

Challenges In Raising Children With Autistic Spectrum Disorder (ASD), From The Family
Systems Perspective: With Special Emphasis on 'Nia Foundation-Joy Center'

Bezawit Mekuria

A Thesis Submitted to
School of Social Work

Presented In Partial Fulfillment Of The Requirements For
The Degree Of Masters of Social Work

Addis Ababa University
Addis Ababa, Ethiopia


June 2013


የአዲስ አበባ ዩኒቨርሲቲ
የትምህርት ማዕከል
Addis Ababa University
Libraries


Addis Ababa University
School of Graduate Studies
MSW Examining Committee

This is to certify that the thesis prepared by Bezawit Mekuria entitled Challenges In Raising Children With Autistic Spectrum Disorder (ASD), From The Family Systems Perspective: With Special Emphasis on 'Nia Foundation-Joy Center': reception and practice and submitted in partial fulfillment of the requirements for the degree of Master of Arts (School of Social Work) complies with the regulation of the university and meets the accepted standards with respect to originality and quality.

Approved by the Examining Committee:

Examiner (Ext) Dr. Sewalem Tsige Signature  Date 09/07/13

Examiner Mengistu Legesee Signature  Date 10/07/2013

Advisor Meseret Kassahun Signature  Date 09/07/13

Acknowledgment

I thank God for he has made everything possible.

I am grateful to my advisor Dr. Meseret Kassahun for her valuable guidance and critical comments. I am also thankful to all the staffs in ‘Nia foundation-joy center for children with autism’, especially the founder Mrs. Zemi Yenus who made the center accessible for such studies and Miss Fasika Habtemariam (Sofi) who has been cooperative throughout the study. I am appreciative of parents who came forward to share me their stories.

I am much indebted to my family whose mentoring, support and warmth have been instrumental to my personal and academic development. Much of my current and future success is due to their remarkable support. Everything that is good in me, I owe it to them. My special gratitude also goes to my friends for their unrestricted support and encouragement.

This thesis would not be possible without the support of the people listed above. From my first classroom experience to the final stroke of the keypad they have made their own influences.

Heartfelt thanks to all.

Acronyms

AD: Asperger's Disorder

ASD: Autism Spectrum Disorder

CDC: Center for Disease Control and Prevention

CDD: Childhood Disintegrative Disorder

DSM: Diagnosis and Statistical Manual for Mental Disorders

NGO: Non Government Organization

PDD: Pervasive Development Disorder

RD: Rett's Disorder

Abstract

This study tried to explore the psychological, social and economic challenges faced by parents of children with autism. To this end, qualitative research design was used in order to have an in-depth understanding of the matter where the selected study site was Nia foundation-Joy center for children with autism and related developmental disabilities. By using interview guide as data collection tool, sufficient data was collected where twenty research participants were selected purposively. The accounts of the study participants were analyzed rigorously using thematic analysis. The thematic analysis was based on interrelated steps involving translating and transcribing the collected data, coding and categorizing where it was reached at major themes. Findings of this study showed that the psychological challenge of parents raising children with autism was mainly stress, the social challenges were interruption of family system, lack of public awareness about autism, inadequate social service, limited social support and controlled social life and the economic challenges were effect on earnings and expenses. In addition, parents with low economic status were found to experience higher psychological social and economic challenges mainly because of lack of support in the above three dimensions. This research concludes the mandate that parents of children with autism need to get psychological, social and economic support from all stakeholders mainly government, community, service giving agencies, and social work practitioners.

Content

Acknowledgment	2
Acronyms	4
Abstract	5
Table of Content	6
Introduction.....	8
Statement of the problem	9
Objective	11
General Objective	11
Specific objective.....	11
Significance of the study.....	12
Scope of the study	12
Limitation of the study.....	13
Operational definitions.....	14
Literature Review.....	15
Theoretical framework.....	15
Autism and Developmental Theories.....	15
Challenges of parents in raising children with autism and related theories.....	18
What is autism?.....	20
Characteristic of a child with autism	21
Causes of autism	22
Incidence and prevalence of autism.....	23
Challenges of parents raising children with autism	24
Empirical findings.....	31
Methodology	34
Study Area	34
Study Design.....	34
Participant selection	34
Data Collection Instrument	35
Data Analysis Procedure.....	36

Ethical Consideration.....	37
Finding.....	38
Description Of The Study Area.....	38
Description Of The Research Participants.....	39
Psychological Challenges.....	39
Social Challenges.....	43
Economic Challenges.....	46
Discussion and Analysis.....	49
Psychological Challenges.....	49
Social Challenges.....	58
Economic Challenges.....	64
Implication to social work.....	66
Conclusion & recommendation.....	69
Conclusion.....	69
Recommendation.....	71
References.....	73
Annex.....	76

Introduction

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living (Centers for Disease Control and Prevention [CDC], 2013). Autism is one type of developmental disability whose cause is not yet fully understood and that does not have as such cure.

American Psychiatric Association [APA] (2000) defines Autism as a neuro-developmental disorder which can be distinguished by impairments in reciprocal social interaction, communication, and restricted, repetitive behavior, interests and activities. The study by Wiggs (2010) further adds that self stimulatory behaviors, self injury behaviors, and obsessive compulsive behaviors are also characteristics of children with autism.

According to Dzubay (2011) the above mentioned characteristics are displayed in children with autism when they reach 18 to 24 months of age inducing parents to develop concern about them.

Childhood is a demanding and challenging period for all parents, and when a child has a problem, the demands and challenges are magnified. When the problem is autism, one of the most devastating and least understood mental disorders of childhood, it is hard to imagine how parents and siblings cope (Glass 2001). Therefore, as there is difference between raising a normal child and a child with disorder, the previously mentioned behaviors charge parents of children with autism special attention, time and energy. Miodrag (2009), states that autism is a lifelong disorder affecting not only the individual but the family as well. Moreover, in Ming's

(2006) study of parents of children with autism, it was described that the characteristics among children with autism pose a unique set of challenges for parents.

Therefore, learning the challenges they face in caring for their children with autism is the first step in identifying ways to improve support for such caregivers or to help them capitalize on the coping strategies that they have been using.

The purpose of this study is thus to explore what challenges parents whose children are cared by Nia foundation-Joy center for children with autism encounter while raising their children with autism. Specifically it will look into the social, psychological and economic challenges in raising children with autism.

Statement of the problem

Recently, more and more children are being diagnosed with autism at an increasingly younger age. Currently, one in every 110 children in the United States is diagnosed with autism (www.cdc.gov).

Statistical evidence on the extent and prevalence of autism is not sufficiently available in Ethiopia at the moment. However, it is estimated that from more than 80 million population of Ethiopia, over 530,000 are suffering from autism and related developmental disorders, with no access to rehabilitation, education and training(www.ethioautism.org). This significance confirms the advance in the number of parents who are supposed to deal with children with autism and the associated psychological, social and economic challenges.

According to Vihar (2013), there are a number of autism centers around the world but there are only two in Ethiopia established to care for children with autism; Nia Foundation-Joy center for children with autism and Nehemia Autism Center.

The issue of parents of children with autism is studied by different international and limited local researchers; for instance the literatures by Balfour (2007), Miodrag (2009), Alteriere (2006), and Efrem (2005) can be mentioned.

The study by Balfour (2007) made needs assessment on parents of children with autism in South Africa and found that the needs of parents of children with autism are not met. In doing so, the study looked at the gaps in services and financial strains as challenges and overlooked the social challenges of parents of children with autism.

On the other hand, the study by Miodrag (2009) examined how various child and parent factors relate to psychological wellbeing in parents of children with autism. This study discovered the presence of depression and parental stress with parents of children with autism but it overlooked the economic and social challenges.

Alteriere (2006) studied family functioning and coping behaviors in parents of children with autism by comparing relationships among different familial variables to determine the contribution of each individual to the developmental outcomes of the family unit.

The research by Efrem (2005) studied the level of parental enrolment in the early intervention program designed and implemented to help their children with autism. It found that all parents of children with autism have positive understanding about the causes and intervention strategies of autism.

Furthermore, the study by Ritche (2008) which looked at the attachment style between parents and their children with autism, the study by Lo, Chak-chuen and Eddie (1994) which focused on the parenting stress in family with individuals with autism and the study by Wnoroski (2008) whose point of concern was to uncover stigma in parents of individuals with autism can be mentioned.

Thus, the above mentioned empirical evidences can give an overview of challenges of parents in raising their children with autism. However the psychological, social and economic challenge of parents raising children with autism in Ethiopia is found to be overlooked. Therefore, this study is different in that it will give an insight on parents' challenges from the psychological, social and economic dimensions since these three dimensions are interrelated to one another.

Understanding the challenges of having a child with autism will be the first steps to support parents develop coping strategies as they care for their child. Hypothesizing that it will be an input in this aspect; this research will try to uncover the parental challenges from parents whose children are cared by Nia Foundation-Joy center for children with autism and related developmental disabilities.

Objective

General Objective

The general objective of this research is to explore what challenges parents face in raising their children with autism who are cared by Nia Foundation-Joy center for children with autism.

Specific objective

The specific objectives of this research are

- To investigate the psychological challenges of parents raising children with autism
- To find out the social challenges of parents whose children are autistic
- To explore the economic challenges of parents who have children with autism
- To analyze the implication of the result of the study in line with social work

Significance of the study

This study has meaning in the aspect that it creates the opportunity for parents to express their feelings and challenges that emerged from their concerns and hopes for their child. This gives society a better understanding of autism in general and specifically about the psychological, social and economic challenges of parents of children with autism.

Relevant studies that explored the challenges in parenting children with autism in Ethiopia are unavailable. Hence, this study will shed lights and makes its own contribution to uncover the issue.

This study will further discuss the implication of the finding that will have significant contribution to practitioners who are working with parents of children with autism. In addition, the implications of the findings will help to initiate policy makers to revise policies regarding services provided to individuals with autism. Last but not least, it will act as an impetus for future studies.

Scope of the study

This research deals with the challenges of parents of children with autism; specifically the psychological, social and economic challenges they encounter while trying to respond to their children's intense needs and behaviors.

In doing so, qualitative research design is used. The data collection tool utilized is in-depth interview guide so that detail information is collected.

The study site for this research is Nia foundation-Joy center for children with autism; which is selected because it is the pioneer foundation relatively aged in working with parents of

children with autism. Therefore, the study participants are those parents whose children with autism are cared by this center.

The theoretical base for this study is family systems theory and thus the issues will be viewed for the point of view of this theory. Although this is the case, this study specifically focused on mothers and fathers only and overlooked the challenges faced by siblings and other extended family members.

Limitation of the study

There are limitations to this study and therefore the findings should be interpreted with caution.

This study is done by taking parents of children with autism who get educational and therapeutic support for their children and psychosocial support for themselves at Nia Foundation-joy center for children with autism. Therefore, it is difficult to generalize the result of this study to the general population of parents of children with autism.

More to that, the research is not done to the greater scale and it is limited to 20 research participants found in one unit of analysis, Nia foundation-Joy center for children with autism.

Methodologically, this study used only one data collection tool which is interview guide. Therefore, the validity of the collected data is not strengthened by other data collection tool due to time constraint although it should have been triangulated with other data collection tools such as observation of the family in their real life setting.

Operational definitions

Autism: A pervasive developmental disorder characterized by the physical, cognitive, emotional and spiritual impairment of a child.

Developmental Disability: An organic disability that becomes limiting to a child before the child reaches early childhood and continues to incapacitate throughout his or her life.

Child: For the purpose of this research a child is defined as an individual who is below 13 years of age.

A child with autism: A child who is below 13 years of age and who is diagnosed with pervasive developmental disorder.

Parent: A mother, a father or a legal guardian who provides care for and raises the child with autism.

Stress: A function of the interaction of the subjectively demands of a situation and the capacity of a parent to respond to these demands.

Parental stress: A stress in the parent-child system as perceived by the parents.

Attachment: The affectional bond that is formed between a parent and a child with autism.

Stressor: an internal or external stimulus that causes stress to parents of children with autism.

Literature Review

This chapter reviews theoretical and empirical literatures pertaining to this study. First it will look at theoretical frameworks that relate autism with child development theories and child-parent relationship. Next, it will go through literatures that give general insight about what autism is, characteristics of children with autism and the causes, incidence and prevalence of autism. Subsequently, it will go through literatures regarding the psychological, social and economic challenges of parents of children with autism. It will then finalize by supporting the discussed ideas with empirical findings of different researches.

Theoretical framework

This section tries to see the development of children with autism in accordance with different child developmental theories. It also looks at the psychological, social and economic challenge of parents associated with the presence of a child with autism in relation with different family theories.

Autism and Developmental Theories.

Understanding child development is vital because it enables us identify the cognitive, emotional, physical, social and educational growth that children go through. Different developmental theories have outlined different explanations for child development. Relating these theories to the development of children with autism will help us identify the impaired development of their children in order to understand the challenges that parents face while dealing with their children with autism.

Cognitive theory.

In regard to children's cognitive development, Piaget's cognitive developmental theory states that children can be thought of as "little scientists" who actively construct their knowledge and understanding of the world. He adds that they play an active role in gaining knowledge of the world through developing 'schemas' (Cook & Cook, 2005).

The development of children with autism in the cognitive aspect is contrary to what Piaget's cognitive developmental theory stated. (Dubin and Graetz as cited in Wiggs 2010) state that research suggests that symptoms of autism relate to a limitation in cognitive development.

Children with autism are rather passive and do not usually show interest to learn what is going on around them. Glass (2001) further argues that cognitive skills are present in autism but seem to function at a low level which he described as "Because of insufficient development of a theory of mind, people with autism lack the ability to engage in imaginative ideas, to interpret feelings, and to understand intentions beyond the literal content of speech".

Behavioral theory.

Behavioral theories of child development which were developed by John B. Watson's, Ivan Pavlov's and B. F. Skinner focus on how environmental interaction influences behavior consider development as a reaction to rewards, punishments, stimuli and reinforcement. It focuses purely on how experience shapes who we are (Center for learning innovation, 2006).

On the other side, children with autism are either very slow or very hasty to react to the environment. Even if doing some specific activity (e.g. self-harming activities such as pounding their heads on a wall over and over again) resulted in punishment (e.g. pain) in the past, they keep doing it repeatedly (Wiggs, 2010). This shows that children with autism have very low interaction with the environment.

Social Development Theory.

Social development theory of John Bowlby underlines that early relationship with caregivers plays a major role in child development. He adds that children are born with different proximity-seeking behaviors that create attachment with their care givers which develops through the routine of care giving (Center for Learning Innovation, 2006).

Regarding children with autism in this aspect, Levine (2010), states that the ability to find comfort by gentle touch, smiling face, or voice tone has no meaning with children with autism. They have problem in regulating and communicating their emotions with others.

Social Learning Theory.

In his social learning theory of child development, Psychologist Albert Bandura entails that, children learn new behaviors from observing other people. He states that children develop new skills and acquire new information by observing the actions of others, including parents and peers (Cook & Cook, 2005). In the case with children with autism, acquiring new skills through observation is possible but it takes much more time that it takes a typical child (Balfour, 2007).

Socio-cultural Theory.

Lev Vygotsky's socio-cultural theory proposes that the development of higher order function is highly affected by parents, caregivers, peers and the culture at large. He adds that children's minds stretch through challenges (Cook & Cook, 2005).

When children with autism are viewed from this dimension, it is seen that the passivity of their sensory system deprives them from understanding what is going on in the environment. Levin (2010) supports this idea by saying that children with autism are not as much influenced by the culture and external activities as typical children are.

According to the above discussed developmental theories and the associated impairments of autism, children with autism have limited abilities in the cognitive, behavioral and social aspects. These limitations hinder them from performing in the level a typically developing child can perform at certain ages. Identifying these limitations is helpful to gain an insight of the areas where parents of children with autism, as primary care givers of a child are challenged while raising their children with autism. Furthermore, knowing in which areas children with autism are different from typically developing children helps in gaining better understanding of the consequences that accompany raising a child with autism. Subsequently, the challenges of raising children with autism as seen from the perspectives of various theories will be discussed hereafter.

Challenges of parents in raising children with autism and related theories.

Family, the immediate environment of an individual affects and is affected by the members embraced by it since it is the smallest structure of society within our vast world of societies where the members are physically, emotionally or spiritually interrelated. As a result, the proper functionality of the members is influenced by the health status of any other member. Family system theory and attachment theory, which back up the above argument, are discussed hereunder.

Family system Theory.

The theory base for this study is family systems theory. Family systems theory views families as living organisms and stresses boundaries, rules, expectations, and behaviors that help the family maintain equilibrium and the status quo or homeostasis. This theory stresses that a change in one part of the family requires other family members to adjust as well (Mallers n.d.).

The study by Mallery (n.d.) describes the relationship between autism and family theory as follows. A family is considered as one emotional and functional unit whereby individuals cannot be understood in isolation from one another. Therefore, a family with a child with autism may need to redefine their original system and its day to day functioning because roles will have to shift and the small family unit may need to be developed into larger unit, one comprised of other families of children with autism where support can be obtained. As such 'boundaries' will need to be broken so that connections can be made to other systems and 'subsystems' need to be created whereby special time is created solely for the other siblings (Mallery, n.d.).

The study by Dzubay (2001) also noted that family member may have to re-establish family roles, power distribution, boundaries, and rules necessary to keep the family functional and relationships within the family positive. Therefore, in the case with children with autism, the family system theory proves that parents of children with autism are affected by the issues that rotate around their children with autism.

Attachment Theory.

Attachment can be summarized as the lifelong developmental system that emerges from the child-parent bond, in which people use increasingly complex physical, cognitive, and communicative strategies to form strong emotional bonds that will protect them from real or perceived threats (Newman, 2006). As for children with autism, Konstantareas & Homatidis (as cited in Ritchie, 2008) say that studies reported that an attachment strain has been specifically noted between parents and their child with autism. Balfour (2007) adds that creating attachment is a very difficult task as they have difficulty to make sense of what is around them.

The study by Ritchie (2008) whose objective was to explore the attachment style between parents and children with autism supports the above statement. It states that the parent-child attachment changes after the child begins to display autistic behaviors and fails to display attachment behaviors such as smiling, reaching or following. This attachment loss and the fact that children with autism do not create secure attachment with their parents create confusion and is a challenge for mothers whereby parental grieving is experienced.

Lo's study (as cited in Lo, Chak Chuen & Eddie, 1994) aimed at finding out the stress, the psychological well being and the belief of parents of mentally disabled children in Hong Kong. 40 pair of parents of children studying in the special child care centers were interviewed and the results indicated that exercising discipline to the disabled child were stressful tasks. In other words, the child's maladaptive behaviors were important sources of parenting stress.

From the above discussed developmental theories, it can be seen that parents are affected by the limitations of their children. The limitations with their children in the cognitive, behavioral and social aspects make parents prone to the challenges of dealing with the consequences of the disability. Both family systems theory and attachment theory explain how the inability of a child- one family member to do the expected 'roles' influences the parent- another family member.

What is autism?

The word *autism* is derived from the Greek word *autos* meaning self. According to the Oxford English Dictionary, the term was first used and defined in the 1912 American Journal of Insanity in reference to "instances where thought is divorced both from logic and from reality" (O'Brien & Daggett as cited in Dzubay 2011).

Autism is a group of developmental brain disorders, collectively called Autism Spectrum Disorder (ASD). The term “spectrum” refers to the wide range of symptoms, skills, and levels of impairment, or disability, that children with ASD can have. ASD is diagnosed according to guidelines listed in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision(SDM-IV-TR.) The manual currently defines five disorders, sometimes called pervasive developmental disorders(PDDs), Autistic disorder(Autism) which refers to problems with social interactions, communication, and imaginative play in children younger than 3 years, Asperger’s Disorder (Asperger Syndrome) which is characterized by children who do not have problem with language but have similar social problems and limited scope of interests as children with autistic disorder, Pervasive Developmental Disorder (PDD) which is a kind of catch-all category for children with autistic behaviors but who do not fit into other categories, Rett’s Disorder(Rett Syndrome) which is commonly occurring in girls is characterized by normal development but lack of social and communication skill and Childhood Disintegrative Disorder(CDD) which is where children develop normally for at least two years but lose most of their communication and social skill afterwards (www.nihm.nih.gov).

There has been much confusion in distinguishing the differences between Autism and Asperger’s Disorder because the clinical criteria are so similar. However, their similarities bring about many of the same cognitive and development problems in children. Therefore, they are grouped into the broad category called ASDs (Ritchie, 2008).

Characteristic of a child with autism

Different Authors explained the characteristics that children with autism show. Dzubay (2011) states that autistic Syndrome is identified by three core features: (a) the child lacks social

understanding; (b) the child has limited ability to have reciprocal conversations; (c) the child has an intense interest in a particular subject or object. Wiggs (2010) agrees with this idea by saying that autistic disorder is characterized by impairments in the areas of social interaction, communication, repetitive behaviors and limited behavior patterns, delayed motor abilities and very literal interpretations. Levine (2010) also argues that individuals with autism spectrum have varying deficits ranging from quite severe cognitive disabilities to less severe impairments in social interactions.

Individuals with autism spectrum disorder have difficulty focusing or concentrating on relevant activities or people. It is easy for an autistic individual to be distracted. This can take a toll on their social life as well as their academic career. Research has found that such inattentiveness may possibly result in delayed language development over time (Bopp, Miranda, & Zumbo as cited in Wiggs 2010)

Causes of autism

Duzbay (2011) states that autism remains a mystery where there are no known causes and no cures for it. The study by Wiggs (2010) furthermore adds that different theorists attributed the cause of autism to family dysfunction and social stress although the cause is currently of much controversy. In the study by Balfour (2007) it is stated that some researchers relate it to vaccination while others relate it to problems with genes.

Another presumption put forward by Hertz-Picciotto et. al. (as cited in Levine 2010) is that the cause of autism spectrum disorders is still relatively uncertain among researchers; however, most believe it is a combination of both a genetic susceptibility in addition to an environmental trigger that cause an individual to develop autism.

The most current research suggests that ASDs could stem from several different sources, including environmental factors, biological factors, vaccinations containing high levels of mercury, and a deficiency in a child's immune and endocrine system (Fombonne et. Al., as cited in Ritche 2008). This shows that the cause of autism does not have a universally and scientifically accepted source.

Incidence and prevalence of autism

Studies report the prevalence of autism to be anywhere from about 5 cases in every 10,000 individuals (APA, 2000) to 60 cases in every 10,000 children 18 years old or younger (Alteriere, 2006). According to Wiggs (2010) autism is diagnosed in at least 1 in 600 individuals, of all age, and about 1 in 200 children show at least some symptoms of it. He further states that the center for Disease Control and Prevention (CDC) currently estimates that about 1 in 110 children in the United States have autism.

A study made in Sweden on children aged 13 years and under by Gillberg, Steffenburg and Schaumann (1991) suggested that there has been an apparent rise in the frequency of autistic disorder and autistic-like conditions in one area of western Sweden over the last ten years. It also states that whether this possible increase in prevalence rate is due to better screening measures and better diagnostic criteria or whether it represents a rise in the frequency of autism over the last ten years remains open to speculation.

In South Africa Balfour (2007) states that 1 in 158 under the age of 6 are diagnosed with autism. The researcher was unable to find enough data that In Ethiopia there is no clear figure as to the prevalence of autism.

Challenges of parents raising children with autism

Different literatures have outlined different challenges that parents of children with autism face. Morgan (1988) considered autism to be the most severe childhood behavioral disorder with the most complex developmental pattern. Some of the researches reviewed hereunder demonstrate that parents face different challenges due to their children with autism. Konovalov (2008) says the challenges of raising a child with autism lay in different spheres of life: getting used to the diagnoses and having realistic plans for the future, economic concerns, social contacts, cooperation with professionals, daily routine.

According to Kumar (2008), parents and children in the family must undergo a variety of changes to adapt to the presence of a disabled member. Most parents expect that their children will be attractive, smart, graceful, athletic, and loving. Parents of a disabled child not only mourn the loss of unfulfilled expectations but often face enormous strain on their psychological and economic resources.

Alteriere (2006) says that caring for a child with autism can be a twenty-four hour, seven day a week job throughout the child's entire lifetime. Moreover, according to (www.ethioautism.org) parents are as well affected by autism. The impact of the child's disability creates psycho-emotional and financial distress on parents too.

A child with autism's influence on the parent's life, the parents' concerns and expectations, and their feelings was studied by the research by Heiman (2002). This study found that parents face different challenges due to having a child with autism, of which the main ones were disruption of family life, disruption of social life, worrying about the child's future independence, adolescence and life management. This study discovered that parents are much

happier and filled with hopes recovering from the negative feelings which disturbed them during their child's diagnosis with autism (Heiman, 2002).

A study by Ambikile and Outwater (2012) made in Dare-selam Tanzania also revealed that parents face psychological, emotional, social and economic challenges. This study tried to identify the different challenges faced by parents from psychological, social and economic dimensions.

Psychological challenges.

The psychological challenge described by many researches that parents of disabled children face are mainly feelings of guilt and shame and psychological stress. Compared to those parents with typical children, it is possible to say that parents of mentally disabled children endure more stress. This stress starts from the time that their child is diagnosed with the disability, to treatment, everyday life and in realization of their children's future. Their stress can also result from the characteristics that their children exhibit. Researchers have said a lot about these issues.

The birth of a disabled child is likely to be one of the most traumatic events experienced by the family. Parents and other children in the family must undergo a variety of profound changes to adapt to the presence of a disabled member (Kumar, 2008).

The crisis engendered by the first intimation or diagnosis that something is wrong with their child is probably the parents' most difficult and shocking experience (Heiman, 2002).

During diagnosis of autism in children, parents are prone to feelings of guilt and blame, wondering if it was something they did or did not do that led to their child's ASD, (Dzubay, 2011). Bristol (as cited in Levine 2010) says that a child with autism is a large stressor on the

family because of the ambiguity of diagnosis, the severity and duration of the disorder, and problems with the child's lack of adherence to social norms.

During treatment, children who have behavior and speech difficulties undergo therapy that requires repeated sessions until the therapist decides they don't need it anymore. For example, speech therapy could take several years in more extreme cases, depending on the severity of autism, because of the small steps that are taken at each therapy session. The repeated sessions over long periods of time can be stressful, especially if there is not a noticeable difference in the child from the parents' perspective (Schieve, Blumberg, Rice, Visser, and Boyle as cited in Wnoroski, 2008).

As to the characteristics children with autism display, according to the study by Alteriere (2006), the combination of difficult emotional and physical behavior displayed by the child with autism creates a high level of stress on the entire family. For example, children with an autism spectrum disorder may display poor eye contact, have little interest in playing with other children, and may fail to engage in give and-take activities with others (www.nimh.nih.gov). Largmash and Johnsoton (as cited in Chee, 1991) say that the increased stress reported by parents of hyperactive children was largely a reflection of the children's characteristics. The elevated score on demandingness made parents suffer from stress. Their child seemed to lack ability to adjust to change in his physical and social environment. These characteristics lead to increased stresses and frustrations for both the child and the parents.

The fact that there is no cure for autism by itself is another issue that further aggravates the parents' stress. For parents of children with autism, the future of their children turns out to

be vague. Wiggs (2010) says that knowing that their children have a significant amount of difficulty in leading an independent life worries parents.

As a result of these, parents are especially affected by the psychological and emotional stress imposed by autism. When parents are stressed, they can become easily irritated and frustrated. It is not surprising then that parents raising a child with autism are significantly more likely to experience elevated levels of anger and depressed mood Benson & Karlof (as cited in Wiggs, 2010). According to Murphy (as cited in Levine, 2010) providing care to a child with disabilities can be a tremendous source of stress for caregivers that may have detrimental, lasting impacts on both their physical and mental health. Alteriere (2006) suggests that a family with a child with autism may need to make adjustments in order to cope and function at an adequate level.

Chee (1991) says development of undesirable behaviors in the child leads to the subsequent frustration of parents. The parents of disabled children have to deal with a set of needs arising from their children's developmental difficulties, increased physical and financial difficulties. It adds that disability brings a problem not only to the individual but also to those closest to him.

Several family life problems were identified as important stressors to the families with mentally disabled children. They were limited time available, the arrangement of regular medical consultation and the worries about the disabled child's future (Lo, Chak-chuen & Eddie, 1994).

In Ritchie (2008), the researcher was looking to explore the attachment style between the parent and child, as well as the process of the parents' changing their expectations of their child,

from the expectation of raising a normal child to raising a child with Autism. The result showed that all parents in the study illustrated the attachment injury after their child's diagnosis, in addition to when the child began showing the classic signs of Autism.

Social challenges.

Having healthy social interaction is a necessary input for the proper functioning of day to day lives of individuals. Disturbed social interaction on the other hand makes people's lives unstable. Tefera (as cited in Efrem, 2005), indicated that in Ethiopia, as in many countries, one of the major difficulties encountered by people with disabilities is social. Specific to autism, different researches show that parents of children with autism face social challenges for one or another reason being vulnerable to stress.

In the study by Gray (as cited in Alteriere, 2006) families reported that they believe it is difficult for society to accept a child with autism and that there is social stigma and embarrassment associated with the inappropriate public behavior that these children might display. Balfour (2007) says that some parents even choose to isolate themselves instead of facing the frustration of taking their child out in public. (www.ethioautism.org) agrees with this idea. It says "Parents are unable to feel at ease to talk about their own children openly. Instead, they feel guilty and are ashamed of their child due to pressure and misunderstanding of the society at large".

Miodrag (2009) describes the rejection by extended family members a challenge. He adds that relatives distance themselves from the family by maintaining cold and generally unhelpful relationship. The combination of the rejection from family members and the stigma

felt from members of the community increases the burden of families of a child with autism (Alteriere, 2006).

It was found that the transition in a family with a special-needs child brought about significant changes in that family's social life. Many parents had to make changes in their social life of frustration and dissatisfaction (Heiman, 2002).

Therefore the judgment posed by others on their child, and on them as a parent becomes a cause of emotional distress for parents. As said above, the lack of definitive, visible signs of autism causes outsiders to view children with autism as 'normal'. Since children are usually a reflection of the parents, this causes stress for the parents because they are being judged as possible "bad" parents for not controlling their child when the children do things that are believed to be beyond the lines of societal 'norms'.

Chee (1991) addressed the importance of social support for parents of children with autism to help them tackle the problems they face in the process of raising their children with autism. It adds that people with spouses, friends, and family members who provided psychological and material resources were in better health than those with fewer supportive contacts (Chee, 1991).

Lewis (2009) said the following on policies regarding service in Ethiopia.

"Education policies and plans often do not reflect what is happening on the ground. They tend to be influenced by Northern approaches to special needs education and inclusive education, and draw only limited inspiration from the country's own culture and context. Ethiopian system tries to include children with special needs in the special units of regular schools which are a long way from accommodating all of Ethiopia's

disabled children for example Nia foundation, which was the only center for children with autism at the time, lack of segregated schools was also raised as the other problem that should be given due emphasis” (Lewis, 2009).

Economic challenges.

Literatures have documented the economic challenges that parents of children with autism face. According to Raina (as cited in Levine, 2010), depending on the severity of their child’s disorder, many parents are faced with unexpected life and even career changes upon the birth of a child with a disability or upon hearing a diagnosis of a disability in their child. Caregivers of a child with a developmental disability are oftentimes forced to assume an unexpected additional role of providing intensive, long-term care for their child

In the study by Gray (as cited in Alteriere, 2006) it is described that some mothers are faced with limitations in their careers. Most mothers want to work outside the home; few were able to seek outside employment due to the high level of care they should provide to their child with autism.

Specifically, research by Crnic et al. (as cited in Miodrag, 2009) has shown that income levels of families are closely related to family functioning in families with children with developmental disabilities. Importantly, Herman and Thompson (as cited in Levine 2010) found that the severity of child characteristics in children with developmental disabilities negatively impacts the way in which parents perceive the effect their child has on time and family finances.

As a result, both the perceived and the actual availability of family resources can be causes of stress in parents raising a child with autism. Family resources include income level, level of parental education, social supports, and time available to attend to the child’s needs Van

Horn, Bellis, & Snyder (as cited in Levine 2010). It has been well documented in the literature that the actual availability as well as the perceived availability of family resources effects family functioning and the ability of parents to provide care in families with typically developing children (Dunst, Leet, & Trivette as cited in Levine 2010).

According to (Ababi 2008), the development of mental disorders and caring for them may result in economic burden on individuals, families and communities. Loss of income, employment; out of pocket expenses, reduced productivity, days out of role, emotional strain, cost of caring or lost opportunity, recurrence of illness causing sudden and unexpected disruption of the lives of family members and disturbed social relations were the points raised as the economic burdens of mental disability. It concludes by saying that mental and behavioral disorders have economic burden with increased health expenditure, loss of job and reduced productivity.

Empirical findings

The empirical findings of different researches outlined the various challenges that parents face in raising children with autism.

In the study conducted by Balfour (2007) in South Africa, the research participants were 5 (five) parents of children with autism. The important finding of the study was that the participants experienced many challenges. The participants informed that they were emotional while receiving the news that their children are diagnosed with autism. They all went through denial and grieving before accepting the fact. It was a challenge for the mothers to cope with having a child with autism in their lives. Financial strain was also found to be another challenge.

Wnoroski (2008) in his study, involved 3 (three) participants who are parents of children with autism. The finding shows that each subject noted negative experiences that have been associated with raising a child with autism. These experiences most often came in the form of the rude comments or harsh treatment of strangers. The subjects perceived that Autism is so behaviorally-linked in its manifestation that it is easy for strangers to make assumptions about parenting based on the child's behavior which is a challenge for them.

The study by Levine (2010) examined the extent to which child severity and family resources are related to parenting stress using parents of 26 young children with autism as participants. He found significant negative correlation between parenting stress and family resources and a significant relation between autism severity and child-focused aspects of parenting stress.

The study by Miodrag (2009) examined the effect of child disability on maternal and parental stress levels in a sample of 141 parents, mothers (76) and fathers (65) of children with autism or Down syndrome. In this study, a high proportion of parents reported clinically significant child related stress (67% mothers; 60% fathers) and to a lesser extent, parent-related stress (49% mothers; 28% fathers).

Lo, Chak-chuen, Eddie's (1994) study compared younger children with autism with the older ones. 50 to 75% from each group reported that their children had limited the development of other family members, affected the family social life, and causing family members feel upset, worried tense and despondent. Moreover, the indicators of high parenting stress included low education level and household income, and grandparents as the major caregiver of young a child with autism.

Unfortunately, the researcher was unable to come across researches in the Ethiopian context that measure parental challenges in raising children with autism. These empirical findings prove that parents face different challenges in raising children with autism.

This chapter has tried to review different literatures that look into developmental theories that give an insight on what autistic children are missing in the cognitive, behavioral and social aspects. It further tried to relate theories with the challenges parents face as a result of raising children with autism especially; family systems approach which is the theoretical base for this study. It also explored literatures regarding the cause and prevalence of autism, characteristics of children with autism, the challenges that parents face due to raising a child with autism and supporting empirical findings. In the next chapter, the methodology used in order to carry out this study will be discussed.

Methodology

This section demonstrates the methodology used in this research. The study area, the study design, participant selection, data collection instrument, data collection procedure, data analysis procedure and ethical considerations followed are illustrated hereunder.

Study Area

This research was carried out in the compound of Nia Foundation-joy center for children with autism, Addis Ababa, Ethiopia. This center is established by a mother of an autistic child in 2002. This institution is selected for this research because it is the knowledgeable and experienced foundation capable of sharing its long year experiences. Currently, there are 70 children with autism that receive care and support under the center. Among the parents of these children 20 parents of children with autism participated in this research.

Study Design

The research was exploratory type of study that answered the 'what' question and it is cross-sectional research as it was carried out at one time of the present period. It is conducted using qualitative approach since this style of research allows researchers to explore social life in its natural setting producing a richer understanding of various social phenomena. Patton (as cited in Ritchie 2008) state that qualitative research method, through open-ended questions enables research participants to provide information they perceived to be important to them, giving the researcher a more-in-depth understanding of how the research participant viewed his or her world or situation.

Participant selection

In order to have representative participants that fit to the purpose of the study, non probability, purposive sampling method is used. In doing so, the judgments of staffs in Nia

foundation were considered. The selection was based on the participant's relevance to the research topic, their availability, their willingness and their ability to provide the necessary information, as well as individuals who meet the inclusion criteria were part of the research. The inclusion criterion is parents who have children with autism who are under the age of 13 and those parents from all educational background, economic background, age group and both sex. From a total population of 70 parents who have children with autism, 20 research participants were selected for this research and they participated in the study on voluntary basis.

Data Collection Instrument

The data collection instrument used is in-depth interview guide which consisted of open-ended questions. The interview guide was developed and the questions were arranged in a way that it first gets information about the background of the participants and then addresses the specific objectives of the study. The primary reason for using interview as data collection tool is mainly because interacting via interview was believed to be helpful in order to get at the feelings and emotions of the parents because of the sensitive nature of the matter to be discussed. During the interview data were recorded on tape recorder and notes were taken. The audio record and the notes were then transcribed to English during data analysis. Relevant literatures that have looked on similar issues were considered and documents that gave insight on the background information of the center were also reviewed.

Data Collection Procedure

The letter of permission from Addis Ababa University, School of Social Work was submitted to the organization in order to make the necessary arrangements with the administration of the center for initial engagement. Introduction was made by the researcher about the research and a

range of discussions were made with the concerned personnel in the center about the convenient time and procedure to undertake the research. Interview schedules were then determined.

The participants were well informed about the purpose of the study and informed consent was signed. The informed consent consisted of description of the study's purpose, expected benefits and risks, procedure, intended use and confidentiality and the voluntary nature of the research participants. Each participant was interviewed separately where common introduction was made with all of them. It was tried to build rapport and positive relationship with the participants through creating a relaxed atmosphere that involved informal and interactive conversations. The interview which was constructed with open-ended questions was helpful in exploring deeply within the inquiry areas. In addition to taking notes, interviews were tape recorded with the consent of the participants so that all the data can be captured more completely.

The interview was conducted in the compound of the center because it was the convenient place to have contact with all the research participants. The interview took an average of forty five minutes.

Data Analysis Procedure

It is known that data analysis goes hand in hand with data collection in a qualitative research (Creswell 2008). Although data analysis was an ongoing process, the formal process started after data collection was finalized. The data analysis method used was thematic analysis. The data collected through interview was transcribed to English. All relevant transcribed statements were coded and categorized based on their relationship in addressing the specific objectives of the research. These were categorized in to sub-themes and major themes.

Ethical Consideration

Discussing with parents about the developmental disability of their child was a sensitive matter. Therefore, data collection and presentation was governed by the social work ethical code. In order to protect the participants of this study, they were informed about all the possible consequences of the study.

Informed consent, stating the purpose of the research, the rights of the participants to withdraw from the interview at any time during the course of the research, the anonymity of the participants; protection of the participant's identity and the confidentiality of the participants; not identifying them publicly was sought from all participants prior to interview sessions.

During interview, the questions were sensitive and were emotionally arousing to some participants. Therefore, it was tried to handle the emotions aroused carefully.

Ensuring trustworthiness was also maintained during interview through inquiring clarification from research participants and also by clarifying questions to them. In addition, continuous probing and cross checking was used to guarantee the dependability of the data.

Finding

In this part, the findings of the study will be outlined within the framework of the objective of the research. The study area, demographic data of research participants and the major themes identified will be discussed.

Description Of The Study Area

This study chose Nia Foundation-Joy center a nonprofit making foundation which is established in May 2002. The vision of the foundation is having a concerned society where individuals lead a quality of life to the best of their potentials in spite of their gender and different abilities while its mission is striving to empower and inspire children, youth and women through education, rehabilitation, vocational training, personality and leadership development.

The two major services provided by the foundation are providing a center based holistic rehabilitation and education services for children with autism and to give psychosocial support for their parents in Addis Ababa.

The children at the center are provided with the rehabilitation services on a daily basis separated in groups based on their disabilities and ages. The center provides intensive program to help the children develop skills in academics, languages, self help, social interaction and motor exercises areas. Children are provided with sensory, speech, occupational, audio-visual and other therapies. The center consists of psychologists, therapists who took trainings on different therapies and social workers.

The parents receive continuing workshops with detailed information about autism and related developmental disorders to help them develop skills in increasing the family's coping skills, by providing an overview of behavioral management techniques. Monthly meeting of

parents is also arranged so that they can discuss about their children's progresses. It helps parents form a system to support one another. Those parents who are not self-sufficient to economically support themselves adequately are helped to engage them in different small skill income generating activities. Currently the center is supporting 70 children with autism and 500 children are on the waiting list.

Description Of The Research Participants

The participants of the study were 20 individuals who are parents of children with autism at the foundation. They were parents whose children are below the age of 13 years old. Fifteen of the research participants were mothers while the rest were fathers. The educational background of the participants ranged from higher education to elementary or no academic education of which the majority was the latter. Most of the participants were between the ages of 35 and 55. As to their economic background, parents ranging from high to low economic status participated.

Psychological Challenges

The finding of this research shows that the psychological challenge faced by the participants is stress which was experienced at different level in different circumstances and times. Stress is a function of the interaction of the subjectively demands of raising a child with autism and the capacity of a parent to respond to these demands.

Stress.

All participants expressed that they experienced high level of stress at the time of diagnosis. They also reported experiencing situational stress during their day to day lives and when they think about the future. Therefore, the sub-themes identified under this major theme

are explained below in two parts: stress during diagnosis and day to day life and stress about the future.

Stress during diagnosis and day to day life.

It was found in this study that the participants encountered high level of stress during the diagnosis of their child with autism and also during their day to day life. Each will be discussed below.

Stress during diagnosis.

The finding shows that all of the participants experienced high level of stress during the diagnosis of their children with autism. Before acceptance, some went through denial and others were highly depressed. They expressed that moment as the most heartbreaking times of their lives. One participant remembers it as;

When the doctor told me that my son is autistic, I had no clue what autism was. After he explained it to me, I did not want to accept that my only child is autistic. I felt that the whole world even God turned his back on me. I was so stressed that I closed my door and stopped my relationship with everyone for long years.

Stress during day to day lives.

All participants informed that although they are less stressed than the time of diagnosis, they still experience stress when they think that they have disabled child and due to the care giving responsibility. A participant expressed his stress that emerged from thinking about having a disabled child,

I am adapted to this life but it does not mean that I am ok with it. It has stresses. I am jealous at parents who have normal kids that go to toilet by themselves.

Within the prolonged care-giving roles that parents confront with, their children's behaviors and their children's unpredictable or fixated needs were found to be causes of stress.

It was found that the participants were stressed by the different behaviors of their children with autism some of which were being aggressive, destructive, restless or hyperactive, making noise, lack of proper eating skills and lack of attachment. The sleeplessness of his a child with autism was described by a participant as,

My child has sleeping problems. He doesn't go to bed until 2pm after midnight. We suffer a lot because we do not sleep either. My wife used to cry in the middle of the night. It is so distressing to experience this every night.

The absence of proper sensory information transmission with the children was another source of stress. One parent expresses her concern by remembering an incidence like this,

My child was once beaten by a dog. But even though he had that experience, he is still not afraid of dogs and stands in front of them. This bothers me because if he can't learn from the things that hurt him, how is he going to protect himself from other harms he did not experience.

It was also found that the unpredictable and fixated needs of their children with autism were sources of stress for the participants. Their children's need for constant adult supervisor was also found stressful mainly for the economically disadvantaged parents. A participant expressed it as,

I have to look after my boy most of the time. I don't have time for my own things. I can't hire maid because I can't afford it. It is stressful.

Stress about the future.

Eighteen participants informed that different unpleasant thoughts flow through their mind about the future regarding their children and themselves. Both are viewed separately.

Stress about the future of the a child with autism.

Thirteen parents viewed the future as challenging and source of stress. Their reasons were the inability of their children to be independent, to protect themselves, to deal with their psychosexual needs during adolescence, and probability of regression.

One participant noted that,

My daughter looks very normal physically. So, I worry that people may take advantage of her or hurt her as she grows up because she is unable to express her feelings.

Another participant whose stress emerged from her worries about regression of children with autism expresses her concern like this,

There was one girl in this foundation that joined formal education because of her successful development. Sadly, she regressed back to zero and came back to the foundation to start all over again. Since then, awful thoughts run through my mind. What if this happens to my child? I am grateful for the little progresses my child makes. But I am terrified to enjoy it because I cannot tolerate getting hurt again if he regresses back.

Stress about the future of the parents.

This research found that five of the participants were stressed about their psychological wellbeing, their career and their ability to deal with their children in the future. A participant expressed her distress about herself as,

My child is growing up and getting older while the burden of caring for him is making me skinnier and smaller from time to time. I look very old because of the disturbance I have inside myself. I have stopped caring for myself since long time.

Another participant whose stress sourced from her concern about her future ability to care for her child said,

When my child is restless, I hug him, put him in bed and try to make him sleep. It bothers me when I think what I am going to do when he becomes an adolescent. Life will become more and more difficult.

Social Challenges

The findings provided an insight into the main social challenges faced by parents of children with autism. The major thematic areas identified were interference on family system, lack of awareness, inadequate social service, limited social support and controlled social life.

Interference on family system.

Challenges that were identified by the research participants as interference on family system were the effect on marital relationship, effect on siblings, adjustment of family plans, and the problem in communication.

Marital relationship was found to be affected both positively and negatively. A participant shared his experience like this,

After we found that our child is autistic, the relationship between me and my wife became even tighter. I support her when she becomes distressed and she does the same. I have a strong and amazing wife. We are there for one another more than ever”.

Two opposing ideas about the effect of the presence of a child with autism on siblings were identified whereby some typical siblings were found supportive of their parents in caring for their autistic siblings while others were found disappointed by the extra attention given to their autistic siblings and by the disruptive behavior of their autistic siblings. A participant told his experience as,

My daughter who is the immediate younger sister of my a child with autism is only 5 years old. Amazingly, she understands the problem with her brother and she tries to help us and him by her own ways.

Lack of awareness.

All the participants of this research expressed that lack of awareness about autism was one challenge that they had to encounter due to having a child with autism. The consequences of lack of awareness as expressed by the participants were that people dashed to criticize their mode of child rearing and conflict arises because of the child's wrong doings. One participant expresses the judgment of others like this,

Sometimes when we take our son to the public playing areas, his behavior is mostly misunderstood by people. People think that we spoiled him and give us a blaming look.

Another participant also expresses the discomfort that others people's wrong judgment created to his regular child as,

My younger son is embarrassed to clean his autistic brothers' unmanageable saliva in public areas because the unnecessary attention and staring from others disturb him.

Inadequate social services.

All of the participants of this study raised the absence and inadequacy of social service for children with autism as a big challenge for them. These challenges focused on lack of schools and health centers intended for children with special needs. One participant described his experience like this:

After we knew that our child was autistic, we had searched for centers that give support for our child but we found nothing. After a while there was the opportunity that I and my family went to USA for some time. We were so frustrated by the lack of service in Ethiopia that we were considering to reside in USA leaving the business and all the life we have in Ethiopia for the sake of our a child with autism. Fortunately we heard about Nia foundation, the only one at that time and got registered. Even after that, we succeeded to join here after 14 months of waiting. I can imagine how many parents suffer who do not have the opportunity like ours. It is very sad.

Limited social support.

Sixteen participants stated that the support they get from their relatives and neighbors is limited while four said that they do not get any support. The monthly meeting of parents arranged by Nia foundation was found to be interesting and very supportive for all participants. One participant describes it like this,

Meeting with other parents like us is really helpful. We brainstorm, we direct each other in the right way, we share ideas, we approve each other's successes and we comment on

our failures. Generally we feel safer and more secure here because we know that we are not judged by the behaviors of our children. I have never missed the meeting.

Controlled social life.

Controlled social life was one issue found in this research as a challenge for the participants. Some expressed that being part of social life activities such as attending wedding celebrations and get-togethers with neighbors was altered while others said that their social life has changed but it did not become unmanageable. A house wife participant expressed the challenges as:

My life is so occupied with my child that I do not participate in social gatherings as I used to before. Through time, my neighbors started to cease informing me what is going on out there.

Another single mother participant who runs the family by herself reported,

I had tried to attend events leaving my son with my neighbors. But I do not feel comfortable. I usually go out early and come home to my son.

Similarly another participant noted,

Our social life is affected but somehow we managed it. In the absence of an adult guardian, one of us goes to weddings and one of us stays home.

Economic Challenges

Effects on incomes and effects on expenses were the two core thematic areas that were identified to challenge parents of children with autism.

Effect on earnings and expenses.

It was discovered in this study that seventeen participants agreed that having a child with special needs has an effect on earnings and expenses although the degree varied highly.

Regarding their earnings, eight participants said that their income was affected due to having children with autism because they were forced to be house wives or worked less hours while the economically advantaged said that their income was not affected. A participant expressed it as,

I quit my work since I gave birth to my a child with autism. I was not able to work and support my husband.

The economically able participants who have nurses at home who take care of their child with autism do not seem to encounter problems on their incomes.

As to the expenses incurred while caring for children with autism, all participants agreed that there are extra expenses incurred. Trying different alternatives in order to satisfy the child because of the inability to understand the child's needs were the main reasons. A participant described it like this,

Caring for the child involves extra expenses. It starts from choosing the type of food we prepare for our child.

Seven financially able parents stated that they incur extra expenses because they hire additional therapists that give trainings to their children with autism at home. A participant described it as,

I could say there is extra expense in raising my child because we assigned him a therapist that come home regularly and teach him. But I am not complaining.

Therefore, as described above, the major themes identified by the finding of this study as the psychological, social and economic challenges of parents of children with autism were stress, disrupted family integration, lack of awareness, inadequate social services, limited social support, controlled social life and influenced earnings and expenses. These major themes and the sub themes under these major themes are discussed thoroughly in line with related literatures and theories in the next chapter.

Discussion and Analysis

In this chapter the challenges experienced by parents of children with autism identified in the previous chapter will be discussed rigorously within the framework of the specific objectives of the study. The difficulties associated with having a child with autism have been well documented in different literatures. Therefore, the psychological, social and economic challenges of raising children with autism will be discussed in relation with different theoretical perspectives and literatures.

Psychological Challenges

The current research identified that parents of children with autism experience psychological challenges, mainly stress. It will be discussed hereafter.

Stress.

Participants of the current research were found to experience stress at different circumstances and times as categorized as stress during diagnosis and day to day life and stress about the future.

Stress is a situation when an individual perceive or face a condition that demands resource than the person has (Medhin, 2011). In Heiman's (2002) study, it was reported that parents of children with autism experienced considerable stress, as well as feelings of depression, anger, shocks denial, self-blame, guilt, or confusion. The study by Chee (1991) which states that caring for a mentally disabled child poses even more stress to most parents as the child will bring uncountable problems related to growth, caring, management of the developmental tasks and the child's unclear future corresponds with the previous statement.

Stress as experienced by parents of children with autism at different periods is discussed hereunder.

Stress during diagnosis and day to day lives.

This study identified that the participants encountered high level of stress during the diagnosis of their child with autism and also during their day to day life. Each will be discussed separately.

Stress during diagnosis.

The participants of the current research remember the diagnosis of their child with autism as distressing one. They experienced shock the first time their child was diagnosed with autism and when they were told that there is no cure for autism. They did not have any information about autism until it was the case with their child.

Heiman (2002) agrees with this by saying that for parents it is the most difficult and shocking experience to find out that there is problem with their child. Ling (1998) further says that the two opposing experiences of a family, which are the joyous experience of having a new born baby and the painful experience of knowing that the child is disabled happen to a family within in few years creating high level of stress on them. The study by Chee (1991) also reached on the same conclusion based on the data collected from twenty two research participants where most of these participants experienced an initial period of stress, anxiety, sadness, shock etc.

After the long journey of pregnancy, having a baby is exciting as it is the affirmation of another chapter of life especially for those parents for whom it is the first time. Parents expect to have a healthy child that will feel their life with joy. They count every progress their child makes. Since the signs of autism are seen couple of years after the baby is born, parents think that they have a healthy child. Therefore, as seen in different literatures and from the finding of the current study, stress is highly experienced by parents of children with autism when they

discover that their child is autistic. A number of questions and confusions create feelings of loss of their children making the situation more distressful. Denial, anger and feelings of sadness associate the stress the parents experience.

Stress during day to day lives.

According to the finding of this study parents experience stress induced by the thought of not having a regular child and the complex care taking responsibilities.

Within the care giving responsibilities, managing their children with autism's challenging behaviors and responding to the diverse, unpredictable, fixated and adult supervisor needs were identified as the major stressors.

Chee (1991) says that parent's stress was situational and related directly to their role as parent and to their interactions with their child. Opposing to this and to the finding of the current research, is the study by Heiman (2002) which found most of the participants saying that their initial negative reactions and feelings have turned into positive and optimistic feelings of acceptance.

The study by Lo, Chak-chuen & Eddie (1994) widely investigated the care-taking responsibilities of parents and categorized the family life in four groups based on the age of the a child with autism: infancy to early childhood, early childhood to late childhood, adolescence and adulthood. This study says that care-taking role of parents is present throughout the life of the a child with autism where it is higher in the first stage; gets lower in the second stage and go higher in the third and fourth stages. Although the current research did not compare the magnitude of the challenge of care-giving role at different developmental stages as the above research did, it agrees with the presence of stress at all levels.

Therefore, the finding of this research and the above literatures show that parents, even after they accepted the fact that their child is autistic, the continuous care parents have to provide to their children mainly, managing the children's behaviors and responding to their children's needs cause them stress.

Managing the behavior of the a child with autism, which is the major care taking role of the participants, was found to cause stress on the participants of this study. Duzbay (2011) supports this finding by saying that a child's behavior related to being autistic causes the greatest amount of anxiety and distress for parents. This is also substantiated by the study by Alteriere (2006) which says that the combination of difficult emotional and physical behavior displayed by the child with autism creates a high level of stress on the entire family.

Moreover, the finding by DeMyer (as cited in Lo, Chak-chuen & Eddie 1994) reports that substantial amount of mothers of preschool children felt upset because of the "nerve-racking" behaviors of their child. Ritche (2008) further says that it is no surprise that the caregiver of a child who has autism may become distressed and begins grieving due to the lack of the child's ability to securely attach to them.

Therefore, the finding of this study and the studies reviewed show that parents are prone to stress because of the autistic behavior of their children. Children with autism, as described in different parts of this study portray different unordinary behaviors. Bizarre responses to various aspects of the environment, pervasive lack of responsiveness to other people, resistance to change, peculiar interests, attachment to carrying odd objects, resistance to minor change in the environment, repetitive peculiar hand /motor movements, unstable mood, unexplainable crying, laughing without unidentifiable cause, under/over responsiveness for sensory stimuli, like light pain and sound, nervous habits and real danger. When children behave in these unusual and

difficult to predict ways, dealing with one of these behaviors is difficult let alone the combination of many of these.

Long discussion may not be practical due to the child's restlessness or continuous crying, Having proper meal time is not always successful because the child may not be able to sit appropriately for extended periods of time, attending different events may not be possible due to the child's aggressiveness, bedtime routines may be interrupted by difficulties of sleep and the child's safety from real dangers may not always be guaranteed because of their low or heightened sensitivity to stimulus. Therefore, parents experience stress because of the additional challenges of dealing with the inflexible and unusual behaviors of their children. These behaviors become emotionally and physically exhausting for the parents even in the presence of an assistant care giver because they have to get involved one way or the other. Raising the a child with autism by dealing with these behaviors will be a stressful challenge that adds anxiety to the parents.

Regarding the other care taking role, which is responding to their children's needs, the child's obsessive desire for sameness, unpredictable needs and the child's need for adult guardian were the major stressors of the participants. Participants, especially the economically disadvantaged ones were found more stressed because their children need a great deal of their time.

According to Chee (1991), parents are the most important primary care takers of the child and a disabled child in a family exerts greater stress and demands on them whereby they ought to deal with a set of needs arising from their children's developmental difficulties. They see themselves as being controlled and dominated by their children's demands and needs. The study

by Lo, Chak-chuen & Eddie (1994) further found that parents are disappointed to see their children continue to need a great deal of custodial care and that independence seems to be unattainable. The same is found in the study by Wiggs (2010) which says that it is difficult for parents to be independent because they have to closely look after their children. Ambikile and Outwater's (2012) study investigated this matter and found that the inability of the a child with autism to express needs was a source of emotional and psychological distress that caused parents to be unable to understand the child especially when he/she had problems.

Therefore, it can be seen from the finding of the current research and the above literatures that a child with autism may not express his/her basic needs as can be understood by the parents. It is difficult for children with autism to explain when they are mistreated by other people. It is also difficult for parents to fully understand what the child is feeling when he is sick and need health care. Therefore, parents are forced to use their past experience with their child that was developed through guessing which may not always work at the first trial. It will not be easy for parents to determine the needs of their child easily and this leaves them frustrated. Not being able to understand what their child needs is quite distressing for parents.

Generally, regarding the care giving role of parents that take place in their daily lives, parents with better economic background are found less stressed because they are less burdened by the caring role since they can hire nurses or bring relatives from countryside that can deal with and respond to their children's behaviors and needs. Therefore, economically disadvantaged families face higher stress by the extra care giving activity.

The study by Lo, Chak-Chue and Eddie (1994) substantiates the above concept. It says that parents with substantial income can afford to pay for training service and special treatment

provided by private practitioner. They are able to hire maid to reduce their burden of child care. It also adds that their level of stress is expected to be lower because there will be less problems in maintenance and will have a greater sense of achievement and higher self esteem.

Stress about the future.

The finding of the current study shows that parents experience stress about the future of their child and their own future.

Regarding the future of the child, the current research found that long time after diagnosis, parents still feel overwhelmed about the future of their children. The major reasons identified were the inability of the child to be independent, the vulnerability of the child, the inability of the child to properly deal with psychosexual issues during adolescence and the possibility of regression.

The study by Heiman (2002) which tried to understand what aspects of the future worry parents of children with autism found that many parents worry about the child being included in society including his/her financial and physical independence, their education and how they would manage without them. Harris (as cited in Lo, Chak-chuen & Eddie 1994) supports this by saying that the issue of separation becomes particularly prominent as parents begin to face their own mortality.

Most of the time parents are the primary care givers of a child. This is more amplified in the case of parents of children with disabilities. They are the ones who provide their a child with autism with exceptional care no matter how distressful and frustrating the process is. They are the ones who can tolerate their children for life long. So, the thoughts and worries about who is going to care for their child constantly bother parents especially in their absence due to the

inability of the child to be independent to the extent that they worry about what will happen if they die.

The reaction of adolescents towards psychosexual issues is substantiated by the study by Lo, Chak-chuen & Eddie (1994) which noted that fear of adolescences response such as masturbation for boys and self-care in menstruation and fear of pregnancy for girls were identified by parents as stressful. This substantiates the concerns of parents about the adolescent's sexual problems. The fact that these children, as any human beings will experience hormonal changes at certain ages which they may not be able to manage appropriately is therefore another source for stress.

The probability of regression was also addressed by Ababi (2008) which reported that there is the constant fear that recurrence of illness may cause sudden and unexpected disruption of the lives of family members. Therefore, regressing back of children with autism is also a point of concern. A lived experience of regression has been seen in the center by one child who having learned lots of skills had regressed back to her first situation. This creates stress on parents because they worry that same might happen to their children and it will be most difficult and frustrating to do the trainings all over again. Furthermore, when the children spend their days at home during summer times, they tend to lose the skills they learned because of lack of constant follow up. This is also another source of frustration for parents.

Having addressed the above issues about stresses relating to the future of the children next will be discussed stresses identified in relation to the parents' future which are their concern about their future psychological well being, their ability to handle their children during adolescence, and being deprived to pursue their dreams.

The study by Lo, Chak-chuen & Eddie (1994) states that management problems with adolescents takes greater importance because of the increasing size and strength of the children and the decreasing strength and energy of the parents. The study further says “If physical aggression becomes a problem in adolescents, this has the potential for acute family crisis unless parents are highly skilled or help is available”. Heiman (2002) also says that parents of younger children with a disability were concerned with how they would deal with their children’s adolescence and puberty.

The permanence of the child’s disability and its implication to the parent’s own lives can be a significant stressor for the family. Knowing that they have to deal with the challenges of having a child with autism as the child grows up is stressful for parents because it forces them to question their ability to handle their children as they grow up. In addition, parents evaluate their efforts and abilities of child care and the sacrifice they have made through limiting their personal growth and development as well as those of other family members (Konovalova, 2008). Especially, since it is difficult for economically disadvantaged parents to work regular jobs with better pays or to advance their education, the concerns about lost opportunities for employment and education are disturbing for them.

Therefore, stress, experienced by parents of children with autism at different spheres of life as discussed above is therefore a major psychological challenge. This challenge deprives parents from functioning as they desire. This parenting stress causes psychological burden on the parents.

Social Challenges

The major social challenges identified in this study are interference on family system, lack of awareness, inadequate social service, limited social support and controlled social life. Each will be discussed thoroughly with the support of literatures.

Interference on family system.

The reasons for family disruption identified in this study as portrayed on the finding part are the effect on marital relationship, the effect on siblings and modification of family plans.

The effect of having a child with autism in the family is investigated by Balfour (2004). The findings of the study by Balfour (2004) report that having a child with autism at home have an impact on family life. In addition, in the study by Heiman (2002) the majority of the parents believe that they are the ones most affected by their child's disability, whereas others thought that the family's other children were the most affected and many felt that it affected the nuclear family.

Concerning the challenges faced within the marital relationship, the finding of the study by Lo, Chak-chuen & Eddie (1994) says that mothers were found to have lower levels of marital satisfaction while Heiman (2002) found that most of the parents reported that the disability of their child strengthened parental relations and few claimed that it created new problems, conflicts, and impatience between the parents, and the dyadic relationship was weakened.

The above literatures and the findings of this study show that some parents go apart emotionally because they are much focused on caring for the a child with autism or they are frustrated with raising a child with autism. This hinders them from having quality time of their own. Others are joined in mutual support of each other helping one another emotionally. Those parents who go apart because of the presence of a child with autism at home need to pull

themselves to one another so that they can strengthen their relationship which is helpful in times of stress and frustration.

As to the reaction of siblings, some children can be supportive of their families and others can be disappointed by the unbalanced attention provision and the disruptive behavior their siblings. This is supported by the study by (Glass, 2001). It says that there appear to be both positive and negative effects on siblings of living with a child with autism. McHale, Sloan, and Simeonsson (as cited in Glass, 2001) report that many children feel they have not received the same amount of attention from their parents as the impaired child, and express feelings of unfair treatment, with their sibling able to get away with more than they could ever do. On the other hand, Mates (as cited in Glass, 2001) found that no difference between siblings of different groups on measures of self-concept, academic achievement or home or school adjustment.

Regarding the need for modification of family plans, Holroyd & McArthur (as cited in Lo, Chak-chuen & Eddie, 1994) say that children with autism are more disruptive of family integration such as meals, vacations, family outings, family get-togethers and the like. A statement by Balfour (2004) corroborates this concept by saying “the behavior of their child forces parents to split as the mother will take care of her a child with autism at home while the father takes the sibling/s on an outing”.

The finding of this research therefore goes in line with the literatures stated above. More to the normal pressure of family life, families with children with autism also face with the adjustment to the presence of the child with a disability. In order to accommodate these pressures and care for the child, parents are forced to change their life routines.

Lack of Awareness

The lack of awareness about autism within the community is found to be a great challenge for participants initiating community members to be judgmental of the parents' way of child rearing and to argue with the parents in case the children did something wrong.

Children with autism do unpredictable things. As a result of this, family outings may be complicated because parents can not anticipate what the child will do next. There are times that the child behaves well but there are also times when the child may become distressed and scream or act in strange ways attracting others attention or disturb or destroy others properties. Thus, the behavior exhibited by the child specially a child who physically looks normal misleads people to rush to conclude that parents are poor at child rearing when they see the child behave in an unusual manner. People hold them responsible for the child's strange act. This is challenging for parents because it is difficult for them to explain.

Conflict with others is experienced when the children do wrong things to other people. Especially those families who share one compound with other households experience dispute when their children destroy properties. The neighbors blamed them why they do not control their children. Families who live within their own compound did not experience such problems with their neighbors but sometimes face conflicts in other setting such as playing grounds and cafeterias when the children disappointed other parents' children or destroyed materials.

Lack of Social Service

Participants of the study were highly challenged by the absence of service providers for their children with autism. They were not able to find them schools or hospitals that could accommodate them based on their autistic behaviors.

Lewis (2009) says the following about the lack of service in Ethiopia. “A further illustration of the impossibility of meeting the educational needs of all disabled children through segregated education is the example of Ethiopia’s only special school for children with autism (that is not government run). In 2006 the school was able to enroll 60 students, but had a further 250 on the waiting list”.

The finding of this research and the above literature show that the absence of schools for children with autism is very distressing and frustrating for parents. Parents spent a lot of time looking for schools that could accommodate their a child with autism. On average, the participants of this study waited from 8 months to 2 ½ years to have their child join Nia foundation. According to the current information collected from the foundation, there are about 500(five hundred) children on the row waiting for their turn to join the foundation. These facts clearly show that there is high scarcity of social service for children with autism in Ethiopia. This problem creates bigger disappointment in parents. They experience frustration while waiting such long times to be accepted by the foundation because there was not enough center equipped with speech and other therapists that would guide them on how to care for their child. The participants also expressed their sympathy for those parents who are not able to have their children join such professional centers for children with autism.

Regarding the policies developed in Ethiopia concerning education provision for children with special needs, the study by Lewis (2009) says that Education policies and plans in Ethiopia have attempted to explain the direction their education sectors should take to ensure education for learners with special educational needs. However, clarity on how policy makers interpret the key concepts of special needs education and inclusive education remains elusive.

Challenges of inadequate social services experienced by parents in this study are similar to what is found by the research conducted in South Africa by Balfour (2011). The absence of health care system, which includes specialized professionals is disappointing and challenging for parents.

Limited Social Support

The finding of the study has shown that most parents get limited support from their significant others. Cobb (as cited in Lo, Chak-Chue and Eddie, 1994) describes social support as information leading the person to believe that he is cared for and loved, esteemed and valued, and part of a network of mutual communication and obligation. Chee (1991) says that there exist four types of social resources that can give support to people. These are informational support, social companionship support, emotional support and instrumental support. Furthermore, this study states that parents said they are socially isolated from their peers, relatives and other emotional support system. A study by Ambikile and Outwater (2012) also stated that some people could not even give help when they found the child in a critical condition like having seizures and do not even give seats with their child on their back while using transportation services.

This is different from what is found by the current study. Majority of the participants reported getting emotional support and understanding from relatives, neighbors, friends and significant others although it is limited to some kind of incident or event. Parents said that most of the problems they face emerged from the lack of awareness but once people knew that the children's problem is related to mental issues, they were sympathetic and collaborative in giving them priorities.

Therefore since the presence of a child with autism makes the parenting role more difficult in comparison to parents of normal children, outside support is helpful for parents. The support which is given to the parents of children with autism should not be limited to certain events. It should be delivered to them with planned and systematic manner.

Parents also emphasized the importance of meeting other parents with similar concerns or experiences in order to feel less isolated and more comfortable. The monthly meeting arranged by Nia foundation is advantageous in providing social support to parents. Sharing of ideas, discussion on challenges and successes and giving and taking advises takes place. The children are not judged by parents of children with autism unlike parents of typical children. This shows that the foundation acts as a comfort zone for the parents as well.

Controlled Social Life

As to the finding, the social life of the parents was found to be interrupted by the presence of a child with autism in the family. For few economically disadvantaged parents who do not have close relatives or cannot hire care givers, the interruption of their social life was felt intensely while it was not uncontrollable for others who get assistance from their parents, relatives, spouses or children.

Economically disadvantaged parents who do not afford to hire care givers and do not have close relatives are obliged either to miss an event or take their child with them, or leave their child with neighbors in order to attend an important event. In unavoidable social events, parents take the latter option but still feel discomfort because they think that they bothered other people with their problems and they worry that their child caused some problem. This forces them to miss social gatherings and to have restricted social life.

The current study's finding differs from what is found by Heiman (2002) which states that the presence of a disabled child affects the parents' social life whereby parents rarely spend time with friends, friends ask them not to bring their child to social events and lose contact with friends, relatives, or even with their extended family.

Unlike the families of most western countries where the nuclear family is fully in charge of itself, the culture in Ethiopia where there exists strong bond between relatives and neighbors is a positive asset that supports parents of children with autism. Therefore, cultural system of the setting where families are residing can affect the social life of parents of children with autism.

Economic Challenges

The economic challenge that could be faced due to caring for an individual with mental disability is well illustrated by (Ababi, 2008). According to Ababi (2008), development of mental disorders and caring for them may result in economic burden on individuals, families and communities. These burdens were described that they could be in the form of loss of income, employment; out of pocket expenses, reduced productivity, days out of role, emotional strain, disturbed social relations.

Effect on earnings and expenses.

The finding of the current research shows that participants were forced to get no or low income due to caring for their a child with autism. This is supported by the study by Gray (as cited in Alteriere, 2006) which says that most mothers are forced to stay home caring for their children. Parents of children with autism are forced to be house wives and some are forced to work limited hours. (www.ethioautism.org) also states that it is more likely that parents, particularly mothers become disabled themselves, burdened and most probably have no or very low incomes as their child's disability directly constrains their ability to work and make a living.

Therefore the finding and literature show that parents need to spend more time with the children and as a result they will not be able to enroll in a full time job that generates average income.

The condition where extra expenses are incurred while caring for children with autism was commonly agreed by all parents. This expenditure was strongly felt by economically disadvantaged parents unlike those with good income. The regular home based private therapy was described as an extra expenditure by some participants.

Parents incur costs while trying different things to understand, fulfill or enlarge the needs and interests of their child. While trying to provide their child with better things, some parents jeopardize the financial security of their family. This leads them to worry about how they can support their family financially. Families of a child with autism experience more financial problems because they have higher expenditures some of which can be expenses for therapy and professional services.

Generally the psychological, social and economic challenges that parents face in raising their children with autism as identified by the empirical findings of this study and as supported by the different literatures reviewed, are found to have influence on the family when looked from the family systems theory.

Family systems theory states that family comprises of elements and structures that are interrelated in nature (Mallers n.d.). Parents, children with autism, other siblings and extended family members living together are elements of a family. According to this theory, each element of a family has characteristics where the characteristic of one member affects the other member because of the interdependent nature of the relationship between members. Therefore in the case of a family with a child with autism, the different behaviors and needs of children with

autism were found to create challenges on the parents leading them to experience stress. Parents experience stress at different life spheres of their children because they have to deal with the consequences of the disability with their child. Thus the challenges arise from the interconnected nature of the relationship between the parents and children with autism.

Furthermore, in striving to play the roles expected from them as elements of a family, they are faced with social and economic challenges associated with the autistic nature of their children that are identified and discussed previously. This forces the parents to redefine their boundaries by seeking support from outside.

Implication to social work

This research has an implication to social work research, practitioners and policy. Intervening effectively in the lives of children with autism and their families is not the sole responsibility of any single agency or professional group, but rather is a shared community concern.

According to Alston and Bowles (2003), social research is the systematic observation and collection of information to make decision or to take an action. Therefore, social worker professionals know that working with the child means working with the whole family and other environmental factors in a culturally competent way, this research forwards suggestions by putting this in to consideration as follows.

Implication to social work research

- There is a need for further research on the issues of children with autism as well as their parents since existing research and the finding of this study cannot give a comprehensive way to look at the issue. Therefore, since the challenges of parents of children with

autism lie in the psychological social and economic spheres, addressing all of these issues with few studies is difficult. Therefore, there are several areas worth further exploration.

- Since the selection of participants was made through the involvement of the center and since the research participants get support from the center, the study experienced selection bias. Therefore, further research should be done on parents who do not get any support from any foundation.
- In addition, since an autistic child's family size, birth order, frequency of contact with parents, severity of the autistic behavior, parental collaboration, and other related issues directly or indirectly influence the challenges of parents of children with autism, studies focused on these areas should also be done.
- As prevention is the first and best way of tackling a problem, studies on preventive interventions should be done. Furthermore, studies that explore the coping strategies utilized by the parents of children with autism should also be done so that they can be assisted to capitalize on their strengths.

Implication to social work to practitioners

- Since social work professionals are on the front line to lobby these facts, their involvement should be promoted so that they can advocate for the provision of psychological, social and economic support for parents of children with autism.
- Various strategies on how to support parents of children with autism should be proposed through the coalition of the concerned stake holders; the society, government, service giving agencies, private sectors, educators and professionals. Practitioners should work

on bringing these stakeholders on the same table and facilitate their cooperation for the shared purpose.

- Although initiatives are done by non government organizations such as Nia Foundation-joy center for children with autism which continue to give psychological support to parents of children with autism through empowerment and counseling, it is still far from ending the challenges because the efforts so far made are very limited and unsatisfactory compared to the need. Service giving agencies especially those working with children should build on programs that can accommodate children with autism and their parents. Therefore, social work practitioners should promote for the involvement of other service giving agencies in this matter.

Implication of social work to policy

- The government must in the short term pursue an active policy of the services that should be made available for children with autism and their parents

Conclusion & recommendation

Conclusion

This study attempted to adopt family systems theory as a theoretical framework to explore the psychological, social and economic challenges of parents face while they raise a child with autism. The study looked at the experience of 20 parents in raising a child with autism. Findings in the current research answered what the challenges of parents of children with autism are.

The recurring themes found to be experienced by parents of children with autism are: stress, interference on family system, lack of awareness, inadequate social service, limited social support, controlled social life and influenced earnings and expenses.

This study has found that regardless of their socioeconomic group or educational background, parents are facing a major psychological challenge, stress. Qualitative data showed that high level of stress was found to be present in all participants during the diagnosis of their child with autism. In their day to day lives as well, the care-giving tasks, mainly managing the complex behaviors of their children and managing the unpredictable, redundant, or guardian dependant needs of their children were found to be distressing for parents. The economically stable parents were found to experience lesser level of stress than the economically disadvantaged parents in the care giving activities. In regard to the future, concern about the future of their child and concern about their future were found to be sources of stress. Dependency and vulnerability of the children with autism were the stressors for most of the parents. In addition to this, the educationally literate parents were found to be concerned about the psychosexual needs of the children during adolescence and the possibility of regression of the children. Some were also found positive about the future. As to their own future, their own

psychological wellbeing, incapability to pursue their career and fear of difficulty to manage their children in the future were found as causes of stress for the parents.

In the social aspect, interference on family system, lack of public awareness, inadequate social service, limited social support and controlled social life were found as challenges. Within interference on family system, marital relationship was one issue where for some it became even tighter while for others it became loose. Dealing with the a child with autism's siblings was also found to be challenging because some regular children were found supportive while others were found disappointed because lesser attention was provided to them. Influenced family plans whereby most parents were forced to think about their a child with autism before making plans, and communication problems whereby they are hindered from fully exchanging their thoughts and feelings with their children with autism were the other challenges found.

Being criticized for their child rearing way due to the behavior of the child and encountering conflict due to the child's wrong doings were the challenges faced due to the lack of awareness of the public about autism. Inadequate social service, specifically scarcity of educational and health centers was another challenge for all parents. Social support which was better available for some and less available for others was another point of concern. The monthly parents meeting arranged by Nia foundation was found very supportive by all participants. Full participation in social life was also found to be unfeasible for all participants. Having a child with autism highly affected the social life of parents who are economically incapable to hire nurses or who do not have close relatives that can help them or who do not have good relationship with neighbors.

The economic challenge identified were the effects on earnings and expenses. Few parents were forced to be either housewives, or work lesser hours than regular hours in order to care for their children jeopardizing their income. Others with better economic background were less or not affected because they have either business that can run by its own or they have people who can cover for them their work or their caring task. Regarding their expenses, all participants agreed that they incur extra expenses in trying to understand or widen their child's needs. The private home based regular therapy they made available for their children was another source of expense which is financially challenging for some and not challenging for other parents.

Recommendation

Based up on the review of literature and the result of this study, suggestions are put forward for consideration. Therefore, this chapter will give recommendation for future practice based on the themes identified in this study thus giving rise to the identification of areas where future research could potentially be developed. In addition, it will recommend the roles that all concerned stakeholders should play to help parents of children with autism cope with their challenges.

There is a need to strengthen and broaden the services focusing children with autism and their parents since there are few initiatives done regarding this issue in Ethiopia for example that are done by nongovernment organizations such as Nia Foundation joy center. The service is limited and unsatisfactory compared to the need. Services aimed at addressing the needs and challenges of both children with autism and their parents must be nurtured by psychological support to parents of children with autism through empowerment and counseling.

Efforts have to be made on educating the society about what autism is otherwise permanent change cannot be maintained. Therefore the focus of the future lies in community awareness which can be attained through awareness programs about children with autism at all levels of society in order to reduce parental challenges faced from the society due to lack of awareness.

Educational institutions should press on departments under them to include in their curriculums courses that provide an understanding of autism so that professionals of tomorrow can have better knowledge while assisting parents of children with autism. In addition, interdisciplinary approach should be practiced with in the educational institutions for example coalition between the school of social work and department of special needs should be promoted so that both can share knowledge and experiences with one another so that a stronger effort is exerted on creating awareness about autism in education, in the public and in service giving organizations.

References

- Ababi Zergaw Giref. (2008). *Economic burden of Schizophrenia and bipolar disorders in Ethiopia*, Addis Ababa.
- Alson, M. & Bowles, W. (2003). *Research for social workers: An introduction to methods* (2nd ed.). Australia
- Alteriere, J. M. (2006). *Family functioning and coping behavior in parents of children with autism*, Michigan.
- Amare Deribew and Yonas Shiferaw, (2005). How are mental health problems perceived by a community in Agaro Town, *Ethiopian Journal of Health Development*, Jimma, Ethiopia,
- Ambikile and Outwater (2012). *Challenges of caring for children with mental disorder: Experiences and views of caregivers attending the outpatient clinic at Muhimbili national Hospital*, Child and Adolescent Psychiatry and Mental Health, Tanzania, Dar Salaam
- American Psychiatric Association, (2000). *Diagnostic and Statistical Manual of Mental Disorders*, (4th ed. text revision). Washington DC
- Autism Fact Sheet, National Institute of Neurological Disorders and Stroke, National Institute of health, US Department Of Health and Human services, Bethesda
- Balfour, L. J. (2007). A needs assessment of parents on how to raise a child with autism, South Africa
- Center for Learning Innovation, (2006). *A basic introduction to child development theories*, State of New South Wales
- Centers for Disease Control and Prevention, (2010). Autism Spectrum Disorders, Retrieved from

- Chee, M. (1991). *Stress of parents with children with autism, Department of social work and social administration, Hong Kong*
- Cook, J. & Cook, G. (2005). *Child development principles and perspectives*, Book chapter, Boston
- Creswell, J. B. (2009). *Research Design, Qualitative, Quantitative and Mixed Approaches*, Sage Publishers Inc., United States
- Dzubay, S. K. (2011). *Parental grief, coping strategies and challenges when a child has autism spectrum disorder*, United States, Wisconsin
- Efrem Sahle, (2005). *The role of parents of children with autism in the early intervention programs*, Addis Ababa
- Gillberg, C., Steffenburg, S., Schaumann H. (1991). *Is Autism more common now than ten years ago?* Child Neuropsychiatry Centre, Published by the royal college of psychiatrists, Sweden, Goteborg
- Glass, P. W. (2001). *Autism and the family: A qualitative perspective*, USA, Virginia.
- Heiman, T. (2002). Parents of children with disabilities: Resilience, Coping and Future expectations, *Journal of Development and Physical Disabilities*, Plenum Publishing Corporation
- Konovalova, N. (2008). *Challenges in parenting a child with autism spectrum disorder*, Oslo
- Kumar, G. (2008), Psychological stress and coping strategies of the parents of mentally challenged children, *Journal of the Indian academy of Applied Psychology*, Mysore
- Levine, G.A. (2010). *The relation between family, resources, child severity and parenting stress in parents of young child with autism*, Nashville, Tennessee

- Lewis, I. (2009). Education for disabled people in Ethiopia and Rwanda, *Education for All Global Monitoring Report, Reaching the Marginalized*
- Ling, (1998). *Raising a child with autism*, Hong Kong
- Lo, Chak-Chuen, Eddie (1994). *Parenting stress in family with autistic individual*, Hong Kong,
- Mallers, M. H. (n.d.). *Systems Theory: Families and autism*, Department of Human Services, CSU Fullerton
- Medhin Selamu, (2011). *Experience and practice of socio-Emotional support for health professionals in Ethiopia*, Addis Ababa
- Menlik Desta, (2008). *Epidemiology of child psychiatric disorders in Addis Ababa*, Sweden
- Ming, (2006). *An exploratory study of flexibility of emotional expression, stress and psychological well-being of parents of ASD children*, Hong Kong
- Miodrag, N. (2009). *Psychological well-being in parents of children with Autism and Down Syndrome*, Montreal, Canada,
- Nia Foundation Joy Center (2010). Retrieved from <http://www.ethioautism.org>
- Ritchie, B. (2004). *The loss of a dream: Parents raising a child with autism*, Department of family studies and human services, Manhattan, Kansas
- Vihar, J. (2013). *Action for autism*, Autism organizations worldwide, India, New Delhi
- Wiggs, T. (2010). *Stress levels and development; A phenomenology of children with autism and their parents*, Virginia, Lynchburg
- Wnoroski, A. K. (2008). *Uncovering the stigma in parents of children with autism*, Oxford, Ohio

Annex i**In depth interview Guide****Interview Date:** _____**Interview Start Time:** _____**Interviewee Id No:** _____**Background**

1. Tell me about yourself and your family (your age, your marital status, your job/work, your children)?

Psychological Issues

2. What was your response when you found that your child is autistic?
3. Are there psychological challenges that came with having a child with autism? If yes, what are they?
4. What do you feel when you think about the future?

Social Issues

5. Are there social difficulties that you are facing that resulted from having a child with autism? If yes, what are they?
6. What is the attitude of the people around you towards the fact that your child is autistic?

Economic Issues

7. Are there financial strains caused by having a child with autism? If yes, what are they?
8. Is your income and expense affected as a result of having a child with autism? If yes, how?

Thank You!

Annex ii

የስምምነት ቅጽ

ጤና ይስጥልኝ!

ስሜ ቤዛዊት መከራያ ይባላል። በአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ የማስተርስ ዲግሪ ተማሪ ስሆን በዚህ በኒያ ፋውንዴን ጆይ ሴንተር አገልግሎት የሚሰጣቸው ልጆች ወላጆች ከኦቲዝም ጋር በተገናኘ በሚያጋጥማቸው ስነልቦናዊ ማህበራዊና ኢኮኖሚያዊ ፈተናዎች ዙሪያ የመመሪያ ጥናትን በመስራት ላይ እገኛለሁ። የዚህ ጥናት ተሳታፊ እንዲሆኑ ስጠይቅ በትህትና ነው።

በዚህ ጥናት ተሳትፎዎ ላይ ማንነትዎ በሚስጥር እንደሚጠበቅና የሚሰጡትም መረጃዎች ሁሉ ለሌላ ሰው እንደማይተላለፉ አረጋግጣለሁ። በቃለ መጠይቃችን ወቅት ማስታወሻና የድምጽ መቅረጫ መጠቀም መረጃዎቹን በትክክል ለመያዝ ስለሚረዱኝ እጠቀምበታለሁ። ሆኖም የተቀዱ ካሴቶች ሁሉ በድብቅ የሚቀመጡ ሲሆን ጥናቱ ከተጠናቀቀ በሁዋላም ከጥቅም ውጪ ሆነው የሚጣሉ ይሆናሉ። ይህም የርስዎን መብት ለመጠበቅ የሚደረግ ነው።

በዚህ ጥናት መሳተፍዎ ለእኔ የሶል ወርክ ትምህርት መሳካት ትልቅ አስተዋጽኦ አለው። በተጨማሪም የኦቲስቲክ ልጆች ወላጆች ከኦቲዝም ጋር በተገናኘ የሚያጋጥማቸውን ስነልቦናዊ ማህበራዊና ኢኮኖሚያዊ ፈተናዎች በተመለከተ ብዙ ጥናት ያልተሰራ በመሆኑ በዚህ ጥናት ተሳትፈው የሚመጣው ውጤት ለዘርፉ ዕድገት የላቀ አስተዋጽኦ የሚኖረውና ወደፊትም የተያያዘ ጥናት የመስት ፍላጎት ላላቸው አጥኚዎች መሰረት የሚጥል ይሆናል። በሌላ በኩል ደግሞ በቃለ መጠይቁ መሳተፍዎ ጥያቄዎቹ የግል ጉዳይን የሚመለከቱ በመሆናቸው የስሜት መረበሽ ሊያጋጥም ይችላል። ነገር ግን ይህን ችግር ለመቅረፍ ከወዲሁ የፕሮግራም ማስተካከል ስራ እንሰራለን።

በቃለ መጠይቁ ወቅት የሚሰጡት መልስ ትክክለኛነት የጥናቱን ውጤት ስለሚወስነው ለዚህ ተከራካሪ ንዲሰጡ በትህትና እጠይቃለሁ። ግልጽ ያልሆነልዎት ነገር ቢኖር በማንኛውም ጊዜ መጠየቅ ይችላሉ። ይህንን ቃለመጠይቅም ሆነ ጥናቱን በማንኛውም ጊዜ የማቋረጥ መብት አልዎት። የዚህን የስምምነት ቅጽ ኮፒ የመውሰድ መብትዎ የተጠበቀ ነው።

ከዚህ በላይ በተጠቀሱት ነጥቦች ከተስማሙና የጥናቱ ተሳታፊ ለመሆን ፍቃደኛ ከሆኑ መስማማትዎን በፊርማ እንዲያረጋግጡልኝ በትህትና እጠይቃለሁ።

አመሠግናለሁ!

የተሳታፊ ፊርማ

Annex iii

Table 1: Tabular representation of identified themes

Specific objective	Major themes	Subthemes
PSYCHOLOGICAL CHALLENGES	Stress	Stress during diagnosis and daily life
		Stress about the future
SOCIAL CHALLENGES	Interference on the family system	Influence on marital relationship
		Influence on sibling relationship
		Influence on family day-to-day plans
	Lack of awareness on Autism	Judgment on parent's way of child rearing
		Conflict because of child wrong doings
	Inadequate social services	Lack of special schools for A child with autism
		Lack of health and related professionals
Limited social support		
Controlled social life		
ECONOMIC CHALLENGES	Influenced earnings and expenses	

Annex iv**Table 2: Tabular representation of participants' demographic data**

Id No	Sex	Age	Marital Status	Level of Education	Occupation	Birth Order of the autistic child
NFJC001	F	40	Married	No formal education	Employed in private organization	3 rd
NFJC002	F	45	Married	8 th grade certificate	Self employed	3 rd
NFJC003	M	52	Divorced	No formal education	Security Guard	4 th
NFJC004	F	41	Single	Elementary education	Self Employed	3 rd
NFJC005	F	38	Married	Higher education	Civil servant	2 nd
NFJC006	F	32	Married	8 th grade certificate	House wife	1 st
NFJC007	F	38	Married	Higher education	Project coordinator in international organization	2 nd
NFJC008	M	47	Married	Diploma	Teacher	4 th
NFJC009	F	39	Married	Elementary education	Employed in Hair salon	2 nd
NFJC0010	F	33	Separated	High school diploma	Self employed	1 st
NFJC0011	F	51	Married	No formal education	Small business	4 th
NFJC0012	F	60	Widowed	No formal education	House wife	8 th
NFJC0013	F	36	Married	High school certificate	Self Employed	2 nd
NFJC0014	F	36	Married	Elementary education	Sales person	1 st
NFJC0015	M	52	Married	No formal education	Security	5 th
NFJC0016	F	37	Married	Elementary education	Working in Hotel	2 nd
NFJC0017	F	40	Married	No formal education	Small household business	3 rd
NFJC0018	M	45	Married	8 th grade certificate	Employed in private organization	2 nd
NFJC0019	F	43	Single	No formal education	Small business	3 rd
NFJC0020	M	49	Married	Higher Education	Self Employed	4 th nd