



# **The Lived Experiences of Mothers Raising Children Diagnosed with Autism Spectrum Disorder in Ethiopia: Perceptions and Challenges**

**By**

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## **ABSTRACT**

**Title:** The lived Experiences of Mothers Raising Children Diagnosed with Autism Spectrum Disorder in Ethiopia: Perceptions and Challenges

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**Key words:** Mothers, Autism, Perceptions, challenges, Ethiopia,

This phenomenological study investigated the lived experiences of mothers raising children diagnosed with autism spectrum disorder in Addis Ababa, Ethiopia. The study aimed at exploring the perceptions and challenges of mothers in raising their children diagnosed with autism. For this study, 'perceptions' were defined as maternal beliefs about the causes of autism in their children before the diagnosis of autism. This research project started after obtaining official Ethical approval. A set of in-depth interviews were conducted with Six mothers of children with autism identified through purposive sampling technique. The interviews with the mothers were recorded, transcribed and analyzed under Interpretivist paradigm along with the theoretical framework of Bronfenbrenner's ecological system theory. The results of the Interpretive phenomenological Analysis containing seven themes indicated that mothers' perceptions towards the cause of autism were based on spiritual explanations such as devil spirit and evil eye possessions. All of the mothers were not aware of autism before receiving the diagnosis and most of the perceptions of mothers were influenced by family members, neighbors and friends. Raising children with autism poses several challenges in different areas of the mothers' life. The main challenges of mothers found in this study were psychological problems, difficulty to manage the family unit, economic strains, social stigma and labelling and lack of access to facilities and services for their children. Multifaceted social stigma and labelling, lack of facilities, services and lack of formal and informal support systems were the most pressing issues that impacted on the psychosocial and financial wellbeing of the mothers and their family which aggravated their challenges in taking care of their children with autism. Based on the finding of the study, it was recommended that the involvement all segments of a society and the government is imperative to provide wholistic support for mothers, their children and the whole family.

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# CHAPTER ONE

## INTRODUCTION

### 1.1 Background

Parenting a child with a developmental disability is extremely challenging compared to parenting a non-disabled child. Parents raising a child with a developmental disability such as Autism face various challenges in managing the regular parental tasks with the additional responsibilities posed on them due to the situation of their child (Paster, Brandwein, & Walsh, 2009).

Autism is a complex developmental condition that is characterized by impairments in two areas; social communication, and restricted, repetitive behaviour or interests (The American Psychiatric Association, 2013). Autism is usually first diagnosed in childhood with many of the most-obvious signs presenting around 2-3 years old, but some children with autism develop normally until toddlerhood when they stop acquiring or lose previously gained skills (APA, 2018). Autism can occur in any and all racial and socioeconomic groups and it has been proven that it is almost five times more prevalent in males (1 in 42) than it is in females (1 in 189). To date there is no single evidence as to a single cause, medical screening and known cure for autism. However, there have been recent advancements in the areas of physiology, neurology and genetics that point to underlying neurodevelopmental causes (Courchesne, Campbell, & Solso, 2011; Dawson, 2008; Elsabbagh & Johnson, 2010). If a family has one child with autism, they have anywhere from a 2% to an 18% greater chance of having a second child diagnosed with Autism (Center for Disease Control and Prevention, 2014). According to World Health Organization, based on epidemiological studies conducted over the past 50 years, the prevalence of Autism appears to be increasing worldwide. The possible explanation for its growing rate includes improved awareness, expansion of diagnostic criteria, better diagnostic tools and improved reporting (WHO,2019).

In western countries the average age for an Autism diagnosis is between 4.5 to 5.5 years of age, with 51–91% of these children exhibiting traits prior to age 3 (National Autism Center, 2011; Wiggs, 2010). However, taking African context, there is still a huge gap in diagnosis of ASD, as late diagnosis has continued to be noted in throughout the continent (Bakare & Munir, 2011; Bello-Mojeed et al, 2011). The possible reasons for late identification and diagnosis of autism among African children include poor awareness about the problem, cultural beliefs, inadequate number of trained staffs, inadequate healthcare and intervention facilities (ibid). Moreover, there is lack of community-based epidemiological study on the prevalence, diagnosis, etiology and treatment of Autism among African children (Mashudat et.al, 2013), which makes it is difficult to estimate exactly the number of children with autism due to the tight statistical data available (Nyoni & Serpell, 2012).

Globally, 1 in 160 children has an autism spectrum disorder (WHO,2019). In the U.S the prevalence of children with autism has drastically risen; 1 in 54 children are diagnosed with an Autism which was 1 in 88 children in 2008 (Center for Disease Control and Prevention estimate ,2020). Studies in Asia, Europe, and North America have identified individuals with Autism with an average prevalence of between 1% and 2% (WHO,2020). Although no population-based prevalence studies and early Intervention studies of Autism have been performed in Africa to date,

due to different barriers such as lack of diagnostic facilities, there is no reason to believe that rates of Autism will be any less low elsewhere (Franz, Chambers, Von Isenburg, & de Vries, 2017). In South Africa, 1 in 86 children under the age of 6 years are affected with autism (Cape, 2016). In Nigeria, prevalence of autism spectrum disorders among children with developmental disorders had been noted to be 0.8% of the total population of children that attended clinics over a one-year period (Bakare & Munir, 2011).

In Ethiopia, currently there is no exact official data on the prevalence of autism, however according to the estimation made by Nia foundation (2015), there could be about 530,000 children with autism and related developmental disorders. This significant number of children diagnosed with Autism means an increase in the number of families and parents exposed to the burden of care. Autism often impose a significant emotional and economic burden on people with these disorders and their families. Especially, caring for children with a severe form of the condition may be demanding where access to services and support is inadequate (WHO, 2019).

In Ethiopian context, where alternative childcare systems are not developed, families, mainly mothers are the main sources of support for their children's overall development (Woldegebreal, 2014). Mothers raising children with autism spectrum disorder in developing world, have a complex and extremely challenging life compared to the developed world. This is because in western countries the community is more aware about autism because of increased media coverage and an expanding body of knowledge published in professional journals (Myers & Johnson, 2007). However, in sub-Saharan Africa, including Ethiopia, relatively insufficient attention has been given to autism and the challenges of parents, particularly of mothers, in caring for children. (Bello-Mojeed et.al, 2013). Although there are documented studies that stated the profound impact of caring for a child with ASD, most of the researches on the issue stems from western societies, particularly the UK and USA (Gobrial, 2018). Therefore, further studies are needed in order to better understand the experiences of families, particularly of mothers in raising children diagnosed with an Autism

## **1.2. Statement of the Problem**

Parenting is challenging experience and it could even be more difficult when raising a child with special needs because of unusual demands that comes with the child (Angold et al, 1998). A number of researches have illustrated the immense challenges of autism to the affected individuals, their families and the impact on the parental well-being including: emotional stress, ongoing financial burden of expensive treatments and therapies, significant strain on family relationships, changes in family roles, structure and activities, feeling of guilt and blame regarding diagnosis and social stigma (DePape & Lindsay 2016; Ekas & Whitman 2010; Altieri & Von Kluge, 2009). The challenges and the difficulties faced by parents of children with autism can be multifaceted especially in traditional and less developed communities as there are lack of awareness and limited resources (Harris & Weiss, 2007). In most families, the complexities of autism can have devastating effects on parents of children with autism especially on the mothers, because they are the most significant and primary care providers in the children's daily lives and typically portrayed next to the child. Sometimes as a main caregiver, their role can be assumed to be even more important than a professional (Shaugee, 2017). Hence, mothers of children with developmental disabilities such as Autism encounter additional obstacles and stressors as they have to redefine their journey of parenthood once their child is diagnosed with Autism (Matenge, 2013). Mothers are one of those



facing significant challenges such as lifestyle change, loss of income and leisure time, difficulty in terms of communication, reduced time and ability to engage in social activities and termination of employment or limited career progression (Beecham et al., 2007). This may lead the mother to feel more worried than typical about their parenting skill and increase feelings of guilt and stress. In addition to being a primary caregiver, several scholars argued that there are various reasons for the burden of mothers in taking care of a child with autism. For instance, Aadil, Unjum, Afifa, and Zahoor (2014), argued that, the possible factors that are associated with mothers increased burden in the families of children with autism includes absence of informal and professional support, feelings of loss of personal control, and lack of awareness in society. Also, the social stigma attached to the disorder as the result of this lack of awareness about autism is another challenge to mothers of an autistic child (Baba ,2014).

In less developed countries particularly in African societies, in addition to lack of services for children and families, lack of knowledge resulted in many negative consequences for parents and children. For instance, in a Zambian study by Joachim and Robert (2012), several parents reported that the burden of responsibility for their child on the spectrum was exacerbated by unsympathetic comments from the general public which shows that many people are not aware of the condition, hence, stigmatizing both the child and the parents. Another study from Uganda by Bwana and Kyohere (2001), found that, caregivers of children with disabilities, who are mainly mothers or grandmothers, are subjected to stress in the form of physical conditions as a result of isolation from the society.

Similarly, in Ethiopia more than 80 % autistic cases face social stigma (Getnet ,2013). Most parents, especially mothers of children with autism end up in divorce, depression, and they live in poverty, due to the societal belief that attribute most developmental problems as caused by evil spirit, curse or sin committed by the respective families (Meresa, 2014; Nehemiah Autism Centre, 2019). Moreover, caring of a child with Autism can be daunting and overwhelming for mothers, due to lack of services for children with disabilities in general, and services specifically designed for children with Autism. As the availability of services for children with autism are very minimal, children with Autism and their families face the likelihood of poor health, social care, mental health service, rehabilitation, lack of special education and access to equal opportunities (Gobrial et al. 2018; Omar 2014; Gobrial 2012; Jenkins et al, 2010; Okasha 2005).

Thus, parents of children with autism, especially mothers need to be not only educated regarding the treatments of their children, but they also need to be supported and helped in the best possible way by the state, professionals and the wider community, even at the emotional level. Studies on experiences of mothers of children with different disabilities show that appropriate psychological support is a necessity for the family of a child with a disability (Barbosa et al., 2008). It is also crucial that the professionals, family, friends and others who are unaware of the impact of autism on the children and their parents are well informed (Woodgate et al., 2008). As it is also indicated in the WHO (2011), world report of disability, one of the main obstacles that hinder the establishment of efficient support programs for parents of children with Autism in developing countries, is the lack of studies that can inform about the impacts of raising children with autism on their parents and lack of adequate number of centers and trained staff. Therefore, it was found imperative to conduct this study in order to fill the above-mentioned gaps through exploring the experiences of mothers raising children with autism in Ethiopia.

### **1.3. Objective**

The main objective of this study was to investigate the lived experiences of mothers raising children diagnosed with Autism in Ethiopia by Focusing on the Perceptions and Challenges of mothers in raising children diagnosed with Autism

### **1.4. Research Questions**

The following research questions guided this study;

1. What are the lived experiences of mothers raising children diagnosed with Autism?

To answer the main research question two subsidiary questions were proposed

- 1a. What are the perceptions of mothers about the causes of Autism in their children before the diagnosis?
- 1b. What are the challenges of mothers in raising children diagnosed with Autism?

### **1.4. Significance of the Study**

In addition to clinical treatments of children with autism, addressing familial and social issues related to supporting children and their parents are important areas of concern. It is crucial to study the Lived experience of mothers of children with Autism, nationally and internationally, in order to inform the policy and legislative process and provide holistic support for children and families (Cicirelli, 2004).

In Ethiopian context, even though there are a large and increasing number of autism cases, there is a dearth of scientific research conducted in the area, particularly in relation to the perspective of parents, because, most of the research's on Autism has centered on the affected child, and focuses on assessments and treatment options for that child (Volkmar et al.,2014). Autism Spectrum Disorder, however, is a condition that has ripple effects throughout the family system (Rivers & Stoneman, 2003). It is the belief within this study that not enough attention and support is given to parents who are continuously striving for the better functioning and integration of their children into the larger society. Therefore, the results of this study may be beneficial to provide relevant and updated information to parents, professionals, schools and autism centers that work on children with autism and their families, and to the larger community in understanding the unique experiences, struggles and needs of mothers and their children.

It may provide additional insight to the autism centers so that they can design various strategies to encourage and support parents in a better way. The results of the study may help professionals by giving them different perspective and insights to better plan counselling and other intervention programs based on the needs of children and parents. It also serves as reference and a baseline information for governmental organization, non-governmental organization, program developers,

policy makers, and international organizations, to develop appropriate care and support systems and intervention programs to bring about sustainable changes to in to the lives of families and children. This study will also serve as a stepping stone for other academicians and practitioners who want to conduct research on the same area.

### **1.5. Operational Definition of Terms**

Autism, or Autism spectrum disorder (ASD) was be used interchangeably in this study; It refers to a broad range of conditions characterized by challenges in social communication and restricted, repetitive patterns of behaviour, interests or activities

Mothers – Biological mother or caregivers of children (below 18 years), whose children were diagnosed with autism

Perception - The way mothers understand or interpreted, or the belief about the causes Autism in their respective children before receiving diagnosis of autism.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1. Earlier Literature Search

A literature search relies on a careful reading of books, journals, and reports, in the first instance. After identifying a few keywords that help to define the boundaries of one's chosen area, electronic databases of published literature can be searched (Bryman, 2016). In the present study, the researcher examined a range of sources that were directly related to the research area including journals, annual reviews, peer reviewed articles, government documents, and the University OF Gothenburg library electronic databases, Such as ProQuest, Scopus and Google scholar, library catalogue sociology collection. The researcher selected relevant and scholarly, and most recent, articles, journals and books after evaluating the search results. The reviewed literatures pertinent to the research topic are presented below.

#### 2.2. Definition of Autism

Autism is a pervasive neurodevelopmental disorder characterized by impairments in social communication and restricted, repetitive patterns of behaviour, interests or activities (APA, 2013). Autism begins in childhood and tends to persist into adolescence and adulthood but most cases of the disorder are apparent during the first 5 years of life (WHO,2019). Usually, Autism is first diagnosed in childhood with many of the most-obvious signs revealed around 2-3 years old, but some children with autism develop normally until toddlerhood when they stop acquiring or lose previously gained skills.

Previously the Diagnostic and Statistical Manual of Mental Disorders IV, the handbook used by health care professionals in the United States and much of the world as the authoritative guide to the diagnosis of mental disorders, characterized autism as a triplet of impairments in three areas which were social interaction, communication and restricted, repetitive and stereotyped patterns of behavior, interests and activities. However, the new edition, DSM-V, published in May 2013, has clustered the social interaction and communication components into one category, thereby generating a classification of autism with two section that are problem in social communication, and restricted, repetitive behaviour or interests (APA,2013). Children with autism exhibit a wide range of behaviours such as difficulty to make friends with other children, to communication, to have an imaginative play and to speak at all. Other signs also include obsessions; fears; a lack of awareness of danger; ritualistic play and behaviour; inappropriate eye contact; hypersensitivity to sound, light and spinning objects; and hand flapping. However, not all children show these symptoms to be diagnosed (Mthimunye, 2014). Early diagnosis, Screening and evaluation are essential for the child and the parents of children with autism to ensure that these children access the services and supports they need (Dzunay, 2011; CDC, 2014). According to world population review, tracking the rates of autism around the world is a bit of a challenge because many nations do not track or report their autism rates. There are also no specific, uniform criteria for assessing autism. Even if there were, there are many nations that do not have the resources to conduct assessments (World population Review,2019).

The diagnosis of autism poses particular challenges for healthcare professionals (HCPs) as, in common with other neurodevelopmental disorders and most psychiatric disorders as there are no biomarkers utilised in clinical practice (Klin, Lang, Cichetti, & Volkmar, 2000). In addition, the condition is heterogeneous, with wide ranging levels of severity and symptom expression and characteristics common to autism may occur in people with other conditions (Huerta&Lord,2012). The diagnosing Autism requires a comprehensive, systematic, and structured approach. Besides meeting the goal of identifying the disorder, the diagnostic assessment provides important information on the child's relative strengths and weaknesses, identifies which maladaptive behaviour and comorbid difficulties are present, clarifies the impact of the child's condition on the family, and benchmarks the developmental skills of the patient. The diagnosis of Autism greatly varied between developed western countries and developing low- and middle-income countries as it is considered largely a disorder of children living in Western Industrialized Countries with high technological development and may be uncommon among African Children (Sanua,1984). Thus, the onset and causes of Autism in Africa may not necessarily fit the criteria set in developed countries (Ametepee & Chitiyo, 2009). Generally, children with Autism in Africa tend to be diagnosed in late ages, when they are severely affected; at the level when they speak few or no words, require substantial help with everyday tasks such as eating or going to the bathroom etc. Thus, efforts about Autism are just beginnings to bring the condition into the open (Zeliadt, 2017).

### **2.3. Parental belief about Causes of Children's Developmental Disability: Cross Cultures**

One way to investigate parents' reviews of their situation as caregivers of a child with ASD is to explore their explanations and understanding of this diagnosis. In the absence of conclusive information on the causes and treatment of ASD, most parents of children with ASD develop their own perceptions of the disorder (Gona, Newton, Rimba, Mapenzi, Kihara, Van de Vijver, & Abubakar, 2015). According to various studies, explanations given for the cause of autism varied across different countries. Parents from well developed country raise more logical and near to scientific explanations where as parents from less developed and developing countries specifically from Africa raise more cultural and non-scientific explanations.

For instance, A study in the United States by Harrington, Patrick, Edwards, and Brand (2006), on Parental beliefs about autism on 62 families of affected children found that majority of parents gave scientific explanation for the cause of their child's problem including immunizations, genetic predisposition, environmental exposure to mother or child, early childhood illness or injury pregnancy complication, and antibiotic taken by child. Similarly, study in the UK conducted by Russell & Norwich (2011), found that parents perceptions to the causes of their child's Autism symptoms were the result of biological factors and neurological differences. Also, a qualitative study from Israel conducted by Shaked and Bilu (2006), on 30 mothers of children with Autism which focused specifically on beliefs surrounding etiology of Autism symptoms found majority of parents reporting physiological causes including labor complications, problematic infant immunization, genetic inheritance, viral infection during pregnancy, serious disease in the first year of life, head trauma and organic defect in the brain as causes for their children's developmental disability.

Additionally, In a Jamaican exploratory study by Mann (2013), revealed that most mothers believed that they were fated by God to have a special needs child and some thought there was a genetic risk that had led to their child's symptoms. Similarly, in South Korea mothers, as the primary caregivers, mothers in bear their child's autism as everything starting from the mother's prenatal mood to post-natal diet ( Kang, Grinker, &Mandell, 2013). However, in most African studies ASD is often viewed as a result of some misfortunes or wrongdoings by the parents or the ancestors of the autism child including witchcraft and evil spirits (Mashudat et.al, 2013). For instance, as demonstrated in Bakare et al. (2009), participants from Nigeria often blames diseases like ASD on witchcraft spirits, hereditary causes or just simply bad parenting and views mothers as cold and uncomfortable to their children. In addition to parents, a study exploring the opinion of Healthcare workers in Nigeria that assessed the opinion of healthcare workers on aetiology of ASD documented a very significant proportion of healthcare workers reported preternatural and supernatural aetiological factors for autism such as lineage curses, enemies, and action of the devil, among others (Bakare, Agomoh, Ebigbo., Eaton, Okonkwo, Onwukwe, & Onyeama, 2009). Further, a study by Anthony (2009), conducted in Ghana which provided a look at the understanding of autism found that parents especially mothers, were blame for their child's symptoms either by not providing quality prenatal care, a failed abortion attempt involving ingestion of tonics and experiencing some illness or accident during the course of their pregnancy as the cause for autism.

Likewise, a phenomenological study by Nyoni and Serpell (2012), in Zambia revealed that several families attributed the cause of ASD to witchcraft and/or noncompliance to customs and traditional norms in marriage. The researchers further explained that such thought leads to family conflicts on gender roles, marriage relationships, poor parental care and denial of the child's condition by parents particularly by the father mainly if the child with Autism is a first born son who is treasured traditionally. Another qualitative study from Kenya conducted by Gona and his colleagues (2015), that explored parents perceptions using 103 participants including parents, special needs teachers, clinicians, and social workers from diverse cultural background found that majority of participants in their study associated ASD with Preternatural causes that included witchcraft, evil spirits and curses either before birth or during early childhood (Gona, Newton, Rimba, Mapenzi, Kihara, Van de Vijver, & Abubakar, 2015).

In Ethiopia, a study conducted by Tilahun and his colleagues (2016), exploring the perspective of 102 caregivers, which most of them were mothers, indicated that more than half of the participants frequently cited supernatural explanations for the cause of autism including spirit possession, a sinful act; a direct result of the caregiver's transgression, punishment from God, evil eye or "*buda*" (a spell cast by the eye, inflicting injury or misfortune on the person being looked) and curse or bewitchment (harm inflicted by magical acts or supernatural powers instigated by another person or by supernatural beings (Tilahun, Hanlon, Fekadu, Tekola, Baheretibeb, & Hoekstra, 2016). Parents' beliefs about Autism shape their explanation of signs manifestation, the time that they take to seek out intervention, and the type of intervention they decide to have for their children (Ravindran & Myers, 2013). Parents' beliefs on the nature and cause of disability provide the context for parents' beliefs for the corresponding intervention (Danseco,1997; Levy & Hyman, 2003). According to different scholars, the variation of parental beliefs and treatment of ASD can be explained in terms of different factors, for instance cultural background, economic status and educational level of parents. For instance, Moh and Magiati (2012), stated that educated parents

with more economic resources may be more alert in noticing their children's atypical developmental earlier, despite the severity of the symptoms, and may thus seek help earlier. It is suggested that parents from low socio economic and deprived educational backgrounds may either not notice or understand non-typical behavior or development earlier (Davis & Carter, 2008). Lack of knowledge makes it difficult for the parent to seek professional assistance and may result in some parents resorting to using the media and other people's experiences to provide a home diagnosis of the child (Glazzard & Overall, 2012). Moreover, families who are living in cultures that believe a child's symptoms to be a result of a curse placed upon the family may be more likely to pursue spiritual means of intervention for their child (Anthony, 2009; Riccio, 2011; Shyu, Tsai, & Tsai, 2010).

#### **2.4. Parents' Reactions to the Diagnosis of Autism in their Children**

Parent's response to the Autism diagnosis is different from one parent to another. Several studies have specifically focused on exploring parental reaction when they initially hearing the news that their child has autism because parents' experiences at the time of the diagnosis predict future family adaptation to the spectrum, parental stress, and parents' information needs (Murphy and Tierney, 2006). A range of studies investigated the mother's responses to the child's diagnosis, for instance, a study from U.S conducted by Lutz, Patterson, and Klein (2012), about the mothers' responses to their children's diagnosis with autism that interviewed 16 mothers, found that reactions of mothers to their child's diagnosis with autism was grouped into four major groups; grief & anger, dis-ease and relations-ship, guilt and doubt, and disappointment and sacrifice (Lutz et al., 2012). The most common initial reaction of mothers at the time of diagnosis is feeling of sadness and anger highlighted by self-blaming. Mothers also experienced psychological problems such as fear and anxiety during the initial stages of learning about their child's situation. Some studies reported the reaction of denial as the first reaction of mothers to their child's diagnosis with autism while others reported experiencing feelings of shame when sharing the news of their child's situation to others (Dababnah & Parish, 2013). Another study carried out with participants from Iran, by Samadi and McConkey (2011), also indicated that parents' immediate reaction after their child's diagnosis with autism was shock and devastation.

Studies on African parents by Nyoni and Serpell (2012), Anthony (2009), and Balfour (2007), in Zambia, Ghana, and South Africa respectively, indicated that African parents experience challenges ranging from frustration, pain, confusion and doubt in the diagnostic period as a result of limited knowledge about autism. Most parents in these studies revealed that they had no knowledge about Autism which led them to poor parenting of the child, parental stress, emotional and psychological distress, strain on the marital relationship and strain on relationships within the family (Glass, 2001), and this limited knowledge of autism by parents led to initial reactions of denial, fear, and shock during and after diagnosis (Hoogsteen & Woodgate, 2013). These parents are generally left in shock and disbelief after diagnosis not knowing what course of action to take to help their autistic child and their families, including the siblings of the autistic child (Ebrahimi, Malek, Babapoor & Abdorrahmani, 2013). Thus, upon receiving the diagnosis, many parents reported that they wished they had received greater information surrounding resources, treatment, and prognosis for their child (ibid).

## **2.5. Impacts of Raising a Child with Autism on Parents**

Autism has life-time consequences with a range of impacts on the health, economic wellbeing, social integration and quality of life of individuals with the disorder, their families and potentially on the rest of society. As family environment has a major role of caring, nurturing, socialization and procreation, the family systems are more prone to face multiple challenges (Sameroff, 1990 as cited in Altieri, 2006). Having a child with Autism impacts on various aspects of family lives including housekeeping, finances, emotional and mental health of parents, marital relationships, physical health of family members, limiting the response to the needs of other children within the family, poor sibling relationships, relationships with extended family, friends and neighbours and in recreation and leisure activities (Sanders & Morgan, 1997). Also, it can create significant stress throughout all family members and creates social and communication deficits effect on total family members. Hence, families become exhausted both emotionally and financially (Hall & Graff, 2011).

### **2.5.1. Overall Emotional Impact**

Studies on parent's wellbeing shows that parents who have a child with autism report higher levels of parental stress and psychological distress than parents of children without autism (Baker, 2000). Several factors have been proposed to account for the higher levels of stress of parents with a child with autism, including the uncertainty surrounding autism diagnosis, the long-term prognosis of individuals with autism, the stressful nature of autistic symptoms and associated behaviour problems, and the lack of public understanding and tolerance for the behaviour of children with autism (Giallo, Wood, Jellett & Porter, 2013). Along with the severe psychological distresses, there is the acknowledgment of potential loss of self and family image and livelihood, which implies a unique parenting experience with different expectations, hopes and dreams for the child and family to what they had anticipated (Woodgate, Ateah & Secco, 2008). In many families, the mother is the primary caregiver, and this role is more common when there is a child with ASD in the home (Heller & Hsier, 2003; Marks, 1998). This may lead the mother of a child with autism to feel more worried than typical about their parenting skills, and increase feelings of guilt and stress (Harris, 1984), anxiety, and depressive symptoms (Estes, Munson, Dawson, Koehler, Zhou and Abbott, 2009).

In the U.S ,a study conducted by Myers and his colleges (2009), on 493 parents of children with autism found that over 70% of parents reported feeling stressed, noting difficulties related to marital strain, school struggles, challenging behaviors, not being able to go anywhere, and disrupted family life (Myers, Mackintosh & Goin-Kochel, 2009). A study on 127 Iranian mothers by Kousha, Attar, and Shoar (2016), found that the frequency of anxiety and depressive symptoms was higher than that of the general female population in their country, and the children's illness affected all aspects of the mothers' lives (Bazzano, Zeldin, Schuster, Barrett, & Lehrer, 2012). The possible reasons for the mothers' greater distress include greater involvement in child raising, increased exposure to negative social reactions by outsiders and the absence of employment and an alternative role to being the parent of a child with autism, concerns about the future of their children because of the failure of children to recover, plus their increasing age (Gray, 2002). Moreover, the stressors that accumulated overtime together with the absence of adequate resources and support lead to depression and burnout (Morgan ,1988).



### **2.5.2. Adjustment with in the Family System**

Parents with autistic children face with difficulties and challenges within their family which cannot be of a positive nature. A child with autism can have a particularly negative impact on the marital relationship (Lee, 2009), as well as on sibling in the family (Meyer, Ingersoll and Hambrick, 2011). Initially, the intimacy between couples can be affected due to several factors such as maternal stress, lack of time accompanied by physical tiredness due to coping and dealing with the autistic children behaviours such as tantrums, running around with extra daily activities such as treatments, and on top of it, balancing life with other non-autistic children which leads the to a significant strain on marital relationship over time (Dillion ,1995).

studies that examined the relationship of couple having Autistic child discovered that parents encounter difficulties in their marital relations and in reciprocal interactions between family members (Benson & Gross, 1989; Baxter et al., 2015). The disability of a child may influence the weave of a marital relationship in several ways; it redesigns the organization of the family life and creates a fertile soil for conflicts. The disability has repercussions on most of the things parents do together: it affects sleeping arrangements, work, meals, time spent away from the child, and more and creates more arguments, expressions of anger, and impatience (Heiman, 2002). A study conducted in the U.S by Myers and his colleagues (2009), on 493 parents of children with autism found that one -third of respondents reported marital strain among couples duet to prolonged arguments, husband's denial about the child's autism, multiple demands of caring for the child and husbands avoidance of coming home. (Myers, Mackintosh, & Goin-Kochel, 2009). Similarly, In Australia a study conducted by Higgins, Bailey, and Pearce (2005), on 53 parents found that parents of children with Autism had lower levels of marital happiness, family cohesion, and family adaptability compared with parents of nondisabled children. Further, the divorce rates among couples has been documented to be higher among parents of autistic child than parents of typically developing child, with divorce rate of 80% and higher (Doherty, 2008; Solomon & Thierry, 2006).

Conversely, a Norwegian longitudinal study by Lundeby and Tøssebro (2008), based on 489 families of children with disabilities that include 17 Norwegian counties found that family structures of children with disabilities were fairly similar to those of the typical family and children with disabilities were more likely to live with two, married parents. Another Canadian study by Scorgie & Sobsey (2000), also reported personally transformative and satisfying relationships among couples despite the considerable and sustained stresses involved in parenting a child with a disability.

In addition to the strain with husbands, the diagnosis of autism could impact on siblings. Parents may be overwhelmed with a number of questions and demands from siblings regarding the behaviour of the autistic child which led to stressful situation in the family (Ozonoff et al., 2002). The feelings of jealousy regarding the amount of time parents spend with their brother/sister diagnosed with autism is a major stressor among siblings. Due to the significant needs of children with autism, the sibling may feel as though he/she is being ignored. It may be hard for some parents to balance time with their other children if their child with autism is in high need and may require assistance with eating, toileting, personal cares and behaviour modification which can occupy the parents time. Hence, the typically developing child may act out in hopes to intercept some of the parental attention (Autism Society, 2011).

### **2.5.3. Economic burden of Autism on the Family**

Raising children with special needs is substantially more expensive than raising a child with a typical development. Research has shown that parents of children with Autism have a substantial financial burden because of two related impacts on the family budget: They earn less money and they have higher medical, educational, and care expenses (Montes & Cianca, 2014). The economic impact of caring an autistic child on the families is related to aspects of intervention, employment situation of parents and other related costs (Jarbrink et al, 2003). A range of studies have revealed the impact of raising autistic child on the mothers' career and associated financial burden to the family.

In the United States, parents of children with Autism reported a negative impact up on their career after having a child diagnosed on the autism spectrum in which mothers reporting moderate to serious limitations on their careers, and denied any opportunity for outside employment due to their child's disability (Gray, 2002; Bayat, 2007). More specifically, parents reported having to put their careers on hold or switching to a career in special needs (Bayat, 2007), or simply experiencing greater levels of work stress when compared to other parents (Smith, Hong, Mailick Seltzer, Greenberg, Almeida, & Bishop, 2010). Moreover, mothers of children with Autism, who tend to serve as the child's case manager and advocate, are less likely to work outside the home. They work fewer hours and earn 56 percent less than mothers of children with no health limitations and 35 percent less than mothers of children with other disabilities or disorders (Autism Speaks Inc, 2019).

Another, preliminary qualitative research conducted on 43 Chinese families indicated that many families and mothers in particular, found themselves changing their work habits in order to better meet their children's needs in many cases quitting their jobs and shifting to full-time advocacy (McCabe, 2007). Likewise, a study conducted on 13 Jamaican mothers reported the impact of raising a child on the spectrum on their career such as work interruptions, having to leave early and having to quit their job in order to better meet their children's needs (Mann, 2013). Similarly, earlier studies in Sweden revealed the significant costs of raising a child with Autism and identified as the main cost drivers schooling and community support expenses (Jarbrink, 2007; Jarbrink et al. 2003; Jarbrink & Knapp 2001). Moreover, parents have economic burden of high household expenses of children with including costs related to clinic visits, transportation, behavioural treatment, and medication; in most cases the annual total household income of parents is insufficient to cover the health care costs (Wang et al. 2012).

Generally, the financial burden of care for a child with Autism is very substantial, although precise estimates that incorporate all associated costs are not yet available. Therefore, in comparing the results from international studies, one needs to realize that the actual cost to the family varies depending on the welfare state model of the country, its system of health care and special education, and the public consensus on what expenditures are parental responsibility and which ones are the responsibility of the commonwealth (Montes & Cianca, 2014).

#### **2.5.4. Impacts of Autism on the Social wellbeing of Parents and Children**

One of the obstacles individuals with mental disorders face, in addition to the cognitive and behavioural deficits that accompany their diagnosis, is the social stigma that arises from those with whom they interact in their social environment. In other words, their diagnosis may be associated with negative stereotypes by the public that go beyond the scope of their actual diagnosis (Myer,2007). Stigma is a multifaceted construct; which is defines as deeply discrediting attributes that do not fit the normative expectations of society and thus result in a spoiled social identity for individuals or groups who possess the attributes (Goffman ,1963). Prior researches conducted on families of children with autism demonstrated that misconceptions and stigma associated with autism are apparent worldwide. For instance, A qualitative study conducted by Gray (1993), among 32 parents of children with autism in Australia found that autism has uniquely stigmatizing aspects for parents due to the extremely disruptive nature of autistic symptoms, the normal physical appearance of autistic children, and the lack of public knowledge and understanding regarding the nature of autism. As a result, most parents perceived themselves to be stigmatized by their child's disorder with mothers having a strong tendency to feel more stigmatized tendency to than fathers as a consequence of the limitations placed on the mother's activities outside the home because of their child's with autism. Moreover, the absence of visible markers of ASD may contribute to stigma, faced by parents and children as unknowledgeable others may perceive a person with ASD, who looks "normal," to be acting voluntarily in ways that violate social norms (Gray 2002).

Similarly, a Mexican study by on 50 single mothers of children with disabilities by McHatton and Correa (2005), found that mothers experienced significant discrimination as a result of culture, disability of the child, and a combination of culture and disability. Where Professionals, service providers and strangers were responsible for the majority of the discrimination. In most cases, disabled children do not go to school because teachers are not patient with them in the mainstream schools and fellow students do not understand their difficulties (Lewis 2009). Likewise, a study by Ellen and her colleagues on 15 Somali parents of children with autism living in the UK, reported that children with autism were labelled and stereotyped as 'sick', 'naughty', 'different' and parents were blamed for not controlling them, leading to social rejection and isolation. Stigma faced by parents and children was associated also with a poor understanding of autism, a lack of vocabulary related to autism in the Somali community, and prejudice against mental illness and disability (Ellen, Fox , Aabe, Turner, Rai, and Redwood, 2018).

In Africa, a child with a disabling neuro-developmental disorders is seen as a mark of shame on the family by the society due to misunderstanding of the etiology of developmental disorders and associated cultural and traditional influences. Therefore, individuals with ASD and their families are often faced with negative attitude, avoidance, rejection, as well as negative and offensive comments which lead families to hide the affected child from the society (Mashudat et.al, 2013). At times, it can led parents feeling locked at home, as they fear taking the child out in public creates a scene or run into danger which is a major source of stress for parents (Allik et al.,2006; Blacher & McIntyre, 2006; Sometimes, many mothers are blamed in some way for causing their child's autism which significantly aggravated the stress and isolation. (Anthony,2009). Giving the enormous social stigma and discrimination, parents do not usually have the option of passing in all circumstances, they have to confront or limit their exposure to the stigmatising reactions of others in different ways. This, they utilize different techniques such as isolation, restricting public

encounters, ignoring or reacting against such judgments through engagement with their children and with the environments surrounding their children (Hays and Butauski ,2018) and confiding in their own parents, siblings, friends, and certain medical professionals regarding private matters. These techniques, either singly or in some combination, provide parents of disabled children with some degree of protection against the stigmatising reactions of others ( Alareeki, Lashewicz, Shipton, 2019)

### **2.5.5. Facilities and Services for Children with Autism and their Families**

The challenges and stressors associated with providing services and caring for a child with autism affect families, educators, and health professionals. Parents raising children with autism need a holistic support system I,e system that includes professionals with the knowledge and understanding of autism, a system that can cater for early diagnosis and early intervention, and a system that is readily available for the parents and their families (Farzana,2017). When a family is able to draw upon adequate resources and if they perceive the situation as manageable then the stress of raising a child with autism may never lead to a crisis (Seligman &Darling 1997).

A range of studies have indicated that parents of children disabilities including autism reported the greatest difficulty in obtaining services and support programs than parents of typically developing child. For instance, Tiffany (2010), indicated that many parents of children with this disorder in the U.S find it difficult to attain educational provision or help with their children compared to those who have children with other disabilities. In most cases parents, had spent extensive time trying to find services for their child with autism which become frustrating, stressful, and discouraging to a family (Altiere ,2009). Supporting this, Dzubay (2011), stated that parents in the U.S, particularly mothers, may be unable to return to work because childcare centers, by which many of them are under private ownership, privately are not willing to take their children. Similarly a study by McCabe (2007), on the experiences of families of children diagnosed with autism in China in accessing services and supports for their child found that even if parents have a desire to have their children go to school, they face rejection from general education schools and it was also noted that special education schools in most areas are limited in China. Further, a study conducted in Jamaica by Mann (2013), indicated that many children diagnosed with autism have very limited access and difficulty to find educational facilities, respite care, appropriate educational settings for their child and most educators and schools in Jamaica are extremely under-prepared for supporting the needs of children with autism and require the relatively high costs of educating a child.

Compared to the western countries with trained professionals, better access to child care facilities and available intervention services, African children have limited access to the few available services (Bakare & Munir, 2011; Bello-Mojeed et al, 2011). The non-availability of child health care and education services and the poor access to the few available ones which are concentrated in the urban areas makes it difficult for families of African children with Autism to get them necessary intervention and education programs (Mashudat et.al, 2013). Supporting this, studies from Egypt indicated that caring for a child with Autism can be daunting and overwhelming for mothers, due to the services for children with disabilities in general, and services specifically designed for children with Autism in Egypt, are minimal or even absent. Children with autism and their families face the likelihood of poor health, social care, mental health service, rehabilitation,

lack of special education and access to equal opportunities (Gobrial et al. 2018; Omar 2014; Gobrial 2012; Jenkins et al. 2010; Okasha 2005).

Some reports from Ethiopia also found that most parents have no accurate and up to date information about their children's developmental disorder because the service system is often limited and fragmented that it is highly unlikely that there will be any single source of information that can tell parents of autistic children all they need to know at any point along the way (Amakelew, Daniel and Fasikawit, 2000). A study by Gray and Holden (1992), examined psychosocial well-being among parents of children and young adults with autism and found that anger and anxiety in parents were negatively proportional to social support. The cumulative results of several studies illustrated that parents who received support related better emotionally to their children where as parents who received low social support was found to have depression and anxiety symptoms.

The above reviewed literatures indicated that parents, particularly, mothers, face multiple challenges in raising children with autism which affected the psychological, social, and economic wellbeing of mothers and the whole family system.

## **2.6. Theoretical framework**

I used an ecological systems theoretical framework developed by Bronfenbrenner (1979), for the purpose of this study. This theory posits that children's development is heavily influenced by the contexts or environments they develop with in (Bronfenbrenner, 1979). More specifically, Bronfenbrenner (1979) stated that there are five important systems (the microsystem, mesosystem, exosystem, macrosystem, and the chronosystem) that influence and are influenced by the child's behaviour and the most important system is the family which includes parent-child subsystems.

The microsystem is the level where interactions and influences are within immediate settings and include the child's immediate relationships with family members, caregivers and school, peers. The influences of these systems are bi-directional in that not only do the parents affect the child's beliefs and behaviours, but the child also impacts the behaviour and beliefs of the parent. At this level, influences are strongest and have the greatest impact on the child (Berk, 2000; Paquette & Ryan, 2001). Mesosystem is the layer that encompasses the connection between two or more microsystems structures of the child's (e.g., the family and the school, peer and family, family and community) that affects the child. An example of this is parent involvement with the school teacher. If the parent actively participates in communication with the teacher and school, the overall growth of the child is influenced (Berk, 2000; Ryan, 2001). Exosystem pertains to the linkages that may exist between two or more settings indirectly influencing the child's development (e.g., parental career factors). Exosystem defines the larger social system in which the child does not function directly but impacts the child's development by interacting with some structure in their microsystem. The child may not be directly involved at this level, but does feel the positive or negative force involved in their system (Berk, 2000; Paquette & Ryan, 2001). For example, social institutions such as community support and health services, world of work and mass media that operate on the layer (Petra, 2012) indirectly affect the child with autism and the parent.

The macrosystem is the larger sociocultural context which comprised of customs, laws, cultural values, the economy, and government. Each system contains roles, norms and rules that shape an individual's development (Barclift, 2010; Berk, 2000; Bronfenbrenner, 1996; Paquette & Ryan 2001). It is layer considered to be the outermost layer in the child's development and it is where the ideological patterns of the various cultures in which the child functions exist (Berk, 2000; Paquette & Ryan, 2001). Lastly, the chronosystem is the way environmental impacts over time affect the individual. It includes the transitions and shifts in one's lifespan. This may also involve the socio-historical contexts that may influence a person. (such as., generational influences). Bronfenbrenner (1986), also distinguished between normative (usual) and non-normative (unexpected) transitions, both of which occur through the lifespan and "often serve as a direct impetus for developmental change".

From my point of view, applying ecological system theoretical perspective on families of children with autism was relevant to better understand and explain the challenges of mothers raising children diagnosed with autism under this study. It provided a context to explore the lives of mothers' as it encompasses various systems that directly and indirectly influences the mothers and their family.

## CHAPTER THREE

### METHODOLOGY OF THE STUDY

#### 3.1. Research Methods

This study explored the lived experience of mothers raising children diagnosed with autism spectrum disorder using qualitative research method. The qualitative method was selected for this study because it helped to acquire “in-depth understanding about a certain phenomenon through exploration instead of measurement (Bernard, 2008). The focus of qualitative research is to find explanations for questions such ‘what’, ‘how’ or ‘why’ of an occurrence (Green & Thorogood, 2014). Qualitative research investigates a phenomenon considering the context of people’s everyday lives and it acknowledges multiple truths and person’s interpretation of their experience (Goldman & Du Mont, 2001). The process in qualitative research approach involves identifying research question, collecting data from participants, analysing data inductively from responses to themes, and interpreting the data by the researcher (Creswell, 2014). Qualitative approach provides non-numerical data in the form of interview response, audio and videotape recording, field notes etc (Lunenburg & Irby, 2008). It allows a greater flexibility and spontaneity or naturalness and adaptation of the interaction between the researcher and the study participants (Rubin & Babbie, 2011; Dey, 1993; Bryman, 2016) and attempts to understand and explain the world from participants’ points of view (Draper, 2004). Therefore, I selected a qualitative method as it was the most appropriate method to meet the research aim of exploring the perception, and challenges of mothers raising children diagnosed with autism.

One of the approaches of qualitative research is phenomenology which I used in this study. Phenomenological approach explains the lived experiences of individuals about a phenomenon as lived by the individuals themselves (Creswell, 2014). The reason why this approach was chosen for the purpose of this study was due to the fact that the lived experiences of mothers were described by themselves as they lived it. According to Van manen (1990), the aim of phenomenological research is to translate the lived experience into words and meanings to achieve true meaning of the experience. Phenomenology suited for this study as the personal voice and experience of mothers provided rich, descriptive data. Further, parents’ experiences, thoughts, feelings, and meanings provided greatest insight into the chosen phenomena. As indicated by Creswell (2007), a phenomenon in a phenomenological study is a variable which is experienced directly, rather than being conceived in the mind as some abstract concept or theory that stands in need of explanation. Therefore, the perceptions of mothers about autism, and the challenges they faced were assessed as phenomena (variables) that are in need of explanation as directly experienced by them.

#### 3.2. Study Area

This study was conducted in Ethiopia, a country found in Eastern part of Africa. It is the second most populous country after Nigeria, with the population of 114,724,281 in 2020 . The capital and the largest city is Addis Ababa. The estimates of female population (50.2 %) outnumbered male population (49.8%). The culture and traditions of the country hold family as a significant part of Ethiopian Life. Women in Ethiopia occupy low status in the society. In spite of their contributions

to the well being of their family and community affairs, women experience lower socio-economic status in general and hence is marginalized from making decisions at all levels (NCTPE, 2003). The history of people with special needs in Ethiopia is not different from other developing countries. Special needs children in Ethiopia are among the most psychologically, socially, economically and politically disadvantaged social groups (Weldeab, 2006). In other words, to be special needs person usually means to be discriminated against as well as suffering social isolation and physical restrictions (Letekidan, 2003). Persons with disability do not have access to rehabilitative services, simply because of the unavailability of such service and due to the low level of attention given to developmentally disabled groups by past regimes and the present government. As a result parents and relatives of disabled were and are still the crucial actors in the provision of care and education for the majority of disabled children and youth (Meron, 2006).

For the purpose of this study, mothers were initially reached through two organizations located in Addis Ababa, namely Nehemiah Autism Centre and Saint Paul Hospital. The researcher reached the mothers through this organization because both of the organizations work with children with autism and their families which gave me the opportunity to find the targeted population easily. I established initial contact with both of the organizations before commencing the research project. My intention to contact these organization was in order to ease the process of the research in finding the mothers not to take the organizations as a case of study.

Nehemiah Autism Centre is one of the two autism centres in Ethiopia. It is a non-profit and non-governmental organization established in 2011 in Addis Ababa. The organization mainly provides education, and behavioural therapies and treatments for children with autism. It also provides psycho social-supports for parents to help them improve the academic and social development of their children. Also, the organization actively works towards awareness creation programs about autism in the society. Parents who has financial problems to cover the treatment expenses of their children get a free treatment from the centre. All the services are provided for free and the centre only receives contributions from parents if the parents are willing to support. Out of all children with autism admitted in the centre, 60% of them are from poor families. The compound is located in the city area. It has refreshing green environment, and a playground for the children. During the time of the interview, there were 43 employees and 60 children in the centre. The manager of the organization and the head psychologist played a key role for this study in the recruitment of participants for individual interviews.

The other organization was, St. Paul hospital, which is the second largest hospital in Ethiopia established in 1975 G.C. The hospital has 350 beds sees an annual average of 300,000. It has a catchment population of more than 5 million. The hospital has 1200 clinical and non-clinical staff and 31 departments including psychiatry department. I was able to contact with the mothers with the help of psychologists who worked with mothers in the psychiatry department. In the beginning, the professionals, mainly, psychologists working in the hospital explained the objective and the nature of my study to the mothers and ask for their consent for participation. In addition, I had the opportunity to meet with the mothers by attending the support group meeting that takes place once in a month in the hospital. Attending the meetings was good opportunity for me to access parents at the same time and location.



### **3.3. Population and Samples of the study**

The only legitimate informants in phenomenological research are those who have lived the reality or those who passed through the experience related to the targeted thematic issue of the study (Creswell, 1998). Hence, the participants of this study were mothers who have lived experiences in raising children diagnosed with autism. I used a purposive sampling technique, particularly, of homogeneous purposive sampling, to recruit participants from this study. A purposive sample is a nonprobability sample that is selected based on characteristics of a population and the objective of the study (Etikan, 2016). This sampling technique focuses on candidates who share similar traits or specific characteristics (ibid). Specifically, phenomenological study suggests sampling to be purposive and broadly homogenous as a small sample size can provide a sufficient data on a given phenomenon (Joanna and Alison, 2006). For this study, a total number of Six mothers were selected as it was the recommended sample size for research of this kind; for phenomenological studies, Creswell (1998) recommends 5 – 25 and Morse (1994), suggests at least six samples that can provide sufficient data on their experience. In addition, Phenomenological studies typically involve conducting individual interviews with small sample sizes or single case studies (Mann,2013). Considering this, purposive sampling was employed to select participants among the population.

#### **3.3.1. Inclusion Criteria of Participants**

I selected only mothers for the purpose of this study, this was because in most families, the complexities of autism have devastating effects on parents, particularly on the mothers, because they are the most significant and primary care providers in the children's daily lives and typically portrayed next to the child (Shauge,2017). In most traditional societies, a female family member, often a mother, takes care of the needs of others in the family and in turn experiences challenges first hand (Gebre,2016). I considered three eligibility criteria to select participants. The first inclusion criteria was that participants need to be mothers or primary caregivers who have a child diagnosed with autism; parents who have children with other types of childhood disorders were not included in this study. Second, mothers residing in Addis Ababa during the time of interview, and third, age of their children should be from 2 to 17 years old. This particular age limit was chosen due to two reasons. First by referring the age of diagnosis for Autism set by the Diagnostic Statistical Manual for Mental Disorders (APA, 2013). The manual describes autism as a behavioural disorder that is usually manifested after a child turns two years old (American Psychiatric Association, 2013). Although, some of the parent's reported becoming aware of their children's condition at different age, generally the disorder is manifested after a child turns two years. Second, I considered age 17 taking the definition of a child set by United Nations Convention on the Rights of the Child; which states that a child is a person under the age of 18 (UNCRC,1989). There were no economic, religious, and marital parameters because the focus of this study was exploring the essence of phenomenon of parenting a child with autism regardless of this parameter. At first 9 participants expressed interest for participation but the researcher selected 6 of them as they fulfil that inclusion criteria. Two of them were excluded because they live outside of Addis Ababa though they had follow-ups in St Paul hospital, and one of them drop out from participation because she was not able to come for the interview. The age range of participants was 30 to 55 years.

### **3.4. Epistemological and Ontological Considerations**

My epistemological position was interpretivism. In contrast, to the model of positivism the focus of interpretivism is on the understanding of the social world through an examination of the interpretation of that world by its participants (Bryman, 2012).

In this study, the experiences of mothers were subjective, unique and interpreted differently by each of the mothers. Interpretivism was relevant in this study as it helped to understand the point of view of participants through their direct involvement to the phenomenon (Bryman 2016).. Interpretivism is also found suitable epistemological framework for phenomenological approach as it enabled the researcher to analyse and interpret the experiences of participants. As indicated by Van manen (1990), the aim of phenomenological research is to translate the lived experience into words and meanings to achieve true meaning of the experience; which is consistent with Interpretivist paradigm. My ontological stance was social constructionism. In qualitative research, reality is viewed as socially constructed and findings are expected to consider subjectivity to a certain extent as the qualitative research approach does not intend to obtain absolute objective findings from the study (Swift & Tischler, 2010). The social constructionist position provided an opportunity to examine how social realities, experiences, and meanings are influenced by a range of discourses operating within the societal system (Samarin, 2013). Moreover, social properties are outcomes of the interactions between individuals, rather than phenomena ‘out there’, separated from those involved in its construction (Bryman, 2012). Therefore, social constructivist philosophical world view was preferable to understand the meaning of different dimension of perceptions and challenges of mothers in raising children diagnosed with autism.

### **3.5. Data Collection Methods and Procedures**

In this study, an in-depth interview was used as data collection method. An in-depth interview is one of the primary methods of data collection used in qualitative research (Bryman, 2016); it is interactive in nature and the material is generated by the interaction between the researcher and interviewee (Dey,1993, Bryman, 2012). Individual interviews are most appropriate in social research when the area of investigation involves gathering information based on peoples’ life experiences and feelings and information based on privileged, personal and sensitive issues (Descombe, 1998). Conducting personal interviews has its own advantages, that includes obtaining detailed information, keeping away misinterpretation of questions by making the interview language adaptable to the level of ability or education of the respondents (Kothari, 2004)

Individual interviews were chosen for the present study because it helps to get an in-depth understanding of the personal stories and experiences of each mother in raising a child with Autism. Issues around disability including autism are recognised as a very sensitive research topics involving emotional and social implications for the parents. Hence, individual interviews provided participants with high level of anonymity to talk about their experiences freely.

An in-depth semi structured interview guide was prepared in a way that addresses the objectives of the study. The guide was originally prepared in English and later translated into Amharic, the official working language of Ethiopia, for the convenience to conduct the interview assuming that the native language of participants will be mostly Amharic. The English version was prepared first to communicate the contents of the guide with the research supervisor. Back translation from Amharic to English was finally made by me and other language translators with the objective of

ensuring the clarity and accuracy of the questions of the interview. Open ended questions were used in the interview which gave participants the opportunity to tell about their experiences using their own words and expressions rather than forcing them to choose from fixed set of responses. This was helpful to acquire detailed data and make the study exploratory in nature. The questions were formed based on the interviews of other previous research's with similar research topic, and by discussing with research supervisor.

The interview guide consisted of two parts; the first sets of questions are set to gather information about the demographic data of mothers such as; parental status, age, academic qualification, marital status and demographic information of children such as; age of the child, gender, age of diagnosis of autism and educational level of the child. The second sets of questions explored the lived experiences of mothers in raising a child with autism by focusing on their perception and the challenges. The interviews were conducted in Amharic, which was the native language of participants and the researcher as well. The duration of the interviews was between 1:13 to 1:30 hours. The venues and time for conducting all the interviews were decided based on convenience for the mothers. Some of the interviews were conducted in the St. Paul hospital counselling rooms while others were held in the participants' home. The data from all participants were recorded using audio recorder. I also used a separate small notebook to mark down different emotional cues and feelings of mothers reflected during the interview.

### **3.5.1. Pilot Test**

A pilot study is one of the most appropriate ways to test some of the crucial factors of the research that is to be conducted. The pilot study needs to be checked as closely as possible to the real research. The choice of participants for the pilot study should also ideally be selected from the target population (Glesne & Peshkin, 1992). The interview guide was pilot tested with two mothers from similar population. Selection of respondents for the pilot study followed the same method as the selection of the main participants. Pilot interview were conducted to test; the research protocols, the appropriateness of the research questions and prompts in order to draw out detailed data, the suitability of the interview settings, the voice clarity of the audio tape recorder that was utilised for the data collection, and the estimated duration the interviews.

### **3.6. Data Management and Analysis**

The collected data were manually transcribed and later analysed by me. The interviews were held in a local language of participant, Amharic, and the transcription was made in English after carefully listening to the Amharic interviews. This was done with the best possible effort to reduce losing contents of each participants accounts and it was carried out after consulting the research supervisor. The transcribed data were carefully kept in a password protected personal computer which was accessible only by me and my supervisor during the study period.

Prior to the analysis of the data, the I performed transcription, coding, and theme identification. Data were read and re-read in order to help the me immerse in to the data and find some interpretive cues from the statements of participants. Then, the data were coded by highlighting text with different colours and making marginal commentaries that consists of paraphrased data, the links noted between the data, and my own preliminary interpretations. This step was repeated and several themes were identified based on the annotations made. The several themes were then

reordered, clustered, and connected to achieve a set of Seven final themes. After this, quotes that aligned with each theme and that depicted the essence of the experiences of mothers were selected. In the whole process of transcription, whenever I felt any confusion and misunderstandings, the I returned back to the audio recorded material and check for clarity and accuracy of the participants' speech.

There are various data analysis methods in qualitative research. For the purpose of this study Interpretive phenomenological Analysis (IPA) was employed. IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences” (Smith et al., 2009). Consistent with its phenomenological origins, IPA seeks to understand the meanings individuals attach to human experience, and is concerned with exploring experience in its own terms (Smith, Flowers, & Larkin, 2009), it is an approach dedicated to glean individuals' direct experiences through encouraging respondents to tell their own story in their own words – participants are considered the experiential experts. when researchers conduct IPA, they must focus upon the context-dependent life worlds of participants, contingent upon social, historical and cultural factors (Eatough & Smith, 2008). As such, IPA is not simply descriptive; the researcher is required to present an interpretive account of what it means for respondents to have such experiences, within their particular context (Noon, 2017). IPA has been used to explore such topics as the meaning that raising a child with autism has for parents (Jardine, 2008). Therefore, IPA was selected for the present study as it was the suitable method of analysing the in-depth meanings of participants experience. It also aligned to the theoretical and epistemological paradigms of the present study.

### **3.7. Reflexivity of the Researcher**

Reflexivity in qualitative research can be described as “disciplined self-reflection” and refers to the examination of the way in which one's own values and assumptions shape one's research. (Wilkinson, 1988,) In qualitative research, the researcher's position such as personal characteristics, gender and personal experiences may have an impact on the study. The researcher's background and understanding of the world affects the data collection and interpretation which reflects on the final conclusion of the study (Berger, 2013). By being aware of how personal positions influence the study, it is possible for the researcher to critically look at the role he or she has in the study. This plays a key role in expressing how the researcher adds value to the research and addresses his or her limitations in knowledge. Hence, clear communication of personal roles enhances the quality of the research study (Guillemin & Gillam, 2004).

My personal experiences and the fact that I was born and raised in the same culture with participants affected the process of my research both positively and negatively. It was a positive influence in that; I was familiar with the social, economic, and political context that the mothers were living in. My educational and work experiences was a positive influence. I am a psychologist by profession and I had few years of experiences working with families especially woman and girls from destitute social backgrounds in Addis Ababa, Ethiopia. These two backgrounds were advantages for me during the study period to understand the context of the study and to find participants easily. Moreover, conducting the research in my local languages was another significant advantage as it was an opportunity to understand the expressions, feelings and emotions of participants, to build trust and to open up and share their stories freely. In all the interviews, I

understand what the mothers were saying from, their speech, their expressions, emotions etc. Moreover, being a woman, was also an opportunity to easily interact and get their consent to participate in the study.

However, in selecting the research problem of this study, I sometimes acted from the preconceptions that I had about what the participants might possibly have encountered when raising a child with Autism in Ethiopian context, for example, I thought that they mostly may have had negative experiences and they may have faced stigma and economic struggles in their lives. However, as my research was phenomenological in nature, I had to be careful with my engagement with participants to avoid misinterpretations later. I tried to discuss this with my supervisor initially and I tried to use the concept of bracketing in the process. Bracketing originated within the phenomenology research tradition (Small,2001; Spiegelberg,1965), and it is a method used to mitigate the potentially deleterious effects of unacknowledged preconceptions related to the research and thereby to increase the rigor of the project. Given the sometimes-close relationship between the researcher and the research topic that may both precede and develop during the process of qualitative research, bracketing is also a method to protect the researcher from the cumulative effects of examining what may be emotionally challenging material. While bracketing can mitigate adverse effects of the research endeavour, importantly it also facilitates the researcher reaching deeper levels of reflection across all stages of qualitative research (Tufford & Newman, 2012)

When I first contact the two organizations to reach the mothers, I was told by the psychologists from the two organization to contact the mothers by myself, by taking their phone numbers from the organizations. However, I felt this process was against the mothers' privacy. Giving the phone numbers of mothers for a stranger, like me, was not ethically correct for me. Thus, I asked the professionals to make initial contact with mothers to ask their consent If I can call them. I also asked the psychologist to give me the opportunity to participate in the parent support group meetings to meet with the mothers face to face and get their consent for participation. I was able to attend the meetings. At the end of the monthly meeting, I gave briefing for mothers about the details of my study; the objective, the estimated duration of the interviews and data management process, and I was able to get their consent to participate in the study. I also submitted formal letter of cooperation that was obtained from the University of Stavanger to both of the organizations and received the approval to commence the research.

Conducting the pilot interview also helped me to evaluate the research questions and my own interviewing style. At times, I found it difficult to remain neutral as a researcher and there were circumstances where I was more emphatic to the mother's expressions and feelings. However, I made efforts in the subsequent interviews to be conscious about it and I tried my best to separate my role as a researcher while also being open to the fact that dilemmas may arise in the process. I also wrote a remark on my notebook after conducting the first two interview to see how I did it and what I could have done better. I also had some struggles When I performed transcription, because some participants use a word that was sometimes difficult to find equivalent term in English. However, to ensure accuracy of my translations, I consulted and shared some of the translated interviews transcripts to few language translators and academicians that I know who speaks both of the languages, and I subsumed their feedback in the process. Sometimes, It was challenging for me to decide when to use bracketing in this study but it was not impossible to do.

I tried to be aware of my preconceptions and suspend my judgments considering that each person might have their own specific stories to tell and their experiences may not be as I expected. I tried to convince myself to listen attentively to what the mothers had to say and at the same time I tried to stay open to the mothers' experiences during the interviews.

When analysing texts, I sometimes found it difficult to move away from mere description of mother's speeches and I felt some guilt about interpreting what the mothers were saying, as if I am exaggerating or undermining their words. However, I was aware that interpretation is required for IPA method and I tried to maintain a balance between my roles in the process of the study.

### **3.8. Trustworthiness and Authenticity**

In qualitative research, the issue of trustworthiness is equivalent to the terms of validity and reliability in quantitative research (Morrow, 2005). Trustworthiness or truth value of qualitative research and transparency of the conduct of the study are crucial to the usefulness and integrity of the findings (Cope, 2014). According to Pilot & Beck (2014), trustworthiness or rigor of a study is the degree of confidence in data, interpretation, and methods used to ensure the quality of a study. In each study, researchers should establish the protocols and procedures necessary for a study to be considered worthy of consideration by readers (Amankwaa, 2016). Although most experts agree trustworthiness is necessary, debates have been waged in the literature as to what constitutes trustworthiness (Leung, 2015). Criteria outlined by Lincoln and Guba (1985) are accepted by many qualitative researchers. They first outlined 4 criteria; credibility, dependability, confirmability, and transferability; and they later added authenticity (Guba & Lincoln, 1994) which appear to be more relevant to constructivist/ Interpretivist research paradigm. This study adopted three of the criteria and followed typically used procedures.

**Credibility:** Credibility refers to the degree to which the research represents the actual meanings of the research participants, or the "truth value" (Lincoln and Guba, 1985). In the present study, the credibility was demonstrated by using appropriate and organized, and standard qualitative research methods and procedures, and by identifying a study area and context that was familiar for me, i.e the home country of the researcher, which provided an opportunity to better understand participants experiences and to avoid language barriers during interviews which increased the truthfulness of findings. I attempted to maintain subjectivity by applying the concepts of bracketing in phenomenological research. whenever emotional experiences arise from mothers during the interview. I tried to maintain balance between the therapeutic feelings I had for participants and my role as a researcher. Again, there was no monetary or immediate gain for the mothers for their participation in the study which increases their tendency to share their true stories and increase the credibility of results.

The concept of peer debriefing proposed by Lincoln & Guba (1985), was applied. I worked closely with other researchers and my former university professors and friends in Addis Ababa and discuss with them my results and interpretation of the data and participants' experiences. These deep conversations included bracketing and debriefings helped me to render decisions of quality and to improvement some areas. In addition, member checking (returning findings to participants to determine if the findings reflect their experiences (Creswell & Miller 2000; Padgett 2008), was performed by the researcher through confirming the data and the interview transcripts with the participants following each interview. Also, the themes and major findings obtained from the data

were validated with the participants to avoid possible misinterpretation and manipulation of data by the researcher.

**Dependability:** Dependability refers to the consistency and reliability of the research findings and the degree to which research procedures are documented, allowing someone outside the research to follow, audit, and critique the research process (Sandelowski 1986, Streubert 2007). I addressed the issue of dependability by documenting and providing detailed methodology on data collection analysis, and the results of the study, and also by providing detailed reflection on myself as a researcher. Reflexivity was carried out to reduce bias and to increase transparency of the study (Guba, 1981, Malterud 2001).

**Transferability:** refers to the degree to which the phenomenon or findings described in one study are applicable or useful to theory, practice, and future research (Lincoln and Guba 1985), that is, the transferability of the research findings to other contexts. This concept is similar to generalizability in quantitative research. Often, it is not possible, or desirable, to demonstrate that findings or conclusions from qualitative research are applicable to other situations or populations (Shenton 2004, Drury et al. 2011). In phenomenological research, the goal is to arrive at a description of the universal structure of a phenomenon. Because it is a unique phenomenon under investigation, it is not expected that the findings will transfer to other phenomena. However, if the phenomenological researcher has been successful, any individual who shares that lived experience should be able to recognize the model or description (De Chesnay, 2014). As phenomenological research is less concerned with objective statements about theories or trends, the issue of transferability to other contexts or similar situations might not be fully achieved. Having this in mind, I attempted to address transferability through describing the context of the study in the methodology section including the presentation of ; the study area, demographic characteristics of participants and methods of data analysis and Interpretation.

**Confirmability:** is the degree to which the findings of an inquiry are a function solely of the subjects (respondents) and conditions of the inquiry and not of the biases, motivations, interests, perspectives and so on of the inquirer (Guba, 1981). This is similar to credibility, where confirmability has particular implications for studies that provide policy recommendations. The issue of confirmability was addressed in this study by reporting my ontological and epistemological positions as a researcher in order to make sure that the results emerged from the experiences are of mothers than those of the researcher. I also performed self-assessment and reflection on the process of the research. Such reflexivity does not necessarily demonstrate a removal of bias, but does help explain how the researcher's position can manifest in the research findings while still yielding useful insights (Shenton, 2004).

**Authenticity:** Although the concept of authenticity was proposed by Guba and Lincoln (1989), the criteria and techniques to demonstrate it has yet to be fully considered. The existing criteria for evaluating authenticity include fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity, some of which overlap with critical paradigms (Lincoln & Guba 1985). Generally, authenticity is the extent to which researchers fairly and completely show a range of different realities and realistically convey participants' lives (Polit & Beck, 2014). I attempted to ensured ontological authenticity by improving, expanding and elaborating and participants' individual experiences and demonstrated fairness by completely showing various

lived experiences of participants. In addition, I selected appropriate samples for the study and I provided them with a rich, detailed description.

### **3.9. Ethical Considerations**

Ethical considerations are one of the most pertinent parts of the research. The present study followed the ethical consideration for social research and qualitative research by addressing issues of informed consent, confidentiality, safety and power relations.

Initially, the proposal of this study was submitted to Norwegian Social Sciences and Statistics Data (NSD) for assessment and obtained Ethical approval to commence the research project. In Ethiopia, National ethical clearance for research is not yet fully developed. Even though there are various levels of ethical approval, the majority of them are applicable for large scale projects instead of Masters study at individual level in Ethiopia (Cochrane, 2015). Thus, the researcher used the NSD approval for this study. The organization that were contacted to reach the mothers, were provided with a formal letter of cooperation in reaching participants. Participants, who were mothers of children with Autism, were provided with a detailed description of the nature of the study. An oral and written Informed consent, in the local language, Amharic, was obtained before conducting any of the interviews including interviews of the pilot study to create trust and good working relationship with participants. The mothers were told in their local language that participation in the study was completely voluntary (Homan, 1992). The respondents were also informed to dropout or refuse at any stage of the study and to withdraw the data they supplied for whatever reasons (Bryman, 2016).

Confidentiality and privacy of participants and their personal and demographic information was kept secret and was not shared by a third party without their consent (Bryman, 2016). This was performed using pseudonyms for the demographic information's of mothers. Sometimes the names of children were mentioned by mothers when sharing their experiences, thus, the names of the children have been replaced with pronouns in presenting the results to keep the confidentiality of their children. Participants in this study were highly vulnerable social groups, as a woman, and as a mother of a child with a disability. Due to this, they might feel the hierarchical power differences between I and them because it is the researcher who has power over the researched within most qualitative research relationship (Fontes, 1998).

However, in the present study I attempted to minimize power differences through introductory talks and briefing the details of the study to mothers; including confidentiality and privacy issues, in order to encourage mothers to tell about their experiences and personal stories and feel safe during the entire interview. Also, familiarity of the participants context including their language, helps me to reduce power issues and create collaborative, trustful and friendly relationships.

### **3.10. Limitations of the study**

The researcher sought three limitations in this study. The first limitation was that I conducted the research by taking only the perspective of mothers, as they were considered to be the primary caregivers and most affected by their children's disability. However, the study would have been more reliable and informative if the perspectives of father were included. The second limitation was that samples were drawn only from a single city, Addis Ababa, due to the limited time frame



and resources for the study, therefore, I was not able to capture the experiences of other mothers who reside outside of Addis Ababa as they might have different personal stories.

The third limitation was related to the effect of the COVID 19 global pandemic on the research process. I travelled to Ethiopia for data collection and I was stranded, hence, there have been some inconveniences to hold face to face supervision with the research supervisor due to health and safety concerns. Thus, most of the communications were carried out using online platforms such as email exchanges. This might affect the quality of communication between researcher and supervisor to some extent.

Therefore, it would be recommended for future researchers to expand on the area of this study by taking the perspective of both parents, with larger sample size by including participants from different areas in Ethiopia. This could help to understand the needs and challenges of both parents and broaden the existing body of knowledge on experiences of both parents raising children diagnosed with autism.

## CHAPTER 4

### 4. FINDING AND ANALYSIS

The major purpose of this study was to investigate the lived experiences of mothers raising children with autism spectrum disorder (ASD) in Addis Ababa, Ethiopia. The study focused mainly on the perceptions and challenges of mothers in raising children with autism. In this chapter, the findings from the data are presented combined with data analysis. This chapter is classified into two sections. The first section is about the socio-demographic characteristics of mothers who participated in the study. The second section presented different themes that emerged from the collected data. Six themes emerged from the data that seeks to answer the research questions under this study. The first theme is about the perception of mothers about the cause of autism in their respective children before receiving the diagnosis of autism, the second theme explores the psychological wellbeing of mothers, the third theme present the challenges in their respective family unit, the fourth theme deals with economic strains , the fifth theme is concerned with social stigma &labelling, while the last themes deals with the difficulty in accessing facilities and services. Different subthemes emerged under the first, second, third and fourth themes. Each of the themes are discussed and summarized according to the objectives of the study. In each of the themes, summaries and quotes from the interview, and my interpretation were included.

#### 4.1. Sociodemographic Information of Mothers

This phenomenological study involved, six mothers ranging in age from 30 to 55. All the mothers were biological mothers of children diagnosed with autism living in Addis Ababa. The ages of the children ranged from 2 to 17 years old. The average diagnosis of children with autism was 3.3 years. Out of the six mothers, two of them were college educated women in the field of Marketing and Management, two mothers completed 12 grade while the other two mothers had completed grades 8, 10. Among all the mothers, one of them has a professional job as a manager while the other mother had temporary work as a cleaning lady. The remaining four mothers were housewives who has no job. Regarding marital status, three of them were divorced while the remaining three mothers were married living with their families.

Mother	Pseudonyms	Age	Education	Occupation	Marital status	Number of Children	Age of a Child having ASD	Child's ASD diagnostic age
1	Elilta	40	8 <sup>th</sup> Grade	Temporary /cleaning lady/	Divorced	1	11	3
2	Rediet	40	Diploma in Managment	Manager	Divorced	3	13	2 years and 8 months
3	Zayd	31	12 grade completed	-	Married	2	6	3
4	Nebat	30	10 <sup>th</sup> grade	-	Married	2	6	4
5	Aisha	55	12th grade completed	-	Married	3	16	6 years
6	Yodit	35	Diploma in Marketing	-	Divorced	1	8	3

#### **4.2.The Themes identified about the Lived Experience of Mothers Raising children diagnosed with Autism**

The lived experience of six mothers in raising their children diagnosed with Autism was captured in six thematic areas which are presented below.

##### **4.2.1. Mothers' perception about the causes of Autism in their Children**

Having noticed several unusual behaviours in their respective children, all the mothers faced a great deal of confusion and concern for days and weeks and eventually formed their own perception about the cause of their children disability. Majority of the mothers perceived that the cause of their children's disability was due to the possession by the devil spirit, or evil eye spirit (locally known as 'Buda': a spell cast by the eye, inflicting injury of misfortune on the person being looked). Some of the mothers consulted with family members, neighbours and friends to find out and to confirm their perceptions about the possible causes of the children's disability and they were mostly told their children's symptomatology was related to spiritual causes; an evil eye or a devil spirit. Two of the participants were uncertain causes of the children's disability, though, sometimes they had perception that the cause of their children disorder might be related to underlying medical causes.

For instance, Zayd, mentioned that, at first, her perception of the child's disability was that the child has been possessed by either devil spirit or evil eye belief. She said: "At that time, I felt that my child had been possessed by an evil eye spirit. My neighbours and my families also said that my child was sick spiritually, like evil eye belief (Buda) "

The perceptions of some mothers were influenced by advices and explanations they received from family members and neighbours. Family members attempted to give explanations about an evil eye spirit and how it could possibly be a cause for the children's disability. This made mothers to confirm their initial perceptions.

“I had a gut feeling that my child might be possessed by an evil eye spirit.... My mother gave me three reasons why she said my child had been possessed by an evil eye spirit. First, my child is handsome and I usually did not cover his face when I took him outside of the home so he might be exposed to buda spirit, Second, he repeatedly fall down from his bed while he sleeps, and third, he likes to eat soil while he plays outside. Then, I felt that my mother was right.” Nebat

Similarly, Elilta had a perception that her child's disability was due to the possession of evil eye spirit. But she also had consultations with few of her neighbours about the child's condition. She was told that her child's disability was due to spiritual causes. At times she had mixed perceptions; she thought her child's condition might also be related to 'madness'.

“... The first thing that comes to my mind was, an evil eye spirit. I know about it because, I am a 'church person'. If it was not evil eye spirit, my child might be insane....I was seeking an opinion from my neighbours, and they repeatedly told me that my child has been possessed by evil eye spirit.” Elilta

Another mother, Aisha, initially had a different perception of her child's disability. On one hand she perceived the inactivity of her child very positively, as a good temperament and good behaviour of her child; but on the other hand, she felt that her child's lack of socialization and loneliness, was caused by a devil spirit. She then confirmed her perception of the child's disability by consulting her neighbours especially of the elderly people.

“At first, I was delighted because my child was so calm, .... At times went by, I started asking myself, why my child was so lonely? I heard about the devil spirit and I was a bit suspicious that was my child's problem. I told to my neighbour and she said that my child might be taken over with devil spirit.” Aisha

The other two mothers Rediet, and Yodit were not certain about the causes of the children's disability. But they felt that it might be due to underlying medical causes. They did not seek information or advice from the extended family and neighbours about the child's problem instead, they decided by themselves to visit the hospital hoping to get a scientific explanation for the child's problems.

Rediet said that "Initially, I could not tell what my child's problem was, but I thought my child has health problem, may be hormonal imbalances, I did not know exactly.”

Yodit also describe her perception this way: “I had the impression that my child has some health problems. ... I did not tell anyone about my child's condition....I took him to paediatrician”

The above interview extracts with mothers revealed that the initial perceptions of most of the mothers about their children's disorder was related to spiritual causes such as devil spirits and evil eye spirit. Also, most of the perceptions of mothers were influenced by family members, neighbours and friends.

#### **4.2.1.1. Seeking Treatment**

The data indicated that the treatment options for the children were decided jointly by the mothers and by family members, and neighbours. The family members had influenced the treatment options some of the mothers. Those mothers who attributed their children's problem to spiritual and traditional causes applied spiritual and traditional treatment options whereas, the other mothers who sought scientific explanations for the child's problem, applied modern treatment options. However, one of the mothers were inclined to the traditional treatment options as well, as she was influenced by the family members.

Nebat said that "My neighbours said it might be Buda spirit....I started to use different cultural and spiritual treatments, since my child was 3..... I used these treatments for one year, but it did not help to improve my child situation"

Another mother, Zayd, has got a recommendation from the mother-in-law to take the child to the witchcraft by which her mother was against it. She mentioned that the child's disability was a cause for a dispute between the extended family due to a lack of consensus to decide on the treatment options. She said: "My mother in law strongly suggested me to take my child to the witchcraft to get spiritual treatment....However, my mother did not allow me to do that.....She rather advised me to take the child to the mosque."

Similarly, Elilta applied the Holly water treatment for long time because she believed that her child will get a complete cure and her neighbours also recommended her to take him to the church. However, the treatment did not improve her child's behaviour.

"I knew the evil eye spirit could be healed with holly water...They also suggested me to take my child to the church for holy water treatment.... he was treated with the holly water until he was 9 years old....But he continued to be restless and aggressive..." Elilta

The other mother, Aisha was initially hesitant to apply traditional treatment as she was not certain about its effectiveness to improve her child's condition. But she did not want to reject the recommendation given from her neighbours and eventually took her child to the mosque. She said: "..... My neighbours and my family suggested me to take him to the mosque, ....I was a little bit hesitant, but I did not want to reject their suggestion"

In the above interview extracts of mothers, I contemplated, the treatment options used by mothers were related to traditional and spiritual construction of Autism and influenced by the extended family and neighbours. From all participants, only two mothers based their perception and treatment on scientific assumptions though they were influenced by family members lately.

#### **4.2.2. Mothers' psychological wellbeing**

One of the challenges reported by all the mothers was psychological problems. Mothers had encountered several psychological challenges since the diagnosis of Autism in their respective children. The psychological challenges of mothers can be generally categorized into initial and ongoing psychological problems. Initial emotional encounters are the experiences of mothers

during the first few days or months following the diagnosis of the child while ongoing psychological problems are the mothers' constant worries and concerns about their children..

#### **4.2.2.1. Mothers initial emotional reaction to the diagnosis of Autism**

Mothers demonstrated a range of emotions immediately following the diagnosis of a child with autism. The most prominent reactions all the mothers similarly went through were sadness, despair, shock, confusion and/or feelings of loss, and difficulty of accepting the diagnosis.

The initial diagnosis came as a shock to Rediet. Hearing a new word, a condition she had never heard of, was an immense shock which was accompanied by several further actions. While she talked about the period of initial diagnosis, she seems to be reliving the moment of shock, repeating herself saying how new and shocking the word 'autism' was:

“When the physician told me that my child has Autism, I did not know what he was talking about. On that day, I paused for a minute and then asked the doctor what autism is. ..I was very shocked. Returning from the hospital, I just get back home and I cut my hair from the root. I was so sad for weeks. Rediet

Another mother, Zayd, encountered emotional disturbances such as worry and insomnia following the diagnosis of her child which leads to mental and physical health deterioration. Prolonged interrupted sleep, change in eating habits which was loss of appetite, and reduced self-care leads her to a significant health problem.

“...I had many sleepless nights. I was very unhealthy since the day of my child's diagnosis. I had a kidney infection and I was urinating blood for some days. This was all because I did not take care of myself, I was not stable mentally” Zayd

On the other hand, moments of difficulty accepting the diagnosis of the child was so intense for mothers. Most of the mothers faced moments of disbelief as they were not aware of autism, not even for its name. Some of them attempted to clearly understand the nature of the child's condition by asking professional for more clarifications. One of the mothers. Rediet's mentioned her struggle to accept the diagnosis of her child. she seemed to have needed a moment to digest what she heard at that time. She also requires verification for what she heard before she could accept such an alien word as a diagnosis about her child's condition. She said:

“It was a difficult for me to accept what the physician was saying. Then I asked the doctor, what Autism mean? ..... My first prayer was asking God to put my life and my child's life to an end. If he is not a normal child, why do I and my child stay alive?” Rediet

Likewise, Elita mentioned her experience of disbelief as accompanied by suicidal attempt “I tried to commit suicide when I received the diagnosis of my child. You know! I was told by the physician that it is a lifelong condition. It was a challenge to welcome this in to my mind”

On the other hand, Yodit had not been able to voice clearly if she was either in disbelief or denial. She felt that her child's condition was due to a mistake made by physicians during the time of

delivery of my child. She was not interested to hear the diagnosis of the child and she was looking for an alternative explanation for the child's condition.

“I thought my child is not a human being, it felt like my child was a different creature. I said to the doctor, my child does not have autism; my kid is normal. It must be a mistake. ....Maybe there was a problem in delivery room, my child might have shortage of oxygen!” Yodit

The other mother, Nebat, struggled to receive the results. she thought that children who have mental and developmental problems including Autism are usually characterized by facial features such as broader faces and mouths, narrower cheeks, flatter noses, and a shorter philtrum and her child has no such facial features; diagnosis as the results seemed in contrary with her assumptions.

“...I thought children who have this kind of mental problems are characterized by facial features....But my child looks normal. He has no facial abnormalities. He is a handsome child! So, he cannot be an Autist..... I just rejected what the physician was telling me and I left the hospital.” Nebat

The above statement by Nebat, reflected that she had misconception about developmental disorders. She associated autism and other disorders in children with only facial characteristics. She assumed that children who have normal facial structure are not supposed to have mental health issues. I reflect this assumption is due to the lack of knowledge and awareness about autism and its features. I also had the impression that the phrase "....But my child looked normal. He had no facial abnormalities. He looked handsome! So I thought he was not Autistic..." seemed to convey that she was denying the child's disorder by justify that her child looks handsome.

#### **4.2.2.2. Ongoing Emotional encounters**

In addition to the emotional encounters experienced for few weeks and months following the diagnosis of their children, mothers experienced ongoing stressors that created a constant and recurring emotional disturbance. Mostly, mothers had depressed feeling, hopelessness and anxiety; because of their permanent worry about the future of their children.

Elilta Said: “My child’s future is the main thing that worries and stresses me coming to my mind permanently. Sometimes, I cried all day and night when I think that my future life is filled with adversity.”

For Rediet, to some degree, the way professionals informed her about the child's disorder was what worsened her worry and frustration for the future. Autism was communicated to her as a lifetime disorder that is devastating and strenuous to improve and change. She said the fact that the disorder is incurable made her anxious about the future of her child. She said: “I feel anxious when I think that my child will be dependent on me for the rest of his life. What made me more frustrated was that the doctor said autism is a lifelong condition that is difficult to improve” Rediet

In addition, some mothers indicated their concern that their children will not be taken care of properly by others if they no longer can be there for their child, and their frustration whether their

children will have the same opportunities in life like that of a typically developing child such as carefree childhood, education, independence, and marriage life.

For instance, Zayd expressed her frustration about the future of her child this way:

“When I think my child future, I feel very sad. what if I will not be there for him? ...will he be married?.....But I do not know if he can get any support, education, from different sources If I no longer can be there for my child. I am the only one for him.” Zayd

Another mother Nebat, expressed her concern related to how the scarcity of welfare provisions in the country either from government bodies or civil society organizations could create feelings of helplessness and frustration on the mothers.

“When I think of the future, I get depressed and frustrated.....The government or other organizations cannot support him. Sometimes it’s better that your child has passed away and you burry his dead body than worrying about what will happen to him every second of your life.” Nebat

Besides, Yodit said that “sometimes I prefer not to think about my child's future. What will happen to him if I am not there? It is stressful to think about this every day.”

Unlike other mothers, Aisha’s permanent worry was the reproductive health issue of her son. Her concern was that her child might not be able to recognize his bodily changes and he does not know how to deal with his sexual desires. She insisted that intensive sexuality education at the level required by teenagers should be designed for children having Autism to save them from committing a social error such as undesired touching.

“I am always worried about the reproductive health of my child. I started to think about this because, one day I observed my son ejaculating on the pillow and I felt so sad because he might not be aware of his own biological changes...our children should be educated in some way " Aisha

From the entire interview extracts of mothers, I had the impression that the emotional encounters following the diagnosis of their children with autism, were so difficult to deal with. The experiences were filled with a paradox of emotions etched on the mothers’ face. Most of the mothers had a brittle tone of voice, they were doleful and they had down casted eyes filled with tears. Some of them reported suicidal thoughts which implies the magnitude of the heartaches and pains they had gone through. I consider that the emotional conflicts of mothers may arise from lack of knowledge about autism, differing level of acceptance of the child’s disorder, lack of support systems, perceived fear of stigma, and mostly from the belief that the disorder is incurable.



### **4.2.3. Mothers and the family unit**

The other challenge reported by all mothers was the problems encountered in the family unit; mainly the difficulty to deal with the marriage life and other children without disability at home. In addition to caring for the child, managing the needs of the husbands and other non-autistic children at home was quite demanding for most of the mothers which in turn abandoned marital relationships and relationship patterns with siblings/non autistic children/ in the family.

#### **4.2.3.1. Marital Relationships**

Mothers have run into various arguments with their husbands since the diagnosis of the child. Often times, they usually start off as a parent who learns first about autism and get involved early in the children's disorder. They mostly become devoted researchers, and attentive advocates to their children, whereas, the role of husbands was more like an 'outsider; when it comes to the issues of children and mostly claimed authority than responsibility. Husband's lack of responsibility, violent behaviour and lack of cooperation among parents and extreme emotional reactions were associated with significant marital tension. Most of the mothers indicated three main sources of disagreement with their respective husbands. The first was husband's difficulty understanding and accepting the child's disorder and lack of commitment to support both the mothers and the children. Second, the grievances of husbands due to reduced care and treatment they received from their wives due to the overwhelming demands of children and mothers' lack of connection with husbands. Third, mothers were blamed for the disorder of their children by the husbands and the extended family.

For instance, Elilta highlighted that she was blamed and insulted by her husband for the child's disorder during the first few months of the diagnosis of her child. She said:

“...My husband argues with me all the time. He always blame me for our child's problem. He always shouts at me that I am sick not the child. He thinks that my child's disorder was because of my fault; it was because I didn't take a good care of him and mistreated the child.” Elilta

Another respondent, Zayd, further indicated she was blamed by her husband and her mother in law and she was avoiding contacts with the extended family for long as she didn't want to face the pain and mistreatment from the family. She said: “My husband and his family still blame me for my child's disorder....They consider that I am the cause of my child's problem. I wish someone can tell them about my child's problem; I wish they knew what Autism means.”

Also, responsibilities were mostly left on the mothers' shoulder which eventually build resentment and feelings of exhaustion on mothers and made them give less attention to their husbands. Moreover, the burden of caring for husbands was considered by mothers as something that requires their extra energy and time. Mothers felt caring for their husbands was as burdensome as caring for the children. For some mothers, prolonged argument and fight with the husband resulted in divorce.

“Sometimes I did not cook lunch or dinner for my family because I am exhausted taking care of my child. It was burdensome to balance caring for my child and my husband. ...My husband was like a child, he did not understand me and the nature of my child’s problem,...our disagreement persisted for long and we got divorced after we stayed for 5 years in marriage.” Elilta

Furthermore, differences surrounding various decisions about the children created marital tension between couples. The mothers’ desire to explore new options for the child was in contrary to the husbands’ interest to stick to conservative principles. Mothers tend to search for information, services, attend trainings and read books to better help the children. However, husbands were not supportive when it comes to mothers’ active involvement in different activities.

Rather, they wanted mothers to stay at home all the time. This breed communication problems followed by recurring conflicts.

“My husband attempted to reject my idea of taking a training in the hospital where my child has follow-ups. That time, we argued for long as he was against my idea....He is always against me when I tried to come up with something good to our child. He always wants me to stay indoors and wait for a miracle from God.” Nebat

Similarly, Zayd, had dispute with her husband because of differing interests towards the child. Although, she had strong desire to discuss with her husband about their child’s condition, she was rejected and ignored by her husband. She recalled a moment that occurred at the child’s school and how her husband reacted towards her. She said:

“...I told my husband what happened in the school,...My husband always warned me that I would be facing a mess if I did not keep my child indoors. He said, just leave my child, he is very young to start school, don’t take him here and there” Zayd

For some mothers like Rediet, lack of communication and misunderstanding was a real concern than financial difficulties and all the burdens of raising an autistic child. She emphasized that only having the financial capacity to raise a special need child was not a guarantee to keep her marriage.

“Sometimes only having financial capacity does not guarantee to maintain the marriage. Money is never unimportant but If there is misunderstanding among couples and if they do not support each other, they might end up in divorced. That is my own case in my family.” Rediet

Similarly, Yodit explained how her marriage was strained and later ended up in divorce because her husband was ignorant to the child since the time the child showed symptoms of Autism. She extremely felt the rejection from her husbands to the point that she felt she was a lone parent to her child. . She said: “We argue more, my husband experiences cycles where he avoids being with me and my child. ...He was not willing to support us when he found out my child was diagnosed with Autism when he was two”

Unlike other mothers, Rediet and Aisha had positive experiences with their husbands before and during the first few years of the diagnosis of their children. Their husbands were encouraging and

willing to understand the nature of the children's disorder, to share the mothers' worries, and to provide the necessary support for the child. However, for Rediet, the positive bond between her husband was weekend and faded through time, which ended up in divorce.

“At the time when my child was diagnosed with Autism, my husband used to read some information about Autism from web sources. He was caring and supportive. ...I lost my patience to deal with his new character and we end up in divorce” Rediet

In contrast, Aisha spoke about the enduring positive relationships with her husband. She described her husband as a humble and cooperative, professional health worker having busy work schedules; but always looking forward to spend time with their child out of his busy working hours. He always monitors the progress of the child and encourage Aisha to take determination to support their child.

“My husband is a health professional and he is so supportive. He is so happy to spend time with our child. He always encourages his improvement. We always try to support each other to teach our child everyday life skills such as pouring water, serving food, washing dishes.” Aisha

The above interviews with the mothers revealed that, mothers had significant challenges to deal with their husbands. All the mothers experienced marital strain and divorce due to the presence of a special need children in the family. The influence of the extended family also contributed for lack of communication among couples.

#### **4.2.3.2. Reactions of Siblings/Non autistic children/**

The other major challenge of mothers in the family unit was the difficulty to give appropriate care and attention to other siblings. From the interviewed mothers, four of them have more than one child who needs their care and treatment. For all the mothers' it was difficult to balance the care and treatment they provide to non-autistic children at home due to the time demands and constant supervision required for the child with autism. Mothers felt guilt and shame because they thought that they are were not fulfilling the expected role of a mother in their communities. Giving more attention to autistic child also creates feelings of rivalry, resentment and jealous in siblings which negatively affects the mother- child bond with non-autistic children in their respective families. For instance, Zayd said:

“I could not give attention to my other daughter, my son was the only focus for me, ...My little daughter felt that I ignored her and I did not consider her as my child. I felt that I could not keep the balance between my two children because everything that is done is around him.” Zayd

Likewise, Nebat had struggled in balancing care and support between her child with autism and her little daughter. The words that she heard from her daughter was heart-breaking for her, and she didn't expect her daughter to speak in a way that explained her jealous towards her child having Autism.

“... one day my little daughter said ‘mummy, you would take a good care of me if I was Autistic child like my brother’ I was very shocked to hear this statement from my little daughter...I am constantly seeking for the right balance between my two kids” Nebat

Moreover, for Aisha and Rediet the reaction of siblings was something that could take all their energy. Aisha mentioned that the siblings needed the support of mothers for the things that they can do by themselves. Hence, she sometimes had to manage the conflict between siblings due to the need for equal treatment with the autistic child.

“... but sometimes it is so stressful to handle their disagreements. ..They said I love him more than them. Sometimes if I feed him with my hand, they want me to feed them as well but they are able to eat with their own hands. It is stressful to deal with all the demands.”  
Aisha

Another mother, Zayd was not capable to maintain balance in caring for siblings which forced her to experience family separations. She sent her daughter to the extended family with the intention to ease her parental stress and to better support her special need child. Separating with her daughter was a very painful experience that left her with feelings of depression and powerlessness.

“My daughter complained that she was not loved and cared like my son. ...I also sent my daughter to my mother’s place to live with her. I was so depressed that time and I felt that I was not a good mother, I felt so powerless that I could not care for both of my children.”  
Zayd

#### **4.2.4. Economic Strains in the Family**

The other challenge reported by mothers was economic hardships in raising their children with autism. All mothers mentioned that they encounter significant economic burden in their respective families. Based on the data, the economic problem indicated by mothers were related to two main reasons I.e Mothers labour force participation and Mothers inability to afford different costs of living.

##### **4.2.4.1 Mothers’ participation in the labour force**

Caring for children with autism immensely affected mothers’ opportunity to get hired for new jobs and to maintain their existing jobs. Except one mother, all mothers were housewives, staying at home caring for their child with autism. Few mothers had no work while others quit their work to take care of their children. One of the respondents, Elilta explained her experience painfully; how hard it is to raise a child with autism particularly the challenges of a mother to secure job opportunities. She expressed the difficulty faced by mothers to generate one’s own incomes either by getting hired for job or in the worst scenario by seeking financial support from others.

“Raising autistic child is a hard work. It is difficult to be hired. You know what! You cannot even beg on the street having such kids. Because you cannot let the child be seated on one place with you and beg for money, they are restless kids, they are difficult to handle ” Elilta

The other respondent, Yodit was not able to maintain her professional job that she secured right after graduating her studies because of her child: “I used to work as a marketing expert, but right now I stopped working because of my kid”

Nebat also had similar experience of losing her job. She said she that there is high financial strains in her family because she quit her job and her husband is the only one working and supporting the family. She said: “I quitted my previous job after I gave birth to my child having Autism. I should be home for my child. My husband’s salary is not adequate for the life we are leading now but I had no option”

On the other hand, lack of social support and absence of child care provisions from the government negatively influenced mothers’ participation in the labour force. As primary caregivers’ mothers were the major sources of care and support for the children. For instance, Zayd said: “...It has been 4 years since I quitted my job and stay at home because I cannot give my child to someone else and go to my work. You know! child care facilities are almost unavailable in the city”

Also, mothers had to fit their work around the needs of their children, or find ways to self-employment or freelance work situations to offer the flexibility required to balance child care and employment. While seeking jobs that allowed for flexibility, sometimes mothers had to take low paying jobs and negotiate the condition of their children to different employers. The perception of employers towards the mother’s capacity and commitment to their job was mostly underestimating because a mother having autistic child was perceived as incapable to balance childcare and work life demands. Elilta described her experience of losing her job due to the lack of confidence by the employer about her competence and work integrity.

“ I used to work as a cleaning lady. One day, my employer suddenly told me that he hired other women in my position...He said I should stay home for my child than coming to work and the newly hired woman can work in a full-time basis. I explained repeatedly that I was a good fit for the work, ....but he told me to quit the work starting from that day.”  
Elilta

From all the interviewed mothers, only Rediet, a mother of 13-year-old son, said she has a job as a manager which gave her a flexibility to manage her time, energy and cost to care for her child. Hence, she had no financial problems when it comes to caring for the child but she highlighted how the sufferings could hit hard to raise autist children at all. She explained: “....Me and my husband work as professionals. We have good income. ...I do not have financial difficulties; that makes it much better to raise my son.....but it is still tough to care for an autistic child.”

#### **4.2.4.2. High Cost of living**

Due to the financial problems in the household, mothers reported that they had constraints to cover the various expenses such children’s school fee, speech therapy, house rent and dietary expenses for their children. The financial constraints especially, the inability to pay for school was a major challenge for mothers. Zayd said:“It is too costly! I had no option but to pay 155 Euros, the amount would have been very hard to afford for my husband if he would not get the support from his brother.”

Some mothers had to struggle to sustain the lives of the family, and cover the costs associated with house rent, household expenses and the school of children. Some of them felt the burden shouldered on their husbands to cover all the expenses of the household because they were not financially contributing to the household.

“My husband pays 4000 Birr monthly for house rent, we have to eat, we need to pay for the school of my child! It is really hard for us to cover all these! I have no job, It is my husband who covers all expenses with his salary, He always left without money at the end of the month! We are struggling to survive in this way of life” Nebat

The other economic concern mentioned by mothers was the costs associated with behavioural therapy, particularly of speech therapy for children. Due to very high price and few options available for speech therapy, it was unthinkable for mothers to help their children get speech therapy. They mentioned that they only know one speech therapy centre in Addis Ababa. As the price was not affordable by most of the mothers, they children were not able to benefit from the therapy.

“I paid two times for my child’s speech therapy...I would say the price is so unfair. I should pay 10 Euros per hour. It is really expensive! I can pay for one or two times but I cannot afford that in a monthly basis.” Aisha

Another mother, Yodit indicated substantial economic challenges related to dietary intervention to the child. Her child is low in some nutrients due to limited food intake and food preferences. He sensitive to taste, color and texture of foods. Hence, she struggled to provide the best diet for hmm in order to relieve symptoms of ASD and improve his behavior.

“..... When it comes to food, there are so many food stuffs that my child should not eat and it costs me more money..... I know which food could make him restless or calm, but it is hard for me to afford all these kind of food as they are expensive in the market.” Yodit

Further Yodit indicated that she always put an effort to build her knowledge of autism and different dietary interventions. She mentioned that she asked for information from her families and sometimes she tried to grasp some information from web sources.

“..... No, I learned this through my experience with my child and also my brother gives me information from web sources about autism in children. There are different food types that I should feed him or not, sometimes I tried to goggle about it by myself.”Yodit

Analysing at the speech of Yodit, I was surprised that, Yodit was the only mother who brought up the idea of dietary intervention to children with Autism. She indicated the role of diet to relieve symptoms of autism in her child. This may arise from her knowledge about autism that she gained through different strategies. Also, the phrase “...I should feed him or not” gave me the impression that she felt it is her duty, as a mother, to provide her child with a balanced diet but she fall short of cash to fulfil her duties.

Taking the whole explanation Yodit regarding diet and costs associated with it, I had two conflicting impressions, on one hand, the knowledge of mothers is a good foundation to provide quality care and provision to their children. On the other hand, I contemplated that Having the knowledge, without the capacity to grant might put an extra strain on mothers because it can enlarge the differences between what is possible and impossible to do for the child. If they have the knowledge, they might be pressured to fulfil all the needs of the child without having the financial capacity; This is to say, the more knowledgeable the mother, the more strained she will be.

#### **4.2.5. Social Stigma and Labelling by the community**

Another challenge reported by all the interviewed mothers was social stigma and labelling which was one of the most difficult aspects of public encounters in the social life of mothers. In most cases, the social stigma and labelling arise from the extended family and relatives, the community and professionals and different service providers. The multifaceted stigma deterred mothers from seeking various services, from participating in their communities and from enjoying the same quality of neighbours as their families, friends and neighbours and It affected mothers lives more than caring for children with autism. Negative attitude and misconceptions about their children disorder accounted for the limited social interaction and non-acceptance of mothers and their children in the society. Children were avoided by their peers because the disorder was perceived as transmittable disease. Flilta said:

“My neighbours and the community believed that autism is transmittable disease. The attitude of people towards my child is so unfair.. He cannot play with other children. ...I do not know how to change people’s mind!! ..... People always does not want to see my child and said I have to lock my son indoors.” Elilta

Also, Yodit, described her concern due to the nonacceptance of her child in different public affairs and exclusion from different social activities. She indicated the shame, disapproval, criticism she encountered in public places, because of the behaviour of her child. She said:

“All eyes are on me and my child when he screams on the streets. He cannot play, and socialize with his agemates. My child is human except he has developmental delay.”

Even though some mothers had strong desire to socialize and to get acceptance by the society, fear of negative reaction and rejection by the society was the prominent factor that hinder their involvement in different social circles. Some mothers struggled to build maintain social interaction with and respect the cultural traditions and expectation of a social life in their community. However, it was difficult for them because other people do not understand the problem of their children. Yodit said: “There are some social activities I should go because it is part of our culture, such as funerals.....When it is so important I have to leave my child alone, lock him in the house. I have no choice.

In addition to the negative attitude by the community, lack of knowledge and understanding about the children’s disorder by the extended family limited mothers’ participation in different social activities including family gatherings because of the fear of negative reaction from relatives.

“I do not take my child to different social activities including our family meetings because people do not understand his behaviour and they do not want to see him make trouble in front of them... so I prefer to stay at my home.” Nebat

Added to their limited social interactions, mothers and their children were labelled by the society. Mothers were labelled as ‘bad’ and ‘negligent mothers’ for raising their children with no discipline and control while the children were labelled as ‘Sick’, ‘naughty’ or ‘deaf’ whenever they display inappropriate behaviour in different public places, mainly in the neighbourhood, on the bus and on the streets.

Rediet mentioned the social stigma that she encountered in the transport facilities. She said: “Sometimes people give me offensive comments on the streets and in the transport.... One guy said to me, “why didn’t you discipline your child while he was young, you are a bad mother”

Another mother, Elilta was also labelled as a ‘bad mother’ by the society. Her child was also insulted by the neighbours which creates a dispute between the neighbours and her for long time. “My neighbours called my child ‘sick’ ...If my child misbehaves in the bus, people shouted at me that it is because I didn’t discipline my child, I am a bad mother, failed to raise a good mannered son.” Elilta

Moreover, some of the mothers explained a very painful experience they encountered with professionals and service providers, such as school of children. Finding a school for children was a challenging experience for mothers as it was mostly associated with stigma. Fear of rejection by schools made mothers to hide the child’s disorder and eventually lead the children to drop out of school when the child’s diagnosis was identified by the school professionals. Hence, mothers were blamed because they hide the child’s disorder when they initially try to get school admission. Zayd, said that:

“I was trying hard to look for a school for my child.... the school principals refused to admit my child when I told them he cannot speak .... But you know, you shouldn’t tell them that your child has Autism.....I had arguments with school principal because I hide my child’s disorder before. Zayd

Mothers also reported the social stigma they faced while using different facilities in public, such as the public transport, and house rent. It was a huge challenge for mothers to find and maintain house rent because of their children.. Mothers mentioned that the disgrace from lessors and tenants were difficult experiences. They also had to change different accommodations and pay increased costs. Aisha spoke about the social stigma she encountered in the transport this way:

“One day, I was in the bus with my child, after a while the driver told me to get off the bus because my child will break the mirror of the bus, I refused and shouted we won’t get off the bus before we reach our stop” Aisha

Similarly, Elilta mentioned her experience of changing house rents for long time because of her child, and due to the unfair treatments of the landlords and tenants. She said “It is always hard for me to find a flat to rent. I have changed 9 flats since the diagnosis of my child. I often hide my child’s disorder from lessors because they will not rent me if they know.” Elilta



In addition, the social stigma from the community created feelings of anger, resentment and inferiority to the mothers. The responses of mothers to the social stigma differed from one mother to the other. Some of the mothers said they tried to be tolerant and non-responsive for the negative reactions from people and they tend to avoid getting in to problems with others because of their children. From all the mothers, Elilta and Nebat reported that they tend to deal with the social stigma with tolerance; by ignoring the negative reactions and avoiding situations that creates feelings of stigma Elilta said;

“Whenever I use a bus with my child, I tried to ignore people who reacts badly until I get off the bus....’ I tried to be patience with what people say even though I am burning inside.”  
Elilta

Likewise, Nebat tends to avoid situations that trigger her emotions, and she tends to give a blind eye for the stigma and unfair treatment from people towards her children than explaining people about her child’s situation or getting in to unexpected conflict with them. She recalled her experience in her child’s school as an example:

“I was very annoyed and sad to the unfair treatment of my child by the care givers at schools. I out cried and immediately took my child away from the center. I did no further actions as I did not want to engage in conflict....I felt so broken.” Nebat

On the contrary, other mothers such as Rediet, Aisha, Yodit and Zayd were more likely to confront the social stigma through creating awareness about autism, they tend to fight for themselves and stand firm to be a voice for their children, sometimes ended up in quarrel and fights for the right of their children. Aisha explained about her experience while using a public transport/bus/ this way:

“...I was very angry! I told the driver that I will be responsible for my child and I shouted at him that I won’t get off the bus! I can pay if my child destroys anything! You know! I should tell people about my child’s condition; he has the right like other people on the bus.”  
Aisha

Likewise, Rediet described that she has a strong desire to inform people about autism. She strongly argued that mothers should not be blamed for their children behaviour in public because the behaviour of the child is the impact of the disorder not the mother’s failure to take responsibility. She said: “...I don’t care about what other people could say....These children are how they are...Sometimes, I intentionally tell to people that my child is Autistic and I tried to explain what it means and how the child might behave.”

Similar sentiment was shared by Zayd, who said that she attempted to inform people that labelling her child is inappropriate in any circumstances. She said: “...But that day I attempted to inquire why the school principal treat my child unfairly. I told her that was not right to label my child. He can learn like other kids .”

Sometimes mothers were considered by the society as if they are using their children as an excuses to get priorities in different services. Yodit described her experience of quarrel with others because

of her child. she was blamed and insulted by people while trying to get priority to use a public transport, and she ended up in fight due to people's negative reaction towards her and her child and misunderstandings occurred in that situation.

“...Once, I was late to his school and I asked people a favor to let me go to the front in a que. A person from the que insulted me, as if I was using my child as reason to sneak the que....It could be lack of knowledge. Yodit

Yodit continued that, sometimes she has a difficulty to balance people's recommendation and her own desire regarding what to do for her child. she explained a paradox of emotions regarding socialization of her child. She was perplexed whether she has to follow her own way or respect what the community expects from her regarding her child's socialization.

“When I keep my child at home, people blame me as if I isolated my child from others and I am bad mother; when I let him to go outside, people mistreat him, other kids have no interest to be with him, I do not know how to manage both?”

From the above interview with the mothers, I reflect that the social stigma encountered by mothers was multifaceted. This might be due to lack of awareness by the general public towards children having Autism. When some mothers mentioned the social stigma from school community, my impression was that lack of awareness was apparent even among the educated segments of the society such as teachers, and other school professionals. Schools which provide inclusive education to children with autism tend to reject admission of children and they were not supportive to the mothers and their children. Even though mothers had strong desire for equal treatment and acceptance from the general public, the social stigma was the biggest hinderance for them not to exercise equal social status with others.

I also had an impression that there were misconceptions about the underlying causes of children misconduct. The society has a deep-rooted assumption that only bad parenting could result in the children's misbehaviour or only undisciplined child could behave inappropriately in public which was not the case for children with Autism.

#### **4.2.6. Difficulty to Access Facilities and Services**

Another major challenge of mothers was difficulty to access different facilities and services for their children. All the mothers were constantly worried about lack of facilities such as schools, autism centres and therapeutic centres, particularly of speech therapy. Mothers reported that their children were underserved due to scarcity of resources, services, and trained professionals to support their children and the whole family. Especially lack of schools and autism centres were pressing issues for all of them. As indicated by mothers, they encountered lack of facilities and services both before to the diagnosis and after the diagnosis of their children.

For instance, Elilta said:

“...the available hospitals were not easily accessible for me. ...I had to travel a long way from where I live to get to the hospitals. It was physically draining....on the other hand, I

was trying hard to look for a school or autism centre for my child. It was really a hard work to find. It was always my worry” Elilta

Furthermore, it was tough for mothers to secure a place in Autism centres because there were only two autism centres operated as local NGOs in Addis Ababa that supports children and their families. Due to limited capacity and resources of the centres, it was unthinkable for mothers to get a place for their children and they either had to wait for long waiting lists to get admission in one of the autism centres or they need to look for alternative solutions by themselves.

“My child was registered to join autism centre but he was registered on the waiting list on number 463. It means there were 462 children waiting before him to join the centre. I could not believe that a lot of students do not have the opportunity to get admission in school and autism centres.” Rediet

In an attempt to find a way for the child to join autism centres, a mother had to fight hard and sometimes use different strategies to secure a place. Yodit talked about her struggle to get admission in autism centre and the strategy she used to secure her child’s admission:

“It was challenging to find a school or autism centre; these services are almost absent for our children! I got a place for my child in one of the two autism centres because I knew the owner, and she helped me in the process.” Yodit

Moreover, Mothers indicated that education at mainstream governmental schools is generally free but registration, uniforms and educational materials such as books incur costs. The schools receive children based on parent’s report and sometimes based on information from authorities. However, main stream schools with inclusive education program for children with Autism are very few in number and securing a place for a child in a limited mainstream school is described as ‘tough’ by the mothers. It also influences mothers from participation in the labor force. Aisha said:

“Government schools are free....you can register for free but We need schools for our children!...number of schools are very limited and also the schools had full admissions. That is my everyday concern!.....otherwise, it is hard to say a mother can work while her child stays at home.” Aisha

Besides, mainstream schools were not designed for special needs education. There was substantial lack of educational aids and trained teachers, and culturally appropriate instruments for children. Nebat spoke about absence of special needs education facilities. “I was not able to find a school or autism centre for long. Then I took my child to a mainstream school but they had no special facilities for autistic children such as assistive devices, and special need professionals. ”

Further, available mainstream schools lack appropriate care and treatment for children. Mothers reported their children were abandoned by the unprofessional treatment and lack of care and supervision from the school community which causes grievances and disappointment between mothers and professionals.

“One day, I saw my child was eating a stone in the school playground. I was very shocked because the school teachers and caregivers were not watching over my child.... I was so angry with the negligent treatment of the caregivers towards my child.” Nebat

Based on the above interview extracts of mothers, I reflect that mothers had a serious of challenges to access services and facilities for their children. Particularly, lack of schools and autism centres were critical issues for mothers. Mainstream schools were not designed for special need children. Hence, Mothers struggled to deal with poor school systems that involved complicated admission issues in one hand and unprofessional treatments of their children by school staff on the other hand. Also, scarcity of childcare provisions impacts mothers’ labour force participation.

## CHAPTER FIVE

### DISCUSSION

This chapter presents the major findings of the study in relation to the research questions and discusses the results in light of reviewed literature and ecological system theoretical framework. The main purpose of this study was to explore the lived experiences of mothers raising children with Autism spectrum disorder. To investigate the lived experiences of mothers, the researcher focused particularly on the perception and challenges of mothers raising children with autism. In this section, the two-subsidary questions 1a. What are the perception of mothers about the causes of autism in their children before the diagnosis 1b) what are the challenges of mothers in raising children with autism? were answered based on the findings of the study.

#### **What are the perceptions of mothers about the causes of Autism in their children before the diagnosis?**

This research question was delivered to specifically understand the perceptions or belief of mothers about the causes of autism in their respective children before they receive the diagnosis of autism. The findings indicated that after noticing several unusual behaviours in their respective children, most of the mothers, except a couple of them, believed that there was a spiritual risk that had led to their children's symptoms, or deviance in behaviour and communication. Most of the mothers believed that their children has been possessed by a devil spirit and evil eye spirit (locally known as 'Buda'; which is defined as a spell cast by the eye, inflicting injury of misfortune on the person being looked, and it is usually associated with certain distinct groups of people, often based on gender or kinship links ( Finneran, 2003). These spiritual beliefs about the child's symptomology are similar to the findings of studies from other parts of Ethiopia and around of Africa (Tilahun, Hanlon, Fekadu, Tekola, Baheretibeb, & Hoekstra, 2016; Mashudat, et.al ,2013; Bakare et.al 2009; Gona et.al 2015), which showed the supernatural explanation for autism including witchcraft, evil spirits and curses, enemies, and action of the devil, and evil eye by parents and other segments of a society. However, this finding is in contrast to other western studies conducted in UK (Russell & Norwich's, 2011), in US (Harrington, Patrick, Edwards, and Brand, 2006) and in Israel (Shaked & Bilu's, 2006), where the majority of parents reported scientific explanation as the underlying cause of autism, participants in their study mentioned that they are not aware of the exact causes of autism but they mentioned biological or environmental causes including immunizations, genetic predisposition, labor complications, genetic inheritance, head trauma and organic defect in the brain and viral infection during pregnancy as possible causes for their children's developmental disability.

From my perspective, the differences in the results of African and Western studies could be explained by the influences of culture, education and available facilities (economic status). As many African societies are traditional societies with lack of modern education, people are more likely to held unto the traditional and spiritual explanation of Autism. In contrary, in the developed western countries the society have better education and they are more likely to attribute the explanations to scientific causes and understand the nature of the child's disability by means of scientific methods and principles. Also, countries have sufficient trained professionals and

facilities that can provide adequate information for parents about the causes, behavioral manifestations, and the treatment options of autism

The results of the study further showed that the perceptions of mothers were influenced by extended family members, neighbours, and friends which in turn affects the mother's decision-making and choices around utilization of treatment for their children with autism. Most of the mothers reported that they consulted with neighbours and extended families to seek advices and to confirm their perception regarding the possible causes of the children's developmental disability. The information that mothers received from family members and neighbours was a spiritual explanation as a cause of autism like devil spirit and evil eye belief (Buda). Hence, mothers who consulted family members and attributed their children's disability to spiritual and traditional causes applied spiritual and traditional treatment options such as Holly water, Quran and bible prayers, and treatments from traditional healers. Mothers who had sought scientific explanations for the child's problem, were eventually, influenced by the attitude of their families to apply traditional treatment options. The reason for mothers to be influenced by the perception and choices of others might be because mothers' lack of knowledge affects their tendency to seek professional assistance and may result in resorting to using the other people's experiences to provide a home diagnosis of the child and treatment for the child (Glazzard & Overall, 2012; Anthony, 2009; Riccio, 2011; Shyu, Tsai, & Tsai, 2010).

### **What are the challenges of mothers in raising children diagnosed with Autism?**

This research question was intended to find out the challenges that mothers faced in raising children diagnosed with Autism. The findings of challenges as presented in the result session will be discussed in relation to the thematic areas of; psychological wellbeing, mothers and the family unit, economic strains, social stigma and labeling and difficulty finding services. Mothers in this study reported multifaceted challenges in their lives, however, social stigma and labeling, and lack of facilities, services and support systems were the most pressing, social stigma being the main issues, for mothers which will be highlighted in this section.

One of the challenges reported by all the mothers was psychological problems. All the mothers reported their experiences of several initial and ongoing psychological problems. At the time of diagnosis of their children, mothers passed through challenging moments followed by various reactions when discovering that their children are diagnosed with autism. All of them reported a range of emotions reactions such as sadness, despair, shock, confusion, feelings of loss, and difficulty accepting the diagnosis. Consistently, Samadi and McConkey (2011), found similar results from Iran stating that parents' immediate reaction after their child's diagnosis with autism is shock and devastation. Studies on African parents by Nyoni and Serpell (2012), Anthony (2009), and Balfour (2007), in Zambia, Ghana, and South Africa respectively, also indicated that African parents experience challenges ranging from frustration, pain, confusion and doubt in the diagnostic period. Further, the findings of this study indicated that, most of the mothers were clueless about autism, not even for its name, and they associated Autism and other mental and developmental disabilities with only facial features or 'facial autism', I, e broader faces and mouths, narrower cheeks, flatter noses, and a shorter philtrum etc. they believed that children who have mental and developmental disorders always have these facial features, unless otherwise, they have normal development. Some of the mothers were not convinced with the results of the diagnosis because

their children have normal facial features, hence the diagnosis led to feelings of confusion and disbelief by the mother. Other studies also indicated that, most families with an autistic child have little awareness about autism or its implications (Glass, 2001) and this limited knowledge of autism by parents led to initial reactions of denial, fear, and shock during and after diagnosis (Hoogsteen & Woodgate, 2013).). The other psychological challenges reported by mothers were feelings of depression, hopelessness and anxiety due to; permanent worry about the future of their children, the demanding role of parenting a child with autism, and the incurable nature of the disability. This is similar to other the findings (Estes, Munson, Dawson, Koehler, Zhou and Abbott, 2009; Estes et al., 2009).

The main recurring fret that affects the psychological wellbeing of mothers was, a permanent worry about the future of their children. They were concerned about their children will not be taken care of when they no longer can be there for them, they had frustrations whether their children will have the same opportunities in life like that of a typically developing child such as carefree childhood, education, independence, and marriage life. The frustration of most of the mothers was due to the lack of formal and informal support systems such as childcare provisions in the country. Similar result was found by (Gray, 2002), who indicated that one of the main source of mothers' psychological distress is, role to being the parent of a child with autism, concerns about the future of their children because of the failure of children to recover, plus their increasing age. Moreover, Morgan (1988), indicated that the stressors of parents that accumulated overtime together with the absence of adequate resources and support may lead to depression and burnout.

The other finding of this study was the challenges of mothers in dealing with the family unit; mainly the difficulty to deal with the marital relationships and other children without disability at home. In addition to caring for the child, managing the needs of the husbands and other non-autistic children at home was quite demanding for all the mothers which in turn abandoned their marriage and relationship patterns with siblings/non autistic children/ in the family. This is similar to the results of studies by (Lee, 2009; Meyer, Ingersoll and Hambrick , 2011).

Except one mother, all participants encountered marital strain and divorce which occurred mainly because of the difficulty of their husbands to understand and accept the children's condition, lack of communication and commitment to support both the mothers and the children, mothers lack of attention to husbands due to overwhelming demands of the child with autism, the blame of mothers by husbands and the extended family for the children's disability. Moreover, mothers were devoted researchers, and attentive advocates to their children, whereas, the role of husbands was more like an 'outsider; when it comes to the issues of their children and mostly claimed authority than responsibility.

Other study from U.S (Myers, Mackintosh, and Goin-Kochel, 2009), also found similar results of marital strain among couples of children with autism due to prolonged arguments, husband's denial about the child's autism, multiple demands of caring for the child and husband's avoidance of coming home. The study in Australia by (Higgins, Bailey, and Pearce 2005) also indicate similar findings of marital strain and lower levels of marital happiness among couples. However, this finding is in contrary to the results of Noregian (Lundeby and Tossebro ,2008) and Canadian

studies (Scorgie & Sobsey, 2000), which found that couples are more likely to live together and develop personally transformative and satisfying relationships despite the considerable and sustained stresses involved in parenting a child with a disability. The variation observed in these countries may be due to different structure of welfare systems found in each country that can possibly influence the family system and functioning, difference in resilience among families, and the number of children in the households.

In addition to marital strain, all mothers struggled to provide appropriate care and treatment to other siblings/non-autist children/ at home due to the time demands and constant supervision required for the children with autism. This resulted in the feelings of exhaustion, guilt, shame, and powerlessness by the mothers because they felt that they are not fulfilling the expected role of a mother in their communities. Mothers' focus towards the children with autism also created feelings of rivalry, resentment and jealousy in siblings which negatively affected the mother- child bond with non-autistic siblings in their respective families. This finding is similar to other literatures (Ozonoff et al., 2002; Autism Society, 2011).

The other findings from the study indicated that mothers experienced considerable economic challenges in raising children with Autism. Economic strains that occurred in the family was related to lack of mothers' participation in the labour force and the high cost of living. Mothers' career opportunities were immensely affected because they were the major sources of care and support for the children as alternative child care provisions in the country are scarce. Hence, mothers had challenges either to take up new jobs and sustain their previous jobs. Sometimes they seek support from the extended family to take care of their children, but it was not permanent source support for them. Apart from one mother, all participants were housewives; providing the necessary care and support for their children with autism at home. This finding is supported by other studies from U.S.A (Gray, 2002; Bayat, 2007) Where parents of children with Autism reported a negative impact up on their career after having a child diagnosed on the autism spectrum in which mothers reporting moderate to serious limitations on their careers, and denied any opportunity for outside employment due to their child's disability . More specifically, parents reported having to put their careers on hold or switching to a career in special needs (Bayat, 2007) or simply experiencing greater levels of work stress when compared to other parents (Smith, Hong, Mailick Seltzer, Greenberg, Almeida, & Bishop, 2010); similarly studies in China, McCabe (2007), and in Jamaica Angela (2013), found that mothers of autistic children change their work habits in order to better meet their child's needs; in many cases quitting their jobs and shifting to full-time advocacy.

Furthermore, mothers in this study reported their challenges to cover the costs associated with various expenses such as children's school , speech therapy, house rent and dietary expenses for their children. The financial constraints especially, the inability to pay for the school fee of their children was a major challenge for mothers as they are not able to afford the costs. This finding is supported by studies of (Wang et al. 2012) that indicated the economic burden and high household expenses of parents children with autism.

The other finding that was highlighted by all mothers as devastating experience was the influence of social stigma and labelling from the community. As indicated by all participants, social stigma and labelling was one of the most difficult aspects of public encounters that affects the lives of



mothers, even more than caring for an autistic child. Social stigma and labelling arise from the extended family and relatives, professionals and different service providers and the larger community. The multifaceted stigma deterred mothers from participating in their communities, from seeking various services, and from enjoying the same quality of life as the other parts of the society. Similar to the findings, Gray (1993; 2002) indicated that autism has uniquely stigmatizing aspects for parents due to the extremely disruptive nature of autistic symptoms, the normal physical appearance of autistic children, and the lack of public knowledge and understanding regarding the nature of autism. Also, a Mexican study by (McHatton and Correa,2005), found that mothers experienced significant discrimination as a result of culture, disability of the child, and a combination of culture and disability.

Negative attitude and misconceptions about the children's disability accounted for the limited social interaction and non-acceptance of mothers and their children in the society. Children's developmental disability was sometimes perceived by the society as 'contagious disease', and children were excluded by their peers from social activities whereas, mothers face disapproval, and embarrassment in public places, because of the disruptive behaviour of their children. All the mothers had strong desire to socialize, to get acceptance, and to respect the cultural expectations of social life in Ethiopian community by taking part in different social circles, however, fear of negative reaction and rejection from others was the prominent factor that hinder their involvement in different social circles and attain equal social status with others. Some mothers struggled hard to build and maintain their social interactions to get positive attitude by the community. However, it was difficult for them as people do not understand the problem of their children. Similarly, studies indicated that, in Africa, a child with a disabling neuro-developmental disorders is seen as a mark of shame on the family by the society therefore, individuals with Autism and their families are often faced with negative attitude, avoidance, rejection, as well as negative and offensive comments which lead families to hide the affected child from the society; at times, It can leave parents feeling locked at home and it is a major source of stress for parents (Mashudat et.al, 2013) (Allik et al.,2006; Blacher & McIntyre, 2006).

Furthermore, mothers indicated that the social stigma from the educated segments of the society such as teachers, school principals, and other service providers such as transportation service providers and lessors was the most difficult experiences for mothers and their children. Finding school admission for children was the most challenging aspect as it was mostly associated with stigma from the school community. Most often, children were mistreated by the school teachers. Consistent with this, Lewis (2009), indicated that disabled children do not go to school because teachers are not patient with them in the mainstream schools.

Also, mothers were labelled by the society as 'bad mothers' and 'negligent mothers'; for not disciplining their children and for not fulfilling the role of mothers 'expected' in their community. Likewise, children were labelled as 'sick', 'naughty', and 'deaf' due to their behaviour. All participants reported the influence of deep-rooted societal assumption that; only bad parenting could result in the children's misbehaviour or only undisciplined child could behave inappropriately in public. This findings are compatible with a study by Ellen and her colleagues that was conducted on Somali parents of children with autism living in the UK, which found that children with autism were labelled and stereotyped as 'sick', 'naughty', 'different' and parents were blamed for not controlling them, leading to social rejection and isolation. (Ellen, Fox , Aabe,

Turner, Rai, and Redwood, 2018). In addition, (Gray, 2002), added that absence of visible markers of Autism may contribute to stigma, faced by parents and children as unknowledgeable others may perceive a person with Autism, who looks “normal,” to be acting voluntarily in ways that violate social norms.

Besides, it was found that mothers used different mechanisms to deal with social stigma and labelling from the community. The responses of mothers to the social stigma was different from one mother to the other. Some of the mothers indicated that they attempted to manage the social stigma with tolerance; by being non-responsive and by ignoring the negative reactions from people and avoiding getting in to problems with others because of their children, whereas, some others reported they tend to defy the social stigma through creating awareness about autism, they fought for themselves and stood firm to be a voice for their children. Similar results were presented by other studies which indicated the use of different mechanisms by parents of children with disability to deal with different circumstance; such as isolation, restricting public encounters, ignoring or reacting against such judgments through engagement with their children and with the environments surrounding their children; and confiding in their own parents, siblings, friends, and certain medical professionals regarding private matters (Hays and Butauski,2018; Alareeki, Lashewicz, Shipton, 2019).

Finally, the other frequently reported challenge by mothers was difficulty accessing different facilities and services both before the diagnosis and after the diagnosis of their children. All the mothers were constantly worried about lack of facilities such as schools, Autism centres and therapeutic centres, particularly of speech therapy. Mothers were not able to support the academic and social progress of their children due to scarcity of resources, services, and trained professionals. The most pressing need of mothers were schools and Autism centres for their children. As indicated by all mothers, there were few mainstream schools and two Autism centres in Addis Ababa that operated as local NGOs to support children with autism and their families. Due to limited capacity and resources of these centres, it was unthinkable for mothers to secure a place for their children. Also, it was found that available mainstream schools were not designed for special need children in terms equipment’s, professional staffs, and ethical standards. Hence, mothers struggled to deal with poor school systems that involved unfair admission rules in one hand and unprofessional treatments of their children by school staff on the other hand. This experiences are similar with other reports from parents in Jamaica (Angela, 2013), Egypt (Gobrial et al. 2018; Omar 2014; Gobrial 2012; Jenkins et al. 2010; Okasha 2005) and Ethiopia (Amakelew, Daniel and Fasikawit,2000) that highlighted difficulty of children with disabilities, particularly children with autism and parents to access educational facilities, respite care, and other services. It could be argued that, compared to the western countries with trained professionals, better access to child care facilities and available intervention services, African children have limited access to the few available services (Bakare & Munir, 2011; Bello-Mojeed et al, 2011). Consequently, the non-availability of child health care and education services and the poor access to the few available ones which are concentrated in the urban areas makes it difficult for families of African children with Autism to get the necessary intervention and education programs (Mashudat et.al, 2013).

In conclusion, the findings of this study revealed that children diagnosed with Autism are not the only one suffering from the disorders; rather, mothers of these children experienced multidimensional challenges on a daily basis that is mostly underestimated. Moreover, most of the

experiences of mothers raising children with autism were extremely demanding and filled with various influences from the family, professionals and the larger community.

### **5.1. Implication of Ecological System Theory**

The theoretical frameworks that guided this study was ecological system theory developed by Bronfenbrenner(1979). This theory describes several systems (microsystem, mesosystem, exosystem, macrosystems, chronosystems) that influence and are influenced by the child's behaviour and the most important system is the family which includes parent-child relationships. The present study considered the interactions within and across these systems in order to better understand the lived experiences of mothers raising children diagnosed with Autism. According to Bronfenbrenner (1979), the influences of microsystems are bi-directional in that not only do the parents affect the child's beliefs and behaviours, but the child also impacts the behaviour and beliefs of the parent. The influence of the microsystem; the immediate environments within which the child and family operate in; was reflected in the lived experiences of mothers. The microsystems were the influence from the extended family, marital relationships, siblings of children with autism in the family.

First, the presence of the child with autism by itself, was the primary factor that influence the psychological and social wellbeing of mothers. As indicated by the all mothers, they had gone through difficult times both before and after the diagnosis of their children with autism. This resulted in various psychological and social challenges and requires mothers to redefine their role as a parent. The other influences that existed in the microsystem, was the extended family. In their attempt to understand the nature of the children's disability, most of the mothers mentioned that they consulted with extended family members to find the underlying causes and treatment options for their children. Even though, they had their own premises about the cause of the children's disability, the information gained from family members influenced them to be convinced that the cause of their children disability was spiritual, like devil spirit and evil eye. Another system that can be counted as microsystem influences were marital relationships, sibling, and peers. Almost all the mothers cited the presence of a child with autism as being the cause of marital strain and negative reaction from siblings (non-autist children) in the family. Mothers reported how the children with Autism restricted their attention and time to other non-autist children at home due to their children with Autism needing more attention and supervision. This led to feeling of rivalry, resentment and jealous among siblings, and marital strain among parents. Moreover, children were discriminated by their peers from various social activities which affects their engagement in various social interactions and made their family to feel stigmatized. Therefore, all the above microsystem influences each other and impacted upon the lives of mothers and the family.

At mesosystem level, the layer that encompasses the connection between two or more microsystems structures of the child (Bronferbrenner,1979), most of the findings of this study indicated the interaction of mothers with different systems. One of the interactions that appeared to be impacting the experiences of mothers was quality of communication with, schools' teachers, transport service providers, and lessors. Mothers' experiences with professionals was mostly negative which resulted in various emotional reactions by the mothers and prevents children from

using different services. For instance, mothers said that, they had communication problems with school teachers, even with a couple of mothers mentioning they were insulted by school principals in their attempt to get admission for their children. As a consequence, mothers had a general attitude of mistrust towards both the school teachers and other service providers. Likewise, one participant mentioned her challenges to find house rent, as she had difficulties to communicate with lessors, and tenants because of the behavior of her child. The other mother also mentioned her problem to use transport as she was not able to communicate with the driver. The quality of all these interactions influenced how the mothers' function in the mesosystem level and impacts the overall development of their children as well.

At the exosystem level, the larger social system in which the child does not function directly but impacts the child's development, the influence are more global factors such as the educational system, government programs, health services, etc. The most notable ecosystem impact indicated by the mothers was difficulty finding the appropriate facilities and services for their children such as schools, autism centers, speech therapy services. Mothers were not able to support the academic and social development of their children in a best possible way due to scarcity of resources, services, and trained professionals. In addition, the available mainstream schools were not designed for special need children and they lack trained professionals. Further, most of the mothers discussed lack of child care provisions from the government and the corresponding financial burden on their family. Except one mother, all the mothers spoke of how their careers had been negatively impacted because of their children in that they were not able either to take up new jobs or sustain their previous jobs to meet the significant needs of their children.

It could be argued that if facilities and services were available for children, mothers would be more enabled to participate in the labor force and support the overall development of their children and their family.

Macrosystem level is related to the influence of cultural values, attitudes, customs, and laws. The influence of macrosystem was mentioned several occasions by mothers under this study. They said that one of the devastating experiences for them and for their children was social stigma and labelling. This may speak to the larger cultural context which affected the lives of mothers in different ways. At first, most of the mothers' perception towards the cause of the children's disability was based on spiritual explanations which is the reflection of the larger cultural and traditional context that they live in. Even, those mothers who attributed scientific explanation as the cause of the children's disability were driven by others to follow the cultural and traditional mindset. Hence, the treatment options followed by mothers were also consistent with the culture and lifestyle of the family that include the use of holly water, Quran prayers, and traditional healers. This reflected how it could be difficult for a mother to build individualistic lifestyle and to hold her own perception, thought, feelings, that is free from the influence of the larger cultural context.

In addition, as indicated by all participants, social stigma and labelling was the other aspect that reflect the macrosystem influence. Social stigma from the extended family, the community, professionals and different service providers was the reflections of the larger culture and attitudes of the society. Mothers were stigmatized and by the society because of their children disruptive behaviour in public, and mostly because they did not fulfil the role of mothers 'expected in

Ethiopian culture', by caring, by disciplining their child, hence, they were labelled as 'bad mothers' or 'negligent mothers'. Children were labelled as 'naughty' and 'sick' because the society believe that being naughty or sick is only the result of lack of parental control towards the children. Moreover, all the mothers and their children were excluded from different social circles due to social stigma and rejection from the community. This exacerbate isolation from relationships and various resources in the mesosystem, and decreases the opportunities for children with Autism to socialize with new places, peer groups, and activities in the microsystem. At times, isolation and lack of acceptance by the community leave parents to stay locked at home which led to psychological challenges. Therefore, the macrosystem has a set of interconnected impacts on the wellbeing of the mother and the whole family. It could be argued that, some of the experiences of mothers are the results of being in a particular culture; if mothers lived in a different culture, may be western culture, they would not have encountered similar cultural influences like they did in Ethiopian culture.

Lastly, chronosystem, is the way environmental impacts over time affect the individual. The chronosystem influence for mothers in this study, could be the long-term effect of divorce of parents on the development of their children with autism and the wellbeing of other siblings and the mothers as well. The other chronosystem influence which occurred in the life transition of mothers, was having a child with unexpected illness (autism) in their life span which is non-normative (unexpected) type of life transition for them and their family.

In conclusion, ecological system theory provided a context to understand the influence of multiple and interacting contexts, such as family, service providers, community and the larger society, on the holistic development of children and the corresponding impacts on parents.

## **CHAPTER SIX**

### **CONCLUSION AND RECOMMENDATION**

#### **6.1. CONCLUSION**

This phenomenological study explored the lived experiences of mothers raising children diagnosed with autism in Addis Ababa, Ethiopia. The main purpose of the study was to investigate the lived experience of mothers in raising children diagnose with autism by focusing on the perceptions and challenges of mothers. The experiences of Six mothers were explored using in-depth interviews. The results showed that mothers' perceptions towards the cause of Autism was attributed to spiritual explanations such as devil spirit and evil eye possessions before the diagnosis of Autism in their respective children. The perception of mothers towards the cause of autism was immensely influenced by extended family members and neighbours which in turn affects their treatment decision for their children.

The diagnosis of Autism in their children, poses several challenges in different areas of mothers' life and they struggled with various roles and responsibilities beyond the mothers of a typically developing children. The main challenges of mothers found in this study are psychological problems of mothers, difficulty to manage the family unit, economic strains, social stigma and labelling and difficulty to access various facilities and services for their children. All mothers experienced several initial and ongoing psychological problems. At the time of diagnosis of their children, mothers passed through challenging moments followed by range of emotional reactions such as sadness, despair, shock, confusion, feelings of loss, and disbelief as they were not aware of Autism before the diagnosis of their children. The main recurring fret that affected the emotional health of the mothers was a permanent worry and concern about the future welfare of their children; whether their children will have the same opportunities in life like that of a typically developing child such as carefree childhood, education, independence, and marriage life. The frustration of the mothers was mostly due to lack services and facilities such as alternative child care provisions, schools, Autism centres and formal and informal support systems in the country. Also, raising children with Autism immensely affected the functioning of the whole family and imposes several problems including; marital strain and divorce, weakened mother-child bond with non-autist siblings, and limited participation of mothers in the labour force which created a significant financial burden on the family.

Moreover, as primary caregivers to their children, mothers struggled with multiple demands to fulfil their parental roles and at the same time, support the acceptance and engagement of their children within the family and wider community. Multifaceted social stigma and labeling from families, service providers, professional and the rest of the community was the most devastating experiences that impacted both the psychological and social wellbeing of the mothers and their family. Lack of awareness and negative societal attitude associated with Autism prevents mothers and their children from participating in their communities, from seeking various services, and from enjoying the same quality of life as the other parts of the society.

Therefore, there is a need for families, professionals, service providers and all segments of the community to recognize the multifaced challenging experiences of raising a child diagnosed with autism in order to provide appropriate and holistic support to the mothers, the children, and their family.

## **6.2. RECOMMENDATION**

Based on the findings of the study the following recommendations are suggested to improve the life of mothers and their children.

For social workers : It is imperative for social workers to play a role in different levels at Macro, Messo and Micro level.

- Macro level; They may advocate for expansion of services and institutions for children and families, advocate for the right of children with autism, and mobilizer resources to reach families.
- Meso level; They may act as researchers, practitioners, planner, consultants. They should design awareness creation programs, design support groups for children and families, engage in research and practice to promoting inclusion of mothers and their children in the society
- Micro level: They may play a role as counsellors, educators, and case managers by providing psychosocial support for children, siblings, and extended families.

For government: It would be crucial if the Ethiopian government give a series of attention to mothers of children with autism through provision of educational, health care, autism centers and alternative day care services. Also, the government may allocate resources to train professionals in order to facilitate effective diagnosis and early intervention. It is also important that federal policy makers design the most appropriate, culturally sensitive programs and policies that give equal access to education for all individuals along with the necessary reviewing, monitoring and evaluation of programs.

Therefore, intervention programs have to give particular attention to the culture and lifestyles of families raising children with special needs at the macro system level and enhance parenting quality of caregivers from different socio cultural background who are often overburdened and feel helpless because the intervention programs and strategies are not consonant with their culture (Algood, Cynthia and Hong, 2013).

Generally, ecological theory recognizes the collaboration of different systems such as families, community agencies and institutions, spiritual leaders, service providers, government etc, as all segments of the society have the responsibility to promote the wellbeing of mothers and their families.

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## APPENDICES

### APPENDIX 1

#### *Declaration of informed consent for fieldwork Informed consent*

#### **Informed Consent**

The following is a presentation of how I will use the data collected in the interview.

In order to insure that projects, meet the ethical requirements for good research I promise to adhere to the following principles:

- Interviewees in the project will be given information about the purpose of the project.
- Interviewees have the right to decide whether they will participate in the project, even after the interview has been concluded.
- The collected data will be handled confidentially and will be kept in such a way that no unauthorized person can view or access it. The interview will be recorded as this makes it easier for me to document what is said during the interview and also helps me in the continuing work with the project. In my analysis, some data may be changed so that no interviewee will be recognized. After finishing the project, the data will be destroyed. The data I collect will only be used in this project. You have the right to decline answering any questions, or terminate the interview without giving an explanation. You are welcome to contact me or my supervisor in case you have any questions (e-mail addresses below).  
Student name & e-mail Supervisor name & e-mail Interviewee

The interview will be recorded as this makes it easier for me to document what is said during the interview and also helps me in the continuing work with the project. In my analysis, some data may be changed so that no interviewee will be recognized. After finishing the project, the data will be destroyed. The data I collect will only be used in this project. You have the right to decline answering any questions, or terminate the interview without giving an explanation.

You are welcome to contact me or my supervisor in case you have any questions (e-mail addresses below).

Student name & e-mail

Betelhem Birhanu

[bety.brihanu@gmail.com](mailto:bety.brihanu@gmail.com)

Supervisor name & e-mail

Tone Haugs

tone.haug@uis.no

## **Appendix 2: Information and Consent Form**

### **Request to Participate in A Research Project**

**Project Title:** The Lived Experiences of Mothers Raising Children diagnosed with Autism Spectrum Disorder in Ethiopia: Perceptions and Challenges

### **Explanation and Purpose of the Study**

My name is Betelhem Birhanu. I am a graduate student in European Master's in Social work with Families and Children at the University of Stavanger, Norway. I prepared this form to ask for your consent to take part in the study which will be carried out for the purpose of the partial fulfillment of my master's degree from 2018 – 2020. The aim of this research is to investigate the lived experiences of mothers raising children diagnosed with Autism Spectrum Disorder in Ethiopia. The study will investigate the mothers' experiences by focusing mainly on their perceptions and challenges.

### **Participation in the Study**

All the mothers who will be participating in this study are selected because they are willing to participate in the study through sharing their experiences of raising a child having Autism Spectrum Disorder. Your participation is completely voluntary, and you are free to withdraw from participating at any time without providing any reason. You can also refuse to answer any question that might be uncomfortable to you to answer. If you agree to participate in this study, you will be involved in an in-depth interview which is used as a data collection tool for this research. The interview is expected to last for 1 hour and 30 minutes with each of the mothers. It will be conducted with the native language of mothers which is expected to be Amharic. The interview will be scheduled based on the availability and convenient time for mothers. This consent form will be communicated through reading to those mothers who are illiterate to get their consent. Participants will share their experience I,e their challenges and coping mechanisms they use in caring for a child with Autism Spectrum Disorder. An interview guide will be used by the researcher to help the researcher focus on different aspects of the questions.

### **Handling the information that you Provide**

The information that you provide will be recorded and stored in a recording device and it will be transcribed afterwards. Your real name will not be used in the research report, instead the researcher will use pseudonyms and it will not be possible to trace who provided which information. The people who have access to the raw information that you provide will be the researcher and the supervisor. Recordings and interview transcripts will be deleted after the research is completed and submitted in June 2020. In general, the collected data will be kept

secured and will be processed according to the University of Stavanger internal guidelines/routines for information security. The use of a personal computer and other removable disks such as USB, by the researcher will be in accordance with these guidelines.

This study has been notified to the Norwegian Centre for Research Data (NSD) to get approval for commencing the research.

### **What do you get out of your participation?**

There are no known risks and harms, or monetary benefits associated with participating in this study. The expected benefits that mothers can get out of this research is to have access to the findings of the study. If the study is submitted for publication in the future, participants will be able to get the compiled information about the experiences of mothers raising children with Autism Spectrum Disorder in Ethiopia.

Participants will have the copy of this signed consent form right before starting the interview.

If you agree to participate in this study, please sign this consent with full knowledge of the nature and purpose of this study.

Signature \_\_\_\_\_

In case, you have any questions or need more clarification please do not hesitate to contact

Researcher: Betelhem Birhanu - [bety.brihanu@gmail.com](mailto:bety.brihanu@gmail.com)

University of Stavanger

Supervisor: Tone Haugs – [tone.haug@uis.no](mailto:tone.haug@uis.no)

University of Stavanger

***Thank you for your participation!***



## Appendix 3: Interview guide/sample questionnaires

### I. Demographic Information of Mothers

1. Parental status

Biological mother

Guardian/caregiver

2. Marital status

Single  Married  Separated  Divorced

Widowed

3. Age \_\_\_\_\_

4. Academic qualification \_\_\_\_\_

5. Mother's occupation \_\_\_\_\_

6. Number of Children \_\_\_\_\_

### II. Information of the Child

7. Age\_\_

8. Diagnostic age\_\_\_\_\_

9. Sex \_\_\_\_\_

10. Grade level \_\_\_\_\_Autistic center\_\_\_\_\_ formal education

#### Questions

1. When and How did you notice that your child behaves differently?
2. How was your prior knowledge about Autism?
3. How was your initial reaction when you were informed of your child's autism diagnosis?
4. How do you understand your child in relation to his/her behavior/developmental disorder?

5. What are the challenges in relation to raising your child having autism?
6. How do you cope with the challenges of caring for an autistic child?
7. How is your relationship with your partner, family and the society?
8. What are your support systems?
9. What could be done to improve the life of mothers raising children with Autism in Ethiopia/Addis Ababa?
10. If there is anything that is not covered in the questions above that you would like to explain more?

## APPENDIX 4 : Consent Form/Amharic Version

### በጥናታዊ ጽሁፍ ላይ ተሳታፊ ለመሆን ፈቃደኝነት መጠየቂያ ቅጽ

#### መረጃና ፈቃደኝነት የያዘ ፎርም

የጥናታዊ ጽሁፍ ርዕስ የአእምሮ እድገት ዝግመት ችግር ያለባቸው ህጻናት እና እናቶች ህይወት ተሞክሮ በኢትዮጵያ አዲስ አበባ መለከከታቸውንና ችግሮቻቸውን የሚያተና ነው

#### የጥናቱ ዓላማና ምክኒያት

ስሜ ሴተልሄም ብርሃኑ ይባላል በኖርዌ ሀገር በሚገኝ ስታቫንገር በተባለ ዩኒቨርሲቲ በሶሻል ዎረከ የትምህርት ዘርፍ የማስተረስ ዲግሪ ተማሪ ነኝ ይህንን ፎርም ያዘጋጀሁት ከ2018-2020 ባለው ጊዜ የመመረቂያ ጽሁፍ ለመስራት በማድረግ ጥናት ላይ ተሳታፊ እንድትሆኑ ለመጠየቅ ነው።

#### የጥናቱ ዓላማ

ይህ ጥናት የእናቶችን ተሞክሮ ለማጥናት የሚሞክረው በዋነኝነት መለከከታቸውንና ችግሮቻቸውን በማጥናት ይሆናል።

#### በጥናቱ ላይ መሳተፍን በተመለከተ

በዚህ ጥናት ላይ ተሳታፊ የሚሆኑ ሁሉም እናቶች የሚመረጡት የአዕምሮ ዝግመት ዉስንነት ያለበት ልጅን በማሳድግ ዙሪያ ያላቸው የህይወት ተሞክሮ ለማካፈል ፈቃደኛ ስለሆኑ ነው። በዚህ ጥናት በማንኛውም ጊዜ ተሳታፊነትዎን ማቋረጥ ወይም ደግሞ ምላሽ ለመስጠት ፈቃደኛ ያለሆኑበትን ጥያቄ አለመመለስ ይችላሉ። በዚህ ጥናት ላይ ተሳታፊ ለመሆን ፈቃደኛ ከሆኑ በግል ለማካሄድ ቃለ መጠየቁ ላይ ተሳታፊ ይሆናሉ። ቃለ መጠየቁ በግምት ከ45 ደቂቃ እስከ 1 ሰዓት ቆይታ ሊኖረው ይችላል። ቃለ መጠየቁ የሚካሄደው በተሳታፊ እናቶች የእናት ቋንቋ ማለትም አማርኛ ቋንቋ ይሆናል። ቃለ መጠየቁ ተሳታፊ እናቶች በሚመቻቸው ጊዜና ቦታ ይሆናል። ይህን የፈቃደኝነት ፎርም በማንበብና በመተርጎም ለእናቶች ግልጽ እንዲሆንላቸው ይደረጋል።

በሚደረገው ቃለ መጠየቅ እናቶች የህይወት ተሞክሮቻቸውን ማለትም የአእምሮ እድገት ዉስንነት ያለበትን ልጅ በማሳደግ ዙሪያ ያጋጠማቸውን ፈተናና የመቋቋሚያ መንግደቻቸውን ያካፍላሉ ተብሎ ይጠበቃል። ይህንንም ለማድረግ ይረዳ ዘንድ ተመራማሪዎች የቃለ መጠየቅ መመሪያ ይዞ የተለያዩ ጥያቄዎችን ትጠይቃላች ይህም ተሳታፊዎች በቂ መልስ ለመስጠት ይረዳቸዋል ዘንድ የተለያዩ ጉዳዮች ላይ ለማተኮር ይረዳል።

የምትሰጡ መረጃ አያያዝ በዚህ ቃለ መጠየቅ የምታቀርቧል መረጃ በመቅረጹ ድምጽ ይቀረጻል ከዚያም በጽሁፍ ይተነተናል። በዚህ ጥናታዊ ጽሁፍ ላይ ትክክለኛው የተሳታፊዎ ስም አይገለጽም በምትኩ ተመራማሪዎ ስዉር ስሞችን መለያዎችን የምትጠቀም ይሆናል ይህም የትኛዎም እናት ምን አይነት መረጃ እንደሰጠች እንዳይታወቅ ይረዳል። የምታቀርበውን መረጃ ሙሉ በሙሉ ማዳመጥ የሚችሉት ተመራማሪዎች

የእረግ አማካሪ ናቸው። በመቅረጹ ድምጹ የተቀዳውና በጽሁፍ የተተነተነው መረጃ ጥናታዊ ጽሁፍ ከተጠናቀቀ ማለትም ከተረከበ በኋላ ማለትም በሰኔ 2020 የሚወገድ ወይንም የሚጠፋ ይሆናል ።

በአጠቃላይ የሚሰበሰበው መረጃ ሚስጥራዊነቱ ሙሉ በሙሉ የተጠበቀ በስታቫንገር ዩኒቨርሲቲ የመረጃ አያያዝ ህግ መሰረት የሚከናወን ይሆናል።

የተመራማሪዎች የግል ኮምፒውተር እና የተንቀሳቃሽ መረጃ መያዣቸውን ለምሳሌ ሚሞሪ አጠቃቀም ሂደትም በዚህ የመመሪያ አያያዝ መመሪያዎች የሚከናወን ይሆናል።

ይህ ጥናት በኖርዌ የጥናታዊ ጽሁፎችና የመረጃ ማእከል እንዲታወቅ ይሆናል።

**በመሳተፍ ምን ልታገኝ ትችያለሽ**

በዚህ ጥናት ላይ ተሳታፊ በመሆን ምንም አይነት ጉዳት አልያም የምታገኝዉ ኢኮኖሚያዊ ጥቅም የለም። እናቶች በዚህ ጥናት ላይ ቢሳተፉ ያገኛሉ ተብሎ የሚታሰበው ጥቅም ቢኖር ይህ ጥናት ወደፊት ለህትመት ከበቃ ያቀረቡትን መረጃ እና የህይወት ተሞክሮ በሪፖርት መልክ ቀርቦ ማየት ወይንም ማንበብ ነው። ይህም ተሳታፊ የነበሩ እናቶች በኢትዮጵያ ውስጥ ያሉ ልጆቻቸው የአእምሮ እድገት ውስንነት ያለባቸው እናቶች የህይወት ልምድ ጠቅለል ባላ መልኩ መረጃ እንዲያገኙ የሚረዳ ይሆናል ። በቃለመጠይቁ የሚሳተፉ እናቶች የዚህ ፈቃደኝነት የመጠየቁያና የመረጃ ፎርም ኮፒ ይኖራቸዋል። በዚህ ጥናታዊ ጽሁፍ ለመሳተፍ ፈቃደኛ ከሆንሽ እባክሽን ይህንን ፎርም በመፈረም ፈቃደኝነትሽን እና ስለጥናቱ መረጃ ማግኘትሽን በፊርማሽ አረጋግጭ።

ፊርማ.....

ጥያቄ ወይንም ግልጽ ያልሆንልሽ ነገር ቢኖር በዚህ አድራሻ ጠይቁ  
ተመራማሪ ቤተሰብም ብርሃኑ  
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ስታቫንገር ዩኒቨርሲቲ

ስለትብብርሽ አመሰግናለሁ!

## APPENDIX 5: Translated Interview Guide/ Amharic Sample Questionnaires

### የቃለመጠይቅ መመሪያ

#### I. የእናቶች መረጃ

1. የቤተሰብ ሁኔታ

ወላጅ እናት

አሳዳጊ

2. የጋብቻ ሁኔታ

ያላገባ

ያገባ

የተለያዩ

የፈታ

ሲን በሞት

ያጣች

3. እድሜ \_\_\_\_\_

4. የተመረቀበት የትምህርት ዓይነት \_\_\_\_\_

5. የእናት የስራ አይነት \_\_\_\_\_

6. የልጆች ብዛት \_\_\_\_\_

#### II. የልጆች መረጃ

7. እድሜ \_\_\_\_\_

8. በሽታዉ የተረጋገጠበት እድሜ \_\_\_\_\_

9. ጾታ \_\_\_\_\_

10. የትምህርት ደረጃ \_\_\_\_\_

### ጥያቄዎች

1. ልጅሽ የተለየ ባህሪ እንዳለዉ እንዴት እና መቼ አወቅሽ?

2. ከዚህ በፊት ስለ አእምሮ እድገት ዉስንነት ያለዎት ግንዛቤ ወይንም እዉቀት ምን ይመስላል ?

3. ልጅዎ የአእምሮ እድገት ዉስንነት ተጠቂ መሆኑን ለመጀመሪያ ጊዜ ሲሰሙ የነበረዎት ስሜት ምን ይመስል ነበር ?

4. ልጅሽ ያጋጠመዉን የአዕምሮ ህመም እንዴት ትረጅቀላሽ ?

5. በአእምሮ ዝግመት ዉስንነት ተጠቂ የሆነዉን ልጅሽን በምታሳድጊበት ወቅት የገጠመሽ ችግር ምን ነበር?

6. የገጠመሽን ችግር እንዴት መቋቋም ቻልሽ ?

7. ከማህበረሰቡ ከቤተሰብና ከጓደኞቻሽ ጋር ያለሽ ግንኙነት ምን ይመስላል ?

8. እርዳታስ የምታገኝባቸዉ ሁኔታዎች ምን ምን ናቸዉ?

9. ወደፊት ከቤተሰብ ከጓደኛ ከማህበረሰቡ ጋር የተሻለ ህይወት ለምምራት ያለሽ ተስፋና ምኞት ምን ይመስላል ?

10. ከላይ በጥቁዎቹ ያልተካተቱ የምትጨምረያቸዉ ሃሳቦች ካሉ ማንሳት ወይም መጨመር ትችያለሽ

## APPENDIX:6

### Non-plagiarism declaration

I hereby declare that the Dissertation titled ‘‘The Lived Experiences of Mothers Raising Children Diagnosed with Autism Spectrum Disorder in Ethiopia: Perceptions and Challenges’ submitted to the Erasmus Mundus Master’s Program in Social Work with Families and Children:

- Has not been submitted to any other Institute/University/College
- Contains proper references and citations for other scholarly work
- Contains proper citation and references from my own prior scholarly work
- Has listed all citations in a list of references. I am aware that violation of this code of conduct is regarded as an attempt to plagiarize, and will result in a failing grade (F) in the program. Date (15/06/2020) .

Signature:



Name: BETELHEM BIRHANU.

## **APPENDIX 7: Attachment**

### **Description of Participants/Mothers**

#### **Mother 1 (Elilta)**

Elilta was a 40-year-old mother of a 11-year-old son with Autism. She was born and grown in Gondar. She moved to Addis Ababa when she was 25. She completed 8<sup>th</sup> grade of formal education and she doesn't have permanent job. She used to work as a cleaning lady for different private firms before her child was diagnosed with Autism. she worked as housemaid occasionally when conditions with her child are convenient for her to work. She often paid an hourly wage. Her only child was diagnosed with Autism when he was 3. He attended a government mainstream school for a half-day session, only in the morning shifts. She was divorced with her husband before 5 years, three years after the diagnosis of her child.

#### **Mother 2 (Rediet)**

Rediet was a 40-year-old mother who had 3 children, a 16-year-old son, a 13-year-old son and a 9-year-old daughter. She was born and grown in Addis Ababa. She was college educated and self-employed. She worked as a Manager of her own organization found in Addis Ababa. She established her organization before 8 years. She hired 43 employees under her management. She had various experiences traveling around different countries, locally and internationally as part of her job. She was married for the last 17 years. However, her marriage did not get off to a very auspicious end as she was on the legal process of divorce with her husband. Her second child who is 13 was diagnosed with Autism when he was 2 years and 8 months. He attended a private school for children with Autism.

#### **Mother 3 (Zayd)**

Zayd was a 31-year-old mother of a 6-year-old son with Autism and a 4-year-old daughter. She was born in Sebeta, the southern part of Ethiopia, and moved to the capital, Addis Ababa when she was a junior high school student. She has completed 12<sup>th</sup> grade and she was unemployed at the time of the interview. She got married right after school. She lived with her family in the house of her parents-in-law. She was a housewife and her husband was a merchant. Her child was diagnosed at the age of 3.

#### **Mother 4 (Nebat)**

Nebat was a 30-year-old young woman of a 6-year-old son with ASD and a 4-year-old daughter. She was born in Selte, the southern part of Ethiopia. She lived in Addis Ababa for the last ten years. She has completed 10<sup>th</sup> grade. She worked as a sales person for several years in a privately held shopping mall. She was not employed at the time of interview.

She was married. Her son was diagnosed at the age of 4 and he attended a mainstream school.

### **Mother 5 (Aisha)**

Aisha was a 55-year-old middle-aged mother of a 16-year-old son with ASD, a 14-year-old son and, a 12-year-old daughter who was diagnosed with heart disease. She was born and grown in Addis Ababa. She has completed 12th grade. Following the completion of her studies, she went to Bahrain, a country in the middle east, as a housemaid, to support her families. She lived in Bahrain for 25 years and gave birth to all her children while she was there. Recently, she moved to Ethiopia with her whole family as she was convinced that she would create a better environment for her children. She was married and a housewife. Her first son was diagnosed with ASD at the age of 6. He was admitted to an autism center. Aisha also went to school in the theological teachings of the Quran for the Muslim community.

### **Mother 6 (Yodit)**

Yodit was a 35-year-old mother of 8-year-old son with ASD. She was born and grown in Addis Ababa. She was a college educated in Marketing. She worked as a marketing expert for 4 years in a governmental organization before the diagnosis of her child. She was not employed at the time of the interview. She was divorced from her first husband after two years of giving birth. Her son was diagnosed with ASD at the age of 3 and he was admitted to autism center. She was remarried to another guy and she was at 8 months of her pregnancy with her second child at the time of interview.