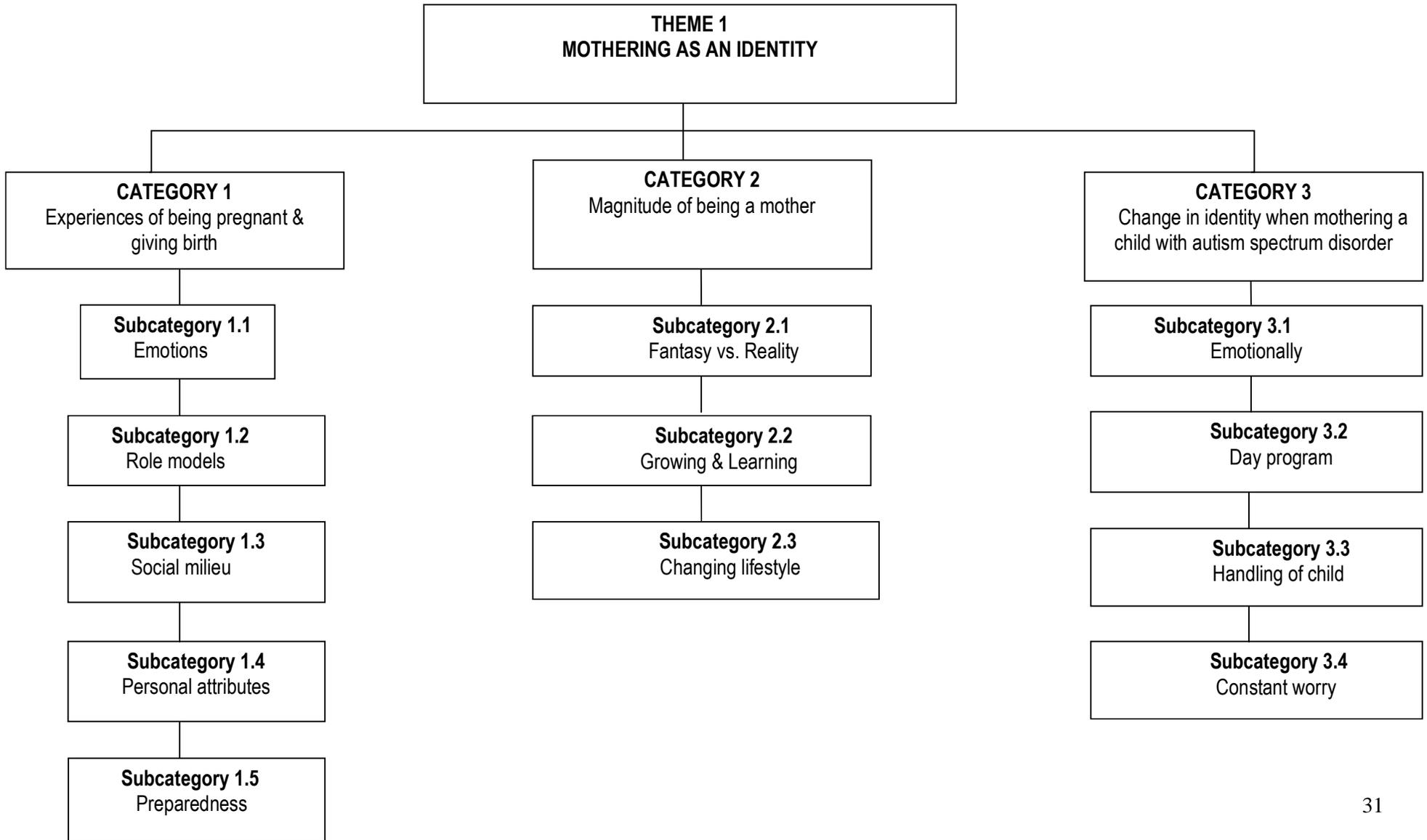
Key to Socio-economic Status: High = Family income of more than R8334 per month

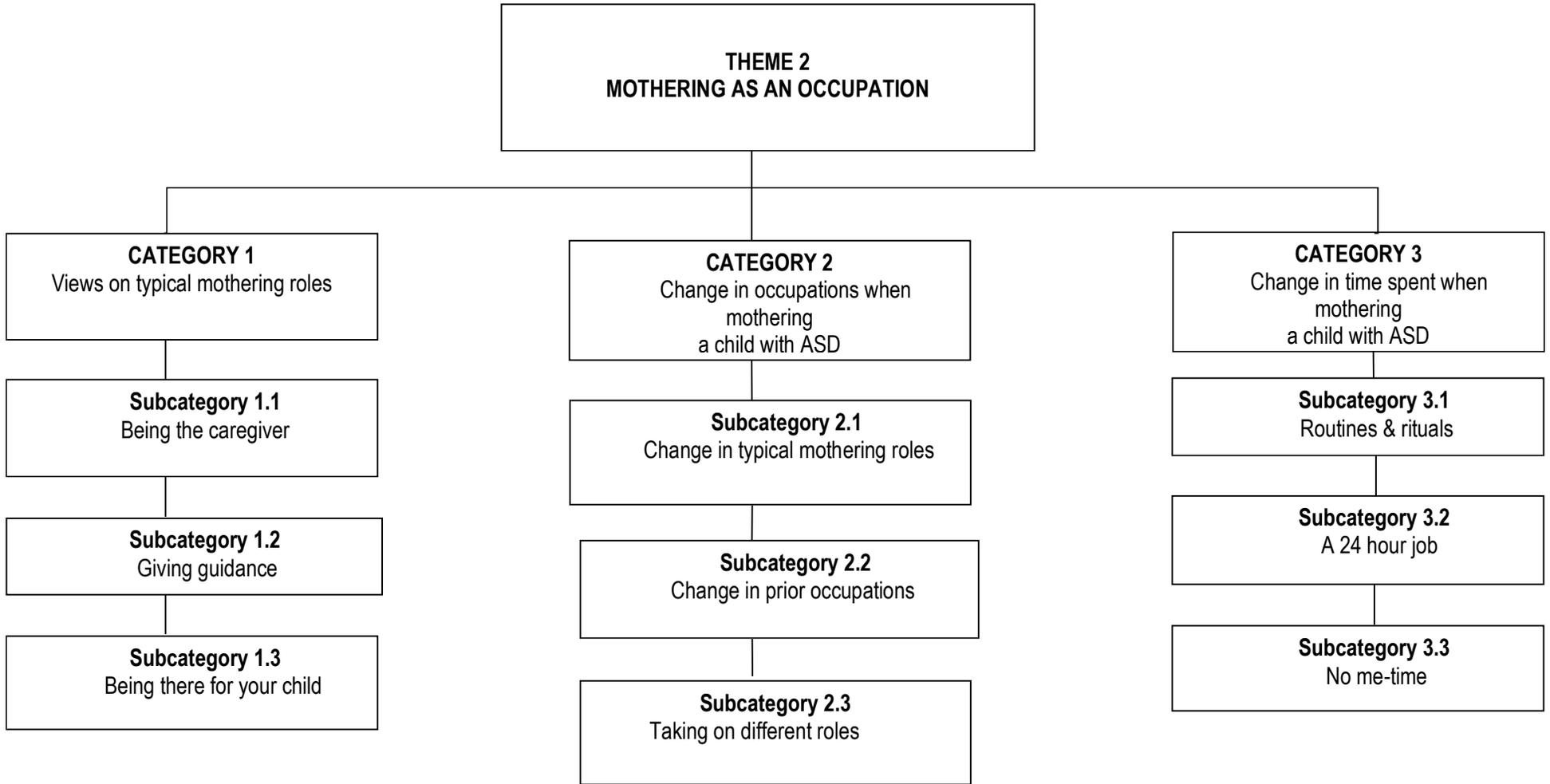
Average = Family income between R4167 – R8333 per month

Low = Family income below R4166 per month

#### **4.2 Analysing the findings**

During the data analysis process, similar information from the transcribed interviews was grouped into themes, categories and subcategories relating to the research aim and –objectives. The three themes which emerged when analysing the data, were the following: “Mothering as an identity”, “mothering as an occupation” and “making sense and moving forward”. The themes, including their categories and subcategories, are summarised in Figure 4.1, and will be discussed in detail in the subsequent sections. The researcher will support the findings with direct quotations from the transcribed interviews as available in Appendix G.





**THEME 3**  
**MAKING SENSE AND MOVING FORWARD**

**CATEGORY 1**  
Barriers & needs

**Subcategory 1.1**  
Support

**Subcategory 1.2**  
Need for normality

**Subcategory 1.3**  
Finances

**CATEGORY 2**  
Coping and adjusting

**Subcategory 2.1**  
Putting child's needs before own

**Subcategory 2.2**  
Accommodating child's differences

**Subcategory 2.3**  
Holding on to faith and religion

**Subcategory 2.4**  
Planning and preparing ahead

#### 4.2.1 Theme 1: Mothering as an Identity

Mothering as an identity captures the totality of who the mother as a person was before, during and after her transition into motherhood. A number of factors were identified which shaped the way how mothers' experienced, responded and changed as they entered motherhood, as well as how they reacted to the diagnosis of autism spectrum disorder in their children.

##### 4.2.1.1 Category 1: Experiences of being pregnant and giving birth

It was clear from the data that mothers based their prior opinions about motherhood, as well as their current performance of their mothering roles, on previous life experiences.

##### **Subcategory 1.1: Emotions**

The health of the mother, the baby and other family members prior to the birth of their children, was identified as one of the significant factors impacting on how the participants felt and responded to the expectation of becoming a parent. The fact that some of them had difficult pregnancies and miscarriages, before made them fear to lose another child. They were hesitant to look forward and to prepare for having a baby initially.

*...um ek het my eerste kind het ek verloor uhm, nè? En ek het nie planne gemaak nie. Ek het ek het ek het miskien planne gemaak met my eerste ene, maar ek het nie planne gemaak met [Clair] nie. Ek het nie "like in" uitgesien daarna nie. (Interview 2, lines 344 – 346)*

On the other hand, mothers were also excited and grateful to have a baby after struggling to become pregnant or when their children were born with health problems.

*Toe het [Trevor] nou, hoe sal ek nou sê, oorleef van al die miskrame en so ek het baie uitgesien daarna. (Interview 10, lines 12-13)*

*So vir my, net die feit dat sy "autism" het is ek geseën, net dat sy by ons is. (Interview 2, line 325)*

Two of the participants suffered postnatal depression after the birth of their first born, although they were never formally diagnosed. One of them verbalised being emotionally distant with her first born, and that she performed her mothering roles automatically without finding any joy. She experienced a big emotional change after her second child was born.

*Even with my daughter, I had post natal depression with her for two years. She was almost two years old when I decided, okay, finally I've got a baby. I just went through the motions with her as a baby and things. I didn't have any physical attachment emotional attachment to them. (Interview 1, lines 206 – 209)*

### **Subcategory 1.2: Role models**

The influence of a role model was another factor mentioned to have an impact on how the mothers viewed and performed their mothering roles. They mentioned raising their children and performing their parenting roles according to the foundation provided by their own parents or grandparents.

*And I think you also you also use you know how your parents raised you and how my husband's parents raised them.  
(Interview 3, lines 184 – 186)*

For some, the negative influences of role models in their own lives, also directed them in making a deliberate choice not to raise their own children according to these examples.

*...ek het ek het uhm my my ma, nê, het...ons is vyf kinders. Nou die die...ekke is het my eie pa, my suster het haar eie pa, dan is dit drie dieselfde pa; die drie laastes. En ek het vir myself gesê, as ek eendag kinders moet het dan wil ek nie in my ma se voetspore...ek wil altyd...ek het altyd vir myself gesê...en as ek altyd gekyk het na my vrinne se se lewens en se susters, dan het ek altyd vir myself gesê, maar ek wil ook nie 'n man hê wat nie 'n "boy friend" het as ek miskien nou 'n kind het, dat hy nie by my gaan staan nie. Want is nie...ek het ek het nog nie ge"experience" nie, maar dat ek kan sien dit is nie lekker om 'n kind alleen groot te maak nie. En ek het vir myself gesê maar ek - in ons taal sê hulle mos nou, snaakse woord, maar "buite-egtlke kind". Ek het altyd vir myself gesê ek soek nie, soos my ma nou, uhm ek soek nie buite-egtlke kinders nie. Ek uhm ek soek ook nie uh buitekant die huwelik kinders nie en...(Interview 2, lines 93 - 103)*

*Jy moenie...soos by ons, niemand rook en niemand drink nie. Nou by my ma-le doen hulle nou weer die teenoorgestelde, "which means" as my kinders gaan weinig daar, want nie dat ek nie wil hê hulle moet daar gaan nie, maar omdat hulle tel gou goeters op. (Interview 2, lines 192 - 195)*

### **Subcategory 1.3: Social milieu**

The impact of the community where the mothers grew up on their current experiences of motherhood, were strongly emphasised by Sharron's struggle to accept her cultural background. Having a Xhosa mother and Caucasian father, made her physical appearance different from the black community where she grew up, but on the other hand her accent and the fact that she spoke Xhosa made her different from the so-called coloured communities. Being rejected and teased about her differences, made it hard to accept that her child might be faced with the same challenges. Her background also had a huge impact on her prior perceptions and ideas about motherhood and even the physical appearance of her baby.

*And now it looks like he's going through exactly the same thing that I went through. (Interview 5a, line 44)*

*I gave birth to [Charles] with the expectation that he's gonna look in a certain way and he came out looking like the opposite. (Interview 5c, lines 120 – 121)*

The social milieu of the participants also had a significant impact on how they currently socialise and interact with others.

*My ma laat my nie sommer net gaan nie. (Interview 11, line 29)*

Being able to continue with prior occupations depended on the support systems available to these mothers. While some could rely on friends or family members to take care of their children, others were single mothers or had no support from others.

*Oh, in the afternoons my mom looks after them when I when I teach guitar lessons. Uhm they don't always cope well with that, they like me to be there. (Interview 3, lines 222 – 223)*

*...want ek maak vir hulle twee alleen groot – die pa het uitgestap. (Interview 6, line 6)*

#### **Subcategory 1.4: Personal Attributes**

The participants felt that their personalities, beliefs and values, played an important part in how they raised her children.

*And also I think parenting, a lot of us parent according to our personalities as well. (Interview 3, lines 186 – 187)*

*And my personality is suited to this. So you know to deal with both my my stubborn children. (Interview 3, lines 331 – 332)*

Most of the participants had very set ideas about ideal mothering qualities, and aimed to incorporate these qualities when raising their children. They viewed being a mother as important, as supported by the following statements:

*..., mothering is a very important thing to me. (Interview 3, line 65)*

*..., maar moederskap vir my is, ek is baie lief vir my kinders. (Interview 2, lines 50 - 51)*

Qualities such as unconditional love, forgiveness, respect, communication, as well as being positive about their children, were all viewed as important when raising a child.

*En uhm dit gaan nie net oor die gee nie, dit gaan oor die liefde, oor die feit dat jy elke dag vir hulle 'n drukkie gee en jy sê jy's lief vir hulle – “especially” my kinders nou. (Interview 2, lines 69 - 71)*

Religion was also mentioned as an important building block in the way the participants raised their children and went about in their everyday lives.

*But obviously we are Christians as well, so I want them to be Godly Godly children as well. They have the Bible as their...  
...foundation, ja. (Interview 3, lines 16 – 19)*

*En 'n ouer moet altyd vir haar kind in gebed dra. (Interview 2, line 123)*

Some of the participants mentioned how their introverted personalities resulted in them to prefer being on their own and to have limited social interaction.

*Ek het ek het - soos ek sê - ek het groot geword, nè en [husband] is ook so, ons ek is 'n ek is 'n mens vir my eie, vir myself (Interview 2, lines 583 – 584)*

*..., ek is nie eintlik een wat buitentoe gaan of wat like vriende het of ek het niks vriende. Ek is net heeldag in die huis.  
(Interview 11, lines 19 – 20)*

For Sharron, the hardships she faced when growing up, made her motivated and driven to change her life. On the other hand, it also resulted in feeling that she never had the opportunity to be young, careless and without responsibilities.

*Like from the early age I was like I faced a lot of difficulties {voice starts shivering} that made me like...all I wanted was make it better for myself and for my for my family. (Interview 5c, lines 224 – 225)*

*So now I I didn't have that uhm...it wasn't...growing up wasn't like...I was I didn't grow up as a child. It looks to me, like if I look at it, I grew up as a you know as a grownup. (Interview 5c, lines 221 – 222)*

### **Subcategory 1.5: Preparedness**

An interesting fact emerging from the data within this group of participants, were that only two of them mentioned planning the pregnancies of their children.

*Uhm and financially we prepared ourselves in that we uhm we always wanted me to be able to stay at home mostly. So we tried to live off one salary and we tried to pay off our bond and we tried to be wise about our money. (Interview 3, lines 153 – 156)*

*Ja, voor ek swanger geraak het met hom het ek die werk gelos, want ek het mos beplan en daar waar ek gewerk het, kon ek nie met die probleme wat ek met swangerskap het nie. (Interview 10, lines 140 - 142)*

On the other hand, four mothers reported that their pregnancies were unplanned and that they were not prepared for having a baby.

*Both my children were unplanned babies. (Interview 1, line 157)*

*So ek het nie, dit het nie eens my "mind" ge"cross" dat ek getroud of dat ek kinders gaan hê nie. (Interview 2, lines 90 - 91)*

Only one of the participants revealed that she prepared herself for motherhood by reading parenting books, and getting advice from other people, where as others verbalised having had a lot to learn initially.

*I did read a lot of books and I still do, I read a lot of parenting books. (Interview 3, line 153)*

*...ek was bang vir [Clair] se naelstring, oe, ek was bang. Ek uhm [Clair], my ma-le moes eerste vir haar gewas het voor, maar ek het gou kom leer. Ek het gou kom leer met [Clair]. Ek het nie ek het nie ek het nogal nie gedink aan hoe 'n ma gaan ek wees nie. Eerlikwaar. (Interview 2, lines 335 - 338)*

Previous experiences, such as their occupations or prior exposure to children, were also viewed as beneficial in the rearing of their own children.

*..., and growing up I did Christian Union camps were the leader and I was always involved in children's ministry and teaching Sunday school. I I love children and I was always involve with them either in a work capacity or a ministry capacity. So I think that definitely helped me. (Interview 2, lines 167 – 170)*

*Uhm you know having been a teacher involved with children uhm I think that influenced me a lot. (Interview 2, lines 166 – 167)*

Nadia reported a very cold and distant approach to other people's children, where as Candice and Anne mentioned a natural fondness for children.

*I wasn't really very much exposed to them - twenty minutes with the baby, hold the baby, but the baby would be held here, I wouldn't cuddle or anything. So physically and mentally I wasn't really interacting with babies and things like that. (Interview 1, lines 200 – 202)*

*I I love children (Interview 3, line 168)*

*...; ek is baie lief vir kinders n "besides" nou my eie kinders. Dit wat vir my ook seker, wat vir jou ook seker 'n ma maak. Maar ek is baie lief vir kinders en uhm ander mense se kinders. Ek sal altyd gee, gee. (Interview 2, lines 67 - 69)*

#### **4.2.1.2 Category 2: Magnitude of being a mother**

Entering motherhood was accompanied with a significant change in the participants' lifestyles, as well as their prior perceptions and views on motherhood. Mother's mentioned being overwhelmed while at the same time awed at the experience of becoming a parent.

*Uhm having a child in the house is a tremendous thing... (Interview 1, line 13)*

### **Subcategory 2.1: Fantasy versus reality**

None of the participants were prepared for the realities that accompanied becoming a parent.

*Like now I'm a I'm another person compared to when I didn't have a child and I wasn't married. Because I think there's two things: having a child and being married changing, it's like change it changes things. Like you're living in another world and then once you get married and have children then it's another world, nè? (Interview 5c, lines 157 – 161)*

They expected to continue with their lives as before once the baby is born. They thought that they will be engaging in enjoyable activities with their children, and never considered the challenges of being a parent.

*Ek het een honderd persent nie verwag waarin ek nou is nie {lag tydens vorige sin}. Ek het verwag ja, die baba sal daar is, die baba sal kom, ek sal kan aangaan met my lewe, ek sal nie alles net daar op 'n punt hoof te los en net te focus op die baba nie. Hy sal skool gaan, hy sal crèche gaan, ek sal vir hom sorg, ek sal vir hom daar wees by alle aspekte. (Interview 4, lines 31 – 34)*

*... I didn't realise it would be so difficult. I definitely I definitely thought, you know, being a parent would be more fun and you know, you picture playing with your children and all the things you're gonna do with them. But I I think especially when [Cathy] was born and all those sleepless nights and I I just remember thinking, why do people do this and why do they do it again? {laughs} Why do they have another one, you know? And uhm so it was quite a quite an eye-opener to me. And I was definitely an expert on child rearing until I had my own children. (Interview 3, lines 22 – 28)*

As mentioned before, Sharron idealised motherhood and had overtly unrealistic expectations of being a parent. She confirmed the opinions from the other participants of motherhood being much more difficult than from what she expected, but expanded by revealing her “fairytale” ideas around motherhood. Even her expectations of what her child would look like were not met, and she was disappointed in his physical appearance.

*..., it's you know life is not...you know like being a girl is like a fantasy, like it's not the real life. But it's like you know you're enjoying your life in some way, but now if you're a mother you enjoy being a mother, but now there's pains that comes with that. Interview 5a, lines 53 – 56)*

*Yes, like he was too dark. And I checked but now where did the child come from, you know? Okay, I come from a black family, obviously he got the half of me and the half of the father and the father is his skin colour, but a bit lighter than him. But now I ask but now how come he is so dark and and we're both I mean we're light. (Interview 5a, lines 206 – 209)*

The participants mentioned the huge responsibility that accompanies being a parent, and how becoming a mother changed their perspectives. They felt that motherhood resulted in them appreciating and value new aspects in life.

*... dit is 'n voltydse amp, né. 24 Hours amp. (Interview 9, lines 9-10)*

..., being responsible for another life is phenomenal. You know, it's it's awring, it's respecting.... (Interview 1, lines 39 - 40)

Also knowing where I could learn that my life prior to being having children my life now with children, that life I had to say goodbye to, basically, completely to be able to say, this is okay, this is me now. This is my life, this is my family. I need to be there all the time for them. (Interview 1, lines 42 – 45)

### **Subcategory 2.2: Growing and Learning**

The mothers experienced new feelings and emotions on entering motherhood. They mentioned a process of continuously learning and growing with their children.

..., you realise, but even as you are the adult you are also the child in the situation. (Interview 1, line 17)

You are learning all the time with them as well. (Interview 1, line 18)

Becoming a mother, resulted in having a special bond with their children, something they did not feel their spouses were able to share with them.

Vir my, ek kry saam seer. Uhm vir my voel dit ek kan daai pyn vat wat hulle het. Ek kan deur, ek kan eerderster daai deurmaak, want wat wat hulle het. Ek sal dit miskien beter hanteer as wat hulle kan. Uhm moederskap, {dink na} 'n moeder is, jy leer elke dag; elke dag leer jy hoe om 'n moeder te wees. En vir my om hulle...ek is eintlik ge"bless" om hulle ouer te wees. So om 'n moeder te wees is...ek kan dit nie beskryf nie, maar is, ek kan nie sonder my kinders nie. Ek is baie geheg aan my kinders. En my kinders gaan nie vakansies nie "unless" ek nie saam is nie. (Interview 2, lines 55 - 62)

Look, I don't think the man and woman feel the same about the children. I carried him, you know? When you carry your child you you got...you know there's things like when okay when the creation is made inside you, you like you the picture you paint, the picture you want your child to be like this and like that and like that. (Interview 5a, lines 182 – 186)

The participants also felt that being a mother, developed a whole different side to their personalities.

..., or me personally as an adult have learned so many things about myself as well with the child being there - where my thresholds are, where my my my forgiveness can be, .... (Interview 1, lines 14 - 15)

... - jou sag jou sagte persoonlikheid, dit kom uit. (Interview 1, line 16)

### **Subcategory 2.3: Changing lifestyle**

Candice planned her pregnancy well in advance and adjusted her lifestyle according to that. She and her husband made a conscious decision for her to stop working once their first child was born in order for her to stay at home and take care of the baby herself, and instead she started to give music lessons from home.

Uhm and then I I obviously I was a primary school teacher and then when [Cathy] was born I didn't want to teach fulltime anymore, so I started giving guitar lessons so uhm so that I can work parttime. (Interview 3, lines 242 – 244)

Although she felt that her activities did not change much since before her children were born, both her and her husband slowed down on their involvement with their church and community, especially when their children were still very young.

*..., but I think [husband] and I were, we are involved with the ministry, but we were more involved, you know with leading worship and my husband was an elder. So now I I guess we're not as involved. We still are involved but not as since having kids we slowed down on that. (Interview 3, lines 250 – 253)*

Nadia also mentioned a very active lifestyle before the birth of her first child, and that she discontinued many of these very physical activities with her first pregnancy. Although she did contribute a change in some of the activities she did before to her son being on the spectrum of autism, she felt that most of the activities would have changed irrespective of his diagnosis.

*..., from time and again I would be going motorcycling, breakfast runs, things like that. With my daughter, prior to her, it was 4 X 4-ing, umm, dune riding, horseback riding ... a lot of those have changed. There was horseback riding, go-karting... very physical activities I did. (Interview 1, lines 288 – 291)*

*..., the more heavy physical activities would have stopped anyway. (Interview 1, lines 320 - 321)*

Anne also mentioned being less sociable after she found out that she was pregnant with her first child.

*Ja, ons het ons het baie uitgegaan. Maar ek het ek het ek het uhm voor [Clair] voor [ Clair] het ek nie meer so baie uitgegaan nie.... Toe ek uitgevind het ek's swanger het ek nie meer baie uitgegaan nie. (Interview 2, lines 411 - 412)*

Some of the mothers could however return to some of their previous activities as their children got older, or took up other activities instead.

*I took up gyming... (Interview 1, line 301)*

*I did I did like volunteer at AIDS Havens and things like that before I had kids. So I was more involved in community and now I think all my energy is...*

*...taken by my own kids. So even though I started visiting a a place of safety with them now, now that they're older...*

*Yes, yes. So So we, I'm getting back into those things as they get older. So I think those things were put on hold when they were tiny (Interview 3, lines 256 – 263)*

#### **4.2.1.3 Category 3: Change in identity when mothering a child with autism spectrum disorder**

All the mothers mentioned a tremendous change in themselves with the diagnosis of their children on the spectrum of autism.

*Your whole personality, emotions, your mental state, your physical state, everything is basically turned around there with that type of child. (Interview 1, lines 71 – 73)*

*It is more over and above the respect of general motherhood. It's more of everything. (Interview 1, lines 63 – 64)*

##### **Subcategory 3.1: Emotionally**

The impact of having a child on the spectrum of autism on the emotional status of the mothers could not be ignored. Mothers described a roller coaster of emotions as they went through the process of realising that their children were different, finding a diagnosis and trying to face the challenges that accompanied the diagnosis of autism spectrum disorder. They expressed feelings of anger and frustration with their children for not being able to do the things that were expected, as well as being frustrated and irritated with other people for not understanding their children's' behaviour or the diagnosis.

*Well, I you know...uhm at first I use to be very furious when I deal with him and I use to be like frustrated at him. (Interview 3c, lines 9-10)*

*..., want somtyds raak ek ook kwaad, omdat mense jou verstaan nie en nou moet jy uhm verduidelik: "okay hy is so en so." Net dat ek kan goed voel, want ek voel ook seergemaak binne omdat hy so is en omdat mense nie vir hom verstaan nie. Dis moeilik. (Interview 6, lines 313 – 316)*

Initial feelings of denial, guilt, blame and shame were common among the participants and they often tried to hold on to the hope that the diagnosis would disappear as their children grew older.

*En soms wonder ek of dit die wat het ek verkeerd gedoen. (Interview 4, lines 157 – 158)*

*And for me it's like you know I'm forever in denial, because I'm telling myself he's still young, he's gonna grow and he's gonna be fine. Maybe this whole thing, you know...everyday everyday he's doing like different things and there's some days when I feel like he's get- he's getting there, but slowly. And you know something tells me he's gonna be fine. And that's the other thing that I realise, it's the same thing with the other mothers. (Interview 5a, lines 89 -93)*

*But if it gets to the point where like obviously next year he might starts attending certain schools, so it's gonna come out whether I don't like it or not. (Interview 5a, lines 173 – 174)*

For some, it was easier not be confronted by their children's diagnosis, while others felt hurt by other people for not accepting their children.

*But now for me talking about him is always like a a painful thing. (Interview 5c, lines 440 – 441)*

*Baie tye as hy miskien tussen ander kinders is en hy speel of hulle sal sê, "vat die deurmekaar kidn hier weg," of so. Dit dit kraak my baie af. (Interview 4, lines 345–346)*

Sadness and despair were emotions experienced amongst many of the participants. Both Olga and Jane mentioned the impact of having a child on the spectrum of autism on their mental health.

*And some days I feel like totally crushed. (Interview 5a, lines 16 -17)*

*En soms dan kan ek nie opstaan nie, want as ek lê, ek staan nie altyd sewe uur op nie. As ek lê, as ek te moeg is, dan is dit amper asof ek slaap maar iets sê vir my staan op, maar ek kan nie opstaan nie. (Interview 11, lines 90 – 92)*

*...en ek was nou vir twee jaar kan my maar sê, twee of drie jaar, was ek deur 'n baie moeilike tyd regarding [John]. (Interview 9, lines 273 - 274)*

Sharron revealed the feeling of total hopelessness by making the following statement:

*So for me it feels like like I said, sometimes it feels like I could give [Charles] away so that he can have a normal growing up. (Interview 5c, lines 302 – 303)*

The mothers also had to face tremendous losses in the light of their children's' diagnosis. They had to give up on their own prior expectations of motherhood, as well as giving up on their dreams and hopes for themselves. They had to say good bye to the expectations they had for their children prior to being diagnosed and they had to face the fact that life turned out to be totally different from what they expected. Seeing their children grow up and reaching their developmental milestones might be something that these mothers would never be able to witness.

*As you raise a child then you see some of these dreams are disappearing, because of what he's going through now. (Interview 5b, lines 6 – 8)*

*..., God gave me a son that I always wanted, but I didn't expect that I am gonna get, not I didn't expect, but I didn't think that I am gonna be, not in this situation, but that he is going to have this disorder. (Interview 7, lines 14 – 17)*

*..., soos ek nou uitgesien het, die geselsies wat jy mos nou met jou kinders het. Dit is die meeste wat ek mis, want hy kan mos nou nie praat en so nie. Dan, die dinge wat jy nou moet doen, hy wil nie sekere goed doen soos ander kinders nou gaan doen nie. (Interview 10, lines 52 – 55)*

The mothers felt isolated and alone in the burden of having a child on the spectrum of autism. They felt robbed from their freedom and mentioned being unable to share their pain with others. Life came to an abrupt halt for these mothers.

*..., omdat ek is op die oomblik is ek alleen met hom opgeskeep. (Interview 4, line 58)*

*En nie uit te kom nie en te sien wat buitekant aangaan nie. (Interview 11, line 381)*

*It's also the hard part, because now it's only me and my husband that share this this pain. (Interview 5a, lines 145 – 146)*

*Everything in my life basically just went to a complete halt. (Interview 1, lines 309 – 310)*

In contrast with all the negative emotions, mothers also experienced positive sentiments. Most of the mothers felt that their children also brought them happiness despite all the challenges.

*Hy dis is baie geluk wat hy in my lewe bring,... (Interview 4, line 158)*

They described feelings of pride and excitement in overcoming their children's barriers and being able to cope with the challenges they faced in the light of their children's diagnosis.

*Nou daar is dae wat dit voel vir my wat ek nou ook 'n bietjie goed voel oor myself dat ek sien ek kan darem vir hom bring daar waar hy moet wees. Dit is darem die moeite werd vir my gewees. Die dinge wat hy nou vandag gedoen het, dit was die moeite werd gewees. (Interview 10, lines 456 – 460)*

*So... dit gaan, dit kom by, die spraak kom by en alles wat hy, even soos hy sal nou gaan en dan sal hy in die sand gaan sit. Dan sal hy soos [therapist] met hom gemaak het met die cream op die skinkbord, dan hy vat sy die vingertjie, dan maak hy die kringetjie. (Interview 8a, lines 175 – 178)*

Proving other people to be wrong, inspired some of the mothers to work even harder in making progress with their children. The mothers valued the positive feedback from friends and family.

*Baie van hulle, ek sal sê hulle het 'n baie groot "respect" vir my en wat ekke ophou met [Liam]. Want baie van van die kinders soos 'n mens in vandag se lewe kan sien, se ma's gee nie te veel om nie. So hulle het 'n baie groot "respect" vir my, want hulle sê vir my, hoeveel kere, hulle kan nie glo wat ek doen nie. (Interview 4, lines 332 – 336)*

*Om vir hom te kry omdat mense so, dit is mos maar mens. Elke mens wat vir hulle anders voorkom of so is nou 'n probleem en dit is nie vir my 'n probleem nie. Vir my het dit meer gemotiveer om vir hom tot beterskap te wil bring. (Interview 10, lines 600 – 602)*

Most of them still hold on to the dream of seeing a total recovery in their children.

*[John]kan soos enige ander normale kind funksioneer en hy kan ook regkom. Hy kan in die midstream kom. Dit is nie iets wat hy vir lifetime sal hou nie. Dit kan 'n moontlikheid wees, maar ons neig nie daarmatoe nie, want ek glo 'n ding... dit kan beter raak. (Interview 9, lines 466 – 469)*

*But I am trying to cope and I believe that he will, he will change. (Interview 7b, lines 17 – 18)*

*Soos ek vir hom kyk, ek dink hy kan nog baie plekke bereik. Hy sal nog, ek weet daar sal beterskap vir hom wees en hy kan nog ver kom. (Interview 10, lines 651 – 652)*

Many of the participants experienced a positive change in themselves and other family members as a result of having a child on the spectrum of autism. The mothers had to mature fast in the light of their children's autism, but felt that they gained emotional strength in the process. They learned to become modest and to see life from a different perspective. Qualities such as being less selfish, less judgmental, having patience and the ability to appreciate other things in life, were all mentioned as positive outcomes due their children's' diagnosis of autism.

*And which is something that I realise, but you can't always get what you want. That is the whole thing that I'm learning from this whole thing, you can't always get what you want. You get other things and you can't get other things. (Interview 5c, lines 123 – 125)*

*And having [Charles] you know it's helping me to realise but I got to accept who I am, because God created me for a purpose to be you know different from other people. That's also helping me to deal with this like I have to accept who I am. And it's maybe going to be easy for me to accept you know what's happening to him. (Interview 5a, lines 68 – 72)*

*Om nie mense sommer net te veroordeel nie. (Interview 4, line 400)*

*Ek sal sê hy't ons ons ons as 'n gesin het hy't baie... "patience" is 'n baie groot woord wat ons almal aangeleer het wat niemand gehad het nie. (Interview 4, line 386 – 387)*

*That is something that...you know like being a mother to him made me grow up, because I think I was a child. So now I expected, if I want him to to play with me, now he must play with me or otherwise I'm not gonna speak to him, because, you know? But now I'm more like a mother than someone who is growing up with [Charles], because I think him not be...his speech delay helped me grow also. (Interview 5c, lines 100 – 104)*

The mothers reported gaining better insight and acceptance into their children's' diagnosis and their behaviour. They gained the necessary skills to manage their children, as well as acquired new skills in other areas of their lives.

*And so for me coming here, I got more educated about how how do I deal with [Charles] the way he is. (Interview 5c, lines 28 – 29)*

*In the last year alone he has made me able to sit patiently and listen to someone, whereas before I would've say, "You're talking to slow, get done. Get to the point." Now I can actually sit up two three hours and just listen to someone without commenting. (Interview 1, line 141 – 144)*

*Uhm tasks, I was never able to complete a task. Now I can sit and I can finish it. (Interview 1, line 144 – 145)*

The mothers also reported having a very special bond with their children.

*Ek sal nie my kind verruil vir 'n ander kind nie. Ek is eintlik ge"bless" (Interview 2, line 318)*

*Ja. Ons het 'n baie spesiale band. (Interview 4, line 356)*

### **Subcategory 3.2: Day program**

The mothers felt that being a mother to a child on the spectrum of autism differed significantly from general motherhood. They perceived motherhood as much more challenging and demanding, and some of them even viewed their identity as mothers as "abnormal".

*Vir my beteken moederskap baie meer as vir hulle, want ek kan dit net so stel, of ek mag verkeerd wees maar is baie is baie anders. Vir my is dit baie baie anders. (Interview 4, lines 19 – 21)*

*So I don't, I wouldn't know what normal mothering is, because I haven't had that opportunity. (Interview 1, lines 121 – 122)*

The fact that the child demands constant attention, along with juggling their other daily responsibilities made them feel overwhelmed. Many of them are responsible for taking care of their autistic children during the day without any assistance. Desiree mentioned travelling from work to the hospital for her son's therapy appointment and back to work again in order to still get paid.

*Daar is tye wat ek moeg raak, ek meen, ek is 'n ma, ek is 'n mens en daar is tye wat ek moeg raak en daar is dan niemand rondom my wat vir my kan help nie. (Interview 8a, lines 35 – 37)*

*Weet jy, ek kom sekerlik so six o'clock, past six, eers by die huis en om daadwerklik nou kos te maak en aan die einde van die dag uit te klok, rustig te kan wees in die huis vir [John] om te kan, dit kan nogals 'n taamlike storie afgee. (Interview 9, lines 342 – 345)*

*Sometimes, like I said, if I come to the hospital, then I have to still go back to work so that I can get paid the full day.*

*Sometimes it makes me tired, but I have to. (Interview 7a, lines 81 – 83)*

### **Subcategory 3.3: Handling of the child**

Constantly having to adapt to their children's behaviour and ways of doing things, also adds to additional strain on these mothers. These children demand constant input and repetition from their parents in order to see results. The participants mentioned the unpredictability of their children's behaviour, and having to adjust to their children's actions on a daily basis. The physical handling of their children when throwing a tantrum, accommodating and managing their routines and fixations, as well as addressing public outbursts, adds to the burden of mothering a child on the spectrum of autism. They also felt responsible for their children's breakdowns when not preparing them for new situations.

*..., maar van my kant af dink ek dit is nogals 'n meer, meer insette wat 'n mens moet gee, meer inspanning, meer jou, hoe kan 'n mens sê, jy moet meer insit om rêrigwaar, uhm, 'n doel te kry wat, uhm, jy wil hê aan die einde van die dag (Interview 9, lines 11 – 14)*

*You are retraining yourself every five minutes. (Interview 1, line 115)*

*It's quite emotionally draining and physically draining to always trying to think ahead or put out put out fires when, you know, something happened that's not in her routine. (Interview 3, lines 40 – 41)*

Nadia mentioned the added responsibility of constantly having to be the perfect role model to her child.

*Is this appropriate behaviour for my child to see me doing? Is this appropriate language I'm using when my child is not even in my vicinity? Its constant reminders. (Interview 1, lines 112 – 114)*

Many of the participants mentioned their children's inability to communicate as a big obstacle that they had to overcome. They felt that they could not give their children instructions and that they were restricted in teaching their children new skills and appropriate behaviour.

*Daar kom net dae wat jy glad nie vir hom verstaan nie. Dan moet jy nou... Dan vat dit 'n bietjie lank soos vir my as ma, ek sal gou weet, want ek is elke dag alleen met hom. (Interview 8a, lines 144 – 146)*

*En dan is daar party dae dan huil sy dan weet ek nie waarvoor sy huil nie. (Interview 11, line 238)*

*..., ek kan nie vir hom sê hy mag dit nie eet nie. (Interview 6, line 49)*

### **Subcategory 3.4: Constant worry**

Having the responsibility, and with many of these mothers being the only parent responsible for their child's care, added to the strain and stress of having a child on the spectrum of autism.

*..., hy's my verantwoordelikheid alleen. (Interview 4, line 60)*

*Daar's nie tye wat 'n mens kan weg glip en daar is nie. Daar is nie kans om weg te glip of te vergeet van van 'n tyd van jou kind vir 'n tyd nie. (Interview 4, lines 414 – 415)*

They mentioned their constant worry about their children's well-being and their future. The fear of their children being labelled and not accepted by the community was evident, and the mothers mentioned being constantly worried, even if the children were not with them.

*That I why I don't want to say things that you know like, then he's gonna be labelled even if he's talking. So now I don't want that. (Interview 5a, Lines 160 – 161)*

*Soos die Sondag was ek in die kerk, maar as ek kerk toe gaan dan is dit, ek dink heeltyd aan haar. (Interview 11, lines 135 – 136)*

These mothers constantly had to put their own needs aside to accommodate their child on the spectrum of autism.

*Maar ek gebruik nie die medikasie nie. Ek is 'n bietjie te bang, want omdat hy outisties is kan ek nie verwag om die medikasie te gebruik nie, want ek is bang ek raak aan die slaap of hy kan net siek word of iets soos dit dan is ek nou bedwelm in van die pille. (Interview 6, lines 39 – 41)*

## **4.2.2 Theme 2: Mothering as an occupation**

The second theme that emerged revolved around the things mothers DO. It highlights this group of mothers' views on what they perceive as typical mothering roles, as well as the change in participation in their daily occupations and the way they spent their time as mothers to children on the spectrum of autism.

### **4.2.2.1 Category 1: Views on typical mothering roles**

The mothers had very definite ideas on what they thought typical mothering roles are and should be, even before the birth of their first child.

#### **Subcategory 1.1: Being the caregiver**

Most of the mothers mentioned typical "care taking" tasks such as being responsible for meals, dressing their children, taking care of their children's hygiene and making sure that they are well looked after. They felt that providing for their children and raising them well were important.

*Dit is nou kos opskep endie kinders moet gebad raak en die klas van dinge... (Interview 8, lines 43 – 44)*

*You just provide. You work yourself Monday to Friday dead just so that you can give the child whatever the child's asking. And you must be able to say, "yes, it's there." (Interview 1, lines 25 – 27)*

Another component the participants added to the caregiver role was that of being the healer, both on an emotional as well as a physical level.

*Being the person who will always be able to heal everything that goes wrong (Interview 1, lines 52 – 53)*

Structuring their children's daily routines such as mealtimes, self-care tasks, entertainment and naptime was also included into the roles of taking care of their children.

*Maar as my ma as my ma miskien daar is en sy help met dinge in die huis, dan vat ek hom net so voor hy moet gaan slaap, soos twee-uur se kant dan vat ek hom na die naaste "parkie" toe. En dan sal hy nou daar speel tot net so voor vieruur en dan sal ek hom weer huis toe. (Interview 4, line 222 – 225)*

*Dan is dit nou slapenstyd, middag slapie. (Interview 2, lines 389 – 390)*

The mothers also had the additional responsibility of doing household chores and taking care of the rest of the family.

*..., is mos nou die huis skoon maak en dan wasgoed was, stryk... (Interview 8, lines 69 – 70)*

*...en die twee kinders wat skool toe gaan, ek moet vir hulle help met hulle huiswerk. As hulle projekte het, moet ek daarmee help... (Interview 8, lines 70 – 72)*

### **Subcategory 1.2: Giving guidance**

Preparing their children for the future and guiding them onto the right track was one of the major roles mothers' felt they had to full-fill. They felt it important to provide their children with the necessary skills and qualities to be independent adults, as well as giving them the foundation to be able to fit in with society.

*I think as a mother you're guiding your children. (Interview 3, line 62)*

*..., showing your child what life has, making them aware that it's for them to live, to enjoy, not to be scared of all the time. (Interview 1, lines 11 – 13)*

The participants felt that by setting an example and teaching their children the values they thought as important, would contribute to building their children's character and making sure that they know right from wrong. They mentioned teaching their children about religion as important.

*...and to develop their characters so that they'll be likable {laughs} people. (Interview 3, lines 15 – 16)*

..., maar jy moet 'n "role model" kan wees in jou kinders se lewe. Jy moet vir jou kinders kan sê, maar {trek asem in}  
"daai's verkeerd en jy moet dit nie so doen nie, jy moet dit so doen." Ek sê nie jou kind moet "perfect" is nie, maar jy moet  
vir jou kinders die "basics" kan leer van uhm wat is verkeerd en wat is reg. (Interview 2, lines 198 – 202)

*And it's always supper, bath, story, bed and we always pray, kneel at our beds and pray. (Interview 3, lines 226 – 227)*

### **Subcategory 1.3: Being there for your child:**

Being available and approachable to their children was another role that became evident during the data analysis process. The participants felt that they should be the one person their children could confide in, and that open communication with their children was important. They also viewed themselves as the ones to protect their children at all times.

*...n ma moet altyd daar wees vir haar kinders. (Interview 2, line 146)*

*Being the one to be spoken to when there's something bothering you. Uhm basically just being the one person that child will turn to when there is something making them happy, making them sad, joyous moments, laughter, be the all round, not not the the the the the the the sister, the mother, the everything. (Interview 1, lines 53 – 56)*

*Want vir my moederskap is uhm ek ek gaan nie ek gaan nie toelaat dat - ek weet nie, is seker maar nou net eke - uhm dat ander mense teneer op my kinders kom nie. (Interview 2, lines 65 – 66)*

### **4.2.2.2 Category 2: Change in occupations when mothering a child on the spectrum of autism**

The participants all reported changes to various degrees in their participation of everyday activities due to their children's diagnosis of autism. The responsibility of taking care of a child on the spectrum of autism became their priority, and left little time for participation in other activities.

### **Subcategory 2.1: Change in typical mothering roles**

The participants mentioned being stuck in their child's delayed developmental stages. They now had the responsibility of still assisting their children with basic self-care tasks, such as dressing, bathing and toileting, which impacted on their own and their children's independence. The participants had to constantly be available to provide assistance to their children with basic tasks. The added financial strain of still buying nappies and their children being on special diets or only eating certain foods was also mentioned by the participants.

*En is 'n rol wat ander moeders nie so grootliks, hulle speel die rol terwyl die baba nog een jaar oud is. (Interview 4, lines 146 – 147)*

*Because the nappies is expensive, but I have to buy every time, ja. (Interview 7a, line 195)*

*Soos die mielies. So ek het ook boeke wat ek lees wat hulle mag eet, maar dis vir my baie swaar omdat die geld, ek kan nie bekostig dit wat hy moet spesiaal eet nie. (Interview 6, lines 67 – 68)*

The participants also had to change according to their children's feeding rituals and routines. Some of them had to follow specific routines to accommodate their children, whereas others had to fall in with the odd times when their children wanted to eat.

*Dit is agtuur dan sal sy eet, maar in die oggend wil sy nie eet nie. (Interview 11, line 290)*

*As ons eet, sy wil nie uit haar eie bord uit eet soms nie. As ons eet dan eet sy saam met ons uit die een se bord, uit daai een se bord. (Interview 11, lines 281 – 282)*

The participants also found that they had to adapt in the way they managed their children's behaviour. Their children's behavioural outbursts, at times even violent, proved to be much more challenging than managing a tantrum or disobedience in other children. Although the participants realised the importance of teaching their children the correct behaviour, many of them found that they had to choose their battles and punish their children in different ways or had to accept inappropriate behaviour at times. Some of the participants found that they were unable to restrict their children in their behaviour as it just resulted in worse behavioural outbursts. They also had to learn techniques on how to calm down their children when their behaviour became out of control.

*Ek sê baie vir my man, ons kan nie heeldag vir hom slaan nie. Ons moet vir hom leer hy moet dit nie doen nie, want nou kom ons by ander mense dan doen hy dit dan die mense is nie altyd miskien so gelukkig met dit nie. (Interview 8b, lines 130 – 132)*

*Ek wil haar straf met iets wat sy wat sy kan doen. Miskien van iets waarvan sy hou "chips", vat dit weg, kry heel dag nie "chips" nie. Of ek sal miskien nou vir haar uhm miskien nou as ek kyk haar gedrag, dit hang van haar gedrag af hoe is haar gedrag. Okay, as ek sien nee dan sê ek "good girl." Dan sê ek "good" en dan gee ek nou vir haar. "But otherwise" as sy hand uit ruk, want daar's tye wat [Clair] sommer heel dag kan onderstebo is en dan vat ek net goeters weg waarvan, haar bottel, dan drink sy uit 'n glas uit, maar sy's baie lief vir haar bottel. Sy hoef dit nie te drink nie, maar sy hou dit by haar. Dis "why" dan vat ek sommer daai weg en ja, daai is. (Interview 2, lines 283 – 290)*

*Ek sal miskien vir haar sing, Twinkle, wat is daai... Dan hou ek haar vas en ek sit met haar. En dan tel ek haar weer op. (Interview 11, lines 244- 245)*

The participants verbalised having to be very cautious and vigilant due to their children's impulsive behaviour and lack of awareness towards danger. They mentioned having to watch their children all the time to ensure their children's safety and to make sure that they do not damage household things. Desiree mentioned how this is making her feel insecure due to her fear of losing her child.

*Amper hy, soos hy slaan bollemakiesies, staan heeldag op sy kop of hy raak waaghalsig. Hy klim bo op die TV en bo op die meubels en dan is dit nou net daai moment wat jy net jou oë heeldag op hom moet hou en as dit kom by dat ek moet wasgoed was, ek moet die wasgoed moet ek doen, ek moet vir hom kyk en... So gaan dit, ek doen dit heeltyd, jou oë moet die heeltyd net op hom wees. (Interview 8a, lines 18 – 24)*

*Ja, want hy hy hy "worry" nie eens oor gevaar nie. Hy sal oor 'n pad hardloop, dan moet ek alles wat ek het net neer sit en hardloop. Soos gister was ek in 'n winkel, my "bag" in die trollie gesit, en het't net hy't die trollie gestoot en skielik het hy net verdwyn. En toe moes ek hardloop onder onder die trollie uit, onder die sak uit, moet ek vir hom gaan soek. (Interview 4, lines 115 – 118)*

*So I feel, nè insecure, but I feel like I must keep him by my side cause he is my only child and where am I going to get another child like him. (Interview 7a, lines 463 – 464)*

The participants described the inappropriate ways their children play, and how they had to adapt according to this. They also mentioned the importance of still being involved and wanting to provide some form of entertainment to their children. The participants had to take on the responsibility of structuring time for play as their children often did not spontaneously engage in age appropriate activities. One of the participants mentioned using playtime and entertainment as an opportunity for her to do some of her other chores, but it also allowed her to incorporate some the family's religious values.

*Hy sal spring op die bed en hy sal kyk op die nommertjies op die DVD. Uhm hy's nie nog iemand wat op gou nie, hy sal met 'n karretjie speel so vir 'n tyd, wat vir my verbasend die eerste keer toe ke sien hier beweeg 'n karretjie, want gewoonlik is hulle mos so "obsess" met die wietjies en so aan. Maar net vir 'n kort tydjie, toe is hy weer vervelig. Toe's dit my pa se "tools", dis nou sy ding daai's wat hy in is. (Interview 6, lines 207 – 211)*

*From twelve o'clock on it's his time; he does what he wants. He can choose between a movie, play a game or go play with pattie or ride his bike up and down like a lunatic. Usually it's the bike and the movie, because he watches in stages as well. And my whole house is a play thing for him. (Interview 1, lines 256 – 259)*

*Ons koop vir hom goedjies wat hy kan ook geestelik ook kan verrek word. (Interview 8b, lines 70 – 71)*

### **Subcategory 2.2: Change in prior occupations**

Having a child on the spectrum of autism impacted tremendously on various areas of the participants' daily occupations. The fact that they had to look after their children full-time, resulted in most of them being unable to resume their previous jobs. Most of the participants felt that they could not leave their children in other peoples' care.

*Die feit dat ek altyd nou daar vir hom moet wees en dat ek nie kan gaan werk nie. (Interview 4, line 76)*

*Ek probeer besigheid by die huis maak, maar soms as hy nou nie wil hê daar moet mense kom om besigheid te maak nie, dan is hy nie in die bui nie en dan kan dinge nie gebeur nie. So dit maak dit baie moeilik vir my om my lewe ook 'n bietjie weer aan te gaan. (Interview 4, lines 76 – 79)*

The impact of the child on the spectrum of autism on the participants' execution of their household chores, were also reported. They mentioned being restricted in doing their household activities due to their children's difficult behaviour. Having to constantly watch their children in order to prevent accidents, resulted in taking much longer with chores than expected, and chores also often had to be interrupted and completed at a later stage to accommodate the children. Some of the participants tried to include their children in their everyday chores in order to make it easier on themselves.

*... Maar soos vir my as 'n ma wat moet huiswerk doen, wat moet wasgoed was, wat moet stryk is dit, is dit aan die einde van die dag is dit 'n bietjie moeilik, want as dit kom by soggens, jy moet die huis skoon maak, nou in die tyd wat jy huis skoon maak, moet jou oë moet die heelyd op hom wees, want daar is tye wat hy doen goed wat hy nie moet doen nie. (Interview 8a, lines 13 – 18)*

*As hy nou geëet het, dan wil ek nou begin skoonmaak. Kyk, as ek my bed wil opmaak, eerste ding as ek my bed wil opmaak, ek kan nie, hy gaan op die bed klim. Dit gaan 'n hele saak vat, kyk soos enige ander ouer gaan nou net haar bed opmaak en dan gaan dit vyf minute vat. (Interview 10, lines 90 – 93)*

*En dan sal [Clair] nou wil help met aartappels skil of "whatever". En uhm dan laat ek vir haar...sy het haar eie messe, dan gee ek nou vir haar dat sy nou maar kan aangaan. (Interview 2, lines 394 – 396)*

Normal activities, such as doing shopping, also became a challenge for some of the participants. Some preferred to rather do their shopping without the presence of their children, whereas others mentioned finding alternative ways in dealing with their children's behaviour during shopping trips. Shopping lists are often based around the needs of the child on the spectrum of autism, often to the detriment of the rest of the family.

*Ons kan nie vir haar saam neem nie. Ons moet maar vereffen die klere huis toe bring, kyk of dit nie pas nie en as dit nie pas nie moet ek dit weer terug neem. Maar [Clair] is rêrig 'n handvol in die winkel en ek is bang [Clair] raak weg. (Interview 2, lines 503 – 506)*

*So certain shops, because last time I saw at Mr Price or so when me and my mother went in so he pulled us back. So I had to stay outside so they had to go alone. So certain shops he don't like going in. (Interview 7a, lines 237 – 239)*

*Of gee net vir hom iets in sy hand of Smarties of... (Interview 9, line 593)*

*Nou elke keer as daar moet geshopping word, die kos draai net om [Elliot]. Alles wat gekoop word, word ingepas vir hom tot die toilettries want, ek weet nie, hy drink verskriklik water, maar hy het die droë velletjie. (Interview 8a, lines 205 – 208)*

The participants also had to find creative ways to accommodate their children's food preferences and bathing routines.

*Alles wat ek doen soos nou vandag as ek nou vandag miskien hoender in die oond sit dan gebruik ek nou miskien chicken spice, dan môre kan ek nie meer dieselfde spice gebruik nie, want hy proe gou. Een ding wat ek opgetel het van hom is hy kan gou proe wanneer 'n ding dieselfde is en wanneer dit verskillend is. Want ek kan nou vanoggend vir hom*

*'n stukkie hoender gee en dan is daar chicken spice op en as jy vanmiddag weer vir hom hoender gee dan sal hy nou, as hy proe dit is dieselfde, dan sal hy dit nie eet nie. So jy, as jy vir hom 'n different stukkie hoender maak, soos miskien nou Kentucky gee, dan sal hy die Kentucky eet. So met hom moet jy baie dinge aanvang. (Interview 8a, lines 255 – 263)*

The impact of a child on the spectrum of autism on the rest of the family and family activities could not be ignored. Although not all of the participants had to discontinue participation in family activities completely, all of them mentioned the impact of their autistic child on the quality of participation in family activities. Some mentioned avoiding family events as their families do not understand their children's behaviour, while others mentioned that family activities now revolved around the entertainment of their child on the spectrum of autism. The participants also felt that they had to protect other children from their child on the spectrum of autism's aggressive behaviour.

*En dan uhm soos ons sal uitnodigings kry soos byvoorbeeld na troues toe en dan sal ek lieverste sê ek gaan maar by die huis bly, want hy gaan netnou iets doen wat die mense nie van gaan hou nie, want hulle verstaan nie vir hom nie. (Interview 6, lines 133 – 135)*

*So vir 'n ander persoon ek verstaan wat hulle miskien van hulle kant af sien. [John] is afknouerig. Soos hulle mos nou.... So op daai, ons was al op so lengte dat ons maar vir [John] van kinders af gehou het. (Interview 9, lines 326 – 328)*

*Ok, ons kan probeer om so af en toe om speletjies saam met hom te speel om sy aandag nou van al die dingetjies wat hy nou so doen dan kry ons darem so bietjie tyd saam. Speel, meeste gaan dit net oor almal wat saam met hom nou wil speel. (Interview 10, lines 256 – 259)*

Lea felt that this change had been positive for her and her family, but Maria felt that her parents blamed her for the loss of a social life.

*Maar hulle hulle verstaan. Almal verstaan en ons is meer na aan mekaar. Ons sal in die aand sal almal in die sitkamer sit en hy sal speel. Almal sal deel in wat hy speel en vir hom probeer help waar dit nooit so sou gewees het nie. (Interview 4, lines 311- 313)*

*Want dit is asof ek hulle social lewe van hulle afgevat het. (Interview 11, line 348)*

The participants also reported poor quality of time spent with their spouses, and the negative impact that the child on the spectrum of autism had on their relationship with their husbands. Having a child on the spectrum of autism also impacted significantly on their siblings. The participants mentioned neglecting their other children in the process of taking care of their children on the spectrum of autism, and for Delia this has already resulted in behavioural problems and a poor relationship with her older son. Lea added to this discussion by saying that she could only enter into a new relationship because she and her boyfriend had been friends for years and therefore he understood her son, and her son was also accepting him. She felt that it might have been more difficult had it been somebody completely new to her situation.

*En dit het 'n stramiteit tussen my en sy pa ook veroorsaak, want kyk baie keer is ek so uitgeput en dank an ek nie eintlik, daar is nie kommunisasie en goed nie. Jy is so moeg jy loop slaap net en julle kommunikeer eintlik nie meer regtig nie. (Interview 10, lines 349 – 352)*

*Ja, my groot, die oudste seun, ek het nou probleme gehad met hom, want hy het begin saans so laat in die huis kom en hy kom net uit die skool uit, hy het nie meer daai tyd wat hy eers saam met my gehad het nie. Hy beweeg net weg. En ek het een keer gepraat met hom, want hy het 'n sort ek weet nie waar, so aggressief begin raak, so woede uitbarstings en so. Toe het ek begin praat saam met hom, toe kom dit uit by hom. Alles gaan net oor die kind alles so. Hy verstaan dit nie. (Interview 10, lines 330 – 336)*

*Ek het ek is ek het nou 'n nuwe "boy friend", maar omdat ons lank aankom, omdat ons vriende was vir jare, sien hy nou kans en weet hy wat is [Liam] se probleem. En hy is hy's baie "supportive" met [Liam]. En {Liam} is baie oor hom. So hulle twee kom goed oor die weg. Dis maar gewees omdat hy...  
...al die tyd daar was as 'n vriend voor hy nog iets anders was dat [Liam] nou weet, okay ek ken. Maar as dit moes iemand anders wees, gewees het, 'n vreemdeling, glo ek nie [Liam] sal verstaan het... (Interview 4, lines 284 – 291)*

Carmen's daughters provided their mother with a lot of support, but it was clear from her statements that they often had to sacrifice their own priorities and that they had to take on adult roles in the process.

*... maar hulle tweetjies help vir my baie. Hulle help vir my baie. Hulle sal sê, "mammie, doen jy of maak jy die kos". Ons gaan speel moet hom. Dan sal hulle miskien hulle huiswerkies los, dan sal hulle eers met hom speel tot ek klaar is met die kos en dan doen hulle gou hul huiswerkies. So elke dag is nie dieselfde as wat hulle uit die skool uitkom en hulle doen huiswerkies nie. Hulle kyk nou eerste wat is die omstandighede by die huis. Het mammie niks gedoen gekry vandag nie... (Interview 8a, lines 88 – 94)*

Out of the eleven mothers who participated in the study, nine mentioned a change in the leisure and social activities they participated in prior to having a child on the spectrum of autism. Many of them mentioned the lack of understanding from other people as one of the main reasons for not visiting friends and family any more. They also observed that people started to avoid visiting them due to their children's difficult behaviour. The participants also limited their social interactions to close family and friends.

*Uhm, ons het op die oomblik het ons nie actually vriende nie, want hulle het ook nie verstaan nie en ons het maar besluit, ok, as dit die manier is hoe mense ander mense treat, dan beweeg ons maar weg. (Interview 8b, lines 5 – 7)*

*Maar as ons gaan kuier, sal ons kuier by my suster en hulle, my suster het actually gaan oplees op die internet en sy verstaan nou vir hom. Hulle probeer vir hom verstaan en hy begin te interact met die kinders in die familie en dan is dit nou net my ma en my pa. (Interview 8b, lines 9-12)*

*... daai gooi partykeer dinge dat dit nou nie, dat ek nie kan na sekere dinge kan toe kan gaan nie. (Interview 9, lines 147 – 148)*

Even when the participants could participate in social events, their attention often still revolved around making sure that their children are safe and not causing trouble. The participants reported not wanting their children to discomfort other people, and therefore preferred to rather not visit friends. Interaction with friends would

happen at odd places, such as in the road on their way home, or in parks where they were busy entertaining their children, while others mentioned being confined to their home, and unable to go out.

*I have conversations, but most of the time I must just watch him, because he'll somer throw things around, ja. (Interview 7a, lines 345 – 347)*

*So ek sal by die "parkie" sit met hom en dan sal van my vrinne daar kom sit. (Interview 4, line 269)*

*Dis amper soos ek moet hom baie tye in 'n gevangene hou. Hy moet in die huis wees. (Interview 4, lines 43- 44)*

Nadia was the only mother who mentioned specific hobbies prior to the birth of her children. Although she felt that some of these activities would have changed anyway when she had children, she definitely contributed discontinuing some of the activities to her son's diagnosis of autism.

*... Gone! Disappeared completely. Everything in my life basically just went to a complete halt. (Interview 1, lines 309 – 310)*

*But the other activities like horseback riding, go-carting, humm, taking wild trips up the West Coast, 4X4-ing, ... that would not have changed... (Interview 1, lines 321 – 323)*

Even attending church became problematic for some of these participants. Some mentioned that they are seldom able to attend church, where as others reported changing to a smaller congregation after previously also being rejected. Jane commented on the fact that she and her husband could not attend church together in the past, and one of them always had to stay at home with their son, although it is starting to improve slightly.

*Dit is ook nou 'n groot ding. Ek kom baie weinig by die kerk uit. (Interview 10, line 196)*

*Die vorige kerk by wie ons gewees het, die mense het nie vir hom aanvaar daar nie. Hy was uitgelag en name genoem en ons het beweeg na 'n ander kerk toe, 'n kleiner kerkie en ons het vir hulle verduidelik en dit gaan goed daar. (Interview 8a, lines 283 – 286)*

Candice was the only mother who felt that their social life did not change much in the light of her daughter's autism.

*... You know, we're still being sociable, we still inviting a lot of people to our house and stay over,... (Interview 3, lines 290 – 291)*

### **Subcategory 2.3: Taking on different roles**

As a result of their children's challenges and special needs, the participants mentioned taking on additional roles to those mentioned earlier.

*Alles in een "actually". (Interview 4, line 110)*

Advocating for their children's needs and protecting them from the judgment of others were viewed as an important role for six of the mothers. The participants felt responsible for teaching their family and friends about the diagnosis, and by doing so lessen the stigma that accompanies a diagnosis such as autism. They also mentioned the important role they play in assisting and making sure that their children's needs are met within the school environment.

*And I think I'm helping them to understand that it's, like I said everyone think of autism with this stigma or whatever, but uhm so most people would say that they would never know if I haven't told them, you know, they didn't know. (Interview 3, lines 314 – 316)*

*... So I'm always going to be needing to see that class is a routine class and just explain to the teacher, "you need to explain to [Cathy] if you're going to change something." You know? (Interview 3, lines 94 – 96)*

The participants felt responsible for helping their children to make sense of the world around them, and to prepare them for the future in the hope that they would one day be able to cope with real life scenarios.

*Hy hy weet hy ken nie die lewe om hom nie. Hy weet nie dat daar reëls en regulasies is en gevare wat jy voor bang wees – hy lewe net vir nou en vir wat hy nou wil doen wil hy nou doen. (Interview 4, lines 6 – 8)*

The participants also had to act as their children's medium of communication to other people, and were often the only connection between their children and the rest of the world. Apart from helping their children speak and interpreting their children's attempts at communicating, mothers often had to use their instinct and special connection with their child to understand their needs and behaviour.

*Helping him talk is the biggest thing for me, because that to me has become priority one. Being able to allow him, or teach him how to communicate with people. (Interview 1, lines 379 – 380)*

*Ek moet sien wat hy sien. Ek siende dat hy nie vir my kan sê wat hy wil, moet ek vir hom kyk en dan moet ek presies kan weet wat hy dink. (Interview 4, lines 85 – 86)*

The participants reported having to fulfil the role of their children's teachers and therapists in an attempt of overcoming their barriers, as well as teaching them about emotions.

*Because I get therapy with him here, I give them therapy there at home... (Interview 7a, line 327)*

*He also needs to learn his own emotions. (Interview 1, lines 78 – 79)*

#### **4.2.2.3 Category 3: Change in time spent when mothering a child with ASD**

Ten of the eleven participants mentioned a dramatic change in how they spend their time. The mothers' time was mostly spent revolving around the care of their child on the spectrum of autism, while at the same time trying to juggle other household- and family responsibilities.

*Dan sê sy mense gaan nou nooit weet wat hier inkom hoekom sit die vrou nou nog in haar nagklere. Hulle weet nie dit vat twee, drie ure se tyd om te... Verstaan? (Interview 10, lines 382 – 384)*

##### **Subcategory 3.1: Routines and Rituals**

It appeared that many of the participants had to structure and spend their time according to their children's routines and rituals. Their children's awkward perception of time, forced them to perform their daily activities at odd times of the day or season as well. Most of the participants reported having to stick to their children's way of doing things in order to prevent tantrums, and to make things easier on themselves.

*En hy verstaan nie, dis nou koud vandag of dit reën of hy wil omtrent so vier keer weet hy wil by die "parkie" speel en twee ure speel. En hy sal nie verstaan, okay, dit reën nou, maar....(Interview 4, lines 271 – 273)*

*Ja, ons probeer om by te hou, ja, want dit maak vir ons makliker. As ons nie die dinge gaan doen soos hy dit wil hê nie, dan maak dit vir ons moeilik,... (Interview 8a, lines 265 – 266)*

Candice, Nadia and Anne mentioned the monotony of always having to do things the same way, while Maria commented on the unpredictability that accompanies her daughters wills and ways.

*So so everything always has to be the same. (Interview 3, line 200)*

*..., want die dae verskil teenoor mekaar,...(Interview 11, line 7)*

##### **Subcategory 3.2: A 24 hour job**

Taking care of their children on the spectrum of autism took up most of the participants' time during the day. They felt obliged to be available for their children all the time, and had little or no support to relieve them in the care taking duties. Due to the mothers' fear of something happening to their children, the child became their constant companion.

..., and that's a 24/7 job, basically. (Interview 1, line 504)

... I need to be there for him all the time basically. (Interview 1, line 4-5)

So ek en [Roy] is elke dag vas aanmekaar, soos daai "movie rainman". {lag} (Interview 6, lines 179 – 180)

To Olga, the biggest struggle was to keep her son occupied during the day due to his limited interests and short attention span. The lack in variety activities the mothers could participate in, and the fact that they were now mostly confined to their home environment, was mentioned by many of them.

Dis waarin die tyd gaan. Nie nie soseer om, sê nou maar vir hom te kry dat hy kan eet of dat hy aantrek of dat hy bad nie.

Dit is meer die die feit dat jy vir hom uhm heeltyd moet "entertain". (Interview 6, lines 391 – 393)

Maar dis soos die dag aangaan; elke dag dieselfde. (Interview 6, lines 108 – 109)

### **Subcategory 3.3: No me-time**

Having their children by their side all the time, and being the ones responsible for the daily care, made the participants feel that they had no time left to spend on themselves. Even basic activities, such as doing their hair became a luxury to some of these mothers.

With a ASD child you don't have that me-time. (Interview 1, lines 108 – 109)

Is ek sal probeer om een dag in die week sal ek probeer om 'n uur of iets uit te waar ekke myself kan indruk waar ek miskien soos my hare versorg of iets. Maar nie rêrig nie. (Interview 4, lines 245 – 246)

The little time that participants had to spend on themselves, still revolved around their children, or had to be used to do things that they otherwise did not have the time for. Nadia and Olga mentioned the fact that even having some privacy when using the bathroom was impacted on by their children with autism.

..., when you are in the same vicinity and you are having your me-time, irrespective if you got it by accident or not, it's still not your me-time, because you're constantly thinking about that child. (Interview 1, lines 110 – 112)

So: "kyk gou net na hom, mammaie vir daai tydjie, dat ek net gou toilet toe kan gaan." En dis ook maar gou-gou maak, want ek "panic" in die toilet want of gaan hy al of watter negatiewe dinge gaan hy nou doen. So. (Interview 6, lines 193 – 195)

The impact of the autistic child on their mothers sleep, were also highlighted. These mothers never had the opportunity to take a break and just relax.

Maar is 'n baie groot verskil tussen anders kinders dat hy... "twenty four seven" moet... en as hy voel hy wil nie slaap nie, dan slaap hy nie. So ek kry baie min tyd vir myself. Ek kry baie min tyd om te slaap. As hy wil heel nag wakker wil wees, dan is dit heel nag wakker. (Interview 4, lines 143 – 146)

*Hy verstaan nie, partykeer gaan daai kind aan tot eenuur in die môre. (Interview 10, line 359)*

*So ek het nie rêrig 'n "break" nie. (Interview 6, line 186)*

### **4.2.3 Theme 3: Making sense and moving forward**

The third theme constituted how the mothers adjusted to having a child on the spectrum of autism, and how they manage to cope with the challenges they face on a daily basis in the light of their children's autism.

#### **4.2.3.1 Category 1: Barriers and Needs**

Going hand in hand, the participants identified a number of factors which they found to restrict them in performing their daily activities successfully, and aspects that would assist them to make their lives easier.

##### **Subcategory 1.1: Support**

All the participants felt that getting support could change their lives significantly. Whereas some of the mothers mentioned the tremendous responsibility of having to take care for their autistic children alone and not having anyone to assist them, others felt that the fact that they could rely on family or friends made their burden lighter and easier to manage.

*... want op die ou einde van die dag, ek is alleen – ek en my man nou – ons is alleen. Ons het nie ondersteuning nie, ons het nie...dis waarom sê ek dis somtyds swaar, maar ons kom daar deur. (Interview 2, lines 320 – 322)*

*Ja, my friends are very are very supportive and very uhm helpful. Like if I need to leave [brother] with one of my friends so that I can bring [Cathy] to [hospital] or if I need to you know they they're very supportive and they're very understanding, because I've been quite open about everything and and you know explain what's going on. So they they've been very supportive of everything. (Interview 3, lines 305 – 309)*

Another aspect viewed to be of assistance to these participants, were the services that they could access. Candice felt that she gained a lot from the therapeutic services offered to her daughter as it provided her with the necessary knowledge and skills to understand and manage her daughter. She felt that support groups providing advice on the parenting of an autistic child would be beneficial to parents, while Lea mentioned the need for advice on her son's dietary issues, as well as the opportunity to vent her feelings and to talk about the difficulties of having a child on the spectrum of autism. For Jane the struggle to get her son diagnosed, was a big barrier to overcome, and it highlighted the lack of sufficient access to the appropriate health services, and the impact of the slow referral process between the different levels of care within the public health system.

*..., because I see that improvement in [Cathy] since she's been going to therapy. So I think I do have that support. (Interview 3, lines 363 – 365)*

*..., maar daar is nou net sekere dinge soos soos die dieet wat hy moet volg, as daar miskien 'n "dietician" was wat miskien met outisme spesialiseer, dit sal baie beteken. (Interview 4, lines 371 – 373)*

*Maar somtyds wens ek net dat daar soos iemand is wat weet waardeur die kind gaan, wat jy een persoon enkel kan vat soos soos 'n sielkundige, dat een ma net sy hele emosies kan...dit sal ook baie help. (Interview 4, lines 374 – 376)*

*Weet jy, as ek en jy nou op die regte level is dan dink ek dit sal gewees het as , dit sou, dinge sou beter gewees het as [John] dalk vroeër gediagnose was. (Interview 9, lines 720 – 721)*

Most of the participants mentioned the fact that mainstream schools and –crèches were unwilling to accept their children, or that they themselves felt that these schools were not sufficient enough to provide in their children's special scholastic needs. They felt that getting their children placed in a special school setting specialising and equipped to deal with children on the spectrum of autism, would change their own and their children's lives significantly.

*So then I said no, I cannot take him back to that crèche, because they are crèche that only takes care of the children that can talk and stuff. (Interview 7a, lines 441 – 442)*

*Maar wat ek vir u kan sê is, die drie weke wat hy hier by Alpha gewees het, het ek gesien daar kan 'n verskil vir my wees as hulle hom net aanvaar by 'n skool. (Interview 10, lines 426 – 428)*

### **Subcategory 1.2: Need for normality**

The participants mentioned the need for having a "normal" life for themselves and their children. Nadia vented her frustration for constantly having to battle to get her child accepted within a schooling environment, and both she and Jane felt that these children deserved the opportunity to play and interact with other children. Others mentioned their need for acceptance and understanding of their children's diagnosis and differences.

*They are also children. They need to be with normal children,...(Interview 1, line 421)*

*I wish like I could have a child that can grow like normally in a normal environment where there's like no differences; he can be like other children. (Interview 5a, lines 41 – 42)*

### **Subcategory 3: Finances**

Some of the participants thought that having sufficient financial support and –resources would enable them to take better care of their children with autism. Most of them felt that if they were able to get a job, their circumstances would also change significantly. For Sharron a job not only meant some financial relieve, but she also viewed being able to work as an escape from her circumstances and emotional pain. For her, having a job would give some meaning to how she spends her time during the day.

*So if I could have a job then things could be better. I could I can raise him in a different way, not like make him do things, but if we can move from that environment to another environment things could be better. (Interview 5c, lines 282 – 284)*

*So I think like if I can get a job maybe life could be better, because now I'm not looking at my problem like...look, even if I'm at home and I'm telling myself, having my my time or I go out and go shop, that's that's always something [Charles]...because I got too much time not being used like for other things like for good things if I must say. My time it feels like my time is being...my time is wasted. I feel like wasted, because now all I do is sit around and think about [Charles] and what [Charles] is and is [Charles] okay. You know, if I can get a job...so I feel if I can get a job and get my mind off [Charles], maybe things could be better and I can make his life better, because right now it's just for me too much. (Interview 5c, lines 523 – 531)*

#### **4.2.3.2 Category 2: Coping and Adjusting**

The participants had no choice but to accept and adjust to their circumstances. Despite all the challenges they had to face daily, they still miraculously managed to continue with their lives.

*Hoe hy is het ek gou aangepas. (Interview 6, line 5)*

##### **Subcategory 2.1: Putting child's needs before own**

The mothers mentioned putting their own life on hold in order to make sure that they remain focussed on their children. Carmen and her husband even altered their house to make sure that their son can be happy. Nadia and Sharron mentioned taking up new activities to replace those that they had to give up due to their children's autism, but both of them found these new activities were not as enjoyable.

*Ek sal haar...ek ek sal liewerster my aktiwiteite en my goeters "aside" sit vir my kind, "because why" dan kan ek al daai energie liewerster in haar sit as wat ek dit in ander mense gaan sit wat my kind gaan gaan "crit". En ek soek nie daai nie. (Interview 2, lines 434 – 437)*

*I took up gyming...To replace most of that physical activities, but it, it does not compare. Nothing compares. There's no other activity in my life at all. (Interview 1, lines 301 – 304)*

*Toe sal ons sien hy hou van die gras ook dan sal hy sy voete vat en dan sal hy so skuur op die gras en toe sien ons maar hy begin te lag. So dit is iets vir hom. Dit tickle, Ek weet nie wat dit maak nie, maar dit tickle vir hom of iets. Toe het ek nou maar begin gras aanplant. En ons het nou gesien die stukkie gras wat ons geplant het, het nou daai speel ook 'n groot rol, want hy sal nou heeldag net op daai gras speel. (Interview 8b, lines 116 – 121)*

##### **Subcategory 2.2: Accommodating child's differences**

The participants had to learn to work according to their children's pace and capabilities, and to take each day step by step. They had to learn and prioritise which battles to fight, and when to rather let go and focus on something more important. These mothers identified the unique qualities in their children, and learned to love them and accept them unconditionally despite their differences.

*..., I do the things that I can do and leave the stuff that I can't do. (Interview 5c, lines 32 – 33)*

*I can't I can't enforce things that are going to cause her to have a fit, you know but choose what is important. (Interview 3, lines 70 – 71)*

*...Ek weet nie wat ek sal verander van haar nie, want sy's "perfect" soos sy is...(Interview 2, lines 567 – 568)*

The participants had to alter their previous hopes and goals they had for their children. Dreams and hopes simmered down to wishing that their children could get school placement, and that they would be able to cope independently in life.

*So I think I would've always guided them and prepare and have goals for parenting, but but now I think my expectations have lowered, because obviously of her situation I have to understand. (Interview 3, lines 66- 68)*

*..., obviously my goal is that she be mainstreamed... (Interview 3, line 92)*

### **Subcategory 2.3: Holding on to faith and religion**

The participants found strength in their religion and held on to their faith to cope with their daily struggles. For Sharron, her faith helped her to accept her son's diagnosis, as well as her own background. Anne held on to her hope in God to provide in their everyday needs as well as curing her daughter's autism.

*Ja, bid heeltdag. Dit is al. Ek sal die Here vra vir krag en so gaan my dag verby. En dag as hy nou 'n bietjie, hoe kan ek sê, as ek hom nie kan hanteer nie, dan moet ek net vir die Here vra vir verwysing. (Interview 8b, lines 75 – 77)*

*..., because God created me for a purpose to be you know different from other people. That's also helping me to deal with this like I have to accept who I am. And it's maybe going to be easy for me to accept you know what's happening to him. (Interview 5a, lines 69 – 72)*

*..., maar ek weet die Here gaan voorsien. (Interview 2, line 590)*

### **Subcategory 2.4: Planning and preparing ahead**

Some of the participants managed to cope with the demands of a child on the spectrum of autism, by being well prepared and organised. Candice mentioned that she had to learn to think ahead about coming events in order to prepare her daughter for a change in routine, and by doing so preventing behavioural outbursts. Nadia also mentioned making sure that her son would be well prepared for new outings by investigating new environments beforehand.

*... and I think with her I just need to I just need to think ahead more maybe. (Interview 3, lines 62 – 63)*

*...so, there is a lot of investigating, checking if it's kosher to go there, is it safe, doing lots of checking before we actually can actually physically take him there. (Interview 1, lines 337 – 338)*

Doing chores according to a structured routine assisted the mothers to make sure that their daily responsibilities could run smoothly, while being aware of the triggers that result in tantrums or aggression, equipped the mothers to prevent these outbursts from happening in advance.

*I usually pack everything the night before. I don't like too much rush in the morning. (Interview 3, lines 209 – 210)*

*I can now analyse things to the point where I can find the root cause of a problem for him... (Interview 1, lines 146 – 147)*

#### **4.3 Summary**

The findings of this study, as discussed in the chapter above, indicated that the participants based their experiences and execution of their mothering roles on prior life experiences. The participants all experienced the life-changing effect on their lives when they became parents, and even more so when their children were diagnosed on the spectrum of autism. The impact of these changes on the occupational health of the participants will be discussed in the next chapter.

## **CHAPTER 5: DISCUSSION**

### **5.1 Introduction**

This study aimed to explore how mothers experience the impact of a child on the spectrum of autism on the performance of their own everyday occupations. Central through the three themes emerging during the data analysis process, namely “mothering as an identity”, “mothering as an occupation” and “making sense and moving forward”, were the significant changes this group of mothers had to endure while faced with the challenges in taking care of their children on the spectrum of autism. Findings from previous studies supported the personal, as well as occupational changes described by the participants when entering motherhood, as well as some of their experiences on the caring of a child with autism, but the findings of this study also highlighted the unique encounters of these mothers within the context they live in.

In the discussion to follow, the researcher will illustrate these changes and it's relation to human occupation.

### **5.2 Mothers' everyday occupations and health**

The participants all confirmed the life changing results when entering motherhood as mentioned in prior studies<sup>8,10</sup>. Becoming a mother were accompanied by conflicting feelings of being overwhelmed, while at the same time being awed by the experience. All of the mothers mentioned not being prepared for the realities of motherhood. The complexity of motherhood is confirmed by authors such as Francis-Connolly<sup>8</sup> and Letherby<sup>9</sup>. The idealistic expectations and dreams the participants had prior to the birth of their children were soon altered by the day to day responsibilities of being a parent. Most of them mentioned that they expected parenthood to be more fun, but instead found the new responsibilities very difficult. The participants mentioned a definite change in the leisure activities they participated in prior to the birth of their children. The findings indicated a decline in community involvement and participation in very physical outdoor activities, especially during the period when children were still very young. Studies done by Francis-Connolly<sup>8</sup> and Horne et al<sup>9</sup> supports the decline in time spent on self-care- and leisure activities, as well as the change in the type of leisure activities mothers participate in when entering motherhood. The initial feelings of incompetence and being overwhelmed, was also mentioned in the study done by Horne et al<sup>9</sup>. McVeigh<sup>10</sup> and Francis-Connolly<sup>8</sup> reported loss of sleep and a decline in marital satisfaction when entering parenthood, but these experiences were not reported by this group of participants when they described the initial changes when they became mothers.

As mentioned earlier, these disruptions and imbalance in occupational participation, is temporary for mothers with typical developing children<sup>9</sup>. For most, the change in the occupations they are able to engage in still provide meaning and purpose, even though the activities are now centred around the needs of their children.

However for the participants of this study, the diagnosis of autism in their children resulted in long lasting changes in their occupational engagement.

Occupational therapists view the participation in meaningful and purposeful occupations as essential for the health and well-being in individuals. However, occupational engagement only contributes to health and well-being when individuals find meaning, purpose and satisfaction during occupational participation<sup>33,45</sup>. It was therefore necessary to identify the factors which influence and interact with these elements in this group of participants.

### **5.2.1 Occupational Risk Factors**

Wilcock<sup>45</sup> described a number of risk factors impacting on occupational health and -well-being. These factors include concepts such as occupational alienation, occupational deprivation, occupational marginalization and occupational imbalance. The findings of this study clearly portray the risks this group of participants faced in terms of the above.

#### **5.2.1.1 Occupational Imbalance**

Wilcock<sup>65</sup> describes occupational imbalance as the incapability of individuals to match their unique physical, social, mental or rest needs with the occupations they engage in. She emphasises the importance of finding a balance between the time spent on activities which are interesting and stimulating, with those activities one undertakes to meet family, social and community responsibilities. Stein, Foran and Cermak<sup>66</sup> confirm Wilcock's description of occupational balance and the importance of engaging in activities which are meaningful and purposeful for the individual. Using the theory of Matuska and Christiansen's Model of Lifestyle Balance<sup>66</sup>, they identified a number of risk factors impacting on lifestyle balance in parents of children on the spectrum of autism, and therefore putting them at higher risk for poorer health and decreased well-being. These factors included the difficulty in maintaining positive and supportive relationships with others, the feelings of incompetence and being unsuccessful in the occupations they engage in, the loss of their prior identities, lack of time and energy to engage in activities of meaning and satisfaction, as well as the increased emotional and psychological burden accompanied by having a child on the spectrum of autism.

For the participants of this study, occupational imbalance was one of the most significant factors impacting on their health and well-being. A major contributor to the experience of occupational imbalance in their lives, were the tremendous change in time spent on the caring of their child on the spectrum of autism, while at the same time trying to manage their household- and family responsibilities, leaving them with little time to engage in activities of choice or enjoyment. For this group of participants, taking care of their children on the spectrum

of autism consumed most of their time during the day and resulted in a monotonous routine of daily occupations. The majority of them mentioned being confined to their home environment for most of the time.

The participants reported limited time to spend on themselves. Even basic activities, such as doing their hair, became a treat for some of these mothers. Some participants mentioned having to sacrifice their privacy when using the bathroom because of their children's constant company. Even when they could manage to take some time for themselves, it still revolved around worrying about their children, or using the time to do tasks they otherwise did not have time for. For them, they lacked the opportunity to take a break and relax.

The participants were required to structure and spend their time according to the routines and rituals of their child on the spectrum of autism. Daily activities were often performed at odd times of the day, or even the season to accommodate their children's way of doing. Performing activities according to their children's ways diminished the risk of behavioural outbursts, but at the same time resulted in mothers perceiving their lives as tedious and frustrating.

Joosten et al<sup>14</sup> supports the findings of this study by stating the increased amount of time spent on child care activities when having a child with a disability. Breslau's<sup>14</sup> statement that mothers of children with disabilities spend more time on household activities, were also proven to be true for this group of mothers. Altieri and Von Kluge<sup>67</sup> also supports the full-time task involved in taking care of a child on the spectrum of autism, and the impact on relationships with friends, family, spouses and siblings.

Backman's study<sup>68</sup> confirms the importance of occupational balance to the health and well-being, when mentioning the findings of Spencer which indicated psychological or emotional distress and boredom in individuals confronted with occupational imbalance. In the same study, Marino-Schorn's<sup>68</sup> findings mentioned the relationship between morale and occupational balance, while Jönsson et al<sup>68</sup> reported the significance of occupational balance to the perception of competence and success to individuals when engaging in occupations.

### **5.2.1.2 Occupational Deprivation**

Another significant occupational risk factor faced by this group of participants was occupational deprivation. Occupational deprivation occurs when factors beyond the control of the individual restricts the individual's choice or opportunity to participate in occupations of choice and meaning<sup>45</sup>. These external influences may include aspects such as poverty, politics, technology, unemployment, cultural values, education, as well as ill health and disability<sup>65</sup>.

The diagnosis of autism in their children had a tremendous impact on the capability of the participants to participate in their prior daily occupations. Due to their children's delayed development, mothers had to continue performing tasks expected for children much younger than their own. Mothers were responsible for still providing assistance with self-care activities such as dressing, feeding, bathing and toileting. Their children's dependence therefore also impacted on their own freedom, as well as added to the financial strain on these parents. The participants had to adjust the way they managed their children's behaviour and the way they could entertain and play with their children. This group of mothers expressed having to be more vigilant and cautious in protecting their children and keeping them safe due to their children's impulsiveness and lack of awareness of danger. Having to physically "rescue" their children from unsafe situations, were not unfamiliar to this group of participants. Cronin<sup>16</sup> confirmed the findings of this group of mothers when mentioning how the management of behaviour often consumes the mothers time to the detriment of other daily activities. Keeping their children occupied became a struggle due to their children's limited interests.

Most of the participants were responsible for the full-time care of their children, and therefore could not resume their previous jobs after the birth of their child on the spectrum of autism. The participants could only continue with their previous jobs when they had the support of family members to take care of their children during the day. Meyerowitz et al<sup>38</sup> confirm the restriction in extra domestic activities such as employment when having a child with a disability in his study.

The participants mentioned the significant impact of their children on the spectrum of autism in the way they were able to do their daily chores. Many of them felt restricted by their children's constant need for attention and protection. The participants felt that household tasks took significantly longer to complete than for mothers with normal children, and they often had to interrupt and complete their chores at a later stage in order to accommodate their children.

Activities such as doing shopping also became very challenging. Again their children's inability to adapt to new environments, new people and their sensitivity to sensory stimuli, often resulted in behavioural outbursts. Most of them found it easier to do their shopping in the absence of their child on the spectrum of autism, while others had to make sure they do their shopping at the shops familiar to their children. One of the participants mentioned adapting the family's shopping needs according to the dietary and toiletry needs of her son on the spectrum of autism, as the family cannot afford to buy different products for each family member.

An added responsibility for this group of participants, were the fact that they were often the parent responsible for attending their children's visits to doctors and therapy. For most, this required making use of public transport adding to the financial burden, as well as long waiting times at clinics. One of the participants

mentioned having to travel all the way to the hospital where the study was conducted via public transport to attend her child's therapy appointments, and then having to go back to work in order to make sure she gets paid for the day.

The impact of the child on the spectrum of autism on the participation of family activities, were mentioned by all the participants. Not all of the participants had to discontinue in the participation of family activities, but all of them mentioned the impact of the child on the spectrum of autism on the quality of their participation in these activities. For some of the participants, it became easier to avoid attending family activities such as Christmas gatherings, baby showers and weddings due to their children's difficult behaviour and the perception that the other family members do not understand their children's actions. For others, avoiding family activities was a way of protecting other children from their own children's aggressive outbursts. Families adapted by doing activities which revolved around the needs and entertainment of the child on the spectrum of autism. For some, this change in family activities were perceived as positive, but others felt that they were blamed for the change in social activities of the rest of the family.

The participants reported poor quality of time spent with their spouses as a result of having a child on the spectrum of autism, and felt that their relationships with their spouses often suffered due to the negative impact of having a child on the spectrum of autism. One of the participants mentioned the difficulty of starting a new relationship, and that her relationship with her boyfriend was only possible due to the fact that they knew each other for a long time and that her son was familiar with him since an early age. Poor relationships with their partners added to additional stress. The participants also stated the impact of a child on the spectrum of autism on their siblings. Some of the participants admitted to neglecting their other children in the process of taking care of their child on the spectrum of autism, and one of the participants mentioned a poor relationship resulting in behavioural problems with her other son. Another participant mentioned having to protect her younger daughter from her child's aggressive and violent behaviour. Older siblings often had to offer support to their mothers in the day to day care of their siblings on the spectrum of autism, resulting in them sacrificing their own needs and priorities and taking on adult roles in the process.

Werner DeGrace<sup>15</sup> also found that in families with a child on the spectrum of autism, most of their time is spent on accommodating the needs of this child. She supported the inability of these families to spend time together as other families do. For these families, the daily activities in which they are able to participate in, holds little meaning and satisfaction. Joyful activities such as, family holidays seems virtually impossible<sup>15</sup>.

Most of the mothers reported a change in the leisure and social activities they participated in prior to having a child on the spectrum of autism. For most, the lack of understanding from other people, were the main

reasons for withdrawing from social activities. The participants also felt that friends and family avoided them due to their child's difficult behaviour. Social activities were restricted to visiting family and close friends where the participants felt their child were understood and accepted better. Even when they do attend social activities, the participants mentioned having to constantly make sure that their children were safe and not causing any trouble. The participants were concerned about causing discomfort to other people due to their children's actions. Interaction with friends would often happen at odd times or places, and often still revolved around the entertainment of their child on the spectrum of autism. Most of the time, the participants felt confined to their homes and unable to participate in social activities. One of the participants mentioned not being able to attend work functions due to not having anybody to look after her son in her absence.

Only one of the participants mentioned having specific hobbies prior to having children. She felt that some of the activities she participated in prior to her son's diagnosis of autism, would have changed anyway, but definitely contributed to the discontinuing of other activities to her son's diagnosis.

Although the participants did not report on a change in their sleeping patterns as they entered motherhood, they did find that their sleeping patterns were impacted by their child on the spectrum of autism. Meltzer<sup>69</sup> confirms these findings in her study which proved that parents with children on the spectrum of autism showed poorer sleep quality, shorter sleep duration and earlier morning waking times than parents of typically devoting children. These sleep disturbances are also directly related to the sleeping problems of their children<sup>70</sup>.

### **5.2.1.3 Occupational Alienation**

Individuals become occupationally alienated when not being able to meet their occupational needs or exercise their capabilities due to societal and cultural demands<sup>45</sup>. The term constitutes the right of populations or individuals, to engage in activities of choice and meaning and is associated with long lasting experiences of isolation, disengagement, emptiness and feelings of a loss of identity, satisfaction and purpose<sup>71</sup>.

For this group of participants, occupational alienation could be related to their experiences of being isolated from their community and family due to the stigma and lack of understanding of the diagnosis of autism in their children. Many of them mentioned not participating in social activities any more as they felt their children were not accepted and often misunderstood. Some even had to change the church they attended due to the community's lack of understanding and acceptance. They mentioned the monotony of their daily occupations and the lack of finding satisfaction and meaning in many of the activities they were able to engage in. Being deprived of participating in activities of choice which they enjoyed prior to the diagnosis of autism in their children, also relate to occupational alienation.

These mothers all mentioned the loss of their identity as a mother and of whom they were prior to their children being diagnosed with autism. They viewed themselves as not being “normal mothers” and commented on their sense of being alone and isolated. Evident in some of the participants were their apathy and lack of interest and drive in facing the challenges of autism in their children.

#### **5.2.1.4 Occupational Marginalization**

Occupational marginalization refers to the need of individuals to have decision making power with regards to everyday choices and participation in occupations<sup>71</sup>. Forced by their children’s behaviour, routines and the lack of support, these mothers had little choice in the activities they were able to participate in. They were compelled to execute activities revolving around the needs of their children, and not the needs and choice of themselves or the family. As mentioned above, even the choice of when, where and with whom they were able to engage in occupations, were determined by the needs and behaviour of their children. They were obliged to take on new roles such as being the teacher, advocator and communicator in order to overcome the challenges of having a child on the spectrum of autism.

#### **5.2.1.5 Occupational Injustice**

Occupational justice refers to the broader exclusion of individuals to engage in activities of choice by external forces such as the political, social or cultural environment. For these mothers, the opportunity to engage in activities of choice and meaning, were relying on getting their children placed in schools for children with special needs. The lack of placement opportunities, contributed directly in many of them not being able to continue working. These mothers made use of the public health system, and often endured long waiting hours with a child who has behavioural problems in order to see a doctor. They also had to endure the challenges of making use of public transport in order to access the health and educational support needed for their children.

#### **5.2.2 Mediators for occupational health**

Previous studies reported on the occupational characteristics necessary to mediate health and well-being. One such study<sup>72</sup>, identified factors such as energy expenditure, social interaction and support, challenge and complexity and perceived competence and achievement, as beneficial for occupational health. Wilcock<sup>45</sup> mentioned factors such as a variety of activities, commitment, energy, alertness, flexibility, interest, contentment, time for rest and sleep, time for others and openness to new challenges as indicators of good health. Ryff, as cited in Reid<sup>73</sup> added elements such as autonomy, personal growth and environmental mastery as essential in the well-being of individuals.

Although similar to the above mentioned elements, the participants of this study identified their own unique indicators supporting occupational health and well-being, or to the detriment thereof. These aspects will be discussed below.

### **5.2.2.1 Occupational Identity**

During the data collection and data analysis process, it soon became evident that the mothers as unique individuals, functioning within the context they live in, could not be isolated from the way they experience and perform their daily occupations, therefore constituting their occupational identities. Hasselkus<sup>35</sup> supports the connection between occupation and the unique experiences of individuals in their day-to-day lives. She stresses the significance of individuals' relationship with others and their environment on their experiences and occupations.

The impact of personal and environmental factors on human performance is well recognised within the field of occupational therapy. Dunn, McClain, Brown and Youngstrom<sup>74</sup> highlights the interaction between people and the environment (context) they live in, and the importance of understanding the individual as well as their environment when investigating occupational performance. Individuals or "the person" in this discussion refers to the group of mothers who participated in the study. Dunn, Brown, McClain and Westman <sup>74</sup> views "the person" as an entity with unique skills, needs and feelings which impacts on their occupational performance. Stewart et al<sup>20</sup> supports this description, while Kielhofner, Forsyth and Barret<sup>75</sup> add by incorporating elements such as personal causation, values, roles and habits.

The environment or "context" includes aspects such as cultural, social, spiritual, physical, temporal and institutional elements<sup>20,74,75</sup> impacting on the individual's performance of occupations.

### **Personal attributes**

Personal experiences such as the health of the mother, the baby or other siblings, caused some of these mothers to be reluctant to look forward in having a baby or to make preparations for the arrival of the new member of the family. Some even mentioned feelings of fear and uncertainty instead of excitement and joy about their pregnancies. The risk of losing their child during the pregnancy or at birth, made mothers grateful for having their children with them, even with the challenges that accompanied the diagnosis of autism as the children grew up. Post-natal depression was mentioned by two of the participants, and one of them mentioned being emotionally distant from her first born. She performed her roles as a mother automatically and without finding meaning and joy in these activities. The complicated birth of her second child resulted in an emotional turn around and impacted positively on her bonding and caring of this child. One could speculate that her

involvement and commitment in the caring of this child when diagnosed with autism could also be contributed to him being at risk of not surviving the birth.

The impact of their own personalities and prior exposure to other children on the way they perform their roles as mothers, were also raised. Some felt that qualities such as patience and endurance enabled them to cope with their child on the spectrum of autism, while others felt that their personalities had an impact on how they currently socialise and engage with other people. Most of the participants had very set ideas about the qualities they felt necessary to be a “good mother”. Unconditional love, forgiveness, respect, communication, and being positive about your child were all viewed as important values in taking care of their children. Thompson and Walker<sup>16</sup> also identified qualities such as mothers enjoying their child, intuitively knowing the needs of their child, and always putting the needs of the child first as important.

One of the participants mentioned her previous occupation as teacher and involvement with children as youth camp leader and teaching Sunday school, being an advantage in the caring of her own children. This mother was also the only participant who mentioned reading up and acquiring information from family members and friends to prepare for the arrival of her baby. Most of the participants did not plan their pregnancies and for them feelings of uncertainty and being unprepared accompanied their initial experiences of becoming a mother.

### ***Contextual influences***

The environment where the participants were raised also impacted on their current experiences of motherhood and their performance of their mothering roles. Nelson, as cited in Cronin<sup>16</sup>, supports the impact of environmental, personal, cultural and social influences on the performance of mothering roles. Ruddick, as well as Apple and Golden<sup>8</sup>, also confirmed the influence of the social and cultural context when mentioning the constant negotiation between the mother’s own perceptions on motherhood and that of the social group she functions within. Zaatari<sup>29</sup> added by highlighting the impact of the current political climate on mothers’ perceptions on the meaning of motherhood.

Being rejected and teased about her own cultural background and differences, resulted in one of the mothers having tremendous difficulty to accept her son’s diagnosis and challenges. Her background also resulted in having even more unrealistic expectations about motherhood and even things such as the physical appearance of her baby. Her fear of rejection also impacted on her ability to reach out and interact with other people. On the other hand, the hardships she faced when growing up, were the motivation for trying to change her circumstances and having a better life for her own children. Being restricted and overprotected by

her parents, another participant mentioned being limited in the activities she participate in and that she were mostly confined to her parents' home.

Participants mentioned the influence of role models on how they perform their current parenting roles. While some held onto the good examples of their own parents or other family members in how they raise their children, others felt that they deliberately did not want to follow in the footsteps of their own parents, and made a definite effort to be better parents for their children. Many of them mentioned the importance of religion on how they raise their children and in how they manage to cope with the challenges of having a child on the spectrum of autism.

The support structures available to the participants, or the lack there of, had a significant impact on how they were able to participate in their daily occupations. Three of the participants were single parents, and did not have any support from their children's biological fathers in terms of the day to day care of their children. The lack of financial support was mentioned by all of them as an additional burden on their role as mothers.

The participants all mentioned the change in occupational identity with the diagnosis of autism in their children. They felt that being a mother to a child on the spectrum of autism differed significantly from mothering children with no disabilities. For this group of mothers, motherhood were perceived to be more demanding, tiring and challenging, and they viewed their identity as mothers as "abnormal". Cronin<sup>16</sup> supports these feelings of "abnormality" in her study done on mothers of children with attention deficit hyperactivity disorder, while Llewellyn et al<sup>39</sup> mentioned the increased demands set by the social environment which mothers with children with disabilities function within.

Mothers mentioned feelings of denial, guilt and anger with the initial diagnosis of autism. Frustration and irritation with others not understanding their children were also mentioned. Sadness and despair were common emotions experienced by the participants as they had to face the loss of dreams and expectations they had for themselves and their children before their children's diagnosis. The mothers felt isolated and alone in carrying the burden of having a child on the spectrum of autism and robbed of their freedom. They were overwhelmed by the constant attention required to take care of their child on the spectrum of autism, while at the same time having to juggle their other daily responsibilities, often without the assistance of others. Participants often had to put their own needs aside to accommodate their children on the spectrum of autism. They viewed mothering of a child on the spectrum of autism as more stressful and requiring more input and understanding than mothering children not on the spectrum of autism. They constantly had to adapt to their children's behaviour and way of doing things. Managing their children's behaviour added additional physical, as well as emotional demands on their roles as mothers. Mothers mentioned being constantly worried about

their children's well-being, as well as their future. Altieri and Von Kluge<sup>67</sup> describes the discovery of having a child on the spectrum of autism as "life-altering", and feelings of despair, sadness, denial, confusion and anger were common among the participants in their study after the diagnosis of autism was made in their children. Feeling "robbed" and isolated was mentioned in the study done by Werner DeGrace<sup>15</sup>, and the article of Woodgate et al<sup>40</sup> quoted parents describing their experiences as "living in a world of our own".

The impact of a child with autism on the mental health of the mothers was also evident in the findings of the study. Two of the participants contributed their diagnosis of depression directly to the challenges of having a child on the spectrum of autism. One of the participants portrayed her reluctance in using her anti-depressant medication due to her fear of falling asleep while caring for her son on the spectrum of autism. The impact of children on the spectrum of autism on the emotional, physical and psychological well-being of their parents has been well documented. Higher incidents of stress, feeling overwhelmed and depressed mood has been reported in numerous studies done on investigating the impact of a child on the spectrum of autism on their parents<sup>13</sup>, Altieri and Von Kluge<sup>67,41</sup>.

In contrast with all the negative emotions accompanying their children's diagnosis of autism as mentioned above, the mothers also revealed positive experiences. They mentioned feelings of pride when overcoming some of their children's barriers and excitement when seeing small changes within their children. The mothers valued positive feedback from friends and family in the progress they made with their children, and mentioned gaining emotional strength and personal growth by having a child on the spectrum of autism. The participants felt that they gained better insight and understanding of their children's diagnosis and behaviour, and that they acquired the necessary skills in order to manage their children. The participants mentioned gaining positive qualities such as patience and endurance, and some felt that the fact that their child has a diagnosis of autism resulted in them viewing life from a different perspective. Being less selfish and being less judgmental of others were also mentioned. Participants in the study done by Altieri and Von Kluge<sup>67</sup>, also reported positive experiences with having a child on the spectrum of autism. Their study confirmed the findings from this group of participants when mentioning a new appreciation of life and not taking things for granted any more. They confirmed the personal changes of having more patience, being more compassionate and having better understanding and empathy, especially to other people with disabilities. The positive impact on family relationships was also mentioned in this study.

Underlying the identity of this group of participants, were their prior ideas and beliefs around the typical mothering roles. Most of the mothers mentioned taking care of their children as a primary mothering role. For them, taking care included tasks such as feeding, dressing and taking care of their children's hygiene. They also felt responsible to provide for their children and raising them well. Being the "healer", on both an

emotional as well as physical level, were also mentioned, as well as taking care of household chores and the rest of the family. Nurturing and caring are roles commonly referred to in the literature when describing motherhood<sup>7,24</sup>. Olsen<sup>36</sup> confirms the participants' perceptions on the role of caring, by identifying feeding/eating, getting ready for sleep/sleeping and comforting as important co-occupations of mothers and young children.

The participants felt responsible for structuring their children's daily routines, such as mealtimes, nap times, self care activities and playtimes. Again the literature upholds these findings when Olsen<sup>36</sup> describes the role of mothers in their children's play. She mentioned that mothers are responsible for providing play objects, equipment, space and time to encourage age appropriate play. The roles of taking care of the household, education, socialisation and employment, was also mentioned in this article.

The participants felt that they had an important role in giving guidance and preparing their children for the future. Providing their children with the necessary skills, qualities and the foundations to be well adjusted adults were seen as part of their parenting responsibilities. Protecting their children and encouraging their growth and learning are supported by the literature<sup>8</sup>.

The participants had to adapt their occupational identities, when faced with the new roles they had to take on as a result of their children's diagnosis of autism.

### ***New roles***

Mothers viewed advocating for their children's rights and protecting them from other people's judgement as important. They found themselves educating family members, friends and even teachers about the diagnosis of autism, and the management of their children's behaviour, and by doing so attempted to lessen the stigma accompanying the diagnosis. They felt responsible for ensuring that the needs of their children with regards to schooling were met. Llewellyn et al<sup>39</sup> verifies this role of activism when discussing the responsibility mothers of children with disabilities has in eliminating social barriers and stigma surrounding their children's diagnosis. They also added by emphasising the role these mothers play when acting as liaison between health professionals, educators and their children. Mothers of children with disabilities often take on the responsibility of researching their children's diagnosis and the management thereof in order to ensure better understanding from others. Woodgate et al<sup>40</sup> confirms the added responsibility of preparing and making sure that their children are safe in new situations and are protected at all times from an unsupportive world around them.

The participants felt they had an important role to play in making sure their children would understand the world around them and to prepare them for real life scenarios in the future. Most of them believed that they

were their children's only connection to other people due to their children's communication difficulties. The participants felt that their ability to understand and "sense" their children's needs enabled them to communicate and interpret their behaviour to others. One of the participant also mentioned teaching her son to understand and show emotions as part of her role.

Many of the participants were involved in trying to teach their children new skills in an attempt to overcome their barriers. Due to the fact that most of these children were unable to attend school, the participants often had to take on the role of teaching their children at home. All the participants were mothers of children receiving occupational- and speech therapy at the hospital where the study was conducted, and were often required to implement home programs to address their delays.

### **5.2.2.2 Occupational Competency**

Support in the day to day care of their children on the spectrum of autism, were identified as one of the prime needs for this group of participants. Many of the mothers were the sole caregiver for their children on the spectrum of autism, and had no one to rely on to relieve them in their day to day duties. For others, the fact that they could rely on family or friends, lightened their burden and even allowed them to continue with prior activities or taking on new ones. A lack of support and understanding was also mentioned in other studies<sup>40</sup> as a contributing factor to the feelings of isolation and being deprived of living so-called "normal lives".

The participants mostly viewed the availability of services such as therapy and support groups as valuable, and felt it provided them with the skills and knowledge they needed to understand and manage their children. Information on dietary issues and psychological support were mentioned as a need by one of the participants. The struggle to get her son diagnosed was mentioned by one of the participants, and highlighted the lack of access to appropriate health services within the public health care system. Almost all of the participants expressed the need for placement of their children in schools where the unique needs of their children would be met. Due to their children's difficult behaviour, they had extreme difficulty to get their children accepted into mainstream crèches and schools. For many of them, placement of their children in a school catering for children with special needs equals the opportunity to go back to work, or to take on new activities they now do not have the time for. Again, the inaccessibility and unsupportive nature of services available to these mothers are not uncommon<sup>40</sup>.

The participants mentioned the wish to have "normal" life for themselves and their children. For them, acceptance and understanding of their children by the community they live in were very important. They all wished for the stigma around the diagnosis of autism to be diminished, and for their children to just be allowed to take part in activities as other children.

For many of the participants, placement and having the opportunity to go back to work went hand in hand. They felt that if they could go back to work and earn a salary, they would be able to improve the lives of their children. The financial burden of having a child on the spectrum of autism is confirmed by studies done in other countries<sup>67</sup>.

### **5.2.2.3 Coping and Adjusting**

The participants all managed to continue with their lives despite the challenges they face of having a child on the spectrum of autism. Coping strategies is viewed as one of the methods by which parents are able to adapt to the challenges they face when raising a child with a disability<sup>76</sup>. Smith, Seltzer, Tager-Flusberg, Greenberg and Carter<sup>76</sup> grouped coping strategies into two categories, namely problem-focused coping and emotion-focused coping. Problem-focused coping involves the techniques addressing the source of the problem or solving the problem, whereas emotion-focused coping entails minimizing or managing the feelings of distress accompanied by stressful situations<sup>76</sup>.

Many of the participants had to put their own lives on hold in order to make sure they remain focussed on their children. Some were able to take on new activities to replace some of the activities they discontinued because of their children's diagnosis of autism, although they did not find the same enjoyment from these activities.

The participants had to adjust in working according to their children's pace and capabilities. They learned that planning ahead and preparing their children for new situations, made each new encounter more manageable. They had to find the unique qualities in their children, and learned to love and accept them unconditionally. Previous hopes and dreams for themselves and their children had to be altered, and mothers mentioned prioritising the battles they chose to fight on a daily basis. Finding strength and hope in their religion provided the participants with the foundation to move on with their lives.

Dunn, Burbine, Bowers and Tantleff-Dunn<sup>77</sup> reported less stress and fewer symptoms of depression when parents could rely on social support. They also reported better management of problem situations with parents who planned ahead for difficult behaviours. According to these authors, strategies such as escape or avoidance (holding on and hoping for miracles, fantasies, avoiding others, and even the use of drugs or food) should be discouraged as it resulted in higher levels of depression and isolation. Bayat<sup>78</sup> also confirms the positive impact of support on the resilience of families with children with disabilities. Marshall and Long<sup>79</sup> found that mothers with children on the spectrum of autism tended to rely on problem-focused strategies when dealing with challenging situations, and cognitive, meaning-making strategies when having to deal with the long term circumstances surrounding the diagnosis of autism in their children. Gray<sup>80</sup> supports these

findings when stating a general shift from problem-focussed coping to emotion-focussed coping as parents go through the process of having a child on the spectrum of autism. He reported a change from initially relying on service providers to cope, towards relying on religion and appreciating their children's unique qualities. Bayat<sup>78</sup> found that families of children with disabilities, who managed to find positive meaning from their circumstances, demonstrated better resilience. Another factor seen as important in the resilience of families with children with disabilities, is having a spiritual belief system<sup>78</sup>. Kuhaneck, Burroughs, Wright, Lemanczyk and Darragh<sup>81</sup> reported factors such as having and taking time for themselves, planning ahead, sharing of responsibilities, gaining of knowledge, removing of the stigma surrounding the diagnosis of autism, and finding joy in their children, all contributing to better coping with their circumstances.

#### **5.2.2.4 Meaning**

Occupations only contribute to the health and well-being of individuals, when they are found to be meaningful and purposeful to the individual.

The concept of meaning has been defined in various ways in the literature. Ikiugu<sup>82</sup> defines meaningfulness as having purpose and significance in one's life. Having meaning therefore refers to occupations that has a goal or outcome, are important and adds value to the individual engaging in the occupation. In order to have meaning, occupations have to be related to the cultural, social and historical context the individual functions within<sup>82</sup>. Hammell<sup>83</sup> added by stating the significance of engaging in activities that provide satisfaction, enjoyment and pleasure on the meaning individuals derive from engagement in occupations. In addition to this, she also reported on the importance of choice, the sense of belonging, social inclusion, self-worth and affirmation on the meaningfulness of the occupations.

For the participants in this study, the lack of choice, control and satisfaction they derived from their daily occupations resulted in negative experiences of occupational meaning. They had to engage in activities revolving around the needs of their child on the spectrum of autism, and most of their time was consumed by the needs of their child on the spectrum and doing household chores. For many of them, having a child on the spectrum of autism resulted in not being able to continue with their previous jobs, impacting significantly on their sense of autonomy and independence. The participants reported the lack of support and understanding from friends, family and their communities, leaving them with feelings of isolation and exclusion from their communities. Their children's challenging behaviour often made these mothers experience feelings of failure and incompetence.

On the positive side, some of them find new purpose and enjoyment in the occupations they now had to fulfil. They found purpose in the new roles they had to take on as a result of their children's diagnosis, and seeing progress in their children provided a sense of competence and self-worth to some of them. The participants

reported a new perspective on life, and for some the challenges of having a child on the spectrum of autism resulted in personal growth, stronger family relationships and new skills.

The next chapter will provide a summary of the findings as described in the previous chapters, and will report on the implications of the findings within clinical settings. It will also indicate the strengths and limitations of this study, and will make suggestions on future research in relation to the research topic.

## **CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS**

### **6.1 Summary**

This study aimed to give readers some insight into the experiences of mothers with regards to the participation in their own daily activities while having a child on the spectrum of autism. The findings illustrated the tremendous changes the participants had to face in terms of occupational engagement in the light of their children's diagnosis of autism. The disruptions in occupational participation, and the imbalance with regards to occupational engagement and the time spent on these occupations, were highlighted. The findings reported on the occupational risk factors intruding on their occupation health and well-being, while simultaneously giving insight to the enabling elements with regards to their occupational participation. This study also emphasized the unique role of occupational therapists in matching their intervention with a child on the spectrum of autism, with the needs and priorities of the families involved, especially in the context of a public health system in South Africa where direct hands on intervention are often limited.

### **6.2 Strengths and Limitations**

- Being new to the process of qualitative research might have had an impact on the elicitation of the participants' responses, and therefore the quality of the information derived.
- The researcher recruited participants from her own case load of children on the spectrum of autism, but due to the non-compliance of participants with appointments, had tremendous difficulties in the recruitment of the required number of participants.
- The study population only reflects the experiences of a particular group of mothers attending public health care services at a tertiary institution in the Western Cape, and the findings can therefore not be transferred to other populations.
- The researcher is of the opinion, that although the findings are limited to a specific population group, it contributes to research within the field of occupational therapy within the South-African context.
- The study also adds value to previous research done in the field of autism, by having a unique focus on the occupational engagement of the participants.
- The findings echoed previous studies done in the field of autism in other parts of the world.

### **6.3 Implications for practice**

Occupational therapists often focus their intervention on addressing the symptoms, diagnosis and components affected by disability or illness, and in the process we often forget the uniqueness of our profession in viewing the client within the context they live, and as individuals with their own needs, priorities and goals. In doing so, the client's own experiences of occupational engagement are often overlooked<sup>84</sup>. Occupational therapists have a vital role in improving the occupational well-being of individuals by ensuring that we meet each individual's need for competence, recognition, activity, unity, companionship, satisfaction and renewal when

engaging in occupations<sup>84</sup>. When working with children, the occupations of the child and the primary caregiver, most commonly the mother, are intertwined and cannot be separated from each other. It therefore becomes important to ensure the healthy participation of occupation in both the mother and the child, when aiming to improve health and wellbeing in the one or the other<sup>32,41</sup>.

When considering the findings of Doble and Santha<sup>84</sup>, the role of the occupational therapist in ensuring the occupational health and well-being of mothers with children on the spectrum of autism, are significant. Occupational therapists are in the ideal position to ensure the mothers need for competence or accomplishment by making sure that the treatment goals for the child with autism is in line with the specific needs and expectations of each family. Treatment goals, and especially home programs, should be graded very carefully to allow mothers and families to achieve progress and to experience a tangible outcome. Therapists should provide mothers with the skills, knowledge and support necessary to achieve success with the treatment goals set. Occupational therapists are also in the position to adapt and make recommendations to the physical environment these families function within in order to ensure success and confidence when engaging in their daily occupations. Doble and Santha<sup>84</sup> also highlight the importance of sharing experiences, learning from others and reflecting on past success on the sense of competence in individuals. Therefore the role of the occupational therapist to provide opportunities for this to occur is vital.

It is important to create recognition for the successes they achieve with their children, and to recognise the effort involved in achieving treatment goals. Although the choice mothers have in the participation of daily occupations are limited due to their children's diagnosis, therapists can create autonomy when allowing mothers to make their own decisions and have a choice in the treatment of their children. Involving the mother in the development of treatment programs in order to fit the program with the needs and priorities of each individual family, provides a sense of control.

Occupational therapists should create opportunities for mothers to engage in activities which have meaning and which reflects their personal values, needs and goals. Guiding mothers to engage in activities they were able to participate in prior to having a child on the spectrum of autism, or to engage in new activities which allow them to use their prior skills and knowledge, would create a feeling of coherence.

The occupational therapist should also allow and create opportunities for participation in social activities. It is important that these mothers engage in activities with others who share their interest, experiences, values and goals. Engagement in social activities, create the feeling of belonging and would lessen the experiences of feeling isolated and alone. Occupational therapists should encourage participation in activities which are pleasurable and which allows the mothers to forget about the stresses and demands of taking care of a child

on the spectrum of autism. Assisting mothers to structure their days in such a manner where they could have time to engage in an activity which they find pleasurable, is important. At the same time, having some time to renew themselves would allow mothers to tackle their daily challenges with new courage.

The primary health care approach emphasises the importance of client-centeredness. Studies investigating the experiences of parents with community resources, may therefore improve the quality of health services provided to parents with children on the spectrum of autism. Sliverstein, Lamberto, DePeau and Grossman<sup>85</sup> highlighted the perceptions of clients not being in control of their surroundings and the feeling that services provided are often generic and not directed to suit their specific needs. Respecting the individual values, needs and preferences, as well as ensuring sufficient accessibility, well integrated services and good communication, will assist in providing positive experience to clients.

Furthermore, occupational therapists' unique understanding of humans as occupational beings, could contribute by advocating the promotion of health through occupational engagement<sup>45</sup>. As occupational therapists, we have vital role in promoting social inclusion and client decision making with regards to participation in occupations, implicating the importance to become involved with broader systems in health, education, community services, transport, education and employment. It is also important for occupational therapists to become involved in advocating for their clients on a broader level, such as educational- and care facilities for these children. Through the education of communities, teachers and other role players, the stigma around a diagnosis such as autism spectrum disorder, can also be minimized.

#### **6.4 Recommendations for further studies**

- While conducting this study, the statements of the participants sparked questions such as the impact of attachment on the fulfilment of mothering roles when having a child on the spectrum of autism.
- The researcher also questioned the impact of post-natal depression on attachment, especially in relation to having a child with a diagnosis of autism.
- Another question that arose from this research was the impact of the mothers' cognitive level of function on the resilience when facing a challenge such as having a child on the spectrum of autism.
- In order to transfer the findings of this study, it is also recommended to broaden the study to include participants of all cultural and socio-economic status.

#### **6.5 Conclusion**

The findings of this study therefore answered the research aim and –objectives as mentioned in chapter 1. By investigating the experiences of the participants on their engagement in their everyday occupations while having a child on the spectrum of autism, the researcher gained insight into the emotional hardships, as well

as positive encounters these mothers had to face in the light of their children's diagnosis. The findings portrayed their perceptions on motherhood in general, as well as the personal and occupational changes they endured as they became parents. The participants revealed their views on typical mothering roles, as well as the contextual and personal factors which they felt had an impact on how they were able to perform their roles as mothers. The participants all had to change or discontinue their prior participation in their jobs, leisure and social activities, as well as family activities. Typical mothering roles were also altered in order to accommodate the needs of the child on the spectrum of autism. The participants had little time to engage in activities of choice or in which they find meaning, and spent most of their time caring for their children on the spectrum of autism. Findings highlighted the participants' needs, both emotionally and financially. It revealed how they sacrifice their own needs, rely on their religion and accommodate their children's differences in order to overcome the challenges they face as mothers of a child on the spectrum of autism.

I conclude with the following quote:

*"Having a child will change your life but one day finding out that your child has special needs, or better yet, Autism, can be so life altering that families can either pull together or be ripped apart" – Author unknown*

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**APPENDIX A: Approval from Health Research Ethical Committee,  
Stellenbosch University**



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvenoot • your knowledge partner

14 November 2011

**MAILED**

Ms E Laminette  
Department of Occupational Therapy  
2nd Floor, Teaching building  
Stellenbosch University  
Tygerberg campus  
7505

Dear Ms Laminette

"Exploring the experiences of mothers on their everyday occupations while having a child on the spectrum of autism."

**ETHICS REFERENCE NO: N09/10/283**

**RE : PROGRESS REPORT**

At a meeting of the Health Research Ethics Committee that was held on 9 November 2011, the progress report for the abovementioned project has been approved and the study has been granted an extension for a period of one year from this date.

Please remember to submit progress reports in good time for annual renewal in the standard HREC format.

Approval Date: 9 November 2011

Expiry Date: 9 November 2012

Yours faithfully

  
**MRS. MERTRUDE DAVIDS**  
**RESEARCH DEVELOPMENT AND SUPPORT**  
Tel: 021 938 9207 / E-mail: mertrude@sun.ac.za  
Fax: 021 931 3352

14 November 2011 11:44

Page 1 of 1



Fakulteit Gesondheidswetenskappe • Faculty of Health Sciences



Verbind tot Optimale Gesondheid • Committed to Optimal Health  
**Afdeling Navorsingsontwikkeling en -steun • Division of Research Development and Support**  
Posbus/PO Box 19063 • Tygerberg 7505 • Suid-Afrika/South Africa  
Tel.: +27 21 938 9075 • Faks/Fax: +27 21 931 3352

**APPENDIX B: Permission of tertiary public hospital**

Departement van Gesondheid  
Department of Health  
iSebe lezeMpilo



Verwysing  
Reference  
Isalathiso

Navrae  
Enquiries  
Imibuzo

Telefoon  
Telephone  
Ifowuni

Dr M.A. Mukosi

021-938 5966

Tygerberg Akademiese Hospitaal en  
Mitchellsplein & Tygerberg Mondgesondheidsentrums

Tygerberg Academic Hospital and  
Mitchells Plain & Tygerberg Oral Health Centres

Isibhedlele Sase Tygerberg Kwakunye Ne  
Mitchells Plain Neziko Lamazinyo Lase Tygerberg

Privaatsak X3/ Private Bag X3  
Tygerberg, 7505

Date: 18<sup>th</sup> December 2009

**Ref: Your Research / Clinical trial No 09/10/283.: Exploring the experiences of mothers on their everyday occupations while having a child on the spectrum of autism.**

Dear Ms Elana Laminette

**PERMISSION TO CONDUCT YOUR RESEARCH/CLINICAL TRIAL AT TYGERBERG HOSPITAL**

In accordance with the Provincial Research policy and Tygerberg Hospital Notice No. 40/2009, permission is hereby granted for you to conduct the above-mentioned research/clinical trial here at Tygerberg Hospital.

**DR PTA CARTER  
CHIEF DIRECTOR: TYGERBERG HOSPITAL**

**APPENDIX C1: Participant Information and Consent form**

**TITLE OF RESEARCH PROJECT:** Exploring the experiences of mothers on motherhood while having a child on the spectrum of autism.

**REFERENCE NUMBER:**

**PRINCIPLE INVESTIGATOR (Researcher):** E Laminette

**ADDRESS:** Occupational Therapy Department  
Tygerberg Hospital  
Private Bag X 3  
Tygerberg  
7505

**CONTACT NUMBER:** (021) 938 4994  
(021) 938 5062

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please feel free to ask the researcher if you have any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decide not to take part. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be done according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

Through the study the researcher would like to find out how you as a mother with a child diagnosed on the spectrum of autism experience doing your everyday tasks. By getting this information, the researcher hopes to gain a better understanding of how a child on the spectrum of autism impacts on motherhood and that this information will assist in providing a more appropriate occupational therapy service.

If you take part in this study, the researcher will ask you to fill in a questionnaire with regards to general information about yourself. You will also be asked to bring photos, pictures, videos, or any memorabilia which represent the highlights and challenges of your experiences of a mother with your child. After this, the researcher will make another appointment with you to interview you on your experiences. These interviews will be done at Tygerberg Hospital, or at a place that you find more convenient and comfortable. The researcher will tape record your answers to make sure that she has a clear understanding of your experiences and in order for her to refer back to the tape recordings when clarity is needed.

### **Why have you been asked to participate?**

All the mothers of children diagnosed on the spectrum of autism and who's child is receiving occupational therapy at Tygerberg Hospital will be asked to participate in the study.

### **What will your responsibilities be?**

The researcher will give you an appointment to complete the questionnaire, and for the interviews to take place. It will be expected from you to attend these appointments if possible. The appointments will as far as possible be on the same day as your other visits to the hospital. The researcher will help you to complete the questionnaire if necessary. Completed questionnaires can be left with the researcher after you have completed it. The appointment for the interviews will last about one to one and half-hours. If the researcher needs any other information from you, you will be contacted telephonically.

**Will you benefit from taking part in this research?**

The study will help the researcher to give families the necessary support that you need with your child on the spectrum of autism and to refine future interventions.

**Are there risks involved in your taking part in this research?**

There are no risks involved for you when you take part in this study.

**If you do not agree to take part, what alternatives do you have?**

You are under no obligation to take part in the study, and if you decide not to take part, it will have no effect on the services that you will receive in the future.

**Who will have access to your medical records?**

The researcher will protect your privacy at all times. No names will be attached to any of the images or text obtained from the questionnaires, artefacts (pictures, photo's drawings, videos, etc.) or interviews, and all information will be safely kept on flash drive in the departmental safe.

**What will happen in the unlikely event of some injury occurring as a direct result of your taking part in this research study?**

As no direct intervention methods or procedures are involved in this study, no direct injuries related to the study are foreseen.

**Will you be paid to take part in the study and are there any costs involved?**

You will not be paid to take part in the research study, but transport costs for each **study visit** will be covered by the research investigator. There will be no costs involved for you, if you do decide to take part.

**Is there anything else that you should know or do?**

You can contact the researcher at (021) 938 4994/ 5062 if you have any concerns or complaints that you would like to be addressed. In the case where your concerns or complaints are not adequately addressed by the researcher, you can contact the Committee for Human Research at (021) 938 9207.

You will receive a copy of this information and **consent form** for your own records.

**Declaration by participant:**

By signing below, I .....agree to take part in a research study entitled: Exploring the experiences of mothers on motherhood while having a child on the spectrum of autism.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language which I am fluent and comfortable.
- I have had the chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished if the research investigator feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*).....on (*date*).....2011.

.....  
**Signature of participant**

.....  
**Signature of witness**

**Declaration by researcher:**

I (*name*).....declare that:

- I explained the information in this document to .....
- I encouraged her to ask questions and took adequate time to answer them.
- I am satisfied that she adequately understands all aspects of the research, as discussed above.
- I did/ did not use an interpreter.

Signed at (*place*).....on (*date*).....2011.

.....  
**Signature of investigator**

.....  
**Signature of witness**

APPENDIX C2: Deelnemer Inligtingstuk en –toestemmingsvorm

**DEELNEMER INLIGTINGSBLAD EN –TOESTEMMINGS VORM:**

**TITEL VAN DIE NAVORSINGSPROJEK:** Ondersoek na die ondervindings van moeders rakende moederskap met 'n kind op die spektrum van outisme

**VERWYSINGSNOMMER:**

**HOOF NAVORSER:** E Laminette

**ADRES:** Department Arbeidsterapie  
Tygerberg Hospitaal  
Privaatsak X 3  
TYGERBERG  
7505

**KONTAK NOMMER:** (021) 938 4994  
(021) 938 5062

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief die inligtingsblad op u tyd deur aangesien die besonderhede van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorser daaroor uit te vra. Dit is baie belangrik dat u ten volle verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname aan die navorsingsprojek is **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook enige tyd van die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die **Etië Komitee oor Gesondheidsnavorsing van die Universiteit Stellenbosch** goedgekeur, en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

### **Waaroor gaan hierdie navorsingsprojek?**

Die navorser wil deur hierdie studie uitvind hoe u as moeder met 'n kind op die spectrum van outisme u alledaagse take verrig. Die navorser hoop dat sy deur hierdie inligting beter sal kan verstaan watter impak 'n kind op die spektrum van outisme op moederskap het, en dat hierdie inligting sal bydra om 'n meer toepaslik arbeidsterapie diens te kan lewer.

Indien u instem om deel te neem aan hierdie studie, sal die navorser u vra om 'n vraelys te voltooi rakende algemene inligting oor u self. U sal ook gevra word om foto's, prente, video's of enige ander objekte te bring wat die hoogtepunte and uitdagings van u ondervinding as 'n moeder met u kind uitbeeld. Na hierdie afspraak, sal die navorser weer 'n afspraak met u maak om 'n onderhoud met u te voer rakende u ondervindings. Die onderhoude sal gevoer word by Tygerberg Hospitaal, of enige ander plek wat u verkies. Die navorser sal die onderhoude op band opneem sodat sy kan verseker dat sy u ondervindings reg verstaan en ook sodat sy weer na die opnames kan luister indien daar enige onduidelikheid bestaan oor wat gesê is.

### **Hoekom is u gevra om deel te neem?**

Al die moeders van kinders wat gediagnoseer is op die spektrum van outisme en wie se kinders arbeidsterapie by Tygerberg Hospitaal ontvang, sal gevra word om deel te neem aan die studie.

### **Wat sal u verantwoordelikhede wees?**

Die navorser sal vir u 'n afspraak gee on die vraelys te voltooi, asook vir die onderhoude om plaas te vind. Dit sal van u verwag word om hierdie afsprake by te woon indien moontlik. Die afsprake sal sover moontlik op dieselfde dag as u ander afsprake by die hospitaal wees. Die navorser sal u help om die vraelys te voltooi indien nodig. Die voltooide vraelys word by die navorser gelos nadat u dit voltooi het. Die afspraak vir die onderhoude sal ongeveer een to een en 'n halwe uur duur. Indien die navorser enige ander inligting van u benodig, sal dit telefonies verkry word.

### **Sal u voordeel trek deur deel te neem aan die navorsingsprojek?**

Die studie al die navorser help om die nodige ondersteuning te verleen aan families met kinders op die spektrum van outisme, en sal ook help om toekomstige behandeling te verfyn.

**Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?**

Daar is geen risiko's verbonde aan u deelname aan hierdie navorsingsprojek nie.

**Watter alternatiewe is daar indien u besluit om nie aan die navorsingsprojek deel te neem nie?**

U is onder geen verpligting om aan die studie deel te neem nie, en indien u besluit om nie deel te neem nie, sal dit geen impak hê op die dienste wat u in die toekoms sal ontvang nie.

**Wie sal toegang hê tot u mediese rekords?**

Die navorser sal u privaatheid ten alle tye beskerm. Geen name word by enige van die prente of teks gevoeg wat uit die vraelyste, artefakte (prente, foto's, tekeninge, videos, ens.) of onderhoude verkry is nie, en alle inligting sal veilig bewaar word op 'n USB stokkie in die departementele kluis.

**Wat sal gebeur in die onwaarskynlike geval van 'n besering wat mag voorkom as gevolg van u deelname aan hierdie navorsingsprojek?**

Anngesien daar geen direkte intervensie of prosedures betrokke is in hierdie studie nie, word daar geen beserings direk verbind met deelname aan die studie nie.

**Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?**

U sal nie betaal word om deel te neem aan die studie nie, maar vervoerkoste vir u **navorsing** besoeke sal deur die navorser gedek word. Daar sal geen koste betrokke wees vir u as deelnemer nie.

**Is daar enigiets anders wat u moet weet of doen?**

U is wekom om die navorser te kontak by (021) 938 4994/ 5062 indien u enige navrae of klagtes wil rig. Indien u navrae of klagtes nie voldoende hanteer word deur die navorser nie, is u welkom om die Etiek Komitee oor Gesondheidsnavorsing te kontak by (021) 938 9207.

U sal 'n kopie van hierdie inligting en die **toestemmingsvorm** ontvang vir u eie records.

**Verklaring deur die deelnemer:**

Met die ondertekening van hierdie dokument onderneem ek, ....., om deel te wees van die navorsingsprojek getiteld: Onderzoek na die ondervindings van moeders rakende moederskap met 'n kind op die spektrum van outisme

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan die navorsingsprojek vrywillig is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek ter eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorser van oordeel is dat dit in my beste belang is, of indien ek nie die navorsingsplan volg nie.

Geteken te (plek)..... op (datum) .....2011.

.....  
**Handtekening van deelnemer**

.....  
**Handtekening van getuie**

**Verklaring deur die navorser:**

Ek (*naam*) ..... verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan .....
- Ek haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/ nie 'n tolk gebruik het nie.

Geteken te (*plek*)..... op (*datum*) .....2011.

.....

**Handtekening van navorser**

.....

**Handtekening van getuie**

APPENDIX D: Biographical Information of participants

**Participant Code:**.....

**QUESTIONNAIRE ON BIOGRAPHICAL AND GENERAL INFORMATION**

The following questionnaire needs to be completed to assist the researcher in gaining a general understanding of your home circumstances and support systems. Please complete the questionnaire as honest as possible. Your confidentiality will be protected at all times. The questionnaire will take approximately 20 minutes to complete. Please feel free to ask the researcher when you do not understand the questions or if you need assistance to complete the answers.

**DATE:**.....

**GENERAL INFORMATION**

**Please fill in the information as requested below:**

NAME OF PARTICIPANT (OPTIONAL):.....

HOME ADDRESS:

.....  
.....  
.....  
.....

CONTACT NUMBER: .....

DATE OF BIRTH (PARTICIPANT):.....

HIGHEST LEVEL OF EDUCATION (PARTICIPANT):

Gr....

Highest Qualification:.....

CURRENT OCCUPATION:.....

NAME OF CHILD:.....

DATE OF BIRTH OF CHILD:.....

WHEN AND BY WHOM WAS YOUR CHILD DIAGNOSED?

Date:.....

Health Practitioner:.....

*(Please ensure that you have read and completed all of the above questions. Please turn to the next page).*

**SOCIAL INFORMATION**

**FAMILY STRUCTURE:**

**(Please tick (✓) the appropriate box below to indicate your marital status)**

Marital Status: Single  Married  Divorced   
 Separated  Widow

**Please fill in the information as requested below. Please use the example to complete the answer.**

Number of children: .....

Age of children:

Children	Age
E.g. Child 1	3 years

**SOCIO-ECONOMIC STATUS:**

**(Please tick (✓) the appropriate box below to indicate your monthly income per family)**

Low (< R4166)  Average(R4167 – R8333)  High(>R8334)

**RESIDENTIAL CONTEXT:**

**(Please tick (✓) the appropriate box below to indicate your living arrangements)**

Formal:  Informal:  Other: .....  
 Owner:  Renting:

Number of Bedrooms:

**(Please indicate the amount of bedrooms in your house).....**

Number of residents:

**(Please indicate the amount of people staying in your house on a permanent basis).....**

**Please tick (✓) the appropriate box below:**

Own Electricity: Yes  No   
 Running water in resident: Yes  No   
 Sanitation in house: Yes  No

*(Please ensure that you have read and completed all of the above questions. Please turn to the next page).*

**SUPPORT STRUCTURES:**

**Please tick (✓) the appropriate box below:**

Do you have access to the following in your area?:

- Library
- Community Centre
- Clinic
- Play Park
- Other:.....

On whom can you rely to help you with your child when needed?

**Please tick (✓) the appropriate box below:**

- Family: Yes  No
- Friends: Yes  No
- Other:.....

**TYPE OF TRANSPORT USED TO GAIN ACCESS TO HEALTH SERVICES:**

**(Please tick (✓) the appropriate box below to indicate the type of transport you use to get to the hospital/ clinic) :**

- Private Transport  Taxi  Bus
- Train
- Other:.....

**MEDICAL INFORMATION**

**FAMILY HISTORY OF MEDICAL/ PSYCHIATRIC PROBLEMS:**

Do you or your family have a history of any medical or psychiatric problems?

**(Please complete the above question in the column below according to the example)**

Member	Diagnosis/ Problem	When Diagnosed
Eg. Mother	Depression	January 2008

*(Please ensure that you have read and completed all of the above questions. Please turn to the next page).*

<b>TREATMENT CURRENTLY OFFERED TO YOUR CHILD AND HOW REGULAR DO YOU ATTEND THESE APPOINTMENTS:</b>		
<b>(Please complete the above question in the column below according to the example)</b>		
SERVICE	FREQUENCY	HOW LONG DO YOU WAIT TO BE SEEN AT EACH OF THE DOCOTR'S/ THERAPISTS/ CLINICS
E.g. Speech therapist	1 x per month	± 30 minutes

**AVAILABILITY OF HEALTH SERVICES IN COMMUNITY?**  
**(Please tick (√) the appropriate box below) :**

Yes  No

**IS YOUR CHILD ON ANY MEDICATION?**  
**Please tick (√) the appropriate box below:**

Yes  No

**If you have answered "Yes" to the above question, please complete the following question in the column below according to the example:**

Medication	What difference can you see in your child when he/ she is on medication
E.g. Ritalin 10mg 2 x per day	Much calmer, more focussed, behaviour is controllable

Thank you very much for taking the time to complete the above questionnaire. Your time and willingness to assist is highly appreciated! You may hand in the questionnaire to the researcher after you have completed all of the questions.

Regards

E Laminette  
 (Study Researcher)

APPENDIX E: Interview Guideline

**INTERVIEW GUIDELINE**

QUESTIONS	KNOWLEDGE	EXPERIENCE	OPINIONS	FEELINGS	FIELD NOTES
1. What is your understanding of your child's problem?	✓				
2. What do you understand under the term "motherhood"?	✓				
3. What were your expectations of motherhood prior to the birth of your child?			✓		

QUESTIONS	KNOWLEDGE	EXPERIENCE	OPINIONS	FEELINGS	FIELD NOTES
4. How does your current experience of motherhood differ from your original expectations?		✓			
5. What is your perception on what the roles of motherhood should entail?			✓		
6. How does your roles as a mother differ towards your child from what you think your role of a mother should be?		✓			

QUESTIONS	KNOWLEDGE	EXPERIENCE	OPINIONS	FEELINGS	FIELD NOTES
7. What do you think is your child's biggest inadequacy impacting on your roles as a mother?			✓		
8. How do you feel about the difference in your mothering role towards your child in the light of what you think your roles should entail?				✓	
9. What is your feelings on the impact your child has on the way you are able to perform your role as a mother to him/her?				✓	

QUESTIONS	KNOWLEDGE	EXPERIENCE	OPINIONS	FEELINGS	FIELD NOTES
10. What did you do to prepare you to be a mother?			✓		
11. What prior experiences or exposure do you think has an impact on how you perform your current role as a mother?	✓				
12. How did these experiences / exposure do you think has an impact on how you perform your current role as a mother?			✓		

QUESTIONS	KNOWLEDGE	EXPERIENCE	OPINIONS	FEELINGS	FIELD NOTES
13. Describe a typical day in caring for your child and the time you spent on these tasks.		✓			
14. In what activities did you participate prior to the birth of your child and how did that change?		✓			
15. What role do you think did your child play in the change in participation, if any?			✓		

QUESTIONS	KNOWLEDGE	EXPERIENCE	OPINIONS	FEELINGS	FIELD NOTES
16. How do you think your participation in activities would have been different if your child did not have a diagnosis of autism and why?			✓		
17. How do you think your child is impacting on your family's activities as a family unit and how does that make you feel?			✓		
18. How do you think mothers in your community view you in your role as a mother to your child?			✓		

QUESTIONS	KNOWLEDGE	EXPERIENCE	OPINIONS	FEELINGS	FIELD NOTES
19. How do you feel about your perceptions of what the mothers on your community think about your role as a mother to your child?				✓	
20. What do you feel good at doing as a mother to your child?				✓	
21. What would you like to be different / change in terms of mothering your child?			✓		

QUESTIONS	KNOWLEDGE	EXPERIENCE	OPINIONS	FEELINGS	FIELD NOTES
22. What are your needs in terms of support and services?			✓		

**APPENDIX F: Introduction of participants****Nadia**

Nadia is a 37 year old coloured woman staying in the northern suburb, Kraaifontein. She completed Grade 12 and was employed full time as a clerk prior to the birth of her children. She is currently not employed. Nadia has two children, a nine year old daughter and Caleb, a five year old boy, who was diagnosed with autism spectrum disorder in 2009. Nadia is married, and the family of four stays in a three bedroom brick house with running water, proper sanitation and its own electricity. They are the owners of the house they live in. Nadia describes the family income as average, with her husband being the only breadwinner. He is employed as a mechanical engineer. Nadia's daughter has a diagnosis of attention deficit hyperactivity disorder. She describes her husband as being anti-social and having difficulties to communicate with other people, but he was never formally diagnosed as being on the spectrum of autism. According to Nadia, the paternal aunt attended a special school due to learning difficulties. According to Nadia, they have access to community resources in their area, which includes a library, community centre and clinic. Nadia is able to drive and attends to hospital appointments with private transport. Her son Caleb is currently attending occupational- and speech therapy on a monthly basis, and they attend appointments with the paediatric neurologist every six months. Nadia is also a regular attendee of the Autism support group at tertiary hospital where the study was conducted. Nadia and Caleb also attend sessions at Autism Do-It-Yourself, a private health organisation, providing parental guidance and behaviour modification intervention to families with children on the spectrum of autism.

**Anne**

Anne is 29 years old, and the mother of seven year old Claire and her younger sister of 3 years. Anne is married, and working as a domestic worker three times a week. Her husband is employed as a factory worker. She completed Grade 10. The family of four stays in an informal building (wendyhouse) consisting of one room in Belhar. Although they have their own electricity, the house does not have its own running water or sanitation. They also do not have toilet facilities inside their house. There is access to a library, clinic and play park in the area where they stay. They make use of public transport to attend to appointments. Claire attends monthly speech- and occupational therapy at the hospital where the study was conducted, and Anne occasionally attends the Autism support group. Attendance of appointments is often compromised by the fact that there are not enough funds for transport to and from the hospital. The family receives a monthly child support grant of R 560.00 for the two children. The maternal grandmother suffers from epilepsy.

**Candice**

Candice is the mother of Cathy, a six year old girl diagnosed with autism spectrum disorder in 2010. Cathy has a younger brother of 5 years old, who is also attending occupational therapy at tertiary hospital where the study was conducted, for specific areas of developmental delay and concentration problems. Candice is 38 years old, married and stays with her family in a four bedroom house in Monte Vista. Candice completed a diploma in higher education as a senior primary teacher, but is currently working as a music teacher from home. Candice mentioned a good support structure from friends and family, and stated that there is access to a variety of community resources in their area. The family makes use of private transport to attend to appointments. Cathy attends speech therapy at the same hospital on a monthly basis, and they see the child psychiatrist once a month. Cathy and her mother also attend private Relationship Development Intervention sessions once a week. Candice's husband is a minister at their church, and the family is very involved in the church activities. Candice added to the biographical information provided that she suffered from post natal depression after the birth of Cathy, but that it was never formally diagnosed and she never took any medication to address this. The symptoms resolved by itself.

### **Lea**

Lea is the single mother of six year old Liam, who was diagnosed with autism spectrum disorder in 2008. Lea, currently 24 years old, mentioned that her pregnancy at age 17 was unplanned, and that Liam's biological father was never involved during the pregnancy or thereafter. Lea completed Grade 11, and was never formally employed. Lea and Liam stays with the maternal grandparents in a two bed roomed flat, along with Lea's younger brother of 14 years old. The flat has running water and its own electricity, with proper sanitation. They have access to a library, clinic, community centre and play park close by. Liam attends monthly speech- and occupational therapy at the hospital where the study was conducted, and Lea also attends the Autism support group on a regular basis. Liam has appointments with the paediatric neurologist on a yearly basis. They make use of public transport (taxi) to attend their appointments. Lea is currently in a relationship with an old friend.

### **Sharron**

Sharron is the mother of four year old Charles, who was diagnosed with autism spectrum disorder in 2011. Sharron is married to Charles' biological father, and they stay with the paternal grandparents. The house has access to its own electricity, running water and sanitation. Charles receives occupational therapy on a monthly basis, and attends weekly speech therapy appointments at the hospital where the study was conducted. They make use of public transport to attend to their appointments. Sharron's biological mother is Xhosa, and her father was Caucasian. She never met her father and her mother also never wanted to reveal any information about him. She grew up in a black township, but always felt excluded due to her light skin colour. Sharron completed a national diploma in retail business management, but is currently unemployed.

Sharron fell pregnant in the final year of her studies. Sharron came across as blunted and made poor eye contact during the first few therapy appointments, but it became evident during the interviewing process that she was still very emotional about Charles' diagnosis. She admitted to being in denial, and as the interviews progressed, her difficulty in accepting her background and the rejection she experienced due to this, became a matter of concern. She was referred to the adult psychiatry unit with symptoms of a major depressive disorder.

### **Olga**

Olga is the single mother of four year old Roy and his older brother of nine years old. Roy was diagnosed with autism spectrum disorder at age one. Olga has completed Grade 9, and previously worked at a cleaning company and home industry. She is currently unemployed, but receives a child dependency grant of R1200.00 per month from the government. Both the children have the same biological father, but the father is not involved with the children at the moment. Olga mentioned that she received therapy for depression previously. At the time of the interview she was not on any medication or receiving any treatment for her depression. Olga's brother also suffers from depression, and there is history of epilepsy with three of the maternal cousins. Roy's brother has mild learning problems. The family stays in an informal settlement with one bedroom at the back of Olga's parents' house. They have access to electricity and running water. The toilet facilities are outside. Olga relies on her parent for physical and emotional support, although she is the one taking care of her parents. Roy receives monthly occupational therapy at the hospital where the study was conducted, and six monthly follow up appointments with the paediatric neurologist. Even though it is more expensive, they travel by taxi to attend appointments as Roy becomes upset by the huge crowds and the noise when travelling by train. At one of the most recent appointments with Olga and her son, she mentioned that she recently had another "breakdown", and is again on medication.

### **Desiree**

Desiree is 26 years old and the mother of three year old Luke. Luke was diagnosed with autism spectrum disorder in February 2012. Desiree is married and the family stays in a one bedroom wendy house at the back of her parents house in Blue Downs. Her parents, along with her 24 year old brother, are staying in the main house. The wendy house has access to its own electricity and running water, but no bathroom facilities. Desiree completed Grade 11, and is currently employed by a cleaning company on a contract basis. She works every week day from 7 am until 4 pm. Her husband is also employed. Resources such as a library, community centre, clinic and play park is available. Desiree and Luke make use of public transport, either the taxi or bus, to attend their appointments at the hospital. Desiree often leaves work, brings Luke for his hospital visits, and then has to go back to work to ensure a full day's pay. They attend speech- and occupational therapy at the hospital where the study was conducted. Desiree's dedication and optimism was noticeable

during the therapy sessions, but during the interview she became emotional and admitted that it is difficult to always remain positive.

### **Carmen**

Carmen is a 38 year old coloured woman staying in Eerste River. She is the mother of five year old Elliot, who was diagnosed with autism spectrum disorder in 2011, and also has two older daughters, aged 15 years and nine years respectively. Carmen is married, and the family stays in a two bed roomed brick house with running water, its own electricity and sanitation. Carmen completed Grade 12, and was formerly employed at a clothing factory. Carmen's husband completed Grade 9, and is the sole breadwinner working at an electrical company. They fall into the low income category. Carmen mentioned that they have access to a library, community centre, clinic and play park in their area. They travel by bus to attend their monthly speech- and occupational therapy appointments. Elliot was recently diagnosed on the spectrum of autism, and they will attend six monthly follow up appointments with the paediatric neurologist. Carmen mentioned that her own mother suffers from "stress", but there is no other history of psychiatric illnesses in the family.

### **Jane**

Jane is 31 years old, and is the mother of 6 year old John who was diagnosed with autism spectrum disorder in 2011. Jane completed Grade 12 and is employed fulltime in a human resource department at the Shoprite/Checkers head office. She is in the process of completing her diploma in human resource management. Jane's husband has completed Grade 12 and works full time as a quantity surveyor in the construction industry. The family's income is average. They are renting a three bedroom house in Kraaifontein after they moved from Worcester in 2007. The house is equipped with running water, electricity and own sanitation. The community provides access to a library, a community centre and clinic. They make use of private transport to attend to their hospital visits. Jane and her husband waited very long before John was formally diagnosed – she mentions a process of three years during which they had to wait for appointments at the respective specialists and then had to wait again for the outcome. During this time, Jane was diagnosed with depression. As mentioned already, the family moved from Worcester in 2007, and according to Jane they have no family to1supportive. Jane is also able to rely on her husband for support. John attends occupational therapy twice a month at the hospital where the study was conducted.

### **Delia**

Delia is the mother of five year old Trevor and his 15 year old brother. Although not married to the biological father of her children, they are together as a family. Delia's first pregnancy was risky and the baby was born prematurely at 28 weeks, and after that she suffered four miscarriages before Trevor was born. Trevor was also born prematurely at 27 weeks. Delia resigned her job prior to Trevor's pregnancy due to the risk to the

pregnancy. The family is renting a two bedroom house in Delft. They have access to community resources, and are able to rely on family and friends for support. The maternal grandmother suffers from Alzheimer's disease. Trevor attends occupational therapy once a month at hospital where the study was conducted. Trevor has recently been admitted for a trial period at a special school for children on the spectrum of autism, and the mother reports a significant change in the way she was able to engage in her everyday occupations. She even mentions the change in attitude and tolerance from the rest of the household during this period.

### **Maria**

At 23 years, Maria is the youngest of the participants. She completed Grade 10, and fell pregnant at age 19. Her four year old daughter, Terry, was diagnosed with autism spectrum disorder in 2011. Maria and her daughter have no contact with Terry's biological father. They stay with the maternal grandparents in a two bedroom flat. During the term, they share the flat with Maria's nineteen year old cousin. Maria and Terry sleep in the same bedroom. The maternal grandmother appeared to be very involved and supportive during the hospital visits, but during the interview with Maria she mentioned that her mother does not provide the same support at home, and that she is the one who has to take responsibility for Terry's care fulltime. Maria mentioned that she has always been restricted from going out and visiting friends, and that her parents are still implementing these rules. She also feels that they are blaming her for getting pregnant and impacting on their lives with a child that has a diagnosis of autism. Maria was very difficult to interview, and the researcher had difficulty to get the conversation to flow. Questions were answered on a very concrete level, and often just a "yes" or "no" could be elicited.

