Addis Ababa University
College of Education and Behavioral Studies
School of Psychology

Psychological Challenges among Parents of Children with Intellectual Disabilities enrolled in Center for Mentally Challenged Children: *Implications for Counseling*

By:
Nati Gebre Bireda

A Thesis Submitted to the College of Education and Behavioral Studies, School of Psychology, Addis Ababa University, in Partial Fulfillment of the Requirements for Master of Arts Degree (MA) in Counseling Psychology

Advisor: Kasahun Habtamu (PhD)

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Approval of Board of Examiners

Head of Department	**Date**	**Signature**
Advisor	**Date**	**Signature**
Internal Examiner	**Date**	**Signature**
External Examiner	**Date**	**Signature**

DECLARATION

I the undersigned, hereby declare that the thesis entitled "***Psychological Challenges among Parents of Children with Intellectual Disabilities: Implications for Family Counseling"*** is my original work and all sources of materials used for this thesis have been duly acknowledged.

Name: **Nati Gebre Bireda**

Signature: ________________

Place: Addis Ababa University, Addis Ababa

Date of Submission: July, 2020

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ACRONYMS

APA	American Psychological Association
ASD	Autistic Spectrum Disorder
CMCC	Centre for Mentally Challenged Children
CSHCN	Children with Special Health Care Needs
DD	Developmental Delay
IBM	Intimate Bond Measure
ICF	International Classification of Functioning
UK	United Kingdom
UN	United Nation
US	United States

ABSTRACT

The situations of individuals with disabilities have relatively received attentions globally and locally. The challenges faced by their parents are, however, often overlooked. This is particularly so in Ethiopia. Parents are the most immediate "significant-others" to a child with disability. This means parents are the most affected by the disability next to, of course, the child with disability. For parents, the birth of a child is a sign of faith and hope, a source of pride, etc. A child is everything to his/her parents. Any parent would normally have plans and expectations for their children. However, having a child with disability may often extinguish those aspirations. It often means losing the child parents wished to have. When a child with disability is born, parents go through the process of acknowledging this reality and embracing the child they were given. This processes however is not a 'one-off' event with a beginning and an end; but rather continues throughout one's lifetime. As is the case with other types of disabilities, a child with intellectual disability is also often a source of disappointment rather than being considered equally human. This is particularly the case in traditional societies, like ours, where disabilities are usually associated with: superstitions, God's punishment and/or, an unfortunate happening caused as a result of a parent's genetic lineage, etc. A number of previous and related studies showed, among other things, that, in Ethiopia, having a child with disability is regarded as a source of shame, which usually leaves parents with significant psychological distresses. This calls for much research in Ethiopia to better understand how childhood disability—Intellectual Disability (ID), in particular—impact parents and families. The purpose of this study is therefore to investigate the psychological challenges of parents of children with intellectual disabilities, enrolled at Center for Mentally Challenged Children (CMCC), in Addis Ababa. The study in particular tries to learn (a) the major views and reactions of parents at the time of their children's diagnosis; (b) the psychological challenges of the parents (c) other challenges and opportunities of having a child with IDs among parents; and (d) the coping mechanisms the parents in question employ to deal with these challenges. The study adopted a qualitative research design, as it provides an in-depth understanding and a rich description of the participants' psychological problems. Six parents, 4 mothers and 2 fathers, were considered for the study, on the basis of theoretical saturation. Semi-structured interviews and FGDs were employed for data collection. The results were thematically categorized as: (i) views and reactions—which include initial reactions such as shock, denial, guilt, anxiety, sadness; (ii) psychological problems, i.e., concerns about child's future, stress from managing the child, relationship strains, disappointment and sacrifices, inter-personal conflicts, being worried, sense of loneliness; (c) copying strategies, i.e., religion, social support, educating oneself about the disability, acceptance, appreciation; and other challenges (e.g., social negative views) and opportunities, i.e., understanding others, being non-judgmental, helping others, etc. These results have massive implications for structural (policy) and practical (services) interventions.

CHAPTER ONE: INTRODUCTION

1.1. Background of the study

Parents are the foundation for a child's development, socialization, and formation of his/her values and beliefs (Yorke *et al*., 2018). Studies emphasize that parents play central role in their child's socialization by encouraging and promoting self-regulation, self-determination, and social competence. Parenting is a complex process involving the responsive provision of varied amounts of care, affection, stimulation, support, and control according to the needs of the child. Parenting or child rearing is the process of promoting and supporting the physical, emotional, social and intellectual development of a child from infancy to adulthood.

Expectant parents experience a range of exciting and daunting emotions when they are anticipating their baby's birth. Often there is much that is needed in terms of support and plans are made to accommodate the arrival of their baby. Yet few parents are aware of the possibility that their baby may have additional needs (Ali *et al*., 2001). Parents may have considered issues around having a child born with disability in the context of antenatal testing during pregnancy. For most families, however, the birth of a child who has impairment is an alien and unfamiliar experience, which may have a profoundly negative impact on what is otherwise, a joyous occasion (Ricci *et al*., 2017).

The birth of a child is a sign of faith and hope, prompting expectations of continuity and perpetuation. The mere existence of the newborn, the baby's traits and appearance, are usually a source of pride. All parents have plans and expectations for their children, often imagining future scenarios and the child's advances (Kandel and Merrick, 2003). However, having a child with a disability often requires parents to acknowledge the loss of the child they wished to have, and to accept and embrace the child they were given (Goodman *et al*., 2011). This process is not a finite event with a beginning and an end, but rather continues throughout one's lifetime. It is often revisited at different stages in the child's development and in the family's life cycle (Keyser *et al*., 2017). Often parents have different coping styles and do not experience this process in the same way. One partner may need more time to process his/her situation more, more outlets for verbal communication and support, and to be more open and direct about his/ her feelings. Another partner may be more private about his feelings, may not come to an acceptance at the same rate as his/ her spouse, or even at all (Takataya *et al*., 2016). Some spouses have a more positive outlook while others have a hard time moving forward from their pain (Bagner *et al*., 2013).

Research in the general population has established association between child psychopathology and elements of parental psychological distress, including parenting stress (Crnic *et al*., 2005) and mental health problems (Goodman *et al*. 2011). Population-based research has shown stress (Keyser *et al*. 2017) and mental health problems (Ford *et al*. 2004) to retain a significant association with child psychopathology after adjusting for other family, child and contextual factors. Longitudinal research has shown support for reciprocal predictive relationships between child emotional and behavioral problems and parent psychological wellbeing, for example depression (Bagner *et al*. 2013) and in certain conditions, parental stress (Stone Stone *et al*., 2016).

Care for a child with a disability is a stressful experience for parents. It triggers a range of emotions and feelings that require a set of behaviors and attitudes to manage daily life. To face this situation, parents use coping strategies (Phillips *et al*., 2017). The range of coping strategies used includes emotion-focused coping (escape avoidance, fatalism, and passivity; and expressive action), as well as problem-focused coping mechanisms (problem-solving). Folkman (2013) maintains that both emotion-focused and problem-focused coping are helpful in reevaluation of the stressor. However, emotion-focused coping is believed to be associated with an unsatisfactory outcome and problem-focused coping is associated with a more satisfactory outcome (Sheikh *et al*., 2018). Problem-focused coping is known to improve mental health outcome in parents of a child with disability (Pourmohamadreza‑Tajrishi *et al*., 2015).

Although psychological problems, such as anxiety and depression, have been studied previously, other areas of psychopathology have not been adequately explored. Further, the role of specific coping mechanisms and its relation to psychopathology has not yet been explored (Ricci *et al*., 2017).

1.1.1. Specific Objectives

For this study the specific objective were:

- To examine the major reactions of parents during the time of their children’s diagnosis.
- To investigate the psychological challenges of parents of children with intellectual disabilities
- To find out the social challenges and opportunities of having a child with intellectual disability among parents

- To find out the coping mechanisms parents who have children with intellectual disabilities use to deal with their problems

1.2. Significance of the Study

Studying the psychological challenges that parents of children with disabilities face and the coping mechanisms they use to deal with those challenges is important to create awareness and provide relevant and updated information on the issue to parents, professionals, centers that work on children with disabilities and the community at large. Listed below were the most significant imperatives that the present study offered:

- The current study obtained extensive and detailed information that is directly relevant to the participating parents and hopefully to other parents of children with disability by providing important insights into the emotions and thoughts inherent in these parents' experiences, which informed current understanding of what it could mean for parents to live with a disabled child.
- It also provided insight on what mechanisms were proved to be effective to reduce the challenges and create a harmonious, coherent family lifestyle which is supportive for their children with disabilities.
- It gave additional insight to centers established to support children with disabilities so that the centers can employ various means and options to encourage parents and professionals to come together to work on the gaps and insufficiencies that the centers have.
- Moreover, the current study pinpointed training needs for concerned professional in traditional as well as modern organizations working with parents of children with disabilities to provide parents with useful parenting tools and advice as well as to support them in handling these problems.
- Above all, the result of this study was significant to make a positive change in attitude of families, neighbours, teachers, health care professionals and communities at large towards disability and parents of children with disabilities and contribute their efforts for the better life of the targeted population.
- The study also forwarded findings that meet urgent need for information to support both policy and programming, and to enable NGOs, donors and programme planners to allocate resources most effectively address the psychological problems of parents

and children with disabilities nationally and regionally.

- This study also served as a benchmark for interested researchers for further studies.

1.3. Statement of the Pproblem

The situations of individuals with disabilities have relatively received attentions globally and locally. The challenges faced by their parents are, however, often overlooked. This is particularly so in Ethiopia. Parents are the most immediate “significant-others” to a child with disability. This means parents are the most affected by the disability next to, of course, the child with disability. For parents, the birth of a child is a sign of faith and hope, a source of pride, etc. A child is everything to his/her parents. Any parent would normally have plans and expectations for their children. However, having a child with disability may often extinguish those aspirations. It often means losing the child parents wished to have. When a child with disability is born, parents go through the process of acknowledging this reality and embracing the child they were given. This processes however is not a ‘one-off’ event with a beginning and an end; but rather continues throughout one’s lifetime. As is the case with other types of disabilities, a child with intellectual disability is also often a source of disappointment rather than being considered equally human. This is particularly the case in traditional societies, like ours, where disabilities are usually associated with: superstitions, God’s punishment and/or, an unfortunate happening caused as a result of a parent’s genetic lineage, etc. A number of previous and related studies showed, among other things, that, in Ethiopia, having a child with disability is regarded as a source of shame, which usually leaves parents with significant psychological distresses. This calls for much research in Ethiopia to better understand how childhood disability—Intellectual Disability (ID), in particular—impact parents and families.

1.4. Research Questions

The following were basic research questions addressed in this study.

- What are the major reactions of parents during the time of their children’s diagnosis?
- What are the psychological challenges of parents of children with intellectual disabilities?
- What are the social challenges and opportunities of having a child with intellectual disability among parents?
- What coping mechanisms do parents who have children with intellectual disabilities use to deal with their psychological and social problems?

1.5. Objectives of the Study

1.5.1. General Objective

The general objective of this study was to investigate the psychological challenges of parents who have children with intellectual disabilities in Addis Ababa.

1.6. Delimitation

The study was limited on parents of children with intellectual disability as the main source of information. In addition the study was conducted at Center for Mentally Challenged Children center that provides assessment, diagnosis, treatments and psychological therapies for many psychological and developmental disorders including intellectual disabilities for the past thirty years. This is due to that the researcher only found this organization that was willing to provide the necessary support for the student researcher and that has professionals that diagnoses and levels the children whether they have intellectual disabilities or other developmental disorders by the criteria of American psychiatric association DSM-5.

1.7. Scope of the Study

The study was delimited to an organization called Center for Mentally Challenged Children (CMCC). The study was conducted to assess psychological problems among parents who have children with disabilities, and it included parents with diagnosed children above three years old to ensure that adequate time had elapsed since the diagnosis.

1.8. Limitations of the Study

There are a number of limitations in this study including difficulty to find more voluntary parent's meeting the criteria of having a well-documented diagnosis of their children on each respective disability.

Second, all of the parents in this study lived in Addis Ababa which is the capital city and therefore closer to the few services that are available in the country. It is possible that Parents living in other cities and more rural areas where access to services such as schools for children with desirability or special need are almost none may have a very different experience when compared to the parents in this study.

The types of intellectual disabilities considered for the study is rather few, which is another limitation of the study. Different types of disabilities can cause different levels of challenges in parents since the manifestation of the problem is different for each disability Therefore, it would be beneficial to expand the study to a larger population by addressing the unique

characteristics of each child with disability through different challenges and burdens they caused on their parents.

1.9. Definition of Key Terms

- ***A Child with disability:*** refers in this study to a child with a group of rather heterogeneous and diverse impairments/conditions and can be of genetic, environmental or trauma-related origin. These may include intellectual disabilities, Autism Spectrum Disorder, Down syndrome, Deaf/Hearing Impairment, Blind/Vision Impairment, Cerebral Palsy, and Epilepsy. The impairments must affect at least three major areas of life activities, such as communication, living independently, self-care, mobility or learning (United States of America Developmental Disabilities Act of 1984). As the focus of this study is on intellectual disabilities, the phrase “a child with disability” is generally used in this thesis to mean “a child with intellectual disability”.
- ***Coping mechanisms:*** Coping mechanisms – refers to the use of mechanisms of adjusting to environmental stresses and challenges without altering personal goals weather it is consciously or unconsciously.
- ***Intellectual disabilities:*** neurodevelopmental disabilities that begin in childhood and are characterized by difficulties in conceptual, social, and practical areas of living.
- ***Social challenges*** - refer to difficulties that people encounter while interacting with people in society or engaging in normal social behaviors.
- ***Parent:*** in the present study refers to primary care givers of a child or children with disability. Parents can be biological, adoptive, or stepparents.
- ***Psychological challenges:*** are difficulties people encounter that cause them unpleasant emotional states such as stress from managing a child, disappointment and sacrifice, interpersonal conflict, concern about child’s future and Sense of Loneliness that can impact their activities of day-to-day living.

CHAPTER TWO: REVIEW OF RELATED LITERATURE

2.1. Introduction

This chapter presents a review of the related literature to the study. The review presents and evaluates previous studies conducted on psychological problems of having a child with disability. To this end, the chapter covers topics related to disability, parental reactions to the birth of a child with disability, challenges and opportunities of having a child with disability. Furthermore, psychological problems of parents of children with disabilities along with gender differences and their coping strategies are discussed.

2.2. Defining Disabilities

The definition of disability is highly contentious for several reasons. First, it is only in the past century that the term “disability” has been used to refer to a distinct class of people. Historically, “disability” has been used either as a synonym for “inability” or as a reference to legally imposed limitations on rights and powers (Kahane and Savulescu, 2009). Indeed, as late as 2006, the Oxford English Dictionary recognized only these two senses of the term (Boorse, 2010). As a result, it is hard to settle questions about the meaning of “disability” by appeal to intuitions, since intuitions may be confused by the interplay between older, ordinary-language definitions and newer, specialized ones. Second, many different characteristics are considered disabilities. Paraplegia, deafness, blindness, diabetes, autism, epilepsy, depression, and HIV have all been classified as “disabilities.” The term covers such diverse conditions as the congenital absence or adventitious loss of a limb or a sensory function; progressive neurological conditions like multiple sclerosis; chronic diseases like arteriosclerosis; the inability or limited ability to perform such cognitive functions as remembering faces or calculating sums; and psychiatric disorders like schizophrenia and bipolar disorder (Guillermo at al., 2006). There seems to be little about the functional or experiential states of people with these various conditions to justify a common concept; indeed, there is at least as much variation among “disabled” people with respect to their experiences and bodily states as there is among people who lack disabilities (Gerstein, *et al*., 2009) . Indeed, some have questioned, in part because of this variation, whether the concept of disability can do much philosophical work (Beaudry, 2016). At the same time, defining “disability” solely in terms of social responses like stigmatization and exclusion does not distinguish disability from race or sex (Bickenbach, 1993). The challenge of distinguishing “disability” from other concepts, without taking a simplistic or reductive view of it, has been

taken up by various specialized definitions. Two common features stand out in most official definitions of disability, such as those in the World Health Organization (2001; 1980), the U.N., Standard Rules on the Equalization of Opportunities for People with Disabilities, the Disability Discrimination Act (U.K.), and the Americans with Disabilities Act (U.S.) : (i) a physical or mental characteristic labeled or perceived as an impairment or dysfunction (in the remainder of this entry, we will refer to such characteristics as "impairments," without assuming the objectivity or validity of that label) and (ii) some personal or social limitation associated with that impairment. The classification of a physical or mental variation as an impairment may be statistical, based on the average in some reference groups; biological, based on a theory of human functioning; or normative, based on a view of human flourishing (U.S. Census Bureau, 2017). However, classified, impairments are generally seen as *traits* of the individual that he or she cannot readily alter. Just what makes a condition a trait or attribute of an individual is obscure and debatable, but there seems to be agreement on clear cases (Kahane and Savulescu, 2009). The International Classification of Functioning Disability and Health (ICF) (2001), defines "disability" as the outcome of the interaction between a person with impairment and the environmental and attitudinal barriers s/he may face. In what follows, discussions of intellectual disabilities are provided.

2.3. Intellectual Disabilities

2.3.1. Definitions

In the past, intellectual disability (also previously referred to as "mental retardation") has been defined by significant cognitive deficits, as has been measured through standardized tests of intelligence. It has also been defined in terms of significant deficits in functional and adaptive skills, which are related to the ability to carry out age-appropriate daily life activities. Today, there are a number of systems used for classifying intellectual disability, two of which used in the western world are: the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), which is published by the American Psychiatric Association.

DSM-5 defines intellectual disabilities as neurodevelopmental disorders that begin in childhood and are characterized by difficulties in conceptual, social, and practical areas of living. The DSM-5 diagnosis of intellectual disability requires the satisfaction of three criteria:

1. Deficits in intellectual functioning— “reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience”—confirmed by clinical evaluation and individualized standard IQ testing (APA, 2013, p. 33);
2. Deficits in adaptive functioning that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility; and
3. The onset of these deficits during childhood.

The DSM-IV, which provides a more comprehensive view of the individual than it was the case in previous editions, defines intellectual disability in terms of impairments of general mental abilities that affect how a person functions in conceptual, social, and daily life areas. In the DSM-5, specific IQ scores are no longer used as a diagnostic criterion, and more emphasis is placed on adaptive functioning and the performance of usual life skills (Papazoglou *et al*., 2014)

2.3.2. Classifications of Severity

In the literature, the terms “mild,” “moderate,” “severe,” and “profound” have been used most commonly to describe the severity of intellectual disability. This approach has been helpful in that aspects of mild to moderate intellectual disability differ from severe to profound intellectual disability. As noted above, the DSM-5 retains this grouping with more focus on daily skills than on specific IQ range.

2.3.2.1. Mild to Moderate Intellectual Disability

The majority of people with intellectual disabilities are classified as having mild intellectual disabilities. Individuals with mild intellectual disabilities are slower in all areas of conceptual development and social and daily living skills (APA, 2013). These individuals can learn practical life skills, which allow them to function in ordinary life with minimal levels of support. Individuals with moderate intellectual disabilities can take care of themselves, travel to familiar places in their community, and learn basic skills related to safety and health. Their self-care requires moderate support (ibid).

2.3.2.2. Severe Intellectual Disability

Severe intellectual disabilities manifests as major delays in development, and individuals often have the ability to understand speech but otherwise have limited communication skills (Sattler, 2002). Despite being able to learn simple daily routines and to engage in simple self-

care, individuals with severe intellectual disabilities need supervision in social settings and often need family care to live in a supervised setting such as a group home.

2.3.2.3. Profound Intellectual Disability

Persons with profound intellectual disability often have congenital syndromes (Sattler, 2002). These individuals cannot live independently, and they require close supervision and help with self-care activities. They have very limited ability to communicate and often have physical limitations. Individuals with mild to moderate disability are less likely to have associated medical conditions than those with severe or profound intellectual disabilities.

2.3.3. Etiology

Environmental factors such as exposure to toxic substances (e.g., prenatal alcohol exposure, prenatal or postnatal lead exposure), nutritional deficiencies (e.g., prenatal iodine deficiency), brain radiation, childhood brain infections, traumatic brain injury, and maternal infections (e.g., rubella, cytomegalovirus) can lead to intellectual disabilities (APA, 2013). Additionally, prenatal and postnatal complications—e.g., complications of prematurity such as hypoxemia and periventricular hemorrhage—may cause brain injury resulting in intellectual disabilities (Gustafsson, 2003).

Genetic factors play a major role in intellectual disabilities. Different genetic causes may lead to intellectual disabilities. Down syndrome (trisomy 21) is the most common genetic cause of intellectual disabilities in the United States, occurring approximately once every 700 live births (Parker *et al*., 2010). Fragile X syndrome is the most commonly known inherited cause of intellectual disabilities, and it affects approximately 1 per 5,000 males (Coffee *et al*., 2009). Many cases of intellectual disabilities in the population are of unknown etiology.

Because of the varied causes and consequences of intellectual disabilities, an initial evaluation should address intellectual and life skills, the identification of genetic and nongenetic etiologies, and the diagnosis of conditions that need treatment (e.g., epilepsy and phenylketonuria). Prenatal and perinatal medical histories, a physical examination, genetic evaluations, and metabolic screening and neuroimaging assessment may aid in the determination of characteristics that may influence the course of the disorder (Parker *et al*., 2010).

2.4. Parental Reactions to the Birth of a Child with Disability

Few people realize how difficult it is to be a parent until they themselves become parents. It is even more difficult to be a parent of a child with disability. Families with children with disabilities want the same thing as other families (Palermo *et al*., 2014). They want to see their children reach their full potential, they want to be included and accepted by their community and they want to enjoy things together and have fun (Baker & Fenning, 2007). The birth of a child is a sign of faith and hope, prompting expectations of continuity and perpetuation. The mere existence of the newborn, the baby's traits and appearance are usually a source of pride (Ayalon, 1983). All parents have plans and expectations for their children, often imagining future scenarios and the child's advances (first steps, nursery school, elementary school, military service, college, etc) (Scorgie, Wilgosh, & McDonald, 1996). The child's success is perceived as the parents' achievement. When a disabled child is born, all expectations and hopes are dashed (Kandel, and Merrick, 2005). The child will not be a source of pride – rather a source of great disappointment.

Parents of disabled children undergo a difficult and painful process involving a revision of their views and expectations (Kandel, & Morad *et al*., 2005). They are obliged to adapt to the knowledge that all their hopes and plans for the future must change (Ayalon, 1983). A parent's initial reaction is likely to be negative and similar to those related to bereavement (Blachar & Bakar, 2007; Hill & Rose, 2009). This is followed by a period of questioning which may go on for many years, as to why this should have happened to them (Rhodes 2003). The parents may tend to blame themselves or each other (Scorgie & Sobsey, 2000). Some may react in an emotionally and physiologically negative way to the diagnosis of their child's disability. The transition in a family with a child living with disabilities brings about significant changes in that family's social life (Hastings, Allen, McDermott, & Still, 2002). Some experience considerable stress, as well as feelings of depression, anger, shock, denial, self-blames guilt and confusion (Heiman, 2002).

The reaction of the family seems to follow the five stages of the Kubler-Ross grief elaboration theory (denial, anger, bargaining, depression, and acceptance) (Kubler-Ross, 1972). This reaction is similar to what we observe in parents with perinatal death or loss (Harmon, Plummer, and Frankel, 2008). It should be emphasized that the functional crisis experienced by mothers and fathers of children with a disability may be accompanied by psychological stress, a feeling of loss, and low self-esteem. In addition, the fact that the child is unable to fulfill their expectations may also be disappointing (Darling, 2004). It may result

in a severe blow to the self-esteem of the parents, create disappointment, and result in the child becoming a social obstacle that will also cause feelings of shame and embarrassment (Singer, 2006).

Parental reactions to the diagnosis of the disability will not be identical. The intensiveness of reactions and their character depend on several dynamic factors, such as individuality, the character of social relations, feelings about the deviation, and the social status (Withers, and Bennett, 2003). In the literature, (e.g. Darling, 2004), a wide range of reactions are mentioned, some considered more frequent than the others: anger, disappointment, shame, frustration, and grief. The coping process is not static, but a constantly changing cognitive and behavioral effort by the person to manage both external and also internal stress factors and pressures (Kande & Merrick, 2003).

Anger, disappointment, and shame reactions result from the fact that the child is not the ideal child that the parent anticipated. The child is unable to fulfill the hopes and ambitions he/she was expected to. There are cases when parents unconsciously consider the child to be responsible for crushing their ambitions (as if he/she is "deliberately" disabled) (McCormack, 2000). However, since many parents consider it inappropriate to direct their negative feelings toward the children, anger may also be directed towards the other parent or towards others (for instance, the physician or other professionals for a variety of reasons, such as having made an incorrect diagnosis, insensitivity, offering false hope, or providing inadequate or ineffective treatment or services) (Kubler-Ross, 1972; Harmon, Plummer, & Frankel, 2000). These feelings of jealousy and anger are common in many families. The emotions may also be directed towards other families who do not have to contend with such stress or those with disabled children who are higher functioning or whose children have improved to a greater extent. Sometimes, the opposite reaction can be observed, which is expressed in overprotecting the child.

In other cases, the parents see the disabled child as a symbol of their own personal failure (Susan K. Dzubay 2011). The feelings of a damaged self-esteem give rise to intensive feelings of inferiority and shame. Frustration over the fact that the child is not able to fulfill the parents' expectations can become even deeper as the slow development of the child makes him/her totally dependent on the parents, often especially the mother, seriously limiting her independence and freedom (Blacher & Meyers, 2005). In addition, social and economic aspects of raising a child with disabilities may provoke additional anger and frustration (e.g., difficulties in maintaining social communication, leisure activities, work,

projects or economic plans) (Jones, *et al*., 2014). Frustration can belong to one of two types (Ross, 2000): (1) frustration resulting from role organization factors, i.e., failure to organize a new role system, since the disabled child is not able to play the role he/she is expected to or (2) frustration resulting from the destruction of ambitions and wishes for a happy family life.

Often the initial diagnosis of the child's disability will produce a grief reaction in parents and other family members (Ross, 2000). This may be the result of initial confusion and uncertainty. Grief and bereavement are normal reactions to the loss of an object (in this specific case the object is symbolic) (Waisbren, 2003). By means of these feelings, the human being temporarily retreats from involvement in the external world and allows his/her ego to focus on transferring the mental energy from the object on which it was concentrated to an alternative object. Transferring the energy is essential for successful conclusion of the bereavement process. However, this solution is not possible in case of the birth of a disabled child, since there is no final separation from the lost object, the child exists; thus, there is no opportunity to grieve over him/her without experiencing constant demands from his/her side (Portowicz, & Rimmerman, 2002). As a result of the demands, which are opposite to releasing oneself from the lost object and accepting the child, a situation is created in which “chronic bereavement” is opposed to counter-feelings. Since this ambivalence cannot be accepted in the parents’ consciousness, it is pushed aside and causes additional difficulties in finishing the lamentation process. Ambivalence towards the object is not a part of the usual bereavement, since the grief process itself is a temporary phenomenon (Portowicz, & Rimmerman, 2002).

Many parents also have little understanding of what the diagnosis of a given disease or syndrome entails and many will have various perceptions and speculations about the disease causing the disability (Featherstone, 1999). Parents should therefore be informed regarding the varied manifestations and aspects of the disability. Sometimes it is also very hard to predict the cause or development of the disability at an early age, which makes it even more difficult for the parents (Wolfensberger, & Kurtz, 1999).

Grief is a complex reaction with the loss of the expected normal child and the necessity to develop a new role of attachment to the abnormal child. Olshansky (1962) describes grief for a disabled child as a lifelong “chronic sorrow” that may accompany the parents all their life, regardless of whether the child lives at home or is in placement. Although the intensity varies from one to another, it seems that all parents experience grief. Olshansky argued that this type of grief should not be interpreted as a neurotic reaction, but rather it should be seen as a

normal and natural reaction to the crisis. According to (Portowicz, & Rimmerman, 2002), the crisis can take the following forms.

- **The change crisis:** this crisis takes place immediately after the diagnosis of the disability and is a most difficult experience. The parents are full of expectation for the birth of a normal child, and when they are informed about the disability, all their dreams are ruined, causing the traumatic reactions. This crisis is not a reaction to the handicap itself; rather, it is a reaction to the sudden change of reality.
- **The ideological crisis:** the change crisis is comparatively short; however, after the parents have digested the news, they must confront this experience every day. This confrontation gives rise to strong emotional reactions, leading to an ideological crisis, which may last for a longer period. The parents are in a state of constant ambivalence. On the one hand, they feel that they must love and protect their child, but on the other hand, social values cause them to feel discomfort, feelings of failure, and inability to accept the child as a “beloved” one. Such characteristic reactions as guilt, shame, overprotection, and grief appear at this stage.
- **The reality crisis:** this crisis is directly related to the objective difficult conditions of bringing up a child with disability. The parents face numerous difficulties that influence their ability to manage the problem. The first difficulty is financial, since expenses grow considerably compared to their previous situation or to that of other families. Many parents are disturbed by fears related to the influence the child has and will have on their lifestyle. Family members may stay in seclusion at home and avoid spending their time in the way they used to, before the child was born.

Many parents express concern regarding the coming of a time when they will not be able to take care of the child themselves. The stages mentioned above are not necessarily pure, since there can be overlap, but in order to assist and support parents, it is important to realize at what stage of the crisis they are.

Guilt is another common reaction to the diagnosis of a disability in a child. Sometimes that has been caused by the medical and professional community, who directly or inadvertently attributed a disease or condition in a child as parental failure, which later turned out to be based on a genetic disorder (Bettleheim, 2005). The possible contribution of additional factors such as environmental toxins has also been discussed. Many parents wonder if they unwittingly did something to contribute to the disability in their child (such as exposure to X-

rays, mercury from injections or dental fillings). There are parents who feel rejection, disappointment, and anger because their child is not the one, they looked forward to (Pit-Ten Cate, & Loots, 2000). Since the parents cannot tolerate or suffer these negative feelings, they deny the feelings by directing the anger towards themselves, the feeling that this is a punishment for their past sins (Portowicz, & Rimmerman, 2002). In other cases, the guilt feeling is directed (as a result of negative feelings) towards other people, such as a spouse or a physician, or towards spiritual matters. We have often heard the following statements by parents with disabled children: “This happened as a punishment for me leaving the religion;” “It is all my fault. Before I got married, I had been ‘flirting about’. I made love before marriage and I always felt terrible about that, and now I have to pay for it.” (Portowicz, & Rimmerman,2002).

2.5. Experiences of Ethiopian Parents Raising a Child with Disability

It appears that the challenges families face in connection to developmental disabilities of children are more serious and complicated in the developing world (Amakelew, Daniel and Fasikawit, 2000). People with special needs in developing countries have encountered many problems as governments of many of those countries had never committed themselves to providing various services for these large groups of citizens (Getnet, 2013).

The history of people with disabilities in Ethiopia is not different from other developing countries. Disabled children in Ethiopia are among the most psychologically, socially, economically and politically disadvantaged social groups (Weldeab, 2006). In other words, to be special needs or disabled usually means to be discriminated against as well as suffering from social isolation and physical restrictions (Letekidan, 2003). Persons with disabilities do not have access to rehabilitative services. As a result, parents and relatives of disabled children were and are still the crucial actors in the provision of care and education (Meron, 2006).

In this part of the world, families who have children with disabilities suffer more problems than their partners in the developed countries. Ignorance and inadequate schooling, extreme poverty and lack of welfare support, and discord between family members are some of the problems. And furthermore subsequent stress and/or separation among family members, unsafe physical grounds together with hostile or segregating neighbors aggravate the problem of mothers raising children with autism in Ethiopia (Amakelew, Daniel and Fasikawit, 2000).

For instance, a study by Aynalem, (2014) indicated that the impact of autism on Ethiopian mothers is expressively visible on their daily routines and life experiences. They do not feel

at ease to talk about their children openly instead they feel guilty and are ashamed of their autistic children due to the pressure and misunderstanding of the society. The study further indicated that social life and participation in social events is limited as a result of raising their children with autism due to preference to isolate one self and fear of taking the child in public as a result of the low level of probability to get acceptance from the society.

Hence, thousands of children with autism are confined to their homes with no access to education or rehabilitation because some children with autism look normal physically; people often mistakenly imagine they are simply unruly or poorly behaved (Tirrussew, 2005). Because of the general lack of awareness, families and children with autism are often blamed for their actions and the disorder is sometimes seen as punishment for some spiritual wrongdoing. In fact, with few Ethiopians even aware of autism's existence, more often than not the symptoms of the disorder are misrecognized and misunderstood, with tragic consequences (Letekidan, 2003). To support this, Chernet and Opdal, (2007) described that throughout Ethiopia, having a child with disability is regarded as a source of shame and misconceptions and unfavorable attitudes. These result in continued stigmatization which in turn led those children to be hidden at home and kept away from schools and other intervention programs.

This level of social standing of having a child with disability is derived from how disability is perceived in society (Abreham, 1998; Tirrussew, 2005; Weldeab, 2006, 1999; Weldeab & Endrerud, 2004). Weldeab (2000) found that labeling persons after their impairment is still common in most parts of Ethiopia. In most places, people use such terms as an insult which really have psychological impact on persons having those impairments and their families. Getnet, (2001) also noted the problem lies in defining disability since definitions of disabilities has been the medical model it is one of the dominant influences in shaping both professional and common sense which resulted in a range of offensive responses by other people.

As is the case in many developing countries, families in Ethiopia comprise the largest group of caregivers for children with disabilities. This is due to the fact that there is a lack of residential services and the vast majority of the children live with their families (Chernet and Opdal, 2007). In a country like Ethiopia where developmental or mental impairments are considered as things related with curse or some sort of bad omen, opportunities to make life better or improve the situation of people with the problem and their families is unsatisfactory (Letekidan, 2003).

According to the "Needs Assessment Report "conducted by Handicap National, (2012), fewer than 3% of children with special needs in Ethiopia have access to primary education, and access to schooling decreases rapidly as children move up the education ladder. Handicap International carried out a survey in Dire Dawa, Harar and Jigjiga to try and assess the causes of children with disabilities dropping out of education. Families were asked to identify reasons for children failing to attend school that fell into two broad categories: "family-level" or, school-level,, causes. Most families and children reported that family issues – often related to work or caring responsibilities – are the main cause. When it comes to school-level issues, "long distance to school" is the number one cause of drop-out.

As the report of Handicap National, (2012) further indicates in one of the Woredas in Addis Ababa it was reported that some parents are not willing to send their children to school or to play for fear of being endangered, hurt and segregated. Generally speaking, these parents face challenges in rearing children with disability and they may not send the children to school because of a number of reasons, i.e. the education of the child with special needs may not be the priority for the parents'; inability to cover school expenses; lack of awareness of parents whether their child can be schooled or not; feelings of parents that the child may not receive the necessary support; fear of shame and guilt, etc. (Handicap National, (2012)

These background societal attitudes and challenges perpetuate to influence parents of children with disability psychologically which affects their lifestyle and life chances (Getnet, 2001). The psychological and emotional stress by parents of children with the problem is immense since most parents of children with autism do not have information and knowledge about the symptoms of autism (Letekidan, 2003).

Some local researches show that most serious and probably most common problems parents of children with disability face in countries like Ethiopia relates to access to professional information and services. Most parents have no accurate and up to date information about their children's disability 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 all they need to know at any point along the way (Amakelew, Daniel and Fasikawit, 2000).

As a result of this lack of knowledge by parents, studies like Amakelew, Daniel and Fasikawit, (2000) reveal that Ethiopian parents feel insecure and guilt-ridden because of imagined responsibility for the child's condition. They do some sort of searching for shortcomings of their own which might have caused disability in their children which made them feel ashamed of their children's and often try to hide them from friends and neighbors.

Through time and after getting more knowledge and experiences with their children's disabilities, parents face another psychological problem. They feel guilt that will never disappear but stay on part of the parent's emotional life of not recognizing the problem with the children in time (Getnet 2013).

Due to lack of awareness, the parents may demand behavior and intellectual achievement beyond the child's abilities in turn they feel ashamed of the mistake done in pushing the children beyond their capacity and losing patience with them (Amakelew, Daniel and Fasikawit , 2000). Similarly, Meron, (2006) described that most mothers in Ethiopia suffer from life time regrets over the disparity of heart-breaking reality that their children would have the problem for life that magnifies other existing problems, creates new area of conflict and feeling of hopelessness.

Consequently, stress and anxiety are the common psychological challenges to these mothers raising a child with disability due to inability of children to express their feeling, future of their child, feeling of sorrow and who will take care if something happens to them (Meron, 2006).

2.6. Challenges and Opportunities of Having a Child with Disability

2.6.1. Challenges

A child's disability is a triadic experience involving three-way interactions among the child who experience dysfunction, the family that is affected by it, and the external environment where the disability is manifested (Zelalem, 2002). Raising a child with disability is an experience which lives the parents with great stress and several caregiving challenges, such as more health problems, greater feelings of restriction, higher level of depression, grief and financial problems. Research revealed that parents encounter a lot of challenges. Some of the challenges they encounter include social isolation, grief, emotional stress and financial problems (Woodman, & Hauser, 2013).

Beresford *et al*. (2007) states that no matter how severe the special needs of the child are the parents are inevitably affected in one way or the other. They further state that parents often struggle with guilt; they feel as though they somehow caused the child to be disabled, whether from genetics, alcohol use, stress or other logical or illogical reasons. This guilt can harm the parent's emotional health if it is not dealt with. Some parents experience a spiritual crisis or blame and the other parent may be for not giving the support which is needed. According to Dobson *et al*. (2001) parents of children with disability undergo the period of

grieving which is like that of bereavement. Parents grieve for the 'death' of the perfect child who existed in their minds. They feel ashamed and embarrassed that their child is not normal. They may move through emotions like grief, anxiety, fear, guilt, depression and anger.

Parents attach to children through core-level dreams, fantasies, illusions and projections into the future. Disability dashes these cherished dreams (Wang *et al*., 2010). The impairment, not the child irreversibly spoils a parent's fundamental, heartfelt yearning (Dobson *et al*. 2001). Dobson and colleagues continue by explaining disability as it shatters the dreams, fantasies, illusions and projections into the future that parents generate as pain of their struggle to accomplish basic life missions. Parents of impaired children grieve for the loss of dreams that are keys to the meaning of their existence to their sense of being. Recovering from such a loss depends in one's ability to separate from the lost dream and to generate a new, more attainable dream (Gallagher & Whiteley, 2012).

Parents of children with disability face social isolation. Taking care of the child with disability requires a lot of time of the parent. As Beresford *et al*. (2007) stated parents of children with disabilities suffer from exhaustion and stress due to the degree of the amount of care needed (feeding, clothing, bathing and diapering). The findings are in line with what Beresford *et al*. (2007) said as all the respondents revealed that when asked about to the issue of social isolation is that they were now isolated from the community, friends and relatives; they said their socializing time was no longer there, because they now spent a lot of time with their children. They also said friends have become few, relatives, some of them are supportive and some are not, some have negative attitudes to the children with disabilities (Beresford *et al*. 2007). This is among barriers preventing families from leading ordinary life as they are excluded from the community. A study conducted in Kenya by Gona *et al*. (2010) revealed that families of children with disabilities felt excluded from the society due to a shortage of services and negative attitudes. The families have enough challenges to overcome, to secure the support they need without also having to cope with prejudice and isolation. They want the same things as other families, they want to be included and supported by their communities and they want to enjoy time together and have fun.

Parents can find themselves overwhelmed by various medical, caregiving and educational responsibilities (Baker *et al*., 2012). Beresford *et al*. (2007), state that no matter how severe the special needs of the child is, the parents are inevitably affected in one way or the other. They have to stop feeling ashamed or embarrassed that their child is mentally challenged. Smith (2002) concurs with Blachar & Bakar (2007) saying that even after diagnosis; parents

often face a whole gamut of emotions before they can grapple effectively with the stark truth that their child has. Having a child with special needs can dig deeper into the pocket of the parent (Lutz *et al*., 2012). Raising a child with disability may be too expensive than raising a typical child. These expenses may arise from medical equipment and supplies such as wheelchairs, medical care, care giving expenses, private education, learning equipment, tutoring or specialized transportation.

Parents of children with disabilities also have to deal with complex issues related to the child's education. Either a private education must be sought, or an adequate public or general education must be available (Pottie *et al*., 2009). Close parental contact with the school system is vital in order for the child to receive a proper education. Parents must collaborate with teachers in order for their child's education to be effective (Smith, 2002). Teachers and parents have to be partners in the education of the child with disability.

Thwala and Simelane (2010) assert that parents and other caregivers are an integral part of their children's education. For this reason, they must be involved in educational decisions affecting their children from initial planning to implementation. Parents of children with disability experience challenges which may lead them to make mistakes in upbringing of their children and which can give rise to learning difficulties and other problems (Johnson, 2012). They need to be motivated to become involved in the education of their children. Parents play a greater role in the education of their children because they know their children better and are able to inform the teachers about their learning problems (Thwala and Simelane 2010). They can help teachers to understand their children better and they can give advice about individual behavior.

A study of 142 families with a child born with spina bifida (Tew *et al*., 2009) (56 families with a surviving child) between1999–2004 was examined in 2009. The divorce rate for families with a surviving child was found to be nine times higher than that for the local population and three times higher than for the families where the child with spina bifida had died. Marriages that followed prenuptial conceptions were especially vulnerable with a separation/divorce rate of 50%. All divorced fathers and only one mother had remarried at follow-up. An additional study also found the divorce rate ten times larger in the families with a disabled child than in the general population (McCormack, 2009).

The disability can cause damage to the married life of the parents in several different ways: it can create strong parental feelings, it can be a depressing symbol of a common failure, and it can change the family organization, or create fertile ground for conflicts (Featherstone,

2000). One frequent problem is the fact that the burden for childcare is not divided equally between the parents. In the common situation, the father is generally at work, while the mother cares for the child with the disability (Waisbren, 2003). The parents must organize a system of roles and a division of the burden of work in order to prevent the burning out of one partner (Withers, and Bennett, 2003). In addition, devotion of the mother to care for her child may make the father feel neglected, which sometimes can result in violence (Lecavalier *et al*., 2006). Sometimes the core of the conflict stems from the fact that each parent conceives the situation in a different way. One parent may relate to the child as a failed case, while the other as a capable, or even as a normal child. In addition, there are parents who are unable to live with what they see as shame or stigma (Lyons *et al*., 2010).

2.6.2. Opportunities

A point of consensus among researchers in the field is that families of children with disability face adversity, or in the very least, significant, out-of-the-ordinary adaptive challenges. Another point of consensus is that while most may struggle, many families of children with disability fare well. Although researchers have consistently found higher-than-usual rates of psychological distress among parents of children with disability, the absolute risk of psychiatric disorder may not be as large as many might think (Montes, and Halterman, 2007). The majority of parents caring for a child with disability are not depressed (Singer, 2006; Seltzer *et al*., 2001; Glidden and Jobe, 2006).

Furthermore, many families of children with disability report positive impacts. McConnell *et al*., (2015) recently surveyed a robust sample of primary parent carers of pre-adult children with disabilities in Alberta, Canada, and found that two thirds agreed or strongly agreed with the statement: “Overall, having a child with disabilities has been positive for our family”. More than four out of five parents in the study reported benefits including but not limited to perspective transformation (e.g., “We have learned what is really important in life”) and the strengthening of family relationships (e.g., “Our family has emerged stronger”).

Shilling *et al*. (2013) reported that the results of qualitative and quantitative evaluation of peer support interventions confirm that having a child with disability can have a positive effect on the psychological health of caregivers, although the findings are not entirely consistent. Based on a synthesis of qualitative findings from ten studies, Shilling *et al* 2012 identify four themes related to benefits. The most common benefit identified was ‘finding a shared social identity with other parents’. In a group with experientially similar others, parents found understanding and acceptance, which reduced their sense of isolation and

enabled them to feel better able to cope. The second benefit identified was ‘learning from the experience of others.’ Peer support interventions can facilitate the exchange of useful, practical information, and parents learn from the experience of other parents. The third theme related to benefit is ‘personal growth’. Parents report having gained strength through peer support. They were more accepting of themselves and felt more confident and in control. The fourth benefit is ‘the opportunity to support others.’ In several studies, parents reported that the opportunity to share their experience and support others validated their expertise as parent careers, giving them an increased sense of self-worth.

2.7. Psychological Problems of Parents of Children with Disabilities

Numerous studies have found higher than ‘population normal’ rates of psychological distress among mothers and, less consistently, fathers of children with disability (Singer, 2006). Recent population-based studies and systematic reviews confirm that mothers of pre-adult children with disability are two to three times more likely than mothers of typically developing children to report clinically significant levels of stress, anxiety and depression (Emerson, 2003; Lee, 2013; Totsika *et al*., 2011). Despite these broad findings, it is also acknowledged that parents of children with a disability vary in the levels of stress they experience and that their levels of stress are associated with a wide range of variables (Frey *et al*. 1989; Quine & Pahl 1991; Baxter *et al*. 2000). Studies found that parenting stress is associated with the severity of the child’s disability (Minnes, 1998), although others have failed to find any similar associations (Beckman, 1983; Walker, VanSlyke, & NewBrough, 1992). Generally, it seems that specific characteristics associated with disability are more important correlates of parental stress (Minnes, 1998). These include child communication skills (Frey *et al*. 1989) and particularly the levels of the child’s behavioral difficulties (Friedrich *et al*. 1981; Konstantareas & Homaditis, 1998; Quine & Pahl, 1991). Chronic stress may underlie the (marginally) increased risk for families of children with disability of marital disruption and family dysfunction (e.g., low cohesion, emotional withdrawal, and relationship conflict and child maltreatment) (Baker & Seltzer, 2012).

Furthermore, several prospective studies have found that child behavior problems predict later parent stress, and this may mediate the relationship between child behavior problems and family dysfunction (Baker *et al*., 2003; Eisenhower *et al*., 2013; Neece *et al*., 2012; Peters-Scheffer *et al*., 2012; Woodman *et al*., 2015). Baker *et al*. (2012), for example, found that the behavior problems of children with disability had an indirect effect on family cohesion and marital satisfaction by way of maternal internalizing symptoms. Parents of

children with developmental delays (DD) have been shown to have very high levels of parental stress (Baker, *et al*., 2003; Baker, *et al*., 2000; Oelofsen & Richardson, 2006; Webster, Majnemer *et al*., 2008). Research has shown that the high levels of parenting stress experienced by these parents is better accounted for by elevated child behavior problems rather than child intellectual or developmental functioning (Baker *et al*., 2005; Baker, Blacher *et al*., 2002; Beck, Hastings *et al*., 2004; Hastings, 2003; Neece, Green and Baker, 2012).

Studies also indicate that parents' psychological health and well-being tends to decrease as children's behavior problems increase (Beck *et al*., 2004; Hassall, Rose, & McDonald, 2005; Hastings, 2003). This association has been found in specific areas such as depression and marital satisfaction (Baker *et al*., 2005), but has been particularly evident in parental stress. For parents of children with DD, greater marital quality has been associated with lower parenting stress, even after accounting for socioeconomic status, child characteristics and other measures of social support (Kersh *et al*., 2006). Given that marital quality is associated with lower parenting stress, it is important to examine this construct in parents of children with DD who generally report high levels of parenting stress.

Previous research comparing marital satisfaction among parents of children with or without DD has yielded mixed results. While some studies have found that parents of children with DD report lower levels of marital adjustment and satisfaction than parents of typically developing children (Santamaria *et al*., 2012; Kersh, at al., 2006; Risdal and Singer, 2004), other studies have found no differences in marital satisfaction between parents of children with or without DD (Donovan, 1988; Stoneman & Gavidia-Payne, 2006). However, within samples of families of children with DD, studies have consistently found that high marital satisfaction is a compensatory factor that buffers the experience of parenting stress, whereby greater marital quality in these parents predicts lower parenting stress (Gerstein, *et al*., 2009; Kersh, *et al*., 2006).

Further, many of the existing studies done have focused on older children using a homogenous sample of primarily Caucasian/Euro-American families of relatively high socioeconomic standing, making their results potentially less generalizable to the general population (Kersh, *et al*., 2006; Stoneman & Gavidia-Payne, 2006). Children in minority populations and with higher rates of poverty are also at higher risk for child behavior problems, and their parents are at higher risk for mental health issues such as parental stress, making it especially important to study this population (Bengi-Arslan, Verhulst, Van der Ende, & Erol, 1997; Horwitz, Leaf, & Leventhal, 1998; Stevens & Vollebergh, 2008).

Previous investigations in this area have also often focused on heterogeneous samples with children in a wide age range (Erel & Burman, 1995; Risdal & Singer, 2004; Santamaria, *et al*., 2012) and studies examining a specific developmental period have largely focused on middle childhood with samples ages 6 to 12 (Henderson, *et al*., 2003; Kersh, *et al*, 2006). However, research has shown the preschool period to be a critical developmental period where families are particularly vulnerable to experiencing high levels of stress and child behavior problems (Neece *et al*., 2012), further underscoring the need to study these variables in a sample of families of young children with DD.

2.8. Gender Difference in the Psychological Problems of Parents Having Children with Disabilities

Though the child's disability affects the whole family, there is considerable evidence that mothers experience greater impact than fathers by their child's disability (Hastings *et al*., 2005; Oelofsen and Richardson, 2006; Gray, 2003). For example, Gray (2003) found that mothers and fathers were affected on different ways and levels by their child's condition. Fathers claimed that their child's condition did not affect them personally as it did with their wives. They also admitted that the way their child's autism affected them was through the stress that their wives experienced. The different levels of stress experienced by mothers and fathers may be explained by gender roles connected to work and child rearing.

While mothers usually are more involved in child rearing, fathers are more into working harder in order to support their family's financial needs. There is difference between mothers and fathers in the coping strategies they use. While fathers tend to suppress their feelings, or to avoid them by working until late or staying away from home, mothers tend to vent their feelings. Mothers tend to experience a wider range of feelings (from grief, sadness, anger and crying) and talk more about their emotional distress with others. Mothers are found to be more stigmatized by their child's disability (Gray, 1993). There are also differences in mothers' and fathers' perceptions or cognitive appraisals. For example, research suggests that they may perceive family cohesion and adaptability differently. When asked about family cohesion and adaptability mothers reported having a significantly more cohesive and adaptable family as compared to the reports from the fathers (Kraus, 1993).

2.9. Coping Mechanisms of Parents of a Child with Disability

Coping strategies refer to conscious efforts to adapt with/solve stressful situations (Glidden, & Natcher, 2009). They are practical active ways of responding to threatening situations. Coping strategies are divided into two major categories: (a) problem-focused coping

strategies which represent an attempt to do what an individual believes it might affect the circumstances that led to stressful situation (b) emotion-focused coping strategies which represent efforts to regulate emotions resulted from the stressful situation (Lazarus, &Folkman, 1984).

As Nabawy and Ahmed (2012) pointed out, coping involves psychological and social resources and strategies that help to eliminate, modify, or manage a stressful event. The age of the parents, number of children, civil status, and their interpretation of the crisis event, the family's sources of support, community resources, and education of the parents are from the factors that affect the kind of coping mechanisms employed by parents (Durban, 2012).

According to Picci *et al*. (2015), past experiences, perceived social support, nature of stressful situation are examples of preference factors of adopting coping strategies. Lopes, *et al*., (2008) also indicated that the nature of the stressful situation may determine the kind of strategies used to cope with, i.e. individuals tend to use emotion-focused strategies in situations where they are incapable to provide direct efforts to handle these situations such as health problems, while they tend to use problem-focused strategies in situations where they can handle and control, such as family conflicts. Pastor *et al*. (2009), on the other hand, summarized this by declaring that in stressful situations where an individual is able to execute productive actions to handle these situations, it's preferred to use problem focused strategies.

The burden of caring a child with disabilities will increase levels of stress in parents, which lead them to look for, develop, and use strategies to handle these stresses. According to Seymour, *et al*., (2013) the outcomes of using such strategies might be in behavioral appearance such as neglecting responsibilities at home and work, or cognitive appearance such as weakness in problem-solving or emotional appearance which includes negative feelings toward the child with disability. In this regard, Woodman, & Hauser (2013) referred to coping strategies as continuous change in cognitive and behavioral efforts by individual to handle the increasing external and/or internal demands of caring the child with disability. According to Picci, *et al*., (2015), parents of children with disabilities tend to use various strategies to cope with stress such as looking for support, avoidance strategies, self-blame, drug abuse, making jokes, reconstruction of stressful situation in positive manner, or denial. Taanila, *et al*., (2012) referred to avoidance strategies and self-blame as coping strategies, while other parents tend to search for positive issues in caring the child with disability such as religious attitudes, which are considered as an important coping strategy. Variation in the use of coping strategies is correlated to many factors. Woodman, & Hauser (2013) and Wang,

Michaels, & Day (2011) indicated that parents tend to use emotional-focused and avoidance strategies in early stages of diagnosing disability, and as the child grows, parents tend to use problem-focused strategies.

This variation in coping strategies was found also between fathers and mothers Sandler and Mistretta (1998) analyzed the coping strategies and stress responses of 135 parents of adults with a disability. Sandler and Mistretta surveyed the participants about their positive attitudes and coping strategies one of which was appraisal. Passive appraisal happens when the parents tell themselves things like" Tomorrow is another day, or 'Let's take things one day a time 'as a way to cope. Selective attention strategies mean that the parents only pay attention to the positive experiences associated with raising a child with disability as opposed to the negative ones as a way to copeThe findings from this study showed that 94% of the respondents used passive appraisal and 92% reported the use of selective attention to cope with the stress of raising a child with a disability. It appears that maintaining a positive attitude and positive thinking strategies are essential when raising a child with a disability.

Scorgie and Sobsey (2000) studied the transformations made by parents that were raising a child with a disability. The author defined transformations as positive or significant changes in the lives of parents who have a child with a disability. The study found a positive outlook on raising a child with a disability coped more effectively than when they served as leaders or advocates for other families raising a child with a disability, they coped more effectively and were able to remain more positive than those that did not. This suggests that helping other families can help parents cope better with their own experiences raising a child with a disability.

Dun, Burbine, Bowers, and Tantleff-Dunn (2001) conducted a study that examined stress levels and coping styles of parents who had children with autism. Dun *et al*. found that the participants who used more escape avoidance behaviors as coping mechanisms had a decrease in positive reappraisal coping strategies. The researchers also found that if the respondents adopted escape avoidance strategies to cope with having a child with autism, they experienced more stress and health problems than the parents that used positive reappraisal strategies. Examples of discouraging positive reappraisal coping strategies include the following: hoping for miracles, having fantasies, using food or drugs and avoiding others.

Taunt and Hastings (2002) investigated coping tactic among parents of children with disabilities using face-to-face interviews and internet surveys. Two samples Participated; the first sample included 14 parents (4 fathers and 10 mothers) who were interviewed one-on-one

while the second group consisted of 33 parents who answered questions on the internet. The interview questions in the first study pertained to the Positive aspects of raising a child with disabilities, the family's hopes or fears regarding their child's future, and the positive effects of having a child with a disability on siblings and family relationships. Phase two of the study used the internet to survey participants about the positives of raising a child with a disability, as well as any positive effects the experience can have on additional family members. Taunt and Hastings (2002) found that parents with positive attitudes envisioned positive outcomes for their child. Parents reported the more positive they were, the more sensitive and caring the entire family was towards the child with the disability. Family members sought out more opportunities to learn about the condition affecting their child/sibling along with the impact on their perspective on life.

Kenny and McGilloway (2007) conducted a study on caregiver strain and coping among parents with children with learning disabilities. The sample consisted of 24 mothers and 8 fathers. The participants were interviewed about caregiver strain, daily activities, support and coping strategies. Kenny and McGilloway found that 2/3 of the participants used professional support to help cope more effectively. The participants also reported that receiving support from the schools their child attended helped them cope more effectively. Clearly, external sources of support are critical to parental coping when raising a child with a disability.

Van Der Veek *et al*. (2009) surveyed 553 families with at least one child with Down syndrome about their coping strategies, resources, and stress. Care, a coping mechanism measure in the study, was described as reflective of the amount of care each partner contributes to the relationship between them. Positive reappraisal occurred when a parent of a child with Down syndrome has a positive thought when thinking about their child. Control was measured by the Intimate Bond Measure (IBM). Example of care is, "Understands my problems and worries," and" Is very loving to me" and an example of control is, "Insists that I do exactly as I'm told," and "Seeks to dominate me" (Wilhelm, 1988). Coping self- efficacy is an internal coping mechanism. An example of this is "I am confident that I could deal efficiently with unexpected events concerning my child with Down's syndrome" (Van Der veek, *et al*., 2009, p.220). Van Der Veek, *et al*. (2009) found that the coping resources of care, control and perceived social support were related to depressive symptoms; that care and social supports lead to-fewer depressive symptoms while control lead to more depressive symptoms. Results also indicated that participants reported that they used positive reappraisal, care, social support, and self-efficacy coping strategies coped more effectively.

Finally, the findings revealed that positive reappraisal was related to positive affect as was receiving more care from partners, and more confidence in coping abilities predicated emotional well-being. Churchill *et al*. (2010) conducted a study of 129 parents of children (85% female) with special health care needs (CSHCN) to examine how they coped with having a child with a disability. Depressive symptoms, coping skills, and the child's medical condition were assessed. Reframing was operationalized as looking at problems' parents' facer from the viewpoint of being positive and accepting. Passive appraisal referred to not taking immediate action on any certain problem the parents may have been dealing with. Findings showed that the better coping skills like social support, reframing, spiritual support, accepting help and passive appraisal meant fewer depressive symptoms for the participants.

Social Support (seeking assistance) is the major coping mechanism that is found to be moderating parenting stress and daily negative mood (Colin and Kathleen, 2008). Supporting this, a study by Lori (2008) found social support a significant contributor to reduce family stress and resulted in family coherence.

Parents of children with disability need support to assist them emotionally and physically by being provided resources (Myers, Johnson and the Council on Children with Disabilities, 2007). While the primary social support includes spouses, partners, neighbors, family, and friends who offer emotional and mental assistance informal support on the other hand involves other parents of children with autism and local organizations that give instruction, guidance, respite care, and social events (Myers et al., 2007). Seymour, et al., (2013), Hartley, et al., (2012) and Glidden, & Natcher (2009) indicated that mothers of children with disabilities were looking for social support and concerned more about emotions, while fathers, in return, tend to use avoidance and problem-focused strategies. Understanding strategies used by parents to cope with stress of caring a child with disability is considered as a major component of psycho-social support programs, especially if we knew that if parents depend on negative strategies to cope with stress, levels of stress might be increased, in other words, different levels of stress in parents of children with disabilities means different strategies of coping they use (Singer, et al., 2007).

A phenomenological research which explored mothers‟ perceptions of effective coping strategies for their parenting stressors in the North Eastern United States by Heather et.al (2010), also demonstrated that participation of their spouses in the parenting was critical for mothers as they split the responsibilities and felt a sense of relief knowing that in their spouse, they had someone who they could relate to as a significant emotional support.

Other studies by Gray (2002); Montes, and Halterman (2006); Boyd (2007); Pottie and Ingram (2008) and Latefa (2014), found that parents of children with autism spectrum disorder who have a strong social support network demonstrated a greater ability to cope and adapt to new and challenging situations. Altiere (2009) maintained that mothers were more likely to report that their family seeks social support during times of crisis than fathers because it gave them confidence and perception of a low stressed lifestyle. Supporting this Boyd (2007) reported for mothers, as opposed to fathers, the perceived usefulness and availability of social support network play a vital role in lessening stress as a result mothers most often want, and first seek, support from their spouse. Correspondently, according to a Philippines study by Durban et.al (2012), mothers tend to get closer to the family for support while the male slowly created distance between him and the family because they do not know how to handle the situation and sometimes would have the feeling of blaming their wife for the disability of their child.

Participation in religious organizations was another positive coping strategy (Gray, 2002; Pauline, 2014). Several families found extensive support from religious organizations and felt that their spirituality was enhanced because of their situation (Altiere, 2006; Joachim and Robert, 2012).

The findings from Tiffany (2010), shows that being involved in a Bible study assisted participants in developing patience, stress management, helped to deal with the obstacles that come with their child's autism and in the healing of their child. Similarly, in a study by Durban et.al (2012), parents were able to find comfort in religion because it can give them strength to continue to go on with their lives despite the challenges, they face with the extra burden of taking care of the child with Disability.

Lataf's (2014) study also showed that positive reappraisal and spirituality are commonly used coping strategies among Jordanian parents raising a child with autism. As illustrated in this study the high reporting of the use of positive reappraisal as a coping strategy may be due to the Jordanian culture where one need to believe in God's will and pray to bring comfort and calm. Parents of children with disability have been also found to use positive appraisal (creating a positive out of a situation) as a coping strategy more frequently while dealing with the stressful situation of having a child with disability by focusing on personal growth (Nisha and Susan, 2010).

A phenomenological study, which explored what meaning does raising a child with disability have for parents (Kristen, 2008), showed that participants made reference to a number of positive changes in their lives that is attributed to cope easily with their children's situation such as a reevaluation of their general outlook on life such that they had become mentally stronger; more resilient in the face of stress; and more appreciative of life and the small things that can make them happy. Consistent with Kristen's study Altiere (2006), described conceptualizing the event of raising a child with disability is an integral part of parents' ability to cope with the struggles they face every day. Parents in this study supposed if they dwell on a negative attribution of this event, it is likely that they will cope poorly with the situation Likewise, Sivberg (2002), identified flexibility, problem-solving, patience, unconditional love and understanding qualities which have enabled them to emerge from the strain of parenting their children with dignity and resilience.

Bayat's (2007) survey with 175 parents of children with autism ranging from two to eighteen years of age provides evidence that, despite extraordinary challenges faced by families of children with autism, a number of these families show resilience. Bayat determined that families who demonstrated resilience (the capacity to endure adversity while becoming stronger and more resourceful as a result) had a greater ability to cope with their child's disability. Lori's (2008) phenomenological study found that when first learning of the diagnosis parents experienced a sense of loss, grief and faced other negative impacts due to disability; however, they were able to prevail and overcome their many challenges and their first step in recovering from their grief was acceptance and understanding.

Research shows that families who have moderate levels of cohesion and adaptability have higher levels of positive coping (Altiere, 2009). Another study by Lara (2007) found that a positive attitude and acceptance of the disability were important aspects of getting through the day for the participant parents which enabled them to find appropriate interventions and education for their children. Finally, in a Sweden study, Sivberg (2002) concurs that a strong sense of cohesion and acceptance had a strong stress reducing effect regardless of a severe life situation as a parent of a child with autism. These parents reported that they developed their adaptability as they educated themselves and learned new strategies to create a cohesive family unit which enabled them to adapt to life's difficult situations.

Information about specific areas of impairment associated with burden of care disability could also help in designing and implementing appropriate interventions to help parents understand and cope with the behavior of a child with disability (Bello-Mojeed et.al 2013).

Harmoniously, more than half of parents reported that information related to resources, treatment, coping strategies, and prognosis were helpful in Angela's (2013) study, in terms of what was the most useful source of information to them, they reported information from family services workers, local support groups, as well as workshops and early years courses offered by the support groups were the most helpful sources of information. Lori (2008) indicated that parents experienced a sense of relief with having knowledge and information about their child's specific disability. They demonstrated educating themselves about it helped them to better understand their children's behavior and could also plan for the future. As well Sivberg (2002) and Heather et.al, (2010), suggested that parents need to fully increase their knowledge about the phenomena of the disability in order to effectively manage the upbringing of their child because knowledge equals power and can motivate parents to be the greatest asset to their children understand and cope with the behavior of a child with a specific disability (Bello-Mojeed et.al 2013) In addition, Murphy and Tierney (2007), in their study of parent's need of information and education about Down syndrome in Ireland consisting 27 mothers and 11 fathers indicated that information was used by parents in this study to gain a greater sense of control over child and family outcomes. The majority of parents reported that other parents of children with Down syndrome and the internet were their greatest sources of information and emotional support.

To summarize, the above literatures clearly indicate that social support, religion, information, acceptance and adaptability are effective coping mechanisms for parents of children with disability to better be able deal with the challenges raising their special needs children.

2.10. Theoretical Framework

This study has adopted the Ecological theory (Bronfenbrenner, 1979) as its theoretical framework. This is mainly because the theory provides explanations on how children influence and are influenced by the institutions in their environment; and how such relationship shapes their development. The ecological paradigm, as it explains human development, can be traced back to Bronfenbrnner's work of 1970's, which looks into a child's development within the context of the relationships that exists with their environment (Bronfenbrenner, 1979). This theory defines complex layers of environmental factors, each having an effect on a child's development. The interaction between these factors in the child's maturing biology, their immediate family/community environment, and the societal landscape directs their development and changes or conflict in any one layer will flow throughout other layers (Catherine, 2011).

The model also postulates that human development occurs as the person actively and reciprocally interacts with the various ecological contexts over time which incorporates: several levels of ecological context; developmental processes or the relations between the individual and the environment; the person's biological, cognitive, emotional, and behavioral repertoires and various time dimensions (Behav, 2007).

Ecological theory, as it relates to children with disability, suggests that, in addition to the direct effects that can occur on a child with disability by interaction with the environment, there might be indirect effects as interactions among the various levels of the ecologies themselves can reciprocally and dynamically transform those ecologies (e.g., parents and providers can affect social policy that then affect the child's more immediate environment and the child him or herself) (ibid). In other words, the ecological theory considers disability not just as a physical condition, but one that also highly attached to various social factors, which impact on how a certain disability is viewed in a society. These social factors somehow affect family members, various service providers, the immediate community, the larger society, and culture as well as the child, in a transactional manner.

CHAPTER THRE: RESEARCH METHODS AND PROCEDURES

3.1. Introduction

This chapter provides a detail discussion about the type of research design and research approach employed in this study. Moreover, topics related to description of the study area, target population, sample size and sampling techniques, methods of data collection, data collection procedures, methods of data analysis and interpretation as well as explanation about ethical issues were included.

3.2. Research Design

The qualitative approach was considered appropriate for this study because it provided an in-depth understanding and a rich description of the participants' psychological problems associated with parenting a child with disability (Creswell, 2007). As the purpose of this study was to investigate psychological and social impacts of having a child with disability and the coping mechanisms they use to deal with those challenges, qualitative research was identified as the most appropriate. Qualitative research is suitable when researchers aim to understand how people experience events, how they make sense of their experiences and to reflect on their experiences (Deborah, 2012).

Similarly, Joanna and Alison (2006) indicated that qualitative research advances knowledge through a series of detailed, small-scale studies which embraces how people construct meaning to a shared understanding, feeling, or perception of a situation. Therefore, a qualitative design was identified as the most appropriate to meet the research aim of exploring the meaning, challenges and coping mechanisms inherent in the experiences of parents of a child with disability. Specifically, the researcher employed phenomenological research design to guide this thesis in accordance to the research questions because it was particularly effective at describing how things are experienced firsthand by those involved (Martyn, 2003).

3.3. Description of the Study Area

The study was conducted in Addis Ababa. It is further narrowed down to focus on parents who have children with intellectual disabilities and enrolled in CMCC. CMCC was founded in 1986 to provide children with intellectual as well as physical disabilities education that commensurate with their specific special needs. Currently, the Center provides support for

376 children with disabilities (Intellectual disabilities, Autism Spectrum Disorder, Down syndrome, Deaf/Hearing Impairment, Visual Impairment, Cerebral Pals and Epilepsy), out of which 265 are male and 111 are female. As a part of its early childhood program, CMCC offers counselling services for parents. As of 2018, the Center had provided 109 psychotherapeutic help to parents and caregivers. CMCC was chosen for various reasons. Firstly, it has been serving the population in question for a long time, certainly, longer than any other centre working on similar issues in Addis Ababa (CMCC Annual Report, 2019). It has long-standing experiences and rich data on the topic of the present study. Secondly, the types and severity of disabilities they dealt with were so varied, making it possible to gather data relating to various disabilities. Thirdly, it was easily accessible for data collection and verification.

3.4. Target Population

Six parents, 4 mothers and 2 fathers, were considered for the study, on the basis of theoretical saturation, which dictates the point in data collection where new data no longer bring additional insights to the research questions and small sample sizes are the norm. All of them are parents of children with disability receiving support at the Centre and the Centre's caregivers were considered as the source population for this study.

3.5. Sample and Ssampling Ttechnique

Sample size in qualitative studies are often determined on the basis of theoretical saturation (the point in data collection where new data no longer bring additional insights to the research questions) (Englander, 2012) and small sample sizes are the norm (Collins & Nicolson, 2002). Hence, as noted above, the researcher identified six parents (2 fathers and 4 mothers) of children with intellectual disability from CMCC who were information rich with respect to the phenomenon. Inclusion criteria for the study were (a) parents/caregivers who self-identified as having or caring for a child with intellectual disabilities, (b) parents or caregivers involved in the day-to-day care of the child with intellectual disabilities, (c) parents or caregivers of children with intellectual disabilities between the ages of 5 and 12 years. This age range of 5 to 12 years was settled to narrow the focus of the study and to decrease the variance that is likely to occur with a wide age range, (d) parents who consented to be interviewed with audio tape and could speak and understand Amharic or English languages.

The study used a type of non-probability sampling technique called purposive sampling, whereby participants were chosen carefully ensuring that they meet the selection criteria described above.

3.6. Data Collection Methods

In this study, Semi-structured interview and focus group discussion (FGD) were used to collect data. In qualitative research triangulation (both in terms of method of data collection and data source) is very important. To this end, interviews and focus groups provided the depth of information that is useful for this study.

3.6.1. Semi-Structured Interview

For the exploration of the central phenomenon of this research, a semi-structured interview was deemed most appropriate. This choice was based on the following considerations, as suggested by (Nohl, 2009):

- The semi-structured interview gave the participants ample time and scope to express their diverse views and allowed the researcher to react to and follow up on emerging ideas and unfolding events.
- Results obtained through semi-structured interviews could be compared among each other since all participants are required to express their views about the same general themes.
- Semi-structured interviews allowed not only for assessing the participants' opinions, statements and convictions, they also to elicit narratives about their personal experiences.
- Anonymity was guaranteed in order to give the participants the opportunity to freely express their views and encourage them to also address politically delicate issues.

A list of guiding questions was compiled and used to guide the interviews in order to make sure that all respondents address in the interview process the issues that are of interest for this study. However, this list was not used for standardizing the data collection procedure, it merely provided a frame for the discussions and intended to trigger and guide the respondents' narratives. The interview included questions that focus on different areas such as demographic information, challenges and opportunities of having a child with disability, the psychological problems of parents of children with disabilities and how they cope. Some of the questions included: How did you feel when you first found out the condition of your child? What strategies do you use in dealing with stress associated with caring for your child? Probing questions will be asked where necessary to obtain information, clarify a point, or expand on ideas. Field notes on the experiences of parents were also made during each

interview to serve as an audit trail. The interviews were made both at CMCC and at homes of the participants. Each parent was interviewed on average for 40 minutes.

3.6.2. Focus Group Discussion

Focus group discussion was the second method of data collection in this study. Focus group discussion aims at collecting high-quality data in a social context (Patton, 2002), which primarily help understand a specific problem from the viewpoint of the participants of the research (Khan & Manderson, 1992). Focus group discussion was used for the following two reasons. Firstly, focus group discussion is a valuable method when the researcher lacks substantial information about the subjects. Focus group provides "a rich and detailed set of data about perceptions, thoughts, feelings and impressions of people in their own words" (Stewart & Shamdasani, 1990, p.140). Secondly, focus groups are predominantly beneficial when a researcher intends to find out the people's understanding. Focus group discussion was conducted to collect basic information from parents to identify psychological problems associated with parenting a child with disability. It also helped to assure the validity of information that was collected from semi structured interview

3.7. Data Collection Procedure

The procedure for administering the above method of data collection was systematically managed by the researcher. First, participants were informed of the study through the CMCC administrators. Then, initial contacts were made with participants to obtain their voluntarily agreed consent to participate in the study. Then, participants were contacted by the researcher via a telephone call with the aid of the CMCC administrators to schedule a meeting at their own time and convenience. The researcher was has prior experience working with parents of children with disability. During the interviews, parents were requested to give detailed descriptions of their experiences relevant to the issues in question. All interviews and FGDs were conducted in Amharic language, digitally recorded, and last for 30 to 60 minutes to allow the participants to freely voice their experiences. For FGDs, the parents were directed to discuss their individual experiences.

3.8. Data Analysis and Interpretation

All interviews and FGD were transcribed verbatim and translated into the English language. Two people having a minimum qualification of college diploma, with experience in qualitative research assisted in transcribing the audio recorded data. The transcribed data

were also reviewed by the researcher to ensure that all the details of the interview are captured accurately.

The following four steps were followed in analysing the data: (a) familiarization with the data, (b) generating initial codes and searching for themes, (c) reviewing themes, and (d) defining and naming themes. First, each transcript was read and reread to get familiar with it and to identify important quotes and phrases within each transcript. The researcher then proceeded to make notes from the transcripts documenting similar quotes and phrases. These notes represent a description of the participants' experiences and the researchers' interpretation of the transcripts. Second, coding was done, by labelling and organizing the transcribed data in such a way that it was possible to identify major themes that could emerge from the data and the relationships between them. Third, the coded data falling into similar or related topics were grouped together to form major themes. Finally, the themes were named, and a thematic network was developed to summarize all the superordinate themes and their subthemes.

3.9. Ethical Considerations

Before the data collection starts at the site of the study, the researcher obtained formal letter of permission from the School of Psychology, Addis Ababa University. Participants were requested to sign a consent form prior to the interview sessions. The consent form provided a description of the nature of the study. The consent form clearly indicated the voluntary nature of the study to participants, and their right to withdraw from the study at any time without any consequence. To ensure confidentiality and anonymity, the researcher created pseudonyms for participants, and this was used throughout the study. Moreover, permission was sought and obtained for the interviews to be audiotaped. Participants were not provided any compensation for participating in the study.

CHAPTER FOUR: RESULTS

4.1. Introduction

This chapter presents the main research findings obtained from the key informant interviews and participants' focus group discussion.

First, the participants' demographic information was presented. Then, summaries of personal narratives of the parents, as to how and why they felt the need to have their children diagnosed, are provided. The third section described the major themes made up of the coded core topics. The themes were then analyzed in terms of the ecological theory, which this study has employed as its theoretical framework. Accordingly, the main issues which came out of the study were categorized under the following five major themes: (a) views and reactions of parents towards intellectual disabilities; (b) psychological challenges faced by parents with children with intellectual disabilities; (c) other challenges associated with having children with intellectual disabilities; and (d) copying strategies by parents of intellectual disabilities.

4.2. Demographic Data of Participants

Table 1: Demographic data of participants

	Type of Diagnosis	**Age of child when Diagnosed**	**Gender of child**	**Parent's age**	**Parent's educational level**	**Parent's occupation**
Mother (Genet)	Autism	20 months	Male	36	BA degree	Marketing Officer
Mother (Hirut)	Autism	3	Female	40	High school complete	Housewife
Mother (Selam)	Cerebral Palsy	5	Female	47	Diploma	Housewife
Father (Solomon)	Down Syndrome	4	Male	49	High school complete	Owns a business
Father (Hailu)	Cerebral palsy	5	Male	43	Diploma	Teacher
Mother (Tsehay)	Down syndrome	9	Female	38	Illiterate	Housewife

* Each participant cited has been assigned a pseudonym to protect their identity.

Table 1 above depicted that, out of the total of six parents who took part in the study, four were female (mother) out of which three of them were married and one was separated. The

remaining two were male (father), both of them married. Two were below 40 years old and the rest were between 43 to 52 years of age. Four participants were diploma holders, one secondary school complete, and the other had a bachelor degree. The study also indicated that five of the parents were employed (2 self-employed and 3 private organization employees) and the remaining a housewife. Each six parents had one child with disability (3 males and 3 females). The average age of diagnosis for the participants' children appeared to be 5.5 years. Two of the interviewed parents had children with Autism Spectrum Disorder, another two parents had children with Cerebral palsy and the remaining two parents had children with Down syndrome.

Table 1: Major Themes and subthemes

Major themes	Subthemes
Psychological problems of parents having children with disabilities	• Concern about Child's Future • Stress from Managing a Child with Disability • Relationship Strain • Disappointment and Sacrifice • Intrapersonal Conflicts • Being Worried • Sense of Loneliness
Coping strategies of parents having children with disabilities	• Religion • Educating Oneself about the Disability • Social Support • Acceptance and Appreciating any Progress the Child Makes
Other Challenges and Opportunities of Having and Raising a Child with Disability	• Effect on Their Family • Reactions of the Community • Opportunities

Source: Field Survey 2019

4.3. Views and reactions of parents of Children with Intellectual Disabilities

Findings pertaining to each of the major themes identified from the analysis of the data are presented below with thick descriptions and demonstrative quotes.

4.3.1. Initial warning Signals and Diagnostic Journey

For the parents having autistic children the first few months with the child were perceived as completely normal. From the age of 12 months onwards, however, they began to observe behaviours that made them suspect some type of developmental problem. These warning signs were of a social (lack of interest for others), communicative (delay or absence of speech), and/or behavioural (repetitive games, aggressiveness, or lack of flexibility), physical (unable to crawl, sit or stand) at the expected time. However, these signs were first attributed as a characteristic of the development of their child. After observing an increase in these warning signs and their persistence, all the interviewed parents set off on a journey through the different healthcare specialties in a search of reasons for these initial symptoms. The following two parents stated their knowledge of initial warning signals and diagnostic journey as:

> *I used to label all my child's behavioural problems as if he was an aggressive child until he approached 1 year and 8 months but was curious of his behaviours being way too different than my first child. After wards I took him to a hospital for his constipation problem and the doctor further suggested that I take him to a psychiatry hospital where I learnt that my child is Autistic. (Genet (Female, aged 36).*

> *She usually doesn't follow instructions unless she is interested. She is still nonverbal but she understands what she is told. She does not stop manifesting undesirable behaviours even if I try to control her other times she behaves as if nobody is around her. She usually screams at, at anybody around her and she gives less response to playful interactions with others. (Hirut (Female, aged 40)).*

For parents having children with cerebral palsy, the experience of pregnancy and labour varied widely. One parent described physical problems and fears of a possible miscarriage. The first few months with the child were perceived as completely normal, and parents described the children as developing appropriately for their age. From the age of 12–18 months, however, they began to observe behaviours that made them suspect some type of motor disability. These warning signs were sensory, communicative, and intellectual impairments. However, these signs were first attributed as a particular characteristic of the development of their child. Two parents stated their knowledge of initial warning signals and diagnostic journey as:

> *We began to suspect some sort disability on her by the time she was unable to sit or stand at the usual age. Finally, when she was one and half year old the doctor sent us back to Tikur Anbesa Hospital where she was diagnosed with cerebral palsy, a disability that prohibited her from walking on her own. (Selam (Female, aged 47)).*

> *He was a healthy normal child up until he was one-year-old. It was then we noticed his feet were slightly malformed and he didn't crawl like other babies. Perhaps naively we assumed it was something we could be able to fix. We took him to an orthopaedic clinic, and they didn't tell us anything crucial. We were advised to take him to a neurologist, and it was there that we were told that he had a brain damage." (Hailu (Male, aged 43)).*

Parents of the children with Down syndrome suspected early that their children were late in almost all of the milestones for their age. While one of the parents thought it was the devil's work and can be cured if he treated spiritually, the other parent considered taking her child to a centre where he can get a special support.

> *She was late in almost all of her milestones for her age i.e. crawling, sitting, standing, walking potty-training, and talking and so on. Because of all these symptoms it was not that much of a surprise for us that she has Down syndrome we only didn't know the name of the disorder" (Solomon (Male, aged 49)).*

> *When she was 6 years old, I took her to a government school with her peers. She was a very friendly and sociable child, and everyone loved her. One of the teachers suggested that I take her to this centre so that she can get a special support she needs and it's been three years since she started getting the service here. (Tsehay (Female, aged 38)).*

4.3.2. Reactions to the Initial Diagnosis

Learning of the diagnosis and hearing the word autism was reported by the parents as a highly emotional moment. A diagnosis of ASD is perceived with the same intensity as a death. The word autism signifies the loss of the "healthy" child with whom they had been living until that moment.

> *As I didn't have the certainty, well I didn't think it was going to be that. But when they gave me the diagnosis then it did hit me. . . Although it's not too bad now, at the time it was as if he had died. It was a blow, as if they had hit me with stick on the head! It was a very bad shock. (Genet (Female, aged 36).*

> *A lot of sadness, a lot of fear, a terrible fear, to learn that you don't know where you're going to end up, and a sadness . . . (she becomes upset). In a way you suffer the death of your child and you must bury her! You must bury everything you have in your head, leave it behind! And you have to face a new reality in which you also have no kind of help; I think we parents are the forgotten ones in this process. (Hirut (Female, aged 40)).*

The ASD diagnosis implied the loss of a life plan as parents and of the future they had imagined with their child. The diagnosis produced feelings of shock, denial, fear/anxiety, guilt, sadness, and distress.

i. Shock and Denial

Shock and denial are strongest immediately after hearing the diagnosis, which is gradually assimilated over time.

> *Since she was my first child I don't know anything about babes let alone a special need child. After one year and a bit I knew that the child had something, but of course I took it very badly. (Hirut (Female, aged 40)).*

Parents were also shocked by the fact that their child was born with Down syndrome. A 38-year-old mother described this as "my child has something wrong, but I surely did not think she had Down Syndrome". *(Teshay, Female, 38).*

ii. Fear and Anxiety

Fear and anxiety mainly concern the future development of their children and their fate when they are no longer there to look after them, worrying whether they will be capable of a normal independent life.

> *At those times when I didn't know what she had' I felt desperate, desperate to the point of not being able to carry on and even telling my mother that I now understand why people throw their children out of the window. (Selam (Female, aged 47)).*

> *Those early years were difficult. We struggled to create an ordinary family life while dealing with the extraordinary needs of a especial need child. I always fear what will happen to her if I am not going to be around? Her Grandmother once said to me that she wouldn't keep her for a second if I am not around. (Hirut (Female, aged 40)).*

iii. Guilt

Guilt appeared around the causes of the disorder and their possible implication in its etiology. Some of the parents blamed themselves for not recognizing the warning signs earlier.

> *The first thing you think is what have I done wrong? Whose fault is it? Did I do something to cause this?" "Am I being punished for something I have done? (Hirut (Female, aged 40)).*

iv. *Sadness*

Sadness and distress were expressed as feelings of emptiness and helplessness. They felt that they could not improve the situation of the child themselves and lacked the ability or resources to deal with their child's disorder or respond appropriately in social situations.

> *When they told me, I was like well . . . how do I face this now? Or how do I tell my family or my husband's family? And when I do, how are they going to react*

and how do they behave around my child afterwards? Well, it has been a trauma for all everyone. (Selam (Female, aged 47)).

With all this comes grief . . . it's that you break down, you know? You go through a terrible emotional stage in which on top of that, not even one foundation remains standing to carry on, because nothing of what you have learned will be useful, nothing of what you have. (Genet (Female, aged 36).

A father of a 13-year-old son with cerebral palsy described his sadness during these times of his life as "I feel sad that all his friends will graduate, will get married and have their own family but not my child; that makes me so sad."

4.4. Psychological Challenges Faced by Parents Having Children with Intellectual Disabilities

The participants spoke of several psychological challenges they endure when raising their children. Permanent worry and being anxious about their children occurred to be the main psychological challenge.

4.4.1. Concern about the Child's Future

Worry over the future of the children as who would care for them when they no longer be there and what the future would hold for their children appeared to be the major source of anxiety for all the parents. For instance, one parent explained:

The thought of our child's future is the main thing that worries and stresses us permanently. We always think what is going to happen to her when we can't be around. Who is going to take care of her when we are not alive? (Solomon (Male, aged 49)).

And another parent further added,

I know you never heard of a mother wishing her child to be dead before her but it's just because I don't know what, where and how my daughter would be if something happens to me since. I can't stand imagining her being afraid and alone on the streets starving. If sometimes she behaves bad and try to hurt herself I take control of her, but I think about when I get older, physically, how am I going to manage her?" (Teshay, Female, 38).

Most of the parents also reported they had to redefine their hopes about their child's future after knowing their child is a special needs child but they still hope if their children be functional and get through all the normal activities that every child goes through. For example, one father indicated:

Now I hope if he could have a good education and go as far as his abilities can take him like everybody does, and hold a job. I hope nobody takes advantage of him because of his disability. So, my main aim now is getting him into school

> *with other kids. I hope that one day he will go to a regular school like his peers. (Hailu (Male, aged 43)).*

While talking about the parents concern for their children's future that was further aggravated due to their children's difficult behaviours that are hard to manage. Several other stressors the parents encountered in accordance to raising a child with disability come along.

4.4.2. Stress from Managing a Child with Intellectual Disability

Most of the parents stated that managing their children's behaviours can often be challenging and stressful. For instance, one mother talked about her daughter's unpredictable tantrums as challenging saying,

> *Her unpredictable behaviour is sometimes a challenge. With other disorders parents can predict what their child's behaviour is going to be like but with autism there is no telling about what is going on the child' mind. I feel frustrated when I think she has understood what I told him but in the next minute she does the opposite. (Hirut (Female, aged 40)).*

Another mother further talked about how she feels bad when her daughter becomes upset and injures herself. She said,

> *Some of the behaviours I consider as challenging. It upsets her when she cat do things that her peers does easily and she sometimes becomes angry, screaming, disturbing and banging hear head against the wall which will be so stressful for me even if it is temporary. (Selam (Female, aged 47)).*

She continued explaining how she felt of embarrassed when these difficult behavioural symptoms are shown by her daughter in front of people and then feeling of guilt for being embarrassed.

Another mother also described being aware of her child's developmental disorder will be there permanently is stressful by itself.

> *I had been so sad and desperate since I have her to see that she has a disorder for a lifetime. It's not that I hate my daughter; I love her more than anything, but it hits me that that she will not be independent and competent enough as her peers. (Tsehay (Female, aged 38)).*

The parents indicated how hard it is to have a child with disability because it needs huge amount of time to care for the child that makes it difficult to have time for themselves to do other things. For instance, one mother said:

> *I usually not used to attend meetings, weddings and different social activities because I can't usually either leave my son at home or take him with me. Generally, I used to have no time at all to myself. I plan everything around my child. (Genet (Female, aged 36).*

And another parent added

> *Sometimes I spend the whole day busy without a rest running around with her to control her especially if she is having a bad day. It has been an evolutionary process because day-to-day life consists of her since she can't move on her own. (Selam (Female, aged 47)).*

Other parents said that even if they want to have a time of their own leaving their children home they often worry about leaving their child alone with others for a long period of time due to their child's lack of ability to communicate, or physically unable to move by their own, their difficulty finding and trusting reliable house maids or nannies to let their children stay with them and their fear that they may be victimized or abused. A mother for instance spoke of feeling guilty on leaving her child alone with a house maid.

> *Sometimes I feel guilty spending time away from my child even if it is a must. I always worry to leave him with the housemaid at home before he entered the center that he stays at currently for a year. There is a lot of feeling of guilt leaving a child with a house maid that each mother has but it's more intense when you have a child with disability. (Genet (Female, aged 36).*

And one father further added,

> *It is very difficult to leave your child with another person especially when you have a child with especial need. You might feel like other people may not treat him well or understands and be patient with him as you. Although we have a house maid, my wife is a stayed at home mom so she is spending all her time with our child even though she had help from the house maid. (Hailu (Male, aged 43)).*

4.4.3. Relationship Strain

Parents experienced relationship strain and psychological disharmony or distress. A commonly expressed emotion was fear. Most of the parents expressed their fears for their child's safety and the well-being of other children. A mother with an autistic child recalled how her son was *"wild"* and destructive when he was younger. She also shared how he left their home and was almost hit by a car. Another mother with a child who has Down syndrome also shared her fear that her 14-year-old daughter has no safety awareness and she may leave the house someday unattended.

Parents identified feelings of anxiety and being overwhelmed as they related the behavioural issues that limited their social outings, ongoing educational and intervention issues, and financial worries. Behavioural problems and the ways parents had to modify social and home activities were identified as *"stressful."* Adding to the stress caused by safety and behaviour issues, there were financial concerns for the family. Selam, mother of 5-year-old girl pointed:

> *I was no longer able to work…sometimes the Center needs an adult to be with him to manage him since he is not able to move by himself and also they need parents of the children so that they do what the therapists do at the center when they went home.*

4.4.4. Disappointment and Sacrifice

Although the parents spoke of positive aspects to having children with disability, there were often disappointing aspects as well. These feelings of disappointment and sacrifice seemed more obvious as the child with disability aged and as parents coped with revising dreams and goals for their children while contemplating the future. Unfortunately, disappointment in how life was *"supposed to be"* was evident in many narratives. Several of the parents expressed feelings of sacrifice as the reality of the disability became more apparent and the future considered. This was particularly true for the parents with older children. Sacrifices were related to time, socialization, other children, and adjustments in lifestyle. Hirut also stated that she and her spouse also relinquished their plan to have more children out of fear of having another child with autism.

> *We always wanted a big family. Then a woman told me about her two kids with autism…devastating. I thought, "I can't have any more kids…my kid requires so much, and we want to give [our other son] the most normal life we can. It's not fair to have another child. (Hirut (Female, aged 40)).*

4.4.5. Intrapersonal Conflicts

Intra-personal conflicts were especially apparent when the parents feel that they had no control over their child's health problems and have a disabled and depended child. A mother stated in this regard: *Maybe I have done something wrong sometime; perhaps I have committed sins and God is taking revenge. I have a twinge conscience"*

In some cases, the parents may also consider themselves as culpable. One father stated: *Of course, I know myself culpable; I shouldn't have this child at that age."*

When encountering the disability and treatment, the distress and damage to the child during the treatment (especially in the early years after the disability diagnosis) and a lack of his or her cooperation with treatment, produces tension in the parents that manifests as nervous pressure. One of the fathers said: "You don't believe; those days I was under great nervous pressure for the disability of the child." (Hailu (Male, aged 43)).

4.4.6. Being Worried

Parents' constant worries include the child's health and education, how to maintain and provide care for the child in the future. They did not expect their healthy children or relatives to care for their special need child in future. Of course, the dependency level of a special need child is associated with the intensity of the parents' concern, so that parents of the child without mental problems and with low physical problems experience less worries. A father stated:

> *When we died tomorrow, who will take care of this child; his brother or sister can't. If he could walk some steps and almost do him daily living activities, we would have less worry. (Hailu (Male, aged 43)).*

4.4.7. Sense of Loneliness

Others' avoidance and ignorance of the parents' needs for communication, the absence of a guide for child care in critical situations, the feeling of being deprived of support in caring for and keeping the child all contribute to a ‘‘sense of loneliness,’’ especially for parents of children with severe cerebral palsy. In some cases, the parents experienced a sense of helplessness by stating that they carry burden on their shoulders, and nobody can help. A mother said:

> *Nobody has supported by now, except people in the organization. No one from our relatives has supported. There's nobody to take the child's hands and walk with her for a few steps. (Selam (Female, aged 47)).*

Participants in the FGD discussed a wide variety of negative emotions that parents' experienced which ranged from mild anger to tiredness and frustration. One of them said that he recalled one parent, at times she got very angry to the extent that she beat up her child. Another participant went to the extent of saying:

> *At times parents feel that it would have been better if they had died: so that the problems would end. The fact that the child is not developing normally stresses most parents, and increases their blood pressure, and leads to other health issues.*

One of the participants in the FGD stressed:

> *There was this time one in which a mother expressed that she is afraid of getting pregnant again because the curse following her husband might lead her to give birth to another child with a disability. She told me she doesn't even sleep in the same room with her husband. She is afraid of getting pregnant and getting another child like this one. She has suffered a lot and to make matters worse her husband does not help her in caring for this one.*

Regarding the psychological problems that parent's raising a child with disability faces, most of the participants in the FGD confirmed that women are still the main carers for children and single motherhood is more common in mothers of children with disabilities as a result of marital breakdown caused by the birth of the disabled child in the family. One of the social worker stated:

> *As an experienced social worker it gives me great pleasure to assert that it is clearly important to introduce programs that particularly benefit women in enabling them to more confidently care for their child. It is also important to design and facilitate group-based psychological interventions…wider and more organized than what we do hear in this centre… which address issues affecting mainly women.*

4.4.8. Other Challenges Associated with Having Children with Intellectual Disabilities

The parents spoke of several challenges in accordance with their daily lives with their children including the effect on their family, negative reactions from the society and difficulty finding education, treatment options and support.

4.4.8.1. Effect on Their Family

Some parents referred specifically to how their child's developmental disability restricted their attention and time to their other children due to their child with disability needing more attention as an effect. Other mothers reported some problems with their husbands as a result of their husband giving less attention for the child with special needs and/or due to exhaustion and conflict on upbringing a child with disability. In this regard, Hirut reported:

> *It placed a negative effect on the family. For example, my husband used to be tired at work because of the fact that we can't sleep at night because our daughter had difficulty sleeping and scream a lot at night. There were also lots of arguments about the child medicines and the costs between me and my husband. (Hirut (Female, aged 40)).*

Selam said:

> *The full responsibility of taking care of her is on me and this makes me feel frustrated. Moreover, her friends and cousins sometimes don't understand her. They get easily angry when she does something wrong as if she is a normal child and I feel sorrow deep down inside when they shout at her or beat her angrily which in turn picks a fight between me and them. (Selam (Female, aged 47)).*

4.4.8.2. Views and Reactions of the Society

The findings under this sub-theme were two types as the participants in this study differed in reporting the types of attitudes and comments they get from the society about their children.

Half the parents reported sympathy and love from neighbours and community members towards their children.

> *People that know me know and love my daughter so much and show countless sympathy towards her. But I can feel people's eyes on us, judging us or showing sympathy. I mean everybody stare at us and stare at her. (Teshay, Female, 38).*

The other half of the parents reported that disabilities were regularly regarded by others as a misfortune, followed by frequently inappropriate behavior from neighbors and society. They reported being regularly humiliated, stigmatized and negatively stereotyped. A social worker closely caring a child with a physical disability repeatedly heard the mother expressed her frustration about how the community treats her due to their misconceptions about disability:

> *If somebody is going out and meets a person with disabilities, they say – it is bad luck, I saw the face of a mother having a child with disability…they are blamed if they are unsuccessful in work; this is the kind of discrimination we are facing. If they participate in any ceremonies and weddings, they say, 'please God help me deliver a healthy child? Everybody will see her and some things may happen.*

Another social worker, remembering the case of a mother having a child with down syndrome stated:

> *Her baby was three and half months old. A woman there said to her that it was pathetic to see a young and progressive mother having a child with disability. She did not recognize the other woman, but she got very angry. She started complaining, "Why did I have to be a character of sympathy when everything was normal? Had the baby been in pain or had it been crying, such comment would have been meaningful. At the end she returned home without staying around.*

The participants in the focus group discussion stated that due to cultural and social mores, families and neighbors regularly spoke negatively about sexual desire and ability to conceive for women who already gave birth to a child with disability. The participants raised the issue of rights and argued that parents having a child with disabilities have the right to have children.

The participants in the focus group discussion stated that stigma and ostracism towards disabled individuals makes it difficult to find someone they can trust who would be willing and able to provide care for their child as a support hand to parents and grandmothers of the disabled children as primary care givers. This concern was illustrated in the following quote:

> *I am really worried about my daughter's future. We can spend money for her marriage. But who will marry her? Even if she gets married, she will get badly treated by her in-laws". "I'm just worried that, when my daughter grows up,*

> *she requires different kinds of care which will continue for her life time. I don't know how long she will have someone paying for her necessary requirements…people hesitate to help her in our family other than me. I am very sure it will continue as long as she survives.*

4.4.8.3. Opportunities

When the researcher asked parents about the opportunities of having a child with disability, almost all of them gave the same answer. That is, it gave them strength. A mother said: *It gave me a whole lot of strength that I didn't know I had when you don't have any option other than to be strong for your child. (Selam (Female, aged 47)).*

Another parent said that it gave her different attitudes towards people with disability.

> *Before having my special need child, I don't know how to react in front of a disabled child or person. But know I know how they might feel when the community looks them differently. (Teshay, Female, 38).*

4.5. Coping Strategies of Parents Having Children with Disabilities

Four themes emerged as significant from the parent's responses with regard to coping strategies.

4.5.1. Religion

The mostly commonly used coping mechanism was religion. Some of the parents stated that they engaged in spiritual beliefs and used spiritual healing methods such as holy water and prayer to their children and themselves to decrease the developmental problems of their children and to cope with the challenges they faced. For example, one mother said:

> *I come from a strong academic background and even if I had expectations for my child I learned to let that go and appreciate what he is doing and the little things he is actually getting done after all my devastation. So I began to pray a lot and I used to drink holy water, let my son drink the holy water too. After wards God answered my prayer and my son's constipation has been cured, he was also able to sleep more than previously. (Genet (Female, aged 36).*

Other parents coped through religion as a result of finding people that are going through the same things and that understands them while they are being involved in a Bible study and other church programs as another mother of a child with down syndrome indicated;

> *My stress levels are lower when I go to church on a regular basis and pray. I am trying to teach my daughter at home by getting advice from a good friend of mine who also has a child with autism that I met at the church. I have met more friends at the church who seem to have better understandings in children and tend not to be judgmental instead they can just act normal with you. (Hirut (Female, aged 40)).*

4.5.2. Educating Oneself about the Disability

In order to cope with having a child with disability and its associated behavioural or emotional problems many parents reported that it was important to be educated, know the facts and gather available information regarding their child's condition. Some of the parents told the researcher that the current knowledge they acquire by reading from the internet helped a lot when it comes to managing their children's behaviours and teaching them important skills. For instance, Genet stated:

> *The fact that I read a lot about this issue gave me knowledge and that knowledge made me able to accept my sons developmental disorder in a way that it has already happened and I can't change it so I shouldn't blame anyone and think of all the negative things from it rather than strengthening myself and control many anxious moments and stressful events. (Genet (Female, aged 36).*

And Hailu similarly said,

> *The additional thing that helped me is reading about how to treat child a with cerebral palsy on the internet and from other available resources to acquire knowledge about the disorder and help my son because I think knowledge helps to relieve stress since it gives directions to deal with the situations that come up. As a parent I want to take advantage of anything that I could for the benefit of my child. So I am gathering every information here and there. (Hailu (Male, aged 43)).*

Other parents reported that they use other people (such as other parents of a child with similar disability) as a great source of information and knowledge to educate themselves on many aspects of the problem because they have similar experiences or concerns.

Participants in the FGD opined that pointing out specific areas where parents can obtain information on disability helped them to adopt more problem-focused coping strategies. According to the participants, information from television programmes helped parents gain knowledge on the different aspects of disability, what to expect and how to teach their children basic skills like hygiene, feeding, safety, and communication. They also stated that it was through the information from such programmes that parents came to know what causes disability, thereby debunking the superstitious myth that it is a curse. They expressed that knowledge from such programmes also helped parents overcome unnecessary shame when in public with their family member with a learning disability. A social worker had this to say "I remember that a mother with Autism told her that she has learnt different ways to cope with her daughter's condition from a TV program they watched." A mother has this to say in the following narrative:

> *In our own case, there was a time a TV program did a documentary on families with such persons. Every member of my family watched that program. This program was very educative. It helped us realize that we are not alone… that some families have the same problem…even white people. It was from it that we now know what to expect and how to teach him activities of daily living.*

Adequate knowledge and information from professionals helped families in making the decision to place the family member with a disability in institutional care.

4.5.3. Social Support

The participants spoke of different kinds of social supports that helped them reduce the psychological and social challenges they faced related to their children's disability. Two of the parents (Genet and Hailu) find the support of the organization their children stay at as an important social support.

> *I can say my child has found education at the center since he is being trained in different skills. The classrooms are excellent. I believe it teaches him appropriate behavior to situations and appropriate social interaction skills. I also found other parents who same as me at the center while picking my son up or while different parent meetings. (Genet (Female, aged 36).*

> *I did not know how I would manage this entire thing without my husband. We have become organized in the distribution of responsibilities as to who does what. I have good family supports with my mother-in-law who is capable of keeping him. If my mother in low is available, she is willing to babysit him. (Hailu (Male, aged 43)).*

The parents reported that having a social support weather from their spouse, extended family and/or an organization helped them to have a sense of appreciating the smallest steps forward that their children made, and helped them to accept and normalize their children's disability and plan ahead in doing everything for their child in order to provide the best for their children.

Participants in the FGD indicated that use of social support from friends and professionals helped. They opined that finding someone to listen to them and giving them words of encouragement helped. This is demonstrated by the following narrative from a social worker:

> *Some female Parents whose children with disability are receiving service in this center are not ashamed to talk to people about their Childs' condition. They keep on telling me that at times when they speak to their friends, some of them are very sympathetic, offering them words of encouragement. Some even give them addresses of places to visit with their son. It makes them not to feel isolated.*

4.5.4. Acceptance and Appreciating any Progress the Child Makes

Some of the parents described a process of accepting and adapting to their child's disability in order to provide the best life they can for their child for instance, Solomon stated:

> *Huh (breathing deeply) … even if my daughter is not necessarily developing at the rate that other children are, she is doing things easier that led me and my wife able to cope with things better and get satisfied with every little progress that our daughter is making because it's like another difficulty that she has overcome.*

Parents tended to describe how their child's disability had *"defined"* their lives. They shared perceptions of what they appreciated in life and how their families' lives had taken on new meaning. Their child's disability was *"always on the mind."* When parents described how the disability affected their families, nearly every parent shared how it defined a life as *"the whole family had respected the disability, not just the child."*

Participants in the FGD described most of the mothers as mothers, wives, educators, and advocates while caring for their child or adult with a special need. A social worker at CMCC stated:

> *In all the years I have worked in this center the mothers acted as the main caretakers, served as teachers for their children, and educators for family, friends, other parents, and school personnel. I am not ashamed to tell you that these mothers assumed a formal role as advocate, seeking employment as a professional advocate or working with individuals with disabilities, as well as informally advocating for the needs of their child.*

CHAPTER FIVE: DISCUSSIONS

5.1. Introduction

This chapter discusses the findings presented in the previous chapter on the psychological problems of raising a child with disability and coping mechanisms. The findings are discussed in line with the theoretical framework, findings of previous studies in the area and the socio-cultural context where the study was conducted.

5.2. The Major Reactions of Parents during the Time of Their Children's Diagnosis

It was found that the parents similarly displayed a range of emotions following the diagnosis as a reaction. These include despair, sadness, shock, confusion and/or feelings of loss, sorrow, shock and feeling of loss.

This finding is consistent with many studies across the world which found feelings of despair, sadness, or being overwhelmed by parents upon first hearing of their children's diagnosis and a period of bereavement associated with those feelings (Angela, 2013 and Lindsey & Roberta, 2013).

The parents reported that they knew very little before they made the diagnosis for their children and this lack of knowledge was one contributor for the encountered difficulties including feeling of loss of a child and denial while learning that their children have a developmental problem. Other studies (e.g., Ashely, 2012; Maggie, 2010; Anthony, 2009; Murphy & Tienery, 2007) also found parents were extremely limited in their understanding of the disorder and this lack of knowledge by parents led to initial reactions of denial, fear, and shock.

The participants also indicated that they were on their own to educate themselves about different aspects of the developmental disorder including intervention options because they were not fully empowered with information about the respective disability by the professionals. Further, all the participants reported that they received very little or no support from the professionals at the hospitals or clinics from where they received diagnosis both before and after the time of the diagnosis, and reported a lack of useful information, direction or guidance.

This is in line with what was reported by other studies (e.g., Gona *et al.*, 2010; Joachim & Robert, 2012) that found parents being dissatisfied with the quantity and quality of information available to them following the diagnosis and the service offered to parents

during the diagnosis of their children by professionals was inadequate, and sometimes manifested insensitivity.

Bello-Mojeed *et al.* (2013), consistently argued that this lack of information and unsatisfactory service during the diagnosis of children with disability may be due to lack of or inadequate knowledge about the disorder of primary health care workers in Africa

because they do not routinely undergo training in developmental disorders such as Autism spectrum disorder.

Consequently, the parents demonstrated that on their way of educating themselves about the disability due to the lack of information and guidance after they learnt their children's conditions, they begun to be changed positively as a person and as a parent. Most of parents mentioned that having a child with disability changed them positively in which they become tolerant, patient, being less judgmental and sympathetic for other people and appreciative of little things over life. In some cases, participants also described that their experiences with their child had increased the level of closeness on their family which emerged the theme being personally changed as a result of children's diagnosis.

This is similar with (Bayat, 2007; Kirsten, 2008; Maggie, 2010 and Angela, 2013) where all found parents" increased level of tolerance, patience, improved assertiveness, being less judgmental of other people, redefining their priorities in life, or taking joy in the small victories of everyday life and strengthened relationships between family members working together as a result of having and raising a child with disabilities.

Finally, the researcher wanted to know the parent's hypothetical believes about the cause of their children's developmental disorder before moving to discuss questions under the next research question. Nearly all the parents thought as they have been chosen by God to have a special needs child as their explanation for the cause of their children's special needs because they didn't do anything wrong during their pregnancy time, during and after birth that can be considered as a threat to the fetus or the infant except one mother that differently reported her child's disorder could be a result of her age being late to have a child.

This finding is consistent with the findings of Chernet and Opdal, (2007) that shows most of the parents in their study attributed the cause of the children's disability to God. However, this finding contradicts with the western studies (e.g., Russell & Norwich, 2011) from the United Kingdom, (Altiere, 2006) in United States, (Shaked & Bilu, 2006) in Israel where the majority of parents agreed with the scientific findings that to this date no one has discovered

an exact cause of autism but either genetic or environmental causes including labor complications, problematic infant immunization, genetic inheritance, viral infection during pregnancy, head trauma and organic defect in the brain as causes for their children's developmental disability.

This finding also contrasts with the many African studies such as Anthony's (2009), that provided a look at the understanding of disability generally in Ghana, mothers were to blame by themselves or others for their child's disorder 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.

Joachim and Robert's (2012), study is also another African study from Zambia that contradicts with the current finding of this study by stating that several families reported the cause of their child's disability was witchcraft or gap of traditional cultural taboos. Gona *et al*., (2010), from Kenya also stated that parents reported the disability of their children is associated with evil spirits, punishment from God or witchcraft.

With regard to the theoretical framework in supporting the first research question Ecological theory has implications for an understanding of the nature of intellectual disability and the manner to structure the services. Such services include the process of diagnosis by stating human development, including that of persons with intellectual disability occurs in the context of multiple dynamic transactional systems, with both immediate and more remote environments affecting the individual with the disability. The diagnostic services, therefore, should be tailored to sort out, understand, construct, and control the transactions among those environments for the ultimate benefit of children with disability and their families. According to ecological theory professionals that make the diagnosis process should consider the parents‟ feelings and provide them enough information support and counseling to reduce their difficult reaction of hearing the results, to increase their acceptance of the disorder and to make them take action quickly. To do so, based on the results of the assessments during the diagnosis, referrals should be made to early intervention services, school districts, other medical service providers and parent supporting organizations as appropriate to initiate services between the child and the multiple ecological levels that affect the child.

5.3. The Psychological Challenges Faced by Parents Raising a Child with Intellectual Disability

The parents spoke of several psychological challenges they endure when raising their children. Thus, permanent worry about their child's future occurred to be the main

psychological challenge as who would care for their child when they no longer can be there for them and what the future would hold for their child. This is consistent with findings in other similar studies (e.g., Paul, 2001; Gray, 2002; Murphy and Tierney, 2007; Bayat, 2007; Kristen, 2008; Angela, 2013).

Other studies also established that parents appear to be the most affected to experience conflicting emotions over the permanency of their child's condition (Aadil *et al.*, 2014; Kourkoutas *et.al*, 2012; Michelle, 2007; Maggie, 2010).

It has been found that parent's face higher level of strain related directly to their child's behavioral manifestations in managing a child with disability which in some cases resulted into parents getting frustrated and exhausted. Further the respondents reported that they felt continuous sorrow being aware of their child's developmental disorder will be there permanently. This finding is similar with several other studies (such as Gray, 2002) which found that parents who were the most distressed were those whose children were aggressive and/or severely obsessive (Abbeduto *et.al*, 2004)

Further, several studies (e.g., Susan, 2008; Kirsten, 2008; Bello- Mojeed *et al*, 2013; Lindsey & Roberta, 2013; Lori 2008; Aadil *et.al*., 2014) found that parents reported stress due to the fact that their child was much harder to care for than most children his or her age. These studies also noted that parents would reported their children often have behavioral issues, tantrums, screaming, physical violence toward themselves and others, unable to move on their own and helping themselves i.e. dressing, feeding, toileting and more behaviors associated with the disorder made parents of children with disability face extreme challenges daily in dealing with the behavioral problems associated with the disorder.

Parents also reported being busy with everyday routines and not being able to find reliable house maids or nannies for their children. This is similar with findings of many other studies (such as Meirsschaut, Roeyers and Warreyn, 2011) which reported that there was little time left for personal activities or outings by parents that care for disabled children. Gona *et al*., (2010), also indicated even if parents needed time to attend to community obligations most of their time was spent on the child with a disability.

Moreover, Aadil *et al*., (2014) found feelings of loss of control of personal life by mothers as another important factor associated with parental stress in families of children with disability. Angela, (2013) found parents having busy daily living that included managing their child's challenging behaviors, acting as their child's therapist or teacher which make it hard for them to have time and think about their own needs.

The above finding is also supported by the theoretical framework since the ecological model takes into account the way in which the interactions between a child with disability and his/her parents produce reciprocal responses that shape the overall psychological wellbeing of both the parents and the child. Furthermore, the model states that the behavior of a child will have an effect on the behavior of parents, friends, child care staff, etc. Besides, other's behaviors will affect the child, therefore, a child displaying a disruptive or aggressive behavior like a child with autism is more likely to elicit restrictive or aggressive parenting behavior which lead to feelings of guilt and stress, while a friendly and attentive child is more likely to evoke positive reactions from the parents and the environment as well (Sameroff and Fiese, 2000).

5.4. The Social Challenges and Opportunities of Having and Raising a Child with Intellectual Disability

The parents spoke of several social challenges in accordance with their daily lives with their child with disability including the effect on their family. Some parents referred specifically to how their child's disability restricted their attention and time to their other children due to their child with disability needing more attention as an effect.

This finding is similar with Ashley (2012) which found that raising a child with disability impacted the relationship of parents with their other children due to the children with disability needing more attention. Meirsschaut *et al*. (2011) also stated that having a child with disability could impair family functioning in several ways including giving more attention to the special needs child which reduced the tendency of families to do normal or spontaneous family activities.

The other finding under this theme was the participants experiencing some problems with their spouses as a result of their husband giving less attention for the child with special needs and/or due to exhaustion and conflicts on upbringing a child with disability. Consistent with this finding Joachim and Robert, (2012) reported marital conflicts emerged which included separations and fighting. All mothers in their study said they were greatly affected due to conflicts with their spouses related to the extreme demands on time and energy on parents and believed that their husbands have not fully accepted the child's condition.

Aadil *et al*, (2014) also found that family members of children with disability are often perceived to experience adverse effects on marital adjustments, sibling relationships and daily family routines. Maggie (2010) revealed participants felt some kind of an impact that are far from positive on their relationship with spouses due their child's diagnosis.

Parents also emphasized how the society views their child’s disability. . The findings under this theme were two types as the participants in this study differed in reporting the types of attitudes and comments they get from the society about their children. Half the parents reported sympathy and love from neighbors and community members towards their child that are similar with Murphy and Tienery (2007) that reported sympathy was extended to the parents of children with disability from different members of society. However, the other half of the parents talked about how lack of understanding from the public gave them a hard time and how being negatively evaluated by people around made them feel judged and stigmatized over time.

Other many studies are consistent with the current finding (e.g., Meirsschaut *et al*., 2011; Paul, 2001; Aadil *et al*, 2014; Angela, 2013; Heather et.al, 2010; Joachim & Robert, 2012 and Lindsey and Roberta, 2013). Participants complained about the lack of understanding of their child’s disability from the society and the unsympathetic comments from the general public made them feel being negatively evaluated, judged and isolated by people around them.

Moreover, Bakare *et al*., (2008); Bello-Mojeed *et al*., (2013); African Network for the Prevention and Protection Against Child Abuse and Neglect (ANPPCAN), (2007) not only found a very low level of knowledge and awareness about many disabilities among the general population, but a low to average level of understanding among health care workers in Nigeria which lead to negative attitude, avoidance, rejection, as well as negative comments. Similarly, studies in Ethiopia (Lewis, 2009 and Getnet, 2013) found that attitudes towards people with developmental disability and their parents in Ethiopia are still characterized by stereotypes and prejudice

In addition, all of the parents similarly mentioned how difficult it was to find education and other support for their child to socialize them with their peers. Many parents also stated challenges related to finding treatment options other than medications commonly prescribed to children following their diagnosis that led to the appearance of the theme difficulty finding education, treatment and support for their children.

This finding shows the lack of access to educational opportunities and other childcare facilities and intervention services in Ethiopia similar with UNICEF‟s (2009), estimation that 98 percent of children with disabilities in Ethiopia have no access to school or vocational training. Further, Lewis (2009) have an estimated number of 1.7 to 3.4 million school-age children with special needs, less than 1% of them have access to education in the country.

Lewis (2009), also attributed that 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; while in the special school system there are too few schools, which are too far from home mostly confined to urban areas and have long waiting lists.

Studies from other African countries (Bakare & Munir, 2011a and Bello-Mojeed *et al*, 2011) from Nigeria; (Joachim and Robert, 2012) from Zambia; (Lara, 2007) from South Africa and (Anthony, 2009) also support the current finding. Quality intervention services, child care facilities, and education are far from satisfactory and African children with developmental disabilities are seriously underserved compared with western countries.

In relation to the challenge the parents face, parents reported that they were even obligated to quit their jobs to manage their child. Ashely, (2012) similarly found participant's career was definitely impacted the most as they reported being fired from several jobs or having to give up their career to care for their child at home. Consistently, McCabe (2007) and Gray (2002) described many parents and mothers in particular, found themselves changing their work habits in order to better meet their child's needs in many cases by either not working at all or restricted their working hours and/or type of employment.

5.5. Coping Mechanisms used by the Parents Having Children with Intellectual Disabilities

The most common coping mechanism parents use is religion. Some of the parents stated that they engaged in spiritual beliefs and used spiritual healing methods such as holy water and prayer to their children and themselves to decrease the developmental problems of their children and to decrease the stress of themselves that came from managing their children. Other parents coped through religion as a result of finding people that are going through the same things as them and that understands them while they are being involved in a Bible study and other church programs.

The finding is consistent with Gray (2006) that reported parents cited religion as a coping strategy remained the same over time from his initial study (Gray, 1994), the parents in this study may have found it more important to acknowledge the permanence of their child's disability and find a way of thinking about it that will put it into a meaningful perspective through religion. Accordingly, Gona *et al.* (2010) and Joachim and Robert (2012) found that when parents found themselves in a state of helplessness, they engaged in spiritual beliefs as faith and belief in God plays an important role in reduction of stress for parents with disabled children.

It was also constant with other studies (e.g., Durban and Rodriguez, 2012; Latafa, 2014; Bayat, 2007; Pauline, 2014 and Tiffany, 2010) which testified parents were able to find solace in religion and being involved in a Bible study because it can give them strength to continue to go on with their lives despite the challenges they face with the extra burden of taking care of the child with disability and as in their case the church members offered emotional support.

In accordance with religion in order to cope with having a child with disability and its associated behavioral and physical problems many parents secondly reflected that it was important to be informed and educated about the facts regarding their child's condition which led to the existence of another theme under the fourth research question which is educating oneself about the problem.

Some of the parents told the researcher that the current knowledge they acquire by reading from the internet and books helped a lot when it comes to managing their children's behaviors and teaching them important skills. Other parents reported other people such as other parents of a child with the same problem as a great source of information and knowledge to educate themselves on many aspects of the disability because they have similar experiences.

Comparable with the current study (Murphy and Tienery, 2007) found that to cope with associated problems of having a child with disability parents valued the information from a variety of sources including internet and other parents of children with the same problem; and (Heather et.al, 2010) stated that participants in their study found their own knowledge as the key to their being a successful advocate for their children.

Moreover, (Hossein et.al, 2013 and Kirsten, 2008) both similarly stated that parent's education significantly can predict the level of parent's empowerment and participants acknowledged the value of learning from other parents as part of being able to get on with things. In relation to talking about other parents as a source of information the parents and the researcher come to discuss about the kinds of social support the participants got from spouses, family members, extended families and organizations and to what extent they helped. Some of the parents reported the support of the organization their children stays at as important because their children's stay there gave them relief from the busy days they had in managing them, made them able to turn back to work and give them the opportunity to meet other parents that also has children with the same problems.

Similarly, Angela (2013), indicated that parents reported finding the Jamaica Autism Support Association (JASA) to be a significant source of support to them in raising their child and to have the opportunity to connect with other parents raising a child on the spectrum through a support group or parent connection network at the center. Gray, (2006) also demonstrated that participants reported the child's attendance at a center provided daily respite for them and the opportunity to make use of the counseling services provided by the staff social workers.

Bayat (2007) indicated the most useful source of formal support for the participant parents seems to be parent support groups, where they feel free to discuss their concerns about rearing a child with disability without fear of being inspected.

Spousal support and support from extended families was also other types of social support found to be helpful in the current study similar with other studies such as (Heather et.al, 2010 and Boyd & Mancil, 2009) that indicated parents found the participation of their spouses in the parenting and care coordination activities associated with raising a child with disability as critical.

Further, similar with this thesis (Pauline, 2014) reported Help from extended family support as another important coping mechanism; and (Latafa, 2014) indicated the extended family system in the traditional Arab cultures was found to significantly help individuals that care for children with disability deal with their life stressors.

The parents finally reported having a social support weather it is from their spouse, extended family and/or an organization was the one contributor for them to have a sense of appreciating the smallest steps forward that their children made, accept, normalize their children's special need and plan ahead in order to provide the best for their children which emerged the last theme acceptance and appreciating any progress the child makes.

Similar with this finding a study by (Heather et.al, 2010) indicated parents described that it is effective to set routines and a plan schedules because the busy schedule and the tendency of their child to have outbursts or tantrums when routines were altered, required continual planning. (Kirsten's, 2008) findings also stated participants described a process of accepting and adapting to their child's disability in order to provide the best life they can for their child and acceptance and normalization is an important part of these parents experience that facilitated their ability to cope with their child's disability. Further, (Lindsey and Roberta, 2013 And Lori, 2008) indicated parents used acceptance to positive personal development

and empowering that directed them to concentrate on learning new skills such as research and advocacy.

The theoretical framework supports the findings under the mentioned last research question since it postulates parenting successes occur when proper social supports are in place at the micro-, meso, and macro-levels such as extended families in the micro system and support from other organizations in the meso system as reported by the participants in this study which is the third theme.

Moreover, many of the parents' responses inform religion as a significant coping mechanism as the interaction between the parents of children with disability as a microsystem and the community at churches as another microsystem had impacted the participants on dealing with some of the challenges they reported previously which makes religious coping the mesosystem level of impact.

Generally, Ecological theory recognizes that community agencies and institutions should assist families of children with special needs, not just children alone. Furthermore, churches, mosques, and other religious communities have a responsibility to help maintain positive relationships in the community, particularly with those that have a child with disability because according to this study, families of children with disability who receive support from their religious community experience an increased ability to cope and lower levels of stress.

CHAPTER SIX: SUMMARY, CONCLUSION AND RECOMMENDATIONS

6.1. Introduction

This chapter provides a summary of the whole thesis focusing on the background and purpose of the study, the methods employed and the major findings. Having a child with intellectual disability would certainly impact not only the individual with the condition, but the parents and a society as well. The impact of having a child on parents and a family has been extensively studied in many countries. These studies have shed light on theoretical and practical aspects of the challenges faced by parents of children with intellectual disabilities. Such information has in turn been utilized to devise support systems for parents in question.

In Ethiopia, the situation of parents who have children with disabilities is not well studied and understood. Due mainly to lack of adequate information, it has not been possible that the complex challenges faced by these parents are given due attention by all concerned. This study therefore aimed at describing the psychological challenges that parents with intellectual disabilities go through. The study also tried to examine other types of challenges faced and strategies used by these parents to cope with their problems.

The study took a qualitative research design, gathering data from six parents of children with intellectual disabilities enrolled at a center for Mentally Challenged Children. Data were collected through semi-structured interviews and focus group discussions. The data then analyzed with qualitative data analysis approaches, and interpreted using Bronfenbrenner's Ecological Theory (1979).

6.2. Summary of Key Findings

The results of the present study showed that psychological challenges of the studied parents with intellectual disability generally begin right from the moment they noticed that their children have issues. They then go through various psychologically painful stages, as they learn about the diagnosis of their children with intellectual disability. Common negative reaction reported by the parents include: shock and denial, fear and anxiety, guilt, sadness, etc. The psychological impacts would not fade away once they learn about their children's condition, but manifest themselves afterwards as well. Parents reported that they constantly would worry about the future lives of their children; that they were stressed in managing their children, that the fact that they have a child with intellectual disability would negative impact

on their relationship with their marriage partners. They also reported that they would go through conflicts with themselves, lowliness and anxiety, among others.

The parents also reported that, due to lack of awareness of intellectual disabilities and associated stigma, they would further be psychologically affected, as a result of the society's negative reactions. The parents also noted that having a child with intellectual disabilities would also have direct or indirect impact on the economic wellbeing of a family, would in turn lead to further stress. They noted that they were not deprived of adequate information to help them better handle their challenges; nor are they have access to quality care and support systems. Getting education and other social services was also noted by the parents as added challenge.

The parents also stated that they employed various copying mechanisms to deal with these complex challenges, which include, appealing to the supernatural power for mercy/healing, educating themselves, seeking out social services, and accepting the challenges and dealing with them.

6.3. Conclusion

Learning that one child has an intellectual disability is certainly not an easy thing for anyone to face, and it is only natural if parent experience all the stated challenges in a country like Ethiopia, where no adequate societal and structural supports are available. Although this study took a small sample size, the findings are very much indicative of the wide range of complex psychological and other types of challenges that parents of children with intellectual disability face in Ethiopia. With increased awareness of intellectual disabilities and the impacts they have on the individuals, their parents/families and their society, a great deal of burden can be lifted from parents' shoulder. This leads to the next section which outlines some of the recommendations extracted from this study.

6.4. Recommendations

The finds of this study, with all its limitations and delimitations, suggest the following recommendations:

- Counseling should be warranted in the time after initial diagnosis and follow up that contain valuable information in terms of coping strategies for parents, accessible services, and links for supports both within the community and professional organizations.

- It can be important for clinicians to ensure that they ascertain parents understanding of the disability when giving a diagnosis and consider preparing parents for the possibility of the special needs as a diagnosis during the assessment period.
- The health centers need to have a Counseling and educational unit to provide information about resources available, ways to improve coping strategies, and treatment options. This creates better outcomes for the parents and the family as a whole: parents, other siblings, and the child with the disability.
- A variety of services are needed from educational, health care and social policies that address the comprehensive burden of children with intellectual disability and their parents.
- It is important that federal policy makers understand and determine the most appropriate programs and equal access to education and intervention services to all individuals with any kind of disability and their family.
- Recommended interventions for children with disability should both remediate the characteristics of the disability in the child to help parents address behavior or physical management concerns at home and community, and ways to cope with their children's behavioral difficulties and interventions that can alleviate the stress level of parents by providing access to sources of social support and parent training programs.
- It is important to establish parent support groups, or group counseling which are an effective means of formal support for parents of children with intellectual disability.
- Parent training programs also may be another strategy for managing the challenges for these parents of children with intellectual disability.
- It is also important to improve the level of awareness of the public of intellectual disabilities and the complex challenges that come with them;
- Further research into the matter is also needed to improve understanding and guide practice.

6.5. Implication for Family counseling

Counseling is of significant benefit to parents and families caring for a child with complex disabilities and is vitally important to the psychosocial functioning of the family unit. The researcher recommends that counseling services at the healthcare setting should focus on the psychosocial needs of the parent and not only the needs of the patient (child) who has

intellectual disabilities. The center's social workers could render these services to parents of children with intellectual disabilities. Counseling should focus on maternal self-esteem, parenting stress, guilt, anxiety and depression, relationship within the family and social support, amongst other things. Counseling could assist with adapting to difficulties in caring for children with intellectual disabilities. It could also provide emotional and informational support which is required to assist parents to come to terms with the child's disabilities. The stresses of the parents would be decreased if counseling services are in place. It is recommended that parents are routinely referred to social workers for counseling services.

Continuing support from healthcare service providers in the community is vitally important to the well-being of the parents. Social workers at CMCC should assist parents in identifying and using available community-based professional resources such as doctors, nurses, social workers, occupational therapists, physiotherapists, clinical psychologists and community organizations, especially the latter, as all the professionals are likely to be in private practice and therefore not affordable to people who are unemployed.

It is recommended that family support should be provided immediately from the diagnostic stage, when the child's intellectual disabilities are confirmed. It would be useful to provide therapeutic services on an individual-, family- or even peer-group- basis, and within their communities where possible. These services could include parenting programmes, peer support groups and individual counseling. They would enhance social functioning of the family unit and give families the opportunity to share their problems with other families to help each other overcome the stressors they experience. The process of coping can be improved by sharing problems with others, who can provide unconditional support and, possibly, a resolution to some of the problems.

References

AAIDD (American Association on Intellectual Developmental Disabilities). (2010) *Intellectual disability: Definition, classification, and systems of supports*. Washington, DC: AAIDD.

Aadil B., Unjum B, Afifa L, Zahoor A. (2014), Challenges Faced by families of Autistic Children. International Journal of Interdisciplinary Research and Innovations Vol. 2.

Abreham, H. (1998, August). Paternal perspectives on mentally retarded children: The case of Addis Ababa. Addis Ababa, Ethiopia: Paper presented at the National Workshop on The Studies of Various Issues Concerning Children and Families in Ethiopia, University of Addis Ababa.

Amakelew Cherkose, Daniel Desta and Fasikawit Ayalew (2000). Parenting a child with disabilities: needs, challenges and strategies. Addis Ababa university, Ethiopia

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Anthony, J. H. (2009). Towards inclusion: Influences of culture and internationalization on Person hood, educational access, policy and provision for students with autism in Ghana

Andrew K. Shenton (2004). Strategies for ensuring trustworthiness in qualitative research Projects. *Education for Information 22 (2004) 63–75 IOS Press*

APA (American Psychiatric Association). (2013). Diagnostic and statistical manual of mental disorders. fifth ed. Washington, DC: APA.

Ayalon, A. (1983). Delicate balance. Coping with stressful situations in the family. Hakibbutz` Hameuhad Publication, 243-291. [Hebrew]

Azeem MW, Dogar IA, Shah S, Cheema MA, Asmat A, & Akbar M. Anxiety and depression among parents of children with intellectual disabilities in pakistan. J Can Acad Child Adolesc Psychiatry 2013; 22:290-5.

Bagner, D. M., Pettit, J. W., Lewinsohn, P. M., Seeley, J. R., & Jaccard, J. (2013). Disentangling the temporal relationship between parental depressive symptoms and

early child behavior problems: A transactional framework. *Journal of Clinical Child and Adolescent Psychology, 42*(1), 78–90.

Bakare, M. O., & Munir, K. M. (2011). Excess of non-verbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa - a trend possibly resulting from late

Bayat M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disabilities Research*, VOL 51 PART 9, 702–714.

Beaudry, J., 2016, "Beyond (Models of) Disability?" *Journal of Medicine and Philosophy*, first published online February 18, 2016, doi:10.1093/jmp/jhv063

Bello-Mojeed MA, Omigbodun OO, Ogun OC, Adewuya AO, Adedokun B. (2013). The relationship between the pattern of impairments in autism spectrum disorder and maternal psychosocial burden of care. *OA Autism 2013 Mar 01;1(1):4*

Bickenbach, J., 1993, *Physical Disability and Social Policy*, Toronto and London: University of Toronto Press

Blacher, J. and Meyers, C.E. (2005) A review of attachment formation and disorder of handicapped children. *Am. J. Ment. Defic.*87 (4), 359–371.

Boorse, C., 2010, "Disability and Medical Theory," in *Philosophical Reflections on Disability*, D. C. Ralston and J. Ho (eds.), Dordrecht: Springer, pp. 55–90.

Boyd, C.O,(2001). Phenomenology the method. In P.L. Munhall (Ed.), Nursing research: A qualitative perspective (3rd. ed., pp. 93-122). Sudbury, MA: Jones and Bartlett.

Cadman, T., Eklund, H., Howley, D., Hayward, H., Clarke, H., & Findon, J.,(2012). Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. *Journalof the American Academy of Child and Adolescent Psychiatry,51*(9), 879–888

Chouhan, S. C., Singh, P., Kumar, S. A. (2016). comparative study of anxiety and depressive symptoms among parents of mentally retarded children. *Journal of Well-Being*. 10:17-28.

Chernet Tekle, Weldeab and Liv Randi Opdal, (2007). Raising a child with intellectual disabilities in Ethiopia: What do parents say?. Paper Accepted for Presentation at Refereed Conference of the American Educational Research Association Chicago, Illinois

Coffee, B., Keith, K., Albizua, I., Malone, T., Jowrey, J., Sherman, S. L., Warren, S. T. (2009). Incidence of fragile X syndrome by newborn screening for methylated FMR1 DNA. *American Journal of Human Genetics*. 85(4):503–514.

Colin G. Pottie and Kathleen M. Ingram (2008). Daily Stress, Coping, and Well-Being in Parents of Children with Autism: A Multilevel Modeling Approach. *Journal of Family Psychology Vol. 22, No. 6,855–864*

Corman H, Kaestner R. (1992) The effects of child health on marital status and family structure. *Demography*. Aug; 29(3): 389-408.

Crnic, K. A., Gaze, C., & Hoffman, C. (2005). Cumulative parenting stress across the preschool period: relations to maternal parenting and child behavior at age 5. *Infant and Child Development,14*(2), 117–132.

Dammeyer, J., (2010). Psychosocial development in a Danish population of children with cochlear implants and deaf and hard-of-hearing children. J Deaf Stud Deaf Educ, 15, 50-58. doi: 10.1093/deafed/enp024

Darling, R.B. (2004) *Families against Society: A Study of Reactions to Children with Birth Defects*. Sage, Beverly Hills, CA.

Das A, Jain P, Kale VP. A cross-sectional study to assess anxiety and depression in parents of children with intellectual disabilities. Indian J Psychiatry 2018;60:S125.

De Bruin, E., Ferdinand, R., Meester, S., de Nijs, P., &Verheij, F. (2007).High rates of psychiatric co-morbidity in PDD-NOS. *Journal of Autism and Developmental Disorders, 37*(5), 877–886.

Dyson, L., 2010. Unanticipated effects of children with learning disabilities on their families.LearnDisabil Q, 33, 43-55. https://doi.org/10.1177/073194871003300104

Farrell, M. (2008). *Educating special children: an introduction to provision for pupils with.* New York, 270 Madison Avenue, USA: Taylor & Francis Inc.

Farrell, A., Krahn, G., 2014. Family life goes on: Disability in contemporary families. FamRelat, 63, 1-6. https://*doi*.org/10.1111/fare.12053.

Featherstone, H. (1999) *A Difference in the Family: Life with a Disabled Child*. Basic Books, New York. Wolfensberger, W. and Kurtz, R.A., Eds. (1969) *Management of the Family of the Mentally Retarded.* Follett Educational Corp. River Grove, IL.

Featherstone, H. (2000) *A Difference in the Family: Life with a Disabled Child*.Basic Books, New York.

Flynn, J. R. (1987). Massive IQ gains in 14 nations: What IQ tests really measure. *Psychological Bulletin*.101(2):171–191.

Folkman S. Stress: appraisal and coping. In: Encyclopedia of behavioral medicine. New York, NY: Springer; 2013. p. 1913-5.

Gallagher, S., &Whiteley, J. (2012). The association between stress and physical health problems in parents caring for children with intellectual disabilities is moderated by children's challenging behaviors. Journal of Health Psychology, 18(9), 1220-1231.http://dx.doi.org/10.1177/1359105312464672

Gerstein, E. D., Crnic, K. A., Blacher, J., &Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disabilities Research*, 53(12), 981–997.

GetnetKebede (2001). Coping with disability: the social relations of disabled children and youths with their parents and the larger community, a case study in selected areas of Addis Ababa. A thesis submitted to the school of graduate studies of Addis Ababa university in partial fulfillment of the requirements for the degree of master of arts in social anthropology

Goodman, S. H., Rouse, M. H., Connell, A. M., Broth, M. R., Hall, C. M., & Heyward, D. (2011). Maternal Depression and Child Psychopathology: A Meta-Analytic Review. *Clinical Child and Family Psychology Review, 14*(1), 1–27.

Gray DE. Gender and coping: The parents of children with high functioning autism. Social Science and Medicine 2003; 56: 631-642.

Gray D. E. (2006). Coping over time: the parents of children with autism. Journal of Intellectual Disability Research volume 50 part 12 Texas USA

Grigorenko, E. L. (Ed.). (2008). *Educating individuals with disabilities: intellectual disabilitiesEIA 2004 and beyond.* 11 West 42nd Street, New York, USA: Springer Publishing Company, LLC

Guillermo Montes, and Jill S. Halterman (2006).Psychological Functioning and Coping Among Mothers of Children With Autism: A Population-Based Study. Department of Pediatrics, University of Rochester, School of Medicine and Dentistry, Rochester, New York

Gustafsson, C. (2003). *Intellectual disability and mental health problems: Evaluation of two clinical assessment instruments, occurrence of mental health problems and psychiatric care utilization*. Acta Universitatis Upsaliensis. Uppsala: 2003.

Harmon R. J., Glicken A. D., and Siegel R. E. (1984). Neonatal loss in the intensive care nursery: Effects of maternal grieving and a program for intervention. *Journal of the American Academy of Child Psychiatry*, 23 (1): 68–71.

Harmon, R.J., Plummer, N.S., and Frankel, K.A. (2000) perinatal loss: parental grieving, family impact and intervention services. In *Handbook of Infant Mental Health.*Vol.4. Osofsky, J.D. and Fitzgerald, H.E., Eds.John Wiley & Sons, New York. pp. 327–368.

Hassall R, Rose J, McDonald J. Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. J Intellect Disabil Res 2005; 49:405-18.

Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 15(3), 269–275.

Hatton, C., Emerson, E., Graham, H., Blacher, J., Llewellyn, G., 2010. Changes in family composition and marital status in families with a young child with cognitive delay. J Appl Res Intellect Disabil, 23, 14-26. https://*doi*.org/10.1111/j.1468-3148.2009.00543.x

Hartmann, Ashley, (2012). "Autism and its Impact on Families”. Master of Social Work Clinical Research Papers. Paper 35.

Heckel, L., Clarke, A., Barry, R., 2009. The relationship between divorce and children with ad/hd of different subtypes and co morbidity: results from a clinically referred sample. J Divorce Remarriage, 50, 427-443. http://dx.*doi*.org/10.1080/10502550902766324.

Hossein Ebrahimi, Ayyub Malek, Jalil Babapoor and Nafiseh Abdorrahmani (2013).

Empowerment of Mothers in Raising and Caring of Child with Autism Spectrum Disorder. International Research Journal of Applied and Basic Sciences Vol, 4 (10)

Hutt, M.L. and Gibby, R.G. (2005). *The Mentally Retarded Child: Development, Education and Treatment*. Allyn and Bacon, Boston, MA.

Joel M. Durban, Ana Maria Rodriguez-Pabayos, Jasper Vincent Alontaga, Gina Dolorfino-Arreza and Catalina Salazar (2012). Coping strategies of parents of children with developmental: a quantitative analysis. Leena and Luna International, Oyama, Japan.

Kahane, G., and J. Savulescu, 2009, “The Welfarist Account of Disability,” in *Disability and Disadvantage* (eds.) Brownlee, K.; Cureton, A., New York: Oxford University Press, pp. 14–53.

Kandel, I., and Merrick, J. (2003). The birth of a child with disability. Coping by parents and siblings. *The Scientific World JOURNAL* 3, 741-750.

Kandel, I., and Merrick, J. (2003). Late termination of pregnancy. Professional dilemmas. *The Scientific World JOURNAL* 3, 903-912.

Kandel, I., and Merrick, J. (2005). Factors affecting placement of a child with intellectual disabilities. *The Scientific World JOURNAL* 5, 370-376.

Kandel, I., and Morad, M., Vardi, G., and Merrick, J. (2005) Intellectual disabilities and parenthood. *The Scientific World JOURNAL* 5, 50-57.

Kandel, I. and Merrick, J. (2007). The child with a disability. Parental acceptance, management and coping. *The Scientific World JOURNAL*: TSW Child Health & Human Development 7, 1799–1809. DOI 10.1100/tsw.2007.265.

Khamis V. Psychological distress among parents of children with mental retardation in the United Arab Emirates. SocSci Med 2007; 64:850-7.

Keyser, D., Ahn, H., &Unick, J. (2017). Predictors of behavioral problems in young children 3 to 9 years old: The role of maternal and child factors. *Children and Youth Services Review, 82* (Supplement C), 149–155.

Kring, S. R., Greenberg, J. S., & Seltzer, M. M. (2008). Adolescents and adults with autism with and without co-morbid psychiatric disorders: Differences in maternal well-being. *Journal of Mental Health Research in Intellectual Disabilities, 1*(2), 53–74.

Kirsten Marie Jardine (2008). What Meaning does raising a Child with Autism have for Parents? A Qualitative Exploration. The University of Edinburgh.

Kubler-Ross, E. (1972). On death and dying. JAMA: *The Journal of the American Medical Association*, 221(2), pp.174-179.

Kushalnagar, P., Krull, K., Hannay, J., Mehta, P., Caudle, S., Oghalai, J., 2007.Intelligence, parental depression, and behavior adaptability in deaf children being considered for cochlear implantation. J Deaf Stud Deaf Educ, 12, 335-349. https://*doi*.org/10.1093/deafed/enm006.

Lecavalier, L., Leone, S., &Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disabilities Research, 50*(3), 172-183. doi: 10.1111/j/1365-2788.2005.00732. x.

Lori Jo-Ann Mierau (2008). Emerging resilience in a family affected by autism. A Thesis Submitted to the College of Graduate Studies and Research Department of Educational Psychology and Special Education University of Saskatchewan, Saskatoon

Magnus Englander (2012). The Interview: Data Collection in Descriptive Phenomenological Human Scientific Research. Journal of Phenomenological Psychology 43 (2012) 13–35

Maggie Olson, (2010). Impact Autism Spectrum Disorders Has On Parents. Research paper submitted in partial fulfillment of the requirements for the Master of Science Degree In education. University of Wisconsin-Stout.

Majumdar M, Da Silva Pereira Y, Fernandes J. Stress and anxiety in parents of mentally retarded children. Indian J Psychiatry 2005; 47:144-7.

McCabe, H. (2007). Parent advocacy in the face of adversity: Autism and families in the People"s Republic of China. Focus on Autism and Other Developmental Disabilities, 22.

Meron G/Tsadik (2006). Autism and Family: problems, prospects and coping with the disorder. Unpublished manuscript, Addis Ababa University, School of Graduate studies.

Mieke Meirsschaut, Herbert Roeyers and Petra Warreyn, (2011). Parenting in families with a child with autism spectrum disorder and a typically developing child: Mothers" experiences and cognitions. Ghent University, Ghent, Belgium

Moor, R., & Moor, T. (2003). Working with families of children with developmental disabilities: What makes professionals effective? Boston, MA: Brooks/Cole

Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A popilation-based study. *Pediatrics, 119*, 1040-1046. doi: 10.1542/peds.2006-2819.

NishaV., and Susan K. (2010). Stress and Coping in Mothers of Autistic Children. *Journal of the Indian Academy of Applied Psychology, Vol.36, No.2,245-248*

Papazoglou A, Jacobson LA, McCabe M, Kaufmann W, Zabel TA. (2014). To intellectual disabilities or not to intellectual disabilities? Changes in classification rates of intellectual disability using DSM-5. *Intellectual and Developmental Disabilities*. 52(3):165–174.

Parker, S. E., Mai, C. T., Canfield, M. A., Rickard, R., Wang, Y., Meyer, R. E. (2010). Updated national birth prevalence estimates for selected birth defects in the United States, 2004-2006. *Birth Defects Research, Part A, Clinical and Molecular Teratology*. 88:1008–1016.

Paul W. Glass (2001). Autism and the family: a qualitative perspective, Dissertation submitted to the Faculty of the Virginia Polytechnic Institute and State University

Pearson Education. (2015) WISC-V. 2015. [May 4, 2015]. www.wiscv.com.

Phillips, B. A., Conners, F., & Curtner-Smith, M. E. (2017). *Parenting children with down syndrome: An analysis of parenting styles, parenting dimensions, and parental stress. Research in Developmental Disabilities, 68, 9–19.* doi: 10.1016/j.ridd.2017.06.010.

Portowicz, D.J. and Rimmerman, A. (2002) Parental reaction to the birth of a disabled child. *Society Welfare* 6(2–3), 176–198 (Hebrew).

Pottie, C. G., Cohen, J., & Ingram, K. (2009). Parenting a child with autism: Contextual factors associated with enhanced daily parental mood. *Journal of Pediatric Psychology, 34*(4), 419-429. doi: 10.1093/jpepsy/jsno94

Pourmohamadreza-Tajrishi M, Azadfallah P, HemmatiGarakani S, Bakhshi E. The effect of problem-focused coping strategy training on psychological symptoms of mothers of children with Down syndrome. Iran J Public Health 2015; 44:254-62

Quittner, A.L., Barker, D.H., Cruz, I., Snell, C., Grimley, M.E., &Botteri, M., (2010). Parenting stress among parents of deaf and hearing children: Associations with language delays and behavior problems. Parent SciPract, 10, 136-155. doi: 10.1080/15295190903212851.

Ricci, F., Levi, C., Nardecchia, E., antonella, A.., & Salvatore, G. (2017). *Psychological aspects in parents of children with disability and behavior problems. European Psychiatry, 41, S792.*doi: 10.1016/j.eurpsy.2017.01.1519.

Ross, A. (2000). The Exceptional Child in the Family. Grune and Stratton, New York.

Russell, G., & Norwich, B. (2011). Dilemmas, diagnosis, and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. Journal of Clinical Child Psychology and Psychiatry.

Salazar, F., Baird, G., Chandler, S., Tseng, E., O'Sullivan, T., &Howlin, P., (2015). Co-occurring psychiatric disorders in preschool and elementary school-aged children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(8), 2283–2294.

Sameroff, A. J., & Fiese, B. H. (2000). Transactional regulation: The developmental ecology of early intervention. In J. P. M. Shonkoff, Samuel J (Ed.), Early Childhood Intervention. New York, NY: Cambridge University Press.

Sanders, M. (2011). *The daily struggle of raising a disabled child.* Retrieved from Hastings, R. P. (2003). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disabilities Research, 47*, 231-237

Sattler, J. M. (2002). *Assessment of children: Behavioral and clinical applications*. San Diego: J.M. Sattler.

Scorgie, K., Wilgosh, L., and McDonald, L. (1996). A qualitative study of managing life when a child has a disability. Developmental Disabilities Bulletin 24(2), 68-90.

Sheikh MH, Ashraf S, Imran N, Hussain S, Azeem MW. Psychiatric morbidity, perceived stress and ways of coping among parents of children with intellectual disabilities in Lahore, Pakistan. Cureus 2018;10: e2200.

Simonoff, E., Jones, C. R., Baird, G., Pickles, A., Happe, F., &Charman, T. (2013). The persistence and stability of psychiatric problems in adolescents with autism spectrum disorders. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 54*(2), 186–194.

Sameroff, A. J., & Fiese, B. H. (2000). Transactional regulation: The developmental ecology of early intervention. In J. P. M. Shonkoff, Samuel J (Ed.), Early Childhood Intervention. New York, NY: Cambridge University Press.

Stevenson, J., McCann, D., Watkin, P., Worsfold, S., Kennedy, C., 2010.The relationship between language development and behaviour problems in children with hearing loss. J Child Psychol Psychiatry, 51, 77–83. doi: 10.1111/j.1469-7610.2009.02124. x.

Stone, L. L., Mares, S. H. W., Otten, R., Engels, R., &Janssens, J. (2016). The co-development of parenting stress and childhood internalizing and externalizing problems. *Journal of Psychopathology Band Behavioral Assessment, 38*(1), 76–86.

Takataya, K., Yamazaki, Y., & Mizuno, E. (2016). *Perceptions and Feelings of Fathers of Children with Down Syndrome. Archives of Psychiatric Nursing, 30(5), 544–551.*doi: 10.1016/j.apnu.2016.04.006

Tirrussew, T. (2005). Disability in Ethiopia: Issues, insights and implications, Conceptualizing disability, early intervention, inclusive education, gender &

disability, resilience, and success, Addis Ababa, Ethiopia: Addis Ababa University Printing Press.

U.S. Census Bureau, (2017). Decennial Census, 1960, and Current Population Survey, Annual Social and Economic Supplements, 1968 to 2017. https://www.census.gov/content/dam/Census/library/visualizations/time-series/demo/familiesand-households/ch-1.pdf, 10 October 2018.

UNICEF (2009). (www.unicef.org/ethiopia/ET_Feature_Joy_Nov_06.pdf. ©2015 United States. Fund for Unicef, All Rights Reserved, 125 Maiden Lane, New York, NY 10038

Waisbren, S.E. (2003) Parents' reactions after the birth of a developmentally disabled child. *Am. J. Ment. Defic.*84(4), 345–351.

Walker, A. P. (2002). Parenting stress: A comparison of mothers and fathers of disabled and non-disabled children. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 62*(7), 3393.

Wechsler D, Kaplan E, Fein D, Kramer J, Morris R, Delis D, Maerlender, A. (2004). *The Wechsler intelligence scale for children—fourth edition integrated technical and interpretative manual*. San Antonio, TX: Harcourt Assessment, Inc.

Weldeab, C. T. (2006). Family, school, and community: Challenges in raising and educating children with intellectual disability: A case study among parents, teachers, and social workers in Ethiopia. Doctoral Dissertation. Oslo, Norway: University of Oslo, Faculty of Education.

Withers, P., & Bennett, L. (2003). Myths and marital discord in a family with a child with profound psychological and intellectual disabilities. *British Journal of Learning Disabilities, 31*, 91-95.

Wolfensberger, W., & Kurtz, R. A. (1969). Management of the family of the mentally retarded: *A book of readings*. Chicago: Parkinson Division, Follett Educational. the Journal of Education and Training Studies Vol. 3, No. 4; 2015 213

Woodman, A. C., & Hauser, C. P. (2013). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with

developmental disabilities. *Journal of Intellectual disabilities Research*, 57(6), 513-530.http://dx.doi.org/10.1111/j.1365-2788.2012.01555.x

World Health Organization, 1980, International Classification of Impairment, Disability and Handicap (ICIDH), Geneva: World Health Organization.

Yorke, I., White, P., Weston, A., Rafla, M., Charman, T., &Simonoff, E. (2018). The Association between Emotional and Behavioral Problems in Children with Autism Spectrum Disorder and Psychological Distress in Their Parents: A Systematic Review and Meta-analysis. *Journal of Autism and Developmental Disorders*.doi:10.1007/s10803-018-3605-y.

Appendix A1: Amharic Version Interview Guide

1. ልጅዎ እክል እንዳለበት ለመጀመሪያ ግዜ ሲያውቁ ምን ነበር የተሰማዎት

- ንዴት
- ሀዘን
- ለእውነታው ለመቀበል መቸገር
- እፍረት

2. ልጅዎትን ሲያሳድጉ ያጋጠሞት የስነልቦናዊ ችግር ካለ

- ጭንቀት (ስለ ልጁ የወደፊት ሁኔታ መጨነቅ)
- ትዳር ላይ የሚፈጠር ችግር
- መሰወአትነት
- እራስን መውቀስ
- ብቸኝነት መሰማት
- ድብርት
- መረበሽ

3. ልጅዎን ሲያሳድጉ ያጋጠምዎት ችግር

- ቤተሰብ ላይ ያለው ተፅዕኖ
- ማህበራዊ ተፅዕኖ
- ትዳር ላይ ያለ ተፅዕኖ
- ስለችግሩ አለማወቅ
- ለራስ ግዜ ማጣት
- ስለችግሩ አለማወቅ

4. ያጋጠመሽ ጠንካራ ነገር ምንድ ነው

- ግንኙነት ማጠንከር
- ከችግሩ መማር
- ተመሳሳይ ችግር ያለውን መርዳት

5. የገጠመውን ችግሮች ለመወጣት የተጠቀምሽበቸው መንገዶች ካሉ

- ማህበራዊ ድጋፍ
- ሀይማኖት
- ቁርጠኝነት
- ስለችግሩ እራስን ማስተማር
- ችግሩን መቀበል እና ትንንሽ ለውጦችን ማበረታታት

Appendix A2: English Version Interview Guide

1. What was your reaction to the first diagnosis?
    - Grief
    - Shame and embarrassment
    - Blaming the spouse or
    - Denial
    - Anger
    - Acceptance
2. What were the psychological problems you faced during raising your child?
    - Stress
    - Anxiety
    - Depression
3. What were the major challenges you faced during raising your child?
    - Social challenge
    - Economic challenges
    - Stress on marriage
    - Burden for child care
    - Lack of knowledge about the disability
4. What were the opportunities you gain during raising your child?
    - Strengthens parental relationship
    - Learning from experience
    - Opportunities to support others with similar situations
5. What were the coping strategies you used to overcome some of the challenges?
    - Social support
    - Coping through religion
    - Resilience and Acceptance
    - Avoidance of the situation

Appendix B1: Amharic Version Consent form

ናቲ ገብሬ እባላለሁ:: በአዲስ አበባ ዩኒቨርስቲ ካውንስሊንግ ሳይኮሎጂ የድህረ ምረቃ ተማሪ ነኝ::ይህ ቃለ መጠይቅ የሚደረግሎት ልጅዎ ላይ ባለው እክል ምክንያት በእርሶ እና በትዳር አጋርዎ ላይ የፈጠረው አዎንታዊም ሆነ አሉታዊ ተፅዕኖዎች ካሉ እነዚህን ተፅዕኖዎች ለማለፍ የተጠቀሟቸው ዘዴዎች ካሉ ብሎም ተፅኖው የትኛው ወላጅ ላይ እንደሚበረታ ለማጥናት ነው፡:

ይህ ጥናት በጥናቱ ለሚሳተፉ ወላጆች ለሌሎች ተመሳሳይ ወላጆች ጉዳዩ ለሚመለከታቸው የተለያዩ ተቋማት እና አጠቃላይ ለማህበረሰቡ ስለ ተለያዩ እክሎች ጋር ስለሚኖሩ ልጆች እና ቤተሰቦቻቸው ውስጥ ስለሚፈጠሩ ጫናዎች ከማህበረሰብ የሚደርስባቸውን ተፅዕኖ ትዳራቸው ላይ ስለሚፈጠረው ተፅዕኖ እንዲሁም እነዚህን ተፅዕኖዎች ለመቋቋም ስለሚደረጉ በተለያዩ ጥናቶች ስለተገኙ ውጤታማ ዘዴዎች የተሻለ እውቀት እንዲኖራቸው በማድረግ የተሻለ ቤተሰባዊ ግንኙነት እና ትዳር እንዲኖራቸው ለማድረግ ያግዛል። ስለሆነም በዚህ ጥናት ውስጥ ለማሳተፍና ከላይ የተገለፀውን የጥናቱን ዓላማ ተረድተው የቃለ መጠይቁን ለዚህ ጥናት ግብአት እንዲሆን በሙሉ ፈቃደኝነት ለመመለስ ፈቃደኛ በመሆነዎት ምስጋና እያቀረብኩ ቃለ መጠይቁን ለመመለስ የማይገደዱ መሆኑንና ከቃለ መጠይቁ በፊትም ሆነ መሀከል ላይ ቃለ መጠይቁን ለማቋረጥ ከፈለጉ ሙሉ በሙሉ የሚችሉ መሆኑን እንዲሁም ለመጠይቅዎት ጥያቄዎች ትክክል ወይም ትክክል ያልሆነ መልስ እንደሌለና የጥያቄዎቹ ዓላማ የእርስዎን ተሞክሮ ለማወቅ ብቻ መሆኑን ልገልፅ እወዳለሁ።ይህ ቃለ መጠይቅ ከአንድ ሰዓት እስከ አንድ ሰዓት ከሰላሳ ደቂቃ ሊፈጅ የሚችልና በቃለ መጠይቁ ወቅት አንዳንድ ግላዊ ወይም ምቾት የማይሰጡ ጥያቄዎች ሊኖሩ እንደሚችሉ በቅድሚያ እያሳወኩ ይህንን ጥናት እርስዎ በሚሰጡኝ መረጃ ላይ ተመርኩዤ ስፅፍ የእርስዎ ስም የማይጠቀስ መሆኑንና የሚነግረኝ መረጃ በሙሉ በሚሰጥር እንደሚያዝ እንዲሁም ከጥናቱ መጠናቀቅ በኋላ የሰጡኝ መረጃ ሙሉ በሙሉ እንደሚጠፋ አረጋግጥልዎታለው።

የወላጅ ፊርማ ----------------------------------   ቀን ----------------------------

Appendix B2: English Version Consent Form

My name is Nati Gebre. I am a counseling psychology graduate student at the Addis Ababa University. You are chosen to do this interview to see if your child's disability caused any Psychological or other challenges and if so to also see what kind of coping mechanism you used to overcome those challenges.

This study provides the participant and also other parents with similar situations the opportunity to learn more about the impact of having a child with disability on parents and their families, the challenges they face from the society, the impact on their marriage and the effective coping mechanisms. And this helps them to better understand the problem and to have better family relationship and marriage. Therefore, thank you for your willingness to participate in this study and to fully understand the purpose of the interview as a resource for this study, I would like to let you know that you are not obligated to answer the questions and have the right to withdraw from the interview at any time. Since the purpose of the questions is simply to know your experience, i want you to know that there is no right or wrong answer. This interview can take from an hour to an hour and half, and there might be some personal or uncomfortable questions during the interview. As I write this study based on the information you haven give me, your name and story will remain anonymous, and I assure you after I finished the project everything will be deleted.

Parents Signature --------------------------------- Date ---------------------------

Appendix C1: English Version Focus Group Discussion Guide for Parents

1. What were the psychological problems you faced during raising your child?

2. Social Challenges you faced while raising your child?

3. What kind of coping Mechanisms did you use to overcome those challenges?

Appendix C2: English Version Focus Group Discussion Guide for Social workers

1. What are the major psychological challenges you see on parents?

2. Social Challenges they faced while raising their child?

3. What kind of coping Mechanisms did they use to overcome those challenges?

Appendix D1: Amharic Version Focus Group Discussion Guide for Parents:

1. ልጅዎትን ሲያሳድጉ ያጋጠሞት የስነልቦናዊ ችግር ካለ

2. ልጅዎን ሲያሳድጉ ያጋጠምዎት ማህበራዊ ችግር

3. የገጠመውን ችግሮች ለመወጣት የተጠቀሙት መንገድ ካሉ

Appendix D2: Amharic Version Focus Group Discussion Guide for Social workers:

1. በወላጆች ላይ የሚያስተውሏቸው ስነ ልቦናዊ ተፅዕኖዎች ምንድን ናቸው

2. ልጆቻቸውን ሲያሳድጉ ያጋጠማቸው ማህበራዊ ተፅዕኖዎች

3. ከላይ የገለፅናቸውን ተፅዕኖዎች ለመወጣት የተጠቀሙባቸው መንገዶች