**Addis Ababa University College of Social Sciences**

**School of Social Work**

# A Qualitative Study on Impacts of the Presence of ASD on Families of the Autistic Children and the Support Systems in Yeka Sub-city of Addis Ababa

By: Abeba Kebede Eshete

A Thesis Submitted to School of Social Work Presented in Partial
fulfillment of the Requirements for the Degree of
Master of Social Work (MSW)

December 2020
Addis Ababa, Ethiopia

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Advisor: Commander Demelash Kassaye, (PhD)

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# Plagiarism Declaration

I Abeba Kebede Eshete do here by declare the fact that this research paper is my original work, has not been presented for the degree of Masters of Social Work , in any other university and for any other purpose and as well all sources used for this research has been fully acknowledged.

Name of Participant: Abeba Kebede Eshete

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**Addis Ababa University**

**School of Social Work**

**MSW Examining Committee**

This is to certify that the thesis entitled as " Impacts of the Presence of ASD on Families of Autistic Children and the Support Systems in Yeka Sub-city” is prepared by Abeba Kebede Eshete and submitted in partial fulfillment of the requirements for the Degree of Master of Social Work, complies with the regulation of the university and meets the accepted standards with respect to Originality and quality.

Signed by Examining Committee

Internal Examiner _________________________ Signature ____________Date________

External Examiner _________________________ Signature __________ Date ________

Advisor _______________________________ Signature ___________Date ___________

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# Acronyms

ABA: Applied Behavior Therapy

BCBA - A board-certified behavior analyst

ASD: Autism Spectrum Disorder

DSM-5: The Diagnostic & Statistical Manual of Mental Disorders, Fifth Edition

ETB: Ethiopian Birr

FHA: High Functioning Autism

GO: Government Organization

IAN: -Interactive Autism Network

IQ: Intelligence Quotient: An attempt to measure the intelligence of someone.

LHA: Low Functioning Autism

NGO: Non-Governmental Organizations

NIH: National Institute of Health

NIMH: National Institute of Mental Health

PPD-NOS: Pervasive Developmental Disorder not otherwise specified

TVET: Technical and Vocational Education and Training

# *Abstract*

*This qualitative study was concerned with exploring the effects of the presence of ASD children on the lives of the families of the autistic children who resided in Yeka Sub City of Addis Ababa, with a specific focus on woreda five, six, and seven. Together with this, the study examined the availability of family support systems for these families. The study deployed an exploratory data collection approach to learn the families' lived experiences through the study participants' understanding of the realities, and to answer the research questions: "what impacts does the presence of ASD children have on the lives of their families resided in woreda five, six, and seven of Yeka Sub-City, and what family interventions are available to these families' to address the families' life problems and restore family stability?" One male and seven female participants were participated in the data collection. In-depth in-person interview was conducted at participants' places to explore the families' life situation, and interview has been audio-taped. A supplementary questionnaire has been administered to the same participants in order to obtain the ASD children's demographic data and examine availability of early intervention services. Snowball or chain referral sampling technique was used, because the population of interest was uncommon and the size of the population was too small to meet the sampling criteria. The target population was caregivers of the ASD children with diverse sociodemographic backgrounds; because they were appropriate to explain the phenomena from different perspective and provide detailed information. The data analysis involved: transcribing audio data, coding data, categorizing codes, developing themes, and presenting the findings using MS-Word and Excel applications. The study identified five major issues: 1) diagnosis and basic therapy services that the parents received to their ASD Children, (2) impacts of raising an ASD Child on the Family, (3) the influencing factors that contributed to the parents' stressful situation, (4) parents' inability to cope with the stressors, and (5) unavailability of family support systems.*

Key words: *ASD, disability, family, children, parent/caregiver, impacts, effects, lived-experience, crisis, stressors, support system, participants, researcher, qualitative research, data, design, methods, themes, findings*

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# Chapter One

# Introduction

## 1.1. Background of the Study

A qualitative study on “Impacts of the presence of ASD child on Families of the ASD Children and the Support Systems in Yeka Sub City of Addis Ababa was conducted to explore the families’ lived-experiences and examine the availability of family support systems to this population. The study was aimed to address the research questions through exploring the families’ lived-experiences in caregivers’ meanings of the realities at the place where participants experienced the issues; and provide the multifaceted picture of: (1) how the presence of ASD child affected the families’ wellbeing, (2) what interacting factors have contributed to the parents’ emotional disequilibrium and impaired family functioning, and (3) what interventions are provided to meet the families’ life demands.

According to CDC, (2020) autism spectrum disorder (ASD) defined as: *“A group of conditions due to impairment in physical, learning, language, or behavior areas that can cause significant social, communication and behavioral challenges. People with ASD may communicate, interact, behave, and learn in ways that are different from most other people; and, their learning, thinking, and problem-solving abilities can range from gifted to be severely challenged. ASD occurs in all racial, ethnic, and socioeconomic groups”.*

Veenstra et al. (2011) stated that disorders within the spectrum include Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). Individuals with ASDs have impaired social interaction, behavior, and communication including lack of reciprocal social interaction and attention dysfunction or absent communication and language skills; lack of spontaneous or pretend play (i.e.

playing by pretending as if' the events are real), intense preoccupation with particular concepts or things; and repetitive behaviors or movements.

My past work experience with ASD children in a day-program and special education settings inspired me to know more about how the presence of ASD child in a family affects the families' wellbeing, particularly in the resource poor countries like Ethiopia. Meeting the complex life demands of their child requires the parents or caregivers a commitment to give up everything they have i.e. time, money, interest, benefit etc. on behalf of their ASD child. In this condition availability of appropriate support systems may contribute a lot towards effecting positive change on the lives of the families.

Parents' or caregivers' understanding of their child's condition is determined by their socio-demographic backgrounds, and availability of professional guidance and social networks that help the family to effectively respond to the family crisis situation. Bogdashina, O. (2006) stated that some mothers have confessed there were times when they wanted to end their lives as they had no strength to deal with the immense pressure which autism puts on family life. Some parents are unable to cope with the challenging behavior of their child (especially aggression and self-injury), and may consider out-of-home placement for the child. An Australian mother killed her ten-year-old autistic son and tried to commit suicide. The boy did not die because he had autism but because of the lack of help his family received. (p.195)

'Over the years, families have tried various types of traditional and non-traditional treatments to reduce autism behaviors and to increase appropriate behaviors. Although some individuals are given medications to improve general well-being, there is no primary drug which has been shown to be consistently effective in treating symptoms of autism'. 'Directorate C – Public Health and Risk Assessment', (2005)

This study deployed qualitative data collection methods i.e. in-depth in-person interview and a supplemental questionnaire to explore participants' life experiences from their own viewpoints in rich-detail, and examine availability of support systems.

## 1.2. Statement of the Problem

The study was aimed to explore the emotional, biological, social and economic impacts of having ASD children on the families' lives, and identify the internal and external influencing factors that have contributed to the family dysfunction. Furthermore the study was concerned with examining the availability of appropriate support systems to address the families' problems. In the Ethiopian context caregivers of ASD children may be one or two-biological parents, relatives, adoptive parents, older siblings, maternal or paternal-grandparents with diverse cultural and demographic background, economic status and social position. Thus, the families' understanding of autism varies depending on one or more of the above stated backgrounds. In addition, each family may have its own level of strength and internal coping ability to respond to the family crisis. Loughlin, L., O., & Loughlin, S., O., (2008) described diversity of family forms as: *"The family consists of relative caregivers such as grandparents, who may be paternal, maternal, or by marriage, can be non-relative carers such as friends, parents or carers who share the same race, class, culture, religion and sexuality or alternatively it may consist of parents or carers who have different race, class, culture, religion and sexuality. There may be one or more children in the family, some of whom may share the race, religion and sexuality of their parents and some that do not". (p.5)*

ASD is an incurable mental condition, and its presence in a family may affect the whole aspects of the family's life in all stages of the family cycle particularly from family expansion through completion of expansion and it makes family contraction difficult. Parenting a child with autism disorder(s) is likely to be more stressful and overwhelming for the parents or caregivers particularly who live in the resource-poor country like Ethiopia. Lack of access to the needed resources and support services may prevent the parents from meeting the family's life demands and contribute to the family disorganization. Possible internal and external factors associated with raising an ASD child may adversely affect the family's life-style by weakening the family's strength and influencing the parents' perception of own self-efficacy.

## 1.3.General objective of the Study

The main objective of the study is to explore how the presence of ASD child in a family affected the lives of the families living in woreda five, six, and seven of Yeka Sub-City, analyze the interacting factors that have contributed to the family's emotional and physical dysfunction; and examine what support systems are available to address the family problems.

### 1.3.1. Specific Objectives

1) to explore how raising an ASD child in a family affects the wellbeing of the family as a whole;
2) to identify the interacting factors that have contributed to the family emotional instability and family dysfunction;
3) to examine availability of family support systems to these families

### 1.4.Research Questions

The study aims to answer the below stated questions.

#### 1.4.1. General Research Question

How does the presence of an ASD child in a family affect the family's well-being, and how do the support systems intervene to meet the families' life demands?

#### 14.2. Specific Research Questions

1) What effects does ASD have on the lives of the families with ASD children in woreda five, six, and seven of Yeka Sub-City?
2) What interventions are available to these families' to address the families' life problems and restore family stability?

### 1.5. Scope of the Study

This study is limited to exploring the emotional, social, economic, and biological impacts of having an ASD child on the family, identifying the internal and external influencing factors that may contribute to the families' problem situation, and examining availability of family support systems. The specific study areas were woreda five, six, and seven of Yeka Sub City in Addis Ababa. Interview was conducted to explore the families' lived-experiences from participants' perspectives at participants' residences. Supplemental questionnaire was also administered to identify status of the ASD children and availability of certain support systems The data collection methods were in-person in-depth interview and questionnaire and data was collected from eight study participants i.e. caregivers or parents of the ASD children. Equilibrium crisis intervention model, cognitive crisis intervention model, and psychosocial treatment model have been discussed in the literature review section. The three intervention models have common features but utilize different approaches to family intervention. Each model views the family's problems from different perspective and recommends its own intervention strategy to meet the families' demands and restore family's stability. The duration of time to complete and submit the thesis project was November 2019 to December 2020

## 1.6. Significance of the Study

Waganesh, A., Z., (2018) stated that large majority of parents with the ASD children in Ethiopia are unaware of the services available to their children and indicated poor parent-agency coordination. Hence this study has been conducted to fill the gap in exploring and presenting: (1) the emotional, biological, social, and economic impacts of the presence of ASD child on the family, (2) the internal and external influencing factors that have contributed to the escalation of parent's emotional dysfunction, and (3) unavailability of family support systems to these families. The study attempted to fill the gap in discovering the prominence of: (i) creating awareness to the families about autism and the diagnosis, (ii) provision of formal network system and professional guidance to help the parents with navigating support and services, (iii) availability of appropriate treatment and resources to the ASD children, (iv) promoting family and social support systems, and (v) necessity of family intervention services in social work profession.

## 1.7. Limitation of the Study

The outbreak of COVID-19 pandemic global crisis created difficulty for the researcher to carry out the data collection within the timeframe originally planned. This study only covered the population within woreda five, six, and seven of Yeka Sub-city in a village named Kebena. Only one of the two parents/caregivers in a family has been interviewed and completed a supplemental questionnaire. Available means of communication to exchange verbal and written information with the research advisor and others who participated in the data collection were telephone and email; for that reason follow-up and feedback were time taking and sometimes difficult. All the expenses required to conduct this study have been covered by the researcher.

### 1.8. Organization of the Paper

The first chapter of this study presented background of the study, statement of the problem, general and specific objectives, research questions, scope of the study, significance of the study, and limitation of the study. Chapter two consisted of the literature review in which findings of previous studies in the same topic were consulted, and crisis intervention and social work family therapy models, and ASD therapy services were discussed. Chapter three comprised: study site, study population, sampling technique, research methodology, research design, data collection approach, data analysis and interpretation strategies, and ethical consideration. Chapter four consisted of the findings and presentation sections. Chapter five presented discussion of the study findings whereas chapter six comprised conclusions, implication for social work practice, policy, and future research.

# Chapter Two

# Literature Review

## 2.1. Introduction

Autism is a complex, lifelong developmental disability that typically appears during early childhood and can impact a person's social skills, communication, relationships, and self-regulation. Autism is defined by a certain set of behaviors and is a "spectrum condition" that affects people differently and to varying degrees. (Autism Society USA, 2020)

Overview of the five main constructs that have been discussed in the literature review part were: (1) ASD in children, (2) therapy treatments and medication to the ASD children (3) Family and impacts of ASD on family, as a whole, (4) crisis and family crisis intervention models, and (5) family support and social work intervention.

The literatures in the context of family emphasized on: concept of family from systems perspective, parenting ASD child and the social, environmental, emotional, and financial impacts of ASD on family, family support in social work profession, family support system for disability, social work theories and social work interventions with families. The literature review has considered reviewing qualitative study findings, family intervention modes, e-books, online journal-articles, and publications on the topic.

## 2.2.Autism

### 2.2.1. History of Autism Spectrum Disorder

According to Mcneil, C. B., Quetsch, L. B., Anderson, C. M., (2018) autism Spectrum Disorder, ASD was first described in case studies by two independent researchers Leo Kanner and Hans Asperger. In 1943 the Austrian-American Psychiatric

Leo Kanner met a 5-year-old child who took no interest in people around him, liked to spin around in circles, and threw tantrums when his typical schedule was interrupted. Kanner also found that the fundamental marker of autism was the "children's inability to relate themselves in the ordinary way to people and situations from the beginning of life. (p. 9)

Mackelprang, R., & Salsgiver, R., (1995) explored that history of the distinctive perception of different groups of people around the world regarding cause of disability. "Neolithic tribes believed disabilities were caused by spirits (Albrecht, 1992), and skull surgeries were performed to release evil spirits. He also stated that ancient Greeks believed disabled persons were not human and that they should be abandoned to die. The Romans, who borrowed the concept of reciprocity from the Greeks, gave assistance to adult persons with disabilities with the expectation they would express their appreciation through complacency (Morris, 1996). But like the Greeks, they also at times abandoned disabled and deformed infants to die, justifying their actions by defining those children as not fully human. (p. 3)

### 2.2.2. Prevalence

A review of the global prevalence of autism did not show the prevalence for sub-Saharan Africa; however the report indicated that this region has the population of nearly 1 billion, and 40 percent of whom are children younger than 14 years. The Lancet, (2016) recommended that studies on autism and other neurodevelopmental disorders in Africa are urgently needed (Amina, Derrick, Petrus, & Charles, 2016). There is no written evidence on prevalence of autism in Ethiopia. Study findings indicate that due to the existence of social stigma most of the parents of ASD children in Ethiopia lack courage to take their children for diagnosis test. As stated by. According to Abeba, G., (2017) autism can be one of the most difficult diagnoses to accept for parents in Ethiopia. It is particularly due to the challenging symptoms associated with autism spectrum disorder(s). As with many things that society does not understand, autism also has a certain stigma attached to it. The negativity can make it quite difficult for families struggling to cope with an individual who has the diagnosis.

### 2.2.3. Disorders Within Spectrum

A recent study has identified numbers of disorders within Autism Spectrum. Renee A., Alli, (2020) described that autistic disorder, Asperger's syndrome, and pervasive developmental disorder not otherwise specified (PPD-NOS) are conditions considered spectrum disorders. Asperger's Syndrome is on the mildest end of the autism spectrum that individuals with Asperger's may be intelligent and able to handle their daily life. However an individual with Asperger's has greater degree of social impairment. Most children whose autism is more severe than Asperger's syndrome diagnosed with pervasive developmental disorder not otherwise specified (PPD-NOS). Autistic disorder is further along the autism spectrum than Asperger's and PPD-NOS, and it includes the same type of symptoms at a more intense level. Rett Syndrome has behaviors similar to autism, but it is no longer considered an ASD, because it's known to be caused by genetic mutation.

#### 2.2.3.1. Down's Syndrome

Down syndrome (DS) is the most frequently occurring chromosomal abnormality in humans and affecting between 1in 500-1500 babies born in different populations. DS is the common genetic cause of intellectual disabilities worldwide and large numbers of patients throughout the world encounter various additional health issues including health defects, hematopoietic disorders, and early-onset Alzheimer diseases Kazemi M., Selehi M., Kheirollahi M., (2016).

As stated by Dan Brennen (2020), in the 2013 Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Down syndrome has been classified as part of autism spectrum disorders, ASD. This condition is called a “High Functioning” type of ASD that the symptoms are less severe than the other types of ASDs. The DSM-5 also includes a new diagnosis called “Social Pragmatic Communication Disorder” which has some symptoms that overlap with Asperger’s.

### 2.2.4. Causes of Autism

According to Bogdashina, O., (2006) the dominant theory of autism etiology identifies several causes, which has a genetic vulnerability within it. Bogdashina has presented four potential triggers to autism:

#### 2.2.4.1. Prenatal, Perinatal or Postnatal Difficulties

Research has shown that mother of autistic children may have problems during pregnancy and/or delivery. However, it is not known yet whether these difficulties trigger autism or autism cause pregnancy and deliver problems (Bogdashina, 2006, p.256).

#### 2.2.4.2. Structural and/or Functional Brain Abnormalities

Bogdashina, (2006) stated that structural brain abnormalities in different autistic people have been found in different parts of the brain. As yet, no abnormality specific only for autism and not for other conditions have been found. Many researchers reported reduced Purkinje cell density in the cerebellum autistic people (Arin, Bauman and Kemper 1991; Bauman 1991; Bauman and Kemper 1985). (p. 256)

### 2.2.4.3. Abnormal Biochemistry of the Brain

Many studies have been conducted to determine neurotransmitter abnormalities in autism. High levels of serotonin in the blood of about one third to one fourth of autistic children have been reported (Cook *et. al.* 1994). However, it is not clear yet if high blood serotonin levels mean that serotonin levels in the brain are high as well. Studies of other neurotransmitters have not revealed any consistent abnormalities in autistic people (Bogdashina, 2006, p.256).

### 2.2.4.4. Metabolic Abnormalities

According to Bogdashina, (2006), it has been suggested that autism may be the consequence of a metabolic disorder or of the combined effects of a number of metabolic abnormalities, the incomplete breakdown of certain proteins, particularly, but not necessarily exclusively, gluten from wheat and some other cereals and casein from milk and dairy products which may result in the production of peptides which are potentially biologically active (Shattock and Savery 1996). (p. 256)

## 2.2.5. Deficits and Impairments in Children with ASD

### 2.2.5.1.. Physical – Sensory Deficit & Motor Deficits

Reynolds, T. & Dombeck, M., (2006) stated that children with autism tend to have extreme reactions to sensory simulations, and their senses may become hypersensitive or hyposensitive. Hypersensitive children find themselves overloaded with even moderate levels of sensation, and they work to block out sensory input such as light, sound, and touch. Hyposensitive children, on the other hand, are not stimulated enough by normal sensory inputs, and typically seek out external stimulation. Children with autism frequently show developmental delays in developing fine motor skills, they commonly have difficulty walking naturally; for instance, they may “toe-walk”, stepping only on the front portion of their feet instead of a normal relaxed walking pattern.

#### 2.2.5.2. Social Deficits

Compounding their communication difficulties, many children with autism show profound empathy deficits. They develop only a very limited appreciation or no appreciation at all, of other people’s feelings and ideas. They don’t recognize and respond to faces as do normal children, and they thus do not learn that each face belongs to an individual separate person. Many children with autism are completely unaware of their surroundings and other people in their surroundings. It is impossible for some children with autism to take another person’s perspective without deliberate training”. Reynolds, T., (2006)

#### 2.2.5.3. Repetitive and Restricted Behaviors, Interests

McNeil, C. B., Quetsch, L. B., & Anderson, C. M., (2018) stated that repetitive and restrictive behaviors often become most apparent when a child begins to play with toys independently and develop language. There is some research reporting repetitive and restrictive behaviors in children with ASD by the second year of life (e.g., Wetherby et al., 2004), while other studies report that those behaviors only become atypical later in childhood (e.g., Werner & Dawson, 2005). Some repetitive and restricted behaviors change as children develop, as interested and skills change. For example, a young child may repeatedly line up blocks or other toys instead of building or playing with them, and then, in later years, begins to insist that his or her clothes be hung in a particular manner and that other precise organizational patterns are followed (Watt, Wetherby, Barber, & Morgan, 2008). Stereotyped behaviors can also appear in the use of language, such as repeating one word or phrase (echolalia) or only repeating information on one topic that is of interest to them, which may also make the individual seem “rigid” (APA 2000). Children with ASD can exhibit rigidity in their adherence to routines, social flexibility, and understanding or rules. Children with ASD may have very restricted interests, such as exclusive focus on batting averages in major league baseball, or in types and functions of different vacuum cleaners. Some children become focused on very specific environmental stimuli such as a moving ceiling fan or reflections in car window (p. 6-7).

#### 2.2.5.4. Cognitive Impairments

As stated by McNeil, et al., (2018) global cognitive functioning and specific cognitive abnormalities are common in children with ASD but there is no singular cognitive profile (Joseph, Tager-Flusberg, & Lord, 2000). Global cognitive ability can range from intellectual impairment to above-average intelligence. Common cognitive abnormalities include deficits in executive functioning, a bias towards details, instead of the larger picture, the ability to process large amounts of information, cognitive flexibility, and learning and processing speed (DeMyer, Hingtgen, & Jackson, 1981; Minshew & Williams, 2007). (p.7)

#### 2.2.5.5. Communication & Language Development Deficit

According to Reynolds, T. & Dombeck, M. (2006), children with autism have sound perception deficits that they do not respond to sound appropriately. For example, many do not respond when others call their names. They may cry inappropriately as a reaction to normal sounds, or they may be completely indifferent to unusual or loud noises. It is common for children with autism to confuse speech sounds, especially hard consonants. They may not be able to distinguish between the sound “ba” and “ka”. Many hear only the first part of a word or the last part of a word, making words like “rectangle” and “triangle” indistinguishable”. Reynolds, T., & Dombeck, M., (2006).

Reynolds, T., (2006) described that children with autism have language development deficits; they have great difficulties understanding spoken words, and have trouble understanding that words relate to objects and activities. The inability to process sounds properly profoundly interferes with language development. Language is not spontaneously acquired in autism. Traditional methods for teaching language are thus not adequate or useful, as they take for granted children’s ability to spontaneously make associations between sounds and concepts and to learn how to form sentences by mirroring what mature language users do. Children with autism have great difficulty understanding nonverbal forms of communication. They do not recognize the meaning inherent in other people’s facial expressions. Children with autism often have blank expressions or they make inappropriate expressions.

#### 2.2.5.6. Adaptive Functioning Deficits

Children with ASD may have motor delays and may be less likely to independently engage in daily living skills. Children with ASD’s adaptive functioning skills are often significantly below their measured cognitive ability (Kanne, et al., 2007). The discrepancy between IQ and adaptive functioning is especially pronounced among individuals with high functioning ASD, who often show improvements in adaptive living skills that are comparable to same-aged peers (Klin et al., 2007). These adaptive functioning deficits may manifest as an inability to independently dress, develop appropriate sleep hygiene, become toilet trained, or complete chores. McNeil, et al., (2018, Pp.7&9).

### 2.2.6. Therapy Treatments & Medication for the ASD Children

McNeil, et al., (2018) described that, because ASD is a lifelong disability, individuals on the spectrum need more intensive care for longer periods of time than individuals without ASD. The types of care include educational, occupational, medical, psychotherapeutic, and familial care to accommodate behavioral, social, and emotional difficulties (p.9). As described by Hearing Sol (2017) the treatment for autism is intensive as the parents and the team of professionals gets involved. The intervention or action to cure disorder can involve medicines as well as behavior therapy by addressing the other medical conditions.

#### 2.2.6.1. Applied Behavior Analysis (ABA)

Jassey, J., (2019) discovered that applied behavior analysis is a system of autism treatment based on behaviorist theories which, simply put, state that desired behaviors can be taught through a system of rewards and consequences. ABA is intended to "extinguish" undesirable behaviors and teach desired behaviors and skills. For example, ABA may be used to8 reduce outbursts and tantrums or to teach a child to sit quietly, use words to make requests, or wait for their turn in the playground. ABA can also be used to teach simple and complex skills. For example, ABA can be used to reward a child for brushing his teeth correctly, or for sharing a toy with a friend. ABA helps children with autism to use "expected" behaviors and control some of their more challenging impulses. These behavioral skills can make a big difference in how well the child with autism manages school and social experiences. A board-certified behavior analyst (BCBA) provides ABA therapy services. ABA therapy programs also involve therapists or registered behavior technicians.

### 2.2.6.2. Developmental Social-Pragmatic Model (DSP)

Developmental Social-pragmatic Model is a developmental intervention which focuses on the communicating behavior of the childlike, spontaneity, fluency, attention, initiating a conversation and motivation. The Developmental Social-Pragmatic Model (DSP) improves the Autistic child's ability to form positive and meaning relationships with other people. In this intervention model, the environment is organized in such a way which initiates a child to interact with others based on the child's choice. The therapist does this by, obstructing an activity in a playful way, placing a required object in an enormous way, changing the child's daily routine, and by placing the object in the inaccessible location to the child so, which the child could ask for help from the parents ("Hearing Sol,"2017).

### 2.2.6.3. Speech and Language Therapy

Speech-language therapy is also referred to as speech-language pathology (SLP) or speech therapy. Speech Language Therapy especially focuses on the evaluation, diagnosis, and treatment of, communication and language disorders, cognitive communication disorder, voice and swallowing disorder, and diagnosis and treatment of Autism spectrum disorder. It consists of therapies like audiology, optometry, occupational therapy, clinical psychology, physical therapy and many more. A child with autism is unable to express themselves due to the deficiency of speech. They cannot read and write alphabets which results in inappropriate pronunciation, which is out of normal person understanding. With the help of speech and language therapy, the child with autism is provided with proper practice over phonation, articulation, and fluency which help them speak with time. (Hearing Sol, 2017)

### 2.2.6.4. Social skill therapy

Social skill therapy focuses on the interaction of the child with ASD to the social rules and relation learning either in the verbal or nonverbal ways. Lack of social development in an autistic child is the reason that autism is not accepted in our society. The staring eyes of the people impacts on the child development making them hesitate to talk or open in front of others that is why autistic child prefers to stay alone. Social skill therapy helps the child with autism to learn social skills and develop social qualities such as; trustworthiness, respectfulness, responsibility, fairness and caring behaviors, coordination, normal body language, and ability to respond to others reaction ("Hearing Sol,"2017).

### 2.2.6.5. Occupational Therapy

Occupational Therapy helps to recover, develop, and maintain the qualities in the child with ASD through the use of assessments and interventions. The Autistic child has fear and hesitates to express themselves to the outer world. In these cases, occupational therapy helps the child with autism to have the courage and stand in front of others. Occupational therapy helps the person with autism to achieve their passion either from participating in school competitions or to becoming an entrepreneur. Occupational therapy consists of rehabilitation and emotional support to experience physical and cognitive changes ("Hearing Sol,"2017).

### 2.2.6.6. Medication

Autism is caused by a combination of genetic and environmental factors. Autism affects information processing in the brain by altering how nerve cells and their synapses connect and organize. Medicines can relief autism core symptoms, and treat

ASD symptoms like psychoactive drugs and anticonvulsants. The psychoactive drugs like risperidone and aripiprazole are found helpful in the side effects of behavioral therapy like; irritability, repetitive behavior, and sleeplessness (“Hearing Sol,”2017).

## 2.3. Family

### 2.3.1. Family As a Social Unit

Family is a central unit of a society where the basic needs of children are fulfilled. A family has an important role in development of different aspects of its members, particularly the intrinsic worth resulting from the experiences gained during the process of socialization. A family plays very significant role by raising a child in such a manner that he/she requires the skills to face the challenges of life (Shanwal, V., & Mishra, S., 2014).

### 2.3.2. Family From the Systems Perspective

Goldenberg, I., Stanton, M., & Goldenberg, H., (2017) demarcated that a family is far more than a collection of individuals sharing a specific physical and psychological space. While families occur in a diversity of forms, cultures, and complexities in today’s rapidly changing society, each may be considered a natural, sustained social system with properties: an evolved set of rules, many assigned and ascribed roles for its members, an organized power structure, intricate overt and covert forms of communication, numerous ways of negotiating and problem solving, that permit various tasks to be performed effectively. Each family system is itself embedded in a community and society at large. It is molded by its existence at a particular place and time in history and shaped further by a multitude of interlocking phenomena, such as race, ethnicity, socioeconomic status, family life cycle stage, religious affiliation, the physical and mental health of its members, level of educational attainment, and family values and belief systems. All these factors and many others influence the system's development, beliefs, standards for acceptable behavior, degree of flexibility in meeting both normal developmental challenges and unanticipated crises, and in general its adaptability and stability over time. (p.1&2)

Holosko, et al. (2013) defined family roles as positions that each member holds within the family that govern their interactions with the other family members. If the mother's role is that of the caretaker, she may be designated as the family member who takes the children to school and doctor's appointments and is expected to take time off from work when the children are ill. One parent may take on the role of primary decision maker. When important family issues are discussed, the other parent will typically defer to the decision maker, who will make the final decision (p.267).

### 2.3.3. Characteristics of Family System

Goldenberg, (2017) delineated the concepts of organization and wholeness are keys to understanding how systems operate. If a system represents a set of units that stand in some consistent relationship to one another, then we can infer that the system is organized around those relationships.  A family, like a human body, is a system in which the components are organized into a whole that transcends the sum of its separate parts. When we speak of the Sanchez family, As Leslie (1988) observes, because of the system's wholeness, the movement of each component influences the whole and is explained, in part, by movement in related parts of the system. Focusing on the functioning of one element (member) becomes secondary to understanding the connections or relationships among family members and the overall organization of the system. A family with two children does not simply add a new member when a baby is born; instead, the family becomes a new entity with accompanying changes in family interactive patterns. (pp. 88-89)

### 2.3.4. Family Functions

Hepworth, D., Rooney, R., Rooney, G., Gottfried, K., & Larsen, J., (Eds.), (2010) explained that irrespective of their form, families share both a history and a future and experience the lifecycle together. The family performs certain functions and has certain responsibilities to and for its members unlike any other social system. Families perform the essential function of attending to the social and educational needs, health and well-being, and mutual care of its members (Hartman, 1981; Meyer, 1990; Okun, 1996; Sue, 2006). Families perform functions that are rarely replicated in other systems and therefore are considered to be the preferred arrangement for minors. For example, when it has been necessary to remove a child from his or her biological home, the preferred placement is with kin or a foster family rather than an institution. It is largely through the family that character is formed, attachments are developed, vital roles are learned, and members are socialized for participation in their subculture and the larger society. Constable and Lee characterize he family as “the basic informal welfare system in any society” (2004, p. 9). All families have distinct patterns of relating, decision making, rules, scripts, and a division of roles and labor. The manner in which these functions are implemented, and by whom, may be influenced by cultural or racial preferences, socioeconomic status, and available resources. Available resources or the lack thereof can determine roles and responsibilities. In single-parent families or when both parents are employed, roles and responsibilities can be more dispersed. (p.228)

### 2.3.5. Parenting an ASD Child

Webster, A., Cumming, J., & Rowland, S., ( 2017) described that parents are experts when it comes to their children and play a critical role in teaching and guiding their children's learning as they grow from early childhood into adulthood. For parents of children with autism spectrum disorder (ASD), this responsibility often starts as soon as their child is diagnosed, with more complex challenges arising as their children mature. As a result, parents are required to take on a variety of roles as they make decisions about their child's learning and advocate for their child in different settings (Stoner & Angell, 2006). Unfortunately, parents of children with ASD often face obstacles as they seek to give their child the educational opportunities that will enable them to develop their skills and achieve a high quality of life. In addition to learning about ASD and what this means for their child, parents also have to navigate a complex system of government policies, societal attitudes, educational programs, and conflicting information from health providers, educators, and other parents (Foster, Rude, & Grannan,2012). Parents of children with ASD are reporting high levels of stress and frustration in accessing appropriate support that will enable their children to become independent and self-determined adults (Hayes & Watson, 2013). (P.3-4)

A child's autism diagnosis affects every member of the family in different ways. Parents/Caregivers must place their primary focus on helping their child with ASD, which may put stress on their marriage, other children, work, finances, and personal relationships and responsibilities. Parents now have to shift much of their resources of time and money towards providing treatment and interventions for their child, to the exclusion of other priorities. The needs of a child with ASD complicate familial relationships, especially with siblings. (Autism Society, 2020)

### 2.3.6. Impacts of ASD on Family

#### 2.3.6.1. Social and Environmental Impacts

According to Webster, (2017) following their child's diagnosis, parents face with a range of extra pressures as they attempt to learn about ASD and what this means for their child. Studies have found that families of children with ASD experience an overall decreased quality of life as a result of dealing with their children's challenging behaviors. Parents also report facing hidden social costs as they decrease their engagement in social activities due to concerns for their child. The ongoing financial, emotional, and physical responsibilities placed on parents of children with ASD put a significant strain on their psychological well-being (Myers et al., 2009). This is exacerbated by the need to continually advocate for services for their child. Parents confirm that much of their stress and exhaustion is caused by the continued necessity of having to fight for services, cope with complicated policies or negative societal attitudes, and constantly having to communicate and build relationships with education and health professionals. (p.13)

Paltrow, (2018) has stated that parents of autistic children had a 9.7 percent chance of getting divorced than did their peers. Marital stressors can include: spending time together becomes difficult because of the numerous commitments and inconsistent schedules, it is often challenging to find child care for autistic children, and financial stress may cause problems between spouses.

Webster, (2017) stated that ASD impacts family dynamics as well as parents' relationships. Divorce rates are higher for families of children with ASD (Hartley et al., 2010), with additional stress placed on families of children with particularly challenging behaviors (Rao & Beidel, 2009). Stress on siblings has also been examined, with some studies finding positive effects such as increased self-concept for siblings (Mates, 1990), whereas others have identified higher levels of loneliness and behavior difficulties for siblings of children with ASD. Researchers have suggested that families have less time for family activities and parents often experience physical and emotional exhaustion as they struggle to cope with their child's poor sleeping and eating patterns. (p.13)

### 2.3.6.2. Emotional Impact

Paltrow, C. (2018) described that autism brings with it a lot of emotional ups and downs for the family members, which start prior to the diagnosis and continue indefinitely. A study in journal Pediatrics states that mothers of children with ASD often rated their status of mental health as fair or poor. Compared with the general population, their stress level was much higher. Besides, having high stress levels, parents of autistic children may experience: embarrassment over their child's behavior in public, feeling socially isolated frustration at the difference between the parenting experience they are having and the one they had envisioned, guilt from thinking that they may be responsible for their child's challenges, despair because of the disorder's incurable nature, and feeling of overwhelm. Paltrow, C. (2018)

Siller, M., & Morgan, L., (2018) stated that parenting itself is often considered to be a stressful experience. While parenting stress in general is considered somewhat normative, parents of children with ASD usually report significantly more parenting stress than parents of typically developing children. Across decades of research ASD continues to rank as one of the most stressful childhood conditions for parents to manage, consistently above and beyond the reported stress of parenting a child with other developmental disabilities or medical conditions. Parents of children with ASD often undergo a lengthy and highly stressful process in obtaining an accurate diagnosis for their child, a process which may be absent for parents of children with other developmental disabilities, such as Down syndrome. Recent research suggests that parents may even exhibit signs of post-traumatic stress following their child's diagnosis of ASD". (pp. 156 &157)

According to Autism Society (2020) there is a typical stress that parents experience from doing daily family routine. This is compounded by such psychological stressors as parent-child conflicts, not having enough time to complete responsibilities and concern regarding a child's well-being. When a family has a child on the autism spectrum, unique stressors are added. An individual with autism may not express their basic wants or needs in the manner we would expect. When parents cannot determine their child's needs, both parties are left feeling frustrated. The child's frustration can lead to aggressive or self-injurious behaviors that threaten his/her safety and the safety of other family members (e.g., siblings). Stereotypic and compulsive behaviors concern parents since they appear peculiar and interfere with functioning and learning. If a child has deficits in social skills, such as the lack of appropriate play, stress may be increased for the family. Raising a child with autism places some extraordinary demands on parents as individuals and on the family as a whole. Prime among these demands is the lack of enough hours in the day to do all one wishes. Specifically, the time involved in meeting the needs of a family member with autism may leave parents with little time for their other children. Many parents feel that even as they do all they can for their child with autism, they are always struggling with how best to respond to the needs of the family as a whole. (p. 16)

### 2.3.6.3. Financial Impact

Families with autistic children often face a huge financial burden. Expenses for autism treatment and therapies are not covered by most private health insurers, and they are quite expensive. According to a study featured in Pediatrics, families with an autistic child underwent an average loss of 14 percent in their entire family income. Working full-time becomes very tough for both parents. So, the family has to bear the increased expenses, in spite of having a lowered household income. Full-time employment is important for many parents for providing health insurance, and so, losing a full-time job may dramatically affect the family's financial condition. Paltrow, (2018)

According to Goldenberg, (2017) debilitating effects of poverty and living in inadequate housing in unsafe neighborhoods: "Often led by a single parent or parents who are unavailable or working for long periods, with few siblings and limited contact with grandparents, such families feel isolated and defeated. They need social networks (healthcare facilities, after-school programs, recreation centers, libraries, community agencies). Being a part of such a social system often represents a step toward reducing isolation and increasing the possibilities of more effective self-care and improved quality of life". (p.3)

## 2.4. Crisis

### 2.4.1. Definition and Stages of Crisis

James, K., R., (2008) presented the six definitions of crisis as: "(1) People are in a state of crisis when they face an obstacle to important life goals—an obstacle that is, for a time, unsolvable by the use of usual methods of problem solving. (2) Crisis results from impediments to life goals that people believe they cannot overcome through routine choices and behaviors. (3) Crisis is a crisis because the individual knows no response to deal with a situation (4) Crisis is a personal difficulty or situation that restrains people and prevents them from consciously controlling their lives. (5) Crisis is a state of disorganization in which people face frustration of important life goals or intense disruption of their life cycles and methods of coping with stressors. The term *crisis* usually refers to a person's feelings of fear, shock, and distress *about* the disruption, not to the disruption itself. (6) Crisis develops in four distinct stages: (a) a critical situation occurs in which a determination is made as to whether a person's normal coping mechanisms will suffice; (b) increased tension and disorganization surrounding the event escalate beyond the person's coping ability; (c) a demand for additional resources (such as counseling) to resolve the event is needed; (d) referral may be required to resolve major personality disorganization" (p.3)

### 2.4.2. Crisis in Families of Children with ASD

Parents of individuals with ASD often report high level of stress and mental health problems, associated with the caring for individuals with complex needs and with navigating multiple service centers across the life course. Parents usually have the major obligation of caring for their child (which includes management of problematic behaviors) and balancing associated stress while overseeing the well-being of the rest of their family (Seltzer et al., 2004). Mothers of children with ASD report greater emotional problems compared to mothers of children of typically developing children (Totsika et al., 2011). Weiss, J. A.,Wingsiong, A., & Lunsky, Y., (2014).

### 2.4.3. Crisis Intervention Models

Three family crisis intervention models i.e. equilibrium, cognitive, and psychosocial transitional models have been discussed in this section. The three crisis intervention models use different approaches to address families’ problems through provision of micro - macro levels family assessment and intervention in a range of practice settings. The crisis intervention models tend to help clients to realize the various dimensions of the family problems and explore various coping strategies to maintain family stability. The psychosocial therapeutic approach also views the environmental and system issues that interact with family system to effect system and behavioral changes. In Ethiopian context, at this time, application of these models may not be fully workable due to unavailability and/or inaccessibility of family support systems to this population.

#### 2.4.3.1. The Equilibrium Crisis Intervention Model

The equilibrium crisis intervention model has been discussed by James, R., K., (2008) as: “the equilibrium model is really an equilibrium/ disequilibrium model. People in crisis are in a state of psychological or emotional disequilibrium in which their usual coping mechanisms and problem solving methods fail to meet their needs. The goal of the equilibrium model is to help people recover a state of pre-crisis equilibrium (Caplan, 1961). The equilibrium model seems most appropriate for early intervention, when the person is out of control, disoriented, and unable to make appropriate choices. Until the person has regained some coping abilities, the main focus is on stabilizing the individual. Up to the time the person has reacquired some definite measure of stability; little else can or should be done. This is probably the purest model of crisis intervention and is *most* likely to be used at the beginning of the crisis (Caplan, 1961; Leitner, 1974; Lindeman, 1944).” (p. 14)

The equilibrium family crisis intervention model emphasizes on discovering the emotional state of the person(s) in crisis and determining whether they are in state of emotional equilibrium or disequilibrium. Application of this model is appropriate when a family is not able to meet the changing demands of its members with its usual coping ability. In this case, the equilibrium crisis intervention model can help the families of the ASD children with: (1) identifying state of their emotional instability and regaining coping abilities, and (2) recover a state of pre-crisis stability. However the equilibrium intervention does not help the person(s) in crisis to gain control of crises by changing their negative thinking.

#### 2.4.3.2. The Cognitive Treatment Model

James, R., K., (2008), stated that the cognitive model of crisis intervention is based on the premise that crises are rooted in faulty thinking about the events or situations that surround the crisis—not in the events themselves or the facts about the events or situations (Ellis, 1962). The goal of this model is to help people become aware of and to change their views and beliefs about the crisis events or situations. The basic tenet of the cognitive model is that people can gain control of crises in their lives by changing their thinking, especially by recognizing and disputing the irrational and self-defeating parts of their cognitions, and by retaining and focusing on the rational and self-enhancing elements of their thinking. The messages that people in crisis send themselves become very negative and twisted, in contrast to the reality of the situation. The cognitive model seems most appropriate after the client has been stabilized and returned to an approximate state of pre-crisis equilibrium. (p.14)

The cognitive crisis intervention model views clients' lack of awareness of heir negative thinking about the crises events or situations. The intervention focuses on finding out the faulty thoughts of the family members and helping them with gaining understanding about their malfunctioning thoughts. Furthermore, it facilitates learning strategies to replace the negative thoughts by rational understanding and to retain the logical perception. In the Ethiopian context families of children with mental conditions are socially isolated due to fear of negative societal attitude caused by the behavioral problems associated with their child's autism. Most of the families may not have adequate awareness about autism disorder(s) and the behavioral characteristics. In this case cognitive treatment model can help the families with: (1) gaining understanding about their malfunctioning thoughts and self-defeating cognition, (2) practicing and rehearsing the positive beliefs, and rewiring the negative thoughts to more positive feedback (3) promoting the self-enhancing cognition and control the crisis situations, and (4) developing self-empowering belief. However the cognitive treatment does not help the families with identifying the external- social factors that influence family's psychological adaptiveness, and facilitating social and environmental resources needed to the families.

#### 2.4.3.3. The Psychosocial Transitional Model

James, R., K., (2008) has discovered that, the psychosocial model does not perceive crisis as simply an internal state of affairs that resides totally within the individual. It reaches outside the individual and asks what systems need to be changed.

Peers, family, occupation, religion, and the community are but a few of the external dimensions that promote or hinder psychological adaptiveness. With certain kinds of crisis problems, few lasting gains will be made unless the social systems that affect the individual are also changed, or the individual comes to terms with and understands the dynamics of those systems and how they affect adaptation to the crisis. Like the cognitive model, the psychosocial transition model seems to be most appropriate after the client has been stabilized. (p.15)

The psychosocial transition crisis intervention model believes that individuals absorb what they have learned from their social environment and those social factors have influence on family's psychological adaptability. The psychosocial approach can assist the families of the ASD children with: (1) defining families problems (2) identify the internal and social-external factors that hinder the family members' psychological adaptiveness, (3) Changing existing behavior, attitude, and their utilization of environmental resources, (4) teaching internal coping strategies to family members, and (5) facilitates social support and environmental resources to the family as a whole.

## 2.5. Family Support

### 2.5.1. Definition of Family Support

Family support is about the creation and enhancement with and for families in need, of locally based (or accessible) activities, facilities and networks, the use of which have outcomes such as alleviated stress, increased self-esteem, promoted parental/carer/family competence and behavior and increased parental/carer capacity to nurture and protect children. (Loughlin, M., O., & Loughlin, S., O., 2008, p.28)

### 2.5.2. Provision of Family Support

As stated by Loughlin & Loughlin, (2008) family support is not limited to families with pre-school children. There are a wide range of projects and services that are provided by both statutory and voluntary agencies across the country. Frost has argued that this represents a progressive form of welfare practice (Frost, 2003) at a time when globalization and rapid social change are impacting on families, creating diverse family structures and challenging traditional role models of parenting. The significance of having a choice of service providers may be particularly significant for black and ethnic minority families, who find it difficult to access services which do not reflect their culture (Butt and Box, 1998a; 1998b; Butt, 1998), or who may feel their parenting style is not understood by white workers. (p.32)

### 2.5.3. Family Support System for Disability

According to “The Arc Autism Now,” (2018) family support is defined as a comprehensive and coordinated set of strategies that are designed to ensure that families who are assisting family members with disabilities have access to person-centered and family-centered resources, supports, services, and other assistance. These strategies are directed to the family unit but ultimately benefit to the individuals with the disability. Family support can include: physical home modifications, early intervention programs, in-home and out-home respite, sibling programs, family counseling, parent support groups, after school programs, education programs, behavioral training, and any service funded to assist families to continue to care for their child or adult child with developmental disabilities in the family home.

### 2.5.4. Social Work Intervention

#### 2.5.4.1. Purpose of Social Work Profession

Hepworth, (2010) stated that the primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty (NASW, 1999, p. 1). The purpose of the profession is to “promote human and community wellbeing (EPAS, 2008, p. 1). Furthermore, that purpose “is actualized through its quest for social and economic justice, the prevention of conditions that limit human rights, the elimination of poverty, and the enhancement of the quality of life for all persons” (EPAS, 2008, p. 1). Hence, the pursuit of social and economic justice is central to social work’s purpose. Social justice refers to the creation of social institutions that support the welfare of individuals and groups. Economic justice, then, refers to those aspects of social justice that relate to economic well-being, such as a livable wage, pay equity, job discrimination, and social security. (Pp.4 & 5)

#### 2.5.4.2. Social Work Intervention with Families from Ecosystem Perspectives

According to Holosko et al., (2013) in social work intervention a difficulty experienced by a family member was viewed as an issue involving family dynamics. The behavior of a child who was disruptive in school, for example, was no longer viewed as simply a child with disruptive behaviors. Instead the social worker might explore family interaction styles, including household rules, discipline, consistency, and communication styles of the parents in defining the goals for intervention (p.266). The ecological systems perspective that guides social work practice calls for intervention on multiple levels to achieve treatment goals. For this reason, social work practice often engages families in sessions rather than working with an individual alone. Family intervention takes many forms, and the definition of the family may vary widely. The ecosystems perspective theorizes that intervening to change dynamics in one part of a system can improve functioning in other parts of the system. Thus, intervening to improve relationships within the family system can improve the functioning of the individual family members (Franklin & Jordan, 1999). Improving the communication between an individual and his or her estranged parent may result in improved communication between the individual and a spouse or child as well. The stress that is alleviated by improving family interactions can result improvements in school performance and mental-health status. Because social workers understand the importance of working with an individual within their environment, family intervention has become a valuable tool in social work practice. (Pp.265 & 266)

#### 2.5.4.3. Crisis from Ecosystem Perspective

James, (2008) stated that ecosystems theory broadens out the base of the system and looks at crisis in relationship to the environmental context within which it occurs (James, Cogdal, & Gilliland, 2003; Myer & Moore, 2006). Systemic interactions may occur from the microsystem (family and community) out to the macrosystem (nation) or vice versa. There is great value in looking at crises in their total social and environmental settings—not simply as one individual being affected in a linear progression of cause-and-effect events (Hardy, 1997; James & Gilliland, 2003, pp. 336–368). The fundamental concept of ecosystems theory is analogous “to ecological systems in which all elements are interrelated, and in which change at any level of those interrelated parts will lead to alteration of the total system” (Cormier & Hackney, 1987, p. 217). Passage of time, proximity to the epicenter of the crisis, and what develops over time and the environment contribute to the ultimate resolution of the crisis. Ecosystems theory comes into play most typically when large-scale disasters occur and affect very large macro systems. (p.12)

#### 2.5.4.4. The Multi-level Ecological Approach

According to Holosko, (2013) the ecological systems perspective defines an individual’s environment using three systemic levels: the microsystem, the mesosystem, and the macrosystem (Bronfenbrenner, 1979). The microsystem is defined by influential others with whom an individual has regular face-to-face contact, such as family and friends (Heffernan, Shuttlesworth, & Ambrosino,1992).Microsystem interventions work with the individual directly and may include those with whom the individual has direct contact, such as family members or teachers (Hepworth, Rooney, & Larson, 1997). The mezzo-system is defined by relationships between the microsystems that do not include the individual but affect the individual’s behavior. The mesosystem includes interactions between a child’s parents, between parents and teachers, or between a child’s peers (Heffernan et al., 1992). It may also include schools, school boards, community organizations, and local government. Mezzo-systems interventions aim to change systems, such as family or peer group, that affect the individual (Hepworth et al., 1997). The macrosystem is defined by societal factors, such as cultural values and social policy. Macro level interventions include social planning and community organization (p.286).

#### 2.5.4.5. Eclectic Methods Social Work Intervention

Hepworth, (2010) presented the work of Fischer, (2017) as: “concerns about the effectiveness of social work services led to an emphasis on employing methods that could be expected to be successful based on proven effectiveness. Rather than seeking single approaches to direct practice in all circumstances, social workers were guided to find the approach that made the best fit for the particular client circumstance and problem". (p.18) Hepworth, (2010) also described that the four approaches are also consistent with systematic generalist-eclectic practice as articulated by Coady and Lehmann (2008, p. 5); the elements are as: (1) a person and environment focus that is informed by ecological theory, (2) an emphasis on establishing a positive helping relationship and empowerment as well as a holistic, multilevel assessment, including a focus on diversity, oppression, and strengths, (3) A problem-solving model that provides structure and guidelines for work with clients, and (4) flexibility in the use of problem-solving methods that allows a choice among a range of theories and techniques based on their compatibility with each client's situation. (p.355)

### 2.5.4.6.. Systemic Family Therapy

Goldenberg, (2017) described that a systemic perspective greatly broadens the context for understanding family functioning by attending to the numerous social systems with which it functions. Such a view addresses the multiple systems in which families are embedded. In this multidimensional view, attention is directed beyond the family to "external" factors that may be influencing family functioning Beyond helping families improve their coping skills, clinicians with this outlook help empower them to make more effective use of available social and community services. No longer restricted to the consultation room, services may be delivered at places more convenient to the family: in schools, homes, community agencies, and elsewhere (p.85). Rather than viewing the family as an isolated, encapsulated system, the systemically oriented therapist is able to intervene at any level to improve family functioning. As Robbins, Mayorga, and Szapocznik, (2003) illustrate problems may be addressed to improve the relationship among family members (microsystem level), to improve a partner's relationship with extended family members or community organization (mesosystem level), to work on a behavior-problem child's parent's connection to Alcoholics Anonymous (exosystem), or by the therapist serving on a committee to develop treatment practices for victims or perpetrators of domestic violence (macrosystem). Maintaining an ecological focus widens the lens to encourage the development of integrated interventions based on ever-broadening social contexts. Social media influences are an important emerging mesosystemic influence in today's families. (p.87)

#### 2.5.4.7. Social Work Intervention with Families of Children with Disability

Holosko et al., (2013) stated that the focus of social work with the family was often on assisting them to forget about the child with the disability and to channel their energies into taking care of other family members (Ferguson & O'Brien, 2005). Deficit-based assessment that highlighted what people with disabilities were unable or incapable of doing was prominent historically, and one of the most common service interventions involved exclusion and removal from mainstream society. However, challenges from families and from the disability-rights movement has brought about a transformation in perspectives and services, and now assessments typically focus on identifying support and resources so that families can care for their children with disabilities at home and encourage participation in all community activities. Social work is now focused on providing advocacy, support, resources, and services to families so that their child can fully participate in their community (Sullivan & Munford, 2005), and assessment has accommodated this significant reorientation. (pp.237 & 238)

#### 2.5.4.8. Family Advocacy

Webster, (2017) stated that advocacy is defined as any action taken by a parent on behalf of their child to ensure adequate support, a proper level of care and basic human rights (Ewles, Clifford, & Minnes, 2014 ). Parents of children with ASD have a history of being strong advocates for their children, engaging in advocacy efforts more frequently and at a higher level of complexity than other parents (Ryan & Cole, 2009). The often-contentious relationship between parents and educators regarding the services available and provided to their children suggests that parents' ability to advocate effectively for their children may play a critical role in ensuring that appropriate interventions are provided to children with ASD in school. In order to advocate effectively, parents need to educate themselves to gain an understanding of the current legislation and policies that affect their child, as well as the options available for their child to engage with evidence-based programs in school and community settings (Wakelin, 2008). (p.185)

# Chapter Three

## Study Design and Methods

### 3.1. Study Site

The study was conducted at three woredas (i.e. five, six, and seven) of Yeka Sub-City, North of Addis Ababa. Yeka sub-city has a total population of 368,418 (Office of the Mayor Addis Ababa, 2017). According to Office of the Mayor Addis Ababa (2020), Yeka Sub-City has various community resources that includes four public and one hundred thirty seven private KGs, sixteen public and five hundred eighty seven primary schools, six public and ten private secondary schools, five TVET, one public and six private colleges, one public university, four public health centers and two public hospitals. However the report does not include information about availability of any of these facilities to the mentally and/or physically disabled children.

### 3.2. Study Population

A total of eight caregivers of the ASD children were selected from the entire population.

**Table 1: Background Information of the ASD Children and their Caregivers**

| Parent/ Caregiver | Age | Gender | Relationship with ASD Child | Age of ASD Child | Gender of ASD Child | Number of households | Resided in Woreda |
|---|---|---|---|---|---|---|---|
| Parent A | 30 | F | Biological parent | 13 | M | 2 | five |
| Parent B | 58 | F | paternal grandparent | 15 | M | 10 | five |
| Parent C | 65 | F | maternal grandparent | 4.7 | F | 3 | six |
| Parent D | 48 | F | biological parent | 14 | M | 5 | five |
| Parent E | 35 | F | biological parent | 8 | M | 3 | seven |
| Parent F | 38 | F | biological parent | 14 | F | 4 | seven |
| Parent G | 33 | M | biological parent | 8 | M | 3 | seven |
| Parent H | 38 | F | Biological parent | 7 | M | 5 | seven |

### 3.3. Sampling Technique

The population I am studying was the autistic community living in Yeka Sub City of woreda five, six, and seven. The study participants were caregivers of the children who have Autism Spectrum Disorder(s) because they are appropriate source of data. Population of interest for this research is uncommon that members have unique cases (i.e. caring for a child with chronic mental conditions), besides, the size of the population was too small to meet the sampling criteria. In this reason snowball sampling method was considered as a better approach to easily access participants from the small size population. A client list of Nehemiah Autism Center was used as a sampling frame. Initially ten members of the population were selected from the three woredas, however two of the participants declined before the orientation. Thus, the final sample was eight consists of: two-single and three-married female biological mothers, one-married male biological father, one-single and one-married female biological grandparents. Selected participants were the caregivers who provide companionship and assist their ASD child with basic needs, thus they were appropriate to represent the population and provide consistent information. Participants were of different demographic and socio-economic backgrounds; hence they were able to explain the realities from different viewpoints. In this respect the data obtained from the interview was sufficient to address the research questions.

Orientation was provided to the study participants on the research topic, purpose of the study, data collection strategies, scope of respondents' participation, and consent was signed by all participants. The study considered application of the ethical practices of anonymity and confidentiality to protect the identity and privacy of the study participants while collecting, analyzing, and reporting the data. (Please see appendix-A). Accordingly, a total of eight participants were participated in the in-person interview and completed a checklist.

## 3.4. Research Methodology

The study employed qualitative research methodology to address the research objectives and to capture the opinions, thoughts, and feelings of the respondents on their problem situation. Moreover, the method considered gathering detailed information on the families' lived experiences from participants' own understanding of the phenomena, in their natural environment. A study conducted by Leavy, P., (2017) outlined that qualitative research approach takes into account individuals' own understanding of their life-experiences and the meanings they assign to the reality. Qualitative approach to research also allows researchers to gain thorough understanding of the topic and discovering the meanings attributed by participants about their problem situation.

Creswell, J., W., (2014) also described the characteristics of qualitative research as: *"The key idea behind qualitative research is to learn about the problem or issue from participants and to address the research to obtain that information. Qualitative researchers tend to collect data in the field at the site where participants experience the issue or problem under study. Qualitative researchers try to develop a complex picture of the problem or issue under study, which involves reporting multiple perspectives, identifying the many factors involved in a situation, and generally sketching the larger picture that emerges. "Qualitative researchers tend to collect data in the field at the site where participants experience the issue or problem under study." (p.234, 235)*

### 3.5. Research Design

The qualitative research design deployed in this study considered exploratory approach to data collection with the aim of exploring the participants' experiences of complex phenomena in a small sample of the population. Qualitative data has been gathered directly from the study participants in rich detail. Semi-structured in-depth interview questions and a checklist have been administered to a sample of the study population to explore how the presence of ASD in a family affected the lives of the family as a whole, and determine the availability and accessibility of family and child support systems. The open-ended nature of the interview questions was helpful for the data collector to direct, use probes and to ask interviewees' clarification when needed. It also allowed the study participants to freely explain their lived experiences from their own perspectives. The interview dialogue was audio-taped through considering participants' right and confidentiality in a way that participants' privacy can be preserved.

### 3.6. Data Collection

The study utilized primary source to data collection, and source of the first hand data were caregivers of eight ASD children. The data collection strategies deployed in this study were conducting in-person in-depth interview and administering supplementary questionnaire. The open-ended interview questions allowed the study participants to freely provide detailed explanation on their lived experiences in a context where each the caregivers can express their feelings. The purpose of conducting twenty open-ended interview questions was to explore the challenges that the parents or caregivers have experienced in raising ASD children, and to identify the internal and external factors that contributed to escalation of the parents' strain and family dysfunction. The interview responses were audio-taped in order to gain holistic understanding of the participants' life experiences in a way that participants' information can be preserved in the entire process of the study. Leavy, P., (2017) presented the idea of Weiss (1994, p. 140) as: *"in order to prepare for data collection researchers create interview guides that range from a list of general lines of inquiry or themes they intend to cover to detailed lists of open-ended questions"*. A checklist was utilized to examine whether appropriate early intervention services were provided for the ASD children under this study.

The data collection considered obtaining sufficient information from the primary sources with broader perspectives in order to attain the study objectives (please see appendix B & C). The study considered application of the ethical practices of right, anonymity, and confidentiality to protect the right and privacy of the study participants while collecting, analyzing, and reporting the field data. Face masks were provided for the participants and an emphasis was given to the issue of social distancing to protect the health wellbeing of the study participants in the outbreak of COVID-19.

The data collection activity has been carried out at participants' residences and it took a total of seven weeks for the data collector to complete. The data collector had two in-person meetings with each study participant: (1) to discuss about participants' consent and conduct the one-on-one in-person interview, (2) to administer a supplementary questionnaire. The study participants were contacted through telephone: (i) to inform about the selection and schedule appointment to interview, (ii) to get clarification on participants' responses.

## 3.7. Data Analysis and Interpretation Strategy

In this study qualitative data has been collected from the eight study participants identified from the target population. The qualitative data collection has been undertaken for the purpose of: (1) exploring the participants' lived experiences, (2) identify the internal and external influencing factors that contributed to the family's emotional instability and state of disorganization, and (3) examining availability of family support systems.

The study deployed inductive approach to data analysis because it allows the researcher to examine the data obtained from the study participants and identify the common themes. Creswell (2018) described inductive method data analysis as: "Qualitative researchers typically work inductively, building patterns, categories, and themes from the bottom up by organizing the data into increasingly more abstract units of information. This inductive process illustrates working back and forth between the themes and the database until the researchers have established a comprehensive set of themes (p.301.)

Interview was conducted in a local language (i.e. Amharic) and the Amharic version audio data was manually interpreted to English by the researcher. The data analysis involved the following steps: (1) Creating database to store and process the row data, transcribing the audio-data into text and familiarizing the transcripts (2) identifying and coding segments of information relevant to the study objectives, (3) categorizing codes (sorting & bringing similar codes together), (4) generating themes and label categories, and (5) presenting the findings of the study.

**Table 2: The Coding Process in the Inductive Analysis**

| | | | | |
|---|---|---|---|---|
| Initial reading of text data | Identify specific text segments related to objectives | Label the segments of text to create categories | Reduce overlap and redundancy among the categories | create a model incorporating most important categories |
| many pages of text | many segments of text | 30 to 40 categories | 15 to 20 categories | 3 to 8 categories |

***Adapted from Creswell, 2002, Figure 9.4, p. 266***

## 3.8. Ethical Considerations

Participants' right to privacy and confidentiality has been protected in the entire process of this study. The informed consent consisted of the brief description about the researcher, topic and purpose of the study, the study sites, methods of the data collection, and the right and role of the study participants including maintaining anonymity and confidentiality has been signed by the participants. (Please refer to appendix-A). The steps of accessing this community have been processed officially (i.e. sending a letter of request to Nehemiah Autism Center for their collaboration, negotiating with the data collector, providing data collection tools and facilitating face masks to the data collector and study participants etc.) Consideration was given to participants' willingness: to participate, freely share their lived experiences, and get their interview audiotaped.

According to Tracy, J., Sarah, (2013, p.243) respondents must know that their participation is voluntary and understand how to opt out. Participants also have a right to confidentiality. In order to protect participant identity and privacy, researchers should secure research data and strip them of identifiers before sharing them with co-researchers, assistants, readers, or audience members. Researchers should carefully consider how certain actors might be identified even if their name is a fictitious.

# Chapter Four

## Finding and Data Presentation

This chapter focused on presenting the key results of what the analysis revealed about participants' explanation of their lived experiences. The study administered nineteen semi-structured interview questions to explore the families' life situation and describe the impacts of having ASD children on the lives of their families. The interview was audiotaped for the purpose of capturing complete data explained by the participants about their families' lived-experiences. A supplementary questionnaire was utilized to examine whether there are community-based and/or professional interventions available for these families.

Presentation of the findings considered detailed description of the important themes emerged from the field data. Five major themes were identified: 1) diagnosis and basic therapy services that the parents received to their ASD Child, (2) impacts of raising an ASD Child on the Family, (3) the influencing factors that contributed to the parents' stressful situation, (4) parents' inability to cope with the stressors, and (5) unavailability of family support systems. Data was organized thematically, and the results have been presented in the forms of participants' narratives, tables, and diagrams.

### 4.1. The Parents'/Caregivers' Socioeconomic Status

The below table describes the marital and occupational status, and the income level of the parents/caregivers of the ASD children to provide the readers with complete information about the study participants.

**Table 3: The Social and Economic Status of the Caregivers of the ASD Children**

| **Parent/caregiver** | **Gender** | **Marital Status** | **Occupation** | Income level |
|---|---|---|---|---|
| Parent A | F | divorced | housekeeper | Low income |
| Parent B | F | married | support staff | low income |
| Parent C | F | widow | Retired | low income |
| Parent D | F | married | housewife | low income |
| Parent E | F | divorced | electro-mechanics | average income |
| Parent F | F | married | housewife | low income |
| Parent G | M | married | mechanic | low income |
| Parent H | F | married | statistician | average income |

## 4.2. Results

The study findings that have been presented in the results section comprised the detailed explanation of participants' experiences categorized into twelve subthemes under the five major themes. The results of the study explicitly showed the relationship between the findings and the research objectives.

### 4.2.1. Diagnosis and Basic Therapy Services the Parents Received for their ASD Children

The below table illustrates the autism diagnosis history of the eight ASD children raised by the study participants. It also discovered that among the eight ASD children four of them have other health conditions.

**Table 4: Autism Diagnosis History and Other Health Condition of the ASD Children**

| ASD Children | Gender | age | Autism disgnosis age | Other condition diagnosed | Diagnosed by |
|---|---|---|---|---|---|
| Child A | Male | 13 | 4 | Seizures | Neurologist, in Ethiopia |
| Child B | Male | 15 | 4 | sensory processing disorder | Neurologist, in Ethiopia |
| Child C | Female | 4.7 | 3 | none | Neurologist, in Ethiopia |
| Child D | Male | 14 | 5 | none | Neurologist, in Ethiopia |
| Child E | Male | 8 | 3 | none | Neurologist, in Ethiopia |
| Child F | Female | 14 | 3.5 | none | Neurologist, in Ethiopia |
| Child G | Male | 8 | 1 | Mild autism, developmental delay, Psysical Disability | Neurologist, in Ethiopia |
| Child H | Male | 7 | 1 | Seizures | Neurologist, in Ethiopia |

The findings also found that Nehemiah Autism Center which is located at Lafto Sub City gave the caregivers the opportunity to use free basic therapy supports for their children; and the children were sometimes available to the services. The services include: assertive behavior analysis (ABA) treatment, occupational therapy, and social skill training. The autism center also allowed the parents to participate in the parents' meetings and some of the parents affirmed that they used this opportunity to discuss their experiences with the other parents, while few the participants were not motivated to participate.

**Table 5:**

**Basic Therapy Services that the Parents/Caregivers Received for their ASD Children**

| ASD Children | Cognitive Behavior Therapy | Occupational Therapy | Preschool class | Social Skills Training | Speech Therapy | Physical Therapy |
|---|---|---|---|---|---|---|
| Child A | received | not received | attended | received | received | not received |
| Child B | received | not received | not received | not received | received | not received |
| Child C | received | received | not received | received | received | not received |
| Child D | received | received | not received | received | received | not received |
| Child E | received | received | attended | received | received | received |
| Child F | received | received | not received | received | received | not received |
| Child G | not received | not received | not received | received | received | received |
| Child H | received | received | not received | received | received | not received |

The findings discovered that 37.5 percent of the ASD children were under medication, whereas 62.5 were not receiving any medication. Aman, M., (2009) stated that there is no medication that can cure autism spectrum disorder (ASD) or all of its symptoms. But some medications can help treat certain symptoms associated with ASD, especially certain behaviors.

### 4.2.2. Impacts of Raising an ASD Child on the Family

The study identified five major challenges that the families of the ASD children have experienced as a result of having an ASD child in their family.

#### 4.2.2.1. Family Disengagement and Role Conflict

The study participants were asked to explain how the presence of ASD in their family affected their family interaction and role division.

Parent D responded:

*"There is lack of closeness in our family and this situation caused me difficulty to deal with the family problem alone! I am so tired! In the previous time my husband and I were helping each other home; he had been dedicatedly assisting the family by performing his parental responsibility, as the years passed he lost his courage to deal with any of the family concerns I think… he is tired of the situations as he is getting old. He isolates himself from the family's situation even he pays no attention when I try to talk to him about the increasing life demands and the behavioral problems of our sick child. For example, when I tell him that Biruk doesn't feel well today, he says, you can take him to hospital, it has a long history! Even the older brothers are not willing to support their younger brother because they do not know what they are supposed to for the family, for example, when they see him making an effort to toilet by his own they leave home as if it is not their concern, this condition makes me more stressful"* I sensed that she felt worthless and hopeless

Parent 'E' reported:

*"For a single mom like me, raising a child with autism is too difficult! Our firstborn child was diagnosed with autism at his age of three. It was difficult for my ex-husband to accept*

*the changing situation of the family. The illness of our child led to changes in our family routine and our husband-wife relationship became affected. Unlike the other parents, he had no interest to know more about the situation of our child or to involve in the family's life situation. For example when I showed him the medical report of our child he expressed that he was bored of this issue and he left home immediately, because of that I experienced loneliness and helplessness, I have burden of parental responsibility and dealing with the life problems became overwhelming for me, I lack time to rest, I usually lack enough sleep"* Her situation tells that she was anxious and downhearted when expressing her life situation.

Parent 'B' and 'F' similarly stated that their family members i.e. husband and older siblings share the family responsibility and willingly support the ASD child in living their family. The rest of the caregivers similarly described that having an ASD child in their family caused them family communication dysfunction and they experienced chronic stress resulting from work burden, difficulty balancing work and family time including loss of strength to attain spousal roles and responsibilities.

#### 4.2.2.2. Parental Dispute and Divorce

The study participants described that they have experienced spousal dispute and divorce due to having an ASD child in their family.

Parent 'A' reported:

*"My husband left home when he knew that our child has autism and I remain in a very difficult life situation. Dealing with the unfamiliar behavior of my child and thinking about the issue of our life needs fulfillment was very upsetting for me. There was a time in which I felt like I have no way to get out of this situation and having that feeling initiated a thought of dumping the child in one of the remote public places, but it was difficult for*

*me to decide."* (She took a deep breath). *"Life continued with my child in a difficult situation. I am rejected by my families and relatives in this situation making income for the family along with assisting an autistic child is intolerable… it is a misfortune!"*

Parent 'E' explained:

*"I and my husband had a relationship problem which ended with separation. It was intolerable for my ex-husband to accept the changing situation of the family caused by having a child who has autism. He was not willing to stand with me to face the family problem together in this case our relationship became hostile. He started to spend time outside home and I came to know that he had been engaging in extra-marital affairs and finally we got divorced… it was so painful for me! "* She cried and her voice was shivering.

The rest of the study participants similarly described their family experiences resulted from having an ASD child as: spousal emotional distance and sleeping in separate bed, dealing with increased family responsibility, divorce and loss of the other parent's income that led to financial hardship and state of being under psychological pressure.

#### 4.2.2.3. Lack of Social Participation

The participants explained how the presence of ASD in their family influenced their social relationships.

Parent 'B' described:

*"I am a paternal grandparent of this boy, Suraphel lives with Autism. His dad and mom left him for me when he was a forty days old baby, because both of his parents were pursuing their college education and his mother was too young to handle the situation. Besides, the parents of my daughter in law were not happy about the birth of this baby*

*and they strongly challenged Suraphel's mom. Now Suraphel is a fifteen year old boy. The issue of spending time outside of the home or mixing with others in the community is impossible for me because I always need to accompany and assist him along with performing the range of household activities to help the other eight family members. For example, it is difficult for me to attend church services because he screams, fights, and disturb the church environment. This situation also prompts individuals to say such annoying words or phrases. I love Suraphel very much and I would never give him up, however I have concern about how Suraphel can survive without me!"* I sensed that she has fear of uncertain future

Parent 'E' also stated:

*"I experienced isolation and loneliness since the birth of my autistic son, Nathan. I had close relationship with my school peers and the other friends in my community; since the occurrence of my child's autism I used to isolate myself from friends, neighbors, extended families and my friends abandoned me. I tried to maintain my relationship with my sisters and brothers because I wanted to comfort me and to extend their support when needed unfortunately they did not want to involve in the relationship, I suffer from a feeling of rejection when I think about that. Some times I and Nathan stay with my mother because Nathan enjoys staying with mama at her place, other than that we do not have any one to spend time together. Life doesn't seem to have any meaning"*. She continued crying.

Parent 'D' also reported:

*"I am not able to participate in any of the community activities because I am always engaged with accompanying and assisting my autistic son along with doing various*

*household activities alone. For example, "I do not show up for "ekub" or "eder" meetings nor participate in any of the activities like funeral or weddings and this condition is well known by the ekub and eder members, they know me well, they usually say that "leave her alone". My life style constrained me from maintaining a relationship with my old friends, extended families even I cannot manage to make time for myself, as you see I am being physically deteriorated."*

I perceived that thinking of her life situations makes this parent feel hopeless and worthless

#### 4.2.2.4. Job Loss and Obstacle to Pursue Education

The study participants explained how the presence of ASD in their family influences their work and education.

Parent 'B' stated:

*"I wish to go back to college to finish my study and have my advanced diploma because I know it helps me to get promotion or a better paid job to help my family. However, the inclusion of Suraphel, (my grandson) to our family enforced me to withdraw from my college education. At this time I am exhausted, it seems me it is unattainable…. life is such a trouble".* She expressed with feelings of frustration

Parent 'A' reported:

*"I am working as a housemaid for a proximate neighbor to make money for our living expenses, because I and my autistic child need to stay alive. Whenever I go work I keep my child with me because there I have no one to watch my child in my absence. Having an autistic child hindered me from pursuing my high school education, raising a child who has autism caused me lots of problems so that it made it hard for me to live a better*

*life, I always feel disappointed, I struggle to meet at least what we mainly need to survive… food, shelter..".* She kept crying.

Parent 'G' also described:

*"Parenting a child who has autism and physical disability is more challenging for both of us* (the parents) *because the condition of our child requires us providing special assistance such as, lifting him to the wheelchair, carrying him (especially when he grew up), pushing the wheelchair. Most of the time I arrive late to work because I have to find safe transportation to my child like a minibus with few passengers because people are not comfortable to travel with a physically disabled person. When there is unpredictable school closure I have to leave work to collect my son, this situation leads to loss of job. I cannot compete for better jobs to work in the distant areas because I have to stay close to support my child".* He explained with feelings of exhaustion.

Parent 'E' expressed:

*"I am educated but I work in a lower-level positon which does not match to my qualification because my parental responsibility requires me to be available for my autistic son. People try to remind me of getting a better paid job and living a better life, because they do not understand my life situation. Some of my colleagues advised me to leave my son with my mom to take advantage of any available opportunities but I do not give attention to their advice. I work in the night because I need to provide daytime care to my autistic son, in addition leaving my baby with a babysitter may not be safe".* She continued crying

The rest of the participants similarly described that i.e. lack of time and financial hardship, exhaustion, lack of family and social supports hindered them from securing fulltime jobs and from pursuing their education.

### 4.2.2.5. Emotional and Physical Health Problems

Participants were asked to explain how the atypical behavior of their ASD child affected their emotional and biological well-being.

Parent ‘D’ stated:

*“My autistic boy is now fourteen but he has difficulty toileting. For example, he is not able to open his trouser zip and urinate properly, if he has to urinate he just put-off his trouser anywhere. When I take him outside home he shows unusual actions such us screaming, crying, or hitting his head due to that I feel ashamed before people. If I have to go somewhere for example, attending a funeral I leave the window open and keep him in a locked room, I knew that he could have thrown himself or he could have been exposed to any physical attack…but I had nothing to do!” as you see me, I am not working or earning money, I do not have time for self-care, I have no means to improve my life … my appearance is being changed that I look more older than my age I feel pain when I think of my life situation, I lost my strength.”* She expressed that with feelings of exasperation

Parent ‘E’ described:

*“Having an autistic child disrupted my life so much. It adversely affected my marriage, my work life, my health, my social life… everything. I divorced from my husband long time ago, I work in a lower-level position, in the night shift, so that I lack enough sleep, I am separated from my friends for years and my families, extended families abandoned*

*me, It became difficult for me to participate in any social activities like lekso, edir, serge etc. When I see his age mates who grow and behave in a normal state I become worried and feel bitter, all these life events caused me depression, and I take medications for hypertension and hormonal disorder".* She described with feelings of dejection and bitterness

Parent 'F' also reported:

*"Condition of my daughter makes me worried. I always ask myself why this problem happened on my family life and for how long does this problem persist? I suffer from gastritis pain and stress disorder. My daughter is now fourteen and handling the issue of her menstrual cycle is challenging for me. She has behavioral problems of taking hold of things, screaming, beating her body, rocking from side to side; she also hits herself against a wall, in response to that the proximate neighbors start to blame our family. When I take her outside home unexpectedly she runs into the street, all these situations are irritating and heartbreaking. I am worried when I think for her future".* She cried.

Parent 'H' stated:

*"I have problem understanding condition of my child, I am always confused. I do not know where to go to learn the skills to handle my child's behavioral problems. It's a heartbreaking to see your child fails to communicate or respond to certain actions! For example when I call his name he doesn't respond and this condition made my life bitter, I am always stressful. People in our community neglect and undermine our family, we stay afar from our extended families, I resigned from my work because my autistic son has epilepsy and it is not safe to keep him with a babysitter, it is a tragedy!"*

The rest of the participants similarly described as they experienced frustration, hopelessness, anxiety, tension, and feelings of rejection and regret about their inability to socialize with others.

### 4.2.3. The Influencing Factors that Contributed to the Parents' Stressful Situation

#### 4.2.3.1. Lack of Knowledge about Autism and Lack of Support Networks

Participants were asked to explain their understanding of autism and the behavioral characteristics of their ASD children, and each of them described their experience from their own perspectives:

Parent 'H' stated,

*"I understand autism as a worst problem that damages children's ability to understand and interact it is really painful to see your child dealing with difficulties".*

Parent 'G' also described:

*"In the earlier time I understand autism as a generational curse linked with the spiritual practices that came from our grand-families. Now I knew that my child has this problem because he drank fluid in the womb* (i.e. amniotic fluid), *and he lacked nutrition in the womb* (i.e. maternal malnutrition). *What can I do?"* He expressed with feelings of bitterness.

Participants were asked to explain how they have been accessing information that helps them to navigate service and support systems.

Parent 'D' expressed:

*"My child's autism caused me a lot of problems, my autistic son put things in his mouth this condition makes the older children upset. Few years ago a woman told me that dealing with my child's autism will be challenging for me when he grows older, she also*

*advised me to have him spend time outside home with normal children to learn healthy behavior from them, besides she alerted me to keep him in an independent bedroom because at their adolescent age autistic children have difficulty understanding their sexual feelings. I do not know how I can handle this situation, it is scary!" I understand autism as a problem that causes suffering to the family".* I realized that what she heard made her terrified

The rest of the caregivers similarly attributed autism as a terrible life situation and the unfortunate of the parents, a problem which causes children a range of difficulties, and a life time problem which is difficult to deal with.

#### 4.2.3.2. ASD Child Behavior and Societal Attitude

Participants explained what they have experienced when they take their ASD children into the community example medical appointments, school, and church.

Parent 'A' reported:

*"When necessary I take my child to different places for example autism center, clinic, or to attend church services, I know that people do not have positive feelings or they do not say good words about my autistic child, I familiarized that people respond to my autistic boy by staring at him, they become scary and show different facial expressions, even there was a time that a man slapped me on a taxi while I was trying to calm my son, one of my neighbors also told me that because I am cursed I have a child who is different from the normal children, it is terrible!"* She has been crying

Parent 'H' explained:

*"It is painful for me to see individuals reflecting what they feel about my child, for example, I saw a father of a normal child in my neighborhood restricting his child from*

*interacting with my child, the society openly discriminates between the autistic and non-autistic children in schools and any other public areas".* She spoke with feelings of exasperation.

Parent 'G' also reported:

*"People do not understand the physical and emotional difficulties that our child has, they do not feel comfortable to travel with him in the same vehicle, they stare at him and show us unhelpful facial expressions, it is painful for us to accept these situations, however we are his parents and we gave up our lives to help him".*

Parent 'B' stated:

*"Most of the time I and my grandson spend our time at home, because when he grew old he became irritable and hostile I have concern that he may hurt people. He can stay home because each of our family members loves him and assist him when I am not around".*

Parent 'C' reported differently:

*"I do not have problem in this concern because no one knows that my granddaughter has autism. When certain persons ask me why she is not speaking I tell them that she will make it in the following years".*

The rest of the participants expressed that taking their ASD children into the community is always challenging for them because their children behave differently and the society do not understand them, as a result the parents became tired of hearing such upsetting words and being embarrassed.

### 4.2.3.3. Financial Hardship

Participants were asked how they cover the living expenses of their family i.e. food, housing, medical care, clothing, and transportation.

Parent 'C' stated:

*"I have a retirement benefit in addition to that my married children support me with limited financial contribution, thank God".*

Parent 'B' described:

*"My husband is source of our family income and our married children support us with limited contribution that is all we have to meet the demands of ten family members".*

Six of the eight participants affirmed that their source of income is the parents' wage or monthly salary.

Participants were asked to explain if they were able to buy special equipment or aid materials needed for their ASD children?

Parent 'C' stated:

*"My granddaughter has a toy she loves her toy because she always play with this toy, she is not interested to play with other children, she always keep to herself".*

Parent 'D' also described:

*"My son has never used any support or play materials in the home because the family is not able even to fulfill the basic life needs; I blame myself when I see him eagerly looks at other children playing with their materials.*

Two of the participants stated that they were able to purchase some inexpensive play materials to their ASD child, and the rest of the participants reported as they were not able to fulfill the needs of their ASD child due to lack of knowledge about the aid materials and financial difficulty.

Participants were asked to tell whether there is disability support for their ASD child to cover their medical expenses.

Six the study participants reported that they do not have disability support for their ASD children; even they do not know whether this support system exists or not, whereas two of them affirmed that Nehemiah autism center provides them limited financial support for their child's medication.

### 4.2.4. Unavailability of Support Systems

#### 4.2.4.1. Unavailability of Public Daycare Services and Special Education

Participants were asked to tell if they have a babysitter/nursemaid to assist them with providing care for their ASD child when they are at work or engage with household activities.

Parent 'B' reported:

*"Among our extended families or friends there is no one who is willing to help us, but my adopted-daughter supports him when I am not around".*

Parent 'H' and parent 'G' similarly described that their spouses support them with caring their autistic child at home even in a better way when they are engaged in personal or other familial commitments. Parent 'C' parent 'E' and parent 'H' declared that they have nursemaids to assist their ASD children in their daily routine; while parent 'A' and parent 'D' affirmed that they are the only one to provide care for their ASD child.

Participants were asked to explain if they know about availability of free or affordable preschool or day-program facilities at their locality.

Parent ‘C’ stated:

*“At her age of two my granddaughter has been receiving free daycare services in a day care facility, but it was for duration of one year”.*

Parent ‘G’ and parent ‘H’ described that they have the information about availability of private pre-school facilities outside their locality but the service payments were unaffordable to them, whereas the rest participants responded as they have no idea about availability of preschool or day-program facilities inside or outside their locality.

#### 4.2.4.2. Unavailability of Family and Social Supports

**P**articipants were asked to explain if they have someone from their extended families, friends, and/or neighbors to support them when needed.

Parent ‘E’ replied:

*“It is difficult for me to build relationship with others in my community because I have a caregiving burden and trouble managing the behavior in my autistic child, my extended families and former friends rejected me since some years ago. I rarely share my life situation with my cousin she is the only one who understands my situation of my life”. She cried.*

Parent ‘F’ also described:

*“My husband is cooperative when I have to do other household activities or if I need to attend church services he makes himself available for our autistic daughter however that doesn’t reduce the exhaustion I have* experienced;

The rest of the participants similarly replied that do not have anyone from their extended families, their former friends, and/or parents in their neighborhood even to ask about the status of their family.

Participants also explained how they discuss autism related family problems with their family members and decide on certain actions together, and how their family members support each other to make their family feel good.

Parent ‘H’ stated:

*“I and my husband discuss and make decisions to resolve family problems in the scope of our financial capacity, for example we discussed on how we facilitate toilet to our autistic child and reduced his toileting difficulty”.*

Parent ‘G’ also described:

*“When something in our family goes wrong, I and my wife sit together to discuss the issue and then we decide and try to fix the problem. For example our autistic son has habits of screaming, hitting walls, and sometimes he cry, due to that our neighbors complained that their family was disturbed by this situation to resolve this problem we shifted our residence…but we scarified a lot!”*

Parent ‘D’ differently responded:

*“I cannot do anything alone, my husband feels bored when I share with him any concern in relation to our autistic son, for example I asked him about what we can do about the toileting problem that our son has been experiencing, he didn’t suggest anything because he was tired of the family issues and the older siblings were not willing to assist me”.*

Parent ‘A’ and parent ‘E’ similarly stated that they have no spouse and dependents other than their autistic child.

The rest three parents described that they discuss their family situation with their family members (i.e. husband, older children) and take action based the family's shared decision, for example, one of the participants described that she took her autistic grandson to a place called 'tsebel' that her ASD son may probably get religious healing.

#### 4.2.4.3. Unavailability of Community-based Services

Participants were asked to explain if they got the chance to meet and talk with the other parents of the ASD children within their community.

Parent 'G' stated:

*"I never get the chance to meet and discuss with other parents of the ASD children in my community but I sometimes discuss with the other parents whom I met during the school meetings".*

Parent 'B' and parent 'D' explained that they missed the chance to meet with other parents of autistic children because they were not available for any of the school meetings.

Five of the participants similarly described that they rarely met and shared their life situation with the other parents when they participate in the parents' meeting organized by Nehemiah Autism Center.

#### 4.2.4.4. Unavailability of Professional Interventions Services

Participants were asked to explain if they got the chance to meet with professional a therapist or psychologist and received professional support services for their ASD child.

Parent 'G', whose autistic child has physical disability affirmed that his autistic son has been receiving physical therapy treatment in one of the public hospitals, whereas seven of the participants haven't met with any of the above mentioned professionals after they received autism diagnosis services for their ASD child

Participants were asked to describe if they were able to meet with a social worker who can handle their family cases.

All participants similarly reported that they have never met with a social worker.

### 4.2.5. Parents' Inability to Cope with the Stressors

The study has identified the presence of the internal – biological, psychological, social, economic, and environmental stressors, and the external – psychological, social and environmental influencing factors that have contributed to the parents' perception of the family crisis and self-efficacy. The presentation used two diagrams to illustrate the extent to which each internal and external stressor contributed to the family emotional instability.

**Figure 4: External Parental Stressors**

The study identified the presence of various external stressors that negatively influenced the parents' emotional wellbeing.

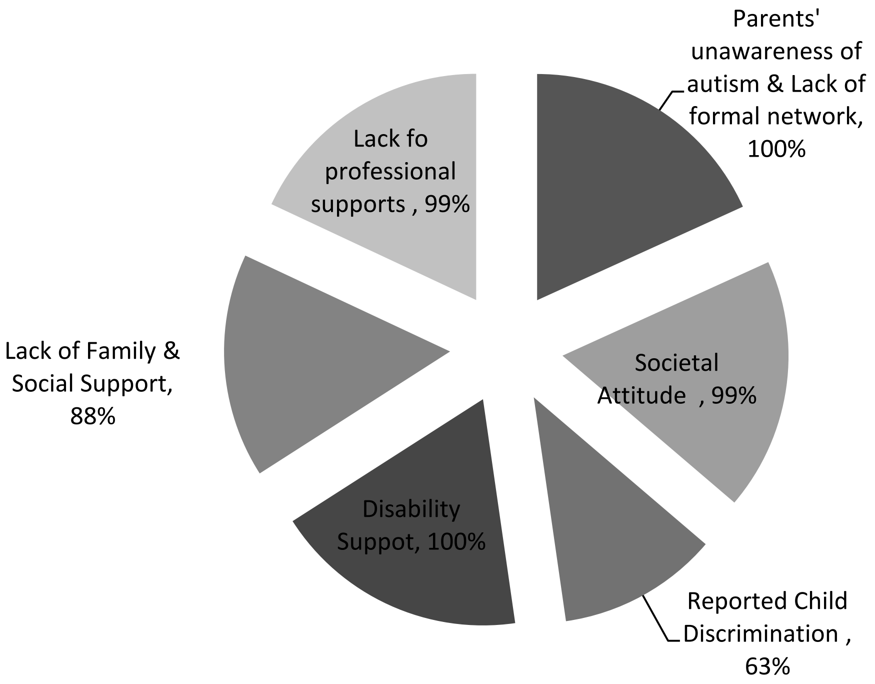

Figure 4 illustrates the extent of the influence of each external stressor on the parents' perception of the crisis events and their ability to cope with the family problems.

**Figure 5: Internal Parental Stressors**

The study identified the presence of various internal stressors that negatively influenced the parents' emotional wellbeing.

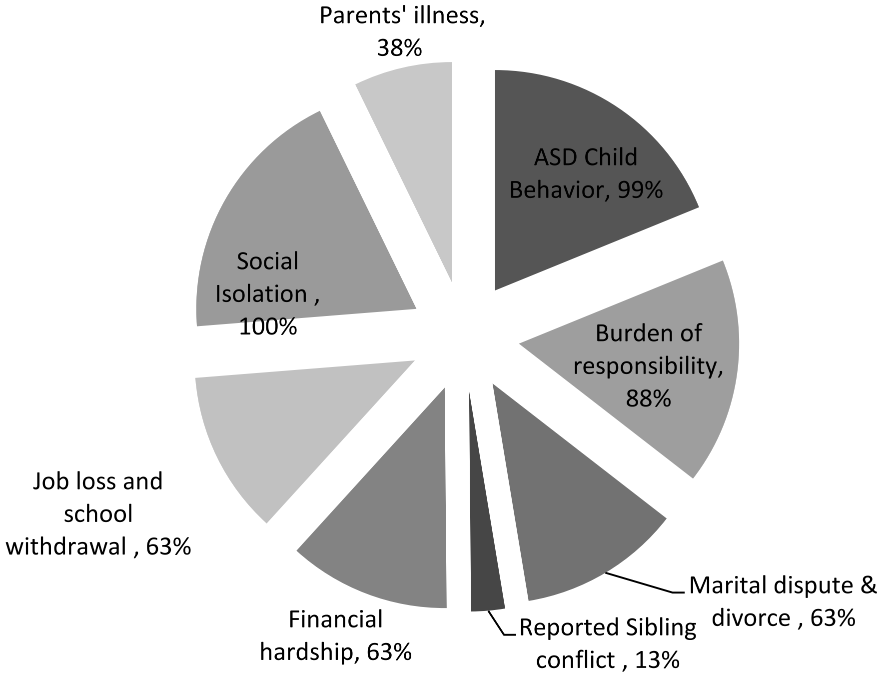

Figure 5 illustrates the extent of the influence of each internal stressor on the parents' perception of the crisis events and their ability to cope with the family problems.

# Chapter Five

## Discussion

The study attempted to answer the research questions: (1) “what impacts does ASD have on the lives of the families with ASD children in woreda five, six, and seven of Yeka Sub-City” and (2) “what interventions are available for the families’ to address the families’ life problems and restore the families’ emotional stability” The study explored the interpersonal, biological, emotional, financial, social and environmental impacts and presented the reports in the results section. The study also discovered the unavailability of medical, social, educational, financial, community and professional support systems and presented the reports of the findings in the results section.

The finding discovered that the presence of ASD child impacted the various aspects of the family life i.e. (1) family cohesion and family function, (2) marital relationship, (3) work and education, (3) social life, and (4) emotional and biological wellbeing. The study also identified the various internal and external stressors that negatively influenced the parents’ perception of self-efficacy and self-esteem. The findings identified and reported the internal stressors i.e. child behavior, burden of responsibility, marital dispute and divorce, siblings’ conflict, job loss and school withdrawal, financial hardship, social isolation, and parents’ illness. Besides, lack of knowledge about autism and lack of support networks, lack of family and social supports, unavailability of family intervention services, unavailability of disability support, societal attitude and child discrimination were identified as external stressors.

The discussion focused on detailed description of five major themes with twelve subthemes presented in the results section: (1) autism diagnosis and basic therapy services the parents received to their ASD Child, 2) effects of raising an ASD Child on the Family, (3) the influencing factors that contributed to the parents' stressful situation, (4) parents' inability to cope with the stressors, and (5) unavailability of family support systems. The study consulted findings of previous studies in similar topic to relate and compare the findings with the present study findings and to use them as complement. Three crisis intervention models and two social work intervention models have been reviewed to validate the study findings. In addition to that, the researcher's personal views of the study findings have been presented.

## 5.1. Diagnosis and Basic Therapy Services Parents Received for their ASD Child

The study findings discovered that hundred percent or eight of the study participants received autism diagnosis test for their ASD child, and the diagnosis test was made by the neurologists working in various public hospitals. The diagnosis history of the ASD children showed as four children have other health condition that two of the them have epilepsy, one of them has sensory processing disorder, and the other one has physical disability. The parents of the four children who have other health conditions described that meeting the treatment and care needs of these children is difficult for them, in other hand they are having trouble navigating appropriate supports and services.  Most of the parents similarly stated that when they were told about the positive diagnosis result of their child, each of them became shocked and frustrated, because they did not have the knowledge about autism and the diagnosis. Abera (2017) stated that autism can be one of the most difficult diagnoses to accept for parents in Ethiopia because of the challenges associated with autism spectrum disorder and social stigma caused by lack of awareness. A few of the participants stated that the physicians who provided the diagnosis test informed them to contact Nehemiah Autism Center situated at Lafto Sub City. The findings discovered that there is no hospital referral system for appropriate supports and interventions that may help the parents with meeting the life demands of their ASD child.

The findings showed that 87.5 percent of the ASD children received basic assertive behavior analysis (ABA) treatment, 62.5 percent of them received basic occupational therapy, and 87.5 percent attended based social skill trainings. The study also revealed that the basic therapy services were given in the autism center by the center staffs and foreign volunteers who have got short term trainings in the field. The study found out a gap with meeting the children's special needs for treatments and supports comparing the accepted standard of the professional quality of therapists including the context of the services. For example, Jassey, J., (2019) delineated that Assertive Behavioral Analysis (ABA) helps children with autism disorder(s) to use "expected" behaviors and control some of their more challenging impulses. These behavioral skills can make a big difference in how well the child with autism manages school and social experiences. A board-certified behavior analyst (BCBA) provides ABA therapy services. ABA therapy programs also involve therapists or registered behavior technicians.

Majority of the study participants reported that Nehemiah Autism Center has given them the chance to participate in the parenting training in order to learn the skills that may help them with understanding the behavioral problems of their children and to respond appropriately. In the other hand most of the parents expressed that they still have trouble understanding their child's needs and handling the behavior related problems. Even they have no the skills to direct, to talk and play with their ASD children. Autism Society (2020) stated that an individual with autism may not express their basic wants or needs in the manner their families would expect. When parents cannot determine their child's needs, both parties are left feeling frustrated. The child's frustration can lead to aggressive or self-injurious behaviors that threaten his/her safety and the safety of other family members. For example, one of the married parents described: *"Understanding my child's condition is challenging for me, it is very painful to see your child has difficulties dealing with his daily routine, he cannot ask what he wants to get! I need to learn the skills to help him!".* Webster, (2017) described that parents are experts when it comes to their children and play a critical role in teaching and guiding their children's learning as they grow from early childhood into adulthood (p.3). In the other hand, Webster (2017) has suggested that in order to advocate effectively, parents need to educate themselves to gain an understanding of the current legislation and policies that affect their child as well as the options available for their child to engage with evidence-based programs in school and community settings. (p.185)

### 5.2. Impacts of Raising an ASD Child on Family

The study findings revealed that the presence of the ASD child in the family impacted: (1) the family functioning in relation to the family's handling of the crisis situation caused by having ASD child in that family, the family cohesiveness, and the family dynamics i.e. the families social interaction, (2) the family's roles allocation and assignment of responsibilities to its members, (3) marital relationship (4) work - parents' work life that determines the family income, parents' social life and self-esteem, (5) education - that determines the attainment of the parents' educational goals, professional development, and economic status, and (5) the parents emotional and biological wellbeing.

## Family Disunity and Role Conflict

The findings revealed that having an ASD child in each family affected the family cohesiveness with regard to members' lack of concern to the family and lack of commitment to support each other. For example, a married female parent described: *"There is lack of closeness in our family and this situation caused me difficulty to deal with the family problems alone! I am so tired!* The illness of the child in this family affected the family role allocation and assignment of responsibilities to its members. Goldenberg, (2017) stated that how the family organizes itself, how it retains its cohesion, how openly it communicates and problem solves together to cope with the threat largely forecasts the family's ability to recover. (p.9) She also described: "*In the previous time my husband had been dedicatedly performing his parental responsibility, as the years passed he lost his courage to deal with any of the family concerns I think… he is getting tired of the situations when he got old.* Lack of expressiveness among the family members hindered the parents from openly expressing what they feel about the relationship problems i.e. between husband and wife, and parents and children. Goldenberg, I., (2017) stated that it is crucial that whatever the demands of child rearing and the evolution of an effective parental subsystem, the parents work to maintain and strengthen their spousal subsystem, which is fundamental to family well-being (p.261). She also stated: "*He isolates himself from the family; even he pays no attention when I try to talk with him about the behavior related problems of our autistic child, for example, when I was telling him that Biruk didn't feel well that day, he just said, you can take him to hospital and immediately he left home!"* This indicates that there was lack of consistent rule and shared responsibility within the family that led to the parents' disengagement. (Hartman, 1981; Meyer, 1990; Okun, 1996, and Sue, 2006) stated that the family performs certain functions and has certain responsibilities to and for its members unlike any other social system. Families perform the essential function of attending to the social and educational needs, health and well-being, and mutual care of its members."(p.228)

The married parent stated: "*Even the older brothers are not willing to support their younger brother because they do not know what they are supposed to do for their family, for example, when they see Biruk struggling to urinate by his own they leave home as if it was not their concern, this condition makes me more stressful".* Goldenberg, I., (2017) presented the work of Minuchin (1981) as: *"Spouses must receive support from one another and together develop a marital subsystem for expressing affection, helping each other deal with stress, and dealing with conflict as equals. If there is a major dysfunction within the spousal subsystem, it will likely reverberate throughout the family". (p.274).* However, for these parents dealing with the parenting stress and maintaining their dyadic relationship may not be easy while they often have trouble dealing with their child's cognitive difficulties and behavioral problems along with performing other numerous familial commitments. Holosko, et al. (2013) presented family roles as positions that each member holds within the family that govern their interactions with the other family members. If the mother's role is that of the caretaker, she may be designated as the family member who takes the children to school and doctor's appointments and is expected to take time off from work when the children are ill. One parent may take on the role of primary decision maker. When important family issues are discussed, the other parent will typically defer to the decision maker, who will make the final decision *(p.267).*

## Parental Dispute and Divorce

Majority of the female caregivers reported the recurring spousal conflict in their family and two of them had divorced from their husbands as a result of the distressful life situation induced by the health condition of their children. For example, one of the single parents described: *“I and my husband had a relationship problem which ended with separation. It was intolerable for my ex-husband to accept the changing situation of the family caused by having a child with autism. He was not willing to stand with me to face the family problems together as a result our relationship became hostile”.* This situation implies that there was lack of mutual support between the parents or spouses because the male parent was irresponsive to the changing family situation and was not interested to involve in certain family activities while the family was in crisis. Goldenberg, I., (2017) delineated that the strength and durability of the spousal subsystem in particular offers a key regarding family stability. How spouses learn to negotiate differences and accommodate to one another’s needs and develop complementary roles impacts the likelihood of family stability and flexibility to adapt to changing circumstances. (p.261) She also stated that: “*He started to spend time outside the home and I realized that he had been engaging in extra-marital affairs and finally we got divorced… it was so painful for me!”* The occurrence of the family crisis elicited by the illness of the child negatively influenced the husband’s fidelity and his interest to the family members; it also affected the family connectedness.

A young single parent also reported: *“My husband left home when he knew that our child has autism and I remain in a very difficult life situation. Dealing with the unfamiliar behavior of my child and thinking about the issue of our life needs fulfillment* *was very upsetting for me.* The findings revealed that the presence of an ASD child in this family impacted the family cohesion (i.e. the male parent's concern and commitment to the family), the family functioning (i.e. parents' handling of the crisis situation resulted from the change in the family system), and the ASD child experiences parental loss. After her husband left the family, the single parent experienced feelings of rejection and loneliness. She described: "*there was a time in which I felt like I have no way to get out of this situation and having that feeling initiated a thought of dumping the child in remote public places, but it was difficult for me to decide."* Her concern about the future uncertainty elicited a thought of child abandonment as a coping mechanism. James, K., R, (2008) presented the influences of marriage conflict and separation as: *"The most common experience that marriage partners have regarding separation is intense and disturbing fear and emotional disorder. Almost all separations produce negative feelings and outcomes that were not anticipated by either party. Even when the separation is desired and sought, it triggers a sense of frustration, failure, loss, and mourning. People suffering from loss due to divorce show significant and consistently higher vulnerability to almost every major physical and mental disorder, particularly to heart disease". (p.373)*

**Lack of Social Participation**

Most of the study participants explained how raising an ASD child affected their social relationship within and outside the family as a result they experienced social isolation. For example a married parent stated: *"I do not have time to participate in any of the community activities because I am always engaged with accompanying and assisting my autistic son along with doing other household activities alone".* According to the findings the female parents of the ASD children experienced rejection within the family by their husbands and the non-autistic siblings as the family members lack healthy interaction; and outside of the family by their extended families, friends, and neighbors. She also stated: *"I do not show up for "ekub" or "eder" meetings nor participate in any of the activities like funeral or weddings and this condition is well known by the ekub and eder members, they usually say that "leave her alone". My life style constrained me from maintaining a relationship with my separated friends and relatives even I cannot manage to make time for myself, as you see I am being physically and emotionally deteriorated."* Having an ASD child in their family made it difficult for the parents to establish relationship with individuals and/or groups in their community, extended families, and friends because they have responsibility of caring for their ASD child and managing the behavioral problems along with serving the rest family members.

### Job Loss and Failure to Pursue Education

The findings uncovered that raising an ASD child in the family constrained the parents from attaining their educational goals and caused them employment related problems in various ways for example, A single young parent reported:

*"I am working as a housemaid for one of a nearby neighbor to make money that helps us with covering our living expenses because I and my autistic child need to stay alive. Whenever I go to the work I keep my child with me because there is no one to support my child in my absence".* While doing a part-time housekeeping job is the only source of the family income, for this single parent caring a child with autism in the absence of family or social supports may unfavorably affect her emotional wellbeing. James, K., (2008) stated that crisis is a crisis because the individual knows no response to deal with a

situation (p.3). She also stated: "*I was not lucky to complete my high school education, because raising an autistic child caused me lots of problems, it made it hard for me to fulfill our basic needs, I feel disappointed, I take my effort to fulfill at least few of our needs i.e. food and housing".* In addition to the challenges associated with raising an autistic child, she experienced other situations like facing hindrance to attain educational goals, divorce, financial challenge, and social rejection. James, (2008) stated that crisis is a state of disorganization in which people face frustration of important life goals or intense disruption of their life cycles and methods of coping with stressors (p.3).

**Emotional and physical health problem**

The findings discovered that raising a child with ASD made the parents suffer from various emotional disturbances. The various stressors such as child behavior, burden of responsibility, marital conflict, financial deprivation, and lack of family/social supports were some of the contributors to the parents' emotional imbalance and the family dysfunction. For example, one of the married parents reported: "*How my son behaves before people constrained me from taking him outside home, he screams, cries, or hits his head and these conditions make me feel embarrassed. When it has been necessary to show up for funeral attendance I leave the window open and keep him in locked room, I know that he could have thrown himself or he could have been exposed to attack…but I had nothing to do, as you see I am not working or not making money, I do not have time for self-care, I have no means to improve my life …"* According to Webster, (2017) the families of children with ASD experience an overall decreased quality of life as a result of dealing with their children's challenging behaviors, and face hidden social costs as they decrease their engagement in social activities due to concerns for their child (p.13). She also expressed: "*my appearance is being changed that I look more older than my age I feel pain when I think of my life situation, I lost my strength*!" Her explanation of the life events that she experienced disclosed the presence of: (1) social stressors i.e. unemployment, lack of family/social supports, lack of time to socialize, financial deprivation, and (2) environmental stressors i.e. child behavior, societal attitude, lack of family/social support, and threat to child safety that triggered her feelings of loneliness, hopelessness, and emotional exhaustion, and causing her to have the beliefs of negative self-image, low self-esteem, and lack of motivation.

A single parent elaborated how raising an ASD child impacted the biological, psychological, and social aspects of her life. She stated: *"Having an autistic child disrupted my life so much! It adversely affected my marriage, my work life, my health, my social life everything, I divorced my husband"* Webster (2017) stated that ASD impacts family dynamics as well as parents' relationships that the divorce rates are higher for families of children with ASD, with additional stress placed on families of children with particularly challenging behaviors. She described: *"I am working in a lower-level position in the night shift and that caused me lack of enough sleep, I got separated from my friends and my extended families abandoned me, it became difficult for me to socialize like lekso, edir, serge".* Autism Society, (2020) stated that parents/caregivers must place their primary focus on helping their child with ASD, which may put stress on their marriage, other children, work, finances, and personal relationships and responsibilities. They have to shift much of their resources of time and money towards providing treatment and interventions for their child, to the exclusion of other priorities. The needs of a child with ASD complicate familial relationships. She also reported:

"*When I see his age mates who grow and behave in a normal state I feel worried and cry bitterly, all these life events caused me depression, hypertension, and hormonal problems and currently I am taking prescribed medication".* Webster, (2017) discovered that mothers of children with ASD have been noted to experience more stress and levels of anxiety than fathers perhaps because of the greater amount of time they generally spend with the child during their early years. Additionally, researchers have suggested that families have less time for family activities and parents often experience physical and emotional exhaustion as they struggle to cope with their ASD child's behavioral problems (p.13). The participants' explanation of the traumatic events and the distressful life situation indicates that the families' usual coping strategy did not help them to handle the troubling life situation, and to meet the changing demands of the family. James, (2008) stated that people in crisis are in a state of psychological or emotional disequilibrium in which their usual coping mechanisms and problem solving methods fail to meet their needs. Thus, the equilibrium crisis intervention can be appropriate to create awareness to the families about their emotional condition, to regain coping abilities, and recover a state of pre-crisis stability.

### 5.3. The Internal and External Influencing Factors

The finding of this study discovered the presence of the ranges of internal and external influencing factors that contributed to escalation of the parents' strain and affected the parents' perception of their self-efficacy and positive self-image in various ways. In the finding section I presented all the internal and external influencing factors in diagrams, and attempted to provide explanation of the major stressors in the discussion section. James, (2008) stated that although the original crisis event may be submerged below awareness, and the individual may believe the problem has been resolved; the appearance of new stressors may bring the individual to the crisis state again (p.5)

## Lack of knowledge about autism and Lack of Support Network

The findings discovered that majority of the participants became frustrated and confused when they were told that their child has autism, because they didn't have the knowledge about autism and its diagnosis. For example, a male parent explained his understanding about the cause for his child's autism as: *"In the earlier time I had been understanding autism as a generational curse that has been transformed across generation. Now I knew that my child has this problem because he drank fluid in the womb and he lacked nutrition in the womb, what can I do?"* This parent presented the meaning he attributed to the cause of his child's autism as 'generational curse' which was derived from his spiritual belief. He also accepted what individuals assumed about causes of autism i.e. child drank amniotic fluid and the child was malnutrition during pregnancy. This situation explicitly shows that the family has lack of access for formal network and lack of knowledge about appropriate sources of information. According to Webster, (2017) following their child's diagnosis, parents face with a range of extra pressures as they attempt to learn about ASD and what this means for their child. (p.13)

Lack of access to useful information and lack of professional guidance also caused the parents increased frustration and it made them feel frightened. For example, a married female parent expressed: *"Few years ago a woman told me that dealing with your child's autism will be more challenging for you when he grows older, and she advised me to mix him with the normal children to get him learn healthy behavior from them, she also alerted me to keep him in an independent bedroom because autistic* *children at their adolescent age have difficulty understanding their sexual feelings. I do not know how I can handle this situation, it is scary!"* Her explanation implies that the information she accessed from the wrong source negatively influenced her understanding about service and support navigation, and her expectation of possible challenges on her future parenting. The findings of Webster, (2017) discovered that parents of ASD children indicated lack of support to help them access or make decisions about appropriate services is a frequent source of frustration and anxiety. (p.14)

The other married parents replied: *"a few year ago a woman in my locality had promised to help me in the process of finding supporting organization I gave her my telephone number and the picture of my son because I trusted her. But I haven't seen her again because she had shifted her residence, it was disappointing!"* Webster, (2017) stated that without adequate information, it is difficult for the parents to know whether services available for their children are really appropriate. (p.185)

### ASD Child Behavior & Societal Attitudes

The findings of previous studies identified that social stigma makes the lives of the parents of the autistic children in Ethiopia more challenging. Hoekstra, R. (2017) stated that many caregivers of the children with autism in Ethiopia say that they are worried about other people finding out about their child's condition, due to that some parents feel the need to keep their child hidden at home. Similarly the findings of this study uncovered that fear of negative biases influenced the beliefs of majority of the study participants due to that they do not feel safe to openly share their child's condition to others. For example, the maternal grandparent of an ASD child stated: A maternal grandparent reported: *"I do not have problem in this concern because no one knows that* *my granddaughter has autism. When some people ask me why she is not speaking I tell them that she will make it in the following years".* Two possible conditions: (1) her strong bonds with her cultural traditions, (2) fear of stigma might have constrained this parent from telling her family situation to people outside the family. A single parent reported: *"I know that people do not have positive feelings or they do not say good words about my autistic child, they stare at him differently, they feel scary and speak with gestures, even there was a time that a man slapped me on a taxi while I was trying to calm my son, one of my neighbors also told me that because I am cursed that is I have a child who is different from the normal children, it is terrible!"* In response to the negative environmental influences, this parent has experienced fear of negative biases, verbal harassment and physical abuse finally she isolates herself. According to Paltrow, C. (2018) parents of autistic children may experience: embarrassment over their child's behavior in public, feeling socially isolated frustration, and may have guilt from thinking that they may be responsible for their child's challenges. A married parent also described: *"It is painful for me to see one of my neighbors restricting his child from interacting with my autistic child and the others openly discriminate between the autistic and non-autistic children in schools and any other public areas".* According to (Autism Society, 2020) taking an individual with autism out into the community can be a source of stress for parents. Because, people may stare, make comments or fail to understand any mishaps or behaviors that may occur.

## Financial Hardship

The study discovered that families of the ASD children under this study are categorized as low-income while the medical, biological, social, and environmental life demands of their ASD child remain unmet. Hepworth, (2010) described that poverty and the related stressors play a role in social problems in particular, child development, family stability, health, and mental health status (417). One of the married moms described: *“My son has never used any aid materials or play materials in the home because our family is poor, we are not able even to fulfill our basic life needs; I always blame myself when I see him eagerly looking at other children playing with their materials.* Webster, (2017) stated that financial strains and time pressures may lead to decreased self-efficacy and increased physical and mental health difficulties for families of ASD children (p.13). Even if employment can be an appropriate means of making family income, most of the participants reported that pursuing their education and/or doing fulltime jobs was difficult for them due to lack of family and social support, time, and motivation. Some of the participants affirmed that they resigned from their jobs to provide daytime care for their ASD child. The findings of Paltrow, (2018) discovered that losing a full-time job may dramatically affect the financial condition of the family of ASD children. The other participant described the family’s poor housing condition as: *“we do not have appropriate toilet, we are five and our living room has no enough space that we do everything here”* The finding discovered that most of the participants do not receive financial supports from any of their relatives, extended families, or friends, due to that meeting their family’s basic needs i.e. food, cloth, housing, health care, and transportation became very problematic for these families. (Hepworth, 2010) outlined the impacts of poor financial resources on family system as: *“Living in poverty can be a constant stressor that affects family stability and mobility and limits the family’s ability to meet basic needs. It influences where families live, including the conditions of the* *housing where the family resides, education that children receive, and the safety of the neighborhood in which they live." (p. 232)*

### 5.4. Unavailability of Family Support Systems

**T**he study found out that family support systems i.e. free or affordable daycare services and educational facilities, family and social supports, community-based programs, and family intervention services were not available for this population. It seems that social service providers, non-governmental organizations, or local healthcare providers did not recognize this population as part of the society. The Arc Autism Now, (2018) presented the definition and the various aspects of family support provisions as: *"family support is defined as a comprehensive and coordinated set of strategies that are designed to ensure that families who are assisting family members with disabilities have access to person-centered and family-centered resources, supports, services, and other assistance. Family support may include: physical home modifications, early intervention programs, in-home and out-home respite, sibling programs, family counseling, parent support groups, after school programs, education programs, behavioral training, and any service funded to assist families to continue to care for their child or adult child with developmental disabilities in the family home".*

### Unavailability of Public Daycare Services and Special Education

The findings revealed that two of the participants have nursemaids; the other three were assisted by their husbands and adopted daughter. One of the single parents lives with her ASD child where providing care for an autistic child and making income for the family were adversely challenging for her. According to the findings even if few of the participants have been supported by the nursemaids or their family members, none of the parents were not able to take break from their caregiving burden. The study found out that public pre-schools or adult day program are not available in the participants' locality. Some of the participants stated that there are private pre-schools and special education programs outside their locality however the service payments are too expensive. Availability and accessibility of family and disability support systems is essential for the family, because parents will take advantages of having break to rest, they can get time work and socialize, and perform other personal and familial responsibilities. In one hand the children may get the chance to get acquire education, to socialize in classroom, and learn the necessary skills that help them in their daily routine. According to Holosko et al., (2013) presently social work intervention typically focused on identifying support and resources so that families can care for their children with disabilities at home and encourage participation in all community activities. Social work is now focused on providing advocacy, support, resources, and services to families so that their child can fully participate in their community (p.238)

## Unavailability of Family and Social Supports

Majority of the participants have experienced social rejection as a result of having an ASD child in their family. The findings revealed that the caregivers have been rejected by their parents, extended families, former friends and even have no social interaction with the people in their neighborhood. Goldenberg, (2017) described that the support of a network of friends, extended family, clergy, neighbors, employers, and fellow employees and the availability of community resources often contribute to family recovery. (p.10). A single parent described the consequences of lack of family and social support as: *"I have caregiving burden and trouble managing the behaviors in my autistic child, my extended* *family members and my former friends abandoned me since they knew about my child's autism.* The findings revealed that lack of access to support networks and the absence of family and social supports have contributed to her distressful life situation and feeling of loneliness. Hepworth, (2010) stated that within some cultures and geographic regions, the extended family may provide an extensive network of support and assistance in crisis situations (p.221). A married parent also stated: *"My husband is cooperative when I need to do other household activities or to attend church services he makes himself available to support our autistic daughter, however that doesn't reduce the exhaustion I have experienced ,I do not know when this problem lasts!"* James, (2008) stated that the cognitive crisis intervention is based on the premise that crises are rooted in faulty thinking about the events or situations that surround the crisis—not in the events themselves. Thus, the basic tenet of the cognitive model is that people can gain control of crises in their lives by changing their thinking, especially by recognizing and disputing the irrational and self-defeating parts of their cognitions, and by retaining and focusing on the rational and self-enhancing elements of their thinking (p.14). Accordingly the cognitive treatment model can help the families' of the ASD children to gain control of their life situation through identifying what they are thinking about their life circumstances and understanding the malfunctioning the troubling negative beliefs and thoughts. The intervention facilitates them to learn the appropriate coping strategies to replace their negative thoughts and beliefs by the new stable understanding.

The findings discovered that some of the participants were able to discuss their family situations with their family members for examples, husband and wife have decided on how to meet the toilet need of their ASD child, the other couples decided and shifted their residence to resolve the conflict with a neighbor caused by their child's behavioral issues, the other family members discussed and tried religious healing for their autistic son. One of the married parents stated that she has been discussing her life situations with the church members and prays together with them to be comforted. According to Hepworth, (2010) families have distinct patterns of relating, decision making, rules, scripts, and a division of roles and labor. The manner in which these functions are implemented, and by whom, may be influenced by cultural or racial preferences, socioeconomic status, and available resources (p.228).

In relation to the two single parents who live with their only child (their autistic child), they affirmed that they have no one to share their life situation so that they keep their feelings of worry and helplessness to themselves. According to Webster, (2017) parents of children with ASD often seek support groups in order to obtain information and emotional support to advocate for their children in education and community programs. Some parents, however, have difficulty accessing support groups due to personal responsibilities and demands on their time. For example, internet support groups provide another avenue for parents as well as providing the added benefit of enabling parents to connect with each other across long distances. (p.205)

### Unavailability of Community-based and Family Intervention Services

The findings revealed that some of the caregivers got the opportunity to participate in the parenting training organized by Nehemiah autism center and the training events opened a platform for the participants to exchange their ideas and discuss their situations among themselves. According to the findings none of the participants never met with a social worker and receive the services, even participants did not have the knowledge about availability of family support services. Participants reported that after their child's diagnosis, none of them got the chance to receive counseling services or they never obtained in-home or in-school therapy services to their ASD child. According to ERIC (2019) there has been severe shortage of services for children with autism in Ethiopia; access to services is further impeded by negative beliefs and stigmatizing attitudes towards affected children and their families. Previous studies discovered that even though there is high demand of addressing the families' problems, the support systems were not available to this population. Hoekstra, R. (2017) also identified that there are only two state-funded child mental health clinics in Addis Ababa where a formal diagnosis can be made". Hoekstra's finding did not indicate the particular location of these clinics. Hoekstra stated that "the vast majority of children with autism remain undiagnosed, with no access to intervention." Even if the parents/caregivers under this study have received the autism diagnosis service to their ASD child, these families were deprived of resources, family and social supports, community-based supports, and professional services. They did not have the knowledge about support networks or professional guidance as a result their support and service navigation remain ineffective.

## 5.5. Parents' Inability to cope with the Stressors

The findings of the study revealed that the internal and external influencing factors have contributed to the family's physical and emotional dysfunction. The internal and external stressors have been presented in diagram 1 and 2 in the findings section. The study attempted to address one of the research objectives i.e. "identifying the interacting factors that have contributed to the parents' emotional instability and family dysfunction". The study identified the internal - biological, social, environmental, and economic influencing factors as: parents’ illness, social isolation, burden of responsibility, marital and siblings’ conflict, financial hardship, behavioral problems, job loss, and school withdrawal. The external- social and environmental influencing factors include:  lack of knowledge about autism and lack of support networks, lack of family and social supports, societal attitude, child discrimination, lack of disability support, and lack of family intervention services. The family stressors that are categorized as non-normative were initiated from the inside, and triggered by the disturbances emerged from the outside. The assessment discovered that parents of the ASD children have difficulty paying their children’s medication expenses, and all the study participants described that they do not know whether there is a disability support system within and/or outside their locality.  The study revealed that majority of the families were from the low economic class (please see table 2). Six of the participants have been complaining about the financial burden they have. For example, one of the single parents stated that she could not hire a babysitter due to the financial shortage; hence, she does part-time housekeeping job and uses the rest of her time to provide care for her autistic child. The interview revealed that meeting the basic needs of her family was very difficult for this parent. Based on the findings the families’ lack of resource includes: safe housing, healthcare, daycare services, special education, aid materials, transportation, and social supports. Most of the parents described that they have trouble dealing with their child’s behavioral problems and have sleepless nights; as a result they have been experiencing physical and emotional exhaustion.

James, (2008) described that the psychosocial crisis intervention model reaches outside the individual and asks what systems need to be changed. Peers, family, occupation, religion, and the community are but a few of the external dimensions that promote or hinder psychological adaptiveness. The psychosocial transition model helps individuals in crisis to understand the dynamics of those systems and how they affect adaptation to the crisis (p.15). Thus, application of the psychosocial crisis intervention model can help the families of the ASD children with: (1) defining the families' problems, (2) identify the internal and the social-external factors that influenced the families' psychological adaptiveness, (3) changing the existing behavior, attitude including their utilization of environmental resources, (4) teaching internal coping strategies, and (5) facilitating access to social support and environmental resources.

# Chapter Six

## Conclusions

The study explored and presented the biological, social, and emotional impacts of the presence of the ASD children on the families' lives. The social impact - lack of interaction and participation, lack of supports from extended families, neighbors, and friends, cultural and religious groups; the psychological impacts (mental disorders, isolation, stigma), the biological impacts (physical illness, physical overtiredness and physical deterioration), and the environmental impacts (from the ecosystem perspective at micro and mezzo level the child's illness affected the interaction between family members, family-neighbors, family-community members, family-employer organization, and family - public service providers (transport service providers, schools, health institutions). The illness of a child in one family affected the lives of all members of the family, the behavioral characteristics of the ASD child disturbed the calm environment of the proximate neighbor and the argument of the proximate required the parents of the ASD child to shift to a new residence, the church environment has been affected by the behavioral problems of the child and lack of facilities and attitudes of the church members hindered the parents from attending the church services. The increased absence and the staff's late to work situation affected the work behavior of the employer organization and the organization's policy affected the work-life of the parent of the ASD child.

The study has identified and presented the various internal and external influencing factors that have contributed to the escalation of the parents strain and affected the parents' perceptions of own self-efficacy. The internal and external influencing factors have been presented in diagram 1 and 2 in the findings section and detailed explanation has been provided in the discussion section. The study also examined the unavailability of medical, social, financial, environmental, educational, and professional support systems for the autistic population who resided in Yeka Sub-City of woreda five, six, and seven. The study highlighted the prominence of creating awareness on Autism Spectrum Disorder(s) in relation to diagnosis and behavioral issues including service and support navigation systems. Based on the study findings, the families of the ASD children were deprived of informational, financial, material, social and environmental resources; in addition to that issues of discrimination and negative societal biases have contributed to the parents' negative self-image and social isolation. According to Hepworth (2010) public policy can be a source of stress for some families, especially poor families, and the extent to which public policy responds or fails to respond to the needs of these families or empower, support, or strengthen them is a concern (p.230).

## 6.1. Implication for Social Work Practice, Policy, and Future Research

The findings of this study have a number of implications to the social work professionals, policy makers, and future researchers. It seems that the autism population in Yeka sub-city remains underserved while having ASD children affected the whole aspects of the families' wellbeing in various ways. Hence, this study accentuates the necessity of availability of social work interventions in family therapy, counseling, case management, community organization and social planning to address the medical, social, economic, and environmental aspects of the families' problems, Holosko et al., (2013) stated that because social workers understand the importance of working with an individual within their environment, family intervention has become a valuable tool in social work practice. (p.266)

The study findings discovered that the families of the ASD children were deprived of social and community resources that they have lack of social participation and interaction, the right for access to safe housing, special education, healthcare, and employment opportunities as parts of disability support systems. Thus, implication of this study for policy highlighted the need for social work practitioners to participate in policy formation process to incorporate the above mentioned issues that the families have experienced.

My study used small sample size and the data collection considered participation of one of the parents/caregivers from each family, and it did not consider observational data collection method that can be helpful to gain thorough understanding on the families' life experiences. Hence, this study suggests future researches to fill the gaps in the above mentioned areas.

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**Appendix-A:**

Date of Interview:  May 2020

## Introduction and Informed Consent

My name is __________; I am a graduate student in Addis Ababa University, School of Social Work. This questionnaire is prepared to gather information for a master's thesis on "Impacts of the Presence of ASD Child on the Families of ASD Children and the Support Systems", in Yeka Sub City of Addis Ababa, for the partial fulfillment of requirements of Master's Degree in Clinical Social Work.

I kindly request your cooperation with providing your response to the written and verbal interview questionnaires. Notes will be taken during the verbal interview and if you feel comfortable, I will use an audio-tape to record the interview for the purpose of retaining complete information.

Please be aware that your participation in this project is voluntary, and you have the right to decline from your participation any time without penalty. You can contact the data collector if you have any questions concerning this study or your right as a research participant. Your identity and anonymity as a research participant in this study will remain secure.

Your active participation and genuine response is highly appreciated!

Participant Signature: ________________________  Date: _____________________

Data Collector Signature: ______________________ Date: ______________________

**Appendix-B:**

## In-depth Interview Questions to the parents/caregivers of the autistic children

1- Gender: ______________________________________________

2- Age: _________________________________________________

3- Marital Status: ___________________________________________

4- Relationship with the ASD child: ____________________________

5- Occupation: _____________________________________________

### I- Questions on Challenges parents/caregivers experience as a result of having autistic child in the family:

1) What is your understanding of autism since you heard your child has autism?

2) How does the presence of ASD child in your family affect the family interaction, marital relationship, and family roles?

3) What challenges do you experience when you take your autistic child out into the community? (E.g. people stare, make comments, and/or misunderstand your child's behavior)? What did you feel at that time, or what actions have you taken as a result?

4) What challenges did you face as a consequence of your child's unusual behavior? (E.g. feeling as you're not able to socialize, having sense of isolation from the community, and/or be stressful).

5) How does the presence of the ASD child in your family affect your work, education, and social participation?

6) How does the presence of the ASD child in your family affect your emotional, biological, and social well-being?

## II- Questions about parents'/caregivers' access to helpful information

1) Do you have someone from your family, extended families, or neighborhood/community to tell/inform you about availability of family support services?

2. Do you have someone to tell you where you can get professional guidance on how to handle your child's behavior?

3) Do you have information about health or community services that are presently available in your locality or other Sub Cities?

## III- Questions about Social and Family support

1) Do you have someone in your family to talk about your concern regarding your autistic child?

2) Do you and your family members discuss the family's problem situation and support each other to get alleviate the stressful situation?

## IV- Questions about child care and/or daycare supports

1) Did/Do you have a babysitter to care for your child when you are at work or engage with other personal or familial commitments?

2) Is there a daycare center and/or special education facilities for your child in your community?

## V- Questions about professional support

1) Have you ever met with a therapist, social worker, or psychologist and received services?

2) Did you receive financial or material supports from the local and/or other non-governmental organizations?

## VI- <u>Questions about community support</u>

1) Were you able to meet and talk with the other parents of autistic children in your community?

## VII- <u>Questions on Families' financial needs</u>

1) Who is currently helping you with paying the expenses for food, housing, medical care, clothing, or transportation?

2) Are you able to buy special equipment or aid materials for your autistic child?

3) Who helps you to pay for your child's medication, daycare or educational expenses?

4) Were/are you able to pay for a babysitter/nursemaid?

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

**Appendix-B:**
(የአማርኛው ትርጉም)

# ማህበራዊ ሳይንስ ኮሌጅ

# ሶሳሻል ወርክ ትምህርት ቤት

## ከኦቲዝም ጋር ለሚኖሩ ልጆች ወላጆዎች ወይም አሳዳጊዎች የተደረገ ቃለ መጠይቅ

1- ጾታ ____________________________

2- እድሜ ___________________________

3- የጋብቻ ሁኔታ ____________________

4- ኦቲዝም ካለዉ ልጅ ጋር ያለዎት ዝምድና ይግለጹ ______________________________

5- መተዳደሪያ ስራዎ __________________________________________________

## ክፍል አንድ፤ በኦቲዝም ስተያዘው ልጅ ወላጅ ወይም ኣሳዳጊ በመሆንዎ የደረሰብዎትን ችግሮች በሚመለከት ጥያቄዎች

1) ልጅዎ ኦቲዝም አንዳለበት ከሰሙበት ጊዜ ጀምሮ ስለ ኦቲዝም ያለዎት ግንዛቤ እንዴት ነዉ?

2) በኦቲዝም የተያዘ ልጅ በቤተሰብዎ ዉስጥ መኖሩ በቤተሰብዎ ህብረት፣ በጋብቻ ህይወትዎ ላይ እና የቤተሰብዎ ኣባላት ሃላፊነት ላይ ምን ምን ተጽእኖ አድርጎአል?

3) በኦቲዝም ከተያዘ ልጅዎ ጋር ለአንዳንድ ጉዳዮች በማህብረሰቡ መካከል ወይም የተለያዩ ሰዎች በሚገኙበት ቦታዎች ሲገኙ ምን ምን ችግሮች አጋጥሞዎታል? ለምሳሌ (ትችት፣ የማይገቡ ቃላትን መናገር፣ በተለያዩ ምልክቶች ሃዘንን መግለጥ ወይም መሸሽ ወዘተ)

4) ልጅዎ በማህበረሰቡ ወይም በሰዎች መካከል ስለሚያሳየዉ ወይም ስለምታሳየዉ ያልተለመደ ባህሪ ሲያስቡ ምን ይሰማዎታል? ስምሳሌ፤ ማህበራዊ ህይወትን ለመኖር ብቃት ማጣት፣ ከሰው ተገልሎ መኖርን የመፈለግ ስሜት መሰማት፣ ወይም የጭንቀት ስሜት መሰማት)፡፡

5) በኦቲዝም የተያዘ ልጅ በቤተሰብዎ ውስጥ መኖሩ በስራዎ፣ በትምህርትዎ እና በማህበራዊ ህይወት ተሳትፎዎ ላይ ምን ምን ችግሮችን እመጣብዎት?

6) በኦቲዝም የተያዘ ልጅ በቤተሰብዎ ውስጥ መኖሩ  በአይምሮዎ እና በሰዉነትዎ ጤና እና በማህበራዊ ሕይወትዎ ላይ ምን ምን ችግሮችን አስከተለ?

### ክፍል ሁለት፤  ጠቃሚ የሆኑ መረጃዎችን ስለማግኘትን ለወላጆች ወይም ለአሳዳጊዎች የቀረቡ ጥያቄዎች

1) ከቤተሰብዎ፣ ከዘመድዎችዎ፣ ከጎረቤትዎችዎ፣ ወይም ከሚኖሩበት ማህበረሰብ መካከል የቤተሰብ አገልግሎት የሚሰጥ ድርጅት ወይም ተቋም ስለመኖሩ የሚነግርዎት ሰው አለ?
2) በኦቲዝም የተያዘ ልጅዎን ያልተለመዱ ባህሪዎችን እንዴት መረዳት እና መያዝ እንዳለብዎት ሞያዊ ምክርን የሚሰጥዎ ባለሙያ አግኝተዉ ያዉቃሉ?
3) እርስዎ በሚኖሩበት ክፍለ ከተማ ወይም በቅርብ የቤተሰብ ጤና ወይም የማህበረሰብ አገልግሎት ስለመኖሩ ለማወቅ የሚያስችል መረጃ አግትኝተው ያውቃሉ?

### ክፍል ሶስት፤  የቤተሰብ እና የማህበረሰብ አገግሎት ስለመኖሩ ለወላጆች ወይም ለአሳዳጊዎች የቀረቡ ጥያቄዎች

1) ከቤተሰብዎ ወይም የቅርብ ዘመድዎችዎ  መካከል በኦቲዝም ከተያዘ ልጅዎ ጋር በተገናኘ በቤተሰብዎ ውስጥ ስላለው ችግር የሚያዋዩት ሰዉ አለዎት?
2) ታማሚ ልጅ በቤተሰብዎ ውስጥ በመኖሩ ሳቢያ በቤተሰብዎ ላይ ያለውን የጭንቀት ጫና ለመከነስ እርስዎና የቤተሰብዎ አባላት ስለችግሮቹ ትወያያላችሁ? እርስ በእርስስ ትረዳዳላችሁ?

### ክፍል አራት፤  የልጆች እንክብካቤ አገልግሎት ድጋፍ ሰጪ እና የቀን የልጆች ጥበቃ አገግሎት ሰጪ ስለመኖሩ ለወላጆች ወይም ለአሳዳጊዎች የቀረቡ ጥያቄዎች

1) እርስዎ ቤተሰብዎን ለመርዳት በሌሎች ስራዎች ሲያዙ ወይም  ከቤት ዉጪ መውጣት በሚያስፈልግዎት ጊዜ ታማሚ ልጅዎን የሚጠብቅልዎት ሞግዚት ወይም ረዳት በቤትዎ ዉስጥ አለዎት?

2) በሚኖሩበት ማሕበረሰብ የልጆች እንክብካቤ አገልግሎት ድጋፍ ሰጪ ወይም የቀን የልጆች ጥበቃ አገግሎት ሰጪ ድርጅት አለ?

### ክፍል አምስት፤  የባለሙያዎች  አገልግሎት ድጋፍ  ስለመኖሩ ለወላጆች ወይም ለአሳዳጊዎች የቀረቡ ጥያቄዎች

1) በኦቲዝም ለተያዘ ልጅዎ ከቴራፒ ባለሙያ ፣  ሶሳሻል ወርከር፣  ወይም ከሳይኮሎጂስት  ሞያዊ አገልግሎት አግኝተው ያውቃሉ?
2) የገንዘብ እርዳታ ወይም ለልጅዎ የቁሳቁስ እርዳታ ከድጋፍ ሰጪ ድርጅቶች ወይም ለጋሽ ግለሰቦች አግኝተዉ ያውቃሉ?

### ክፍል ስድስት፤  የማህበረሰብ ድጋፍ  አገልግሎት ስለመኖሩ ለወላጆች ወይም ለአሳዳጊዎች የቀረበ ጥያቄዎች

1) ከሌሎች በኦቲስቲዝም የተያዙ ልጆች ወላጆች ወይም አሳዳጊዎች ጋር ተገናኝተዉ ስለ ልጅዎ የጤና ሁኔታ እና በዚህም ሳቢያ በቤተሰብዎ ላይ ስለ ደረሰው ችግር ተወያይተው ያውቃሉ?

## ክፍል ሰባት፤ <u>በኦቲዝም የተያዘው ልጅ ቤተሰብ የገጠመው የገንዘብ እጦት ስለመኖሩ ለወላጆች ወይም ለአሳዳጊዎች የቀረቡ ጥያቄዎች</u>

2) ለእርሶ እና ለቤተሰብዎ አባሎች ለምግብ፤ ለልብስ፤ ለህክምና፤ ለቤት ኪራይ እና ለትራንስፖርት የሚያስፈልገውን ወጪ ለመሰሸፈን የሚረዳዎት ማነው?
3) እርስዎ በኦቲዝም ለተያዘ ልጅዎ ጠቃሚ የሆኑ ወይም እገዛ የሚሰጡ ቁሳቁሶችን ለመግዛት የገንዘብ አቅም አለዎት? (ለምሳሌ የሚፈልገውን ነገር ለመጠየቅ ወይም ለማመልከት የሚያስችል)
4) በኦቲዝም ለተያዘ ልጅዎ ለህክምና፤ ለቀን ውሎ ጥበቃ አገልግሎት፤ እና ለትምህርት ቤት ክፍያ የሚረዳዎ አለ?
5) እርስዎ በኦቲዝም ለተያዘ ልጅዎ ሞግዚት ለመቅጠር የሚያስችል የገንዘብ አቅም አለዎት?

## ስለ ተሳትፎዎ አመሰናለሁ!!!!

**Appendix-C**

## Questions about the Parents/Caregivers & Services Provided to the ASD Children

**1)** Gender: Female _______ Male ______

**2)** Age: 21-25 _____, 26-30 ______, 30-35 _____, 36-40 _____, 41 and above ______

**3)** Education: High School Graduate ______, Diploma _____, Bachelor's ______, Other _________________

**4)** Marital Status: Single _____, Married _____, Divorced ______, Widowed ______

**5)** Occupation: Employed ____, Retired _____, Self-employed ____, Out of Work ____,

**6)** In what range is your family monthly income?

☐ 2,000 Birr or less

☐ 2,001 - 4,000 Birr

☐ 4,001 - 6,000 Birr

☐ 6,001 - 8,000 Birr

☐ More than 8,000 Birr

**7)** Your relationship with the autistic child? __________________

**8)** At what age did your child get autism diagnosis service? __________

**9)** Please select gender of your ASD child

☐ Male
☐ Female

10) Which professional provided autism diagnosis for your autistic child?

☐ Pediatrician,
☐ Neurologist,
☐ Psychiatrist
☐ Other: _____________________________________________________________

11) Do/did you receive any of the following services for your autistic child?
☐ Behavior Therapy/ABA
☐ Speech Therapy
☐ Occupational Therapy
☐ Physical Therapy
☐ Social Skills Training
☐ Parenting Skills ☐ None

11) Did/does you ASD child receive professional services from the following?
☐ Psychologist
☐ Psychiatrist

12) Are there formal support networks for ASD in your neighborhood?

☐ Yes
☐ No
☐ Don't Know

13) If available, did you get the chance to participate in any of the support groups?
☐ Yes
☐ No

14) Do you have disability support for your ASD child?
☐ Yes
☐ No
☐ I do not know

Thank you for your participation!

## Appendix-C:
(የአማርኛው ትርጉም)

## ማህበራዊ ሳይንስ ኮሌጅ

## ሶሳሻል ወርክ ትምህርት ቤት

## ስለ ወላጆችን ወይም አሳዳጊዎች እና ከኦቲዝም ጋር የሚኖሩት ልጆቻቸው ስላገኙት የህክምና እገልግሎት በተመለከተ የተደረገ ቃለ መጠይቅ

1) ጾታ፤ ወንድ ______________ ሴት ___________________

2) እድሜ፤ 21-25 _____, 26-30 ______, 30-35 _____, 36-40 _____, ከ41በላይ ______

3) የትምህርት ደረጃ፤ ሁለተኛ ደረጃ ያጠናቀቀ _______፣ ዲፕሎማ _______፤ የመጀመሪያ ዲርሪ _____፣ ሌላ ____

4) የጋብቻ ሁኔታ፤ ያገባ ___________ ፤ ያላገባ ___________፤ የፈታ ________________

5) የስራ ሁኔታ፤ ተቀጥሮ የሚሰራ _____ ፤ በግል ስራ የሚተዳደር ______ ፤ ጡረታ የወጣ ______፤ የማይስራ ____

6) የቤተሰብዎ የወር ገቢ ከታች ከተጠቀሱት የገንዘብ መጠን መካከል ከየትኛው ጋር ይዛመዳል?

☐ 2,000 ብር ወይም ከዚያ በታች

☐ 2,001 - 4,000 ብር

☐ 4,001 - 6,000 ብር

☐ 6,001 - 8,000 ብር

☐ ከ8,000 ብር በላይ

7) በኦቲዝም ከተያዘዉ ልጅ ጋር ያለዎትን ዝምድና ይግለጹ

____________________________________________

8) ልጅዎ ስንት አመት ሲሆነው የኦቲዝም ምርመራ አገልግሎት አገኘ ?_____________________________________

9) በኦቲዝም የተያዘ ልጅዎ ጾታው ምንድነው? ወንድ ____________________ ፤ ሴት ____________________

10) ለልጅዎ የኦቲዝም ምርመራ አገልርሎት የሰጠውን ባለሞያ ከታች ከተዘረዘሩት መካከል ይምረጡ?

☐ የህጻናት እስፔሻሊስት

☐ የነርብ እስፔሻሊስት

☐ የአይምሮ ሃኪም

☐ ሌላ ________________________________________

11) ከታች ከተዘረዘሩት መካከል ለልጅዎ የትኞቹን አይነት የህክምና እርዳታዎች እያገኙ ነው ወይም አግኝተው ያውቃሉ?

☐ ቢሄቪየር ቴራፒ
☐ ስፒች ቴራፒ
☐ ኦኪፔሽናል ቴራፒ
☐ ፊዚካል ቴራፒ
☐ ሶሻል ስኪል ቴራፒ
☐ ፓረንቲንግ ስኪል
☐ ምንም አይነት አላገኘሁም

12) በኦቲዝም የተያዘው ልጅዎ ከዚህ በታች ከተጠቀሱት ባለሞያዎች ሙያዊ አገልግሎት ይቀበላል? ወይም ተቀብሎ ያውቃል?

☐ የስነ ልቦና ባለሙያ
☐ የአይምሮ ሃኪም
☐ ኦኪፔሽናል ቴራፒ

13) በምትኖርበት ማህበረሰብ መካከል ከተለያዩ ሰዎች ጋራ በተናጠል ወይም በህብረት ማህበራዊ ግንኙነት እና ተሳትፎም እንዲኖርህ የሚረዳ አገልግሎት አለ?

☐ አዎን አለ
☐ የለም
☐ ስለዚህ ነገር አላውቅም

14)ካለ፤ እርስዎ ተሳትፎ ለማድረግ ሞክረው ያውቃሉ?

☐ አዎን
☐ አልሞከርኩም

15) በኦቲዝም ለተያዘው ልጅዎ  መንግስታዊ ወይም መንግስታዊ ካልሆነ አካል ድጋፍ ወይም እርዳታን ያገኛሉ?

☐ አገኛለሁ
☐ አላገኝም
☐ አላውቅም

ስለተሳትፎዎ እናመሰግናለን !!!!!!!!!!