Families Living With a Child Diagnosed With Autism: Challenges And Coping Mechanisms

Aynalem Tadesse

A Thesis Submitted to

School of Social Work

Presented in Partial Fulfilment of the Requirements for the

Degree of Master of Art (Social Work)

Addis Ababa University

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This is to certify that the thesis prepared by Aynalem Tadesse, entitled *Families Living With A Child Diagnosed With Autism: Challenges And Coping Mechanisms* and submitted in partial fulfillment of the requirements for the Degree of Master of Arts (school of social work) complies with the regulation of the University and meets the accepted standards with respect to originality and quality.

Signed by the Examining Committee

Examiner _______________ Signature ____________ Date ____________

Examiner _______________ Signature ____________ Date ____________

Advisor _______________ Signature ____________ Date ___________

Declaration

I declare that *Families Living With A Child Diagnosed With Autism: Challenges And Coping Mechanisms* is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of reference and that the work has not been submitted before any others degree at any other institution.

Aynalem Tadesse

Signature: ___________________________

Date: _______________________________

Place: Addis Ababa University, Ethiopia

ABSTRACT

Families are facing a number of challenges in raising a child with developmental disability. Though there are different types of developmental disabilities, autism is one of the most important developmental disabilities to be studied. The functional family system is experiencing a challenging situation due caring a child with autism which further affects family members and the community at large. The main objective of this study is to understand the challenges in relation to psychological, social, economic, marital and sibling aspects and coping mechanism of families living with a child diagnosed with autism. A qualitative approach particularly a case study was used in this study. The tool for collecting primary data was in depth interview to gather detail information about family challenges. Six families whose children are enrolled at Joy Center for Children with Autism and Related Developmental Disorder were involved in the study. Finding of the study was analyzed using finding of case study with thematic areas. The finding from the study confirmed that study participant families living with a child diagnosed with autism are facing psychological, social, and economic challenges. Stress, anxiety, social isolation, discrimination, limitation in labor market participation and financial burdens are the main challenges. Families have employed various coping mechanisms to minimize the magnitude of these challenges. In addition, the result of the finding has implication to social work practice. Provision of psychosocial support and awareness creation has to be addressed with different stakeholders in health and social sector. In addition, research works in the area of disabilities particularly autism has to be encouraged.

Key words: Challenges, Coping Mechanisms, Families, Psychosocial support

Acknowledgment

First I would like to thank God for his help throughout my life journey. This study paper was only possible with the cooperation of joy center for children with Autism and Related Developmental Disorder, particularly W/ro Zemi Yenus for her support in accessing families living with autistic children and material from Joy Center library. All my immense gratitude goes to families living with autistic children for sharing their life challenge and experience while living with their autistic children.

My advisor, Dr. Hailom Banteyerga has been an academic and moral pillar of strength throughout my study. He shared his knowledge, thought with me new ways of ‘Knowing’ and meticulously monitored my progress in my paper work. I also want to acknowledge the support and contribution of Joy center staffs particularly w/ro Eleni Damtew and w/rt Woineshet Shenkute, without their facilitation, accessing families living with autistic children would have been a dream.

To my friends at school of social work, Atsednesh Getachew and Mekdes Shibru, I am glad I met you both. In so many different ways you have added value not just to my academic life, but also to my life in general. Last, but not least to my loved family, my husband, Genene Regassa, you are my courage to succeed in my study, thank you for your unreserved love and support. My two kids Biruk and Binyam were patient and stood by my side during my study. My family members thank you all for your encouragement and support.

Acronyms and Abbreviations

ADDM - Autism Developmental Disability Monitoring

AIDS - Acquired Immune Deficiency Syndrome

APA - American Psychiatric Association

CDC - Center for Disease Control

HIV - Human Immune Deficiency Virus

JCCARDD - Joy Center for Children with Autism and Related Developmental Disorder

NICD - National Institution of Deafness and other Communication Disorder

NIMH - National Institute of Mental Health

NUH - National University Hospital

PDD-NOS - Pervasive Developmental Disorder Not Otherwise Specified

TEACHC - Treatment and education of Autistic and Related Communication Handicapped Childre

Table of Content

References

Annexes

Annex I

CHAPTER ONE: INTRODUCTION

1.1. Background

Developmental disability represents a chronic, mild or severe group of disabilities resulting from mental or physical impairment or a combination of both (Cabatan, 2001, p.2). Over the last decades, there has been increasing awareness of childhood developmental disorders. It is important to know that with early identification and intervention by health and education professionals, children with developmental disorders have every chance to lead normal and happy lives (National University Hospital [NUH], 2004, p. 1).

A developmental disorder occurs when a child does not acquire normal developmental skills expected for their age. This affects their ability to learn, behave and socialize. Although a developmental disorder may be present from birth, it often does not become evident until a child is challenged with more complex social and cognitive tasks (NUH, 2004, p. 1).

Autism is one of the most common developmental disabilities. American Psychiatric Association's [APA] (2000) defines autism spectrum disorder as a group of disorders that include autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger's Disorder. The core deficits associated with autism are impairment in social interaction and communication as well as the presence of unusual behavior and/ or interest. In addition, other behavioral, developmental, psychiatric, and medical problems can co-occur with autism presenting the family with the most difficult challenges to manage (as cited in Plumb, 2011, p. 3).

According to National Institute of Deafness and other Communications Disorder [NIDCD] (2010, p.1) autism affects people of every race, ethnic group and socioeconomic background. Boys are four times more likely to have autism than girls. Prevalence of autism can be presented from various sources in different age category, sex, ethnic and racial group. The main sources in presenting the prevalence are family and professional reports and children's evaluation records. A study by Autism and Developmental Disability Monitoring Networking indicate the overall prevalence of 11.3 per 1000 (one in 88) from selected 14 ADDM sites of children aged 8 years old during 2008(Center for Disease Control [CDC], 2012, p. 1). A report of Blumberg, Bramlett, Kogan, Schieve, Jones and Lu (2013, p. 1) presented the prevalence of children diagnosed with autism as reported by parents of school-aged children (ages 6–17 years) was 2% in 2011–2012 G.C.

In Ethiopia there is no official data that indicate the prevalence of autism. Different studies have presented their estimation as follows. According to Nia Foundation ("n.d," Autism in Ethiopia, para. 1) the prevalence rate of autism in Ethiopia is roughly the same as in other regions of the world. In United States of America, one in every 115 children is diagnosed with autism and in Ethiopia's population of more than 80 million a fair estimation of at least 530,000 children suffer from autism and related developmental disorders. Getnet Dribsa (2013, Abstract section, para.1) also presented an estimation of 0.70% of the total population lives with autism. In Ethiopia and all over the world, the number of children affected by autism from time to time is increasing and shows the extent of issue in concern.

The impact of autism not only rest on the individual diagnosed with autism but also to family members. According to Dyches, Wilder, Sudweeks, Obiakor, and Algozzine (2004) autism is considered to be a severe disability secondary to the intense lifelong effects it has on the diagnosed individual and their family (as cited in Plumb, 2011, p. 3). The deficits associated with autism manifest in early development and are pervasive in nature, affecting individuals throughout their life span. The impairment of autism not only affects the diagnosed individual but also caregivers, family, teachers, and community (Karst & Van Hecke, 2012, p. 247).

Families caring for a child diagnosed with autism are facing challenging situations due to low level of awareness and limited availability of support and therapeutic centers in Ethiopia. According to Creedon (2008, Autism section, para. 1), the diagnosis of a child with autism intensifies the challenge of family in managing the disorder of the child.

1.2. Statement of the problem

Families caring or living with a child diagnosed with autism are at the center for issues related to diagnosis of a child with autism. The diagnosis of a child or family member with disability puts a significant impact on the whole family member. Seligman and Darling (1997) state that diagnosis of a child or family member with chronic disability alters the functioning of the family unit (as cited in Altiere, 2006, p. 2).

Having a child diagnosed with autism affects or challenges individual family members and family unit as a whole. Research by Patterson (2005) and Turnbull, Turnbull, Erwin, and Soodak (2006) has shown that having a child autism presents a unique set of challenges that impacts the entire family unit and individual family members' health, well-being, and experiences across the life span (as cited in Plumb, 2011, p. 1).

The multifaceted challenge of living with a child diagnosed with autism encloses various aspects of the family system. Stressors from autism diagnosis can cause a strain on parent's marital relationship, increase financial burdens in the family and result in parents socially isolating themselves from others (Naseef, 1989 as cited in Hartmann, 2012, p. 7).

In the family system the search for effective coping mechanism has great concern to maintain the balance of family functioning. Gray (2002) found that the most popular coping strategy was support from family members. Participation in religious and other individual activities are considered as other positive coping strategies and withdrawal from other family members, friends and society is popular negative coping mechanism (as cited in Altiere, 2006, p. 13).

Today, in developed countries, there is a growing awareness of the particular needs and difficulties that a child with autism faces. With continuous research, knowledgeable professionals and more effective techniques for treatment, the future of child with autism is far more promising. Unfortunately, children with autism in Ethiopia are still the most forgotten and vulnerable ones. The majority of the public including many professionals in the medical, educational and vocational fields are still unaware of how autism affects people and to effectively work with individuals with autism. As a result, children with autism have been deprived of the opportunities to gain or improve their academic, social and communication skills (Joy Center for Children with Autism and Related Developmental Disorders [J-CCARDD], 2005, p. 1).

Many children with autism in Ethiopia are neglected and extremely vulnerable. Because some children with autism look normal physically, people often mistakenly imagine they are simply unruly or poorly behaved. 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 wrong doing. 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 (Nia Foundation, “n.d”, Autism in Ethiopia, para. 4). Children diagnosed with autism face challenging situation from the community and parents. Getnet Dribsa (2013, Abstract section, para. 1) presented that children diagnosed with autism face a lot of stigma even by their parents, more than 80% of these individuals are locked down in dark rooms being chained to control their unusual behavior.

A child with autism has posed its own impact on the family. In a country like Ethiopia where physical 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 is insignificant. The psychological and emotional stress by parents of children with the problem is immense (Letekidan Birhane, 2003, p. 6).

Nia Foundation (“n.d”, Autism in Ethiopia, para. 6) indicates that most parents of children with autism do not have information and knowledge about the symptoms of autism. In particular, mothers of autistic children who have lost their spouse to HIV/AIDS, other diseases, or who are victims of spousal abandonment due to their child’s disorder are left with few resources. With little explanation for their children’s behavior, and few sources of assistance, they carry an incredible burden. They remain without any aid, left alone to futilely plead for help. They must stay home to manage their children, though financial demands mount. They are unable to work because their children are often not allowed to attend regular schools for children their age. These mothers cannot even leave their children with relatives or neighbors; because their child's uncontrolled behaviors are misunderstood; recognized as the expression of poor parenting, or as punishment for sin. As a result financial instability and outright poverty are happening to families.

The impact of autism on mothers is expressively visible on their daily routines and life experiences. According to J-CCARDD (2005, p.1) most mothers of autistic children are single handedly crying in the dark. 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. Hence, thousands of children with autism are confined to their homes with no access to education or rehabilitation.

Mothers are additionally burdened as a result of lifelong problem of their child and wrong belief of the society about autism. Letekidan Birhane (2003, p. 6) indicated that the pains and burden due to the problem is much heavier on mothers of the victim. Most mothers suffer from life time regrets over the disparity of heart breaking reality that their children would have the problem for life. What is even more saddening to such mothers and what makes the situation even worst for people with the problem are the wrong belief of the community that dictates many to keep their kids behind closed doors

Meron G/Tsadik (2006, p. 83) conducted a study on autism and family: problem prospects and coping with a disorder is a mixed research and had showed that most parents do not have clear idea about the symptoms of autism and how it affects people.

As a result the families give their own explanation to the condition which affects families to accept or face the reality and how to work effectively with individuals with autism. The study also showed the impact of autism on families as it magnifies existing problem, creates new area of conflict and feeling of hopelessness due to long time autistic characteristics of their kid.

Another study conducted by Efrem Sahle (2005) gives emphasis to parent's role for early intervention of autism. As early diagnosis of autism has a major contribution in the early intervention of autism, the study revealed various roles of families in caring a child and intervening autism at early stage.

The perspectives of different dimensions of challenges and coping mechanism of families living with a child diagnosed with developmental disorders especially autism is unstudied area in social work research. The two studies which are conducted in Ethiopia did not give emphasis to the perspective of different dimensions of challenges and to social work perspective. The extensive challenge the family faces as a result of caring a child with autism and coping mechanisms employed will require a separate study to reveal the extent of challenge and to understand the appropriate psychosocial support needed for the family.

In Ethiopia the availability of therapeutic and support centers for children with autism and related developmental disorder is inadequate and only situated in Addis Ababa. Joy Center for Children with Autism and Related Developmental Disorder and Nehemia Autism Center are the only institutions serving very limited number of autistic children and their families in Addis Ababa.

The perspective of different dimension of challenge of families having a child with autism is one research area which requires deep understanding of the situation. In order to identify the perspectives of different dimensions of challenges of families with children diagnosed with autism, understanding their perception, experience and existing practices of coping mechanism in relation to the situation is very important. Therefore, this study describes the challenges of families from perspectives of different dimensions, sources of psychosocial support and coping mechanisms of families in relation to lifelong burden and fills the knowledge gap that exists.

1.3. Research questions

The study answers the following research questions:-

1. What is the perception of families about the diagnosis of autism?
2. What are the major challenges of families with autism in relation to social, psychological, economic, and marital and sibling aspects?
3. What practical measures/strategies do families develop to address the challenging situation?
4. What are the sources of psycho-social supports for enabling the families to cope?

1.4. Significance of the study

Studying the challenging situation experienced by families living with children diagnosed with autism and coping mechanism in Ethiopia will promote the wellbeing of challenged families and their children. The provision of care and support service for children diagnosed with autism and their families is inadequately available. There are small lights to address the needs of families with autism and related developmental disorder. J-CCARDD and Nehemia Autism Center are the only institutions in the country providing therapy, care and support for children diagnosed with autism and related developmental disorder and their families.

In Ethiopia, studies about autism are few, the issue of developmental disorder especially autism in relation to different dimensions of challenges and psychosocial support unstudied area in Ethiopia context. So this study may help to understand different dimensions challenges, perception, coping mechanisms and psychosocial support accessed by families living with children diagnosed with autism in Ethiopian context. In addition understanding the challenging situation of these families can be used as input in designing suitable care and support service centers. The establishment of these centers has a great contribution to improve the well- being of families and their children diagnosed with autism.

1.5. Limitation of the study

The study involved only six families whose children are enrolled at joy center for children with autism and related developmental disorder. It would have been better if there was involvement of families whose children are not enrolled at institutions in order to get information from families who are caring their children at home. Another limitation the study faces is only families who are living in Addis Ababa were included in the study. This was due to time and resource limitation which made it impossible to include families out of Addis Ababa to participate in the study. This has influenced the quality of the study finding, as the experience of families living out of Addis Ababa may be unique.

The availability of limited number of researches in Ethiopia context is also another limitation of the study. This has influenced to understand families experience in Ethiopia context from different perspectives.

1.6. Objectives of the study

The general objective of the study is identifying the challenges families living with a child diagnosed with autism face and their coping mechanisms.

The specific objectives of the research, it tries to:

1) Explore the perception of families about diagnosis of autism.
2) Identifying psychological, social and economic challenges of families living with children diagnosed with autism.
3) Examine the influence of caring a child diagnosed with autism on sibling and marital relationship.
4) Explore family source of psychosocial support and ways of coping mechanism.

1.7. Working Definition

Autism - developmental disability associated with impairment in social interaction and communication.

Family - individuals living or caring a child diagnosed with autism.

Challenges - difficulty faced by families in living or caring a child diagnosed with autism.

Coping mechanism - efforts made by families to address the challenges faced by families that include thoughts, feeling and actions.

Psychological challenges -psychological challenges experienced by families in caring a child diagnosed with autism.

Social challenges – social challenges experienced by families in caring a child diagnosed with autism.

Economic challenges-economic challenges experienced by families in caring a child diagnosed with autism.

Marital challenges - marital challenges faced by families in caring a child diagnosed with autism.

Psychosocial support – supports provided to families to address the psychological and social problems.

CHAPTER TWO - LITERATURE REVIEW

This chapter discusses relevant literatures and research conducted in the area of autism in relation to the perspectives of different dimensions of challenges and coping mechanisms.

2.1. History of autism

The word autism was coined from the Greek word autos mean self. The term was first used to describe behavior in 1943 by Leo Kanner, a child psychiatrist at John Hopkins University (Ozonoff, Dawson, & Mcpartland, 2002, p. 5). The term ‘early infantile autism’ was used to describe the unusual patterns of behavior observed in young children that were characterized by severe impairment in social interaction and communication and an intense resistance to change. Infantile autism is identified by Kanner as a distinct diagnostic entity for description of eleven children seen at Johns Hopkins University. All the eleven children were unable to develop normal relationships with people (‘extreme autistic aloofness’). In behavioral categories, they were different from the general child clinical population. With normal physical appearance, the children showed delay in speech development, engaging in repetitive and stereotyped play activity …etc in very early infancy(Keenan, Dilenburger, Doherty, Byrne, & Gallagher, 2007, pp.14-15).

2.2. Cause of autism

The exact cause of autism is unknown by scientists, but gene and environmental factors are suggested by researchers as an important role player (National Institute of Mental Health [NIMH], 2011, pp.1-2). Scientists who study genetic factors as a cause of autism have identified genes involved. The environmental aspect as a cause of autism is about everything that can affect health outside the body. Siegel (2003, p.13) presented the cause of autism in two levels. The growth of a physically different brain with innate process of genetic differences and the write up of experience on a physically different brain are stated in two levels as a cause. In addition to the above mentioned facts there are risk factors that cause autism more likely. Parental age, fertility treatments, pregnancy risks and risks to fetal development are the major risk factors stated by Siegel (1996, pp.26-30).

2.3. Symptoms of autism

Symptoms of autism vary from one child to the next, but in general, they fall into three areas: social impairment, communication difficulties, repetitive and stereotyped behaviors (National Institute of Mental Health [NIMH], 2011, p.1).

In identifying the symptoms of autism in the absence of biological marker, family reports have a crucial role in the diagnosis process. In the first years of life parents of children diagnosed with autism are aware of atypical development in their children (Baird et al., 2003 as cited in Keenan et al., 2007, p.28). In addition to atypical developments, parents are aware of behavioral problems (Hall & Elliman, 2003, as cited in Keenan et al., 2007, p.28).

Autism symptoms typically can be identified in children as young as 18 months, and the American Academy of Pediatrics recommends developmental screening of all children by age 24 months. Nevertheless, many children with autism especially those with only mild or limited speech delays may not be diagnosed until they are of school age, when parents become concerned about an inability to make friends and teachers notice difficulties with peer interactions (Blumberg et al., 2013, p.2).

Tuchman (2003) explain that social impairment experienced by individuals with autism include being socially isolated and exhibiting inappropriate social behavior (as cited in Keenan, et al., 2007, p. 28).The participation of children diagnosed with autism in social activities with their initiation is very limited. Charman and Baird (2002) explained lack of social emotional reciprocity and loss of initiation in social activities in children affected by autism (as cited in Keenan et al., 2007, p.28). Spence et al. (2004) and Nikopoulos and Keenan (2006) also stated children diagnosed with autism have participation in social activities with initiation of others (as cited in Keenan et al., 2007, p.28).

Parents reported that children diagnosed with autism exhibit symptoms of social impairment. The symptoms of social impairment as presented by most parents are isolation from surrounding environment, failure to play like other children, empty gaze, loss of attraction of attention, empty gaze and exhibition of apparent deafness (Gillberg et al., 1990 as cited in Keenan et al.,2007, p. 29).

Jordan and Powell (1995) state that in many children with autism abnormalities and delays in the development of language are obvious, having a characteristic of communication difficulty (as cited in Keenan et al.,2007, p.29).The communication difficulties are categorized into verbal and non – verbal communication which are various and complex in nature. According to Manning-Courtney et al. (2003) the difficulties are complete failure to develop expressive and receptive language skills (as cited in Keenan et al., 2007, p. 29). Other difficulties identified by Brook and Bowler (1992) and Rapin (1997) indicated fluent speech with specific semantic or pragmatic impairments in children with autism (as cited in Keenan et al., 2007, p. 29). The difficulties in the nonverbal communication stated by Tanguay (2000) include profound lack of gestures in communication, deficit inappropriate use of eye contact and failure to engage in attention sharing behaviors of showing or pointing to objects (as cited in Keenan et al.,2007, p.29).

The repetitive and restricted behavior experienced by individual with autism is the result of sensory motor gating deficit (Perry & Condillac, 2003, as cited in Keenan et al, 2007, p. 29). According to Spence et al. (2004) the major repetitive behaviors identified are opening and closing doors, flipping light switches on and off and repetitive water play (as cited in Keenan, et al, 2007, p. 29). Filipek et al., (2000) and Tuchman (2003) identified finger flicking, hand flapping, body rocking, self-spinning, or running in circles as common motor stereotypes, that is self -stimulating behaviors during preschool years (as cited in Keenan et al, 2007, p.30) .

Autistic behaviors are the major concerns of a family. In addition to behavioral and developmental characteristic of an autistic child, other behavioral and psychiatric disorders are exhibited by children of great or equal concern to families than autistic behaviors. According to Loveland and Tunali-kotoski (2005, p. 265) obsessive compulsive or ritualistic behaviors, hyperactivity/ inattention, psychosis, mood disorders or anxiety are the major once leading to increased difficulty with behavior management, learning and social relationship.

2.4. Treatment options of autistic child

The treatment of autism varies from child to child. According NIMH (2011, p. 1) research indicate that early intensive behavioral therapy of autism during toddlers or preschool years can significantly improve cognitive and language skills in young children with autism. Evidences indicate that early behavioral and therapeutic interventions have a great contribution for the life of a child with autism through improving communication, forming relationships, decreasing maladaptive behavior and developing independence (Larsson, 2005 as cited in Sharpe & Baker, 2007, p. 247). The treatment options, indicated by Ozonoff et al. (2002, p. 78), are applied behavior analysis, Treatment and Education of Autistic and related Communication Handicapped Children (TEACHC), denver and green span models, social skill groups, educational support, language and communication therapy functional behavioral analysis , medication, sensory integration therapy and individual psychotherapy.

2.5. Reaction of families to child's diagnosis with autism

The diagnosis process of autism varies from institution to institution from professional to professional. The diagnostic process includes all of the activities in which a clinician engages in trying to understand the nature of an individual's difficulty (Volkmar, Paul, Klin, & Cohen, 2005, p. 1). NIMH (2011, p. 1) categorize the diagnosis process in two stages. The diagnosis process begins with general developmental screening with a pediatrician or early childhood care provider. Children identified with developmental problem in first stage are referred to second stage of evaluation for diagnosis of a child with autism and other developmental disorder. Nejman (2009, p. 12) also argues the requirement of trans-disciplinary assessment team based on the needs of the child.

For parents and care givers the diagnosis or evaluation process creates a learning session to acquire advice from the team. In the contrary diagnostic times are challenging due to unexpected reaction of families. According to Siegel (1996, p. 125) diagnostic debriefing are necessary for some parents to assure the fit between the observations of unusual child behavior and real entity. The reaction of families to the diagnosis varies from individual to individual. The families experience a range of reaction to the diagnosis of autism from extreme shock, grief or denial to relief and happiness in the other extreme. Negative and positive feelings are the common mixtures experienced by parents (Ozonoff et al, 2002, p. 52).

Disbelief or dissociation: parent's first reaction to the diagnosis of autism is disbelief which is coping mechanism by keeping bad news at an emotional distance from our most inner core (Siegel, 1996, p. 125).The families accept as there is something wrong with the children but their expectation is a case different from autism.

Numbness: listening from the doctor about the wrong thing on your child is felt as a bombard. And also for some parents the blow is experienced in a physical way as numbness (Siegel, 1996, p. 125). The family has reached at saturation point and no new information penetrates through raising a question.

Outcry: the first reaction of families to diagnosis of autism is an outcry and questioning" why me? ". The family feels unlucky, hopeless and defeated by the odds as a result of having a child with autism (Siegel, 1996, pp. 125-126).

Hopelessness: the core emotional fear parents experience when first given with the diagnosis of autism is how much difference treatment can make. They think that the child will always remain as we see him presently (Siegel, 1996, p. 127).

Bargaining: the families negotiate with the doctor as if he has the power to deal. Some parents also try to cope by "asking a reduced sentence" (Siegel, 1996, p. 128).

Denial: after diagnosis process the parents react to the finding by asking what if you are wrong. Denial can prevent a parent from responding judiciously to particular situation and often hinders the initiation of appropriate timely treatment (Siegel, 1996, pp. 128-129).

Blame and guilt: understanding what went wrong does not change the past. Family's experience of feeling hopelessness about child's diagnosis turns to externalized anger and blame (Siegel, 1996, pp. 126-127). For parents with feeling of hopelessness and blame, informing about the possible cause is a double sword as far as coping goes.

2.6. Dimension of challenges on family

Autism has life-time consequences with a range of impacts on the health, economic wellbeing, social integration and quality of life of individuals with the disorder, and also on their families and potentially the rest of society. Family environment has a major role of caring, nurturing, socialization and procreation. In handling of all these responsibility a number of challenges are faced by the family. Members of the family, mother, father and siblings have different role in the family system. The family system, as part of the environment, plays a central role in the child's developmental outcome (Sameroff, 1990 as cited in Altiere, 2006, p. 1). The effective functioning of the family is challenged at different level. Families with children diagnosed with any developmental disorder experience a challenging situation in different aspect of their life. Autism has a defined peculiar characteristic of causing major disturbances in the family dynamics and generates needs in all areas and contexts of development (Altiere, 2006; Baker et al., 2005; Shu, 2009; Smith, Hong et al., 2010 as cited in Pozo, Sarria & Brioso, 2011, p. 107). Literature review studies by Crnic, Friedrich, and Greenberg (1983) that assess parental attitudes, personality, emotional difficulties, marital satisfaction and psychosocial problems related to raising a child with mental retardation. The findings of the study indicate that families are at greater risk of marital, emotional and physical problem (as cited in Altiere, 2006, p. 8).

Recent literatures about parents of children with autism and other chronic illness have shown the positive implication on the family (Bayat, 2007; Marcus, Kunce, & Schopler, 2005 as cited in Plumb, 2011, p. 1). A new or renewed sense of spiritual connectedness, emotional growth, a sense of purpose, and a larger community network are some of the positive outcomes (Scorgie, Wilgosh, & McDonald, 1996; Twoy, 2007 as cited in Plumb, 2011, pp. 1-2).

2.6.1. Psychological challenges

Families of children diagnosed with autism are at risk of experiencing psychological problem due to lifelong burden. Dumas, Wolf, Fisman, and Culligan (1991) stated that autism other than other childhood disabilities is a more stressful condition for families. The mothers of children with autism described situation as under more stress and experiencing more depression and father's also report higher level of stress (as cited in Altiere, 2006, p. 8). The emotional well- being of mothers were another factor which is severely affected by caring an autistic child. This impact goes to the extent that mothers experience distress requiring psychotherapy and /or medication (Gray, 2003 as cited in Meron G/Tsadik, 2006, p. 20). The possible reasons for the mothers' greater distress include greater involvement in child raising, increased exposure to negative social reactions by outsiders and the absence of employment and an alternative role to being the parent of a child with autism (Gray, 2002, p. 218).In addition, Sharpley, Bitsika, and Efremidis (1997) found that parents of a child with autism reported higher levels of anxiety and depression than the normal population (as cited in Altiere, 2006, p.7). Morgan (1988) also state that the stressors of raising a child with autism accumulate overtime and absence of adequate resources and support lead to depression and burnout (as cited in Altiere, 2006, p.7).

The psychological problem of caring autistic child encompasses the whole family members. In relation to nature of the disorder, economic challenges, absence of formal and informal psychosocial support, family members of children with autism experience negative psychological effects. Studies have found parents of autistic children to be at a higher risk for depression, social isolation and marital discord. Some parents go through periods of disbelief, deep sadness, self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt (Gupta & Singhal, 2005, pp. 63-64).

In addition, studies have demonstrated that parents of children diagnosed with autism experience greater amounts of anxiety, and stress than parents of typically developing children or parents of children with other types of developmental delays (Dumas, Wolf, Fisman, & Culligan, 1991; Plant & Sanders, 2007 as cited in Plumb, 2011, p. 1).

2.6.2. Family stress

Raising a child with autism involves considerable stress. One of the most widely studied impacts of autism on family is family stress. As compared to other developmental disorders autism has unique characteristics in presenting grief and parental distress. On the first hand absence of biological marker and definitive test in comparison to other developmental disabilities like blindness, deafness, and mental retardation makes the diagnosis and prognosis of autism ambiguous. The ambiguity results in denial of families to accept child condition. Secondly, the problem of social interaction such as attachment forming and showing affection ,and denial of parenthood rewards have brought to consider autism as complex and intractable disorder which a family has to cope (Gupta & Singhal, 2005, pp. 62 - 63).

The comparison of parents with autism and typically developing child has conflicting evidence on parent's ability to endure more stress. A study by Koegel, Schreibman, O'Neill, and Burke (1983) indicated that no significant difference in the measure of stress between parents of children with autism as compared to a normative group of happily married couples (as cited in Altiere, 2006, p. 6). On the contrary another study by McKinney and Peterson (1987) indicate that parents of a child with autism endure more stress than parents of children without autism (as cited in Altiere, 2006, p. 6).

Initial stressors are the major causes to families of children with autism to experience stress and other additional factors increase parental stress level. According to Martinez – Pedraza and carter (2009) initial stressors of parents are associated with parents inability to correctly identify the degree and nature of the problem. The uncertainty about their child's problem accompanied with difficulties in obtaining diagnostic assessment increase parental stress level (as cited in Plumb, 2011, pp. 12-13).

Autism society (2011) categorized factors that put family in stressful situation into five categories: Child in ability to express his /her own need, taking child diagnosed with autism out of the community, concern of child's future welfare, parents financial aspect and feeling of grief (as cited in Hartmann, 2012, pp. 8-9).

Child's inability to express his/her own need is one of the major stressor affecting both parents and children's. Parents will experience difficulty in clarifying their child need while the child will experience difficulty in expressing their own needs resulting in aggressive behavior for the child diagnosed with autism. Children who are non - verbal are more affected as parents are unable to understand feelings of hunger, sickness, tiredness, sadness or madness of their child. Parents also experience extreme worry in case of abuse and neglect as their child is unable to report (as cited in Hartmann, 2012, pp. 7-8).

The second stressor is taking child diagnosed with autism out in the community. Community's inability to understand and be sensitive to behavior of child diagnosed with autism enforces parents to keep their child at home rather than taking to relatives and friends house. In addition parents also feel that their child is unable to socialize or relate with other children. As a result parents experience a sense of isolation from their family, friends and the community (Autism Society, 2011 as cited in Hartmann, 2012, p. 8).

As stated by Autism Society (2011) the third stressor is parents concern over their child future welfare. Parents experience fear concerning their child's future plan and ways of proper care as they are the best care provider. In children who require special assistance in toileting and bathing, if family members are no longer able to care their child, future care giving presents stress in parents (as cited in Hartmann, 2012, p. 8).

In caring a child diagnosed with autism financial aspect is the fourth stressor for parents. In provision of care for a child diagnosed with autism several services are needed like evaluation, home programs and various expensive therapies. In addition, one of the parents may resign from his /her job to care a child intensifying the financial stress of supporting the entire family on one parent (Autism Society, 2011 as cited in Hartmann, 2012, pp. 8-9).

According Autism Society (2011) feeling of grief is the final stressor to parents. The diagnosis of a child with autism has brought a dramatic change in family life style and family dynamics. Parents grieve the loss of the child they expected for themselves and their family. The feeling of grief can occur throughout the parent’s life triggered by events of birthday, holiday, continuous care giving wedding and reproduction (as cited in Hartmann, 2012, p. 9)

As stated by Bristol (1984) a child with autism is a large stressor on the family because of the ambiguity of diagnosis, the severity and duration of the disorder, and problems with the child’s lack of adherence to social norms (as cited in Altiere, 2006, p. 2). In addition Liwag (1989) indicated that stress level of parents increases as a result of realization of autism as non-curable disorder (as cited in Altiere, 2006, pp. 2-3). Other factors that increase family stress level as indicated by Johnson (2013, p. 3) are inadequate support from family member, the community and difficulty of coping with aberrant behavior like aggression and self-injury.

A number of studies explain that behavioral, social and cognitive dimensions of the disorder have association with family stress. The child’s cognitive impairment, externalizing behavior problems and internalized distress, disturbed mood or irritability, functional dependence, hyperactivity, noncompliance, lack of self-care abilities and low adaptive functioning, language deficits, learning disability, imposed limits on family opportunities, need for care across the lifespan, inappropriate eating, toileting, and sexual expression, broad social difficulties, and high likelihood of remaining in the home

(Bebko et al.,1987; Brown et al., 2011; Gray, 1994; Hall & Graff, 2011; Ingersoll & Hambrick, 2011; Koegel et al., 1992a, b; Lecavalier et al., 2006; Lee et al., 2008; Little & Clark, 2006; Lyons et al., 2010; Tomanik et al., 2004 as cited in Karst & Van Hecke, 2012, p. 250).

In addition to the nature of the disorder parental stress in families of children with autism has association with other factors. Feelings of loss of personal control, absence of spousal support, informal and professional support, and adjustment to the reality of the child's condition, housing and finance are some of the other factors that influence parental stress. Families with aggressive and violent children experience high level of stress in the presence of few resources for treatment or residential placement to deal with the situation (Gupta & Singhal, 2005, p. 63). According to Gupta and Singhal (2005, p. 63) the common characteristics among children's with autism that contribute to parental stress are scattered intellectual abilities or isolated skills and pervasive problem behavior such as self-stimulatory behaviors are mutual features.

Volkmar and Pauls (2003) argue that the effect of having a child with autism on parents and families is expressed as the disorder itself with multifaceted and pervasive nature. The cognitive and /or adaptive limitations of individuals with autism affect the ability to live independently as a result long term measure of care or assistance from their parents and families is mandatory (as cited in Karst & Van Hecke, 2012, p. 248).

The longitudinal study of parents of children with developmental disabilities by Seltzer (2001) indicate that more than 50% of parents aged 50 or older are still living with their child as compared with a rate of 17 % for typically developing children. The difficulty of parents and siblings of children with autism exacerbates due to lifelong burden resulting in altering perception of caregivers' parenting, and likely decreases optimism about their own future (as cited in Karst & Van Hecke, 2012, p. 248). Altiere (2006, p.7) described the long term effect of caring an autistic child as a job of twenty four hours, seven days a week encountering hardship and stress through the entire life of the child.

A survey conducted by Sharpley et al. (1997) on 219 parents of children with autism indicate more than 80 percent of mothers experienced a high level of stress and stretched beyond their limits as compared to fathers. In addition, concern over the permanency of the condition, poor acceptance of autistic behaviors by society and often by other family members and the very low level of social support received by parents are identified as stressful factor (as cited in Johnson, 2013, p. 3). Barson (1998) also identified external sources like financial demands, limitation placed on career goals and feelings of isolation as significant contributor to stress family members (as cited in Meron G/Tsadik, 2006, p. 25).

Caring an autistic child requires practical demands additional to emotional burden which intensifies family stress. According to Lord and Bishop (2010); Morrison et al. (2009); Pakenham et al. (2005); Woodgate et al. (2008)

> The demands include continuous time pressures, significant financial burden, the need to provide support and accommodations for their child's education, greater investment in health care and greater delays in accessing medical care, increased necessity for vigilant parenting, constant self- and child-advocacy, fewer opportunities to work, and often the presence of one or more therapists in the home (as cited in Karst & Van Hecke, 2012, p. 25).

2.6.3. Social challenges

In social relationship, families caring a child with autism experience various social effects. Based on families' reports, Gray's (1994) study indicate that the society had a difficulty to accept a child with autism. The low level of probability to get acceptance from the society exposes parents to experience social stigma and embarrassment associated with inappropriate behavior displayed by these children (as cited in Altiere, 2006, p.15). Extended family members also practice rejection of children with autism or distance themselves from the family. Schall (2000) explained that relatives of parents with a child diagnosed autism as cold, distant and unhelpful (as cited in Altiere, 2006, p.15).

Public area attendance is another issue which affects the social life of parents living with a child diagnosed with autism. As families have fear of their children's behavior and act, parents prefer to isolate themselves instead of facing the frustration of taking their child in public (DeMyers, 1979 as cited in Altiere, 2006, p.15)

Gray (1993b) research indicated that parents most commonly mothers and extended family member's experienced severe socializing problems and frequent social rejection. Finding from the follow up research also indicate that majority of parents experienced stigma in which mothers are more likely to experience than fathers (as cited in Gray, 2002, p. 221). In leading a normal social life according to Gray (2002, p. 221) getting friends who accept the child's disability are important component to improve social relationship.

2.6.4. Challenges on marital relationship

Autism is believed to impact family system through creating difficulty in marital relationship. The effect of autism on marital relationship begins with weakening of parental bond of affection. DeMyer's (1979) study revealed that more than half of the families in his study had a weak affection bonds with the parents. In addition there is high risk of marital discord in parents of children with autism (as cited in Altiere, 2006, p.7).

In marital relationship parents marital intimacy is very strong and goes down due to several reasons. Studies about parents of children with autism indicate that the level of marital intimacy is lower as compared to parents of normally developing children (Fisman, Wolf, & Noh, 1989 as cited in Altiere, 2006, p .8). In addition the effect of autism on family goes to the extent that marital relationship results in divorce. Brobst et al. (2009), Freedman et al.(2012) and Hartley et al. (2010) found that the increase in parenting stress, conflict, and child behavior problems contributes to a higher rate of divorce for parents of children with autism than in families of children with typically developing children (as cited in Karst and Van Hecke, 2012, pp. 253 -254).

In evaluating family members level of burden the high burden of caring an autistic child rests on mothers. Patterson (1989) indicates the high level of burden on mother is explained in marital distress. As the mother is sole care provider to an autistic child, the attention given to other children is less and less time is given to her and her husband (as cited in Altiere, 2006, p. 9).

2.6.5. Challenges of sibling

Siblings as part of the family system come across with various challenges as a result of having an autistic brother or sister. As stated by Hartman (2012, p.10) in addition to parents, the diagnosis of autism very much impacted siblings. Siblings, however, may not fully understand the diagnosis as they do not receive explanations from specialists and are still developing explanation by themselves. Children's having a sibling diagnosed with autism have raised a number of questions about his /her sibling like why he/she doesn't talk to me, why does he /she do weird things , how come he will not play with me , does she/he hate me and can I catch autism (Ozonoff et al., 2002, p.150). In questioning about these issues, their great concern to know and clear their confusion put them in stressful situation. The sources of stress in siblings having a sister / brother with autism are several factors. According to Autism Society (2011) the following are factors identified as the main stressors of sibling.

Embarrassment around peers is one stressor for siblings. In having a sibling with autism, they may say or do things that others find "weird" and/or exhibit aggressive behaviors. A sibling may feel awkward or nervous bringing friends around their brother/sister with the fear of the unknown (Autism Society, 2011 as cited in Hartmann, 2012, p. 11).

Autism Society (2011) states that concern of siblings regarding the amount of time parents spend with their brother/sister diagnosed with autism as second stressor. The significant needs of children with autism, puts the sibling to feel as if she /he is ignored (as cited in Hartmann, 2012, p.11)

A third stressor for siblings is the frustration over not being able to engage or receive a response from their brother/sister with autism. Siblings who are young have faced a difficulty how to engage with their brother / sister with autism. These siblings may also become the target of aggressive behaviors, pushing them away from wanting to engage and play with their brother/sister with autism (Autism Society, 2011 as cited in Hartmann, 2012, p. 12)

Siblings concern regarding their parent's grief and stress is the fourth stressor (Autism Society, 2011 as cited in Hartmann, 2012, p. 12). Stress experienced by parents is sensed by children which in turn stresses children as parents unconsciously pass their grief and stress on the sibling.

Finally, the concern over their role in future care giving of the child diagnosed with autism can be stressful for siblings. In cases where families are no more able to care a child diagnosed with autism, sibling may feel obligated to take over for the parents (Autism Society, 2011 as cited in Hartmann, 2012, p.12). In addition, siblings may experience (Hartmann, 2012, p. 2) worry, anger, embarrassment and inability to understand autism diagnosis.

2.6.6. Economic challenges

The birth of a normally developing child has economic demands to provide proper care and fulfill basic needs. Caring an autistic child requires more finance in provision of care, special education, day service provisions, and family expenses as compared to a typically developing child. Jarbrink et al (2003) estimated that the total cost of raising a child with disability is three times greater than as compared to cost incurred in raising a normally developing child(as cited in Keenan et al., 2007, p. 39).

The economic impact of caring an autistic child is also related to aspects of intervention, employment and other related cost. Costs that are first incurred due to caring a child with autism are expensive costs of intervention strategies. According to Sharpe and Baker (2007, p. 248) many of intervention strategies require long hours one to one interaction with a trained therapist, and use of costly foods or drug supplements. Parents of a child with autism often face greater outlays of time and money than they would for typically developing child to access specialized care needed for longer period of time. Participation in extracurricular activity for children with autism also puts additional costs to the family.

The participation of families in the labor market is another factors affected in relation to economic aspect. Gray (2003) found that brining up a child with autism also had a significant effect on career. For those who did manage to work, they were often forced to miss work, perform below their normal level or drop back to part time status (as cited in Meron G/tsadik, 2006, p. 21). Gould (2004) added that one or both parents often must reduce work hours or step out of the labor market altogether (as cited in Sharpe & Baker, 2007, p. 248).

2.7. Coping mechanisms

Coping mechanisms can be defined as our efforts to master the demands of stress and include the thoughts, feeling and actions that constitute these efforts (Hutchison, 1999, p. 137). Coping mechanisms employed by different families varies from family to family. Families with a child with autism employed more avoidance coping behaviors (distancing oneself from the rest of the family), whereas families without a child with autism scored higher on self-control, social support, and problem-solving coping mechanisms (Sivberg, 2002 as cited in Altiere, 2006, p.7)

Person's response to crisis or challenging situation can be seen in two ways. According Hutchison (1999, p. 141) coping efforts may be problem focused or emotion focused. Problem focused coping tries to change the situation by acting on the environment. Situations which are controllable by action are dealt by focusing on the problem. Emotion focused coping function to change either the way situation is attended to (by vigilance or avoidance) or the meaning to oneself of what is happening.

Families caring an autistic child carry out a number of adjustments of the care giver and family system to cope with challenging situation. According to Dunn et al. (2001), Pottie and Ingram (2008), and Sivberg (2002) overall, having a child with autism can clearly be a difficult experience for parents and families, and it is important to identify the development of coping strategies and use of social support by families raising a child with autism, as both have been shown to be associated with positive adjustment in the individual caregiver (as cited in Karst & Van Hecke, 2012, p. 254).

In balancing the functioning of the family system Gray (2002) found popular positive and negative coping strategies. Support from family members, participation in religious and individual activities are positive coping strategies. The negative coping strategies are withdrawal from family members, friends and society (as cited in Altiere, 2006, p.13). Bristol (1984) finding also indicate that in comparison of families with and without a child with autism, strong moral and /or religious standards for coping are emphasized by families with a child diagnosed with autism (as cited in Altiere, 2006, p.13).

According to Gray (1994) and Rodrigue et al. (1990) parents of children with ASD have been found to use a variety of adaptive coping strategies simultaneously, including the use of community services, support from friends and family, information seeking and individual methods of stress management. However, Rodrigue et al. (1990)

also noted that parents of children with autism frequently utilize maladaptive coping strategies, particularly self-blame (as Cited in Karst and Van Hecke, 2012, p. 254).

Previous research has shown that having a child with a disability such as autism presents a unique set of challenges that impacts the entire family unit and individual family members' health, well-being, and experiences across the life span (Patterson, 2005; Turnbull, Turnbull, Erwin, & Soodak, 2006 as cited in Plumb, 2011, p. 1). These stressors include challenges navigating the myriad of educational, medical, and behavioral services; financial hardships related to the cost of care; and emotional aspects of having a child with a disability (Plant & Sanders, 2007 as cited in plumb, 2011, p.1).

2.8. Psychosocial support

Families living with a child diagnosed with autism are at risk of experiencing social and psychological impacts and crisis. In order to deal with these the provision of psychosocial support at different level has valuable contribution in family adjustment and coping. According to Fischer, Corcoran, and Fischer (2007) social support has been found in a number of studies to be an important buffer against family crisis factors, and to be a factor in family resiliency promoting family recovery, and as a mediator of family distress (as cited in Plumb, 2011, p. 18). The psychological or social support can take a form of formal or informal support. Schopler and Mesibov (1984) define formal social support as assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organized group or agency. Informal support is a network that may include the immediate and extended family, friends, neighbors, and other parents of children with disabilities (as cited in plum, 2011, p. 19). In the provision of assistance both formal and informal supports have significant contribution. But Herman and Thompson (1995) found that based on parents report informal supports provided the most assistance, while formal support opportunities, such as parent groups, social clubs, and day care centers were not available (as cited in Plumb,2011, p. 19).Gray and Holden (1992) indicate that mothers who perceived higher levels of informal and formal social support reported lower levels of depression, anxiety, and anger (as cited in Plumb, 2011, p.18).

Autism is one of developmental disabilities affecting the family functioning. Families living with a child diagnosed with autism are experiencing challenging situation in various aspects of their life. In this context this study tries to identify major challenges faced by families in caring a child diagnosed with autism, sources of psychosocial support and their coping mechanisms. In addition, identifying the challenges of families will have a contribution to involve different stakeholders in improving the wellbeing of families and children.

2.9. Conceptual Framework

A conceptual framework is described as a set of broad ideas and principles taken from relevant fields of inquiry and used to structure a subsequent presentation (Abiy Zegeye et al, 2009, p.56). A Reuben hill, family stress theory is a theoretical framework for this study. Family stress theory is based on ABCX model of family stress and coping. According to Hill (1949) the ABC-X model, with A being the stressor event, B the family resources or strengths, and C the family's perception of the event, or how they define or attribute meaning to the event. Event or stressor that cannot immediately figured out how to solve the problem by the family will lead to crisis, the X component of the model (as cited in Smith, Hamon, Ingoldsby & Miller,2009, p.

96).The ABCX model describes a "family transition process" following a stressor event. A period of disequilibrium is followed by three possible outcomes: (1) recovery to the family's previous level of functioning; (2) maladaptation, or permanent deterioration in the family's functioning; or (3) bonadaptation-improvement in the family's functioning over and above the previous level (Hutchison, 1999, p. 417).The model is chosen since it addresses a family stress and coping mechanism of families after stressful event. In this study having a child diagnosed with autism is a stressful event challenging the effective functioning of the family. In addition, the perception of families about this stressful event varies from family to family based on level of awareness and resources available. Families living with a child diagnosed with autism utilize different ways of coping mechanism to cope with challenging situation. As stated in the model, the families' period of disequilibrium may follow one of three possible outcomes: recovery to the family's previous level of functioning, mal-adaptation or bon-adaptation. Based on this model the study will identify which outcomes of family disequilibrium happened to families living with a child diagnosed with autism.

CHAPTER THREE - RESEARCH METHODOLOGY

This chapter tries to present the research methodology used for assessing the issue under research.

3.1. Study design

Study designs are plans and procedures that involve decision of basic assumptions to detail method of data collection and analysis (Creswell, 2009, p.3). In decision of research design philosophical world views are the basis for selecting research design to study a topic. Philosophical world views are social constructivist, positivist, pragmatic and advocacy. In conducting a study on research topic under study a social constructivist philosophical world view is chosen. According to Creswell (2014, p. 8) social constructivists believe that individuals seek understanding of the world in which they live and work. Individuals develop subjective meaning of their experience, meanings directed toward certain objectives or things. Using the social constructivist philosophical world view the research seek to understand the meaning of different dimension of challenges, coping mechanisms and sources of psychosocial support as presented by families directed towards having a child diagnosed with autism.

In addition to philosophical world view decision of research designs also considers purpose and time dimension of the research. Researches have different purposes. According Kreuger and Neumann (2006, p.21) social research purposes are organized into three groups, exploratory, descriptive and explanatory. From the above mentioned purposes a descriptive research presents a picture of the specific details of a situation, social setting or relationship (Kreuger & Neumann, 2006, p.22). Hesse –Biber and Leavy (2011, p. 10) also state that a research with descriptive purpose seeks to describe the aspect of social reality under investigation. The purpose selected for a topic understudy is a descriptive purpose presenting a detail of a phenomena understudy. As a result the study is a descriptive research that describes the challenges of families living with a child diagnosed with autism, sources of psychosocial support and strategies employed by families to minimize the magnitude of the problem.

In social research another dimension is time. According to Kreuger and Neumann (2006, p.31) researches give a snapshot of a single fixed time or a moving picture of events over a period of time. The time dimensions of a research are cross-sectional research in which the data is collected at single point in time and longitudinal research where multiple points of time are used to collect data (Kreuger & Neumann, 2006, p.31). In relation to time dimension this research is a cross- sectional research where families are interviewed at single point in time.

Based on the philosophical world view(social constructivist),descriptive research purpose and cross sectional time dimension a research method that answers research questions understudy is a qualitative research method The focus of qualitative research is textual (Hesse-Biber, 2011, p.4). This study design is helpful to describe the social meaning families attribute to their experience and coping mechanism presented in text. Creswell (2014, p. 4) also explained qualitative research as an approach for understanding the meaning individuals or groups ascribe a social or individual human problem.

A qualitative research bases on the five inquiry approaches namely narrative research, phenomenology, grounded theory, ethnography and case study. This study uses the case study research approach. Explanation about case study as methodology or research design is contradictory. According to Stake (2005) case study research is not a methodology but a choice of what is to be studied (as cited in Creswell, 2007, p.73). Denzin and Lincoln (2005), Merriam (1998) and Yin (2003) stated that case study research as a strategy of inquiry, methodology or a comprehensive research strategy (as cited in Creswell, 2007, p. 73). But Creswell (2007, p.73) view it as a methodology and defined case study research as a qualitative approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases over time) through detailed , in- depth data collection involving multiple sources of information (observations , interviews, audiovisual materials, documents and reports). Case study approach provides a researcher for holistic understanding of a problem, issue or phenomenon within its social context (Hesse-Biber & Leavy, 2011, p.254). In this context using case study approach the researcher understands the challenge of autism in holistic manner within the family system.

3.2. Study area

The study area selected for this research is a center which provides support for autistic children and their families. Joy Center for Children with Autism and Related Developmental Disorder is selected as a research area to access families living with a child diagnosed with autism. The reason why the center is selected as a study area is because of its long term experience in provision of support for families and their children diagnosed with autism and related developmental disorder.

3.3. Participants

The participants of the study are families living with a child diagnosed with autism. The study was conducted with six families. The main rationale for selecting six families is the use of case study approach. According to Creswell (2014, p.189) case studies include about four to five cases. In addition families' willingness, available resource and time were taken into consideration in selection of participants. The selection of participants was done with the support of founder of Nia foundation. This helped to identify families living with a child diagnosed with autism from the database.

3.4. Participant selection techniques

According to Krueger and Neumann (2006, p. 209) qualitative research is not mainly concerned with drawing representative samples rather, it focus on how the sample or small collection of cases, units, or activities illuminates social life. Samples are selected on their ability to clarify and deepen understanding of cases, events or actions and rich knowledge of the research issue to provide a good insight. In addition to this qualitative research as stated by Hesse –Biber and Leavy (2011, p. 45) has a logic concerned with in-depth understanding, usually working with small samples. Accordingly, this research utilized non-probability sampling method, specifically purposive sampling based on eligibility criteria to get cases that fit particular criteria and who will provide in-depth information about the research issue (Creswell, 2014, p.189). Participants of the study were selected based on inclusion criteria of the research.

3.5. Eligibility criteria

The research has set eligibility criteria to select appropriate samples for the study; the following are the criteria's

1. Families who are willing to participate in the study.
2. Families living with a child diagnosed with autism.
3. Families living with a child diagnosed with autism who reside in Addis Ababa.

3.6. Participant selection process

In selection of participants with Purposive sampling Kruger and Neumann (2006, p. 211) explain that use of judgment of an expert in selecting cases, or it selects cases with a specific purpose in mind. The selection process of the participants was carried out in consultation of founder of Joy Center for Children with Autism and Related Developmental Disorder. By explaining the purpose of the study and obtaining their willingness to participate, six families were selected to participate in the study.

3.7. Data collection procedure

Data collection procedure began with short meeting with participant families to acquaint about the purpose of the study on individual bases. The briefing session was conducted on monthly parents meeting day for the month of April at Joy Center for Children with Autism and Related Developmental Disorder. After obtaining their consent, convenient time and place for interview were chosen by families. The convenient place and time chosen by all the participants were the Joy Center and all agreed to come 2 hours early at 1.00 pm on their way to pick children. On interview date before beginning the interview, briefing the purpose of the study was conducted. The briefing session was followed by requesting families to sign written consent form. For those participants who were unable to read, the researcher read the consent form. The data was collected by note taking and using audio recorder. The audio recording was based on the willingness of participants to be recorded. As a result audio recording was done only for five families. The recorded data has been kept secured and will be destroyed after the completion of the study.

3.8. Data collection methods

Qualitative research depends on multiple sources of data to obtain comprehensive understanding of the research issue (Creswell, 2007, p. 38). In this context, the research used primary and secondary data sources. As indicated by qualitative study, inquirers collect multiple forms of data and spend considerable time in natural setting gathering information. The procedure of data collection in qualitative research falls in four categories; observation, interview, documents and audiovisual materials (Creswell, 2009, p. 178 & Creswell, 2014, p. 188). To acquire primary information from the study participants, this qualitative research utilized in-depth interview using an open ended questions. Open ended questions will provide good opportunity for participants to freely share their views and social meaning they attribute to their experiences. The open ended question were developed in English and then translated to Amharic to understand challenges, sources of psychosocial support and coping mechanism of families living with a child diagnosed with autism in their own words. Abiy Zegeye et al. (2009, p. 39) and Crotty (1998) (as cited in Creswell, 2009, p. 8) state that qualitative research primarily utilize unstructured data collection tools to gather the required information using open ended questions. The research also reviewed secondary data sources like book, electronic materials and other materials relevant to the research topic.

3.9. Ethical Consideration

Research activities from the beginning to end consider ethical issue. Ethical issues identified by Lipson (1994) are informed consent procedures, confidentiality toward participants, benefits of research to participants over risks…etc (as cited in Creswell, 2007, p. 141).In the interview session involving study participant began with thorough explanation of research purpose to obtain their consent prior to their participation in the study. To assure ethical consideration of informed consent, each participant was signed on informed consent letter indicating that they have read the letter and agree to participate in the study. The issue of confidentiality were ensured by not using their names in any written material or disscusions concerning the reserarch and storing interview materials in safe palce free from disclosure.The researcher also ensured to keep audio records in safe place and promises to destroy after defense of thesis.

3.10. Trustworthiness of the study

Issues related to trustworthiness as stated by Lincoln and Guba (1999) are how the researcher convinced his/her audience as the issue worth paying to attention, criteria and arguments used and persuasive questions asked (as cited in Hesse-Biber & Leavy, 2011, p. 48). To enhance trustworthiness the study used multiple sources of data from in depth interview and observation. The primary data was collected from in depth interview of study participants and observation. Using rich and thick description to convey finding is a strategy to enhance trustworthiness of a study (Creswell, 2009, 191). In presenting finding of the study, rich and thick descriptions were used to enhance trustworthiness.

3.11. Data analysis

Data analysis in qualitative research consists of preparing and organizing the data (that is text data as in transcript or image data as photographs) for analysis, then reducing the data into themes through a process of coding and condensing the codes and finally representing the data in figures, table or a discussion (Creswell, 2007, p. 148). In qualitative research the process of data analysis proceeds simultaneously with data collection (Creswell, 2014, p. 195 & Hesse Biber & Leavy, 2011, p. 123).The data analysis of the study was an ongoing process. The analysis process began with organizing note and transcription of audio records collected from in depth interview of study participants in Amharic language. Transcriptions of audio record were followed by compiling note taken in the interview session with transcribed audio record. The compiled transcript was translated to English and transcribed into written form by summarizing into categories and then into themes. Then, I read the data repeatedly and organized to get the meaning as well as the general idea of what the participants want to express. After thoroughly examining the data the necessary coding followed. I, then, organized the data into sub-themes. Later the codified themes were described in narratives form to convey the results of the analysis. At the final, I moved on the meaning derived from the critical analysis of the primary data, the literature and conceptual framework.

CHAPTER FOUR- DATA PRESENTATION

4.1. Findings of the study

In the following findings section challenges, sources of psychosocial support and coping mechanism of families living with a child diagnosed with autism are presented. The primary source of the data was in depth interview of purposively selected 6 families living with a child diagnosed with autism whose children are enrolled at joy center for autism and related developmental disorder.

The finding section is classified into two sections of which the first section is about the socio-demographic characteristics of families participated in the study. The second section of findings is about perception of families about autism, major challenges of families in relation to social, economic, marital and psychological aspects, sources of psychosocial support and coping mechanism and sources of psychosocial support are presented. The findings are presented and summarized according to the objectives and conceptual framework of the study.

4.1.1. Socio demographic characteristics of families

The study involved 6 participants, three mothers, one grandmother and two fathers. The age of the participant range from 27 to 63. Out of six participants, two of the participants have studied up to grade six, two of them have completed grade 12 in which one of them is diploma graduate, the other two families have attended study until grade five and one participant is illiterate. Four of the participants are married and two of the participants are single and widow. In relation to employment status of the participants, it ranges from house mother to business man. The socio-demographic characteristics are summarized in the table below.

Participant	Sex	Age	Education	Occupation	Relationship	Marital status
1	F	27	5th grade	Waitress	Mother	Single
2	F	35	12 complete	House mother	Mother	Married
3	M	63	11 complete	Pensioner	Father	Married
4	F	55	Illiterate	Petty trader	Grandmother	Widow
5	F	28	5th grade	House mother	Mother	Married
6	M	61	12+3	Business man	Father	Married

Table 1: Summary of socio demographic finding of study participants.

4.1.2. Knowledge and perception of families about autism

In order to understand the challenges of families living with a child diagnosed with autism, the study begins findings with knowledge and perception of families on autism.

The level of awareness of all participants about autism is insignificant. Before their child is diagnosed with autism, participant number 1, 3, 4, and 5 never heard about autism. Two of the participants, participant number 2 and 6 don’t have detail information about autism, but have heard from chat or know by name only respectively. Autism is sometimes confused with mental health problem. Participant number 4 have related autism with mental health problem, due to act of kicking people, tantrum and throwing items.

Participants' of the study have different level of perception about autism. Some of the participants have perceived autism as life incident or event that can happen to anyone. Other also perceived autism as an event given from *God*, and they have accepted the situation due to the fact that they do not have any opportunity or choice.

Participant number 1and 2 say that:

> Autism is a situation or incident that will happen to all without considering ethnic group, gender and economic class. But things will change if families put all their effort on their child. (Participant number 1, age 27 & participant number 2, age 35).

Participant number 6 explained his perception about autism as follow: "Autism is God given gift. It is difficult to run away from God. I have acknowledged autism as a gift from God". The other two participants also share their perception about autism with participant number 6 as something bestowed by God.

Participant number 3 explained his perception about autism as "incurable problem''. He says:

> My son has been at Joy Center for the last five years until now he is unable to identify the Amharic letter 'ha.' Since I have not seen major change in his life, it makes me feel sad all the time. (Participant number 3, age 63)

4.1.3. Family's reaction to diagnosis of autism.

Participants of the study reacted to the diagnosis of autism in various ways based on their knowledge and level of perception. The diagnosis process the families passed through is long and complicated. For some families it was a state of confusion and for other a learning session. The participants of the study reacted to diagnosis of a child with autism in a multifaceted form. For participant number 1, 2, 4, 5 and 6 due to low level of awareness the initial reaction was disbelief and they did not believe the diagnosis as autism. Participant number 1, 2 and 4 resorted to blame, guilt, shock, and outcry through the diagnostic briefing. In the diagnosis process participant number 5 considered autism as a simple thing, also thought the behavior of her child would be the same as early years as he grows up.

Participant number 1 reports that she was advised how to handle her child in the diagnosis briefing session. She says:

> I was concerned when I learned that my daughter at the age of four is unable to communicate and was restless. I decided to see a pediatrician. The pediatrician explained the problem as impaired brain development and confirmed the case of autism. Surgical procedure was the appropriate treatment if it was before 2 years. Since it is too late to carry out surgical procedure, the physician told me detail information about management of a child with autism and the situation would improve with good care. (Participant number 1, age 27)

The initial reaction of participant number 1 for the diagnosis of her daughter with autism is accepting the situation with feeling of blame and guilt. In the diagnosis briefing session she was much concerned to acquire advice from the physician. She adds:

> I gave birth at the age of 14 out of wedlock. My gestation period was full of challenge and aggravated when I ran out of home at 7 month of pregnancy and start residing on street. Staying without food for 3 to 4 consecutive days was common. As my fastness and the challenge I faced during pregnancy, nothing has happened to my daughter. It is because of my fault that my daughter born with

> autism. Even after diagnosis of my daughter with autism, I did not expect as I face difficulty to care. I am sure if it was not early pregnancy and I get proper care my daughter would have normal development. (Participant number 1, age 27)

For participant number 3 the diagnosis process was a state of confusion. The father came across with many steps before he knew about his son's situation. He says:

> I have been at different medical centers; none of them came up with diagnosis of autism. As I didn't get response from medical aspect, I decided to visit religious places for holy water treatment. In all my effort after long period of time a physician at private medical center diagnosed my son with autism and told me to visit joy center for autism and related developmental disorder. My son has special history that has relationship with autism. In the delivery time the mother had retained placenta and the health center was incapable to solve the problem. She was referred to a hospital. In saving the life of the mother, no proper care was provided to the new born infant. He was not fed with breast and also left on the corridor. The less concern given to the newborn infant exposed him pneumonia. To treat the case of pneumonia, he was given gentamycin. From the information I had from a foreigner physician, the cause of autism is inappropriate treatment given at his early age. In the diagnosis process also the physician explained the tendency of curability of autism is only 50% which is determined through progress. (Participant number 3, age 63)

The initial reaction of the father (participant 3) to diagnosis of autism is hopelessness. The father was concerned about the curability of autism. Since he was unable to know his son’s level of curability, the reaction was feeling of hopelessness and sadness.

Participant number 2 was not around while her child was diagnosed with autism. While the father informed her through phone, she reacted with shock and outcry. She says,

> It was hard time when I heard that my son has been diagnosed with autism, (crying, observation) I thought to the extent that if I was aware of autism problem of my son, I wouldn’t have my second daughter. (Participant number 2, age 35)

4.2. Dimension of challenges

The following section of finding present , the different dimension of challenges or difficulties experienced by participants of the study in relation to psychological, social, marital , sibling and economic aspect.

4.2.1. Psychological challenges

Participants of the study have experienced anxiety, deep sadness and stress in caring a child with autism. Almost all study participants have experienced stress, anxiety and depression. Participant number 3 describes her case in the following way. He says:

> Psychological impact of caring an autistic child is significant. My wife and I have experienced stress and anxiety due to caring a child with autism. Especially my wife became older before her age due to high level of stress. (Participant number 3, age 63)

Some, nevertheless, have accepted the situation and decided to do what they could do. For example participant 1 says:

> Psychologically, I became strong and decided to put all my effort in providing care for my daughter with autism rather than being involved in various bad habits like addiction to drug and alcohol as youths of the same age group. My thinking has changed. I have set a purpose to life and took full responsibility managing and fulfilling basic needs of my daughter by exerting all efforts. (Participant number 1, age 27)

Participant number 6 has associated autism with some good happening to his family. He says:

> Psychologically, I never experienced any one of the negative impact of autism. I am enjoying happy life, as I have perceived autism as given from God. In addition the birth a child diagnosed with autism has brought blessing to my life. The living condition of my family is improving from day to day and I am capable to provide proper care as needed. (Participant number 6, age 61)

Factors that contribute to parental stress vary from participant to participant based on the issue that stresses the family more. Child in ability to express his /her own need, concern of child's future life and who will take care if something happens to me are the concerns of all participants that contribute to their stress. Participant number 1, 2, and 3 highlight the stress of who will take care my child if something happens to me? The families are too much stressed in cases when they have flu infection or other health problem, since they are responsible to take and bring back their children from school. Rather than the problem they experienced, what stresses the participants is who will take care if I passed away or had serious health problem? A participant says:

> My daughter is currently at the age of 12 and she has started menstrual cycle. The time is not good. She might have a chance to be exposed to abuse and violence. Since she is unable to express her feeling I am much stressed. Who will care of my daughter if something happens to me is also stressful to me. I always pray to God to give me long life, even when I see old people on the road, I pray to have the same age. (Participant number 1, age 27)

Participant number 3 explained factors that contribute to stressful experience of the family in relation to caring a child diagnosed with autism as follows:

> I and my wife are the only responsible persons to care for our son. Due to the nature of my job, I have more time to take care of my son and also it is me who takes and brings him back from school. In case if I am sick, my wife is unable to get permission from her work place. It is very difficult to give responsibility for any other body for sending and bringing back my son to school. The death or serious health problem to family aggravates family stress. I know one family who had a child with autism at the age of 14. The mother was single, when she passed away; his sister took the responsibility to look after him. Unfortunately, he passed away after 3 months. After I heard this I am much stressed and became much concerned about my son's future life in the absence of me or any one of us. Feeling of grief for what has happened to my son also in another factor that stress the family. (Participant number 3, age 63)

Participant number 2 has different view about her son which stresses her in thinking about his future life. As explained by participant number 2 she says:

> The normal physical development is going on as his age increases. I am stressed about his future life. I am concerned how leading dependent life would he procreate to continue his generation. In addition to this I am living for two people (me and my son). His life depends on me. The happening of unexpected life event such as death or serious health problem could inhibit me from providing proper care. In such situation who would take care of my son? This stresses me. To get relief from all this stresses, I praying for God to give me long life until he is able to lead an independent life. (Participant number 2, age 35)

4.2.2. Social challenges

The social impact of caring an autistic child has implication in social life .The degree of participation in social life varies from study participant to participant. Some the participants are actively engaged in social life and no visible social impact are experienced. Others, however, in caring a child diagnosed with autism they have limited their ability to participate in social life. Social life is also about family's attitude to appear in public with a child diagnosed with autism and to attend community and family affairs without fear. The level of participation of the family in social life is affected by the reaction of the community to a child diagnosed with autism. Participant number 1, 3, 4, and 5 have limited participation in attending social life event like *idir*. To ensure their participation, the availability of a responsible person to take care of child with autism matters. For participant number 2 most of her participation is in family affair, participation in *idir* and other community affairs is limited as she lives in private rented house.

Participant number 1 explained her experience of participation in social life as supported by the relatives and families understanding.

> Since I have a daughter who requires more attention my participation in social life is limited. Most of the times they don't expect me to attend funeral ceremony or social events as they understand my situation. (Participant number 1, age 27)

As participant explained, the social impact of autism on the family is presented in the form of social isolation, embarrassment, fear to appear in public area. Participant number 1, 3, 4, and 5 have experienced one of the social impacts of living with a child diagnosed with autism to be difficult. Participant number 3 presented the social impact of autism as follow:

> The social life of my family is significantly affected by caring a child diagnosed with autism. My ability and time to involve actively in various social activities is bounded in child care. The community and our neighbors do not have positive reaction to our child situation. I remember one event which is heart touching. My son and our neighbor's daughter are of the same age. But due to autism my son was not able to pass developmental stages appropriate to his age. When both children's are on the playing ground, my neighbors came to pick their daughter. They picked their daughter by saying 'baby he will kick you'. In that situation they have considered my son as a wild animal harming others intentionally and autism as a contagious problem transmitted from child to child through playing together. The stigma and discrimination that I experienced due to autism is as equal as people infected with HIV/AIDS. Our neighbors have isolated us; they show false sympathetic gestures rather than love, care and support. In public

> places also due to the behavior of my son I feel shame and afraid of to attend public events and family affairs. (Participant number 3, age 63)

The other social impact raised by the participant is being identified by the community with the problem of their child. The way they identify individuals as presented by participant number 1 is saddening. She says: “When outsiders came to our living compound for visit, and call me not by name but by using the name of my child with autism. The community identifies me and my daughter with autism problem”. (Participant number 1, age 27). Nevertheless, some report of love, care and acceptance from the community and neighbors. Participant number 6 presented his experience “my neighbors have positive attitude to my son. I am not afraid to attend public places.”(Participant number 6, age 61)

4.2.3. Marital challenges

Participants of the study have been in marriage ranging from 8 to 20 years. In having a child diagnosed with autism all participants except one didn’t consider marital discord as an issue. In their marriage life rather than affecting marital relationship, autism has strengthened the cooperation in taking responsibility and share life burdens.

Other participant presented difficulty in engagement of new marital relationship. The mother has a child with autism as a result community and family members of her partner were mistreating her. Participant number 1 presents the situation as follows:

> The birth of my daughter with autism was out of wedlock. As life event, I met with one guy and started love affair. The love affair resulted in marriage. To set up a new life we went to Nazareth where my husband’s family live. At the beginning my husband was happy with my daughter and has accepted the case of

> autism. On the other side the community, neighbors and family members of my husband have considered me as unfit marriage partner to their son due to having an autistic child. We were of the same age but since I gave birth to a child with autism all of them took me as unfit to marriage. The community and family members have put major impact on my life. On event which I remember as bad experience is when one day I left my daughter with step-father and went out. When I came back, his mother told me, it is not my sons responsibility to care your daughter and she bitten me. In all the hardship, the marriage stayed only for three year and resulted in divorce (Participant number 1, age 27).

4.2.4. Challenges of sibling

Four participants of the study have explained the issue of sibling environment with a child diagnosed with autism. Sibling perception, reaction and stress are issues addressed in relation to sibling aspect of challenges. Participant number 2, 3, 5 and 6 have presented their experience in relation to sibling action and stress level.

4.2.4.1. Sibling perception

In living with a sibling diagnosed with autism, sibling's perception varies based on their age and level of awareness. Participant number 3 has presented the perception of siblings as follows:

> Siblings are older than him. He is the youngest son in our family. They have perceived autism as a situation which necessitates more attention and care. The siblings have experienced similar psychological impacts as of me. We share the experience of stress, depression and anxiety (Participant number 3, age 63).

Other participants who have young siblings have explained the perception of siblings to autism is inconsiderable. Knowingly or unknowing the sibling are caring for them. Participant number 2 has a daughter at the age of 4. In her own words:

> My daughter is at the age of 4. She doesn't have any information about autism. Even it is difficult to reason out why she is doing this. After his arrival at home from school she helps him to take off his shoe and cares him with special love (Participant number 2, age 35).

4.2.4.2. Sibling stress

Out of all participants, participant number 6 has only presented his experience of sibling stress and factors that contribute to stress sibling. He says:

> All the siblings have perceived autism as a normal thing. Our positive perception about autism has brought positive feedback in our children perception. As I understood from the action of eldest brother, he is more stressed in front of his friends. He feels embarrassment when his brother appears naked in front of his friends. The other two siblings have great concern to their brother especially the youngest daughter's care and love is amazing and surprising (Participant number 6, age 61).

4.2.5. Economic challenges

Participants of the study have presented the economic impact of autism in relation to its effect in labor market, and financial burdens.

4.2.5.1. Labor market participation

Participant number 1, 2, 3, 4, and 5, presented to care a child diagnosed with autism, their participation in the labor market or employment status is implicitly and explicitly affected. Participant number 1 and 3 share the experience of limited time availability for appropriate engagement in the labor market is impaired. One participant explains:

> I was employed at government office as cook earning income on monthly basis. When my granddaughter was diagnosed with autism since her mother was not around, I am forced to resign from my employment and losing my monthly income. As a result I have faced difficulty in fulfilling basic family needs. Currently, as the cost of living is at increasing rate, I have begun small business by selling “injera” (Participant number 4, age 55).

Participant number 2 also raised the issue of inability to be involved in the labor market. In her own words she says:

> I was a housemother but I want to share the burden of household expense through involvement in the labor market. I am not able to be involved in income generating activity as I have a child with autism which requires more care and attention.

4.2.5.2. Financial burdens

As presented by participants of the study, in provision of proper care to a child diagnosed with autism, there are additional costs affecting the economic wellbeing of the family. High cost of food, clothing and transportation costs are issues of financial burdens posed as a result of autism. One of the participants explained her case as follows:

> A child personal hygiene has to be taken care when sending to school. To ensure personal hygiene extra clothing is necessary. For example to purchase one trouser

> for my daughter, it costs about a minimum 300 birr. Purchasing a cloth with high cost is difficult as compared to income I earned. In shopping place also the shopkeepers abuse you as a child with autism wants to have everything displayed for sale, and enforcing you to expend beyond your capacity. To deal with this problem rather that attending the purchasing session together, I decided to purchase all items in her absence based on money available in my pocket (Participant number 1, age 27).

Participant number 3 presented the financial burden of autism in the family system as follows:

> In the diagnosis process I have expend too much amount of money. After the diagnosis of my son with autism, transportation cost for sending a child to school, and increase of food expenses above monthly budget are the main financial burdens. We are living in a small room, due to unexpected action of my son, since we do not have place to keep away prepared meals he pours off meals prepared for consumption. As a result of this action, the family is forced to pass the night without having dinner due financial difficulty to cover additional costs (Participant number 3, age 63).

Other participants also present financial burdens in provision of balanced diet. For participant number 2, 4 and 5 as the cost of food items is high; all of them are unable to feed their children as expected. Participant number 4 explained her experience in the following manner. She says:

> My granddaughter always wants to have special and delicious meal. If the meal served is not well prepared and delicious she refuses to consume by closing her mouth. In food preference meat is her favorite. Providing balanced diet and meeting the need of my granddaughter as per her interest is difficult (Participant number 4, age 55).

4.3. Ways of coping

According to study participants, the coping styles employed by different parents are various. The entire participants presented their focus on emotion as a coping mechanism to a stressful event of caring a child with autism. As a different way of coping one participant presented engagement in action as a way to deal with challenging situation.

Participant number 2, 3, 4, and 5 identified the following coping mechanisms; accepting the situation, changing the meaning of autism to a positive, blaming God or themselves, feeling of sadness, changing hopelessness thinking to hopefulness, forgetting and considering as it is beyond our control. According to participant number 3 (age 63) "in all challenging situation I cope the problem by myself. I experience variety of emotions but after all those things I bring back hope and other positive feelings to myself". One of study participant has said: "I have accepted the case of my child. After I experienced all the challenges, I try to give up thinking about it. In other situation also, for the case of autism I put blame on myself or God". (Participant number 2, age 35)

Participant number 1 has identified coping style of taking action in dealing with challenging situation. In her own words;

> The main challenge I faced in caring a child diagnosed with autism is financial limitation. I am sure if I were financially self-sufficient; I will not sit and talk to you about autism. I am working as waitress and the income I earned is insufficient to fulfill all needs. In this situation I will look for alternative money sources specially accessing other individual's resource improperly. Due to the nature of my work, I have a chance to meet with many individuals. I know I don't want to have any affair with them but I need their money. Through all this time I didn't as such faced a serious challenge. For minor conflicts with those individuals who considered my action as cheating, I am sensitive and react with crying and explain why I did so. I can say I have built good relationship with them after understanding my reason. Considering my strength some of them are coming for counseling on different life issue. For an economically well performing family autism is nothing (Participant number 1, age 27).

4.4. Sources of psychosocial support

Participants of the study did not access any psychosocial support from professionals or other sources after diagnosis process. Providing detail information about autism is one form of psychosocial support. As families know more about autism, its impact on the family wellbeing might change to minimal level. Low level of awareness about autism and the long process of the diagnosis have complicated the life of the families. Participant number 5 presented inadequacy of psychosocial support in some medical centers in the following way. She says:

> I went to a physician for medical examination of my son. After thorough examination, he gave me medical certificate only. He didn't say anything about

> the case of autism. I get confused since I didn't find a solution to my son problem. Then I decided to send the medical certificate to a physician whose is my relative. He read the paper and provided me with detail information of autism (Participant number 5, age 28).

In the diagnosis process, out of the six participant's only one participant acknowledged the provision of psychosocial support from a physician. She says:

> I never heard about autism. Naturally, I am a person like who consider situations as simple thing. Not only for the case autism but also for my early pregnancy my response was taking it as a simple thing. The physician who involved in the diagnosis process provided me detail information about autism in relation to care and management. He also assured me that if I provide proper care to my daughter at the age of 10 my daughter will have noticeable change. I promised to celebrate if this happens to my daughter. His expectation was correct, since my daughter had noticeable change I have celebrated her 10th year birth day at hotel by inviting 30 individuals (Participant number 1, age 27).

4.4.1. Psychosocial support from institution

The Joy Center for Children with Autism and Related Developmental Disorder has great contribution for children's and family wellbeing. Participants identified that enabling of children's to bring visible change in various aspects, creating an opportunity to meet and play with children's of the same condition, access to playing items which are not affordable at individual level, and learning of skills through school attendance are some of issues shared as the contribution of the Center.

As identified by participants monthly parent’s discussion day at Joy Center for children with Autism and Related Developmental Disorder is the main sources of psychosocial support. None of the participants identified family members, neighbors or relatives as a source of psychosocial support due to low level of awareness about autism.

In enabling family functioning, the monthly family day has great contribution as a learning session and source of psychosocial support. The participants also emphasized in accessing psychosocial support, the family discussion day is the main source of psychosocial support. One of the participants presented the significance of monthly family discussion day a follows:

> Different individuals have different level of understanding. In holding a discussion with families of normally developing children, we don’t have shared interest. The monthly Parent’s discussion day for me is a learning session and source of psychosocial support. I can talk about autism and my child openly in front of people who have similar experience. For a challenging situation, we are able to find solution from others experience in the discussion session (Participant number 2, age 35).

CHAPTER FIVE - DISCUSSION

In the discussion part the challenges and coping mechanism of families living with a child diagnosed with autism are presented in light of established knowledge. Among the study participants the challenge and coping mechanism of families is different. Based on the identified thematic areas, the differences will be analyzed in relation to the research objectives and in light of the reviewed literatures and conceptual framework.

5.1. Knowledge and perception of autism

As indicated in the finding of the study participants have little knowledge about autism. In relation to perception, participants of the study forwarded their perception about autism as life incident happening to anyone, something given from God (punishment and as incurable problem). According to National Institute on Deafness and other Communication Disorders (2010, p.1) autism is one of the most common developmental disabilities affecting people of every race, ethnic group, and socioeconomic background. The low levels of awareness about autism in all participants of the study imply that as none of the participant perceived autism as developmental disability. The only understanding shared with some of the participants is as it affects every people. Perception of participants forwarded in the findings as gift of God and incurable problem are not supported by literature. The finding about knowledge and perception in general indicate that participant’s low level of awareness and unclear perception about autism.

5.2. Family reaction to diagnosis of autism

The finding of study participants with their reaction to diagnosis of autism indicate the initial reaction for all of the participants was disbelief backed with shock, blame , guilt, outcry and hopelessness. Siegel (1996, pp. 125-129) indicated that initial reaction of families to diagnostic briefing is experienced as disbelief, outcry, hopelessness, numbness, denial, blame and guilt.

Almost all of the participants have presented disbelief as initial reaction. The participant's initial reaction forwarded in the finding as disbelief does not fit to explanation presented in the literature. The family's reaction was in the form of acceptance as something was wrong with the child. Siege (1996, p. 125) indicate that disbelief is parent's first reaction to the diagnosis of autism which is coping mechanism by keeping bad news at an emotional distance from our most inner core.

Reactions of blame and guilt were also forwarded in the finding section. One the participants has explained blame and guilt as addition reaction to the disbelief. Her initial reaction was disbelief but as she understood more in the diagnostic debriefing session, she has backed her reaction with guilt and blame.

The overall initial reaction of families as presented in the finding part is supported by literature. Ozonoff et al. (2002, p. 52) states that families experience a range of reaction to the diagnosis of autism from extreme shock, grief or denial to relief and happiness in the other extreme. Negative and positive feelings are the common mixtures experienced by parents. From the entire family in the finding session none of the participants presented numbness and denial.

5.3. Dimension of challenges faced by families

The findings of challenges as presented the finding session will be discussed in relation to thematic areas of psychological, social, marital, sibling and economic aspect in light of literatures reviewed.

5.3.1. Psychological challenges

Challenges of families as forwarded in the finding session indicate that they whole family system has been impacted by autism. In the psychological aspect, the entire participants have experienced stress, and anxiety. Dumas, et al. (1991) stated that autism other than other childhood disabilities is a more stressful condition for families. The mothers of children with autism also described situation as stressful and experiencing more depression. Father's also reported higher level of stress (as cited in Altiere, 2006, p.8).

The findings from the entire participants indicate that stress and anxiety are the common psychological challenges to families living with a child diagnosed with autism. Initial factors that stress families' as told by participants are inability of children to express their feeling, future life of their child, feeling of sorrow and who will take care if something happens to me are forwarded in the finding session. This goes in line with literature of Autism society (2011) categorization of factors that put family in stressful situation : Child in ability to express his /her own need, taking child diagnosed with autism out of the community, concern of child's future welfare, parents financial aspect and feeling of grief (as cited in Harmann, 2012, pp. 7-9).

A new or renewed sense of spiritual connectedness, emotional growth, a sense of purpose, and a larger community network are some of the positive outcomes (Scorgie, Wilgosh, & McDonald, 1996; Twoy, 2007 as cited in Plumb, 2011, pp.1-2). The findings from study indicate that autism has brought positive psychological outcome. Two of the participants said that autism has brought positive psychological outcome to set purpose in life and emotional growth.

5.3.2. Social challenges

As forwarded in the finding session participants social life and participation in social events limited. For all participants the reaction of the community matters to be actively involved in social life. In attending public places one participant told that low level of awareness about autism is the main factor to experience social isolation or discrimination and embarrassment.

This finding of social challenge of autism is related to Gray's (1994) study indicating that the society had a difficulty to accept a child with autism. The low level of probability to get acceptance from the society exposes parents to experience social stigma and embarrassment associated with inappropriate behavior displayed by these children(as cited in Altiere, 2006, p.15).

Preference to isolate one self and fear of taking child in public are other social impact forwarded in the finding session. One of the participant told that neighbors have isolated us; they show false sympathetic gestures rather than love, care and support. In public places also due to the behavior of my son I feel shame and afraid of to attend public events and family affairs. The finding presented by this participant goes in line with literature of DeMyers (1979) indicating that families have fear of their children's behavior and act and parents prefer to isolate themselves instead of facing the frustration of taking their child in public (as cited in Altiere, 2006, p.15)

Unlike Schall (2000) relatives of parents with child diagnosed autism expressed as cold, distant and unhelpful (as cited in Altiere, 2006, p.15). The findings forwarded from one participant show that contrary to social isolation relatives, neighbors and community have friendship relationship with my son. In attending public places also I do not get afraid.

5.3.3. Challenge on marital relationship

DeMyer's (1979) study revealed that more than half of the families in his study had a weak affection bonds with the parents. In addition there is high risk of marital discord in parents of children with autism (as cited in Altiere, 2006, p.7). From the data collected, the findings indicate that marital discord was not as such a serious life experience. As told by two of study participants the impact of autism on our marital relationship is invisible. Our marital relationship is rather strengthened through sharing the burden of caring our child. The participants also never thought autism as it will weaken affection bond and exposes to marital conflict.

Even though it is not directly consistent with Demyer's (1979) literature of high risk of marital discord in parents of children with autism (as cited in Altiere, 2006, p.7) , finding forwarded from the study indicates that setting up a new life with new partner was challenging due to having a child with autism. As told by the participant getting acceptance from the community and family members of the partner were the main difficulties. Both parties have treated the mother as incapable for marriage and unable to carry the burden of caring additional child from the new marriage.

5.3.4. Sibling challenges

The perception and reaction of siblings as forwarded in the finding session indicate that young and old siblings have reacted in different form. As told by participants young siblings didn't fully understand autism but they are more helpful and supportive for their brother/ sister. The eldest siblings have better understanding about autism as a result they experience the same impact as of their parents. Hartman (2012, p.10) strengthen the finding by stating that in addition to parents, the diagnosis of autism very much impacted siblings. Siblings, however, may not fully understand the diagnosis as they do not receive explanations from specialists and are still developing themselves.

The other finding is sibling stress as told by one participant embarrassment in front of their friend as a result of odd action and aggressive behaviors of their brother /sister identified as stressor. Autism society (2011) states that embarrassment around peers as one stressor for siblings. In having a sibling with autism, they may say or do things that others find "weird" and/or exhibit aggressive behaviors. A sibling may feel awkward or nervous bringing friends around their brother/sister with the fear of the unknown (as cited in Hartmann, 2012, p.11).

5.3.5. Economic challenges

The findings from the study indicate that participant's economic wellbeing matters to see the economic impact of autism on the family. The financial burden and participation in the labor market are the main challenges forwarded in the finding session by participants.

Participants presented the financial burdens in relation to clothing, food and transportation cost. As said by participants the cost of clothing is high beyond the financial capacity of the family. To keep personal hygiene of a child with autism on daily basis you need to have extra clothing. In provision of balanced diet, the high cost of food items is challenging the family. The data from the finding indicate that except one participant educational cost is not the concern of all participants as they are accessing service through sponsorship. But in relation to school attendance covering transportation costs on daily basis is challenging to the family. Sharpe and Baker (2007, p. 248) state that many of intervention strategies require long hours one to one interaction with a trained therapist, and use of costly foods or drug supplements. Parents of a child with autism often face greater outlays of time and money than they would for typically developing child to access specialized care needed for longer period of time. However, finding from the study didn’t indicate the cost of intervention strategies and interaction with trained therapist.

Almost all participants have noted that autism has impact by limiting in labor market participation. As presented in the finding session some of the families have quitted their job, some other have time bounded participation and others are unable to get involved in labor market. The overall findings indicate the impact of autism on family’s labor market participation. The above finding is in consistent with Gould (2004) one or both parents often must reduce work hours or step out of the labor market altogether (as cited in Sharpe & Baker, 2007, p. 248).

5.4. Coping mechanisms

From the data collected the findings have forwarded coping mechanisms of families with a child diagnosed with autism. The finding of coping mechanism will be discussed in relation to literature and the conceptual framework.

In the finding session as forwarded by participants accepting the situation, changing the meaning of autism to a positive, blaming God or themselves, feeling of sadness, changing hopelessness thinking to hopefulness, forgetting and considering situations as beyond our control are coping mechanisms presented. This finding is in line with Hutchison (1999, p. 141) Emotion focused coping function to change either the way situation is attended to (by vigilance or avoidance) or the meaning to oneself of what is happening.

The other finding presented by one of the participant is taking actions or measure by focusing on the problem. As told by her money is the major challenge. To find money I look for every alternative source of income and solve the problem. Hutchison (1999, p. 141) problem focused coping tries to change the situation by acting on the environment. Situations which are controllable by action are dealt by focusing on the problem.

5.5. Sources of psychosocial support

Dunn et al. (2001), Pottie and Ingram (2008) and Sivberg (2002) state that having a child with an ASD can clearly be a difficult experience for parents and families, and it is important to identify use of social support by families raising a child with an ASD, as it has association with positive adjustment in the individual caregiver (as cited in Karst & Van Hecke, 2012, p. 254).

The entire participants forwarded in the finding session monthly family discussion as main source of psychosocial support. Even though there is no individual counseling but in group session participants share experience each other accompanied by teacher explanation of each child. As said by one participant it is very interesting learning session and source of psychosocial support.

The findings of study in relation to conceptual framework of the study indicate that the diagnosis of a child with autism is a stressful event. Once the families experience a stressful event families are figuring out the problem through accessing resources. As forwarded by families after the diagnosis of a child with autism, to deal with the situation all participants were looking for resources from family or institutions. Families who are aware of institutional care for a child diagnosed with autism have applied to be enrolled in the support systems. The perception of families and the meaning attributed to stressful event also has contribution to figure out the problem. As forwarded by participants, families' who perceived autism as God gift and life incident that happens to anyone, they have made effort to deal with the stressful event. Participants, who perceived autism as "incurable problem", their thought in turn has influenced families ability to address stressful event.

As indicated in the ABCX model, stressful event that cannot be managed by families leads to crisis. But the findings of study indicate that none of the participants have experienced crisis. Participants forwarded that diagnosis of a child with autism is stressful event, but they have managed the problem through accessing resources and changing their perception.

The ABCX model describes that following a stressful event a period of disequilibrium is followed by three possible outcomes; recovery to the family's previous level of functioning, mal-adaptation and bon-adaptation. In the study finding the diagnosis of a child with autism is a stressful event. The findings from study indicate that the outcome of disequilibrium is recovery to previous level of family functioning. In stressful events of diagnosis of a child with autism none of the participants experienced a mal adaptation or permanent deterioration or bon -adaptation-improvement in the family’s functioning over and above the previous level of functioning.

CHAPTER SIX - CONCLUSION AND SOCIAL WORK IMPLICATION

6.1. Conclusion

This study is designed to give insight about challenges and coping mechanism of families living with a child diagnosed with autism. The study focused on families living with a child diagnosed with autism where their children are attending school at joy center for autism and related developmental disorder. The study has described family challenges of caring an autistic child in relation to psychological, social, marital, economic and sibling aspects. It also described coping mechanisms employed in relation to challenges faced in different life aspects and source of psychosocial support.

Most of the families in the study are not aware of autism before the diagnosis process. In the diagnosis process also provision of psychosocial support is limited. The diagnosis process is also tiresome and long as most professionals in the medical setting were not aware of autism. The family is facing a multifaceted challenge in and after the diagnosis process. The complication related to tiresome diagnosis process and lack of psychosocial support risked family to experience stress, shock, and anxiety.

Families under study caring a child diagnosed with autism are facing social isolation and discrimination in their social life. In public places also since the community point out finger to families and gossip each other, most families are in fear or afraid to appear in public. The participation of families in social life is limited by caring a child diagnosed with autism.

As compared to families normally developing economic wellbeing families caring a child diagnosed with autism is disrupted with imposed additional cost. The ability to provide balanced diet and cover additional cost is difficult for most families who are dependent on one bread winner. In addition families are forced to resign, engage in part time work, and unable to take part in labor market. The diversified challenge is not limited to families. Siblings are experiencing the same impact as of their families. Factors that contribute to all challenges are low level of awareness about autism in the community, absence of psychosocial support in the diagnosis process; availability of limited centers in providing care for children with autism, and economic wellbeing of the families.

6.2. Social Work Implication

This section tries to describe the implications of the study conducted for social work practice with emphasis to challenges of families living with a child diagnosed with autism experienced by parents due autism. The findings of the challenges of family's in relation to psychological, social, economic, sibling and marital impact of autism on their families have the following implication for social work practice

6.2.1. Awareness creation

Families living with a child diagnosed with autism are living in stressful situation. The community's reaction to a child diagnosed with autism is firing back its impact on families. In order to brighten the hope of families community is at the center to bring change of attitude. The major change should begin from the community. Changing the attitude and perception of the community through organizing awareness raising campaigns in cooperation with different stakeholder is the main activity in social work practice. Preparation of pamphlet, blogging on newspaper and web sites can be used as an alternative approach in reaching the community. The large community at country level can be addressed through extensive media coverage about autism involving government and non-governmental bodies.

6.2.2. Advocacy for the right of an autistic child

Declaration of the Rights of the Child indicate that the child by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection before as well as after birth. The long wait in the enrollment of a child at center who provided special support is against child right. In convention child right include right to education. Whether he is a child with disability or normal development, right to education is basic. Social workers are agent of social justice. They need to advocate for the right of a child with autism in accessing every service as per their need.

6.2.3. Advocacy for expansion institutions at country level

The numbers of institutions providing care for a child diagnosed with autism are two in number at country level located in the capital city Addis Ababa only. Even two centers are available in Addis Ababa; the numbers of individuals who want the service are increasing at alarming rate. Communities who are living out of Addis Ababa are not taken into consideration. In provision of support to families living out of Addis Ababa social workers need to advocacy to the expansion of support center at country level.

6.2.4. Provision of psychosocial support

Psychosocial support is intervention strategy for families living in stressful situation. Most families diagnosed with autism have experienced psychosocial challenges in the diagnosis process and throughout their life due their child’s case. Centers involved in the diagnosis process also have to provide appropriate counseling involving a team of professionals from the health, psychology and social work field in preventing psychological and social impacts.

6.2.5. Social work research

The number of research’s carried about autism in Ethiopian context is insignificant from social work perspective. There are no studies that indicate the prevalence of autism. Research’s on autism focusing the family system need to be addressed in social work research. Research is the base for carrying out various activities to improve the wellbeing of children diagnosed with autism and their families. Based on the finding of the research social workers can advocate for policy and further intervention.

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Annex I

Informed Consent

My name is AynalemTadesse, and I am a post graduate student at Addis Ababa University, school of social work. Currently, I am doing a qualitative study on challenges and coping mechanisms of families living with a child diagnosed with autism. I am doing this study in partial fulfillment of my master's degree in social work. The study has a purpose; to understand major challenges experienced by families living with a child diagnosed with autism from different aspects and coping mechanisms, to aware different stakeholder (governmental and non- governmental) in provision of appropriate psychosocial and economic support, and serve as a resource material in establishment of care centers to improve the wellbeing of the child and the whole family.

Your participation in the study will involve an in depth interview. The in depth interview is with an estimated length of one hour and half. This interview will be audio recorded for later analysis. Besides I will ensure confidentiality by not citing your actual name within the study report. You may choose skip any question that is not interesting to you or quit the interview session at any time. If you have any question or concerns, you may contact the researcher by the following telephone number 0911471708.

By signing below you agree that you have read and understood the above information, and would be interested in participating in this study.

Name ____________________________

Signature __________________________

Date _____________________________

Annex II

የመጠይቅ ስምምነት ቅጽ

ስሜ አይናለም ታደሰ ሲሆን በአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ትምህረት ቤት የድህረ ምረቃ ተማሪ ነኝ፡፡ በአሁኑ ሰዓት እኔ የኦቲዝም ችግር ያለባቸው ልጆችን የሚንከባከቡ ወላጆች የሚያጋጥሙአቸውን ችግሮችና የችግሮቹን መፍቻ መንገዶች በተመለከተ ጥናት እያካሄድኩ ነው፡፡ ይህ ጥናታዊ ጽሁፍ በሶሻል ወርክ የሁለተኛ ድግሪ የማሟያ ጽሁፍ ሆኖ ያገለግል፡፡ በዚህም መሰረት ጥናቱ የኦቲዝም ችግር ተጠቂ ልጆችን በመንከባከብ ቤተሰብ የሚያጋጥሙትን አስቸጋሪ ሁኔታዎችና የሚተገብሩትን የችግር መፍቻ መንገዶች ለመረዳት አላማ ያደረገ ነው፡፡ ከጥናቱ የሚገኘው ውጤትም የተለያዩ ጥቅሞች አሉት፡፡ እነዚህም የቤተሰብን ችግሮች ከተለያየ አቅጣጫ በመረዳት ከችግሮቹ በመነሳት ቤተሰቡ ተገቢውን እርዳታና እንክብካቤ እንዲያገኝ የተለያዩ አካላት ለማነሳሳትና የቤተሰቡን የኑሮ ሁኔታ ለማሻሻል ለሚደረጉ የህክምና እና እንክብካቤ ማዕከላት ምስረታ እንደመነሻ ሆኖ ያገለግላል፡፡

በዚሁ ጥናት ውስጥ እርስዎ በቃለ መጠይቅ ተሳትፎ ያደርጋሉ፡፡ ይህን ቃለ መጠየቅ ለማካሄድ በግምት አንድ ሰአት የሚወሰድ ሲሆን ይህ ቃለ መጠይቅ ወደፊት ለሚደረገው የጥናቱ ትንተና እንዲያገለግል በድምፅ መቅረጫ ይቀዳል፡፡ በተጨማሪም ሚስጥራዊነቱን ለመጠበቅ በመጠየቁ ውስጥ የተገለጸውን ስም በጥናቱ ውስጥ በቀጥታ ባለመጠቀም ፣ሚስጥራዊነቱን ያረጋግጣል፡፡በመጠየቁ ውስጥ ካሉት ጥያቄዎች ውስጥ ለመመለስ የማይፈልጉትን ጥያቄ ባለመመለስ ወይም መጠይቁን በማንኛውም ሰዓት ማቋረጥ ይችላል፡፡በጥናታዊ ጽሁፍ ላይ ጥያቄ ወይም ሀሳብ ካለዎት በስልክ ቁጥር 0911 47 17 08 የጥናቱን ባለቤት ማነጋገር ይችላሉ፡፡

ይህን የስምምነት ቅጽ ካነበቡና በትክክል ከተረዱት በኋላ በጥናቱ ለመሳተፍ ፍቃደኛ መሆንዎን ለማረጋገጥ ከዚህ በታች በተዘጋጀው ቦታ ላይ በመፈረም ፍቃደኛነትዎን ያረጋግጡልኝ፡፡

ስም ________________________________

ፊርማ ________________________________

ቀን ________________________________

Annex III

Interview Guide

Dear esteemed participant, the following questionnaire is developed for conducting a study in partial fulfillment of MA degree in social work at Addis Ababa University, school of social work. The study focuses on understanding the challenge of families living with a child diagnosed with autism and coping mechanism. In this regard to undertake the study successfully and understand the challenges of families living a child diagnosed with autism and coping mechanisms, your participation has a valuable contribution. So, I invite you to participate in the study by attending an in-depth interview session and answering the following open ended questions.

1. Personal information:

- Name :(optional)
- Age:
- Sex:
- Marital status:
- Educational status:
- Employment status:
- Where does the family lives?

2. Knowledge about autism

- Have you heard about autism before if yes can you tell me about what you know about autism?
- What do you think is the cause of autism in your child?
- How do you define or perceive autism?

- How do you explain your understanding about autism before and after your child is being diagnosed?

3. Family and child information

- How many children do you have and which child has a problem of autism?
- When did you know about your child's problem?
- At what age did your child diagnosed with autism?
- Where was the diagnosis carried out and who informed you about your child's case?
- What was your initial reaction when you were informed of your child's autism diagnosis?
- Have you got any psychological support after the diagnosis a child with autism?
- What are the major challenges the family faced before and in diagnosis process of a child with autism?
- What are the major challenges the family faced after the diagnosis of a child with autism?
- Which behavior or actions of your child are very difficult in handling?
- Who is more involved in caring your child with autism (father or mother)?
- Why he or she is more involved in caring activity?

4. Sibling aspect

- How is the perception of siblings about their brother /sister situation?
- What is the influence of having a child with autism and sight or hearing problem on siblings?

5. Marital aspect

- For how long did you lived in marriage?
- How was your marital relationship before the diagnosis of a child with autism?
- Did the diagnosis of a child with autism influence your marital relationship?
- How do you explain the influence of having a child with autism on marital relationship?
- How are you managing the difficulty faced in your marital relationship?

6. Social aspect

- How was your participation in social relationship before the diagnosis of a child with autism?
- How did having a child with autism affect your social life?
- How did extended families or community react to the diagnosis of autism and how extended family or community is supporting the family?
- How the community reacts to appear in public place with a child diagnosed with autism?
- What do you want to be known by the community?

7. Economic aspect

- How were you making a living before the diagnosis of a child with autism?
- How did having a child with autism affect your daily routine, employment situation?
- What are the major economic challenges the family faced after the diagnosis of a child with autism?
- Which costs of living increased as a result of having a child with autism?
- How are you managing the economic challenges?

8. Psychological aspect

- What are the major negative psychological effects the family experienced due to the diagnosis of your child with autism (like depression, shock, guilt, self-blame…..etc)?
- What are the major positive psychological aspects experienced by the family?
- What are the major factors that contribute to family stress?

9. Coping mechanism

- How did you cope with challenges of caring an autistic child?
- What are the major sources of support systems that you accessed in relation to the challenges faced by family?
- Can you list down support services you accessed in relation to the challenges faced by the family?
- For how long have you waited to access the service and for how many years did your child accessed the service?
- What is the contribution of support system that you accessed in improving the well-being you and your child?
- What do you want to be done by different stakeholders (government and non-government) in improving the wellbeing of a child diagnosed with autism and their family?

Annex IV

የቃለ መጠይቅ ቅፅ

ውድ የዚህ ጥናታዊ ጽሁፍ ተሳታፊ ፣ይህ ቃለመጠይቅ የተዘጋጀው በአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ትምህርት ቤት የሁለተኛ ድግሪ የማሟያ ጽሁፍ ጥናት ለማካሄድ ነው፡፡ ጥናቱም ትኩረት ለማሳየት እና ቤተሰቡ የሚተገብራቸውን ችግር መፍቻ መንገዶች ለመረዳት ነው፡፡ በዚሁ መሰረት ኦቲዝም ያለበትን ልጅ መንከባከብ በቤተሰብ ላይ የሚያሳድረውን ተፅዕኖ እና የችግር መፍቻ መንገዶችን ለመረዳት የእርስዎ ተሳትፎ ለጥናቱ መሳካት ትልቅ አስተዋጽኦ አለው፡፡ ስለዚህም ከዚህ በታች ከኦቲዝም ጋር በተያያዘ የተዘረዘሩትን ጥያቄዎችን በመመለስ እንዲተባበሩኝ በትህትና እጠይቃለሁ፡፡

1. የግለሰብ መረጃ

- ስም
- ዕድሜ
- የጋብቻ ሁኔታ
- የትምህርት ደረጃ
- የሥራ ሁኔታ
- የቤተሰቡ የመኖሪያ ቤት ሁኔታ

2. ስለኦቲዝም መረጃ

- ከዚህ በፊት ስለኦቲዝም ችግር ሰምተው ያውቃሉ ሰምተው የሚውቁ ከሆነ ስለኦቲዝም የሚያውቁትን መረጃ ቢገልፁልኝ?
- በልጅዎ ላይ የተከሰተው የኦቲዝም ችግር የተከሰተ ምክንያት ምን እንደሆነ ቢገልፁልኝ?
- ኦቲዝም ለእርስዎ ምን ማለትነው?
- ስለኦቲዝም ያለዎት እውቀት የልጅዎን ሁኔታ ከማወቅዎ በፊትና ካወቁ በኋላ ያለው ልዩነት ቢያስረዱኝ?

3. የቤተሰብ እና የልጅ መረጃ

- ስንት ልጆች አለዎት?
- የትኛው ልጅ የኦቲዝም ችግር አለበት?

- ስለልጅዎ የኦቲዝም ሁኔታ ካወቁ ስንት ጊዜ ይሆኖታል?
- ልጅዎ በስንት አመት እድሜው የኦቲዝም ችግር እንዳለበት በምርመራ ተረጋገጠ?
- ልጅዎን ሁኔታ ለማረጋገጥ ምርመራው የት ተካሄደ፣የምርመራ ውጤቱን ማንነገርዎት?
- የልጅዎን የምርመራ ውጤት አቲዝም መሆኑን ሲሰሙ መጀመሪያ ምን ተሰማዎት?
- ውጤቱን ከሰሙ በኋላ የተደረገሎት የምክር/የድጋፍ አገልግሎት አለ?
- ከምርመራ በፊት እና በምርመራ ወቅት ቤተሰቡ ያጋጠመው ችግሮች የትኞቹ ናቸው?
- ከምርመራ ውጤቱ በኋላ ቤተሰቡ ያጋጠመው ዋና ዋና ችግሮች የትኞቹ ናቸው?
- የትኞቹ የልጅዎት ጸባይ ወይም ድርጊት ለመንከባከብ ወይም ለመያዝ አስቸጋሪ ናቸው?
- ለልጅዎ/ሽ እንክብካቤ ለማድረግ ብዙውን ጊዜ ተሳታፊ የሚሆነው ማን ነው (እናት ወይስ አባት)?
- ለምን አባት/እናት ብዙ ጊዜውን ወስዶ እንክብካቤ ያደርጋል?

4. የወንድም/እህት ሁኔታ

- ወንድሞቹ ወይም እህቶቹ፣በልጅዎ ላይ ያለውን የኦቲዝም ችግር እንዴት ይመለከቱታል?
- የኦቲዝም ችግር ያለበት ልጅ መኖሩ፣በወንድሞቹ/እህቶቹ ላይ ያሳደረውን ተጽዕኖ እንዴት ይገልጹታል?

5. የጋብቻ መረጃ

- በትዳር ስንት አመት ኖራችሁ?
- የልጅዎን የኦቲዝም ምርመራ ውጤት ከማወቅዎ በፊት፣በትዳር ውስጥ ያለው ግንኙነታችሁ እንዴት ነበር?
- የልጅዎ የኦቲዝም ችግር በትዳር ህይወትዎ ላይ ያመጣው ተጽዕኖ ካለ ቢገልጹልኝ?
- በትዳር ህይወትዎ ያጋጠሞት ችግሮች እንዴት ይፈቱታል?

6. ማህበራዊ ኑሮ መረጃ

- በማህበራዊ ህይወትዎ ልጅዎ የኦቲዝም ችግር ተጠቂ ከመሆኑ በፊት ምን ያህል ተሳትፎ ያደርጉ ነበር?
- ከልጅዎ ሁኔታ ጋር በተያያዘ በማህበራዊ ኑሮዎ ያጋጠሞት ዋና ዋና ችግሮች የትኞቹ ናቸው?

- ማህበረሰቡ ወይም የሩቅ ዘመዶች ለልጅዎ የኦቲዝም ሁኔታ ያለው ምላሽ ምን ይመስላል፣ምን አይነት ትብብርስ ያደርጋል?
- ማህበረሰቡ ኦቲዝም ችግር ያለበት ልጅዎን ይዘው ህዝብ በተሰበሰበበት ቦታ ሲገኙ ምላሹ እንዴት ነው?
- ማህበረሰቡ ስለኦቲዝም በአጠቃላይ ቢያውቅ የሚሉት ምንድን ነው?

7. ኢኮኖሚያዊ ሁኔታ መረጃ

- የልጅዎን ሁኔታ ከማወቅዎ በፊት በምን ስራ ላይ ተሰማርተው የመተዳደሪያ ገቢ ያገኙ ነበር?
- የልጅዎን ሁኔታ ካወቁ በኀላ በእለት ከእለት ኑሮዎ ወይም በሰራዎ ላይ ያመጣው ተጽዕኖ ወይም ለውጥ አለ ካለ ቢገልጹልኝ?
- የኦቲዝም ችግር ያለበትን ልጅ በመንከባከብዎ የትኞዎቹ ኢኮኖሚያው ችግሮች አጋጥመውታል ወይም የትኞቹ ወጪዎች በፊት ከነበረው ወጪዎች ጨመሩ?
- እነዚህን የኢኮኖሚ ችግሮች ለመፍታት ምን አደረጋችሁ?

8. ስነ ልቦናዊ ሁኔታ

- የትኞቹ አሉታዊ የስነ ልቦና ችግሮች ቤተሰቡ አጋጥሞታል?
- የትኞቹ አወንታዊ የስነ ልቦና ችግሮች በቤተሰቡ ውስጥ ተከስተዋል?
- ከልጅዎ ጋር በተያያዘ የትኛዎቹ ሁኔታዎች ጭንቀት ውስጥ እንዲገቡ ያደርጎታል?

9. የችግር መፍቻ መንገዶች

- የኦቲዝም ችግር ያለበትን ልጅዎን በመንከባከብዎ ያጋጠሞትን አስቸጋሪ ሁኔታዎች እንዴት ፈታችሁት?
- ካጋጠሙዎት አስቸጋሪ ሁኔታዎች ጋር በተያያዘ የእርዳታ ወይም ድጋፍ አገልግሎቶችን የሚያገኙት ከየት ነው?
- ከልጅዎ ሁኔታ ጋር በተያያዘ ያገኟቸው የእርዳታ አገልግሎትዎች ካሉ ቢዘረዝሩልን ?
- አገልግሎቱን ለማግኘት ለምን ያህል ጊዜ ጠበቁ?
- ለምን ያህል ጊዜ የአገልግሎቱ ተጠቃሚ ሆኑ?
- እነዚህ ያገኗቸው የእርዳታ/ድጋፍ አገልግሎቶች ለእርስዎም ሆነ ለልጅዎ መለወጥን ያደረጉት አስተዋጽኦ ምንድን ነው?

- መንግስታዊም ሆኑ መንግስታዊ ያልሆኑ አካላት በኦቲዝም ተጠቂ ለሆኑ ልጆች እና ቤተሰቦቻቸው የኑሮ ሁኔታ መለወጥ ምን ቢያደርጉ ጥሩ ነው ብለው ያስባሉ?