



**ST. MARY'S UNIVERSITY SCHOOL OF GRADUATE STUDIES  
INSTITUTE OF AGRICULTURAL AND DEVELOPMENT STUDIES MASTERS  
PROGRAM IN SOCIAL WORK**

**FAMILY EXPERIENCE OF COPING AND ADAPTATION FOR  
HAVING CHILDREN WITH AUTISM SPECTRUM DISORDER: THE  
CASE OF JOY AUTISM CENTRE**

**BY: EMEBET GEBRE**

**JULY, 2023,  
ADDIS ABABA, ETHIOPIA**

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**A THESIS SUBMITTED TO ST. MARY'S UNIVERSITY SCHOOL OF GRADUATE  
STUDIES INSTITUTED OF AGRICULTURAL AND DEVELOPMENT STUDIES  
MASTERS PROGRAM IN SOCIAL WORK.**

**JULY, 2023  
ADDIS ABABA, ETHIOPIA**

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## **DECLARATION**

I'm Emebet Gebre by declare that this thesis entitled of Family Experience of Coping and Adaption for Having Children with Autism Spectrum Disorder the Case of Joy Autism Center.is my own paper work and that it has not been submitted before anywhere either at master's level or undergraduate for any award. Any information used from other works has been acknowledged.

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Date- July 2023

## **ENDORSEMENT**

This is to certify that Emebet Gebre carried out this research project work on the topic entitled Family Experience of Coping and Adaption for Having Children with Autism Spectrum Disorder the Case of Joy Autism Center and submitted in partial fulfillment of requirements for the degree masters of Social Work complies with the regulation of the University and meets the accepted standards with respect to originality and quality.

Name of advisor: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

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## **ABSTRACT**

*The research study focuses on family experience of coping and adaption for having children with autism spectrum disorder the case of joy autism center. The study adapted the qualitative approach and the research design adopted for this study was phenomenological research. To achieve the objective of the study from the total populations 89 families out of those, 15 responses were valid for analysis. The samples of the study were selected through none probability sampling method with purposive sampling was used for the study. In-depth interview, open ended questionnaire and observation were used to obtain primary data collection and thematic analysis was used to analyze the data. The results of the interpretive phenomenological analysis containing nine themes indicated those families' perceptions towards the cause of autism were based on spiritual explanations such as devil spirit and evil eye possessions. All of the families were not aware of autism before receiving the diagnosis and most of the perceptions of families were influenced by family members, neighbors and friends. The main challenges of families found in this study were psychological problems, difficulty to manage the family unit, economic strains, social stigma and labeling and lack of access to facilities and services for their children. Multifaceted social stigma and labeling, lack of facilities, services and lack of formal and informal support systems were the most pressing issues that impacted on the psychosocial and financial wellbeing of the families which aggravated their challenges in taking care of their children with autism. Based on the finding of the study, it was recommended that the involvement all segments of a society and the government is imperative to provide holistic support for families, their children and the whole family.*

**Key words: Family, Autism, Joy Autism Center, challenges.**

## **ACRONYMS**

CASD: Coping Autism Spectrum Disorder

FGD: Focus Group Discussion

ASD: Autism Spectrum Disorder

# CHAPTER ONE

## INTRODUCTION

This chapter starts by presenting the introductory part of the research and focus on background of the study, definition of operational and theoretical terms, statements of the problem, research questions, and objective of the study, significance, scope limitation and organization of the study

### 1.1 Back ground of the Study

In recent years, there has been growing concern about a Disconnect between researchers and the autism community (autistic people, their parents and family members). It has been shown that there is a large gap between research priorities identified by academics and funding bodies, and those identified by autistic people and their family. While the majority of funded research focuses on basic research into biology, brain function and cognition, the autistic community would prefer more research on aspects related to day-to-day living situation, such as improving services and developing programmers to enhance individuals' life skills (Snowy et. al, 2018).

Coping skills, or the use of coping mechanisms, can be defined as any labor or actions emotional, cognitive, or behavioral that aim to mitigate stressful events or emotional reactions (Zablotsky et.al, 2013). Research has shown that coping strategies that are appropriate and tailored toward addressing the unique stressors that parents with children who have ASD, alongside adequate support from extended family, friends, and community, leads to a reduction of parental stress and other mental health pressures (Miranda,2019). While the research is clear on the need for coping skills to be present, there is little to no research that measures why some parents can effectively reduce their parental stress to subclinical levels while many others do not. The inclusion of parents in treating children who have ASD may provide insight if there is a reduction of any parental stress or mental health issues.

Child rearing a child with a formative inability is greatly challenging compared to parenting a non-disabled child. Parents raising a child with a formative inability such as, Extreme autism face various challenges in overseeing the normal parental errands with the extra duties postured

on them due to the circumstance of their child. Autism may be a complex formative condition that's characterized by disabilities in two areas; social communication, and limited, monotonous conduct or interface (The American Psychiatric Association, 2013). Autism spectrum disorder is ordinarily to begin with analyzed in childhood with numerous of the most-obvious signs displaying around 2-3 a long time ancient, but a few children with extreme in autism create regularly until toddlerhood when they halt procuring or lose already picked up aptitudes (APA, 2018).

Agreeing to World Wellbeing Organization, based one epidemiological think about conducted over the past 50 years, the predominance of Autism spectrum disorder (ASD) shows up to be expanding around the world. The conceivable clarification for its developing rate incorporates made strides mindfulness, development of demonstrative criteria, superior symptomatic instruments and progressed announcing (World Health Organization, 2019). It shows up from the writing that children with ASD who are transitioning to adulthood frequently involvement negative results related with work, socialization, college to get, and community integration See (Chen et.al, 2018; Shattuck et.al, 2020).

This significant number of children analyzed with Extreme autism implies an increment within the number of families and caregivers uncovered to the burden of care. Extreme autism regularly forces a noteworthy passionate and financial burden on individuals with these clutters and their families. Particularly, caring for children with extreme frame of the condition may be requesting where get to administrations and back is inadequate (WHO, 2019). In Ethiopian setting, where elective childcare frameworks are not created, families, mainly mothers are the most sources of back for their children's by and large advancement (Woldegebreal, 2014). Women raising children with extreme autism range clutter in creating world, have a complex and amazingly challenging life compared to the created world.

In spite of the fact that there are archived thinks about that expressed the significant effect of caring for a child with ASD, most of the inquiries about on the issue stems from western social orders, especially the UK and USA (Gobrial, 2018). Subsequently, advance considers are required in arrange to way better get it the encounters of families, in raising children analyzed with an Extreme autism.

## 1.2 Statement of the Problem

The challenges and the difficulties faced by parents of children with autism can be multifaceted especially in traditional and less developed communities as there are lack of awareness and limited resources (Harris & Weiss, 2007). In most families, the complexities of autism can have devastating effects on parents of children with autism especially on the mothers, because they are the most significant and primary care providers in the children's daily lives and typically portrayed next to the child. Sometimes as a main caregiver, their role can be assumed to be even more important than a professional (Shaugee, 2017). Hence, mothers of children with developmental disabilities such as Autism encounter additional obstacles and stressors as they have to redefine their journey of parenthood once their child is diagnosed with Autism (Matenge, 2013).

Based on the background information, the research problem stems from the lack of continued programming and services after a child with ASD enters adulthood and large crevice in individualized benefit arrangement, Encourage, subjective investigate centering on in-depth, wealthy techniques is missing. Most of these consider were planned to get it common standards and were not custom-made to recognize person contrasts that contribute to victory or disappointment transitioning to adulthood with ASD (Robertson, 2018).

Autism spectrum disorder, extra impediments and stressors as they have to be Rethink their travel of parenthood once their child is analyzed with Extreme autism (Matenge, 2013). Moms are one of those confronting noteworthy challenges. Such as, way of life alters misfortune of salary and relaxation time, trouble in terms of communication, diminished time and capacity to lock in social exercises and end of business or restricted career movement (Beecham 2007).

This may lead the mother to feel more stressed than commonplace approximately their child rearing ability and increment sentiments of blame and stretch. In expansion to being an essential caregiver, a few researchers contended that there are different reasons for the burden of moms in taking care of a child with extreme autism For instance, Aadil, Unjum, Afifa, and Zahoor (2014), contended that, the possible variables that are related with moms expanded burden within the families of children with extreme autism incorporates nonattendance of casual and proficient bolster, sentiments of misfortune of less created nations' specially in African social orders, in

expansion to need of administrations for children and families, need of information come about in numerous negative results for guardians and children.

For occurrence, in a Zambian think about by Joachim and Robert (2012), Several parents detailed that the burden of duty for their child on the range was exacerbated by unsympathetic comments from the general public which appears that numerous individuals are not mindful of the condition, consequently, stigmatizing both the child and the parents, caregivers of children with incapacities, who are basically moms or grandmas, are subjected to push within the shape of physical conditions as a result of separation from the society. Additionally, in Ethiopia more than 80 % extremely introverted cases confront social stigma (Getnet, 2013).

Studies on experiences of mothers of children with different disabilities show that appropriate psychological support is a necessity for the family of a child with a disability (Barbosa, 2008). It is also crucial that the professionals, family, friends and others who are unaware of the impact of autism on the children and their parents are well informed (Woodgate, 2008). As it is also indicated in the WHO (2011), world report of disability, one of the main obstacles that hinder the establishment of efficient support programs for parents of children with Autism in developing countries, is the lack of studies that can inform about the impacts of raising children with autism on their parents and lack of adequate number of centers and trained staff.

Therefore, it was found imperative to conduct this study in order to fill the above-mentioned gaps through exploring the experiences of family experience of coping and adaption for having children with autism spectrum disorder the case of joy autism.

### **1.3. Objective of the study**

#### **1.3.2 General objective of the study**

The main objective of this study was exploring family experience of coping and adaption for having children with autism spectrum disorder the case of joy autism.

#### **1.3.3 Specific objective of the study**

1. To identify family experience of coping and adaption for having children with autism spectrum disorder.
2. To identify the recognitions of family almost the causes of extreme Autism in their children some time recently the determination.

3. To investigate the challenges of family experience of coping and adaption for having children with autism spectrum disorder in raising children diagnosed with Autism.

#### **1.4. Research Questions**

The following research questions guided this study;

1. What are the family experience of coping and adaption for having children with autism spectrum disorder?
2. What are the recognitions of family? almost the causes of extreme Autism in their children some time recently the determination?
3. What are the challenges of family experience of coping and adaption for having children with autism spectrum disorder?

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

In children with autism, addressing familial and social issues related to supporting children and their parents are important areas of concern. It is crucial to study the Lived experience of family of children with Autism, nationally and internationally, in order to inform the policy and legislative process and provide holistic support for children and families. It's also considered may help experts by giving them diverse point of view and experiences to better arrange directing and other intercession programs based on the requirements of children and caregiver. It too serves as reference and a standard data for legislative organization, non-governmental organization, program designers, approach producers, and worldwide organizations, to create fitting care and frameworks and mediation programs to bring almost economic changes to in to the lives of families and children.

#### **1.5 Scope of the study**

This study intended to address the lived experiences of parents who have children with ASD transitioning to adulthood. There was a gap in service provision once children transitioning to adulthood were no longer eligible for secondary school entitlement programs. In addition, the sample size was small 12 to 15 and only included parents who had children with a formal ASD diagnosis. This provided a more credible depiction of the phenomenon that was in-depth and thick with qualitative descriptions of the experience. The initial recruitment and data collection



process included partnering with an organization that provides support for people with ASD and their families.

## **1.6. Limitation of the study**

There were multiple challenges that were address while conducting this study. First, in qualitative research the research was the primary data collection instrument and has the potential influent and has the potential to influence the process and results of a study (See Patton, 2015). Transparency throughout the research process must be obvious to address subjective views that could affect the trustworthiness of the results. These biases must be addressed during all parts of the writing process. To address the researcher positional as the primary instrument of the study, a phenomenological framework was employed. Documentation was through journaling and memos prior to the research and throughout the recruiting, interviewing, data analysis, and result stages. This documentation strengthened the trustworthiness of the results by identifying accuracies and inconsistencies between participants based on the interpretation of the researcher experience.

## **1.7. Operational Definition of Terms**

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

**Family** – Biologically or caregivers of children (below 18 years), whose children were diagnosed with autism

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

**Buda:** if family having children with autism, families believe that the causes of autism is that Buda.

## **1.8 Organization of the study**

The study was organized to five consequential chapters. The first chapter was deal with the introduction part of the paper encompassing background of the study and, statement of the problem, objectives of the study and other relevant issues. The second chapter was focus on relevant literature review. In this chapter a review the relevant literatures in relation to the topic

under discussion will be made. The third chapter deals with research Method's; that was, the research design, approaches used throughout the data collection and analysis processes were discussed. The fourth chapter was that the major finding of the study, and the fifth chapter was also conclusion recommendation and future research direction.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1. Theoretical Review**

##### **2.1.2. Definition of Autism-**

Autism is a pervasive neuron developmental disorder characterized by impairments in social communication and restricted, repetitive patterns of behavior, interests or activities (APA, 2013). Autism begins in childhood and tends to persist into adolescence and adulthood but most cases of the disorder are apparent during the first 5 years of life (WHO, 2019). Usually, Autism is first diagnosed in childhood with many of the most-obvious signs revealed around 2-3 years old, but some children with autism develop normally until toddlerhood when they stop acquiring or lose previously gained skills. Already the Symptomatic and Factual Manual of Mental Disarranges IV, the handbook utilized by wellbeing care experts within the Joined together States and much of the world as the definitive direct to the determination of mental clutters, characterized extreme autism as a triplet of disabilities in three ranges which were social interaction, communication and limited, dreary and stereotyped designs of behavior, interface and exercises.

Be that as it may, the unused version, DSM-V, distributed in May 2013, has clustered the social interaction and communication components into one category, in this manner producing a classification of extreme autism with two areas that are issue in social communication, and limited, dreary behavior or interface (APA, 2013). Children with extreme autism display a wide run of behaviors such as trouble to create companions with other children, to communication, to have a creative play and to talk at all. Other signs more over in corporate fixations; fears; a need of awareness of threat; ceremonial). Early diagnosis, Screening and evaluation are essential for the child and the parents of children with autism to ensure that these children access the services and supports they need.

#### **2.2 Coping and Adaption for Having Children with Autism Spectrum Disorder**

Coping skills, or the use of coping mechanisms, can be defined as any labor or actions emotional, cognitive, or behavioral that aim to mitigate stressful events or emotional reactions

(Zablotsky, 2013). Research has shown that coping strategies that are appropriate and tailored toward addressing the unique stressors that parents with children who have ASD, alongside adequate support from extended family, friends, and community, leads to a reduction of parental stress and other mental health pressures (Miranda, 2019). While the research is clear on the need for coping skills to be present, there is little to no research that measures why some parents can effectively reduce their parental stress to subclinical levels while many others do not. The inclusion of parents in treating children who have ASD may provide insight if there is a reduction of any parental stress or mental health issues.

The diagnosing Extreme autism requires a comprehensive, precise, and organized approach. Other than assembly the objective of recognizing the clutter, the symptomatic evaluation gives critical data on the child's relative qualities and shortcomings distinguishes which maladaptive behavior and comorbid troubles is display, clarifies the effect of the child's condition on the family, and benchmarks the formative abilities of the persistent. The determination of Extreme autism incredibly shifted between created western nations and creating moo- and middle-income nations. Because it is considered to a great extent a clutter of children living in Western Industrialized Nations with tall innovative improvement and may be unprecedented among African Children (Sanua,1984). Generally, children with Autism in Africa tend to be diagnosed in late ages, when they are severely affected; at the level when they speak few or no words, require substantial help with e

veryday tasks such as eating or going to the bathroom etc. Thus, efforts about Autism are just beginnings to bring the condition into open (Zeliadt, 2017).

(Dzunay,2011). According to world population review, tracking the rates of autism around the world is a bit of a challenge because many nations do not track or report their autism rates. There are also no specific, uniform criteria for assessing autism. Even if there were, there are many nations that do not have the resources to condition the diagnosis of autism poses particular challenges for healthcare professionals (HCPs) as, in common with other neurodevelopmental disorders and most psychiatric disorders as there are no biomarkers utilized in clinical practice (Huerta&Lord,2012).

### **2.3. Family belief about Causes of Children's Developmental Disability:**

To examine parents' audits of their circumstance as caregivers of a child with ASD is to investigate their clarifications and understanding of this determination. Within the

nonappearance of conclusive data on the causes and treatment of ASD, most guardians of children with ASD create their own discernments of the cause (Gona, 2015). Concurring to different thoughts about, clarifications given for the cause of extreme autism changed over distinctive nations. Families from well created nations rise more consistent and closer to logical clarifications, whereas families from less created and creating nations particularly from Africa raise more social and non-scientific clarifications. For instance, A ponder within the Joined together States by Harrington, Patrick, Edwards, and Brand (2006), on Parental convictions around extreme autism on 62 families of influenced children found that lion's share of guardians gave logical clarification for the cause of their child's.

In expansion to guardians, a consider investigating the conclusion of Healthcare laborers in Nigeria that surveyed the conclusion of healthcare laborers on etiology of ASD archived an awfully critical extent of healthcare specialists detailed supernatural and extraordinary etiological components for extreme introverted ness such as ancestry curses, foes, and activity of the demon, among others. Assist, a study by Anthony (2009), conducted in Ghana which given a see at the understanding of extreme introverted ness found that guardians particularly moms, were fault for their child's side effects either by not giving quality pre-birth care, a failed abortion attempt involving ingestion of tonics and experiencing some illness or accident during the course of their pregnancy as the cause for autism. Likewise, a phenomenological study by Nyoni and Serpell (2012), in Zambia uncovered that a few families credited the cause of ASD to witchcraft and/or noncompliance to traditions and conventional standards in marriage. The analysts advance clarified that such thought leads to family clashes on sexual orientation parts, marriage connections, destitute parental care and dissent of the child's condition by guardians especially by the father primarily in case the child with Extreme introverted ness could be begin with born child who is prized customarily.

Another subjective think about from Kenya conducted by Gona and his colleagues (2015), that investigated guardians recognitions utilizing 103 members counting guardians, uncommon needs instructors, clinicians, and social laborers from different social foundation found that lion's share of members in their ponder related ASD with Supernatural causes that included witchcraft, fiendish spirits and In Ethiopia, a think about conducted by Tilahun and his colleagues (2016), investigating the viewpoint of 102 caregivers, which most of them were moms, demonstrated that more than half of the members as often as possible cited extraordinary clarifications for the

cause of extreme introverted ness counting soul ownership, a wicked act; a coordinate result of the caregiver's transgression, discipline from God, fiendish eye or "buda" (a spell cast by the eye, incurring damage or mishap on the individual being looked) and revile or bewitchment (hurt dispensed by mysterious acts or extraordinary powers affects by another individual or by extraordinary creatures (Hoekstra,2016). Parents' convictions around Extreme introverted ness shape their explanation of signs manifestation, the time that they take to seek out intervention, and the type of intervention they decide to have for their children (Ravindran& Myers, 2013).

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

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

Family reaction to the Extreme autism determination is distinctive from one parent to another. A few thinks about have particularly centered on investigating parental response when they at first hearing the news that their child has extreme introverted ness since parents' encounters at the time of the determination foresee future adjustment to the range, parental push, and parents' data needs (Murphy and Tierney, 2006). A extend of considers explored the mother's reactions to the child's determination, for occurrence, a think about, almost the mothers' reactions to their children's determination with extreme introverted ness that met 16 Family, found that responses of moms to their child's determination with extreme introverted ness was assembled into four major bunches; despondency outrage, dis-ease and relations-ship, blame and question, and disillusionment and give up (Lutz et al., 2012).

The foremost common beginning response of moms at the time of conclusion is feeling of pity and outrage highlighted whereas others detailed encountering sentiments of disgrace when

sharing the news of their child's circumstance to others (Dababnah&Area, 2013). Most guardians in these ponders uncovered that they had no information around Extreme introverted ness which driven them to destitute child rearing of the child, parental push, passionate and mental trouble, strain on the conjugal relationship and strain on connections inside the family (Glass, 2001), and this constrained information of extreme Introverted ness by guardians driven to beginning in shock and disbelief after diagnosis not knowing what course of action to take to help their autistic child and their families, including the siblings of the autistic child (Abdurrahman, 2013).

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

Extreme autism has life-time results with unextend of impacts on the wellbeing, financial prosperity, social integration and quality of life of people with the clutter, their families and possibly on the rest of society. As family environment encompasses a major part of caring, supporting, socialization and reproduction, the family frameworks are more inclined to confront different challenges (Altieri, 2006). Having child with the extreme introverted ness is impacts on different perspectives of family lives counting housekeeping, accounts, passionate and mental wellbeing of guardians, conjugal connections, physical health of family individuals, constraining the reaction to desires of other children inside the family, destitution connections, connections with amplified family, companions and neighbors and in amusement and recreation exercises (Sanders & Morgan, 1997). Too, it cans make noteworthy push all through all family individuals and makes social and communication shortfalls impact on add up to family individuals. Consequently

### **2.5.1. Overall Emotional Impact Studies on Family wellbeing**

Appears that Family guardian, who have a child with extreme autism are higher levels of parental stretch and mental trouble than Family of children without extreme autism (Dough puncher, 2000). A few variables have been proposed to account for the higher levels of push of Family with a child with extreme autism counting the instability encompassing extreme autism conclusion, the long-term guess of people with extreme autism s, the unpleasant nature of extremely introverted indications and related behavior issues, and the need of open understanding and resilience for the conduct of children with extreme autism (Giallo, Wood, Jellett&Doorman, 2013).

In conjunction with the extreme mental troubles, there's the affirmation of potential misfortune of self and family picture and business, which suggests a special child rearing encounter with distinctive desires, trusts and dreams for the child and family to what they had expected (Woodgate, Ateah&Secco, 2008). In numerous families, the Family is the essential caregiver, and this part is more common when there's a child with ASD in the domestic, Within the U.S, a think about conducted by Myers and his colleges (2009), on 493 guardians of children with extreme introverted ness found that over 70% of guardians detailed feeling pushed, noticing troubles related to conjugal strain, school battles, challenging behaviors, not being able to go anyplace. A study 127 Iranian Family by Kousha, Attar, and Shoar (2016), found that the recurrence of uneasiness and depressive indications was higher than that of the common female populace in their nation, and the children's sickness influenced all viewpoints of the Family' lives.

The conceivable reasons for the Family' more prominent trouble incorporate more noteworthy association in child raising, expanded presentation to negative social responses by pariahs and the non-appearance of business and an elective part to being the parent of a child with extreme introverted ness, concerns almost long run of their children since of the disappointment of children to recover, plus their increasing age (Gray, 2002). Moreover, the stressors that accumulated overtime together with the absence of adequate resources and support lead to depression and burnout (Morgan, 1988).

### **2.5.2. Adjustment with in the Family System Parents with autistic children**

Face with difficulties and challenges within their family which cannot be of a positive nature. Child with extreme introverted ness can have an especially negative affect on the conjugal relationship as well as on kin within the family (Meyer, Ingersoll and Hambrick, 2011). At first, the closeness between couples can be influenced due to a few variables such as maternal stretch, need of time went with by physical tiredness due to adapting and managing with the extremely introverted children practices such as fits, running around with additional every day exercises such as medicines, and on best of it, adjusting life with other non-autistic children which leads the to a critical strain on conjugal relationship over time. Study that inspected the relationship of couple having extremely introverted child found that guardians experience troubles in their conjugal relations and in complementary intelligent between family individuals (Baxter et al., 2015).



Assist, the separate rates among couples has been archived to be higher among family of extremely introverted child than guardians of regularly creating child, with separate, found that family structures of children with inabilities were reasonably comparable to those of the ordinary family and children with incapacities were more likely to live with two, hitched guardians. Another Canadian study too detailed actually transformative and fulfilling connections among couples in spite of the significant and supported stresses included in child rearing a child with incapacity. In the expansion to the strain, with spouses, the determination of extreme introverted ness might be effect on kin Guardians (Ozonoff et al.2002).

The feelings of jealousy regarding the amount of time parents spend with their brother/sister analyzed with extreme introverted ness could be a major stressor among. Due to the noteworthy needs of children with extreme introverted ness, the kin may feel as in spite of the fact that he/she is being disregarded. It may be difficult for a few guardians to adjust time with their other children on the off chance that their child with extreme introverted ness is in tall require and may require help with eating, toileting, individual cares and conduct alteration which can possess the guardians time. Consequently, the ordinarily creating child may act out in trusts to catch a few of the parental consideration (Extreme introverted ness Society, 2011).

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

With special needs is substantially more expensive than raising a child with a typical development. Research has shown that parents of children with Autism have a substantial financial burden because of two related impacts on the family budget: They win less cash and they have higher therapeutic, instructive, and care costs (Montes & Cianca, 2014). The financial effect of caring an extremely introverted child on the families is related to angles of intercession, business circumstance of guardians and other related costs (Jarbrink et al, 2003). A run of thinks about have uncovered the effect of raising extremely introverted child on the mothers' career and related budgetary burden to the family. Within the Joined together States, guardians of children with Extreme introverted ness detailed a negative affect up on their career after having a child analyzed on the extreme introverted ness range in which moms announcing direct to genuine impediments on their careers, and denied any opportunity for exterior work due to their child's inability .In addition, moms of children with Extreme introverted ness, who tend to serve as the child's case director and advocate, are less likely to work exterior the domestic. They work less hours and win 56 percent less than moms of children with no wellbeing restrictions and 35

percent less than moms of children with other disabilities or disorders (Extreme introverted ness Talks 2019).

Another, preparatory subjective inquiry about conducted on 43 Chinese families demonstrated that numerous families and moms in specific, found themselves changing their work propensities in arrange to superior meet their children's needs in numerous cases stopping their employments and moving to full-time promotion. Moreover, a consider conducted on 13 Jamaican moms detailed the effect of raising a child on the range on their career such as work intrusions, having to take off early and having to stopped their work in arrange to superior meet their children's needs (Mann, 2013). So also, prior thinks about in Sweden uncovered the noteworthy costs of raising a child with Extreme introverted ness and distinguished as the most taken a toll driver By and large, the monetary burden of care for a child with Extreme introverted ness is exceptionally significant; in spite of the fact that exact gauges that consolidate all related costs are not how ever accessible. Subsequently, in comparing the comes about from worldwide thinks about, one has to realize that the real fetched to the family changes depending on the welfare state demonstrate of the nation, its framework of wellbeing care and uncommon instruction, and the open agreement on what consumptions are parental obligation and which ones are the duty of the commonwealth (Montes & Cianca, 2014).

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

One of the deterrents people with mental disorders confront, in expansion to the cognitive and behavioral shortfalls that go with their conclusion, is the social disgrace that emerges from those with whom they associated in their social environment. In other words, their conclusion may be related with negative generalizations by the open that go past the scope of their genuine determination (Myer, 2007). Shame may be a multifaceted develop; which is defines as profoundly disparaging qualities that don't fit the standardizing desires of society and in this way result in a ruined social personality for people or bunches who have the properties

Earlier inquiries about conducted on families of children with extreme introverted ness illustrated that misguided judgments and disgrace related with extreme introverted ness are clear around the world. As a result, most guardians seen themselves to be stigmatized by their child's disorder with moms having a solid inclination to feel more stigmatized propensity to than fathers as a result of the confinements set on the mother's exercises exterior the domestic since of their child's with extreme introverted ness. In addition, the nonappearance of unmistakable markers of ASD may

contribute to shame, confronted by guardians and children as unknowledgeable others may see individual with ASD, who looks “normal,” to be acting deliberately in ways that abuse social standards (Gray 2002).

Additionally, a Mexican consider by on 50 single moms of children with inabilities by McHatton and Correa (2005), found that moms experienced critical separation as a result of culture, incapacity of the child, and a combination of culture and inability. Whether Experts or benefits suppliers and outsiders were responsible for the majority of the separation

In most cases, impaired children don't go to school since instructors are not patient with them within the standard schools and individual understudies don't get it their challenges (Lewis 2009). Moreover, a consider by Ellen and her colleagues on 15 Somali guardians of children with extreme introverted ness living within the UK, detailed that children with extreme introverted ness were named and stereotyped as ‘sick’, ‘naughty’, ‘different’ and guardians were faulted for not controlling them, driving to social dismissal and separation. Shame confronted by parents and children was related to with Africa, a child with debilitating neuron-developmental disarranges is seen as a check of disgrace on the family by the society due to misconception of the etiology of formative disarranges and related social and conventional impacts. Hence, people with ASD and their families are frequently confronted with negative demeanor, shirking, dismissal, as well as negative and hostile comments which lead families to stow away the influenced child from the society (Mashudat et.al, 2013).

Giving the colossal social disgrace and separation, guardians don't more often than not have the choice of passing in all circumstances, they have to be going up against or restrain their presentation to the stigmatizing responses of others in several ways. This, they utilize diverse methods such as segregation, limiting open experiences, overlooking or responding against such judgments through engagement with their children and with the situations encompassing their children (Hays and Butauski ,2018) and trusting in their possess guardians, kin, companions, and certain restorative experts with respect to private things. These methods are either separately or in a few combinations, give guardians of crippled children with a few degrees of security against the stigmatizing responses of others.

Offices and Administrations for Children with Extreme introverted ness and their Families The challenges and stressors related with giving administrations and caring for a child with extreme introverted ness influences families, teachers, and wellbeing experts. Guardians raising children

with extreme introverted ness require all-encompassing bolster framework that incorporates experts with the information and understanding of extreme introverted ness, a framework that can cater for early conclusion and early mediation, and a framework that's promptly accessible for the guardians and their families (Farzana, 2017). When a family is able to draw upon satisfactory assets and in the event that they see the circumstance as reasonable at that point the push of raising a child with extreme introverted ness may never lead to an emergency. Extend of considers have shown that guardians of children inabilities counting extreme introverted ness detailed the most noteworthy trouble in getting administrations and bolster programs than guardians of regularly creating child. For occasion (Tiffany,2010). Show that numerous guardians of children with this clutter within the U.S discover it troublesome to accomplish instructive arrangement or help with their children compared to those who have children with other incapacities. In most cases family's, had spent broad time attempting to discover administrations for their child with extreme introverted ness which gotten to be disappointing, unpleasant, and debilitating to a family (Altieri, 2009).

Supporting this, Dzubay (2011), expressed that guardians within the U.S, especially moms, may be incapable to return to work since childcare centers, by which many of them are beneath private proprietorship, secretly are not willing to require their children extreme autism in China in getting to administrations and bolsters for their child found that indeed on the off chance that guardians have a crave to have their children go to school, they confront dismissal from common instruction schools and it was moreover famous that extraordinary instruction schools in most ranges are constrained in China. Advance, a ponder conducted in Jamaica by Mann (2013), shown that numerous children analyzed with extreme introverted ness have exceptionally constrained get to and trouble to discover instructive offices, break care, suitable instructive settings for their child and most teachers and schools in Jamaica are greatly under-prepared for supporting the wants of children with extreme introverted ness and require the generally tall costs of teaching a child.

The non-availability of child wellbeing care and instruction administrations and the destitute get to the few accessible ones which are concentrated within the urban regions makes it troublesome for families of African children with Extreme introverted ness to urge those fundamental intercession and instruction programs (Mashudat et.al, 2013). Supporting this, thinks about from Egypt demonstrated that caring for a child with Extreme introverted ness can be overwhelming

and overpowering for moms, due to the administrations for children with incapacities in common, and administrations particularly planned for children with Extreme introverted ness in Egypt, are negligible or in deed truant. Children with extreme introverted ness and their families confront the probability of destitute wellbeing, social care, and mental wellbeing. A few reports from Ethiopia too found that most guardians have no exact and up to date data approximately their children's formative clutter since the benefit framework is frequently restricted and divided that it is exceedingly improbable that there will be any single source of data that can tell guardians of extremely introverted children all they have to be known at any inspected psychosocial well-being among guardians of children and youthful grown-ups with extreme introverted ness and found that outrage and uneasiness in guardians were contrarily relative to social bolster. The aggregate comes about of a few considers out lined that guardians who gotten bolster related way better sincerely to their children whereas guardians who gotten moo social back was found to have misery and uneasiness side effects. The over checked on literary works shown that guardians, especially, moms.

## **2.6. Theoretical framework**

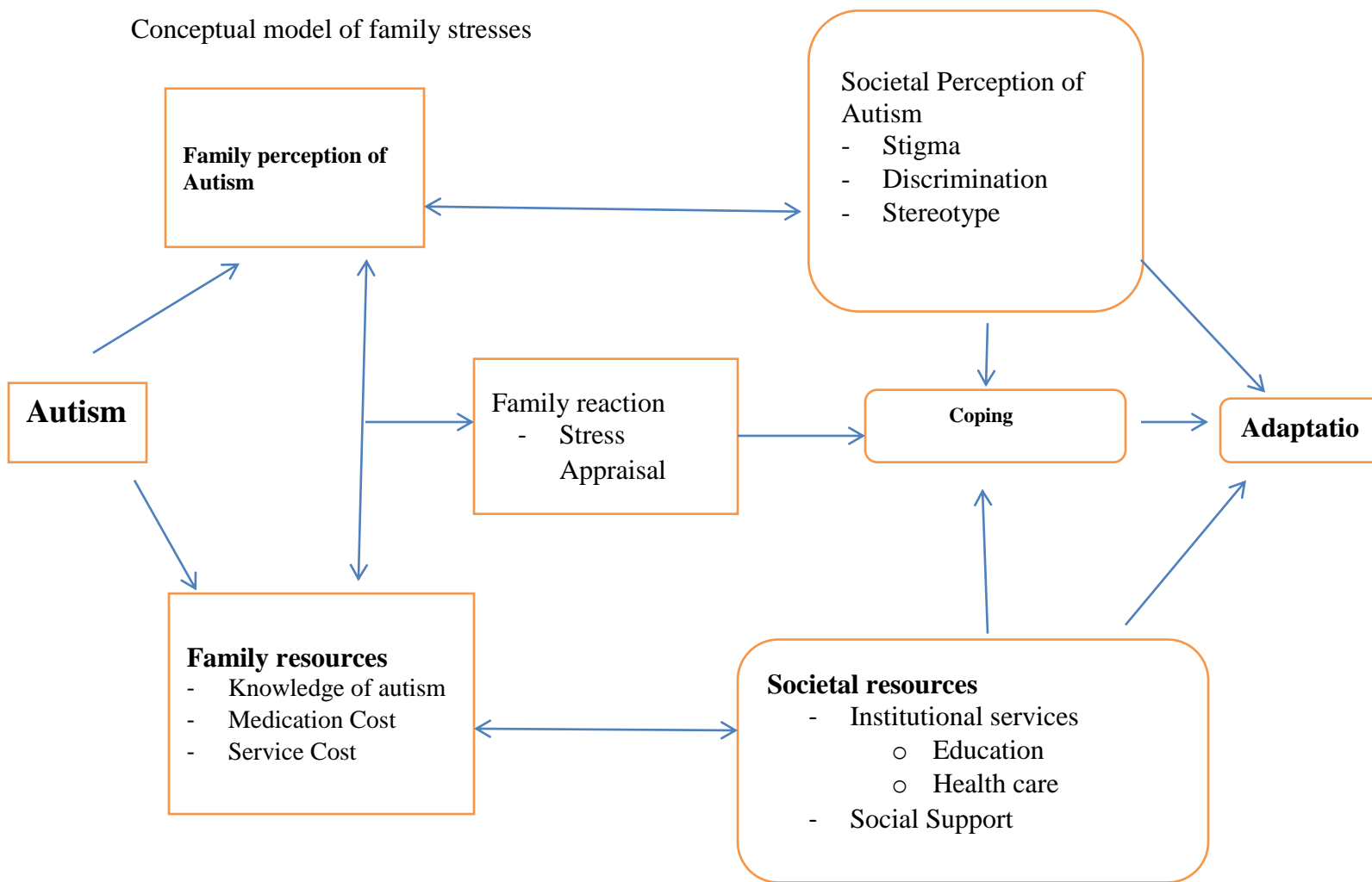
I utilized environmental frame works hypothetical system created by Bronfenbrenner (1979), for the reason of this ponders. This hypothesis sets that children's improvement is intensely affected by the settings or situations they create with in (Bronfenbrenner, 1979). More particularly, Bronfenbrenner (1979) expressed that there are five imperative frameworks (the microsystem, mezzo system, environment, microsystem, and the chrono system) that impact and are impacted by the child's behavior and the fore most critical framework is the family which incorporates parent-child subsystems. The microsystem is the level where intelligent and impacts are inside quick settings and incorporate the child's quick connections with family individuals, caregivers and school, peers. The impacts of these frameworks are bi-directional in that not as it were do the guardians influence the child's convictions and behaviors, but the child moreover impacts the behavior and convictions of the parent

At this level, impacts are most grounded and have the most prominent effect on the Mesosystem is the layer that includes the association between two or more microsystems structures of the child's (e.g., the family and the school, peer and family, family and community) that influences the child. In case of usually parent association with the school instructor, On the off chance that

the parent effectively takes part in communication with the educator and school. The general development of the child is impacted Ecosystem relates to the linkages that will exist between two or more settings by implication affecting the child’s advancement (e.g., parental career components). Biological system characterizes the bigger social framework in which the child does not work straightforwardly. But, the impacts of child’s Improvement by collaboration with a few structures are their microsystem. The child may not be specifically included at this level, but does feel the positive or negative constrain included in their framework (Berk, 2000; Paquette & Ryan, 2001). For illustration, social teach such as community back and wellbeing administrations, world of work and mass media that work on the layer (Petra, 2012) in a roundabout way influence the child with Autism and the parent

## 2.7 Conceptual Model

Conceptual model of family stresses



## **CHAPTER THREE**

### **RESEARCH METHOD**

#### **3.1. Description of Study Area**

This study was conducted in Addis Ababa family experience of coping and Adaption for having children with Autism Spectrum Disorder the case of Joy Autism Center. The capital city was Addis Ababa. The culture and conventions of the nation hold family as a critical portion of Ethiopian Life. Persons with disability do not have access to rehabilitative services. Because, the in availability of such service and due to the low level of attention given to developmentally disabled groups by past regimes and the present government. The researcher come to the family through this organization since both of the organizations work with children with extreme autism and their families which gave me the opportunity to discover My deliberate to contact these organization was in arrange to ease the method of the investigate in finding the family not to require the organizations as a case of study. Nia foundation Joy autism center was one of the autism centers in Ethiopia Kirkos sub-city woreda 23 kebele 10, around Vatican Embassy. the founder of the origination is Zemi Yenuse. It is a non-profit and non- governmental organization was established in 2011 in Addis Ababa.

#### **3.2. Research Approach**

This study explores the lived experience of family raising children diagnosed with autism range utilizing qualitative study. The qualitative study was choosing for this study since it made a difference to secure “in-depth understanding” almost certain through investigation rather than estimation (Bernard, 2008). The center of qualitative inquire about is to discover clarifications for questions such ‘what’, ‘how’ or ‘why’ of an event (Green &Thorogood, 2014). Qualitative research investigates a phenomenon considering the context of people’s everyday lives and it acknowledges multiple truths and person’s interpretation of their experience (Goldman & Du Mont, 2001).

The process in qualitative research the lived experience of family raising children diagnosed with autism approach involves identifying research question, collecting data from participants, analyzing data inductively from responses to themes, and interpreting the data by the researcher

(Creswell, 2014). Qualitative approach provides non-numerical data in the form of interview response, observation, field notes (Lunenborg & Irby, 2008). It permits a more noteworthy adaptability and suddenness or instinctive nature and adjustment of the interaction between the analyst and the study members (Bryman, 2016) and endeavors to get it and clarify the world from participants' focuses of see (Draper, 2004).

### **3.3. Research Design**

According to Akhtar (2016), research design is the conceptual blueprint that guides the direction of research. It involves the use of specific research methods and tools for data collection and analysis, based on an underlying philosophical assumption. I chose a Phenomenological research design, because it was the fore most fitting strategy to meet inquire about point of investigating the recognition, and challenges of family raising children analyzed with extreme autism. One of the approaches of qualitative investigate was phenomenology which I utilized in this consider. Phenomenological approach clarifies the lived encounters of people around as lived by the people themselves (Creswell, 2014).

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

The initial recruitment and data collection process included family with an organization who provides support for people with ASD and their family. In this way, the individuals of this consider family who has lived experiences in raising children analyzed with extraordinary autism. This method centers on candidates who share comparative characteristics or particular characteristics. Specifically, phenomenological consider being purposive and as a little measure can give an adequate information on a given wonder I initially had an intended sample size of 12 to 15 participants. Mason (2010). Phenomenological studies indicated that generally between five up to 25. But, no less than six. The number of participants will choose because it appeared to be a feasible group to recruit and interview within a reasonable time with only one researcher. In expansion Phenomenological considers regularly include conducting person interviews with little sizes or single case study (Mann, 2013).

### **3.5. Method of data collection**

In this study, an in-depth interview was used as data collection method. An in-depth interview is one of the primary methods of data collection use in qualitative research (Bryman, 2016). it is



interactive in nature and the material is generated by the interaction between the researcher and interviewee (Bryman, 2012). Individual interviews were most appropriate in social research when the area of investigation involves gathering information based on peoples' life experiences and feelings and information based on privileged, personal and sensitive issues.

An in-depth interview guide was prepared in a way that addresses the objectives of the study. The guide was originally prepared in English and later translated into Amharic, the official working language of Ethiopia, for the convenience to conduct the interview assuming that the native language of participants was mostly Amharic. The English version was prepared first to communicate the contents of the guide with the research supervisor. Back translation from Amharic to English was finally made by research and other language translators with the objective of ensuring the clarity and accuracy of the questions of the interview. Open ended questions were used in the interview which gave participants the opportunity to tell about their experiences using their own words and expressions rather than forcing them to choose from fixed set of responses. This was helpful to acquire detailed data and make the study exploratory in nature. The questions were formed based on the interviews of other previous researches with similar research topic, and by discussing with research supervisor.

### **3.6. Method of data Analysis**

The analysis was used to analyze data generated from the interviews and researcher notes. The analysis is appropriate because the raw data will unfold and provide patterns identified through codes, categories, and themes which will assign meaning to the daily experiences (Saldana, 2015). Analysis is appropriate for phenomenological approaches. Because the process attempts to explore the life story, beliefs, experiences, and constructs and assigns meaning to the phenomenon by creating common themes (Saldana, 2015). The main analysis provided credibility to the research because it is an established method applied to phenomenological frameworks. Research credibility refers to the plausibility of the study and is accomplished by creating reliability, accuracy, and consistency (Tracy, 2010). In addition, dependability and conformability was strengthened through an external expert versed in phenomenological design and thematic analysis who was audit the research data, memos, journals, and analysis results. This provided a layer of transparency to the analysis process.

## **3.7. Issues of Trustworthiness**

### **3.7.1 Credibility**

Research credibility associated with qualitative inquiry must include strategies to prove dependability, transferability, and conformability that validate the trustworthiness of the reconstructed research results (Morse, 2015). To create credibility, I provided prolonged engagement and member checks with participants throughout the interview process, once interviews were transcribed, during data analysis, and after the results were synthesized. Further, peer-debriefing by my chair and committee was paramount to the accuracies of my interpretations and processes. Transferability was achieved through thick description of the data specific to the participants and their contextual experience (Korstjens&Mosher, 2018). Triangulation was achieved through peer debriefing from other researchers, participants, and outside expert auditors and review boards to confirm or question accuracy and interpretation (Morse, 2015).

### **3.7.2. Transferability**

For the purpose of this study, to access information from a small group of participants to gain a rich description of parents who are transitioning their child with ASD to adulthood. Choosing such a small pool of participants may limit transferability to other studies. But, it's necessary to achieve a qualitative understanding of the phenomenon (Guest, 2010). To improve transferability, I documented the research process to allow researchers to accurately replicate my results. Further, a reflexive journal was used throughout the process to examine my own beliefs, decisions, and how or if it influenced the research process.

### **3.7.3. Dependability**

Dependability provides a traceable way for the reader to understand how steps were achieved, and how certain conclusions were reached (Nowell, 2017). This research process included approval of an interview guide and questions, a trail of notes, memos, and data. Audit trails provided conformability and dependability through a transparent documented approach describing how and why decisions are made and how data is understood (Korstjens&Moehher, 2018). In addition, participants reviewed their transcripts for accuracy and to validate or revise the transcription.

### **3.7.4. Conformability**

Qualitative research must reach conformability when all components of credibility, transferability, and dependability are proven within the research process (Nowell, 2017). A transcription service will use to provide neutrality with raw data analysis. Researcher bias was recognizing and addressed through transparent documentation prior to the data being collected, during the interview process and raw data collection through notes and journaling, and peer review of conclusions and interpretation of data. Insight into researcher bias and committing to an iterative process provides rigor to qualitative research necessary to achieve trustworthiness (Johnson, 2020).

### **3.8. Ethical Considerations**

The researcher considered it exceptionally vital to set up shared believes and regard (Burns, 2003). In this study included assent, confidentiality and secrecy, security, and the proper to pull back from the study. Encourage letter gets for educated assent was the primary imperative moral pre-requisite. All members openly chosen to take part in this consider. They were educated around all essential data with respect to investigate. The researcher must be delicate to the members 'emotions when testing questions that may mentally hurt the members and gave sufficient time for the members until they got to be steady.

## **CHAPTER FOUR**

### **DATA ANALYSIS AND INTERPRETATION**

#### **Introduction**

To address the research objectives and to answer the research questions the finding of the study was analyze and discuss in this chapter. the chapter covers different sections, which includes, the background of the respondents, family perception, seeking treatment, families psychological wellbeing, families initial emotional reaction to the diagnosis of autism, ongoing emotional encounters, and family units, reactions of non-autistic children, economic strains in the family, family participation in the labor force, high cost of living, social stigma and labeling by the community, difficulty to access facilities and services and coping and adaption mechanisms for family experience of coping and adaption for having children with autism spectrum disorder. the data presentation was done in the form of narration.

#### **4.1. Background of the participant**

The overall objective of the study was to investigate family experience of coping and adaption for having children with autism spectrum disorder the case of joy autism center. to achieve the objective of the study incorporated fifteen families for having children with autism spectrum disorder respondents.

This phenomenological study involved 15 participants of the in-depth interview, fifteen in number all were families for having children with autism spectrum disorder participant ranging in age 35-65. out of the 15 families 9(nine) respondents were women and the remains 6(six) participant were men. With regard to their educational level five participant were grade 9 to 12; two participants were not read and write; three participants were read and write and the remaining five participants were grade 1 to 8. Regarding to marital status four of them had divorced, six participants were married, and the remaining five participants were single. Finally, with regarding to job eight participant were daily work, four participants were participating in trade and the remaining three participants were unemployed or in other word house wives.

Table 4.1. Back ground of the Respondent (Demographic Information of the participant)

Respondent	Pseudonym	Age	sex	Education	Job	Marital Status
1	Ayisha	35	F	Grade 10 <sup>th</sup>	Unemployed	Divorce
2	Alem	42	F	Grade 5 <sup>th</sup>	Unemployed	Divorce
3	Kamila	37	F	12 <sup>th</sup>	Trade	Divorce
4	Samirawit	37	F	12 <sup>th</sup>	Daily work	Marriage
5	Ayinalem	42	F	9 <sup>th</sup>	Trade	Marriage
6	Fatuma	53	F	0	Daily work	Marriage
7	Meseret	44	F	Rea and write	Unemployed	Marriage
8	Mandefro	65	M	Red and write	Daily work	Marriage
9	Kedir	45	M	12 <sup>th</sup>	Daily work	Single
10	Alemayehu	48	F	8 <sup>th</sup>	Daily work	Divorce
11	Ahmedin	55	M	0	Daily work	Single
12	Musa	43	M	5 <sup>th</sup>	Daily work	Single
13	Ali	54	M	5 <sup>th</sup>	Trade	Marriage
14	Seada	37	F	7 <sup>th</sup>	Trade	Single
15	Elesabet	35	F	10 <sup>th</sup>	Daily work	Marriage

## **4.2. Family perception about the causes of Autism in their Children**

Having taken noticed a few unordinary behaviors in their particular children, all the family faced a great deal of confusion and concern for days, weeks and eventually formed their own understand about the cause of Autism spectrum disorder.

The majority that families believe that the cause of autism their children's is that was due to the ownership by the fallen angel soul, or fiendish eye soul (locally known as 'Buda': a spell cast by the eye, incurring harm of incident on the individual being looked). a few of the family counseled with house individuals, neighbors and friends to discover out and to affirm their discernments approximately the conceivable causes of the children's disability and they were generally told their children's symptomatology was related to otherworldly causes; a fiendish eye or a demon soul. The members of participant were questionable causes of the children's disability, in spite of the fact that; some of the time they had discernment that the cause of their children clutter can be related to fundamental therapeutic causes.

For occasion, Ayisha said that, at to begin with, her recognition of the child's disability was that child has been had by either fallen angel soul or fiendish eye conviction. She said: "at that time, I felt that my child had been possessed by a fiendish eye soul in other word evil eye spirit. My neighbor's and my families too said that my child was wiped out profoundly, like fiendish eye conviction (Buda)"

The recognitions of a few families were affected by advices and clarifications they gotten from house individuals and neighbors. Family individuals endeavored to donate clarifications approximately a fiendish eye soul and how it seems conceivably. Because for the children's disability. This made family to confirm their initial perceptions.

"I had an intestine feeling that my child may well be had by a fiendish eye soul. My families gave me three reasons why she said my child had been had by a fiendish eye soul. to begin with, my child is nice looking and in more often than not did not cover his confront when I took him exterior of the domestic. So, he can be uncovered to Buda soul, moment, he over and over drops down from his bed whereas he rests, and third, he likes to eat soil and other unwanted things whereas he plays exterior. At that point, I felt that my families were right."

Abebech had also recognition that her child's disability was due to the ownership of fiendish eye soul. But she moreover had discussions with few of her neighbor's around the child's condition. She was told that her child's disability was due to otherworldly causes. At times she had blended discernments; she thought her child's condition might moreover be related to 'madness'.

“To begin with thing that comes to my intellect was a fiendish eye soul. I know approximately it since; I am a ‘church person’. On the off chance that it was not fiendish eye soul, my child can be crazy I was looking for a supposition from my neighbors, and they over and over told me that my child has been had by fiendish eye spirit.”

Another family, at first had a diverse discernment of her child's disability. On one hand she seen the dormancy of her child exceptionally emphatically, as a great personality and great behavior of her child; but on the other hand, she felt that her child's need of socialization and forlornness was caused by a fiend soul. at that point affirmed her discernment of the child's disability by counseling her neighbors' particularly of the elderly person.

“At to begin with, I was pleased since my child was so calm, at times went by, I begun inquiring myself, why my child was so forlorn? I listen approximately the fallen angel soul and I was a bit suspicious that was my child's issue. I told to my neighbor and she said that my child may well be taken over with fallen angel spirit.” Alem

The other five families were not certain almost the causes of the children's disability. But they felt that it may well be due to fundamental therapeutic causes. They did not look for data or exhortation from the amplified family and neighbors' around the child's issue instep, they decided by themselves to visit the healing center trusting to induce a logical clarification for the child's issues.

Alemayehu said that "At first, I might not tell what my child's issue was, but I thought my child has wellbeing issue, may be hormonal lopsided characteristics, I did not know exactly.” Meskerem moreover portray her discernment this way: “I had the impression that my child has a few wellbeing issues. I did not tell anybody approximately my child's condition I took him to pediatrician” The over meet extricates with families uncovered that the starting recognitions of most of the families almost their children's disability clutter was related to otherworldly causes

such as fallen angel spirits and fiendish eye soul. Moreover, most of the discernments of families were affected by family individuals, neighbors and friends.

### **4.3. Seeking Treatment**

The information demonstrated that the treatment alternatives for the children were chosen mutually by family members, and neighbors. The family members had impacted the treatment alternatives some of the families specially mothers. Those mothers who attributed their children's problem are spiritual and traditional options. Whereas, the other family who sought scientific explanations for the child's problem diagnosis present to treatment choices. Be that as it may, one of the families was slanted to the traditional treatment choices as well, as she was impacted by the family members.

Kamila said that "My neighbors said it may well be Buda soul, I started to utilize distinctive social and otherworldly medicines or cultural and traditional treatment, since my child was 4 I utilized these medicines for one year, but it did not offer assistance to move forward my child situation" Another family, Alem, has got a proposal from the mother-in-law to require the child to witchcraft by which her mother was against it. She specified that the child's inability was a cause for a debate between the amplified families due to a need of agreement to choose on the treatment alternatives. She said: "My family in law unequivocally proposed me to require my child to the witchcraft to induce otherworldly treatment in any case; my family did not permit me to do that she or maybe exhorted me to require the child to the mosque."

Also, Samrawit applied the Holly water treatment for long time since she accepted that her child will get a total remedy and her neighbors also suggested her to require him to the church. Be that as it may, the treatment did not make strides her child's behavior. "I knew the fiendish eye soul may be recuperated with holly water they too recommended me to require my child to the church for heavenly water treatment he was treated with the holly water until he was 13 a long time ancient. But, he kept on be fretful and forceful" Samrawit.

The other family, Ayisha was at first initially hesitant to apply conventional treatment as she was not certain almost its viability to progress her child's condition. But she did not need to dismiss the suggestion given from her neighbor's and in the long run took her child to the mosque. She said: "My neighbor's and my family recommended me to require him to the mosque, I was a



small bit reluctant, but I did not need to dismiss their suggestion' 'In the over meet extricates of family, I mulled over, the treatment alternatives utilized by family were related to conventional and otherworldly development of disability and impacted by the expanded family and neighbor's. From all members, as it were four families based their discernment and treatment on logical presumptions in spite of the fact that they were affected by family individuals recently.

#### **4.4. Families Psychological Wellbeing**

One of the challenges detailed by all the families was mental or psychological issues. Families had experienced a several mental or psychological challenges since the diagnosis of Autism in their children. The psychological challenges of family can be generally categorized into initial and ongoing psychological problems. Initial emotional encounters are the experiences of family during the first few days or family following the diagnosis of the child while ongoing psychological problems are the family constant worries and concerns about their children.

##### **4.4.1. Families initial emotional reaction to the diagnosis of Autism**

Families illustrated a run of feelings quickly taking after the determination of a child disability. The most noticeable responses all the families similarly went through were. Sadness, despair, shock, confusion, feelings of loss, and difficult of accepting is diagnosis.

The initial diagnosis came as a stun to Ayinalem. Hearing a new word, a condition she had never listened of, was a colossal stun which was went with by a few assist activities. Whereas she talked almost the period of introductory diagnoses, she seems to be reliving the moment of shock, repeating herself saying how new and shocking the word 'autism' was:

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

Another participant, Fatuma, encountered emotional disturbances such as worry and insomnia following the diagnosis of her child which leads to mental and physical health deterioration. Prolonged interrupted sleep, change in eating habits which was loose of appetite, and reduced self-care leads her to a significant health problem. She Said "... I had many sleepless nights. I was very unhealthy since the day of my child's diagnosis. I had a kidney infection and I was

urinating blood for some days. This was all because I did not take care of myself, I was not stable mentally”

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

“It was a difficult for me to acknowledge what the doctor was saying. At that point I inquired the specialist, what Autism implies? My first prayer was asking God to put my life and my child's life to an end. If he is not a normal child, why do I and my child stay alive?”

Fatuma Moreover, Mesert specified her encounter of doubt as went with by self-destructive endeavor “I attempted to commit suicide when I gotten the determination of my child. You know! I was told by the doctor that it could be a deep-rooted condition. It was a challenge to welcome this in to my mind”

On the other hand, Seada had not been able to voice clearly on the off chance that she was either in skepticism or dissent. She felt that her child's condition was due to a botch made by doctors amid the time of conveyance of my child. She was not interested to list the conclusion of the child and she was seeking out for an elective clarification for the child's condition.

“I thought my child isn't a human being, it felt like my child was a diverse animal. I said to the specialist, my child does not have Autism spectrum Disorder; my kid is ordinary. It must be a botch.

May be there was an issue in conveyance room, my child might have shortage of oxygen!” seada The other families, Ahmedin, battled to get comes about. He thought that children who have mental and formative issues counting Autism were as a rule characterized by facial highlights such as broader faces and mouths, smaller cheeks, compliment noses, and a shorter philtrum and

his child has no such facial highlights; determination as the comes about appeared in opposite with his suspicions.

“I thought children who have this kind of mental issues were characterized by facial highlights, but my child looks ordinary. He has no facial anomalies. He may be a nice-looking child! So, he cannot be Autistic, I fair rejected what the doctor was telling me and I cleared out the hospital.”

The over articulation by Ahmedin, reflected that he had misinterpretation almost Autism disarranges. He related Autism and other disarranges in children with as it were facial characteristics.

He expected that children who have ordinary facial structure were not gathered to have mental wellbeing issues. I reflect this suspicion is due to the need of information and mindfulness almost Autism and its highlights. I moreover had the impression that the phrase "But my child looked ordinary. He had no facial anomalies. He looked good looking! So, I thought he Autistic" appeared to communicate that she was denying the child's clutter by legitimize that her child looks good looking.

#### **4.4.2. Ongoing Emotional encounters**

In expansion to the passionate experiences experienced for few weeks and months taking after the determination of their children, families experienced continuous stressors that made a steady and repeating passionate unsettling influence. For the most part, families had discouraged feeling, misery and uneasiness; since of their changeless stress almost long-term of their children.

Elesabet Said: “My child’s future is the most things that stresses and stresses me coming to my intellect for all time. Now and then, I cried all day and night when I think that my future life is filled with misfortune.”

For Samirawit, to a few degrees, the way professionals educated her almost the child's Disability clutter was what worsened her stress and dissatisfaction for end of the. Autism was communicated to her as a lifetime clutter that's obliterating and strenuous to make strides and alter. She said the reality that the clutter is serious made her on edge approximately long run of her child. She said: “I feel on edge when I think that my child will be subordinate on me for the rest of his life. What made me more baffled was that the specialist said Autism Spectrum Disorder may be a deep-rooted condition that's troublesome to improve” Kedja in expansion, a

few families shown their concern that their children will not be taken care of legitimately by others on the off chance that they cannot be for their child, and their dissatisfaction. their children were having the same openings in life. Like that of an ordinarily creating child, carefree childhood, instruction, autonomy, and marriage life.

For occurrence, Alemayehu communicated his disappointment approximately long run of his child this way:

“When I think my child future, I feel exceptionally pitiful. What in case I will not be there for him was he is hitched? But I don't know on the off chance that he can get any bolster, instruction, from distinctive sources in case I now not can be there for my child. I am the as it were one for him.” Alemayehu

Another family Musa communicated his concern related to how the shortage of welfare arrangements within the nation either from government bodies or respectful society organizations might make sentiments of powerlessness and dissatisfaction on the family.

“When I think of the longer, term I get discouraged and baffled the government or other organizations cannot back him. Some of the time it's superior that your child has passed absent and you burry his dead body than stressing approximately what will happen to him each moment of your life.” Musa

Other than, Andualem said that “sometimes I incline toward not to think around my child's future. What will happen to him in the event that I am not there? It is unpleasant to think around this each day.”

Not at all like other family, was aster changeless stress the regenerative wellbeing issue of her child. Her concern was that her child might not be able to recognize his substantial changes and he does not know how to bargain with his sexual wants. She demanded that seriously sexuality instruction at the level required by youngsters ought to be outlined for children having Autism spectrum Disorder to spare them from committing a social mistake such as undesired touching.

“I am continuously stressed around the regenerative wellbeing of my child. I began to think almost this since, one day I watched my child ejaculating on the pad and I felt so pitiful since he might not be mindful of his own biological changes...our children ought to be taught in a few way ” Aster

From the whole meet extricates of family, I had the impression that the passionate experiences taking after the conclusion of their children with Autism Spectrum Disorder, were so troublesome to bargain with. The encounters were filled with a conundrum of feelings carved on the family' confront. Most of the family had a fragile tone of voice, they were doleful and they had down casted eyes filled with tears. A few of them detailed self-destructive considerations which infer the size of the heartaches and torments they had gone through. I consider that the enthusiastic clashes of family may emerge from need of information almost Autism spectrum Disorder, varying level of acknowledgment of the child's clutter, need of bolster frameworks, seen fear of shame, and for the most part from the conviction that the clutter is serious.

#### **4.5. Family units**

The other challenge detailed by all family was the issues experienced within the family unit; basically, the trouble to bargain with the marriage life and other children without Autism spectrum Disorder at domestic.

In expansion to caring for the child, overseeing wants of the spouses and other non-autistic children at domestic was very requesting for most of the family which in turn abandoned marital connections and relationship designs with non-autism children within the family.

##### **4.5.1. Reactions of Non-autistic children**

The other major challenge of moms within the family unit was the trouble to donate fitting care and consideration to other Non-autistic children. From the met family, six of them have more than one child who needs their care and treatment. For all the family' it was troublesome to adjust the care and treatment they give to non-autistic children at domestic due to the time requests and consistent supervision required for the child with Autism spectrum Disorder. Family felt blame and disgrace since they thought that they are were not satisfying the anticipated part of a Family in their communities. Giving more consideration to Autism child moreover makes sentiments of competition, hatred and desirous in kin who contrarily influence the Family child bond with non-autistic children in their individual families.

For occasion, Aynalem said:

“I seem not deliver consideration to my other girl, my child was the as it were center for me, my small girl felt that I overlooked her and I did not consider her as my child. I felt that I seem not keep adjust between my two children since everything that's done is around him.” Lemlem

Moreover, Fatuma had battled in adjusting care and back between her child with Autism spectrum Disorder and her small girl. The words that she listened from her girl was heart breaking for her, and she didn't anticipate her girl to talk in a way that clarified her envious towards her child having Autism. "one day my small girl said 'mummy, you'd take a great care of me on the off chance that I was Extremely introverted child like my sisters' I was exceptionally stunned to listen this explanation from my small daughter I am constantly seeking for the correct adjust between my two kids"

Additionally, for Fatuma and Alemitu the response of children was something that might take all their vitality. Ftuma said that the children's required the back of family for the things that they can do by themselves. Thus, she some of the time had to oversee the struggle between children's due to the require for rise to treatment with the Autism spectrum Disorder child.

"But in some cases, it is so upsetting to handle their differences. They said I adore him more than them. Some of the time in the event that I bolster him with my hand, they need me to bolster them as well. But, they are able to eat with their claim hands. It is unpleasant to bargain with all the demands."

Another family, Fatuma was not competent to preserve adjust in caring for children's which constrained her to involvement family divisions. She sent her girl to the amplified family with the purposeful to ease her parental push and to better back her extraordinary require child. Isolating with her girl was a really difficult involvement that cleared out her with sentiments of sadness and feebleness.

"My girl complained that she was not cherished and cared like my child I too sent my girl to my family put to live with her. I was so discouraged that time and I felt that I was not a great family, I felt so feeble that I may not care for both of my children."

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

The other challenge detailed by family was financial hardships in raising their children with Autism spectrum Disorder. All family said that they experience critical financial burden in their particular families. Based on the information, the financial issue demonstrated by family was related to two fundamental reasons i.e. family labor drive support and family failure to manage distinctive costs of living.

#### **4.6.1. Family Participation in the Labor Force**

Caring for children with Autism genetically influenced family opportunity to urge hired for modern employments and to preserve their existing occupations. But one family, the other moms were housewives, remaining at domestic caring for their child with Autism spectrum Disorder. A few families had no work whereas others stopped their work to require care of their children. One of the respondents, Fatuma clarified her involvement horrendously; how difficult it is to raise a child with Autism spectrum Disorder especially the challenges of a mother to secure work openings. She communicated the trouble confronted by mothers to create one's claim livelihoods either by getting enlisted for work or within the most exceedingly bad situation by looking for monetary back from others.

“Raising extremely introverted child may be a difficult work. It is troublesome to be contracted. You know what! You cannot indeed ask on the road having such kids. Since you cannot let the child be situated on one put with you and ask for cash, they are fretful kids, they are troublesome to handle” Fatuma

The other respondent, Aster was not able to preserve her proficient work that she secured right after graduating her ponders since of her child: “I utilized to work as a promoting master, but right presently I halted working since of my kid”

Kamila too had comparable encounter of losing her work. She said she that there are tall budgetary strains in her family since she stopped her work and her spouse is the as it were one working and supporting the family. She said: “I stopped my past work after I gave birth to my child having Autism spectrum Disorder. I ought to be domestic for my child. My husband's compensation isn't satisfactory for the life we were driving presently but I had no option”

Conversely, inadequate social backing and lack of child care provisions provided by the government had an adverse effect on family involvement in the workforce. As mothers were the primary caregivers, they were the main sources of care and support for their children. For example, Alem stated: "It's been five years since I left my job and became a stay-at-home parent because I couldn't leave my child with someone else and go to work. Child care facilities are scarce in the city." Additionally, families had to adjust their work schedules around their children's needs or seek self-employment or freelance opportunities that allowed for the necessary flexibility to balance child care and employment. While looking for jobs that offered

flexibility, families sometimes had to accept low-paying positions and negotiate their children's arrangement with various employers.

The discernment of bosses towards the family capacity and commitment to their work was generally belittling since a mother having extremely introverted child was seen as unable to adjust childcare and work life requests. Alem portrayed her encounter of losing her work due to the need of certainty by the manager approximately her competence and work judgment. “I utilized to work as a cleaning woman. One day, my boss all of a sudden told me that he contracted other ladies in my position...He said I ought to remain domestic for my child than coming to work and the recently contracted lady can work in a full-time premise. I clarified over and over that I was a great fit for the work, but he told me to stop the work beginning from that day.”

From all the met family, as it were Kedja, a family of 15-year-old child, said she includes a work as a director which gave her an adaptability to oversee her time, vitality and taken a toll to care for her child.

Subsequently, she had no monetary issues when it comes to caring for the child but she highlighted how the sufferings might hit difficult to raise Autism spectrum Disorder children at all. She clarified:

“Me and my spouse work as experts. We have good income I don't have money related challenges; that produces it much way better to raise my child but it is still extreme to care for an extremely introverted child.”

#### **4.6.2. High Cost of living**

Due to the money related issues within the family, family detailed that they had limitations to cover the different costs such children's school charge, discourse treatment, house lease and dietary costs for their children. The money related imperatives particularly; the failure to pay for school was a major challenge for family. Musa said: “It is as well expensive! I had no choice but to pay 6400 birrs, the sum would have been exceptionally difficult to manage for my spouse in the event that he would not get the back from his brother.”

A few families had to battle to support the lives of the family, and cover the costs related with house lease, family costs and the school of children. A few of them felt the burden carried on their spouses to cover all the costs of the family since they were not monetarily contributing to the family.



“My spouse pays 5000 Birr month to month for house lease, we got to eat, and we got to pay for the school of my child! It is truly difficult for us to cover all these! I have no work, it is my husband who covers all costs with his compensation, and He continuously cleared out without cash at the conclusion of the month! We are battling to outlive in this way of life” Meseret

The other financial concern specified by family was the costs associated with behavioral treatment, especially of discourse treatment for children. Due to exceptionally tall cost and few alternatives accessible for discourse treatment, it was unbelievable for family to assist their children get discourse treatment. They specified that they as it were known one discourse treatment center in Addis Ababa. As the cost was not reasonable by most of the family, they children were not able to advantage from the treatment.

“I paid two times for my child’s discourse therapy...I would say the cost is so out of line. I ought to pay 3500birr per hour. It is truly costly! I can pay for one or two times but I cannot manage that in a month to month basis.” Fatuma

Another family, Ali shown significant financial challenges related to dietary intervention to the child. Her child is moo in a few supplements due to constrained nourishment admissions and nourishment inclinations. He delicate to taste, color and surface of nourishments consequently, she battled to supply the most excellent count calories for well in arrange to soothe side effects of ASD and make strides his behavior.

“When it comes to nourishment, there are so numerous nourishment stuffs that my child ought to not eat and it costs me more cash I know which nourishment seem make him fretful or calm, but it is difficult for me to bear all these kind of nourishment as they are costly within the market.”

Ali

Advance Ali shown that she continuously put an exertion to construct her information Autism spectrum Disorder and diverse dietary intercessions. He said that she inquired for data from his families and some of the time he attempted to get a handle on a few data from web sources.

“No, I learned this through my experience with my child conjointly my sister gives me data from web sources around Autism in children. There are diverse nourishment sorts that

I ought to bolster him or not, some of the time I attempted to goggle approximately it by myself.” Ali

Analyzing at the discourse of Ali, I was astounded that, Ali was the as it were family who brought up the thought of dietary mediation to children with Autism spectrum Disorder. She had shown the part of slim down to soothe indications of Autism in her child. This may emerge from his information around Autism that he picked up through diverse procedures. Too, the express “I ought to nourish him or not” gave me the impression that she felt it is his obligation, as a family, to supply her child with an adjusted eat less but she falls brief of cash to fulfill her obligations.

Taking the complete clarification Ali with respect to diet and costs related with it, I had two clashing impressions, on one hand; the information of family could be a great establishment to supply quality care and arrangement to their children. On the other hand, I mulled over that having the information, without the capacity to allow might put an extra strain on family since it can extend the contrasts between what is conceivable and impossible to do for the child. In case they have the information, they may well be constrained to fulfill all the wants of the child without having the budgetary capacity; typically to say, the more learned the family, the more strained she was.

#### **4.7. Social Stigma and Labeling by the Community**

Another challenge detailed by all the met families was social disgrace and labeling which was one of the foremost troublesome aspects of open experiences within the social life of families. In most

Cases, the social disgrace and labeling emerge from the expanded family and relatives, the community and experts and diverse benefit suppliers. The multifaceted disgrace discouraged families from looking for different administrations, from taking part in their communities and from getting a charge out of the same quality of neighbors as their families, companions and neighbors and It influenced families lives more than caring for children with Autism. Negative demeanor and misinterpretations around their children clutter accounted for the constrained social interaction and non-acceptance of families and their children within the society. Children were dodged by their peers since the clutter was seen as transmittable malady.

Elesabet said: “My neighbor’s and the community accepted that Autism spectrum Disorder is transmittable illness. The demeanor of individuals towards my child is so out of line. He cannot play with other children. I don't know how to change people’s intellect!! Individuals continuously don't need to see my child and said I need to bolt my child indoors.” Elesabet

Moreover, Ali, depicted his concern due to the no acknowledgment of his child completely different open undertakings and prohibition from diverse social exercises. He shown the disgrace, dissatisfaction, feedback she experienced in open places, since of the behavior of his child. He said:

“All eyes were on me and my child when he shouts on the roads. He cannot play, and socialize with his age mates. My child is human but he has formative delay.”

Indeed, in spite of the fact that a few families had solid want to socialize and to induce acknowledgment by the society, fear of negative response and dismissal by the society was the conspicuous figure that hinders their association in several social circles. A few families battled to construct keep up social interaction with and regard the social conventions and desire of a social life in their community.

In any case, it was troublesome for them since other individuals don't get it the issue of their children. Ali said: “There are a few social exercises I ought to go since it is portion of our culture, such as funerals. When it is so vital I got to take off my child alone, bolt him within the house I have no choice.

In expansion to the negative state of mind by the community, need of information and understanding around the children's clutter by the expanded family restricted families' interest completely different social exercises counting family get-togethers since of the fear of negative response from relatives.

“I don't take my child to different social exercises counting our family meetings because individuals don't understand his behavior and they don't need to see him make inconvenience before them so I lean toward to remain at my home.” Fatuma

Included to their constrained social intuitive, moms and their children were labeled by the society.

Moms were labeled as ‘bad’ and ‘negligent mothers’ for raising their children with no taught and control while the children were labeled as ‘Sick’, ‘naughty’ or ‘deaf’ at whatever point they show improper behavior completely different public places, primarily within the neighborhood, on the transport and on the streets.

Seada said the social disgrace that she experienced within the transport offices. She said:

“Sometimes individuals grant me hostile comments on the lanes and within the transport One fellow said to me, “why didn’t you teach your child whereas he was youthful, you’re a terrible family”.

Another family, Elsabet was moreover labeled as a ‘bad family’ by the society. Her child was moreover insulter by the neighbor who makes a debate between the neighbor’s and her for long time.

“My neighbors called my child ‘sick’ in the event that my child misbehaves within the transport, individuals yelled at me that it is since I didn’t teach my child, I am an awful family, failed to raise a great mannered son.” Elsabet

Additionally, a few of the family clarified a really agonizing involvement they experienced with experts and benefit suppliers, such as school of children. Finding a school for children was challenging encounter for family because it was mostly related with shame. Fear of dismissal by schools made family to hide the child’s clutter and in the long run lead the children to drop out from school when the child’s conclusion was distinguished by the school experts. Subsequently, family was faulted since they cover up the child’s clutter when they at first attempt to urge school affirmation. kedr, said that:

“I was attempting difficult to search for a school for my child the school principals denied to confess my when I told them he cannot talk. But, you know, you shouldn’t tell them that your child has Autism I had contentions with school central since I stow away my child’s clutter some time recently. kedr

Family too detailed the social shame they confronted whereas utilizing diverse offices in open, such as the open transport, and house lease. It was a colossal challenge for family to discover and keep up house lease since of their children. Family specified that the disfavor from lessors and occupants were troublesome encounters. They too had to alter diverse lodging and pay expanded costs. Madefro talked around the social disgrace he experienced within the transport this way:

“One day, I was within the transport with my child, after a whereas the driver told me to induce off the transport since my child was break the reflect of the transport, I denied and yelled we won’t get off the transport some time recently we reach our stop” Ayisha

Essentially, Elsabet said her involvement of changing house rents for long time since of her child and due to the out of line medicines of the proprietors and inhabitants. She said “It is

continuously difficult for me to discover a level to lease. I have changed 7 pads since the determination of my child. I frequently cover up my child's clutter from lessors since they will not lease me in the event that knows." Elsabet

In expansion, the social shame from the community made sentiments of outrage, hatred and inadequacy to the families. The reactions of families to the social shame varied from one family to the other. A few of the families said they attempted to be tolerant and non-responsive for the negative responses from individuals and they tend to maintain a strategic distance from getting in to issues with others since of their children. From all the families, Elsabet and kedja detailed that they tend to bargain with the social disgrace with resilience; by overlooking the negative responses and dodging circumstances that makes sentiments of disgrace Elsabet said;

"Whenever I utilize a transport with my child, I attempted to disregard individuals who respond severely until I get off the bus's I attempted to be tolerance with what individuals say indeed in spite of the fact that I am burning inside." Elsabet

Moreover, kamila tends to dodge circumstances that trigger her feelings, and she tends to donate a daze eye for the disgrace and unjustifiable treatment from individuals towards her children than clarifying individuals approximately her child's circumstance or getting in to unforeseen strife with them. She reviewed her encounter in her child's school as a case:

"I was exceptionally irritated and pitiful to the unjustifiable treatment of my child by the care suppliers at schools. I out cried and quickly took my child absent from the center. I did no assist activities as I did not need to lock in in struggle I felt so broken." kamila

On the opposite, other families such as kedir, kedja, Fatima and Alem were more likely to go up against the social shame through making mindfulness almost Disorder, they tend to battle for themselves and stand firm to be a voice for their children, sometimes ended up in squabble and battles for the proper of their children. Kedja clarified approximately her encounter whereas employing a open transport/bus/ this way:

"I was exceptionally irate! I told the driver that I was capable for my child and I yelled at him that I won't get off the transport! I can pay if my child crushes anything! You know! I ought to tell individuals around my child's condition; he has the correct like other individuals on the bus." kedja

Moreover, Fatima portrayed that she contains a solid crave to illuminate individuals almost Autism spectrum Disorder. She strongly argued that families ought to not be faulted for their children behavior in open since the behavior of the child is the effect of the clutter not the family's disappointment to require obligation.

She said: "I don't care almost what other individuals seem say these children are how they were Some of the time, I intentioned tell to individuals that my child is Extremely introverted and I attempted to clarify what it implies and how the child might behave."

Comparative opinion was shared by kedja, who said that she endeavored to illuminate individuals that labeling her child are unseemly in any circumstances. She said: "But that day I endeavored to ask why the school foremost treats my child unjustifiably. I told her that was not appropriate to name my child. He can learn like other kids."

Some of the time families were considered by the society as in the event that they are utilizing their children as an excuse to induce needs in several administrations. Fatima depicted her encounter of quarrel with others since of her child. She was faulted and insulter by individuals whereas attempting to get need to utilize an open transport, and she finished up in battle due to people's negative response towards her and her child and errors happened in that circumstance.

"Once, I was late to his school and I inquired individuals a favor to let me go to the front in water. A person from the water insulter me, as in the event that I was utilizing my child as reason to sneak the Water It can be need of information. Fatuma

Fatima preceded that, some of the time she includes a trouble to adjust people's suggestion and her claim craves with respect to what to do for her child. She clarified a conundrum of feelings with respect to socialization of her child. She was puzzled whether she needs to take after her possess way or regard what the community anticipates from her with respect to her child's socialization.

"When I keep my child at domestic, individuals fault me as in case I disconnected my child from others and I am awful families; when I let him to go outside, individuals abuse him, other kids have no intrigued to be with him, I don't know how to oversee both?"

From the over meet with the families, I reflect that the social disgrace experienced by families was multifaceted. This could be due to need of mindfulness by the common open towards children having Autism. When a few families said the social disgrace from school community,

my impression was that need of mindfulness was clear indeed among the taught sections of the society such as instructors, and other school experts. Schools which give comprehensive instruction to children with Autism tend to dismiss confirmation of children and they were not strong to the families and their children. Indeed, in spite of the fact that families had solid crave for rise to treatment and acknowledgment from the common open, the social shame was the greatest prevention for them not to work out rise to social status with others.

I moreover had an impression that there were misinterpretations approximately the fundamental causes of children unfortunate behavior. The society features a deep-rooted suspicion that as it were awful child rearing may result within the children's Fatima behavior or as it were undisciplined child might carry on improperly in open which was not the case for children with Autism.

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

Another major challenge of families was trouble to get to diverse offices and administrations for their children. All the families were continually stressed approximately need of offices such as schools, Autism centers and helpful centers, especially of discourse treatment. Families detailed that their children were underserved due to shortage of assets, administrations, and prepared experts to back their children and the entire family. Particularly need of schools and Autism were squeezing issues for all of them. As demonstrated by families, they experienced need of offices and administrations both sometime recently to the conclusion and after the determination of their children.

For occurrence, Elesabet said: "The accessible healing centers were not effectively available for me. I had to travel a long way from where I live to induce to the healing centers. It was physically depleting on the other hand; I was attempting difficult to search for a school or Autism center for my child. It was truly a difficult work to discover. It was continuously my worry" Elsabet

Besides, it was in spite of the fact that for families to secure a put in Autism centers since there were as it were two Autism centers worked as neighborhood NGOs in Addis Ababa that supports children and their families. Due to restricted capacity and assets of the centers, it was unbelievable for families to urge a put for their children and they either had to hold up for long

holding up records to urge confirmation in one of Autism centers or they ought to explore for elective solutions by themselves.

“My child was enrolled to connect Autism center but he was enrolled on the holding up list on number 354. It implies there were 353 children holding up some time recently him to connect the center. I seem not accept that a part of understudies doesn’t have the opportunity to urge confirmation in school and Autism centers.” Fatima

In an endeavor to discover a way for the child to connect Autism centers, families had to battle difficult and, in some cases, utilize diverse techniques to secure a put. Ali talked almost her battle to induce affirmation in Autism center and the procedure she utilized to secure her child’s confirmation:

“It was challenging to discover a school or Autism center; these administrations are nearly missing for our children! I got a put for my child in one of the two Autism center centers since I knew the proprietor, and she made a difference me within the process.” Ali

In addition, families shown that instruction at standard administrative schools is by and large free but enlistment, regalia and instructive materials such as books bring about costs. The schools get children based on parent’s report and some of the time based on data from specialists. In any case, fundamental stream schools with comprehensive instruction program for children with Autism were exceptionally few in number and securing a put for a child in a constrained standard school is portrayed as ‘tough’ by the moms. It moreover impacts families from support within the labor drive. Kedja said:

“Government schools are free you’ll be able enroll for gratis but we require schools for our children! Numbers of schools were exceptionally constrained conjointly the schools had full admissions.

That’s my regular concern! Something else, it is difficult to say a mother can work whereas her child remains at home.” Kedja

Other than, standard schools were not outlined for extraordinary needs instruction. There was significant need of instructive helps and prepared instructors, and socially suitable rebellious for children.

Fatima talked approximately nonappearance of particular needs instruction offices. “I was not able to discover a school or Autism center for long. At that point I took my child to a standard



school but they had no uncommon offices for extremely introverted children such as assistive gadgets, and extraordinary require professionals.”

Advance, accessible standard schools need fitting care and treatment for children. Families detailed their children were surrendered by the amateurish treatment and need of care and supervision from the school community which causes grievances and disillusionment between families and experts.

“One day, I saw my child was eating a stone within the school play area. I was exceptionally stunned since the school instructors and caregivers were not observing over my child I was so irate with the careless treatment of the caregivers towards my child.” Fatuma

Based on the over meet extricates of families, I reflect that moms had a genuine of challenges to get to administrations and offices for their children. Especially, need of schools and Autism centers were basic issues for moms. Standard schools were not planned for extraordinary require children.

Consequently, families battled to bargain with destitute school frameworks that included complicated confirmation issues in one hand and amateurish medicines of their children by school staff on the other hand. Moreover, shortage of childcare arrangements impacts family’s labor drive support.

#### **4.9. Coping and Adaption Mechanisms for Family Experience of Coping and Adaption for Having Children with Autism Spectrum Disorder**

Families have developed coping strategies to help mediate the adaption experience and coping with having children with autism spectrum disorders. Focusing on CASD, such as watching television and calming techniques, was preferred. Sometimes bribes were made. We would take them to a playground, buy them new clothes, and make them play with other children. Practical ideas were to observe routines or allow CASD's unique t-shirts. Strategies were not always successful. If it's something big, I try and calm him down, but if it's screaming and crying, you try to understand him or hug him or just you, I don't know, but I just manage (Brella). It was important to identify triggers and prevent meltdowns. I look at behavior. I could see. Some signs with him (viola). Sometimes all a parent can do is walk away at that point.

It was important to make changes in daily activities and social outings to prevent anger and anxiety. After counseling by teachers, patients were successfully 'relieved of their pain'. They tell me what to try before we leave home, where we are going, why we were going there, where we are going after we leave. In addition to learning appropriate management techniques, parents used coping strategies to avoid potentially damaging situations. Families elaborate on avoiding harmful comments: If you stay away from it all and stay away from it, that's a coping mechanism for us. On the contrary, other families did not limit socialization, and grew up ignoring public cognitive strategies involve managing the emotions that accompany stress and choosing effective solutions. They react immediately without you even thinking about it. I have to think about this and I don't feel very emotional. Thinking about situations and preparing a response in advance takes the stress out of the situation. Working was a relief from the situation at home. When we're busy, we feel good, and we overdo it.

Spiritual and religious beliefs have helped in acceptance and stress reduction. We always pray that God will give us patience and that our son will be saved. This created hope, thereby building resilience and acceptance. Actions, which helped them, cope with the situation.

Families facilitate coping by discussing crises and alternative solutions. Self-enhancement was important for families who developed knowledge and skills through Internet searches, contacting professionals, and discussions with others. We started Google what kind of autistic person and all that stuff (brella). Three parents attended workshops and additional training. One parent became certified in applied behavior analysis and helped other families. I give them books; I will photocopy the ABA guidelines (Rachel).

His desire to help others and support children living with autism was a coping mechanism. All participants need information and support groups. Support groups to connect with parents with similar issues.

To bounce ideas of them if parents frame their reality through CASD with coping skills and acceptance, their experiences are positively modified. Viola's description of her trip illustrates this: You are afraid of heights and someone tells you to climb a chain ladder on a steep wall. By

the time you get to the top, you'll find that even your fear of heights has left you. Then you can breathe while looking out. You can look at the landscape and see it as a whole new world.

They react immediately without you even thinking about it. I have to think about this and I don't feel very emotional. Thinking about situations and preparing a response in advance takes the stress out of the situation. Working was a relief from the situation at home. I feel better when I'm at work, too much work. Spiritual and religious beliefs have helped in acceptance and stress reduction. We always pray that God will give us patience and that our son was saved. This created hope, thereby building resilience and acceptance.

## CHAPTER FIVE

### SUMMARY OF MAJOR FINDINGS, CONCLUSION AND RECOMMENDATIONS

#### Introduction

In this chapter, major finding, conclusions and recommendation of the research findings that had been analyzed and discussed in the previous chapter were briefly presented. Furthermore, based on the findings of the study possible recommendations were made.

#### 5.1. Major Finding of the Study

This study aimed to investigate the beliefs and perceptions of families regarding the causes of autism in their children prior to receiving a diagnosis. The results revealed that, except for a few, most families attributed their children's unusual behavior and communication difficulties to spiritual risks. Specifically, they believed that their children were possessed by evil spirits like 'Buda'.

The challenges identified in the results section were analyzed in relation to various themes, including psychological well-being, family dynamics, economic strain, social stigma, and access to services. The families in the study reported facing several complex challenges, with social stigma and lack of support systems being the most significant issues.

All families reported experiencing psychological difficulties, both during the initial diagnosis and ongoing care of their children. They expressed a range of emotions, including sadness, despair, shock, confusion, and difficulty accepting the diagnosis.

The primary recurring concern that impacts the emotional well-being of families was a constant worry about the future of their offspring. They were anxious about their children not receiving adequate care when they are no longer around to provide it. They also had concerns about whether their children would have equal opportunities in life compared to typically developing children, such as a carefree childhood, education, independence, and marriage.

Another discovery from this study was the difficulties that families faced in managing their family unit, particularly with regards to marital relationships and other children who do not have disabilities. Along with taking care of their child with autism, managing the needs of their spouse and other non-autistic children at home proved to be quite challenging for all families. Consequently, some families give up on their marriage and relationships with their siblings and non-autistic children within the family.

All families highlighted the devastating impact of social stigma and labeling from the community, which was one of the most challenging aspects of public encounters for families. The stigma and labeling came from extended family, relatives, professionals, service providers, and the community, deterring families from participating in their communities, seeking various services, and enjoying the same quality of life as others. The study findings showed that families of children diagnosed with Autism faced multidimensional challenges on a daily basis that were often underestimated. These challenges were demanding and influenced by family, professionals, and the larger community.

## **5.2. Conclusion**

The main purpose of the study was to investigate the family experience of coping and adaption for having children with autism spectrum disorder in joy autism center. The experiences of fifteen families were explored using in-depth interviews.

The results showed that families' experiences of the cause of autism were due to spiritual explanations, such as the devil's spirit and possessions of the evil eye, before their children's autism was diagnosed. Families' perceptions of the cause of autism were strongly influenced by extended family members and neighbors, which in turn influence treatment decisions for their children.

The determination of Autism in their children, postures a few challenges in several regions of family's life and they battled with different parts and obligations past the families of an ordinarily creating children. The most challenges of families found in this consider are mental issues of families, trouble to oversee the family unit, financial strains, social disgrace and labeling and trouble to get to different offices and administrations for their children. All families

experienced a few introductory and continuous mental issues. At the time of conclusion of their children, families passed through challenging minutes taken after by run of passionate responses such as pity, lose hope, stun, disarray, sentiments of misfortune, and incredulity as they were not mindful of Autism sometime recently the conclusion of their children.

The most repeating fuss that affected the enthusiastic wellbeing of the families was a changeless stress and concern almost the longer-term welfare of their children; whether their children will have the same openings in life like that of an ordinarily creating child such as carefree childhood, instruction, autonomy, and marriage life. The disappointment of the families was for the most part due to need administrations and facilities such as elective child care arrangements, schools, Autism centers and formal and casual back frameworks within the nation. Also, raising children with Autism spectrum Disorder monstrously influenced the working of the total family and forces a few issues counting; conjugal strain and separate, debilitated mother-child bond with non-autism children, and constrained support of families within the labor constrain which made a noteworthy money related burden on the family.

Besides, as essential caregivers to their children, families battled with numerous requests to fulfill their parental parts and at the same time, back the acknowledgment and engagement of their children inside the family and more extensive community. Multifaceted social disgrace and labeling from families, benefit suppliers, proficient and the rest of the community was the foremost annihilating encounters that affected both the mental and social prosperity of the families and their family. Need of mindfulness and negative societal state of mind related with Autism anticipates families and their children from taking an interest in their communities, from looking for different administrations, and from getting a charge out of the same quality of life as the other parts of the society.

Subsequently, there's a require for families, experts, benefit suppliers and all fragments of the community to recognize the multifaceted challenging encounters of raising a child analyzed with Autism spectrum Disorder in arrange to supply fitting and all-encompassing bolster to the children and their family.

### 5.3. Recommendations

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

**Macro level;** they may advocate for development of administrations and educate for children and families, advocate for the correct of children with Autism, and mobilizer assets to reach families.

**Meso level;** they may act as analysts, specialists, organizer, specialists. They ought to plan mindfulness creation programs, plan back bunches for children and families, lock in to investigate and hone to advancing incorporation of mothers and their children within the society

**Micro level:** They may play a part as counselors, teachers, and case supervisors by giving psychosocial back for children, kin, and amplified families.

**For government:** It would be vital on the off chance that the Ethiopian government allow an arrangement of consideration to moms of children with Autism through arrangement of instructive, wellbeing care, Autism centers and elective day care administrations. Too, the government may designate assets to prepare experts in order to encourage successful conclusion and early mediation. It is additionally imperative that government approach producers plan the foremost fitting, socially delicate programs and arrangements that donate rise to get to instruction for all individuals together with the essential checking on, checking and assessment of programs.

Therefore, mediation programs have to be delivered specific consideration to the culture and ways of life of families raising children with uncommon needs at the large-scale framework level and upgrade child rearing quality of caregivers from distinctive social foundation who are frequently overburdened and feel powerless. Since: the intercession programs and methodologies are not consonant with their culture.

Generally, environmental hypothesis recognizes the collaboration of diverse frameworks such as families, community offices and educate, otherworldly pioneers, benefit suppliers, government etc., as all portions of the society have the obligation to advance the prosperity of families and their families.

The early recognizable proof of formative issues ought to lead to advance formative and restorative assessment, conclusion, and treatment, counting early formative mediation. In case a child is analyzed with a formative shamle through the assessment and demonstrative handle, they ought to be distinguished as a child with uncommon wellbeing care needs, and chronic-condition administration ought to be started. Distinguishing proof of a formative clutter and its basic etiology may too drive a run of treatment arranging, from restorative treatment of the child to hereditary counseling for his or her guardians.

Childhood and children ought to be alluded for symptomatic assessment when expanded hazard for formative clutters (counting ASD) is recognized through screening and/or reconnaissance. Children ought to be alluded for mediation for all distinguished formative delays at the time of recognizable proof and not hold up for an ASD demonstrative assessment to require put.

#### **5.4. Future Research Direction**

There are some limitations that the researcher encountered that could be improved for further research. The first is the possibility of omitted variables. Perhaps considering some other variables which have not been included in this study may lead to more accurate prediction and understanding of the family experience of coping and adaption for having children with autism spectrum disorder. Although family experience of coping and adaption for having children with autism spectrum disorder have been operated throughout the country, this study has been geographically limited only to Addis Ababa Joy Autism Center which might be limiting the generalization to the country level. Therefore, further studies are recommended to consider another part of the country including rural areas because of their possible effects of the factors. Since this study is conducted by using only qualitative source and open-ended questions, further studies are suggested to include quantitative source and methods like clos ended questions (i.e., Likert scale types).



## REFERENCE

- Altiere, M.J, & Von Kluge, S. ((2009). Family functioning and coping behaviors in parents of children with autism. . Journal of Child and Family Studies.
- American. (Washington, DC: Author.). American P (2000). Diagnostic and statistical manual of mental disorders (4th ed., text revision). . Washington, DC: Author.
- Anderson, K. A, Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of individuals with autism to adulthood: a review of qualitative studies.
- Avdi, E, Griffin, C. and Brough, S. (2000). Parents' constructions of the 'problem 'during assessment and diagnosis of their child for an autistic spectrum disorder. Journal of Health Psychology.
- Baba, P. (2014). Living and dealing with autistic children: a case study of a Nigerian family in.
- Baba, P. (2014). Living and dealing with autistic children: a case study of a Nigerian family in.
- Bakare, M.O. and Munir, K.M. (2011). . , . E. xcess of non-verbal cases of autism spectrum disorders.
- Bakare, M.O, Agomoh, A.O., Ebigbo, P.O., Eaton, J., Okonkwo, K.O., Onwukwe, J.U. (2009). . and.
- Baxter, A.J, Brugha, T.S., Erskine, H.E., Scheurer, R.W., Vos, T. and Scott, J.G. (2015). , . The.
- Bazzano, A., Zeldin, A., Schuster, E., Barrett, C. and Lehrer, D. (2012). . , . Vaccine-related beliefs .
- Bello-Mojeed, M.A., Omigbodun, O.O., Ogun, O.C., Adewuya, O.A. and Adedokun,
- Bello-Mojeed, M.A, Omigbodun, O.O., Ogun, O.C., Adewuya, O.A. and Adedokun, B. (., 2013.).
- Benson, B. a. (1989.), The effect of a congenitally handicapped child upon the.
- Berger, J. (2013). Statistical decision theory and Bayesian analysis. Springer Science & Business.
- Berhane, H. (2016), Reactions, Challenges and Coping Mechanisms of Mothers Raising Children.
- Blacher, J, & McIntyre, L. L. (2006). . ) . . Syndrome specificity and behavioral disorders in young.

- Blackledge, J.T. and Hayes, S.C. (2006). , . Using acceptance and commitment training in the support of parents of children diagnosed with autism. *Child & Family Behavior Therapy*, 28(1), .
- Bronfenbrenner, U. (1986). . *Ecology of the family as a context for human development: Research*.
- Bryman, A. ( 2012), *Qualitative data analysis. Social Research Methods*, 565–588.
- Bryman, A. (2016)., .*Social research methods*. Oxford university press.
- Bryman, A. (2016.). , *Social research methods*. Oxford university press.
- Center for Disease Control and Prevention. (2014). . *Data& Statistics on Autism Spectrum Disorder*.
- Creswell, J.W. and Poth, C.N. (2016). , . *Qualitative inquiry and research design: Choosing among*.
- D., G. (2013). *Autism and Alzheimer’s disease in Ethiopia: A present glance*.
- Dababnah, S. and Parish, S.L. (2013). , . “At a moment, you could collapse”: Raising children with.
- Davis, N.O. and Carter, A.S. ( 2008). ,. *Parenting stress in mothers and fathers of toddlers with autism*.
- Dzubay, S. (2011). . *Parental grief, coping strategies, and challenges when a child has autism*.
- Ebrahimi, H., Malek, A., Babapoor, J. and Abdorrahmani, N. (2013). ,. . *Empowerment of mothers in*.
- Farzana, S. (2017) ,*Journey towards hope with hope: An interpretative phenomenological analysis*.
- Harrington, J.W., Patrick, P.A., Edwards, K.S. and Brand, D.A. (2006.). , *Parental beliefs about autism: Implications for the treating physician*, .
- Hoogsteen, L. and Woodgate, R.L. ( 2013). ... *Centering autism within the family: A qualitative approach to autism and the family*.,. *Journal of pediatric nursing*.
- Hutton, A. M., & Caron, S. L. (2005). . *Experiences of families with children with autism in rural*.
- Mandell, D. S, & Novak, M. ((2005). ).*The Role of Culture in Families' Treatment Decisions for*.
- Mann, A. ( 2013. ). ,*The experiences of mothers of children with autism in Jamaica: an exploratory study of their journey*.

Mashudat A. Bello-Mojeed, Dr. MuideenOwolabiBakare and Dr. KerimMuni. ((2013). r ).

Matenge, B. (2013.). An exploration of the lived experiences of mothers raising children with.

Moh, T.A. and Magiati, I (2012). . Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum*.

Montes, G. a. (2014), Family burden of raising a child with ASD.

Morgan, S. (1988). The autistic child and family functioning: A developmental-family systems.

Nyoni, J. and Serpell, R., . (2012). . The impact on parents of raising a young child with autism: A.

Okasha, A. (2005.). . Mental Health in Egypt. *Journal of Psychiatry and Related Sciences* 42:116–25.68.

Omar, M. ( 2014). .. Early intervention services as perceived by parents of children with.

Organization, W. H. (2019). . Autism Spectrum Disorder. <https://www.who.int/news->

Organization, W. H. ((2020). ). Autism Spectrum Disorder. <https://www.who.int/news->

Preventio, C. f. (n.d.). n, Autism and Developmental Disabilities Monitoring.

Rao PA, B. D. (n.d.). . The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior modification*.

Ravindran, N. and Myers, B.J. (2013.). ., Beliefs and practices regarding autism in Indian families.

Rodrigues, H. (2008). ., . Weldable fibre Bragg grating sensors for steel bridge monitoring. *Measurement Science and Technology*.

Samadi, S. A. ((202). . Parental Beliefs and Feelings about Autism Spectrum Disorder in Iran. *International. Journal of Environmental Research and Public Health*, 17(3), 828.

Samadi, S.A. and McConkey, R.,. (2011). 2011. Autism in developing countries: Lessons from Iran. *Autism research and treatment*,.

Society., A. ( 2101). 1. Autism Facts and History.-. Retrieved from <https://www.autism.org.uk/about/what>.

Speaks, A. (2019). Autism Facts and Figures. <https://www.autismspeaks.org/autism-facts->

Tilahun, D, Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y. and Hoekstra, R.A. ( 2016.). ., U, B. (n.d.). The ecology of human development: Experiments by nature and design.

Volkmar, F. R, Paul, R.,Klin, A. & Cohen, D. Editors(Ed. (2014). s). . Handbook of Autism and.  
Weldeab, C. (2006), Family, school, and community: Challenges in raising and educating.  
Weldegabreal, R. (2014), A Qualitative Study on Single mothers Experience of Raising their.  
Woodgate, R.L., Ateah, C. and Secco, . ( 2008). L.,.Living in a world of our own: The  
experience of.  
Woodgate, R.L,Ateah, C. and Secco, L. (, 2008). . Living in a world of our own: The experience  
of.

## **Appendix1. Instruments of Data Collection**

### **St. Mary's University Department Of Social Work MA Program**

Dear study participants, I am a student of MA in Social Work in St. Mary's University. Currently I am doing my thesis entitled Family Experience of Coping and Adaption for having Childers with Autism spectrum disorder: the case of Joy Autism center. Since you are one of the respondents selected to participate on this study, I am sure you will give attention to forward your correct and complete information to have a representative finding on the current status. In doing so I confirm you that the information that you share will be kept confidential and used for the Academic purpose only.

Thank you in advance for taking your valuable time and collaboration to fill out the questionnaire!

Emebet Gebre

## **Appendix**

### **Annex: Participant information sheet for the Family Experience of Coping and Adaption for Having Children with Autism Spectrum Disorder.**

#### **I. Demographic Information**

1. Age \_\_\_\_\_

2. Sex            M \_\_\_\_\_    F \_\_\_\_\_

3. Educational status

4. Occupation

a) Trade            b) Student            c) daily work            d) Unemployed

f) Other specify, \_\_\_\_\_

5. Marital status

a) Single   b) Married   c) Widowed   d) Separated   e) Divorced   f) Others Specify,

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## **II. Open ended questions:**

1. What was your understanding or knowledge about autism?
2. How and when did you find out that your child has autism spectrum disorders?
3. How did you feel when you first heard that your child was autism diagnosis?
4. What was the problem you faced while raising your child who was affected by autism diagnosis?
5. How is your relationship with your family and friends in the community?
6. How do family members react to people with autism? What about friends, neighbors and community?
7. How does autism affect your marriage, work, academic performance and social participation?
8. How do you cope with the challenges of caring for an autism child?
9. What could be done to improve the life of family experience Coping and Adaption for Having Children with Autism spectrum disorder in your life?
10. How do you understand your child's autism illness?
11. What are the conditions under which you can get help?
12. How has this diagnosis changed your expectations of your child?
13. How do you see the attitudes of your family members, relatives, friends and other community members towards people with autism in your community?
14. How did you learn about autism?

A/ It was told by family/relatives.

B/ Told by health professionals/

C/ Told by someone else.

D/ Obtaining information about the symptoms from the media/spoken by local healers

f/ other/ \_\_\_\_\_ explain

15. What do you think is the cause of autism?

A/ Curse

B/ Disaster/ God related or spiritual

C/ Hereditary

D/ Germ/ Bacteria

E/ Other/ Specify

16. How do people around you and society understand the causes, aggravating factors, and social influences of autism?

17. Have you or your family experienced a negative impact on engaging and using social services? Can you tell us some experiences if any?

18. What are the coping and adaption strategies to overcome the challenges related to the psychosocial and economic impact of autism?

19. What do you suggest to improve the psycho-social and economic conditions of autism patients? Investigator, what coping strategies did you use to overcome these problems?

20. How has having a child with autism affected your daily activities? Were you able to work full-time or did you have to give up career plans to take care of him/her at home?

21. How do you see your child's autism interacting with your other children? (Meaning less attention to them, more to her)

22. If there is anything not covered in the above questions, would you like to explain further?