



**ADDIS ABABA UNIVERSITY**  
**COLLEGE OF SOCIAL SCIENCES**  
**SCHOOL OF SOCIAL WORK**

**ASSESSMENT OF PSYCHOSOCIAL AND ECONOMIC EXPERIENCES OF AUTISM  
ON PARENTS OF AUTISTIC CHILDREN AT NEHEMIAH AUTISM CENTER IN  
ADDIS ABABA, ETHIOPIA**

**BY:**  
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**ADDIS ABABA, ETHIOPIA**

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**THESIS SUBMITTED TO THE SCHOOL OF SOCIAL WORK COLLEGE OF SOCIAL  
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## ABBREVIATIONS

ASD	Autism Spectrum Disorder
WRD	World Report on Disability
FDRE	Federal Democratic Republic of Ethiopia
MOH.	Ministry of Health
MWCY	Ministry of Women Children and Youths
RBS-R	Repetitive Behavior Scale-Revised
NIMH	National Institute of Mental Health
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
LT	Local Time

## ABSTRACT

ASD is the fastest-growing developmental disorder and emerging public health issues globally that is associated with a huge psychosocial and economic burden. Studies so far look at the causes and cure for autism. However, little work has been done on the impacts of autism on parents of children with autism face in their upbringing. This study brought out the psychosocial and economic experiences parents with autistic children face as well as the support needs and the coping mechanisms these parents adopt to deal with the condition of their children. Data were collected through an In-depth interview from the qualitative method. Purposive non-probability sampling was employed to select study participants from the total population. Prominent themes the study highlights on parents' knowledge about autism, parents 1st feeling, acceptance, psychosocial, and the financial burden of taking care of them, support needs, and coping mechanisms. On the other hand, stigmatization, misconception, misjudgment of their autistic children as well as themselves, and the demandingness of the autistic children were highly practiced by these parents. With these problems, parents in the study adapted to their situation by accepting the situation of their wards, depending on God for strength, receiving support and encouragement from some family members and friends, joining support groups, as well as taking leave from work to help their children seek proper medical care.

## Chapter One

### Introduction

#### 1.1 Background of the Study

Autism is a neurological and developmental disorder that usually appears during the first three consecutive years of a child's life (Willis, 2006). According to Meron (2006) justification, some people believed it is mental illness or retardation, other also believed it is caused by parents sin and evil eye which can be cured by strong prayer and doing some religious practice but others still didn't understand what it is, how it affects the individual and their parents. She approved "parents are still unaware of autism, didn't have information on how it affects people and limited public knowledge and understanding regarding autism in general and also the community and the neighbors who live around these parents do not allow their children to play or be with their children. Others also believed that the children are acquired the disorder due to their parent's sin or not Obedient in front of God or Allah Meron (2006).

It has multiple characteristics that affect children and their parents. Communication impairment, social interaction, emotional functioning, engagement in repetitive activities, and stereotyped movements are some characteristics associated with autism (Willis, 2006).

According to the US Centers for Disease Control and Prevention (2011), 1.16 in every 100 children is diagnosed with autism. This reported prevalence is substantially higher than that of a decade earlier. Similar increases have been noted in the UK, Europe, and Japan (Landrigan 2010, p. 219). The reason is not known why such a rapid increase in autism. Autism affects all children regardless of color, race, and gender. However, a lot is still not known on the possible risk factors and causes of ADS. Researchers believed that both genetic and environment play a great role. Regarding the prevalence of autism, there appeared a lack of appropriate and evidence based information in Ethiopia. Psychosocial problems, economic hazards, support needs, and the way of dealing with autism were not studied very well.

According to the World Report on Disability (WRD) (2011), there were 15 million people with disabilities including autism in Ethiopia. However, the available data do not provide sufficient evidence on the type and the prevalence of persons with autism by degree and specific category of impairment. This is because of public associates developmental problems with spiritual evil and caused by one's sin most people do not let autistic persons go out in public. This stereotypic

attitude also forces parents to hide their autistic children, which in turn lead to inaccurate information and statistics on autism. Thus, statistical evidence on the extent and prevalence of autism in Ethiopia is not sufficiently available. Although it is difficult to know the accurate number and the prevalence of autism in Ethiopia, it is estimated that 500,000 people lived with autism throughout the country (Burton 2016).

Parents of autistic children have many psychosocial and economic experiences regarding autism. Parents of autistic children are experienced with disappointment, social isolation added stress, frustration, and helplessness. This compound stresses and having a child with autism may affect the parent's wellbeing and child's development. Parents are the one who is responsible for caring for their children. Autistic children and many special needs are unbreakable things and they require full-time care and treatment. To meet the need of their autistic children it needs high scarification, this also makes another challenge to parents of autistic children who are economically weak. Due to this dual burden (economy and autism), these parents are particularly vulnerable to psychosocial and economic impact. The psychosocial and economic effect of parents also affects children in multiple ways, affecting their cognitive, behavioral, and social development. Also, the lack of clear biological marker in autism makes ambiguity for the parent to accept the child is as it is. In fact, the study has shown that autism can create greater Parents' psychosocial and economic effect than Parents of non-autistic children (Hastings &Johnson2001).

The degree of personal affection is varying between mothers and fathers. In most Ethiopian culture caring for children, cooking, and handling the house are considered as the only task of the mother than the father.

In most cases fathers distinguished the severe impacts that their child's autism presented for their family members, they usually claimed that their child's disorder did not have a vast effect on them personally. The comparatively less severe impact of the child's autism on most of the fathers seemed to be at least partially due to the gender roles connected to work and child-rearing (Gray, 1983).

According to Meron (2006), most parents of autistic children in Ethiopia had no clue and understanding of autism and its nature in general. Although different people give their own explanations, it is far from the concept and definition gave by professionals.

## **1.2 Statement of the Problem**

Living with autistic children is one of the most painful, challenging, and full-time task for parents of autistic children. This is because the role requires a continuous lifetime commitment and responsibility. Among other disorders, autism is unique and challenging in many ways such as problems with communication, emotional expression, and antisocial behaviors. Among childhood pathologies, autism is the most challenging one due to its severity, lifetime, and impact on the parents (Gray, 2002, p.215).

FDRE (2002) country profile on disability, Ethiopia characterized by stereotypes and prejudice, based on traditionally held views that link autism with immorality, punishment, and curses. Labeling people according to their limitations is still common, and autistic children and their parents are stigmatized. One of the challenges faced by these parents is social isolation. Friends and family members may not understand the special needs of a child. Those people in such social networks may not be able to provide child-care support.

With too many professionals and parents, the number of children with autism seems to be increasing at a faster pace than before. Statistical evidence on the extent and prevalence of the problem is not sufficiently available in the developing countries in which Ethiopia is unexceptional. But since autism is found throughout the world and amongst all ethnicities, nationalities, and social classes, we can expect that in Ethiopia there is roughly the same prevalence as in other regions of the world. This vast population of children with autism has no access to intervention, education, or life skills training. Autism spectrum disorder coupled with poverty makes it unbearable for parents, communities, and Government. Most parents in Ethiopia with a child with autism end up in divorce, mental depression, and live in poverty. There is also a lot of stigma and discrimination in society due to the reason that people believe most mental problems are caused by the parent's curse or sin. (Argaw, B.2010).

Even when autism is diagnosed, the services available for its treatment are limited. Besides, the basic reward of parenting, which is showing love and forming attachment is limited as autism causes impaired social and communication skill (Gupta & Singhal, 2005, 62-63)

Apart from the type and severity of the specific stressors caused by having a child with autism, coping with the general stress of a developmental disorder requires significant, long-term adaptation within the family, and these changes affect both the individual family members and the family unit as a whole. For a significant number of individuals, the entire burden of providing emotional, social, and economic support falls on the family members, especially the parents. There is a greater burden on caretakers and a higher probability of disruptive routines within the family of a child with autism than in the families of children with other disorders (Randall & Parker, 1999).

Studies indicate that the associated stress effects of having a child with autism, impact most aspects of parents lives, including housekeeping, finances, the emotional and mental health of parents, marital relationships, physical health of family members, limiting the response to the needs of other children within the family, poor sibling relationships, relationships with extended family, friends and neighbors, the opportunities for the personal development of each family member and time spent in family recreation and leisure activities (Sander & Morgan, 1997).

The parent-professional collaboration approach views the child and the family in the broader environmental context. Parents may look to professionals such as social workers, physicians, psychologists, therapists, and others, who have the expertise in working with children with disabilities to determine what they feel, are the best services for their children.

Many studies have been conducted on autism and its symptoms or characteristics by different researchers and academics. However, only a few researchers investigate the impact of autism on the family. Still, parents of autistic children are extremely affected by autism. The present study was assessed on how the problem was severe due to the lack of community awareness to understand and accept the person with autism. Many people still think affected children are possessed by the devil because of their parents' sins thus most parents hide their autistic children in their home setting. Since, there are institutions and schools in Ethiopia that have been giving care and support for autistic children and their parents. Still those Institutions and Schools are not enough to accommodate all autistic individuals and this also leading to an increase in the

psychosocial and economic burden of autism on parents of autistic children in Ethiopia, especially in the study area.

In this framework, the present study was assessed the psychosocial and economic experience of parents of autistic children and their support needs and also identified the reason for those psychological and economic problems with their coping mechanisms in Nehemiah Autism Center. Information about psychosocial and economic effects on parents of autistic children is crucial for planners and policymakers, but as far as the researcher's knowledge is concerned in Ethiopia as well as in the study area, little is known about psychosocial and economic effects on parents of autistic children. So the current study helped to fill this gap.

### **1.3 Research Questions**

The present study was attempted to answer the following research questions.

- ✚ What psychosocial Burdens are experienced by parents of autistic children?
- ✚ What Economic Burdens are experienced by parents of autistic children?
- ✚ What major supports do parents of autistic children need?
- ✚ What coping strategies do parents of autistic children adopt to handle the effects as a result of autism?

## 1.4 Objectives of the study

### 1.4.1 General Objective

The general objective of this study is to assess the psychosocial and economic experiences of parents of autistic children, support needs, and coping mechanisms in the case of Nehemiah autism center.

### 1.4.2 Specific Objectives

- ✚ To assess the Psychosocial experiences of parents of autistic children,
- ✚ To assess the Economic experiences of parents of autistic children,
- ✚ To identify major support needs of parents of autistic children for mitigating the impacts of autism, and
- ✚ To identify Strategies parents of autistic children are using to deal with the experiences of autism

## 1.5 Significance of the Study

The study will have bases of evidence for those who are willing to undertake a similar study on the case and promote future studies that are concerned with the stated problem. The results of this study will also be influential input for councilors, planners, and policymakers including the Ministry of women's Children and Youths (MWCY) and Ministry of Health (MH). Institutions working on autism care and treatment can be benefited from this study as an input for the enhancement of their programs.

## 1.6 Definitions of Terms

The following text was defined to enhance the knowledge of the readers and to provide them with a better understanding of autism.

- **Autism:** is a developmental disorder, present from early childhood that can affect how people understand, see, hear, and sense the world around them. It is characterized by impairment in social interaction, impairment in communication, and restricted, repetitive and stereotypic patterns of behavior, interests, and activities.

- **Psychosocial experiences:** many parents of autistic children experience the following emotions: Feelings of being overwhelmed, grief, sadness, anger at their spouse, despair at the incurable nature of the disorder, feelings of social isolation, embarrassment at child's behavior in public, social stigma, discrimination.
- **Economic experiences:** economic experiences of parents of autistic children were very massive. Most parents of autistic children are sitting at home due to caring for their child. This makes extremely difficult for both parents to continue working full-time. On other hand, there are added financial burdens like specialized educational toys; medical expense and diaper cost is the major.
- **Support need** is the material, financial, psychosocial, aid, and service that parents of children need to cope with autism and the effect of raising an autistic child.
- **Parent:** is a person who is a father, a mother, or a legal guardian of an autistic child below the ages of 18 and who are regularly coming to the center and who is living and raising the child with autism and provides care and support for that child.
- **Child:** is a person of either sex who has not attained the full age of eighteen years. For this study purpose, the researcher focused on autistic children.

### **1.7 Scope of the study**

The current study aimed at assessing the psychosocial and economic experiences of parents of autistic children at Nehemiah autism center. The study is delimited, to parents of autistic children who are regularly coming to the center in matters related to their children and themselves and interested parents to participate in this study.

## Chapter Two

### Review of Related Literature

This chapter presents an extensive review of the available literature and research related to the study. It has four sections. The first section deals on definition of autism, the second section discuss about the impact of autism on parents of autistic children and the third section on their support needs and coping strategies that parents use and the last section on theoretical framework.

#### 2.1. Introduction of Autism

Autism is a neurologically based developmental disorder that occurs in the first three years of a child's life. This causes restless movement, attention deficit, and destructive behavior, impairment in communication, hearing, and focus. It is determined by repetitive behaviors like body rocking, hand plopping, and head rushing, problems with verbal and nonverbal communication, social and emotional functioning which makes it challenging for an autistic individual to understand the world around them (American Psychiatric Association, 1994)

A child psychiatrist Dr. Leo Kanner revealed that "autism is an inborn disturbance of affective contact and unusual language development like not having the proper tone, echolalia or pronoun reversal". According to Kanner's earliest diagnoses on eleven children with autism, the children particularly exhibited resistance to change. He described resistance to change as insistence on sameness or routine, like requiring or taking the same route, wearing the same kind of clothes, eating the same kind of food, etc. He also used the term resistance to change to refer to some of the unusual behaviors frequently seen in autism-like, stereotype purposeless motor behaviors such as body rocking, hand flapping, toe walking, unusual staring, etc (Volkmar&Wiesner 2009, p.2).

Autism is classified as the main subgroup in pervasive developmental disorder and it is come up with social interaction, having a delay or/and unusual functionality in language or symbolic and imaginary games, which are used in social communication and various fixations DSM-IV-TR (2007).

## **2.2 Characteristics of Autism**

ASD is typically diagnosed in children by the age of three where difficulties are recognized in the area(s) of social interaction, language for communication, and/or restricted, repetitive, and stereotyped patterns of behavior. When Karner first reported his finding of autism; he stated that the main features for the diagnosis of autism are social isolation and insistence on sameness. Other succeeding studies and researches also include communication problems as an important element in the diagnosis of autism. In 1980, the American Psychiatric Association published an official guideline on the diagnosis of autism. It was intended to serve as diagnostic criteria (Volkmar&Wiesner 2009, p.27)

Even though all individuals with autism are unique, there are still some common characteristics that these people encounter. These features also serve as a hallmark to diagnose the disorder. There are three distinguishing characteristics that all professionals in the field use. These features are; impaired social development, impaired language, and communication, flexibility impairment or resistance to change.

### **2.2.1 Impaired Social Development**

Impaired social interaction is one of the hallmark features of autism. Children with autism have difficulties interacting both with peers and adults. From infancy to age years three they exhibit a lack of social skills such as disinterest in social games, having little attention for family members, having abnormal eye contact or limited attention to other people, poor playing skills, etc. Children with autism demonstrate rigidity and limitation in social interaction and have problems establishing relationships. This is because they are unable to process social information properly and to use appropriate social skills to create and maintain relationships (Columbia Ministry of Education, 2000)

Since they have difficulties in language processing and communication, they are unable to understand social situations and the environment in general. This in turn makes them disinterested in the world of people around them. They mostly do not interact with others as most people do. According to the American Psychiatric Association (1994), although the type and degree of social skill severity differ from person to person, an autistic child, in general, lacks imaginative or social play and could not be able to use their imagination for creative purposes, have limited use of toys and show limited pleasure in social games. Additionally, since they

have trouble understanding other people's feelings or talking about their own feelings, they have difficulties in making friends and show significant difficulty with any interaction that requires knowledge of other people and what they think or know. Consequently, autistic children have impaired ability to initiate or sustain a conversation.

Some children with autism show difficulty in noticing people who are talking to them and others might be interested in people but do not know how to talk, play, or relate to them. (Ruble & Gallagher, 2004)

### **2.2.2 Impaired language and communication**

About 40% of children with autism do not talk at all, and others have echolalia or repeating what was said by others. Even if they can communicate, autistic children's communication skills are limited to getting needs met rather than information sharing or complex interaction with other people. An individual with autism shows the considerable difficulty in using languages as faculties of communication and interaction and information gathering and dissemination. This can include delayed development of spoken language, difficulty holding a conversation, or repetition. (Ruble & Gallagher, 2004)

The communication problems of autistic children extend to their use of non-verbal communication agencies such as avoidance of eye contact, inability to use hand gestures and facial expressions, and repetitive and idiosyncratic speech pattern. The communication problems of autistic children extend to their use of non-verbal communication agencies such as avoidance of eye contact, inability to use hand gestures and facial expressions, and repetitive and idiosyncratic speech pattern. Some may have an odd pitch, unusual rhythm, or stress while others may have a faster or slower rate of speech than normal (Columbia Ministry of Education, 2000).

Some autistic children have problems in initiating conversations, and even if they initiate it, they encounter difficulties in maintaining the conversation. Some may continually discuss one topic again and again. They also have restricted vocabulary which is dominated by nouns. They use their vocabulary for requests or rejections to regulate one's physical environment rather than for social functioning. (Ruble & Gallagher, 2004, Volkmar & Wiesner 2009)

### 2.2.3 Flexibility Impairment or Resistance to Change

Demonstrating unusual and distinctive behavior is one characteristic of autistic children. These stereotypic and unusual behaviors are typically exhibited through repetitive behavior like a restricted range of interest and preoccupation with specific interest or objects or parts of objects (spinning of the fan, turning of wheels on toys, etc), stereotypic and repetitive motor mannerisms, such as hand flapping, finger flicking, rocking, spinning, walking on tiptoes, spinning objects. Autistic children might repeat actions over and over again. They might want to have routines where things stay the same, so they know what to expect. (Gray, 2000)

Many of the odd and stereotypical behaviors may be caused by other factors such as hypersensitivity or hyposensitivity to sensory stimulation, difficulties in understanding social situations, difficulties with changes in routine, and anxiety. Most of the time, environmental stimuli may be disturbing or even painful to someone with autism. (Columbia Ministry of Education, 2000).

### 2.3 The causes of autism

While the exact cause of ASD is still unknown, researchers have linked ASD to biological or neurological differences in the brain. There may be a physical cause that affects the development of parts of the brain. There are many theories as to why this might happen. Theories include genetics, viruses, poor immune system, chromosome abnormalities, and pollutants. (Autism Ontario. 19, 2013). We do know that autism is not caused by the way a child is raised. The best evidence to date also indicates that ASD is not the result of infections, contagions, or vaccines. Misconceptions exist about a link between vaccines and ASD. The reality is that vaccines are among the safest medical products available and no vaccine, including the MMR (measles, mumps, and rubella) vaccine, is responsible for causing ASD. (Health Canada. February 19, 2013)

Autism is a complex brain disorder that affects a child's ability to communicate, respond to surroundings, or form relationships with others. In early times the cause of this complex brain disorder was believed to be parenting style (especially the mother's style). Careless and cold parenting was believed to contribute to the problem. However, in the 1970s, studies began to show that autism was a brain-based disorder. The brains of individuals with autism appear to have some structural and functional differences from the brains of other people. (Volkmar&Wiesner 2009, p.27)

Although it is not known exactly what causes this disruption of the neuropath ways development, it is obvious that children on the spectrum share similar characteristics. For example, they may all show some degree of difficulty focusing on tasks, poor social skills, lack of organizational ability, and/or a tendency to withdraw, with alternating periods of excessive activity. These boys and girls require early remedial work that engages the whole body, energizing the brain to re-establish neuro-pathways and creating healing from within. Involving children in activities that stimulate organs and the autonomic nervous system generates new brain cells. And by creating new cells, synapses (or connections) are formed that bridge the gap. This allows information to flow through neuro-pathways, as it should. (Janet Tubbs p.25.

More recent studies reported that children with autism were more likely to have had problems either before birth or during and other reported associations of autism with a number of medical conditions that can affect brain development. Currently, there is growing evidence that autism is a genetic condition, and that there are likely several different genes involved (Ruble & Gallagher, 2004). Environmental factors such as viral infections, metabolic imbalances, and exposure to environmental chemicals and harmful substances ingested during pregnancy are currently gaining wide attention in the causes of autism as well (Landrigan, 2010).

Various studies have been done to identify the cause of the disorder and multiple theories have been proposed to date. However, the absolute cause of autism remains unknown. And by creating new cells, synapses (or connections) are formed that bridge the gap. This allows information to flow through neuro-pathways, as it should. (Janet Tubbs p.25 Research in the last decade has produced data that show that environmental factors could possibly be a cause of ASD prevalence (NIMH, 2011). Environmental factors are anything from outside of the body that affects health (NIMH, 2011). Scientists are studying a process called epigenetics, which could show how certain environmental factors may affect certain genes (NIMH, 2011; Rutter, 2005). One such environmental factor primarily studied is the link of a parental age to ASD.

#### **2.4 Prevalence of autism**

Autism was once considered a relatively rare condition. Recent epidemiological data have radically altered this perception. Based on large surveys in the US, the Centers for Disease Control and Prevention (CDC), estimates the prevalence of ASD as 1 in 88 children, occurring in all racial, ethnic and socioeconomic groups, although it is five times more common among boys (1 in 54) than girls (1 in 252). The CDC website also offers data from numerous studies in Asia, Europe and North America showing an average prevalence of ASDs of about 1%. A recent survey in South Korea, which screened children in the schools, reported a prevalence of 2.6% (3.7% among boys and 1.5% among girls) (Kim et al, 2011). Another study in England estimated a prevalence of ASD at almost 1% in adults (Brugha et al, 2011). However, epidemiological studies are difficult to compare.

According to National Health Statistics report (2013) based on parent reported autism spectrum disorder in school aged U.S children the prevalence of autism spectrum disorder in 2011-

2012 among school children between the ages of 6-17 was estimated to be one in fifty. And the same report shows that school aged boys were reported to have autism more than four times as likely as school aged girls. As to Center for Disease Control and Prevention(CDCP, 2014) in 2010, the general prevalence of Autism among the Autism and Developmental Disabilities Monitoring (ADDM) sites of USA was 14.7 per 1000 one in sixty eight children aged eight years. In Ethiopia there is no statistical evidence as to the extent and prevalence of the disorder. However, according to Nia foundation (2012) estimation it is expected that there is the same prevalence with other countries because autism is found in all without differences in race, ethnicity, social status and other criteria, so in USA if one in every 115 children is diagnosed with autism in Ethiopia with a population of 80 million it is estimated that there are around 530,000 children with autism.

## **2.5 Psychosocial and Economic Experiences of Parents of autistic children**

### **2.5.1 Psychological Experiences of Parents**

According to (Cappe, Wolff, Bobet, Adrien, 2011) Parents of Autistic children reported the lowest level of parent's harmony in comparison to parents of children with other special needs. Parents of autistic children are more experienced by psychological problems such as depression, exclusion, anxiety, fear, etc. In addition to this, many parents of children with autism experience the following emotions : feelings of being overwhelmed, relief at having a name for the challenges their child faces, anger at their spouse, resentment of the child and guilt for that resentment, despair at the incurable nature of the disorder, guilt that something they did may have caused their child's challenges, frustration that the parenting experience they have is not what they envisioned, feelings of social isolation, stress and depression, embarrassment at child's behavior in public. Emotional tension between partners is high; as they look to understand both the diagnosis and impact it will have on their lives (Daireet a 2011).

The study finding revealed that autism is an emotional related disability that begins before diagnosis and continues throughout life. Mothers of children on the autism frequently rated their mental health status as "poor" or "fair". They had a much higher stress level than the general population. (McConachie et al., 2005). Autism manifests not just in developmental delays but in striking deviations in development. It is suggested (Seltzer, Krauss, Orsmond and Bestal) that it affects the overall psychosocial and economic wellbeing of parents of autistic children lies. In

order to ensure healthy development of the child, it is important to ascertain that primary caregivers need to be in a positive psychological state. It is believed that although research evidence supports parents of children with autism face variety of challenges and stressors, there is hardly any work focusing on parental perceptions and experiences.

### **2.5.2 Social Experiences of Parents**

In fact, most children with autism in Ethiopia are not even diagnosed as autistic. They are widely deprived of their basic rights, including the right to get an education, or the possibility of any treatment, because of a pervasive lack of awareness. These children are considered useless and unworthy of resources. They are often denied any rights whatsoever, even the right to see the daylight, enjoy the sunshine or the right to in some way participate in society. Autism is interfering in interpersonal relationships. The characteristics of autism consist of, social interaction, nasty behavior, and limited interest, as well as low social skills.

The parents of Autistic children and their family members are facing various types of challenges that start early and it lasts a lifetime. It's associated with other problems such, as personal, professional, marital, and financial. These problems occur across a wider social context .autism is no effect on parents but also the entire family is involved including; the marital system, the parental system, the sibling system, and the extended family system. It is due to parents not sending their children outside to play or for social participation. Seigel (2003)

Parents are greatly affected by the effects of stress on their social lives when raising a child with ASD, which can lead to unhealthy parent-child interactions (Haskett et al., 2006). The responsibility of the parent revolves around filling the needs of their child, which in turn, causes extreme frustration and isolation for the parent (Datz, 2006; Doherty, 2008; Gray, 2002; Moes, 1995). The outcome of the parental frustration can relate to a number of negative characteristics on the part of the parent such as low levels of parental warmth and reciprocity, and the use of the harsh discipline (Haskett et al., 2006; Rogers, 1993; Shiflet& Windsor, 2002).

Maladaptive behaviors such as sleep issues, not being able to do things as a family, extreme parenting demands, taking a child with ASD into the community, excessive stereotypical behaviors, and socializing issues make parents feel ostracized from others (Gray, 2002; Hartley et al., 2012). Many children with autism in Ethiopia are neglected and extremely vulnerable. Because some children with autism look normal physically, people often mistakenly imagine

they are simply unruly or poorly behaved. And because of a general lack of awareness, they and their parents are often blamed for their actions, with the disorder sometimes even seen as punishment for some spiritual wrongdoing. In fact, with few Ethiopians even aware of autism's existence, more often than not the symptoms of the disorder are misrecognized and misunderstood, with tragic consequences.

Most parents of children with autism do not have sound information and knowledge about the symptoms of autism. In particular, mothers of autistic children who have lost their spouse to HIV/AIDS, other diseases, or who are victims of spousal abandonment due to their child's disorder is left with few resources. With little explanation for their children's behavior and few sources of assistance, they carry an incredible burden. And these parents are unable to feel at ease when speaking about their children openly. Instead of receiving support, they experience great guilt about their child's condition and often imagine that they are somehow to blame. They are ashamed of their child due to the misunderstanding of society at large.

They feel personally responsible for their children's condition, or believe that the symptoms of autism are a curse from God, rather than the manifestation of a neurobiological condition. Humiliation and extreme social stigmatization result from these regular misunderstandings. (<https://niafoundation.wordpress.com>)

### **2.5.3 Economic Experiences of Parents of autistic children**

Raising a child with autism is not easy job they needs full time care due to the fact that these parents stay at home with jobless time and this makes an additional economic pressure placed upon parents, as raising a child with autism is three times more costly than raising a typically developing child. This is compounded by the fact that many parents, particularly mothers, are faced with a reduction in their ability to work, as the care of their child becomes the primary concern (Daire et al, 2011).

According to Glendinning's (1986) description the economic impact on parents of children with autism is enormous. Most private health insurance plans do not cover all expenses related to therapy and treatment for children with autism, and the co-pays for office visits and medications often results in huge financial debt. In addition to therapy and medical expenses, there are added financial burdens like specialized educational toys, puzzles, equipment like weighted blankets and vests, and much more. Having a child with autism resulted in an average of 14% loss in total family income. It is often extremely difficult for both parents to continue working full-time,

which means a reduction in household income to go along with the increased expenses. Since many parents need a full-time job in order to provide health insurance, loss of full-time employment can have a dramatic and negative impact on the family's finances (McConachie et al., 2005)

Commonly parents of autistic children in Ethiopia, particularly mothers, become disabled themselves. Burdened with the full responsibility of care, and likely having very little income, their child's disability directly constrains their ability to work and make a living; to take care of their children and themselves. Often, the exceptional demands of the child's disability also create emotional and financial problems for the parents. They remain without any aid, left alone to futilely plead for help. They must stay home to manage their children, though financial demands mount. They are unable to work because their children are often not allowed to attend regular schools for children their age. These parents cannot even leave their children with relatives or neighbors, because their child's uncontrolled behaviors are misunderstood; recognized as the expression of poor parenting, or, again, as the punishment for sin. This leads to financial instability and, more often than not, outright poverty. (<https://niafoundation.wordpress.com>)

## **2.6 Support Needs of Parents of Autistic Children**

Autism is a serious challenge, for both the afflicted individual and parents. Parenting autistic child though is the most demanding and challenging task which creates physical and emotional exhaustion. Many parents greet the news with shock and denial and keep looking ways to prove it is not true. At the same time they often experience tremendous guilt anger. The majority of parents will need a range of supports in order to cope up with the demands of caring for a child with a developmental disability. The type of support needed may vary according to child's behavioral problems, motor impairments, parents' gender, parenting roles, parents' socioeconomic background and parents' attitudes to childrearing. However, according to experts in the field, most parents of autistic children support needs are; information support, social support, access to professionals services, respite care and financial support (Guptha&Singhal 2005).

In Ethiopia, finding professionals for support is difficult because there are no such professionals in the field. This also confirmed by Argaw (2010), on a study of parental involvement at the intervention program of Joy center for children with autism. As he stated that, there is a lack of

professionals that can give individual based support and guide parents through their involvement in the intervention program. All parents interviewed for the researched stated this as a problem.(Argaw 2010).

## **2.7 Parents coping mechanisms to deal with autism**

Autism Spectrum Disorder is a complex neurological disorder that causes impairments in multiple areas of development including social interaction, communication, and behavior. There is clear evidence that parents of children with autism face many challenges in dealing with their children's difficult behaviors that can lead to negative psychological outcomes, including exhaustion, stress, and depression.

Moreover, parents encounter social challenges such as problems in family relationships and lack of understanding attached to the disorder by the society that leads to discrimination not only of the autistic child but also of the family as a whole. However, despite the many challenges parents of children with autism usually identify coping strategies that will work for them. A study aims to explore the lived experiences of mothers raising children diagnosed with autism on the psychological and social challenges they faced as well as coping mechanisms they found effective in dealing with those challenges. After passing the first stage parents cope with the situation differently. One parent may cope by giving every attention to the child and others may become avoidant or depressed (Volkmar&Wiesner 2009, p.28).

To deal with autism parents of autistic children use their personal experience and for more coping they need family support, religious and professionals' advice and information, and also social support (Argaw 2010). The study indicated parents who were allowed to connect with other parents of children with autism, may likely reduce stress and social isolation while allowing them to network and find appropriate resources (Meadan et al., 2010).

Another study indicated parents utilized parent support groups and social support to cope with the stresses of an autism diagnosis. It was also found through several other studies that support from marital partners were helpful when coping with stress (Mancil, Boyd, &Bedesem, 2009). A different study found a high need for support groups. It was found that parents gained knowledge and were empowered to advocate in the community with other parents whose children were diagnosed with autism (Banach et al., 2011). Another study demonstrated the significance of social support when families are coping with an autism diagnosis (Altiere& Kluge, 2009).

Parents can adapt adequately when they receive support from others through networking. Information from health care providers and agencies is also helpful (Meadan et al., 2010). Further suggestions parents can utilize to cope with the stress of raising a child with autism include prayer, exercise, deep breathing/relaxation exercise, writing in a journal, keeping a daily schedule of things to accomplish, advocacy, and individual, marital, or family counseling. Coping with a loss is significant and will make it easier to find acceptance in that loss (Autism Society, 2011).

## **2.8 Theoretical framework**

The empowerment perspective was applied in this research. The empowerment perspective is crucial because this study aims to assess the psycho-social and economic impact on parents of autistic children. An empowerment framework is a composite group of theoretical perspectives. Central to all of these theoretical approaches is the objective of social justice and a reduction in social inequality and oppression.

Empowerment perspectives address the dynamics of power and discrimination. They propose that empowerment requires linking a sense of self-efficacy with critical consciousness and effective action. This theory empowers parents who are affected by their autistic child. The focus of the theory is to help individuals who are directly impacted by the condition, and parents improve treatment over their life condition. The theory also shows how these parents handle the situation when they are in a very hardship condition. Social work professionals are the ones to empower parents of autistic children who are facing the difficulty of the case in different ways such as, by appreciating their lived experience, giving appropriate advocacy, counseling, and other related issues. Social workers need to support parents of autistic children to see themselves as causal agents in finding solutions to their problems and to see social workers as peers and partners in solving problems. In addition to this Social work, professionals empower these parents by connecting them with appropriate resources, any supportive groups, psychiatrist, therapist, and providing them with evidence based information. Social work professionals use this theory to support parents of autistic children lead a more sustainable life by developing their own professional strategies (DeJong & Berg, 2008).

The other theory that can be used by parents who encounter an ASD diagnosis was the strengths perspective. For this study the proponent of the strengths perspective focuses on more on helping parents of autistic children build on their own resource. For this study the strengths perspective

were used to find out and to strengthen parents of autistic children that they are facing by psycho-social and economic problems due to autism diagnosis. This theory needs parent-professional collaboration to identify parents' strengths. The strengths perspective assumes that power re-sides in people and those social workers should do their best to promote power by avoiding labeling these parents, avoiding superiority treatment, and building trust in these parents to make appropriate decisions Saleebey (2001, 2006).

This also allows different professionals and especially social work professionals to emphasize the parent's experience, success, and move away from the parent's dysfunctions. This prevents the discrimination and disparagement of parents and promotes parents' initiation to accomplish their more tasks. It is essential to use this perspective when working with parents of autistic children as it supports autistic individuals, family members, and communities to apply their acknowledged strengths in real-life situations. This will make the opportunity to improve the quality of life of these parents. In addition to this, this will help Social work professionals and other disciplines to focus on parent's strengths rather than judging or blaming the parents of autistic children. Therefore, the overall focus of the strengths perspective is to support these parents to become more aware of their strengths and successes they experienced in handling and coping with the problem those they facing (DeJong & Berg, 2008).

Finally, yet importantly, family systems theory is important when working with parents of autistic children. In addition to professional support, the family is another support system for parents of autistic children. The focuses of this theory are on the transferring of an impacted individual perspective to a family systems perspective. The family is seen as a unit; therefore, by using this theory, social workers can select parents of autistic children who are facing the psycho-social and economic burden (Paylo, 2011). Farther more, Family systems theory is one of the vital theories when working with parents of autistic children. Family support is the most coping mechanism for parents of autistic children, so that, family as a whole and parents particularly work together to ease their child's problem. (Paylo, 2011).

## Chapter Three

### Methodology

The study employed a qualitative methodology to gather relevant data and information from the parents of autistic children. Based on the assumption that qualitative methodology is highly relevant to meet the study objectives, to get the required information, and to undertake a deep exploration of the views and lived experience of parents of autistic children

#### 3.1 The Study Design

The qualitative study method was selected to assess the psychosocial and economic experiences of parents of autistic children at Nehemiah Autistic Centre. From the qualitative method, a phenomenological approach was employed for this study. Phenomenology as a qualitative methodology enabled the participants to share their experiences and voice their concerns. The phenomenological approach entails finding the meaning in human experiences, as related by the participants in the situation. The process allowed the researcher to understand the perspectives of study participants, as recounted by the participants themselves. A phenomenological approach is also suitable for understanding subjective experiences, and understanding what motivates people to behave in a certain manner

The phenomenological approach is the best way to understand different parents of autistic children who have common or shared psychosocial and economic experience about autism on their psychological wellbeing, social relationship, and economic status.

#### 3.2 Research Site

The study was composed of parents of autistic children at Nehemiah Autistic Centre. Nehemiah autistic center is found at Kirqos sub-city in Addis Ababa. Relatively, it is located near Agona Cinema, or Behind Gotera condominium. It is one of the two centers in Addis Ababa, Ethiopia. It is located and operating only in Addis Ababa. Currently, it is providing care and support for more than 60 autistic children. For this particular study, Nehemiah autism center was taken as a research site purposely for a couple of reasons. Firstly, in this center, there are integrated services provided both for the children with autism and for their parents. Next, the center is working on networking activities with different collaborative government and non-government institutions for the sake of sharing information, experience sharing, transparency, and fundraising activities and to make community awareness regarding autism and its impact. Now the center is giving training and treating Autistic children at its facility in Addis Ababa. The center provides free of

charge for treating children and transportation costs for those parents who can't afford to send their autistic children to the center due to the reason that it is difficult to use public transport for these kinds of children. Nevertheless, it accepts contributions from parents based on only their willingness. Finally, the center is working hard to accommodate the rest autistic children to the center from the waiting list.

### **3.3 Study population**

A sample that best represents the diverse source of information and opinions of those potential sources of information willing parents of autistic children have been considered regarding choosing participants from the center. According to Creswell, J.W (2007) in the phenomenological approach, the recommended number of participants in the study is between 5 and 25. Therefore, based on the inclusion criteria the eight participants from the center have been selected purposively. Also while choosing the sample, the researcher, and the management body of the center were tried to make an appropriate allocation of numbers for severe autistic cases, medium, and low cases as much as possible.

### **3.4 Sampling Methods**

The sampling method to select participants for the study has been a purposive sampling of non-probability sampling method which entirely depended on the willingness of the informants to answer the interview questions. Even though, the interview depends on their willingness. The parents of autistic children were selected according to the following criteria:

- ✚ All participants have an autistic diagnosed child,
- ✚ participants who are regularly coming to the study center,
- ✚ participants who are willing to share their experience, and
- ✚ Participants who are residents of Addis Ababa.

### **3.5 Data Collection: Tools and Procedures**

Data was collected through in-depth interviews under qualitative research methods. An in-depth interview is a qualitative research technique that involves conducting intensive individual interviews with a small number of study participants to explore their perspectives on a particular issue. In-depth interviews encourage study parents to determine the direction of the response and encourage them to reply at length. The major advantage of using an In-depth interview tells more information about what is on interviewees' mind, as opposed to what researchers suspect is on

their minds but because of the covid-19 coronavirus pandemic the researcher was enforced not use key informant interviews and focused group discussions to collect data from study participants. Visiting the parents' house and autism center is done to measure and ensure the reliability and validity of the data in the study.

As far as the preparation of an interview guide for parents of children with autism was concerned, questions that could elicit relevant information were prepared by the researcher from the available literature and own personal experience. Once the interview guide was prepared, it was commented on and reshaped by the advisor, and peers to assure that each item was in line with the stated research objective. After the researcher had revised and shaped the interview guide in line with the objective of the study, it was made ready to be used in the fieldwork. The next task was translating the interview guide was carried out by peers together with the researcher.

Since Amharic was a vernacular language for the researcher, it had made the interview process smooth and without any communication barrier. Besides, the participants were friendly as the interviewer used their mother tongue language. And detailed clarifications were given on matters that needed a brief explanation.

### **3.6 Data Quality Assurance**

Data triangulation and reflexivity were conducted to assure the quality of the data. I will assure the quality and the reliability of the data and examine the data gathered from participant in-depth interview and telephone interview by using data triangulation. The study was maintained by using the following supportive operational techniques: collecting rich data by careful interview of individuals (single parent) and groups (couple) from homogeneous participants, and using the multi-method strategy of data collection, which consists; in-depth interviews and some telephone interview. Reviewing of the interview guide by advisor and peers those who have experience on the area of qualitative study; Member check of the analysis result is made to check that the analysis result is exactly as participants experiences before writing of final result report by inviting to read the translated data for study parents. Six of eight interviews has been audio-recorded and noted on a hard copy to provide back up.

### **3.7 Method of Data Analysis**

Data collected from participants were thematically grouped, transcribed, organized, and analyzed qualitatively in a narrative form (direct speech of participants). In doing so, the thoughts,

feelings, emotions, and beliefs of participants have been emphasized. Hence, attempts are made to put the direct speech of participants. The researcher pays special attention to the actual words that participants use frequently. The obtained interview data were translated directly from the parents' mother tongue to the English version by the researcher with the consultation of the advisor. Study findings were coded like parent 1, 2, 3.....8. Finally, a discussion of major findings was made by categorizing findings into the following major themes

These were: Knowledge about Autism, Feelings about Autism, parents' Acceptances, Psychosocial experiences, economic experiences, the support needs these parents want, and the coping strategies to address the issue.

### **3.8 Ethical Considerations**

The study was conducted transparently. An approval letter was taken from the management body to undertake the study with full disclosure of the study process and potential benefits and implications. All participants of the study were informed about the purpose of using an audio-recorder, the nature of the study and should request their consent to participate. This is primarily meant for the parents of children with autism. Only those potential respondents who would give their consent to participation without pressure participated in the study. The data collected only used for the study purpose. Individual identifiers like names have been changed in the report to protect the participants' privacy. The researcher is also committed to reporting the research findings completely and honestly, without misleading others about the nature of the study.

## **Chapter Four**

### **Study Findings**

At this stage, the researcher had collected the data from the field, through the in-depth interview which was relatively the most rigorous stage of the study. Hence, this chapter is exclusively dedicated to present the major findings of each participant independently. Accordingly, the background information of participants including the age, sex, educational level, socioeconomic status, parent background which were believed to have their own contribution on the

psychosocial burden, economic burden of autism on parents of autistic children, their Support needs and coping strategies were presented.

From this study finding the parents' age ranged from 27-55 years, two participants were uneducated and socio-economically disadvantaged whereas the other participants were found to be educated. One of the study participants was diploma holders in the field of information technology and in teaching and the other is engaged in their own business after taking some business courses. The psychosocial experiences of parents of children with autism such as their feeling, self-confidence, fear, worries, aspirations, and other related psychological conditions of each participant were also presented in detail.

The social experiences of parents of autistic children mainly revolve around social isolation, exclusion, social support; friendship formation, and related social experiences of participants, the support needs and coping strategies of existed for these parents at the center and outside of the center are presented. The economic experience of parents of autistic children such as employed, individual, laborer, homemaker, and related issues of these parents are presented. For the sake of privacy, fictitious names are used instead of the original names of study participants.

### **Parent #1**

She is a 38 years old woman and she has three children one of eight years child was autistic. She discovers the diagnosis of her son when he was 4 years old and there were no symptoms that lead to the case until three and a half years. She does not have any idea about autism before until she discovered the issue. About this, she said;

‘‘Immediately the doctor told me the child’s behavior is because of a condition called ASD. I was shocked, I did not understand, I had never heard of it. I wanted to kill myself and it was not

easy to accept and I was in a coma for the 1st 15 days. Finally, after having a conversation with my family members and physicians, I calmed myself and accepted and started giving special treatment to my child”

Nevertheless, having a child with autism where it is considered as the sin of parents and God’s punishment for them. These were the big challenges for her to share the issue with others and to go to the public. Still labeling individuals by their disability was common. This leads to parents to get the psychosocial and economic impact of autism. The psychological impacts on her life were due to the low-level awareness of society about autism. Some people think that autism is caused by the sins and curses of the parents, while it is not known. Most of the people black mouth about the parents of the child with autism and they draw unwanted attention towards the autistic child and their families. This leads her to get stress, anxiety, depression, and disappointment. Regarding this she reported;

“I always worry about the next child and I thinks that I was misfortunate when I compare my child with others.”

Now she believes, it can be improved and could be like other normal children. Autistic children can be taught and improve their behavior. She has a big hope that her boy will improve very much. In another hand, the social experiences are not a concern for her until now since her boy is too silent and doesn’t show any noticeable autistic behaviors. In addition, she has family support to handle the problem since one of her brother's works in the health area and her mother knows about autism well.

“Having a family support and joining Nehemiah autism center plays an important role in my life to know about autism and the way how I treat and develop a lot about taking care of my child and emotional support for myself”

Since her source of income was only from her husband’s job. There was a very difficult situation to manage the autistic child for her. Economically she suffered too much. It was much cost to raise an autistic child since they won’t eat everything provided for them. They are very selective and need frequent treatment and care. Moreover, there was no means of support from anybody and it is understood that if there were anyone who could support her she would love to be helped. Regarding this she reported;

“Due to the special needs (he like meat always) of my child, I can’t afford it”

The center gave monthly training on how to feed, dress, eat, and make her child sleep soundly at night. In addition, also gave a fee-free transport service for her autistic child. This was psychosocial and economic relief for her because it is difficult to use public transport for individuals who lived with autism.

### **Manner of dealing with autism**

1. As she said, first she had a conversation with her family, so it helped her to deal with the first emotional crisis by having a number of conversations and information’s about autism from her family.

2. Secondly, she joined Nehemiah Autistic Center, and she got a chance to share ideas, thoughts, methods of handling an autistic child, and some other emotional and social support from the center.

Individually she tries to teach her boy some things and doings. As she observes him doing things that she taught, she feels that he can learn and improve his communication. Therefore, she always had a big hope that he can improve and live like normal people.

### **Parent # 2**

She is a 35 years old woman who lived in Addis Ababa around AddisuGebiya next to Sarem International Hotel. She is married and has three children. One of the children, the youngest who was eight years old has autism and the other two do not. As far as her family background was concerned, her husband was a businessperson and has a good income. Concerning the child, at first, she discovered some stereotypical abnormal behaviors and took him to a family doctor. The doctor there told her that the child is autistic and immediately she reacted as if she was struck with thunder. With regard to this situation, she reported in her own words like this:

"When he told me that my child is autistic, I was very shocked and couldn’t accept the fact for a long time. Farther more, I felt ashamed to share my feelings with others even friends, because I have no clue about autism before, then after calming myself up, I again went back to my doctor and asked him what I should do, and advised me to consult professionals and get help.”

Consequently, she went to talk about the issue to her husband in case he helped her but he was not able to accept the issue. After a month’s he went back to the issue and he suggests her to take the child to her mother. She gave her child with autism over to her mother to watch him over by

budgeting a large amount of money and the needed material that helps the children who lived with autism but that did not even work out because the grandmother complained of his unusual behavior and the negative attitude as well as comments of the scold people around and eventually she gave him back to her. After that, she started taking care of him by herself by quitting her job. With regard to this situation, she reported in her own words like this:

“Hearing and looking at such a response from my own mother was a painful and dual burden for me. Then after, I decided to never give him away from me no matter what but through the continuity of unusual behavior of my son, I began to experience loneliness, depression, socially isolated and stress especially when my other two children were away from school due to the relationship with their brother and finally I got sick. Then, I go to the doctor who diagnosed my child before and I told my story about the issue and he advises me to take some immediate solutions such as finding the right place to teach my child important life lessons .”

The next step she did was to look for a center/school to get support for both of them. She replied that; “In fact, it was not an easy job to look for a center and got acceptance. Fortunately, when I confided in my child’s situation to some friends, they directed me to this center. Then, I went there and requested them to take in my child. Nevertheless, they told me that I had to wait on the waiting list until they called me when they got a vacant place.”

In the end, they accepted her child and started to care for him basic life skills like talking, toileting, writing, playing, eating, drinking, dressing, and the like even though the change was very slow. The fact was many of her problems with regard to her child were being solved despite her child’s being resistant to change. She said;

“It is very interesting that I am beginning to experience happiness just because primarily I get the center to teach and care for my child. Second, the monthly formal training and the feedback about his daily activities from the communication book together with a series of tips such as the kind of food I should feed him and the like are helping me a lot in shaping my child when he is at home with the family. What is more, before he was admitted to the center, he was very nasty in the car when I took him to some recreational centers but now he is becoming peaceful. This change is achieved because of the appropriate support he gets from the center and I am grateful for this. ”

She further reported that she was a homemaker and economically dependent on her husband but as a parent she wished her child to become healthy if appropriate support is given for him. She suggested that having an autistic child strengthened her belief in She explains that; 'I had begun to pray more when I discovered my child had autism and that, for me, was an important religious experience.

### **Manner of dealing with autism**

1. With their family, they have been communicating and advising each other. They already have come to understand the behavior of the child and with clear communication between the families; they are handling all the impacts together.
2. By consulting with physicians and with Nehemiah Autistic center they have come to understand autism and the behaviors of autistic children. They are able to understand the challenges and their management.
3. Spirituality is another important coping mechanism for her, she began to strongly pray to Allah and she attended mosque frequently.

### **Parent # 3**

He is a 42 years old man who lived in Addis Ababa around AddisuGebiyaDilber. He has two children & one who is six years old boy is autistic. As far as his educational background was concerned, he has had 1st degree and he works in a government office. It has been believed by many that it was mothers how have mostly suffered by the caring child with autism but when it comes to him the reverse was true.

He has no idea about autism before, but after the occurrence of the issue in his child, he was tried to refer to different materials related to the issue and he understood what autism is. Up until this year, the boy as well as his family members could get no support from anyone in particular. He comes to know about autism after having many diagnostics on their child confirmed that it is autism by physicians. He believed that the reason for autism is not a religious issue, doing sinful things, or a curse. He also believed that there was an accident that happened to him when he was eight months baby that probably cause this autism. He knows some children who have autism, improves their behavior, and joins the school with normal children. Therefore, he believed that his son also will change his behavior and join the school. He explained that;

“At first I suffered from emotional and psychological issues due to having an autistic child. I was confused and I don’t know how to handle it.”

He was very sad when he heard the people make some comments and talking about his boy. People discuss that the reason is sin and curse when he hears these comments he was so ashamed and sorrowed. As he speaks; “I was ashamed and ask myself why they are talking like that? Moreover, I tried everything to find a solution for it. I did what some people advise me to do. Nevertheless, in the end, have been come to understand that there is nothing I can do to cure it instead, I accept as it is and live with it. Now I can see that he is improving and I am happy to live with him.”

The most difficult thing for him was handling the social crisis or social impacts because due to his autistic child he could not be able to join family meetings and invitation to any family ceremony. The child was very nasty in behavior so he could damage (ruin) anything within a minute. Both couples are enforced to reschedule their working hours in order to take care of their child. Due to these changes, they have reduced and weakened their social interactions. “He reports this situation in his own words “

“I couldn’t be able to say something I wish or wanted to say at work and any other meeting as he was working less time compared to other workers.”

He thinks that the company helped him by reducing his working hour up to 9:00 LT and due to this he feels less confident to ask for any promotion. The family has to work hard to overcome the economic impacts induced due to the autistic child. He and his wife have to take care of the child themselves since the caregivers could not handle the behavior of the child and they are not willing to in such kind of child. Raising a child with autism is a full-time job for that matter they could not be able to work and earn money for a living easily. He himself could not take a job offer with a higher salary because they could not rearrange their schedule for him like the one he is working on now. Even he could not work overtime and get some extra income and request for promotion. Know today, he was happy; because of the support, he was given from the center and

there is progressive of their child. In addition, he stays at home, due to the pandemic covid-19 corona-virus, and he giving full-time care and attention to his child

### **Manner of dealing with autism**

1. He did not get any economic support from any organization or agency but joining Nehemiah Autistic center help him to get rid of some social and psychological issues.
2. Individually he tried to know his boy and take the responsibility to teach him. He gave love and teach him frequently he thinks he has made some difference.
3. He started reading more about his religion; want to know more, like what wrong he did? He keeps asking like, Please, God, cure my child, and what can I do in return.

### **Parent #4**

He is a 55 years old man who lived in a small house rented from “kebele” with his family and he has three children out of which the youngest 10 years old child is autistic. With regard to his family educational background, both of them were 10th completed and he was lived with a disability, which is blindness their life was in poverty.

At first, he did not know anything about autism up until he heard about it from other persons secretly talking about his own son. Some of them even asked the couple whether it could affect their children while playing with him. Then, they started searching for some information about the kind of problem. . Autism for him is a very difficult mental condition and kids with autism are very difficult to handle. Especially when the parents have disabilities like him, (he is blind). He finds out when the boy is 2 years old and it was very horrible at the time. He explains the situation as;

“I didn’t accept it easily I was shocked and feel sad. I cannot be able to express the moment when I have been told. Now it is been 10 years so, he has been improving and has changed a lot.”

There was a very difficult time for him psychologically he suffered a little while the first 2-3 years and then he has come to accept it. He said, accepting the situation helped him to make a helpful arrangement for the boy. Regarding his child, he has not faced with that much discrimination and social isolation, because of the greater effect that comes from a society where based on your child’s severity and nasty behaviors. The only problems with his child were communication. He reported this issue in his Owen words;

“My child is great fun when wherever he, but he cannot express himself at all. This was a challenge to meet his basic need.”

Socially there have been so many comments and suggestions but nowadays, he comes to pass those challenges. The most difficult challenge was the issue of the economy and he has been challenged still he should have to care for him. For the survival enforcement, he had worked at the Ethiopian disabilities association but he stops know, due to the pandemic covid-19 coronavirus. Whereas his wife worked at a small business (Gulite) though, she stopped it because of his son. He has found the fee-free service provided in the center to be satisfactory. It helps him to ease the economic burden of him in some amount.

### **Manner of dealing with autism**

1. Joining Nehemiah Autistic center help him to understand autism and the way that he cops the behaviors of his autistic child.
2. Support groups are another coping mechanism for him, there is a time to discuss with parents who have a similar case and they are confident to discuss it in free.

### **Parent # 5**

She is a thirty-one years old woman living in Addis Ababa with her husband’s family. She was married and has two children. Both of them have autism. They are male and female, the male one was 6 years old whereas the female was 4 years old. As far as her family background was concerned, her husband was a freight transport driver, and she was a homemaker. Nevertheless, he had little concern about the sick children except for providing them financially and deliberately acted as if the child did not belong to him and this has always stressed the mother out. Up to now, he did not accept what happened to his children.

She had a little concept about autism and previously she believes that the cause for autism was; When women give birth at their late age, taking some vaccines were given when the mother where pregnant and there was an accident happened while she pregnant with the first child. She clearly defines autism as a behavioral disorder when a similar case happened to her second child (Girl). She believes that her reasons are not acceptable as a real cause of autism. She explains as; “Concerning the child, at first I discovered some stereotype abnormal behaviors like sleeping sickness, aggressiveness, picking an object, again and again, noisiness and destructiveness were some of the behavior where I saw from my autistic children. Especially on my young female, such characteristics were observed more.”

The next step she did was to look for a center/school to get support for both of them. She replied that; “In fact, it was not easy to look for a center and got acceptance. Although, after critical finding, I got the contact number of Nehemiah autistic center through the website and I contacted the head. Nevertheless, she told me that I had to wait on the waiting list until they called me when they got a vacant place. After years ago, they call and inform me that I got the chance to afford my children on it.”

She was somewhat happy with the service given in the center primarily because he got relief and could manage to do other routines; secondly, the child has also become responsive because of the support from the center. When too many people talk about her and her children especially old-aged people, she always cried and was so emotionally abused. Because most of them talked that, this autism is caused due to sin and curse. Even her husband told her it was her fault to give birth to such a child due to this she feels sad and unfortunate. She has been crying and very emotional for a long time. After having a clear conversation with doctors, she was able to understand the case and help herself in order to withstand such comments and misjudgment of society. Now she believes that if autistic children have given treatment in their early stage they could improve their behavior.

Due to the Societal Misjudgments, Social discrimination, she becomes less confident and emotionally weak. She has been thinking she was punished and tired of being judged she even cries when she saw carton movies. She reports this situation in her own words;

“I have been miss judged even my husband blame me. I feel like I have been punished and there is nothing I can do I even cry with simple things like when I watch cartoon movies. I didn't

know what I should do. Recently I have been ignoring things and accepting the situation. Now I believe my only choice is accepting and live with it.”

She could not be socially integrated with anyone since the behavior of her children was very difficult to handle she was the only one for six years. She could not have any social relations with her family members as well as her neighbors. She always stays at home for her children. Somehow, the stress-induced from misjudgment of the people will make her socially awkward. Her husband was the only source of income for her, she could not have any job. She has graduated with a Diploma but she never works or used it for a job. Now the pandemic covid-19 coronavirus was affecting their life more because her husband stops working.

#### **Manner of dealing with autism**

1. She has taken some advice and teaching about autism from Nehemiah Autistic Center which helps her to give good care of their children.
2. To handle the economic crises they move from Addis Ababa to Oromia,Regional State. Because they were living in the house they rent in Addis Ababa, now they move to the house, which they are building. This will reduce the cost of living and still she is the only one who cares for her children

#### **Parent #6**

He is a forty-two years old man and has three children. One of the children is a 13 years old child with autism. As far as his family background is concerned, he works as an instructor at Ethiopian Civil Service University and his wife was a school teacher. His carrier helped them to have a clue and understand autism before they had one autistic child. He found that his son was autistic when he was two years old. The case could not create any emotional and psychological impact on him even though they were told that it was a curse. Emotionally he was stable even though some people talk a lot about the cause of it. He believes that there is no clear reason for autism and he believes that if the child with autism has been given proper treatment and care they could become better and like other normal kids. The only burden created on his life where economic impact and caring for a child with autism was not as easy because they need full-time attention.

#### **Manner of dealing with autism**

1. The families know and understand about autism before the boy is born so they didn't suffer too much. Mostly by themselves, they have handled their issue as a family, since they both are well-educated, and knowing about autism helps them to overcome the social, psychological, and economic crises.

2. They share ideas and thoughts from Nehemiah Autistic center, which helps them to increase their communication with their child.
3. Both couples are working to secure the economic issue.

### **Parent #7**

She is a 27 years old woman who lives in Addis Ababa. She has three children and one of them has autism. His Name is Alli and he is 5 years old. She found that her boy was autistic when he was 3 years old. She had little information about autism and now after having an autistic son she becomes more aware and she defines autism as a situation or behavior, which is very difficult to handle. When he discovered the problem she was feeling sad and it was a challenge to accept. She reports the situation in her own words;

“I couldn’t believe that my son was autistic he was just a cute boy and he always being silent. I was expecting that he will start speaking until the age of (3) but he could not speak. Some people and family members were assuming it might be the cause of autism and I didn’t want to believe them and just I wish it was not”.

When she expressed the feeling by the time, she said; “I feel so sad by the time it took me days to accept. I was thinking about what the doctors told me. I ask myself am I dreaming or not? But it was true my son was autistic.”In the first 6 months, she was challenged with psychological cries and she blamed herself while there is not any reason for her to blame herself. Later she just accepts the case and lives by giving great care for her son. Her husband also took a long time to process and accepts the situation of his son. Nowadays they work together to overcome the psychological effect. The only support they have got from Nehemiah autistic center, physicians, and expertise was very helpful for them to overcome the psychological effect induced on them. After she discovered the issue there was nothing to do. There is not any social impact or influence induced on her due to her autistic son and she was safe from the economic aspect. Her husband were the driver and their only source of income where his job. She always spent her time at home in her child’s care.

### **Manner of dealing with autism**

1. The only help she and her family gets is from Nehemiah Autistic center, physicians, and expertise it very helped fully for them to overcome the psychological impact-induced on them.

2. There is no other economic and social support for their family. As she said, she spent at home every time and she always looks for events and speeches about autism so that she is actively participating to increase her understanding of autism. She always follows the events organized by Nehemiah Autism Center. Now she is caregiving her son to improve his behavior and become like normal boys.

### **Parent # 8**

He is a 43 years old man who lives in Addis Ababa and he works at the Commercial Bank of Ethiopia. He has two children and one of them is autistic. His autistic daughter is 9 years old and they find out she is autistic at the age of three. His family was so confused and very sad about the situation at first when their child becomes autistic.

He said, “I had information about autism because one of my closest friends had a child with autism and I have seen him suffer a lot. Due to that, I had clue about autism before coming to my life.”

As he explains the moment when he hears the case on his daughter he said, “I feel like I will be walking in my friend's footsteps and suffer like him immediately when I know my daughter is autistic. It was very difficult to accept even my wife tries to kill herself she couldn't be able to handle it easily.”

He does not really know the real cause but he said, “The reason we suffered emotionally was that our first son is healthy and we used to believe that the cause for autism would be something which is related to genetic of the parents.” His families were suffering psychologically because they also believed as in other society autism was caused by sin, curses, and genetic or biological causes. In addition to this, they become socially isolated due to the nasty and difficult behavior of their daughter. The other thing he said about their economic problem since he is the only one working currently they have a single source of income. They face difficulties in managing his autistic child because she is the most severely autistic child. So, she costs a lot. Even though he works hard, but the family needs economic support from his family members or any other source. As he said most of the time it was difficult to find any support. They need special medical and professional support but currently, they get support from the autistic center. Since the child is in severe cases she needs intense care and education in order to improve her behavior.

## **Manner of dealing with Autism**

1. Advises from family members and from his close friend helped him to overcome his psychological and social needs. He always asks their friend for advice when he observes new behavior in his child. He also asks help from family members regarding caregiving for some time.
2. He got professional support from the autistic center where their child is attending. He always asks medical professionals like therapists for them in order to care for her. He also uses religious practices to overcome his emotional, psychological problems.

## **Chapter Five**

### **Discussion**

ASD is the fastest-growing developmental disorder and emerging public health issues globally that is associated with a huge psychological and economic burden. The study was conducted to assess the Psychosocial and Economic Experiences of autism on parents of autistic children. A total of 8 parents of autistic children were included in this study. The present study was act as a source of evidence for future planners, researchers, and policymakers. In this section, major

findings of the study are discussed based on the themes includes knowledge about autism, feelings, acceptances, psychosocial and economic experiences of parents, support needs, and parent's coping strategies.

### **5.1 Knowledge about Autism**

From the data collection, the characteristics of autism spectrum disorder are what made the parents realize that their children had the disorder. The majority of the parents did not have any prior knowledge about the disorder. Study participants were asked about their previous knowledge about autism and what their action during the time of autism diagnosis. The majority of study parents have no clue about the diagnosis of their autistic children. Even some of them never heard what autism was. At first, they suffered from emotional and psychological issues due to having an autistic child. They were confused and did not know how they handle it. One parent reports: “Immediately the doctor told me the child’s behavior is because of a condition called ASD. I was shocked, I didn’t understand, I had never heard of it”.

The major source of information for parents in this study was their doctors, with a few looking the disorder up on the internet for more information, family members, and peers as to how best they can help their children. Most parents in this study joined the parental meeting and training session in Nehemiah autistic center to help them deal with their situation.

The study findings revealed that many parents had no prior knowledge of the disorder. Parents gained an interest in information about the disorder after their children were diagnosed with the disorder. From the study, all participants to gain information on the disorder usually relied on their doctors and other medical practitioners as their main source of information. The findings of this study agree with a recent study on their assertion that parents relied on doctors as their source of information on their children disorder, however, parents in this study also relied on their doctors, family members, peers and look through the internet for other sources of information that may help them with their situation. On the other hand, study parents of the present study considered autism as other disabilities, like mental retardation and other health problems. Regarding this one study parent reported this; “I couldn’t believe that my son was autistic he was just a cute boy and he always being silent.”

## **5.2 Feelings about Autism**

It is difficult to explain parents feeling regarding autism especially when they received a child with autism. For the current study, eight parents were asked about their first reaction when they heard the news of their child's limitation.

The majority of study parents have experienced more negative feelings about their child's autism diagnosis. Some of them reported feelings of grief, shock, sadness, and fear. These beard difficulties for them to do the right and appropriate care and support for their children accordingly. The absence of professionals in the field was another challenge and it was not easy to share their child's condition with other even friends. As one parent reported;

“I feel so sad by the time it took me days to accept. I was thinking about what the doctors told me. I ask myself am I dreaming or not? But it was true my son was autistic.”

## **5.3 Acceptances**

Having a child with autism was considered as shame and it was the result of a parent's sin or other related issues because accepting the problem where challenge and difficult for these parents. Due to the lack of acceptance of the behaviors associated with autism by parents by themselves, family members, and community, and the low levels of support provided to parents of autistic children. For example, one parent has said;

“Up to know my husband did not accept the issue that happened in our child”.

One other parent also supports this; “It was not easy to accept, and I went to kill myself, and I was in a coma for the 1<sup>st</sup> 15 days.”

## **5.4 Psychological and Economic burdens of Autism on Parents of autistic children**

Autism has a major effect on the lives of the affected children, their parents, and the whole family.

Parents are the ones who shoulder the responsibility of caring for their children. It becomes a burden when it comes to those parents of children with autism. A child with autism is true with many special needs and requires close attendance.

### **5.4.1. Psychological Burdens**

A psychological problem is one that affects and changes the life of an autistic individual, the parents as well as the family as the whole. The parents of a child with autism often experience

disappointment, social isolation, added stress, frustration, and helplessness. These compound stresses and the presence of a child with autism may affect the family's wellbeing and interfere with the child's development. Therefore, to prevent the incidence of these socio-emotional barriers and for further the development of children with autism and the wellbeing of their family members. Parents of an autistic child will have an extra burden for the sake of their child's care and treatment. Understanding the way how they care and meeting the need of their autistic children were the effortful task for them.

These problems are exactly the case of seven parents in the study. Thus, their state of depression leads to the feeling of inferiority, and self-hate redness should not be surprising. The fact that, parents of children with autism are secluded and underrated by their own families, friends, and others who had close relationships with these parents and the society often advise and comment them to hide themselves with their autistic child. This happened because especially the lack of commitment and involvement of government, media, and the communities are compressively not doing their very best in educating the people through different programs to create awareness.

The present study identified that parenting a child with autism can be extremely stressful and can affect a parent's physical and psychological wellbeing. This was a view shared by nearly all the parents interviewed, and all of them emphasized the demanding nature of the care. For example, one of the parents has said: "It's stressful, life-changing, not what you planned."

The majority of study parents spoke of the challenges they faced when they were out in public with their child. They cannot travel on foot or on public transport, that for sure. Everything they want to do, they have to think, "What are we going to do with our son? Where are we going to put him?".

The continuity of the issue in the life of parents brings many emotional impacts. A study shows that parents of autistic children always blame their status of mental health as poor or fair, especially for mothers. Compared with the parents of the non-autistic child, their stress level was much higher.

The recent study indicated, besides having higher stress levels, parents of autistic children were experienced in different ways. Such as fear over their child's nasty behavior in public, Feeling of a lioness, Frustration in the different parenting experience they have and the one they had envisioned, feeling of Guilt due to their child's condition, the nature of incurability and Feeling

of overwhelming. The current study shows that the degree of impact that parents faces vary depending on the severity of the autism, but the autism-related issues that parents have to deal with are similar whether a child is severely affected or has high-functioning autism. Since the center is established to reach children with autism and their parents, Nehemiah Autistic center has every responsibility to train them in the home level as deeply as possible to bring about tangible changes on all the family members. Consequently, this endeavor helps those parents who cannot come to the center to take the training. Therefore, task-burdened parents can be relieved psychosocially.

The study finding revealed that autism is an emotional related disability that begins before diagnosis and continues throughout life. Mothers of children with autism frequently rated their mental health status as "poor" or "fair". They had a much higher stress level than the general population. Autism affects the overall psychosocial and economic wellbeing of parents of autistic children lies. To ensure the healthy development of the child, it is important to ascertain that primary caregivers need to be in a positive psychological state. It is believed that although research evidence supports parents of children with autism face a variety of challenges and stressors, there is hardly any work focusing on parental perceptions and experiences. The parent will experience difficulty clarifying the needs of their child diagnosed with autism while the child will experience difficulty expressing their own needs. This can often result in aggressive behaviors for the child diagnosed with ASD as parents may be unaware of their child is hungry, sick, tired, hurt, sad, or mad. This is somewhat similar to the present study.

#### **5.4.2 Social Burdens**

Parents were experienced by Inevitable and old hazardous traditional beliefs of discriminating and looking down of parents of autistic children were common. Hence, the social well-being of parents of children with autism is profoundly jeopardized. The present study shows that parents of children with autism were the central targets of social stigma and discrimination. Also, their social relationship with other societal groups is found to be very limited, and it makes them have a feeling of isolation and loneliness. Also, the superstitious thinking of the society is so hard that they do not even want to share things with these parents. Labeling individuals with their limitations are common, and society shows pity and sympathy whenever these parents are out on the streets with their children with autism. But these feedbacks would not help the parents rather

than destroy their confidence. Parents were experienced with various types of challenges that start early and last a lifetime.

The recent study finding revealed that parents with autistic children were ashamed of their child due to the misunderstanding of society at large. They feel personally responsible for their child's condition or believe that the symptoms of autism are a curse from God, rather than the manifestation of a neurobiological condition. Autism does not only affect individuals with autism but also their parents and family as a whole including; the marital system, the parental system, the sibling system, and the extended family system. Due to these compound societal problems parents not sending their child out into any family program, the community to play, or for social participation. This is all most all similar to the present study.

Therefore, for this and other reasons, parents in particular and the families as the whole comprehensively have to integrate into the society unconditionally by educating the people at large.

#### **5.4.3. Economic Burdens**

The economy is the other challenge for parents of autistic children when they received their child with autism. Parents with autistic children face a huge economic burden. Cost for autism care and treatment and cost for different therapies that are not covered by government and other stakeholders especially in health insurance.

The present study shows the fact that caring for a child with autism was a full-time job. Many people do not know the costs associated with raising a child with autism even family members. In most cause, parents of autistic children stay at home with jobless hours due to the severity and nasty behaviors of their children, and this makes it difficult to leave an autistic child with caregivers (servant). Poor parents could not afford the cost of equipment like a dipper, toys, puzzles, and other educational materials for their children. The dipper cost was the most serious and inevitable economic burden for these parents to manage and to keep the personal hygiene for the severely autistic child. Furthermore, financial stress may cause problems between spouses. Therefore, the economic capacity of these parents was poor, and they practiced a subsistence way of life.

The recent study finding revealed that having a child with autism resulted in an average of 14% loss in total family income. It is often extremely difficult for both parents to continue working full-time, which means a reduction in household income to go along with the increased expenses.

Since many parents need a full-time job to provide health insurance, loss of full-time employment can have a dramatic and negative impact on family finances.

One study finding indicated that parents of autistic children in Ethiopia, particularly mothers, become disabled themselves. Burdened with the full responsibility of care, and likely have very little income, their child's disability directly constrains their ability to work and make a living; to take care of their children and themselves. Often, the exceptional demands of the child's disability also create emotional and financial problems for the parents. They must stay home to manage their children, though financial demands mount. They are unable to work because their children are often not allowed to attend regular schools for children their age. Direct and non-direct costs were a challenge for parents with autistic children. The Economic burden of autism on parents with autistic children was high.

in some the study findings are similar with the present study and on some issues, there is a difference is conducted in-country level and the magnitude of the economic burden were majored by ratio whereas the present study is limited in Nehemiah autistic center Addis Ababa, Ethiopia. And the rate of economic burden has not major, and it was written in narrative form.

## **5.5 Support Need of parents**

Parents of autistic children have various support needs. Based on the study, the participants' main concerns included the security of their children's future, specifically on how their children will manage the pressures and responsibilities that adulthood entails. The researcher highlights the major support needs of study parents as follows:

### **5.5.1 Professional support**

The present study finding shows that the major need for parents of autistic children were having professional support and better services. Parents also explained that government and NGO involvement must be essential in finding adequate professional and institutional support for their children. As some parents Indicated, the absence of a specialist in the field leads parents to search for professional support. These are significant indicators of the importance of getting proper support for though the problem is widespread and needs immediate intervention, the solutions, particularly professional help and services available are practically non-existent. This shows that it is an area that needs social work intervention through different methods including advocacy.

One study finding revealed that “parents of children with autism need professional support to cope up with the disorder positively.”

### **5.5.2 Social Support**

According to the parents interviewed for this study, social support groups are also essential in helping them cope with the challenges of parenting and social impacts induced to them. Social support groups were able to provide these parents with a means of outlet and a safe environment. In addition to the psychosocial support these parents are giving one another, the support group is also helpful in sharing new information regarding the support available and other helpful information about the disorder. The problem was not something you talk about with anyone. The majority of the study parents are not comfortable discussing in confidence due to a lack of societal awareness about the problem. However, they confess that their social meeting at the center helped them to overcome the social problems in their living environment.

The study revealed that the support from spouses and immediate family members remain fundamental to overcome some impacts of having an autistic child. Although other relatives, friends, and neighbors give out their support to these parents, their basic needs could only be supported within the nuclear family.

### **5.5.3 Government Supports**

Governmental support is crucial. It is expected that the government looks into the limited number of autism centers and their shortages of materials and equipment. Throughout the whole of Addis Ababa, so many parents of autistic children are waiting for their turn to enroll their children in the center. Imagine in a country level how many people are waiting to try their chance in these countable centers. Government support is also expected to hire different professionals like social workers, psychologists, psychiatrists, and therapists in well-organized autistic care and treatment center and even in health centers. Due to this, government support is highly required for the development of a new and well organized huge autistic center.

### **5.5.4 Media support**

Media support is also another important support need for parents of autistic children and it may play a great role for parents of autistic children in creating awareness in public towards autism and its psychosocial and economic effect on these parents. Due to a lack of media support, public knowledge about autism is still very low. It is obvious; Media has played an important role in

building strong networks between parents of autistic children who have common and similar problems and to find different support groups to improve psychosocial and economic wellbeing for parents of autistic children.

## 5.6 Parents Coping Strategies

Coping strategies are crucial for parents of children with autism because of the challenging behavioral problems that the disorder manifests and it can have a significant impact on parent's quality of life. Autism causes a wide range of behavioral and intellectual challenges, and parents will necessarily have to develop strategies based on the degree of surveillance and assistance that the child requires.

A study executed involving parents of autistic children indicates a positive evaluation of direct services to their child. The present study examines coping mechanisms were parents used to manage to raise a child with autism it was studied by categorizing into four groups.

**First Coping Mechanism is Seeking Answers:** - It means among all study participants mentioned seeking answers as a coping mechanism through educating themselves and seeking treatments. This helped them to cope with the grief and anger they encounter due to the situation of their child.

The second Coping Strategy is **Support Group:** - It means discussed issues with a support group of similar people: all in all participants said that they found support groups to be very helpful because they were able to discuss their problems with parents who had similar experiences. One of the participants said:

“We share our ideas and experiences, which significantly help us to overcome some psychological and social problems. Mostly we do not need to share stressful ideas not only for ourselves but also for others too. We discuss things for those who can really understand and empathically sense what we are talking about”. Two out of the interviewees said they had founded a support group of their own because there had been no equivalent organization available with Nehemiah by the time. The other participant also said:

“We helped each other to accept our kids first, and then helped them with whatever resources we have here in Nehemiah. Besides, we helped each other with experiences about good treatments, what worked with you, and what did not.

Support groups are beneficial for several reasons. Parents can gain knowledge from professionals or other parents, make friends, and discuss resources. For example, one father explained how

meeting with other people who had a child with autism enabled them to offer psychological and emotional support to each other. One of the parents said: “When we know that there are others who are facing similar challenges, it helps us to accept and overcome the psychological and emotional crises because we believe that we are not lonely and it wasn’t our fault for our child to be autistic, and that’s the key driver”

**Finding Something Positive in any Comment of the Society:** - It was the third coping mechanism: focusing on the positive perspectives and developing an appreciation of life as their way of dealing with their child’s situation. In imagining their child’s future, all in all, study parents discuss the importance of accepting the reality and recognizing the limitations that their child were facing. Moreover, these parents explain that they chose to focus on their child’s happiness, safety, and functioning. Above other kinds of dreams, what their children could become.

Finally Practices of **Spirituality:** - This is also used as a coping mechanism. The role of spirituality as a coping mechanism has been discussed in this study as parents (cases 3 & case 5) mentioned. They have discussed how attending church helped them to find support for their struggle. They look to their religion and faith in God or Allah for their coping processes. These parents tend to accept their child’s situation as the will of God or Allah and they believe that some miracle could happen and their child could be cured someday.

### **5.7 Implications for Social Work**

This study helps current and future social work when working with parents of autistic children. It also supports social workers to have deep knowledge about the issue, to give appropriate professional guidance for these parents, and to understand the way to communicate with them. The current study also helps social workers for the development of strategies to intervene in the challenge these parents are facing and to create a strong network with parents and the community through continuous discussions to mitigate the psychosocial and economic challenges of these parents.

This study provides social workers to identify the personal existing experiences of parents of autistic children and to meet the needs of these parents. The implications of this study help social workers on how to support these parents and find resources available for dealing with autism.

These dealing include any supportive groups, other parents of autistic children, religious leaders, social work professionals, speech therapists, professionals of special need, and other health professionals. The study shows parents of autistic children were experienced by psychosocial and economic impacts of autism. Therefore, the implication helps social work professionals to understand the issue and to work in collaboration with parents who have children with autism to improve the psychosocial and economic well-being of these parents.

## CHAPTER SIX

### Conclusions and Recommendations

#### 6.1 Conclusions

ASD affects not only the child but parents and families as well. ASD creates lasting psychosocial and financial distress on parents that can and should be dealt with, along with treating the child. It brings changes in nearly every aspect of a parent's daily life. Therapy sessions, medical appointments, and various other activities can dominate the parent's schedule, leaving little time and energy left for typical parent interaction. Stress levels associated with the issue of autism in parents of autistic children make marital issues more likely with divorce. It is not uncommon for parents, particularly mothers to become weak physically and mentally, burdened, and most probably with no or very low incomes as their child's autism directly constrains their ability to work.

Parents of autistic children are overwhelmed with the prospect of raising a child with autism. Feeling of grief, looking down and blame themselves, disappointment, depression, and even anger are common in their daily life. Parents often feel isolated, having little in common with the parents of average children, a feeling that often grows more pronounced as children get older and the differences in development as compared to other children in the neighborhood become more obvious. The Behavioral issue of autistic children brings that isolation, making interactions with neighbors, friends and even family members are difficult and simple outings to the grocery or mall stressful events for these parents. In a country like Ethiopia; prevailing attitudes towards an individual with autism are not positive. Also accepting individuals with their limitation and their parent is challenge for community, family members and friends.

#### 6.2 Recommendations

- ✚ Social workers should work together with the parents of autistic children to develop strategies in the way they meet the needs of parents of autistic children.
- ✚ The community should know the truth and impact of autism to avoid misconception, misjudgment, stigma, and social discrimination and to make strong solidarity with the parents by reducing the burden they facing.
- ✚ School of social work, Institutions of special needs, governmental and non-governmental organizations should work in collaboration to open other centers for children with autism

primarily to enroll other autistic children who are waiting for their chance to join Nehemiah autism center.

- ✚ Different professionals (like social workers, health professionals, psychologists, psychiatrists, and therapists) and different charity associations should create a strong network with parents of autistic children and the community through continuous discussions to manage autism center frequently and mitigate the psychosocial and economic challenges of these parents.
- ✚ Social media, NGOs, and other stakeholders should work in collaboration to create awareness in public and to have parents free from any social discrimination, stigma, and miss conception.

## References

1. Willis, C. (2006). Teaching young children with autism spectrum disorder. Beltsville, MD: Gryphon House, Inc.
2. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 5th ed.; American Psychiatric Association Publishing: Washington, DC, USA, 1994, 2013.
3. Autisms peaks. (2010). Facts about autism. Retrieved from: [www.autismspeaks.org](http://www.autismspeaks.org)
4. Landa RJ (2008). "Diagnosis of autism spectrum disorders in the first 3 years of life". *Nat ClinPract Neurol.* 4 (3): 138–47. Doi: 10.1038/ncpneuro0731. PMID 18253102.
5. Autism Spectrum Disorder, 299.00 (F84.0). In: American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. American Psychiatric Publishing; 2013.
6. Orsmond GI, Seltzer MM (2007). "Siblings of individuals with autism spectrum disorders across the life course" (PDF). *Mental Retardation and Developmental*
7. Dominick KC, Davis NO, Lainhart J, Tager-Flusberg H, Folstein S (2007). "Atypical behaviors in children with autism and children with a history of language impairment". *Res DevDisabil.* 28 (2): 145–62. doi:10.1016/j.ridd.2006.02.003. PMID 16581226.
8. Ben-Sasson A, Hen L, Fluss R, Cermak SA, Engel-Yeger B, Gal E (2009). "A meta-analysis of sensory modulation symptoms in individuals with autism spectrum disorders". *J Autism DevDisord.* 39 (1): 1–11. doi:10.1007/s10803-008-0593-3. PMID 18512135.
9. Matson JL, Nebel-Schwalm M (November 2007). "Assessing challenging behaviors in children with autism spectrum disorders: A review". *Research in Developmental*
10. Burgess AF, Gutstein SE (2007). "Quality of life for people with autism: raising the standard for evaluating successful outcomes" (PDF)
11. Sigman M, Dijamco A, Gratier M, Rozga A (2004). "Early detection of core deficits in autism".
12. London E (2007). "The role of the neurobiologist in redefining the diagnosis of autism".
13. Lam KS, Aman MG (2007). "The Repetitive Behavior Scale-Revised: independent validation in individuals with autism spectrum disorders". *J Autism DevDisord.* 37 (5): 855–66. doi:10.1007/s10803-006-0213-z. PMID 17048092.
14. Tager-Flusberg H, Caronna E (2007). "Language disorders: autism and other pervasive developmental disorders". *PediatrClinNorthAm.* 54 (3):469–81. doi:10.1016/j.pcl.2007.02.011. PMID 17543905.

15. Matson JL, Nebel-Schwalm M (November 2007). "Assessing challenging behaviors in children with autism spectrum disorders: A review". *Research in Developmental Disabilities*. 28 (6): 567–79. Doi: 10.1016/j.ridd.2006.08.001.PMID 16973329.
16. Burgess AF, Gutstein SE (2007). "Quality of life for people with autism: raising the standard for evaluating successful outcomes" (PDF). *Child Adolesc Ment Health*. 12(2): 80–doi:10.1111/j.1475-3588.2006.00432.x. Archived (PDF) from the original on 3 December 2013.
17. Sigman M, Dijamco A, Gratier M, Rozga A (2004). "Early detection of core deficits in autism". *Mental Retardation and Developmental Disabilities Research Reviews*. 10 (4): 221–33.CiteSeerX 10.1.1.492.9930. doi:10.1002/mrdd.20046.PMID 15666338.
18. Sacks O (1995). *An Anthropologist on Mars: Seven Paradoxical Tales*. New York: Knopf. ISBN 978-0-679-43785-7.LCCN 94026733. OCLC 34359253.
19. London E (2007). "The role of the neurobiologist in redefining the diagnosis of autism". *Brain Pathol*. 17 (4): 408–11. doi:10.1111/j.1750-3639.2007.00103.x.PMID 17919126.
20. Frith U (October 2014). "Autism – are we any closer to explaining the enigma?". *The Psychologist*. 27. British Psychological Society. pp. 744–45.
21. Silverman C (2008). "Fieldwork on another planet: social science perspectives on the autism spectrum". *Bio Societies*. 3(3): 325–41. Doi:10.1017/S1745855208006236.
22. Rutter M (2005). "Incidence of autism spectrum disorders: changes over time and their meaning". *Acta Paediatr*. 94 (1): 2–15. Doi:10.1111/j.1651-2227.2005.tb01779.x.PMID 15858952.
23. Anon (1998). *All in the family autistic spectrum disorders and sibling relationships*. Communication
24. Kaminsky L, Dewey D. (2002) psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*; 43: 225-232.
25. Gray DE. (2003) Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine*; 56: 631-642.
26. Glendinning C. (1986) *a single door: Social work with families of disabled children*.
27. Howlin P, Yates P. (1990) *a group for the siblings of children with autism*. *Communication* 1990; 24: 11-16.

28. Kaminsky L, Dewey D. (2002) psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*; 43: 225-232.
29. Sander JL, Morgan SB. (1997) Family stress and Adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy*; 19:1532.
30. Leo Kanner. A. (1943). Assessing Need for Social Support in Parents of Children with Autism and Down syndrome. *Journal of Autism & Developmental Disorders*, 36(7), 921-933.
31. Wallander JL, Varni JW. (1998) Effects of pediatric chronic physical disorders on children and family adjustment. *Journal of Child Psychology and Psychiatry*; 39: 29-46.
32. Bedesem, P., Boyd, B., &Mancil, G. (2009, December). Parental stress and autism: Are there useful coping strategies? *Education and Training in Developmental Disabilities*. 44 (4),
33. American Psychiatric Association. (2000). *American psychiatric association's diagnostic and statistical manual o/mental disorders (4/11 ed.)*. Washington, DC: American Psychiatric Association.

# APPENDIX

## INTERVIEW GUIDELINE

### ADDIS ABABA UNIVERSITY COLLEGE OF SOCIAL SCIENCES SCHOOL OF SOCIAL WORK

Dear participants, the following interview questions are designed to collect data for the MSW thesis study on the assessment of Psychosocial and economic impacts, the support needs, and coping strategies of parents of autistic children. Therefore, I would like to thank you in advance for your kind cooperation.

#### **Annexure I: Interview Guide for Parents of autistic Children**

**I. Demographic information about parents** 1. Sex: M \_\_\_\_\_ F \_\_\_\_\_

2. Age \_\_\_\_\_

3. Marital Status: Married \_\_\_\_\_ Single \_\_\_\_\_ Divorced \_\_\_\_\_ Widowed \_\_\_\_\_

4. Relation with the child: Mother \_\_\_\_\_ Father \_\_\_\_\_ other (specify) \_\_\_\_\_

5. Educational Level: Literate \_\_\_\_\_ Primary education \_\_\_\_\_ Secondary education \_\_\_\_\_ Collage and above \_\_\_\_\_ Illiterate \_\_\_\_\_

6. The standard of living of the family to accommodate the child \_\_\_\_\_

7. Occupation: a. Employed at governmental organization \_\_\_\_\_ b. Employed at private or NGO \_\_\_\_\_ c. Daily laborer \_\_\_\_\_ d. House wife \_\_\_\_\_ e. Business person \_\_\_\_\_ f.

Others (specify) \_\_\_\_\_

#### **II. Parents understanding and attitude of autism**

1. Did you have any idea about autism before?

2. What is autism for you?

3. What do they think are the causes of autism?

4. Do you feel comfortable discussing autism with another person?

5. What was your feeling when you know your child has autism? What was your action?

6. Do you believe that a child with autism can be as effective as the normal ones if necessary support is given?

#### **III. Psychosocial and Economic Experiences of Having a Child with Autism**

1. Does having an autistic child affect your psychological wellbeing? How?
2. What kinds of psychological impacts do affect you more? Can you mention some of them?
3. How do you deal with the psychological impacts?
4. Is there any negative impact having an autistic child caused upon your social life? Can you mention them?
5. Have you ever received a negative comment from people because you an autistic child? What kind of comment?
  1. How do you deal with the negative comments?
  2. How does the awareness of your family members' and the community on autism affect your social relationship?
  3. Does having an autistic child affect you financially?
  4. What are your sources of income?
  5. What are your strategies to deal with your financial burden?

#### **IV. Specific support needs of parents**

1. Do you have any support group to ease your psychosocial and economic burden? Can you mention them?
2. Do you believe that those support groups play an important role to meet your needs?
3. Where do you find to be the most important source of support?
4. What kind of assistance or support do you get?
5. Do you have anything more to add?

#### **V. Parents Coping strategies towards autism**

1. Would you tell me your coping strategies that you use in dealing with the impacts of being a parent of an autistic child?
2. How do you see the effectiveness of those coping strategies? What do you suggest for other parents who have autistic children?

3. What challenges do you encounter in your day-to-day caring of your child with autism?
4. How do you cope with these challenges?
5. How do you communicate with your autistic children?