

The Experience of Parents of Children.....

**The experience and coping mechanism of parents of children with autism: the case of Nia**

**Foundation Joy Centre**

**A thesis submitted to school of social work, Addis Ababa University**

**In partial fulfilment of the requirement for the degree of masters in Social Work**

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**Abstract**

*This is a case study that attempted to assess the experience and the coping mechanisms of fourteen parents who are giving cares for their children with autism. To this end, qualitative case study research design was employed in order to have an in depth understanding of the issue. The study area selected was Nia Foundation-Joy Centre for children with autism. The study employed an in-depth interview, focus group discussion and observation to collect data. The finding of the study indicated that parents have low awareness about the illness that is associated to the cultural and regional views. And the study also revealed that parents are struggling with the practical care giving, economic and psychological. The parents have used different coping methods these are problem cantered coping such as searching schools for their children, consulting doctors and using other traditional methods was widely used by parents. The study also indicates that parents utilized different support systems that are available in their environments. Finally, this study forwards implications for social work practice, policies and for further researchers.*

*Key words: autistic children, parents, challenges and coping mechanisms*

**Acronyms**

ASD: Autism Spectrum Disorder

CSSP: Civil Society Support Program

FGD: Focused Group Discussion

MOH: Ministry of Health

QRS: Questionnaire of Resources and Stress

SPG: Strategic Partnership Grant

WHO: World Health Organization

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## **I. Introduction**

### **1.1 Background of the Study**

Autism is a mental illness or neurodevelopmental disorder with primary treatment on behaviour of a person and psychological and medication treatment also play vital role (Peter, 2008). According to Ellen (2005) autism is a brain-based disorder that affects a child development in the core areas of communication, social interaction and behaviour and mostly caught as neurodevelopmental disorder (Ellen, 2005).

Mental Illness is a difficult concept to define. The social deviance model defines it as “a failure to adjust with the social environmental and social group circumstances. Therefore, mental illness is a problem in living that displays deviations and non-conforming behaviour and the patient is defined as sick in psycho, social, ethical and legal way but not medical”( Mehanic, 1989.p.26). Wakefield (1992) as cited in Fellin (1996), defines mental health from a “harmful dysfunctional perspective and in his definition he reviewed the values and scientific components. He presented the idea that harm to the person’s wellbeing concerns social values and norms with dysfunctional viewed as biological term referring to a failure in a person’s physical, mental and internal mechanisms”.

Mental and behavioural disorders are also common in Ethiopia affecting more than 25% of the population at during their lives (Ministry of Health (MOH), 2007). It accounts for 12.45% of the Ethiopian and 12% of the burden of diseases in Ethiopia and 12% of the Ethiopian are suffering from some form of mental health problems of which 2% are severe cases (Deribaw & Tamirat , 2005).

Mental illness such as Autism can be considered as unpredictable challenges for the family because it is unexpected even in the family's life and disturbs the family's status quo and have the potential to raise the family's level of stress (Smith, Hamon, Ingoldsby & Miller, 2009; Turner & West, 2003). The term family challenges according to Riesser, Schorshe & Wason, as cited in Sands (2001), indicates that "strained parents and other family members experience in coping with their ill children's behaviour, the gaps between his\her needs of the services and politics that are available" (p. 113).

According to Clark and Schene, as cited in Schene, Wijngaarden & Koeter (1998), "caring for mentally ill child is psychologically stressful for parents, they may confront with uncertainty, emotion of shame, guilt and anger" (p.610). As stated by Knudson, Benjamin and Coyle (2002), "patients impairment of role functioning, self-care, inappropriate affect, social isolation and not responding well to medication are psychologically damaging for caregivers" (p.170). The constant fear that the recurrence of illness may cause disruption is additional stressor for the parents (MoH, 2007).

The nature of the illness which is associated to the inability of self-care and behavioural problems force parents to provide more care than that would be appropriate for some one of the patient's age. It also indicates that giving more care also associated with the sex of the child (Seltzer, Jan, Greenberg & Floyd, 2001). Furthermore, a study conducted on siblings with mental illness indicates that, siblings feel a sense of obligation and hence may increase their involvement in order to satisfy parental expectations and they are part of the fabric of the lives of those patients (Seltzer, Greenburg, Gordon & Judge, 1997).

Among the family members/parents, mostly the females are more burdened with care giving. Hong, Slzer and Greenberg (2008) attested that “care giving and parenting are still more of the responsibility of women than men and men usually engage in economic activities outside the home” (p.303). Parents face various challenges such as, economic, social and psychological (Shibrei et al., 2003).

Pennington(2002), argued that” because it removes individuals from society during most productive years of their lives and limite their employment opportunities, the societal cost including long term medical treatment and custodial care lies on the parents”(p.211). The economic problem is also associated with caregiver’s absenteeism from work, low productivity at work places and quitting jobs (WHO, 2003). A study done in Butajira, indicates that out of the problems that such families face, economic problem is the primary one that accounts for 71% of the respondents and women caregivers predominantly mothers reported significantly more financial problem than men (Shibrei et al., 2003).

Pennington (2002) also stated that, “the expressed emotion which means the extent to which family members communicate with a patient in a critical, hostile or emotional over involved way creates conflict between the patient and family members (p. 215). Moreover, if parents are not capable enough to handle the situation, they, might inter in to conflict. They hesitate to depend on one another for support, may avoid one another and start to blame each other for what happened to the family, which affects the marital quality and parents may end up in divorce Lamanna & Riedmann (2000).

According to Alem(2011), mental illness however, is given less attention in Ethiopia. This is related to different factors such as lack of awareness within the community, considering behavioural problems as naughty rude or deviant, the absence of the mental health facilities, the complexity of mental health treatment, absence of appropriate policies and lack of attention from policy makers and poor school system. This makes family members specially parents or guardians more vulnerable to the challenge of care giving (Alem, 2011).

In Ethiopia there is also lack of awareness on the existence of autistic disorder and children with autism are deprived of most of their rights and are locked behind doors when parents get it difficult to manage their behaviour. Currently there are no studies made on the prevalence of autism in Ethiopia however according to the estimation made by Nia foundation there could be about 530,000 children with autism and related developmental disorder. However, so far, there are only two centres for children with autism Joy centre and Nehemiah and both centres are established by the mothers of children with autism ([www.ethioautism.org](http://www.ethioautism.org), 2016).

Nia Foundation's - Joy Centre for Children with Autism is a pioneer organization in East Africa starting to serve persons with autism and related developmental disorders. It is the first and one of the two organizations in Ethiopia (Nia Foundation, 2010). Nia Foundation is non-profit making organization that have established in May 2002. The organization got its legal recognition by the Ministry of Justice as a local humanitarian NGO. Still, it is actively engaged in community awareness creation activities along with the centre based holistic rehabilitation services. The awareness creation engagements also encouraged parents to send their confined children with autism to the centre. Hence, the number of children that are served increased from 13 in 2005, to 24 in 2007, 40 in 2009, and about 80 in 2016. ([www.ethioautism.org](http://www.ethioautism.org), 2016)

As a challenge to the family, autism must rank among the most stressful of childhood developmental disabilities. Problems with communication, emotional expression and antisocial behaviours, all combined to place tremendous stress on the families of children with autism (Gray 2006). When a child is diagnosed with a physical disability or a developmental disability, parents are often thrust into a flurry of emotions. Experience around the time of the diagnosis, particularly in relation to the manner in which the diagnosis is disclosed or managed by professionals, can have a significant and long-term impact on parents' psychological wellbeing (Baird, 2000).

## **1.2 Statements of the problem**

In Ethiopia where morbidity and mortality due to malnutrition and infectious diseases are very common, mental disorders do not get enough attention (Alem, 1997). As a result mental health services are inadequate in terms of quality and quantity. It is in 2006 that “seventy regional\ district hospitals and seven health centres opened a small psychiatric unites and each unit have staff one or two psychiatric nurses. Among these, Amanuel Hospital is the only referral mental health hospital in the country with 360 beds for the whole country's psychiatric needs (Shibrei, Spangeus, Henriksson, Negash & Jacobsson, 2008, p.87). In relation to human resource, there are 0.02 psychiatrists, 0.3 psychiatrists' nurses, 0.2 psychologist and social workers per 100,000 population of the nation. The density of psychiatrists and nurses in Addis Ababa is very high (WHO & MoH, 2006).

The government does not also organize any social support systems to help psychiatric patients and their families. There is also scarcity of social services that give alternative care for these patients and their families. Therefore, in a situation where medical services for autistic

children are inadequate, the overall burden of caring for autistic children's lay on the caregiver's shoulders primarily on parents (Alem, 2001; Shibri et al, 2008). The only two non-profit organizations in Ethiopia that provide service on autism are Nia Foundation and Nehemiah. Nia Foundation mainly works on three issues such as rehabilitation service for children with autism and related developmental disorders, family support group programs and awareness raising programs and events ([www.ethioautism.org](http://www.ethioautism.org), 2016).

The ability to survive from the complex challenges discussed above requires a great deal of flexibility, some sort of coping or adoptive strategies both for the internal and external environment (Pollio, 2006). In Ethiopia where family network is very strong, availability of social service are very scarce (Shibre et al., 2003), coping mechanisms, seem to depend mainly on the available resources, such as social support and with the county's socio cultural context( Alem, 2001). A study done on Butagira indicates that "family members and extended relatives such as, grandparents, and aunts are the first available resources for the individuals to cope up with their problems" ( Shibrei et al., 2001, p.301).

In general, as we see from the above discussion caring for mentally ill children's particularly autistic children has challenges, which are associated to individual, family, social, cultural and environmental factors. It is also important in Ethiopia to point out where there is a situation of limited health care services, absence of social service organizations and community based support system and legislations, the burden of caring for the patient totally lies on the shoulder of primary caregivers mostly on parents.

This research focused on challenges and the coping mechanisms of the parents of children with autism with special emphasis on Nia foundation Joy Center for children with autism. Various researches have been conducted on children with autism.

Eveslage (2012), in her study school social workers' perspectives on working with children with autistic spectrum disorder explained the need for equipping social workers with education and training on autism spectrum disorder that would help them identify the characteristics of children with the disorder.

Teaching students with autism have a positive outcome on their social interaction ability and teachers have a great influence (Mwakalinga, 2012). The findings of this study show that teachers need to be patient in teaching students with autism in order to bring about change. Herbert (2003) discusses many therapeutic intervention strategies for children with autism for example the author explains that their communication problem and lack social skill of relating with others limit them in play so play therapy is considered as crucial part of the therapeutic and educational process

As we can understand from the above studies, the first study focuses on the role of social workers' in dealing with children with autism. The study conducted by Mwakalinga is on how teachers impact on the development of social interaction of children with autism. Herbert also focused in her study on the effect of nature or natural environment on health condition with special emphasis on individuals with autism.

Specifically, this study will explore the experience of being a parent for autistic children with an emphasis of their emotional, social and economic dimensions of challenges they

encountered. In addition, the study will attempt to single out the coping mechanisms used by those parents to overcome the challenges they faced in their everyday care giving process.

### **1.3 Research Question**

#### **1.3.1 General Research Question**

- What are the overall experiences of parents of children with autism and their coping mechanisms?

#### **1.3.2 Specific Research Question**

- How well informed are the caregivers\Parents regarding autism?
- How do parents explain the social challenges?
- How do parents of children with autism explain their psychological and economic challenges?
- How do the parents use cope mechanism when they face challenge?

### **1.4 Objective of the Study**

#### **1.4.1 General Objective**

The overall objective of the study is to examine the experience of parents of children with autism and identify the coping mechanisms.

#### **1.4.2 Specific Objective**

- To understand the awareness of parents about autism
- To identify the social challenges of parents of children with autism faced

- To identify the psychological and economic challenges parents of children with autism encountered
- To identify the coping mechanisms used by those parents for their autistic children

### **1.5 Significance of the Study**

Considering the shortage of researches that targeting mental health issues in general and the long-term treatment experience of people with chronic form of mental illness in particular (WHO & MoH, 2006, p.20), I believe this study will provide an insight about the parents experience on care giving for their children with autism. Moreover, it will serve as a point of reference for the organizations that work with autistic children's (Nia Foundation and Nehemiah) in providing orientation and other related supports for the caregivers. It also serves as reference for governmental and non-governmental organizations like policy makers, program developers, international organizations, GOs and NGOs to facilitate opportunities for the parents regarding awareness rising, counselling and providing income generating activities. This study will also serve as a stepping stone for other academicians and practitioners who want to do research on the same area.

### **1.6 Scope of the Study**

In Ethiopia, there are two centers for children with autism Nehemiah and Nia foundation joy center. This study is conducted in Nia foundation Joy center for children with autism since it is the first organization and have number of years of experience and greater number of beneficiaries compare to Nehimia . And it is located in the capital city of Ethiopia Addis Ababa around the area commonly called 'sar bet'. It is a native, nonpolitical, non-religious and

nonprofit making foundation established in 2002. The study is conducted on the experience of the parents of children with autism and their coping mechanisms.

### **1.7 Limitation of the Study**

The study has limited itself to the experience of parents of children with autism. And also during the research it was difficult to collect sufficient past studies to support the study representing the Ethiopian situation especially with respect to parent's experience. The research includes small number of the respondents that consists only the view of the parents of autistic children.

### **1.8 Operational Definition of Terms**

**Autism:** Pervasive developmental disorder characterized by the physical, cognitive, emotional and spiritual impairment of the child.

**Parent:** a caretaker of a child that can be the birth mother and father of the child or the adoption caregivers of the child.

**Autism Spectrum Disorder:** is the most common condition in a group of developmental disorders and it is neurologically-based disorder which has an impact on growth of social, behavioural and language/ communication area.

**Coping Mechanism:** an adaption to environmental stress that is based on conscious choice and that enhances control over behavior or gives psychological comfort.

### **1.9 Organization of the Paper**

The study explores the experience of parents of children's with autism and it is organized under six main sections. The first section embrace the background of the study, which highlights

the focus of the research, followed by the statement of the problem, objectives of the study, research question, significance of the study, scope of the study, limitation of the study, operational definition of terms and organization of the paper. The second part of this thesis consist the review of literatures that are reviewed from previous work of scholars at international and national level in relation to the issue of parents with children's of autism and it also consists conceptual framework of the study. The third part presents the methods used for the study such as study participant, study procedure, sample technique, data collection tools, data analysis technique, limitation of the study and ethical consideration are in cooperated. Then, the findings are presented in section four followed by discussion of the major findings in section five. The final section consists of the conclusion and social work implications.

## **II. Literature Review`**

This chapter provides a brief overview of autism in order to offer basic understanding on the disorder. It also reviews different literatures on the issue of the experiences of parents of children with autism encountered:

### **2. Overview of Autism**

#### **2.1.1 What is Autism?**

According to Gallo (2010) a Latin term “autismus” was first used by a Swiss psychiatrist called Eugen Bleuler in describing some symptoms of Schizophrenia. The term “autismus” originated from the Greek word “autos” which mean self and the English translation is autism. Therefore, the meaning of autism describes one of the symptoms of autism that is being alone or in their own world.

Autism is a common neurodevelopment disorder of complex genetic etiology. It is a life-long disability with onset before 36 months and characterized by impairments in reciprocal social interactions, impairments in verbal and non-verbal communication skills, stereotyped behaviour, interests and activities. A variety of biochemical, anatomical and neuro radio graphical studies imply a disturbance of brain energy metabolism in autistic patients (Rodney, Amber and Janine, 2004).

Boucher (1993) stated that autism (sometimes called “classical autism”) is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASD). There are three distinctive behaviours that characterize autistic children in that they have difficulties with social interaction, problems with verbal and nonverbal communication, and

repetitive behaviours or narrow, obsessive interests. These behaviours can range from mild to severe impact (Boucher,1993).

### **2.1.2 The Cause of Autism**

Since the mid-1980s, the general public awareness of autism has increased as indicated by the number of television and radio press releases, published literature, and funded research projects (Robin, 2002). Despite the media coverage and available literature on autism, families and professionals continue to struggle to understand causes and ‘cures’ for autism. Autism can be quite puzzling because children vary in extremes in the degree of symptom and associated symptom presentation (Robin, 2002).

According to Michael, in severe form of "Classic Autism" effective speech was absent. It could include symptoms of repetitive, highly unusual, aggressive and self-injurious behaviour. Those afflicted had extremely abnormal ways of relating to people, objects, or events. Parents noticed that something was "not right" generally within the first three to six months of life. These children did not coo or smile. They resisted affection and did not interact normally (Michael, 1998).

An important concept is that all cases of autism do not have the same cause (Robin, 2002). There are several contributing factors, and many combinations. This may account for the fact that cases vary in severity such as vaccination, difficulty eliminating toxic metals, damaged digestion/leaky gut, nutrient deficiencies, born toxic and depleted and a social anxiety disorder some of them (Miller, 2004).

### **2.1.3 The Genetic Components of Autism**

Autism most of the times affect approximately three times as many males as females. Taken together with studies looking at families and twins, this suggests that autism has a genetic component. It is likely that a number of genes are involved. However, the exact mechanism by which genes are implicated in autism is uncertain and is an important focus for future research. In addition, future studies aim to determine how genes interact with environmental factors in autism (Robin, 2002)

The genetic findings suggest that genetic factors account for over 90% of the population variance in the underlying accountability. In view of the new evidence indicating that the prevalence of autism is considerably higher than used to be believed, there must be some caution about the precise heritability (Folstein & Rosen-Sheidley 2001). The history of medical genetics indicates that it must be expected that autism will prove to be genetically heterogeneous: in sorting out genetic heterogeneity, there must be consideration of the possibility of either multiple mutations of the same gene or multiple different genes (Greenberg, .et al 2001)

### **2.1.4 The Challenges of Communication for Persons with Autism**

Impairments in verbal and non-verbal communication are both central and fundamental to autistic disorders. The verbal difficulties may include a delay in the development of language, comprehension (discrepancies between the use and understanding of language), literalness, poorly modulated intonation and delivery of speech, echolalia (echoing speech), unusual vocabulary, and repetitive use of language. Non-verbal difficulties include failure to empathise with others and to appropriately use and interpret social cues, body language and facial

expressions and gestures may be stiff, stilted or alternatively, far too dramatic or exaggerated (Sheelagh, 2001).

According to Eric (2014), persons with autism have a delay in or a lack of language development, which they do not compensate for by using other nonverbal means of communication. About half of the children with autism never develop speech. There is great variation among the children some only use single words others use many words and speak correctly, but mostly repeat stock phrases or things others have said regardless of the situation. A smaller number have a well-developed and spontaneously spoken language. Yet all have difficulties in initiating and maintaining conversation, and all have deficiencies in understanding language. Especially impaired is the understanding of language's deeper meanings, even among those who have a large vocabulary and converse spontaneously, it is common that they have a fixed and literal interpretation of language (Eric, 2014).

Children with autism often fail to understand the purpose and meaning of language as a means to influence their surroundings (Jarrold, Boucher & Smith 1993). Since language is not consistently used as a communicative tool, it is difficult for children who develop meaningful speech to initiate and maintain a conversational topic and incorporate others' ideas and feelings into the conversation. Instead, they may provide an outpouring of details or engage in a monologue rather than a conversation. Children with autism may echo what they hear others say without taking into account whether or not the listener is following the discussion. Comprehension of language is literal, with abstract concepts being particularly difficult for them to comprehend (Roben, 2002).

Children with autism also show abnormal play and limitations in imagination. This is particularly apparent in symbolic and pretend play (Jarrold, Boucher & Smith 1993; Roeyers & Van Berckelaer 1994). As a result of poor imaginative ability, children with autism lack flexible and creative use of imitation as a way to learn from the environment. Playing imaginatively and socially is particularly difficult for these children, and some of their difficulties with language may in part be due to their reduced opportunities to practice language in play situations (Howlin & Yates, 1998).

### **2.1.5 The Distinctive Behaviours of Persons with Autism**

Eric (2005) stated that children with autism often engage in a restricted range of behaviours, interests and activities in a repetitive and stereotypic way. For example, they may concentrate intensively on an activity such spinning the wheels on a toy car or lining up toys time and time again, but much more engage in spontaneous and varying games of pretend and role playing.

Fixations on different objects are common, as well as fixations on very complicated habits and routines that must be repeated in exactly the same way each time (Alessia, 2008). A departure from such a routine or ritual can cause an outburst of despair or rage. Any sort of change, such as something being in a different place or something being done in a different order than usual, can also be hard to tolerate for a person with autism. Slightly older, well-gifted children may especially have periods of one-sided and narrow interests such as time tables, others' birth dates, etc. It is also common for children with autism to continuously wave their hands, rock back and forth and walk on tiptoe (Alessia, 2008).

Repetitive stereotyped movements are often the most outstanding manifestation of autism. These actions often cause parents a great deal of discomfort, since they are external expressions of the ‘strangeness’ of their children (Shulman, Tidhar & Bukai 2001). Children with autism may exhibit a fascination with particular, often odd, objects, and they may have a temper tantrum if these objects are lost or removed. They may be preoccupied with details or information, such as bus, schedules or numbers (Lord 1995). Parents report that their children’s obsessive activities cause disruption as they interfere with other family activities. Routines and rituals become important to many individuals with autism, and they often cling rigidly to sameness in their daily routines. Apart from having social problems, communication impairments, and restricted play and interests, many children with autism have other behavioural issues and problems (Lord 1995).

### **2.1.6 Psychosocial and Economical Distress on Parents of Children with Autism**

As a challenge to the family, autism must rank among the most stressful childhood developmental disabilities. Problems with communication, emotional expression and antisocial behaviours, all combined to place tremendous stress on the families of children with autism (Gray, 2006). In a survey of 219 parents of children with autism, Sharpley, et al. (1997), found that more than 80% reported sometimes being “stretched beyond their limits,” with mothers reporting higher stress levels than fathers. He stated that the three most stressful factors are “(a) concern over the permanency of the condition; (b) poor acceptance of autistic behaviours by society and, often, by other family members; and (c) the very low levels of social support received by parents.” Subjective parental pain and consequent stress went unobserved.

Dabrowska (2010) administered the Questionnaire of Resources and Stress (QRS) to 162 parents of preschool children with autism, she correctly predicted that the level of stress would be higher in parents of children with autism than in parents of children with Down's syndrome or in typically developing children. Parents of children with autism also scored higher than Down's parents on three QRS scales (e.g., limits on family opportunities), and higher than parents of typically developing children. As well, she found that mothers of children with autism felt more stress than fathers, but, interestingly, she did not find this problem in either the Down's or the typically developing population.

Kirstin sated that parents of children with autism are faced with difficult and unique daily stressors associated with their child's disorder. The personal characteristics of parents can influence how they approach stressful life events and potentially help them cope with some of the deleterious effects associated with extreme stress ( Kristin, 2014).

Family members are often the primary caregivers of people with mental disorder they provide emotional and physical support, and often have to bear the financial expenses associated with mental health treatment and care. It is estimated that one in four families has at least one member currently suffering from a mental or behavioural disorder. In addition, to the obvious distress of seeing a love done disabled by the consequences of a mental disorder, family members are also exposed to the stigma and discrimination associated with mental ill health (World Health Organization 2003).

## **2.2. Theories of Coping**

Different people employ use of different coping mechanisms (Araya, 2007). This paper will use two theories of coping used to explain the experience of parents with autistic children.

**The international theory of stress and coping:** the international theory of stress and coping developed by Lazarus and Folkman argued that individual's adjustment to the stressful situation depends on the nature of the stressor, the strategies adopted by the individuals and the resource available to facilitate coping (Lazarus & Folkman, 1984). Stressors are events that are experienced by families and cause a change in the family or upset their sense of normalcy. These stressors can have both positive or negative; they can also be normative, which is anticipated one that occurs in every family and does not lead to crises. The other one is non-normative which unanticipated one is more likely to lead to crises (Smith, Hamon, Ingoldsby & Miller, 2009)

According to Lazarus & Folkman, (1984) there are three primary strategies adapted by individuals to define how families cope. The first one is direct action or problem focused such as searching the community for resource or encouraging patients who have social withdrawal to actively engage in family and societal activities. The second is intra psychological or avoidance coping refers to cognitively reframing the problems so that it does not seem overwhelming or insurmountable. The third one is controlling the emotions or emotion focused coping which is associated with the stressor itself. It can be in positive ways such as taking with a friend or going to a religious service, other use more distractive means, such as turning to alcohol or drugs in an attempt to dull the pain or alleviate the emotions (Kundson, Benjamil & Coyle, 2002).

According to Kim et. Al (2003), "using a particular coping strategy does not necessarily mean it will have beneficial effects on psychological wellbeing of an individual's" (p.314). Parents who use emotional focused coping strategies have higher levels of desperation and stress whereas problem focused coping over time relates to lower levels of subjective burden,

depression and better relationship with patient, which creates positive result to the cries (Lazarus & Folkman, 1984).

**Process Model of Coping:** the process model of coping also defines coping as” a complex interaction between the individual and the environment, with the goal of managing challenges rather than mastery (Armstrong, Lefcovitch & Ungar, 2005,P.271). Physical and mental wellbeing of the parents and the knowledge parents have about mental illness and economic wellbeing are some of the personal factors that help parents to cope with the stress of care taking are managing the patient’s behaviour ( Gautam & Nijhawan, 1984)

The success of family meet crises also depends on the accessibility/availability of different policies, legislation and social services in the social environment. These social services includes” medical and health care services and services of other institution in the family’s environment such as schools, churches, employees” (Lamanna& Riedmann, 2000, p.549). the cultural attitude of the society and the spirituality of an individual’s, which influence their attitude, might also affect negatively or positively how parents cope(Sands, 2001 & Turner & West, 2002).

### **2.3 Conceptual Framework**

In theoretical perspective:” theory is an abstract system of concepts that helps to understand the phenomenon and serves as a lens to interpret specific concrete experiences” (Turn & West, 2002, p.44). The experience of parents caring for children with autism can be explained by a theory of family ecology. It is a holistic family theory, which explores how family

influences and is influenced by the environment that surrounds it. ” (Lamanna & Riedmann, 2000)

The ecological theory represents the interdependence between people and their socio geographical environment (Olson & DeFrien, 2003). This interdependence is between the four basic systems that make up our ecological environment. The first is the micro system, represents the immediate environment of the individual, such as the family, and so forth. The second level is the mezzo system, which recognizes those various components of the individual’s immediate environment but have an impact. It includes friends, neighbours, and extended kin, place of work, social service agencies, and the media. Beyond that is the macro system, which includes the customs, attitudes, values and law of the culture in which the individual lives (Smith, Hamon, Ingoldsby & Miller, 2009.p.125)

As critically reviewed in the literature, the parental challenge and coping mechanisms influenced by individual, families, culture, the available social services and policies. Therefore, this theoretical framework has been chosen because of its comprehensiveness to view problems and their solution in light of the four levels or multiple resource involving individuals, families and the large socio environmental factors (Robbins, Chatterjee & Canda, 1998). In addition, this theory concerned with different procedures, regulations and goal of the government that affects the family and leads the researchers to investigate how various socio cultural environment impact families positively and negatively (Lamanna& Riedmann, 2000, p.31-32).

Thus, this study uses the conceptual framework to shape the data collection plan based on the research questions and data analysis. It helps to organize the entire case study and to define

alternative explanations to be examined. Below (Figure 1) is a diagram that describes the different systems and their interdependence towards the challenges and coping experiences of parents. The lines which have two arrows show the interdependence between the parent environment and different systems.



Figure 1: Conceptual Framework

## **Chapter Three**

### **3. Methodology**

This chapter demonstrates the method of research used in the study. It explains the research design, study area, study participants and eligibility criteria, sampling technique, data collection instruments, method of analysis and ethical consideration.

#### **3.1 Research Design**

In this study qualitative research approach was used. According to Padgett (2008) qualitative method is appropriate “to capture a lived experience from the perspectives of those who live it and create meaning out of it” (p.16). Qualitative research gives an opportunity for the respondents to identify their challenges and response strategies by their own way. (Maxwell, 2005). This study was exploratory because there had been few qualitative study found on the experience of parent’s children with autism.

Furthermore, case study was employed because of the type of research question the study tried to answer. Case study is “an empirical inquiry that investigates a particular phenomenon within its real life context and produce contextually rich and meaningful interpretation”(Yin, 2003, p.13). It provided a holistic and better understanding of the life experience of the study participants. According to Cresswell (2007), case study research involves the study of an issue explored through one or more cases within a surrounded system that is a setting or context.

Accordingly, the case, under study in this research was the experience and coping mechanism of parents of children with autism. Among the different kinds of case studies, this study assumed the design of few case studies. This was because of the limited time of the research and size of the participants.

As Gerring (2007), stated that a case study may be understood as the intensive study of a single case where the purpose of that study is, at least in part, to shed light on a larger class of cases (a population). At the point where the emphasis of a study shifts from the individual case to a sample of cases. The feature distinguishing the case study format from a sample-based (or “cross-case”) research design is the number of cases falling within the sample one or a few versus many and the corresponding thoroughness with which each case is studied. Unless a study is extraordinarily long – the case study research format is usually limited to a dozen cases or fewer. (p. 20- 22)

### **3.2 Study Area**

The study was conducted at Nia foundation's Joy centre for children with autism and other related developmental disorder. The name of Joy centre is derived from the name Jojo and it has the meaning of joyful place. Nia Foundation is a native, non-political, non-religious and non-profit making foundation established in 2002 and got its legal recognition by the ministry of justice as a local humanitarian NGO in January 2006 (Nia foundation, 2012). Nia foundation is believed to be appropriate place to conduct this research. Because it is the pioneer organization for children with autism and also it is one of the two centres available in the country.

### **3.3 Study Participants and Eligibility Criteria**

The study illustrate the experience of parents of children with autism, the challenges, and the coping mechanisms they use while taking care of their autistic children. Therefore, the target study participants were the parents of the children with autism who fulfil the inclusion criteria and willing to participate in the study.

The inclusion criteria were: a) the parent or the primary caregiver of autistic children, b) both parents together or a single parent can be part of the study, this enabled the researcher to assess the dynamics of parenthood, c) parents/caregivers who provided care for two or more than two years after the child's medical diagnosis, to explore better on the coping mechanisms they used, d) participants or parents who are willing to be part of the study and share their experience e) parents of autistic children who are getting service provision from Nia Foundation are the set boundaries or eligibility criteria for the study. Parents who haven't provide care for two years long are excluded and also those who cannot speak Amharic are excluded as I am unable to understand other local languages.

### **3.4 Data Collection Procedures**

I had already established a working relation with the staff of Nia Foundation as I work on a project called Strategic Partnership Grant (SPG (II)) that is funded by CSSP. Upon the approval of the research proposal, I requested Addis Ababa University School of Social Work to produce a formal cooperation letter to the Nia Foundations. Thus already existing working relationship between these two establishments along with the good rapport I had already formed with the staffs helped facilitate the process.

When I meet with each participant, I briefly explained myself and the purpose of the research project. I assured them of the confidentiality of the process by stating that no one else would access the information they disclosed. After I get their consent, the interview went on for a maximum of one hour to one hour to thirty minute.

### **3.5 Sampling Technique**

The study employed purposive or judgmental sampling in which the samples are selected intentionally (kreuger and Neuman, 2006).” Purposive or judgmental sampling is important in exploratory research for in-depth investigation and deeper understanding of cases than generalizing to the large population study “(p. 211). Since the focus of the study is on the parents of children with autism the parents are selected purposively from Nia Foundation and the respondents have provide the needed information that help to maximize the information that have gained.

### **3.6 Data Collection Instruments**

In this study both primary and secondary data sources are used. The primary source were conducted through in-depth interview, observation and focused group discussion (FGD). In-depth interview was employed since it is appropriate to obtain detailed expressive information and help to gather information about the issue to be studied from the individual perspective using his/her personal expressions (Kalof et. al, 2008, p.120). Observation of the non-verbal sign or emotional expressions of the respondents was employed.

In addition, focused group discussion was used as a primary source of data. According to Morgan (1997) focus group offer access to information that is not acquired through either individual interview or participant observation. In this study, two focus group discussions was conducted with eight parents who have helped the study to obtain information that were not obtained through interviews and observation. The participants have provided with the overall

purpose and their role in the study before the discussion. The focus group discussion was conducted at Nia Foundation with the consideration of the participants comfort.

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

In qualitative research, data analysis began at the same time of collecting the data (kreuger and Neuman, 2006). It also requires prior management of the raw data in order to categorize systematically (Maxwell, 2005). Therefore, the data that was collected from the interview were transcribed, read and the observational notes and memos were also reviewed. During the transcriptions, maximum effort was made to maintain the original meaning of the information. The researcher recorded the respondents' silence, weeping, long breath and the like so as to understand the respondents' emotion for the issue. During the process transcription in order to maintain confidentiality different name were given for the respondents. After the transcription of 14 respondents' interviews, it was translated in to English for the analysis. The researcher read the reviewed literature interview transcripts until reached to an understanding, identify and organize possible codes, themes and categories. The researcher used coding and thematic developments which are the most widely used analytic procedures (Padgett, 2008). Based on the guiding questions, conceptual framework, reviewed literature defining cods with same categories was made and sub-categories also been created to refine the coding.

Therefore, I started the data analysis at field level and it is analysed using qualitative analysis. The information gained from observation, interview, and focus group discussion is summarized or transcribed with maximum effort to maintain the original meaning of the information and also reviewed for reliability and completeness. During interview additional

questions were asked to understand the subject much better and list of key issue was prepared and then the findings were organized according to the list.

During the process of the data analysis, I looked for patterns, difference, visualization and contradiction of the information given by the respondent. Finally, I made a combination of the information obtained from research participant with existing knowledge from the literature to arrive at a final conclusion in relation to the experience of the parents.

### **3.8 Data Quality**

#### **3.8.1 Trustworthiness**

To prevent the three major threats in qualitative research, such as researcher bias, reactivity and respondent bias (Padgett, 2008), I used different strategies. To minimize my own bias, I used respondent validation which is systematically soliciting feedback about my data from the people I interviewed. As Maxwell(2005), argued, “ it is an important way of identifying the researcher own biases and misunderstanding of what he or she observes by ruling out the possibility of miss interpreting the meaning of what the participants say, do and the perspective they have on what is going on”.(p.111). As a result after I did organize my first coding and theme I returned back to those parents I interviewed to check the data. I did select six parents and discussed with them. The discussion was to make sure whether I interpreted the data they provided, these are the interviews and the notes I took during interview which also includes my observation of their feelings during interview are interpreted based on their own perspectives or not. After making sure that I interpreted everything based on their perspectives, I did the final thematic development and start analysis.

Double blind technique was also used on three couples by interviewing both parents (mothers and fathers) so as to minimize both the respondent and researchers bias on a case. It also helped to see the different views parents have for one case and to probe more on the issue.

The other way of minimizing reactivity and respondent bias is creating rapport with the respondents. As a result, I conducted the interview after the first contact. The first contact was at Nia Foundation as the parents came to take their children home. I briefly explained to them about the research, the general objective of the study, the advantage and the disadvantage of their participation in the research affect the study and the issue of confidentiality. The second meeting was for interview and it was conducted after they signed the consent. The interview was conducted at the place and time they preferred. However, all the parents choose Nia Foundation, the parents that are selected for the FGD preferred to discuss during their monthly gathering at Nia Foundation. And the in-depth interview participants agree to do it as they come to take their children home. Creating rapport and conducting the interview at the appropriate place they preferred increase the probability of gaining genuine information from the parents.

During the interview I also used my own notes, probing, paraphrasing and observation skills. The interview with the parents took a time interval from 1:00-1:30. Besides the parents, I have reviewed documents that provide me with history of the child, so can use it as I interviewed the parents to probe more. On the top of that, to avoid the threats of trustworthiness, I make sure that all the data gathered are properly documented.

### 3.9 Ethical Consideration

The participants are given clear information about the purpose of the study before they engage in any kind of interview. As a researcher I have used informed consent to let the participant know that participation of the research is voluntary and confidentiality of the information and privacy of the participant are also respected.

**Informed consent:** in this study participant's informed consent was obtained before the start of the study. The purpose of the study is explained properly. Moreover, they have the right to decide on their free will, even their right to withdraw or drop out after interview begins if there is a feeling of discomfort.

**Confidentiality:** during the interview whatever information the interviewees considered confidential and do not want to be revealed to the public are confidential.

**Privacy:** privacy is one of the ethical issues in research work. In this study, the privacy of the participants was respected, to this effect, the researcher wouldn't call names during interview and participants are not allowed to describe their name while responding to the question. The discussion issues were never go beyond the purpose of the research.

## **Chapter Four**

### **4. Findings**

The purpose of this chapter is to present the findings of the study in line with the objectives of the study. In the findings a semi-structured interview about the parent's experience of care giving for their autistic children has been presented. And it has been report by two sections. The first is the socio demographic characteristics of participants and the second has three sub-sections. The first sub-section consists of the awareness of the participants. The second is about the challenges of the participants encountered during their care giving such as economically, social, family, and psychological challenges of the participants. The last sub-section is about the coping mechanisms used by the participated parents.

#### **4.1 Socio-demographic Characteristics of the Participants**

In this study fourteen parents with an age range from 31-59, composed of two sexes were interviewed. All the parents live in Addis Ababa single parents and married couples were participated in the study. Regarding their religious background there were Orthodox, Protestants and Muslim. As the table-1 illustrated the sex composition of both parents and their children are listed below. The table also shows the age range of the parents and their children with autism and all the children's are below 18.

**4.1.1 The name, sex and age of the parents and their children with autism**

S.No.	Sex of the parents	Age of the parents	Sex of the autistic children	Age of the autistic children
1	M	31	M	8
2	M	59	M	15
3	F	57	M	16
4	F	53	M	13
5	F	55	F	15
6	F	46	M	12
7	M	36	F	9
8	F	38	M	11
9	M	58	F	17
10	M	44	F	11
11	F	49	F	14
12	M	50	M	18
13	M	32	M	8
14	F	39	M	9

**Table -1**

#### **4.2 The Awareness of Parents about Autism**

One of the objectives of this study is to understand the daily challenges parents face in their daily life. Before finding out about their challenge I have tried to see their awareness regarding autism. In this study, it was found out that none of the parents know about what autism means before the diagnosis of their children. Among the fourteen, nine of the parents have general knowledge about mental illness. In the study, most of the parents put the cause of mental illness as a genetic factor, evil doings, trauma and stress. These participants reported that medical treatment and religious believes as a solution. As the data indicates, parents considering the illness as caused by stress and evil mentioned that holly water, prayer at Mosque” salat” and prayers at protestant as a treatment, while the other parents also considered medical treatment as an option. Parents who mention evil as a cause explained it as; it is possession by evil spirit, evil eye, and people doing evil on other person.

In this study the parents also indicated that their source of information regarding mental illness was the communities or cultural and religious view. Parents reported that what is being commonly said in the community, in the church and their observation of those mentally ill individuals on the street or religious places as their source of information. And those parents who reported that genetic and stress as the cause of the illness mentioned that information gained from the media such as radio, television and newspapers. For exception of four parents their educational background and the course they took on mental health is there main source of knowledge.

Parents were asked about how they first understand the sickness and symptoms their children demonstrated. As indicated in the data there were two types of understanding. These were the understanding of the sickness or the symptom as evil and the second one is as a mental illness. When their children first demonstrated the symptoms of the illness parents considered it as evil. These are those parents who were reporting the cause of the illness as evil. These parents explained that the symptoms their children showed at the early stage of their life such as not being able to talk, show the sign of irritation and repetitive behaviour and not being able to make direct eye contact with or respond to their parents lead them to understand it as an evil. So they thought that their children are possessed by evil sprite.

A parent, who has past experience of care giving expressed that “I know my child was sick when he couldn’t talk at the age of three he couldn’t even say Ema or Aba” unlike my other children”. There was also a parent who first related the symptoms of the illness with her daughter’s bad behaviour. As she explained, “while she was a child she was aggressive and take her sisters things and wouldn’t return it back and start quarrelling with her, and as this thing continuously happed we thought that her behaviour was getting worse”.

The parent starts to identify the above mentioned signs and understand the symptoms as evil and took their children to holly water. As a parent explained her reason to taking her son to holly water “I did consider the illness as evil and decide to take him to Shenkora holly water. At the time I believed that was the only option I have”. There are parents who took their children to Protestant church for prayers and Mosque” salat”. A parent stated that “I took my son to church, as I mentioned the symptom of the illness and the health condition of my child to the church pastor I worship, he arranged a prayer program for my son”.

In contrary to this, the second group understand the symptoms of the illness as mental illness or disorder. These are the parents who have knowledge on mental illness/disorder and the symptoms they saw on their children, such as fear, not being able talk, repetitive behaviour, show the sign of irritation and not being able to respond their parents were a reason to identify their child is not well. A parent who was aware about the symptoms as mental disorder took his daughter to hospital. As he explained, ‘I knew that something is wrong with my daughter and it seems mental disorder, Therefore I took her to Yekatit Hospital as soon as I make the decision with my wife’. There are also parents who used to mix holy water and traditional medicine together. As the study indicated, there is a parent who bought her child to cultural treatment like performing rituals. She narrated her story as,

I have taken her to holly water and to hospital as well. However, at hospital they told me that she is diagnosed with autism and it is a lifelong developmental disorder, I couldn’t believe what I heard so I have tried to find another options to cure my child so I took her “Awaki bet” where cultural treatment or ritual is performed.

In addition to those parents who took their children to holly water others reported that they took their children to hospital. When we see the time interval parents bring their children to the hospital, those who made their first action towards the hospital brought them within a month and for those whose first action was holly water and traditional treatment they bought their children between the time intervals of two months to two years.

### **4.3 The Social, Psychological and Economical Challenges of Parents with Autistic Children**

For parents, whose children are diagnosed with autism means that they are loaded with the practical challenges of care giving. The parents participated in this study express their day to day care giving tasks as a challenge beyond one's capacity. It was found that parent's daily care giving activities are challenged by behavioural problems of the children, such as physical aggression, damaging properties and going out unknowingly. The effect of the illness such as lack of self-care, inability to work, social isolation and relapse are the other factors which make the daily care giving of the parents difficult.

The behavioural problems of the children such as physical aggression involves hitting their families, throwing stone and hard materials and damaging properties were the behavioural problems of the parents of children which their parents encountered. Parents mentioned that these behavioural problems were very challenging during the first time of their children's sickness. From those physical aggressions there were also family members who faced injuries and got stitches. An informant illustrated the incidence she experienced as,

One day he asked his younger brother to give him the toy he has and the younger brother resists. Then he started to bit his younger brother and broke his hand. That day he almost seriously injured his brother. Finally, I used all my force and managed to stop him and cool him down.

In addition to the physical abuse, damaging properties including breaking the household materials, furniture, windows and doors were the challenging experiences parents encountered.

Damaging prosperity seems more distractive in the case of a parent. As she explained, her daughter broke television, desk, tape and other household materials.

Furthermore, their children's care giver, parents reported that there were also times they are forced to search their children when they went out and disappeared. As indicated in the study, the child will not be returned for days or weeks and when they returned mostly they got dirt and sometimes their feats and faces wounded, swollen and injured. This break their parent's heart and brings additional burden to the caregiving such as nursing and taking them to hospitals.

In order to protect their children, in a case of a one of the couple they took their child to Nia Foundation and also bring him home themselves. As the mother explained that challenges as:

I don't have other job rather than taking care of him and do the house chores. I have lost him several times and his father and I have suffered a lot. Therefore, everywhere he goes at least one of us should be there. We took and bring him home from Nia Foundation, we don't allow him to play outside the house without our presence.

The other dimension of parents that make care giving challenging is the lack of self-care. The children's lack of interest to be washed, brush their teeth, not wanting to care for their hair, lack of initiation to cut their nails and unwillingness to change their clothes and eat food are the problems parents encountered. For a parent, she always straggles to get him to barbershop he hates the sound of the device that cut his hair so he would not allowed anyone to touch him.

However, very recently five of the children's show a good improvement as they join Nia Foundation. As one of the parent explained "my son is improving much, he started brushing his teeth without the help of anyone and also use toilet based on the training he have received at the

organization” the other four parents also explained that their children are showing progress from time to time based on the training they have received for themselves and their children by the psychiatrist, caregivers/nurses and also by the founder of the organization since she have an autistic child and receive trainings and educations from oversees.

For the rest of the parents, they are expected to wash their children’s clothes including their underwear, cut their nails, and brush their teeth. The mothers with a daughter also take care of their children’s menstruation cycle, prepare modes or pad and wash their underwear. The lack of self-care is an exhausting task for the parents and when this struggle continues as we see from the study, there are situations parents get fade up and give up. A parent who is taking care of her daughter stated that” unlike the other children at Nia Foundation the progress of my child is very slows she couldn’t take care of herself or show any initiation and sometimes I get frustrated and give up”.

As the parents get frustrated their working ability and initiation to perform activities decrease. Lack of ability and initiation to perform household activities such as cooking, washing, arranging homes or any activities that demands labour and concentration are commonly mentioned by the parents. As indicated in the data this also adds additional task for the parents, because they are expected to fulfil all the household tasks. However, for those parents whose children started taking care of their self is not their problem now.

The parents also stated that the loss of initiation to interact with people is one of the effects of Autism. In this study, most of the parents explained that their children are not interactive and mostly they prefer to be isolated and play by their own:

I have three sons each of them have one-year difference. My third child is autistic and he is not close with his siblings as they are with each other. When they try to get close or play with him he run away and plays by himself. He isolates himself from any interaction with his brothers and neighbourhood kids.

In the study, for parents of children with autism they fear the most is relapse. Among the fourteen parents three of them experience relapse on the health and behaviour of their children. When the illness relapsed parents become burdened with the problem of managing their children's behavioural problems. The cause of the relapse for a parents happened when she gets a job and hires caregiver to take care of her child. However, the child stop eating food and cry for long time when he missed his mom. Even though, the parents thought he will stop as the time passes he didn't instead start to show new behaviours such as crying for long time and unable to eat without the support of his mother and easily irritated. This led to weight loss and make him totally dependent on his mother and stop performing the improvements he encountered for the past three years through education and training.

As assessed the overall burden of care giving, it is found that from the parents participated on the study, the burden of care giving rests on the shoulder of the mothers most of the time. Those married mothers whose husbands did not participated in the study also explained that they are burdened because, for one of the parent, her husband is getting old and he needs care too. For the others since their husband's works outsides they have to take care of their children, family and do house chores. Those who are working single parents or widows are also burdened with care giving and other responsibilities, because as they mentioned they do not have a support at home.

In addition to the nature of the disorder, the care giving challenges parents face also associated to different factors such as lack of knowledge, inadequate medical services in the hospital and absence of social services that give alternative care for these patients and families.

Parents participated in this study reported that, lack of knowledge on how to manage the behavioural problems of the children and the effects of the illness makes the treatment difficult for them. One father elaborated as,

When you care for sick people you just follow the prescription of the doctors on what the patient should eat and what you can do for that person but this illness is very different and you cannot be sure what to do. For example, the method used by one parent with autistic child cannot be applied for other children since they don't have the same need or preference even though there are some common symptoms.

Parents participated in this study identified lack of family centred treatment both for the parent and the family and shortage of doctors and hospitals that give treatment for the autistic individuals. Parents from Nia Foundation participated on the study mentioned these factors as an obstacle for their daily care giving processes.

Moreover, all the parents in this study mentioned the lack of family centred treatment as their main challenge. They stated that there is lack of proper orientation about the illness. It is one of the commonly mentioned problems by parents. Parents indicated that they did not get proper orientation on the medication, and its side effects. For a parent lack of cooperation from the staff is another issue. A parent mentioned that the absence of awareness raising programs in the hospitals about autism was a challenge. A parent expressed his feeling like as,

In hospitals for example for people living with HIV/AIDS there is awareness raising programs when they come for follow up. However, at hospitals especially at government hospital they don't have any programs that give orientation regarding mental disorders or autism. I have been to most of them because of my son but couldn't find proper treatment or orientation. But, now days Yekatit and St. Paule hospital psychiatric departments are starting to orient their staffs regarding autism but it still needs lot of work.

Lack of social support/service providers was also mentioned as one the challenge they have face. Parents mentioned the absence of rehabilitation centre that children where they can stay and a vocational training centre were the children can learn skill and develop their working ability, social relationship and create income opportunity is the other problem highly emphasized by all parents. Most of the parent in the study waited for minimum of two years to join Nia Foundation. A parent mentioned that:

When I was looking school for my autistic son the only place I could found is Nia Foundation. I have been to several private and governmental schools but they don't have conducive environment or know how to educate autistic children. As I get to Nia they register my name and called me after 2 years at the time it was the only organization for autistic children and lot of children were on waiting list.

Shortage of doctors at hospitals for individuals with mental disorder is the other dimension that affects the daily care giving of the parents. Most of the parents in the study mentioned it as a challenge. A parent explained it as "since my daughter can't express her

feelings and answer the doctor's questions they referred her to psychiatric department and the psychiatric department to other department in middle me and my daughter suffered a lot. I always wish to have medical staffs that are specialized and can treat children with special need not only their psychiatric cases but other problems as well”.

The daily care giving challenge as explained by the parents has its own impact on their health blood pressure, heart problem, headache and kidney problem are the main diseases mentioned by the parents. As a father explained “when you care for your child you do not only get tiered but physically you will also go down. It is after my son become ill that my hair becomes completely grey”.

#### **4.3.1 Economic Challenge**

Caring for autistic children has its own economic consequence as it was found in the study. The care giving process parents incurred different kinds of economic burden due to different factors. Out of the 14 parents, mothers of the 5 children don't have work out side home but the fathers do. And the other 4 of the parents both have job on office and own their business and have two source of income. For most of the parents their salary is their primary source of income and for the single parents it is their only source of income. All the parents mentioned that the illness has its own impacts on their economy since; they cover the children's medical cost and the cost for traditional treatment. And for working mother hiring housemaid is additional cost.

As the parents talk about medical cost there are two types of costs in this study such as buying medicines and transportation costs occurred when their children admitted to the hospital

are identified by parents. As a parent explained “when my child get sick I can’t use public transport because it is not convenient for my child, she get frustrated and hate to be around lot of people. For that reason, instead of public transport I use private taxi and took her to hospital”. In addition, cost for traditional treatment in this study such as treatment for holly water, traditional medicine and witchcraft were mentioned as economic challenge for the parents. The transport cost and hiring individual for giving care are also the major factors that incurred cost when parents took their children to holly water. One of the mothers explains that “I took him to holly water every summer for the past 8 years. I took him to shenkora, entoto, kukeylesh and also other places and every time I did that the transport and the travel cost increase by each summer however since I saw progress every time I took him I will continue to do that”.

Parents are paying for traditional healers and going to witchcrafts house for consultation was another cost. As a mother explained, “I have done lot of things that are recommended by the traditional healers sometimes it is expensive for me. For example, he told me to buy a black goat and slaughtered it the first Saturday of every month and makes my son drink the blood for a year”.

Quitting jobs and losing productivity are the other factors which exaggerated the parent’s economic challenges. As the data indicated, there are mothers who leave their business of selling traditional cloths and other businesses for the case of caring their children.

#### **4.3.2 Social Challenge**

Addressing the questions of the social challenges parents who are care givers caring for their autistic children encountered was one of the objective of this study. Therefore, questions

were forwarded for parents to share their challenging experiences they have been encountered with the social environment they are living in. In this study, the relationships they have with their families, relatives, religious associations, neighbours, friends, community based organizations like Iddir (an indigenous community based organization for the purpose of funeral and social events). Based on the forwarded questions the following challenges have been identified by the participant parents.

Stigma and discrimination was one of the challenges identified by the parents participated in this study. This stigma and discrimination as mentioned by parents came from neighbours, close family members, extended families, relatives and in laws. Even though the extent and source of the stigma and discrimination varies, parents encountered such as rejection, embarrassment and threat of rights. However, there are also parents who did not face stigma and discrimination at all. Having their own house with separate fence, children's not being aggressive for outsiders, supportive neighbours and iddir and good understanding of their relatives are the main reasons for these parents not to be discriminated.

Rejection is one of the ways parents mentioned on how people discriminated them. All parents who are stigmatized face a rejection directly on the children and the family members as a whole. The rejection is from neighbours, close family members, extended families and relatives and in-laws. This rejection is manifested in different forms such as not responding well when they need assistance especially when the child disturbs, not coming to their home, lack of interest to invite them home, not being asked about their child's wellness and pushing away the child and themselves.

As indicated in the data with the exception of three parents who was rejected only by the neighbours, the rest of the parents experienced rejection from more than one source. These are also parents who become rejected by their close family members that are the siblings of autistic children.

As a parents expressed her experience” I have two kids, my youngest son is autistic. His brother is not interested in him. He doesn’t want to tell his friends about him or bring his friends home since he doesn’t want his friends to know about his brother. He also mentioned that after he graduate and get job he want to move out and live by himself”. In the case of another parent who is a parent of four kids mentioned that “my kids have said to me why do you bother just throw him and live your life and when I hear this it breaks my heart I always think what would happen with my child when I and my wife are gone because I’m sure his siblings wouldn’t be there for him”.

One of the parent also mentioned that her experience of rejection also goes to the extent of her in-law as she expressed, “my in-law told my husband to divorce me and get married another women so he can live his life peacefully and they stopped coming home”.

Embarrassment is another challenge revealed in the study, as parents mentioned, it is experienced from their neighbours and relatives, rumour, labelling, taunting, pointing fingers and non-verbal cues are identified by parents as an indicator for embarrassment a parent whose daughter has a problem social interaction expressed her experience like this, “my neighbours point fingers at my daughter and spread rumour that my child is suffering because of me and my husband’s sin”.

The participants of the study give different explanation on why people stigmatized and discriminate them. One of the explanation given by the parents are lack of awareness from the community such as, associating the illness with evil, thinking that the children are aggressive, useless and considering the behaviour as deliberate. Parents also mentioned that there was a situations people relate it with parental sin.

The other issue raised by the parents was *social isolation*. The parents of this study explained that social isolation is one form of the social challenges they encountered. Except for a three parents who does not face any social isolation at all and for a parent her poor social relation mainly with iddir and her neighbours is due to her work nature. As she said she is busy and has no time for social interaction at all. Others have been isolated from close families, relatives, neighbours, friends, in laws and from the social activities such as iddir, burial and wedding.

In the study, care giving was another factor for the poor social relationship of all parents. Parents involvement in social activities like with their iddir and from visiting relatives or friends, asking sick people, going to weddings, burial and going to church hinder by different care giving challenges. The main reasons identified by parents were they are afraid to leave their children alone home, with the thinking that they might hurt themselves or other family members and parents who have an outgoing child also stayed home to keep their children.

In the case of a couple, isolated by stigma and discrimination mentioned that caregiving is not their problem. Because when their daughter was sick, they managed their social relationship mainly with the iddir by assisting each other. The case of isolation is more seen on

those five parents who have no supporter at a home. Considering the married parents, the mothers are more isolated due to care giving.

A father who was 49 years old and married man with three kids. Among the three kids he has his first child is autistic. The father has masters in Curriculum study and currently work in government institute. Both he and his wife have a job they first identify their child behaviour when he was three and took him to hospital. They find out their son is autistic after visiting four different hospitals at Yekatit Hospital. After diagnosis of their son both parents came directly home to their son after work even though the father try to support his wife at house chores she wouldn't have time for other social engagements.

#### **4.3.3 Psychological/Emotional Challenge**

In this study lots of efforts were made to explore the emotional challenges parents experienced. As the parents indicated, their emotional disturbance started from the first time they knew about their children's health status. Besides, it's indicated that factors associated to care giving, and socio economic challenges are other stressors for parents.

First reaction of the parents, as the parents mentioned, the incidence of autism is major life stressors they have been experienced and shock, confusion, denial, blaming self and others were the reaction of parents. For a parent he blamed himself a lot, he used to think God is punishing him for his wrong doings. There were also parents in this study who related the feeling of blaming others with the cultural attitudes of associating the illness with evil and they shift the cause towards other people by thinking that people did some evil things on their children. Parents give different explanation for their first emotional reaction. A parents mentioned it as "it

was the most painful thing I have experienced he is my only son and knowing he is autistic was devastating. Everything was blocked for me; I cried a lot that day”.

Parent’s care giving process is one of the causes for the emotional disturbance for all parents. The behavioural problems and the effects of the illness that are mentioned on the care giving were part were identified as factors for parents to be disturbed. Feeling of fear, anxiety, stress, forgetfulness, bad dreams, night mares, hating self, feeling of guilt, burn out and giving up are identified by the parents as their experience of emotional disturbance. What makes the stress more intense for the parents is that of the children are showing progress after they join Nia Foundation. However, there is a chance of relapse as a result of different causes and for most of the parents it is a big fear and source of stress. A parent explained it as “I have a fear and mostly stressed when I think about relapse, because one of my friend’s child is autistic and he was fine and showing a good progress but suddenly things have changed unknowingly and he is not in a good condition. After that I get stress every time I think about relapse”.

There is also worry that their children might get hurt. This is more of the worries of parents whose children have outgoing behaviour. The parents of autistic children are emotionally burdened because of the fear that one day they will hear the death of their children or fear their children injured. This have created more emotional burden on the parents. For the case of a couple their son Abdi is outgoing kid he loves to run and play around. But, when they leave him with the care giver and went to work they couldn’t concentrate on their job. Because, they fear he might go outside and car might hit him or get in to accident.

Furthermore, the uncertainty for how long to give care, the long years of care giving lead parents to ask when the caregiving is coming to an end. Parents feel hopeless when they compare the time, the effort they endorsed and their children's progress. Parents also get stressed when they think about what will happen after they die. It is disturbing question all of the parents could not handle their emotion and they burst in tears. In general, uncertainty of how long to care is the worry and concern of all parents except for a couple, whose hope is revived by their daughter's health improvement. In contrary, there are couples who have fear if something happened to one of them or one of them died first who can take their place and takes care of their child.

Economic challenges or worries of financial constraints were found as emotional disturbance. Especially for the widow and single parents having one source income and straggle to cover the expense of the household, medical, care giver and other costs by themselves is stressful. Two of the parents that are separated stated that they want to change their job because of the low salary they couldn't manage their expenses. But at the same time they couldn't find other job that give them time when they need to go home to their children, when they are not well or disturb the care giver.

A conflict occurred between siblings, and parents themselves creating a feeling of failure, anger and regret for parents. Those parents whose children entered to conflict with their autistic sibling were worried because of the assumption that when these conflicts get intense relapse might be occurred. Besides, parents got confuse when their children fight each other. A parent also illustrated "I feel very sad when his siblings don't understand and fight with him. At first I thought because they are young they might not get it but as time passes things don't change and

getting bad instead. This makes me sad and at the same time makes me nerves what if relapse happen because his doctor told me several times not to make him angry”.

Moreover, parents that stigma and discrimination faced also mentioned that this is one of the causes for their emotional disturbance. Due to the experience of stigma and discrimination they have with neighbours, relatives, friends, and the self-stigma parents attached to it, they are exposed to anger, sadness, hating self, people and their living place. In this study those who reported that they faced stigma and discrimination from their closest relatives felt more emotionally burdened. As a parent illustrated: “I feel empty and I have no one to relay on my sisters don’t want me anymore. Every time I visited them they think I might ask them for help or anything they don’t look happy or unwelcoming”.

Furthermore, for the parents who take care of their kids at home spending most of the time home alone with their children affects the parent’s emotional wellbeing. Feeling of being lonely, hopeless and secluded were mentioned that sometimes they became depressed and felt like prisoner. As a parents Expressed “my day-to-day life is a routine. I woke up early in the morning and cook breakfast for all family and after that I help my daughter who is autistic while she gets dressed and took her to Nia Foundation. Following that I do the house chores and bring back my daughter when it’s time to get back and also get back to the house chores and take care of her at the same time. This routine is depressing to me, there is no time for myself I feel suffocated”.

#### **4.4 Coping Mechanisms Used by Parents**

From the presentation of the above section it is known that parents pass through several care giving, economic, social and psychological challenges when they care for their autistic children. However, as indicated in the data while they were passing up all these challenges parents were in a constant interaction between themselves and the environment they live so as to manage their challenges. In this study different mechanisms or strategies and available resources used by parents in order to tackle and overcome the challenges identified.

Finding in this study indicated that parents used different kinds of strategies to directly tackle and overcome the problems they encountered. Guarding children from committing dangerous act and going out is one of the strategies mentioned by parents. Hiding dangerous instruments such as knives, other sharp materials and chemicals, avoiding rolls and electric wires keeping them home and putting the medicine away from child or locked it are the most commonly used strategies. Parents used more than one of the above strategies. For those parents who are giving care for autistic children keeping an eye on them is not only a strategy used to protect them from abuse by outsiders. For a parent it is also a way to be safe from stigma because, “keeping her home means not disclosing the issue for neighbours”.

The technical support the parents get from Nia Foundation and also the education of the children in order to improve their eating, communicating, toileting, walking and social skills along with the professional counselling, training and awareness raising sessions provided to the parents raised their understanding of their children’s and help them to manage things and cope

up with their straggles. All the parents' stated that whenever they are down or confused in relations to their children, they talk to psychologist in the organizations and set solution together.

All parents also reported that they usually consult the doctors when they faced problems; observe progress or when they want to take an action. In addition, searching alternative treatments for the children was another strategy and parents tried different kinds of treatments as to cure for their children. Holly water, prayer in protestant church and mosques, traditional medicine, witchcraft and rituals are the other problem focused strategy used by parents.

Confrontation is the other problem focused strategy used by parents for the social stigma they have been encountered. The study indicated that there are people who use confrontation in the positive way that in a negative way like quarrelling. However, the study also indicates that for a working single parents and parents who is widow, they preferred to use avoidance coping, that is reframing the idea for the stigma and discrimination they encountered. As a mother said” my neighbours don't want my kid to go to their home and play with their kids. They think she will harm their kids. I have tried to explain to some of the neighbours but they are not interested so I wouldn't go to them or let my kid go there’.

Emotion focused coping is the other form of strategy reported by the parents. This coping mechanism mostly to the psychological and social challenges they encountered. Crying talking to someone and praying are the widely used strategy by parents. The study also reveals that parents have preference with whom they want to talk. In the case of this study, children, relatives, peoples who have the same problems, friends and neighbours are prioritized by parents. All use at least one of the sources mentioned.

As the study indicated, those parents who preferred to talk with people of having the same problem, reported that they prefer those people because they understand each other and share experiences. As a parent illustrated, “I have a friend whose child is also sick and I usually preferred to talk with her, because she can easily understand and feel my pain”.

Forgiveness was the other emotion focused coping strategies mentioned by the parents. Parents reported that when the children disturbed they associate with the illness and forget their anger. As a parent illustrated, there are times he broke things while trying to open it like TV remote control and DVD player. But even though I get mad I couldn't scold him like my other kids instead I try to calm myself and help him understand how to use it”.

The other form of coping mentioned by all parent is comparing their cases with others. In this study parents said that when they saw the worst cases they became thankful and think that their case is much better. To the reverse seeing those who are getting better has a positive impact, because as they said their hope will be revived. They mentioned the experience sharing session prepared by Nia Foundation on the first Saturday of each month was so helpful. They talk about the progress of their kids and the challenges they are facing. In the discussion they share information and comfort each other. Going to church was also one method used by the study participants.

#### **4.5 Available Resources**

From the data it was found that people use different strategies to keep themselves intact. In order to do that, they also use different resources.

**Children:** children or siblings of the autistic child are the resources used by most of the parents participated in this study. Even if the extent and the kind of help varies and not all the children are supportive, parents reported that their children are the source of their support in terms of care giving, economic, emotional, and family and social challenges they encountered. Those parents, who have children living with them with the exception of five parents, reported that they are supported on care giving. For a case of a parent the extent of their care giving is expressed by her like this "When I'm not around her sister or brother was the one who take care of her. There are times both me and my husband might not be home because of work but since we have strong support at home we can do our job". There also parents who sated they have the support of extended family members and relatives, friends, in-laws and neighbours.

**Formal support system:** hospitals, religious institutions, iddirs and Nia Foundation were mentioned as a formal support system. For all the parents Nia Foundation is their main support system they are more grateful for the founder\director, management, psychologist, caregivers and all the safes in the organization. Religious institutions such as Orthodox churches, protestant churches and Mosque are the other resources that help the parents next to Nia Foundation and hospital.

**Personal factors:** the parent's characteristics helped them to cope up their problems. In this study it has been indicated that all parents utilized their different characteristics to rebound their problematic situations. In addition, having good health and g awareness about the illness are commonly used factors by parents. As they mention their being healthy is what helps them to cope with the different challenges they encountered. However, for some parents reported that their health condition is deteriorated and a father also shared their condition as "my health is getting worries I couldn't manage my blood pressure as i used to do anymore the age also additional factor for my poor health.

## **Chapter Five**

### **5. Discussion**

In this study the major findings of the study that were identified in the previous chapter are discussed with the chosen theoretical framework, the reviewed literature and related studies. The finding is discussed under three main themes these are, awareness of the parents about the illness, their challenges and coping mechanisms.

#### **5.1 The Awareness of parents about Autism**

Parents relate mental illness with evil. Such as being possessed by evil spirit, evil eye, people's doing evil things on others and punishment for individual sin. This finding coincides with researches done in Ethiopia that indicated awareness on the mental illness is influenced by the cultural and religious views of the community that associate mental illness with evil and super natural forces(Alem, 1994; 2001; Shibrei et al., 2008).

As my finding revealed that those who have a good awareness about the illness are those who use the media, their educational background and their past experience of care giving as a source of information. As they get more education they stop association the illness with culture. This is supported by Cockerham's (1981), argument that says in most preliterate cultures peoples' source of information about mental illness as mainly based on the cultural and spiritual views of the society.

The cultural and religious knowledge that lead parents to consider mental illness as evil also influences in perception, understanding of the symptoms and treatment seeking behaviour of

the parents. This also goes in line with the finding of researches that indicate the important role culture and religion played (Alem, 1994;2001, Shibrei et al., 2001;2008; Sands,2001;Tuner and West, 2002). Parents who have the awareness that mental illness is associated with evil also understand the symptoms as an evil and choose traditional treatment such as holly water, traditional healers and performing rituals their first action. This study again coincides with one view of previous researches in Ethiopia (Alem, 1994: 2001, Shibrei et al.,2001 & 2008), which indicate traditional treatments as the preference of most people in Ethiopia.

In addition, on the cultural influences, there was a tendency of associating the behaviours displayed by the child as problems of attitude, Alem (2001), on his journal on Mental Health Services and Epidemiology of Mental Health Problems in Ethiopia, indicated that when there is lack of knowledge about mental illness, the symptoms are association with being rude, naughty or deviant.

Another important finding of this study is that most parents had a negative attitude towards the illness prior to the development of the illness in their child. This might be related with the difficult nature of the illness. The perception also influences the parents' choice of the hospital. Parents were not comfortable to take their children to hospitals since they fear of stigma. As argued by Yang and Cho (2008), the perception and labelling that stigmatized the illness affect the treatment choice people have. This is an indication that for a kind of diseases like mental illness which makes people vulnerable to stigma, making the treatment in general hospitals is more appropriate and have positive influence on people's choice towards medical treatment. In general the awareness, perception and treatment choice parents have are mainly influenced by the cultural, religion and traditional practice that are predominant in the

community. This is also the argument of the ecological perspective that argues people are influenced by the customs, attitudes, values, and laws of the culture in which they live (Smith, Hamon, Ingoldsby & Miller, 2009)

## **5.2 Caregiving Challenges**

The finding of this study stipulated that parents come across various forms of care giving challenges. These challenges include the behavioural problems of the children like physical aggression, damaging properties, uncertainty, going out, and sexual abuse. Other challenges are related to the effects of the illness included, lack of self-care, inability to work, social isolation, lack of adherence and relapse. Parents are loaded with the work of protecting and preventing children from quarrelling and committing dangerous acts. Besides they are also expected to wash their children's body, clothes including their under wears and urge their children to keep their hygiene. These challenges endure additional role and tasks on the parents and parents become forced to provide more care than what is needed for a child of certain age. This is supported by studies that reported the behavioural problems the patient displayed and the effect of the illness towards the patient create new and additional role for the parents. Besides, parents become burdened by providing more care than what is needed for a child of that age. (Schene, Wiinagaarden & Koerter. 1998: Sands. 2001: Seltzer.Jan.Greenberg & Floyd,2001:Benjamin& Coyle.2002). In this study we have noted that as the age of the parents increase care giving becomes more difficult unless there is an improvement in the child's health.

Going out and disappearing from home is one of the additional challenges in care giving parents are loaded with the additional role of nursing their children when they get hurt, washing

them when they returned with dirt, and searching for days when they got disappear. This is related to the fact that autism increases the risk of the individual being affected by diseases and exposed individuals to injuries, long-term disabilities and dependency because of the behavioural problems and the effects of the illness (WHO, 2007).

The shortages of doctors and hospitals that provide treatment for mentally ill individuals are one of the factors that become a challenge for parents. When there is such shortage it is obvious that the overall needs of the people become dependent on the existing resources. This makes the doctors and those limited health providing hospital more burdened. As a result, parents are not getting proper orientations, counselling and are less involved on the treatment processes. The finding is also supported by WHO (2006) report that indicated how difficult it is to address the whole psychiatric needs of the country with 0.02% of psychiatrists, 0.4 sociologists and social works each.

It is when parents get counselling, orientations or are organized by support group that they will develop their own solution for the challenges. However, as the study indicates there is no such counselling or support group for these parents in the hospitals. WHO (2006), on its report also revealed this fact as a challenge for care givers. As indicated there are only two associations for mental ill individuals.

Absence of social service such as rehabilitation and vocational centres, lack of social service providers like NGOs and lack of attention from the government are the factors give emphasis as a reason for their being burdened. Parents with the absence of such social service are straggling to improve their children's self-care, role impairment and other influences of the

illness. This finding is in line with report that suggested inadequate medical services for the mentally ill individuals in terms of quality and quantity, scarcity of social services and lack of attention from government are some of the reasons for families to be burdened (Alem, 1997; Alem 2000;WHO, 2006; Shibre et al.,2008).

Lack of knowledge on how to manage the behavioural problems of the child and how to help those children who have role impairment are what makes the practical care giving challenging for parents. This is consistent with researches that suggested lack of knowledge as a main reason for families to be challenged by care giving (Alem, 2001; Sands, 2001;Seltzer, Jan, Greenberg & Floyd 2001). In this study the parents' lack of knowledge goes to the extent of not knowing exactly what type of mental illness their children have.

In general, in a situation where parents do not have any awareness about the illness and how to care, the lack of appropriate services from the hospital and social service providers forced parents to face the burden of care giving alone. This in return influences the effectiveness of care giving among parents, in this study those working single parents who have no supporter at their house are found to be more burdened on care giving. In addition, the finding reveals that being working parents has an impact on the child's treatment. Because, it hinders parents from helping their children and creates some treatment discrepancies such as not going to the hospital at the appointed date. This also has another implication on the health improvement of the children and the children might relapse.

The practical challenge of care giving is aggravated due to lack of knowledge and absence of social services influence the physical, economic, family and psychosocial well-being

of the parents. The practical care giving in addition to the role strains it created on parents, it also affects their physical health. It is stipulated that when the age of the parents increase their physical health goes down and the burden of caring for their children make the problem more intense. The practical care giving courses also threatens the economic wellbeing of parents by forcing them to quit their jobs, earn low salary and loss of productivity. As the study revealed from the married parents participated in the study mothers are more burdened with care giving and those who have a job are forced to quit their jobs. Since males are bread winner of the house, it was the females who were forced to quit their jobs, which is also culturally acceptable and believed to be appropriate. As studies indicated the females are more burdened with care giving. This may be because of the fact that care giving and parenting are still more the responsibility of women than men and men usually engaged in economic activities outside the home (Shibrei et al., 2008; Vanwilligen, Hong, Sltzer & Greenberg 2008).

As parents care more for one child the attention they give for others will be minimal and other children in the family will be affected by the lack of care. This finding goes in line with Herbert's (1998) argument that when there is a sick or problematic child parents attention might be shifted to the child and other siblings might not get enough attention and their wellbeing will be at risk.

The daily care giving process that is associated with managing the behavioural problems and the nature of the illness are also psychologically damaging for caregivers. In addition to the stress of coping with disturbed behaviour and the effects of the illness puts parents in a constant fear. This is also supported by the reviewed literature of knusdson, Benjamin and Coyle (2002) and MOH (2007).

### **5.2.1 Economic challenges of parents**

Giving care for autistic children is cost incurring for parents economic challenges in this study is not only the problem of those who have low income but also those who have good living. The researchers which portray the economic challenge in relation to giving care for their mentally ill child identified long term cost on medical treatment and custodian care as a major challenge ( Selzer et al., 1997; Shibrei et al., 2003; Shibrei et al., 2008; WHO, 2008). It is also the experiences of the parents in this study. The medical cost and custodian care such as fulfilling livelihoods and other basic needs are waiting to be covered by parents.

As the study reveals purchasing medicine for those who do not get free service is cost incurring. There are also times parents whose children have follow up in St Paul hospital do not get the medicine from the hospital's pharmacy and forced to buy from outside. This indicates that free access does not mean parents are free from any medical costs. This can be related to the availability of psychotropic drugs in the mental health hospitals. The WHO aims report of Ethiopia (2006), also indicated this truth and reported that psychotropic drugs are mostly available in Mental Health Hospital and inpatient units and sometimes in outpatient mental health facilities. Because of this parents seem burdened with additional cost.

Transportation is the other cost associated with medical treatment. It becomes more challenging for parents who come from outside Addis Ababa. As the study indicates the shortage of hospitals is a reason for a parent who lives outside Addis Ababa to drop out from treatment and it is also a reason for parents to be away from these children when they come for follow up. Hospitalization in this study has also two views. Even though parents feel relief for their

children's being admitted, the cost of transportation and the cost in relation to leaving their home are huge.

In a country like Ethiopia where culture and religion played pivotal role on the treatment of mental illness, this adds additional treatment cost on parents. Traditional treatments mainly holly water, traditional medication, rituals and witchcrafts are found to be additional costs for the parents. The cost of traditional treatment as revealed in the study goes to the extent of forcing parents to spend their accumulated wealth. Parents use their deposited money, the capital of their business, severance payment and sold their gold jewellerys for paying the treatment cost. In line with this researcher in Ethiopia and elsewhere also indicate, mental illness undermines the stability of the household's by jeopardizing the available resources (Selzer et., 1997 & Shibrei et al., 2008).

### **5.2.2 Family Challenges Parents Encountered**

As Smith, Hamon, Ingoldsby and Miller (2009) and Turner and West (2002), argued mental illness is an unpredictable challenge that affects the families statuesque. Parents in this study mentioned that their situation as a family is affected due to the conflict that occurs between family members. Conflicts between siblings and autistic child, between siblings and parents and between couples are common experiences. These conflicts affect the positive relationship that family members should have to each other besides, the role of parents to maintain stable and satisfactory communication within the family members becomes jeopardized. Even though no study considering this topic is done in Ethiopia, researches done in other country also proof that

autistic as a subject to crises undermines the stability of the family and create conflict between family members (Sands, 2001; Selzer et al.1997; Turner & West, 2002).

The children's behavioural problems are one of the main reasons, for poor communication within the family members. This behaviour of the child mostly lead them to conflict with their siblings, sometimes siblings consider the autistic child does this purposely as a result they enter in to quarrels and when the conflict gets intense siblings and the autistic child use physical forces. The situation of using force, calling police and isolating the autistic child are indications on how the family members' communication is disrupted. This finding goes in line with different literatures that indicate the same facts. (Gawtam & Nijhawan, 1984; Sanda, 2001; WHO, 1998).

Hostile type of treatment which is treating the child in a harsh or uncomfortable way becomes source of conflict in the family. Due to that, the autistic children develop hatred and fear towards their siblings. This study to some extent goes with Pennington's idea of expressed emotion. According to Pennington (2002), the extent to which family members communicate with a patient in a critical, hostile or emotionally over involved way creates conflict between the family members. However, in this study no conflict reported due to emotionally over involved treatment. Instead of that, lack of proper care siblings give for their autistic sibling is identified as a source of conflict. For few parents this leads them to use physical punishment on the children.

For the case of partners, however, failure on care giving is not identified as a reason quarrelling between couples in this study. Even though husbands are mostly engaged in work

they are not negligent of the care giving processes and they are also involved on their free time. However, partners experience conflict due to the lack of common understanding on the care giving that is associated with the different cultural and religious views. In some cases couple end up separated. This finding is consistent with, Lemanna and Riedmann (2000) argument on their book of Marriages and Families. They argued that when parents become incapable enough to handle the situation they might enter in to conflict, hesitate to depend each another, blame each other and may end up in divorce. From what is indicated in the study one can stipulate that culture and religious views in addition to influencing once understanding and choice of treatment it is also found out to be influencing the families' relationship and become a reason for conflict between family members.

### **5.2.3 Social challenges parents encountered**

This study noted that stigma and discrimination and social isolation are the challenges parents encounter in their everyday interactions with their environment. Stigma and discrimination from families, close relatives, in-laws and neighbours are the experience of parents that is reflected directly to their children, towards the parents and their families as a whole. Considering the formal institution parents mentioned being discriminated by policy and hospital nurses as their experiences. However, this might not mean other institutions are not discriminatory, because in the absence of social service providers parents have nowhere to go.

This stigma and discrimination manifested in a formal rejection, threats of rights and embarrassment which is expressed by rumour, taunting, side talk and nonverbal cues. This is consistent with WHO(2003), publication of investing on Mental Health, that argued, stigma and

discrimination are manifested by “ stereotyping, fear, embarrassment, anger and rejection, avoidance and denial of the most common basic human rights”(WHO, 2003,P.13).

Threat of losing rights is also experienced by parents from their neighbours, work place and close relatives. The finding also indicates that the consequence of stigma reached to the extent of forcing the parents to change their areas of residence. This is supported by Yang and Cho(2008), in their journal of stigma and mental illness that argues stigma acts decreased the life opportunities of those patients and the families, by reducing housing options, employment opportunities and access to services.

Communities associating the illness with the supernatural power and lack of understanding on the illness are what make parents vulnerable to the social stigma. This is consistent with the other researches done on our country. Lack of knowledge and a widespread belief that associates mental illness with supernatural power make millions of family’s struggle with its social consequences (Alem, 2000; Shibrei & et al., 2001; 2003; 2008). Considering the child as dangerous, lazy and foolish and considering the behaviour as deliberate and rudeness are the other reason for parents to face stigma from people. Other researches also indicated, labelling of mentally ill individuals negatively as dependent and helpless, thoughtless, dangerous and unpredictable are the reason behind stigmatize (Alemu, 2000; Selzer et al., 1997; Shibrei, 2003; Yang & Cho, 2008).

As argued by Schene, Wijnagaarden and Koeter (1998), self-stigma is the other form of stigma which families experienced. As revealed in this study, parents feel stigmatized. Feeling of inferiority, humiliation, shamefulness, unwanted and indifference are what the parents mentioned.

Like the community parents also associate the illness with cultural view, afraid of people's rumour due to past experiences of social stigma. The incidences occurred repeatedly in the family on other members and keeping the child home for the sake of avoiding stigma can be mentioned.

These researches also imply that both self and being stigmatized by others are a reason for the parents to be isolated from their social relationships or reduce the individual social contacts. Parents loss or reduce their contacts with their relatives, neighbours and reduce or stop their participation with social activities. Parents who are stigmatized by their close relative indicated that they totally stopped the relationship they had with them.

#### **5.2.4 Emotional challenges Parents Encountered**

Many literatures argued that parents when they heard the news for the first time that their children are autistic, they enter in to shock, uncertainty, anger, denial and guilt (Hong, Seltzer & Greenberg, 2008; Mulhauer, 2002).

This is also the experiences of the parents participated in this study. For some of the parents a feeling of guilt and blaming self or others are related to the cultural attitudes that associate mental illness with evil and cultural altitude of raising children. The emotional reactions are also associated with the illness being unexpected one. Even though I did not find a research or literature done on this aspect in Ethiopia, different researches in other countries indicated that it is emotionally disturbing for the parents (Greenberg, Seltzer, Krauss, Chou & Hong, 2001; Schene, Wijnagaarden & Koeter, 1998). It is also true in this study where, the

lowest age when the children first diagnosed is 3 years old. This means they find out not immediately after giving birth.

In this study what is gained out of the reviewed literature is the children's good reputation such as for some their being a first born child has a meaning for parents' emotional disturbance. Smith, Hamon, Inogoldsby and Miller(2009) argued that a first born child is like a parent who tries to play parental role and mostly take the honour of the family. This is also culturally true in Ethiopia where the first born child is male which goes in line with this research, where some parents' first born sons become autistic.

In a culture where women are given less attention and gender inequality is still a norm, women are exposed to huge socio cultural and economic pressured (Howard and Smith, 2006). Single mothers participated in this study also share this view. As they explain, raising their children alone and seeing their children's success was an achievement for them that needs to be celebrated. However, the illness shattered their celebration and brought sadness.

### **5.3 Coping Mechanisms used by the Parents**

In the study parents used different coping mechanisms while they struggle to manage their care giving burden and the influence of their environment on the course of their care giving. As Lazarus and Folkman (1984) argued, individuals' adjustment to the stressful situation depends on the strategies adopted by the individual and the resource available to facilitate coping and on the nature of the stressor itself. It coincides with the finding of this study in which parents use different strategies of coping.

Guarding children from committing dangerous acts, from taking too much drugs or tying up their children with chains, keeping them not to go out and calling the police are used as a strategy to directly tackle the practical care giving challenges that have been encountered. From what has been seen in this study, however, it is clear that not all strategies that are directed towards handling the problem are appropriate or without any negative consequences. As Kim, Greenberg, Seltzer & Krauss(2003) argued, using particular problem centered coping does not necessarily mean it will have beneficial effects both on the child's and parents' well-being. Tying up children with chain has its own consequences in terms of the physical psychological health of the child. Besides, as the finding indicates parents are emotionally disturbed for tying up their children with chains keeping the children home with the fear of stigma and other consequences such as abuse and accidents might also hiding their children so as to avoid being stigmatized by people affects the parents access for different services. Hence the practice of tying with chains and hiding children are practices that can be seen as violation of human rights.

In this study however, there are parents who do not have any future plan for their children because of long term care giving, very poor health progress of the children, economic problems and the age of the parents. Here we can argue that long term care with very poor progress and lack of resource leads the parents to lose hope. Besides, when the parents get older their capacity to give care also decreases. As Schene, Wijnagaarden & Koeter (1998) and Smith et al. (2009), argued the more intense the nature of the stressor, the more people become challenged to cope; and income also has a significant impact on the parents' coping responses. In line with this, the cumulative mode of coping argued that a child with mental illness would be magnified during the older age of the parent (Hong, Seltzer & Greenberg, 2008).

Traditional treatment such as prayer, holy water, traditional medicine, witchcraft and rituals are also found in this as a problem centered strategy. This goes in line with many researches in Ethiopia and literatures in other parts of the world that state as culture and religion provides a primary system of meaning for parents' experience of coping. As a result they use traditional treatment mentioned in this study as a strategy (Alem, 1994; Alem, 1997, Shibrei et al., 2008; Sands 2001). As it is indicated in this study there are conditions in which culture becomes an obstacle but to the other side people also use it as a coping strategy. This is consistent with the ecological theory that states culture played a pivotal role on the perception of challenges and coping mechanisms parents developed (Lamman & Riedmann, 2000).

Emotion focused coping strategies are commonly mentioned in this study. This strategy mostly used to cope up the family and the psychosocial challenges they encountered. Parents use different forms of emotion focused coping. The most commonly identified are crying, talking to someone, praying, and going out for a while. Besides, forgiveness and quarrelling are also used by parents. As it is indicated, not all types of coping have positive impacts.

As the study indicates crying is the female's strategy for coping. This might be related to the cultural attitude people have in Ethiopia that says male are strong and should not cry, while females are weak and usually expressed their emotion by crying. On the other hand, going out for another indication of how culture influences the individual's coping mechanisms. However, unlike the arguments of Lazarus and Folkman (1984) and Knudson, Benjamil and Coyle (2002) that associated going out and some negative responses such as drinking alcohol or other distractive events, most of the parent in this study don't experienced this behaviour as coping mechanism. Instead they go out to church, talk with their friends or close relatives.

Talking to someone is another means for coping as the finding indicates parents prefer to talk with their close family members and those people who share the same problem. This is as indicated that parents need family therapy and a kind of support group so as to share their experiences which has an advantage of developing good skill on care giving in addition to getting emotional relief. As researches done in Ethiopia indicated prayer is the most practiced coping mechanism (Shibrei et al., 2001; Shibrei et al., 2003; Shibrei et al., 2008). In this study also it is used by the parents very well. Prayer in this study also included reading the Bible and Kuran and listening to spiritual songs.

The parents who are taking cares of an autistic child, the behavioural problems that lead to conflict create a stressful reaction. However, parents use forgiveness as a coping strategy, forgiving the children's act by explanation that they did all these because they are sick. This strategy as indicated in this study reduced the parents' sadness and anger. Worthington and Schere (2008) also argued that forgiveness is an emotion focused coping strategy that reduces unpleasant acute stresses. Even though parents use forgiving as a coping there are also situation that parents quarrelling with siblings, partner and with the autistic child as to let out their anger. However, this strategy leads parents in a more stressed condition because of the feeling of guilt and anger it created after a while of relief. This in return affects the relationship they have with their children create conflict which is another burden for parents. This indicates that the parents like the case of forgiveness or sleeping they need positive anger management skills.

Not thinking that being alone or thinking that there are also the worst cases are one way of coping that makes parents to be thankful. In contrary seeing the progressed cases revived the parents' hope which is important for the emotional well-being of the parents. Parents in this

study are utilizing whatever they have for coping. For a parent sleeping is also a form of coping from worries and anger, so as to have a better outlook afterwards.

Parents use avoidance coping as a means of coping with the social stigma they have been encountered. However, unlike, researches done in Ethiopia or other parts of the world that indicates males employ more isolating strategies than dealing with the challenge (Shibre et al., 2008; Lazarus & Folkman, 1984; Knudson, Benjamil & Coyle, 2002), in this study all males used both problem focused and emotion focused strategies than the avoidance coping. Since the avoidance coping neglect care giving, it hinders or becomes a reason for the children's health to be deteriorated. This also has further implication of parents being stressed emotionally. However, except the avoidance for social stigma parents do not use this strategy for the purpose of coping from their grind of giving.

The available resources in their environment are what helped parents to use the above strategies and to cope up their challenges. In this study, children, extended family members, relatives, in laws, friends, neighbours, religious organizations, Iddirs, hospitals, police station and Kebele are found out to be the resources that helped the parent to cope up. This also found out to be true in different researches in Ethiopia and outside Ethiopia (Alem, 2001 & Sand, 2001).

In this study children are found out to be the front line supporters for their parents in terms of care giving, financial and emotional comfort. The siblings are supportive not only for their parents but also directly to their autistic siblings. This is consistent with study done on siblings of adults with mental illness that indicates, siblings feel a sense of obligation and they are part of the fabric of the lives of those patients (Seltzer et al., 1997). For those couples they

are also a source for each other on handling the care giving, economic, family and psychosocial challenges they have been encountered. Next to close family members, extended family members, close relatives and in laws are supportive both emotionally and financially for the parents and sometimes there are situations in which they become involved in the practical care giving. This finding concedes with the researches done in Ethiopia that indicates, these people are mostly available resources for care giving (Alem, 2001; Shibrei et al., 2001). From this finding it can be stipulated that the social environment is a means of challenges and at the same time a means for coping. This goes with the ecological theory that asserts that environment is open for influencing both opportunities and limitations although not in an exclusive manner.

The study also found out some situations that parents do not consider the support they get from their relatives as helpful in their process of coping. This is occurred when the parents think that the relatives support unintentionally ruins their plan and when the kinds of support parents need and those relatives provide mismatched. This indicated that social support will have meaning when both parties have same understanding on the support provided and received. As a result, this finding shows some contradiction with Armstrong and his colleagues' (2005), argument that says social support is a support when it is preferred by social intimates. Parents also use the available community resources that are found around their environments. These are their neighbours, friends, religious associations, soul fathers, church families, mosques, hospitals, Kebele and police stations.

Apart from the available resource personal factors such as having good health, awareness about the illness and good income are the three commonly used factors by parents to rebound their different challenges. This is consistent with researches done outside Ethiopia that indicate

physical wellbeing, income and the knowledge parents have about mental illness, are some of the personal factors that help parents to cope with the stress of care taking and managing the patient's behaviour (Armstrong, 2005). As the data indicates those parents who have a good health, awareness about the illness and good income are mostly used problem focused coping strategies and they also have a future plan for their children. Knowledge in addition to the benefits it has on care giving it also helps parents to manage their stress, which later has a positive impact on their care giving. Resilient, love, optimism are the additional characters that helped the parents to aspire a better tomorrow, which has great impact on their psychological well-being.

In general, from this discussion one can conclude that the challenges and coping mechanisms used by the parents are emerged from their socio cultural environment that includes the autistic child, the self that is with the parent herself, the family and the social environment that includes all the available formal and informal resource. These four pillars played an important role both on the challenges and coping mechanisms of the parents with their daily living.

## **Chapter Six**

### **6. Conclusion and Social Work Implication**

#### **6.1 Conclusion**

This study believed to have a contribution in advancing the existing knowledge in Ethiopia regarding the parents of the children with autism. The study looks in to the life experience of the fourteen parents who are giving primary care for their autistic children. The incidence of autism in the family changed the parents' normal role in care giving. This care giving has practical challenges in relation to the types and amount of care giving provided by the parents. The findings of this study shows that the behavioural problems the children displayed and the effects of the illness create additional tasks for the parents such as guarding their children from committing dangerous acts, from going out and washing their children's clothes, preparing food and so on. Outgoing behaviour of the children and that they get irritated easily are found out to be additional roles for parents in this study. It is indicated that the role of the parents is so stretched because of different reasons. These are, the lack of knowledge on how to manage the behavioural problems of the children and how to help with their children's role impairment, lack of adequate service in the hospital, low attention given by the government and shortage of social services that provide care and support for the parents and in addition less attention is given to the concerns of parents by service givers. Therefore, parents are more burdened with care giving. It also appears that single parents are more burdened than married parents.

Autism hinders the individual from work because it affects them at their early age and puts a huge financial burden on parents because they have to rely on the family's resources for

various expenses. Another important finding of this study is that family members enter in to conflict with each other. The main factors identified as a reason for the conflicts were, the lack of common understanding of the illness in terms of cause, course, symptoms and types of treatment, in addition the lack of care for the other children because of the shift in caring for mentally ill child affects the family dynamics with regards to the children.

This study also noted that parents are exposed to social challenges as a result of stigma and discrimination attached to the illness by peoples, the parents themselves and the daily care giving challenges creates emotional disturbance on the parents. Parents experienced the feeling of shock, confusion, anger, denial, blaming, sadness, depression, hatred towards themselves and the people around them including their area or residence.

Finally, with all the challenges parents encountered, the study indicated that parents used different coping mechanisms such as problem centred coping, emotion focused and avoidance coping so as to cope with the daily hassles that occur due to the practical care giving, economic and psychosocial challenges. Different resources have been used by parents in order to utilize these different strategies. Parents utilized different support system available in their social environments. These are mainly their children, extended family members, cloth relatives, in-laws, friends, and neighbours. Besides, parents also use formal and informal institutions such as hospitals, religious organizations, police and Iddirs. In addition, they also use their personal characteristics such as their knowledge, economy wellbeing, health, spirituality and like, as a source for their coping. The study also indicates the characteristics of autistic children have such as showing health progress, starting to do things by themselves and so on as a means for coping.

## **6. 2 Social Work Implication**

Social work is a kind of profession that works towards the better life of vulnerable groups of people. As it is indicated in the study parents of adult children with autism are one of the vulnerable groups of people in Ethiopia. These parents are vulnerable to different kinds of challenges. Therefore, different social work interventions are needed to address their challenges. As the study indicated the challenges parents encountered are multi-dimensional and interrelated. As a result, a holistic kind of intervention is needed. Case management that address the issue of a client by considering the social environment the individual lives is preferred to address the different challenges parents faced. The client in this case parents being the centre of the intervention, this strategy targets intervention on the autistic child, the family and the socio cultural environment including the community and both the formal informal organizations that parents interact. In such a way it creates an opportunity to strengthen their support system and to coordinate and utilize resource found in their environment. The following are some of the interventions that need to be addressed at different levels.

### **6.2.1 Intervention on the parents**

- Provide proper orientation for parents about the nature of the illness.
- One of the guiding principles of social work profession is the emphasis it gives to the strength perspective. The strength, capacities and potentials of people to address their own problems have been emphasized and considered in social work. This study has also focused on exploring the different strengths such as the personal characteristics of the parents and the available resources parents used in order to cope with their

challenges. Therefore, in order to facilitate conditions for the parents to use all the available resources providing counselling will be appropriate. So that parents can propose their own solutions for their own problems and help them to plan for the future of their children and themselves using the existing resource around their environment. In such a way, parents can minimize their worry about the future of their children.

- Even though there is very limited support group for parents they mentioned talking to someone who shares their problem as their means of coping. This indicates the importance of support group therefore organizing parents with support groups can help parents to share their experience so as to develop a better psychological well-being and skills of coping.
- Providing psychological education on how to handle the behavioural problems and the other effects of the illness is also important for parents to handle their practical care giving and emotional challenges.
- Training on stress management skills can also have a considerable impact in helping the parents to manage their emotional disturbance.
- Promoting the legal and human right issues can also empower parents to fight for their rights.
- Facilitate conditions of income generating schemes for parents' is the other aspect of intervention that can provide the parents with the means of tackling their financial burden. As the parents are aged, the plan needs to consider the parents age and must be less energy and time consuming.

### **6.2.2 Interventions on the Autistic Children**

These children need to be involved in the intervention since they are the main causes for the parents' challenges. Therefore, in order to improve their well-being that has also an impact for parents' coping the following interventions are suggested.

- Organize skill trainings that can help them to develop better self-care, working ability and social relationship.
- Facilitate opportunities for the children to get skill training and organize them in income generating activities that consider their situations.

### **6.2.3 Family Level Intervention**

As it is indicated in the study autism as unexpected crisis affects the families' statuesque and jeopardized the role of the parents. Therefore, family level intervention is needed.

- Organize family therapeutic sessions to create awareness about the nature of the illness and to enhance the family members' participation on the care giving processes and on the future plan of the children and family members as a whole.
- Provide training on how to care for the other family members/relatives.
- Provide stress management, conflict management and communication skill trainings that are important for the family members normal communication.

### **6.2.4 Community Level Intervention**

All the social challenges identified in this study such as stigma and discrimination and social isolation are associated with the parents' interaction with their socio cultural environments.

This indicates that a huge work is needed on the community level to create awareness about the illness so as to alleviate their cultural views that associate mental illness with evil and to prevent stigma and discrimination for those mentally ill family members and on the patients themselves. Organizing different awareness raising campaigning such as public demonstration, forums, media, community conversation and coffee ceremonies can have beneficial effects. Besides, it creates an opportunity to mobilize the community for care and support of the parents caring for their children and for the parents themselves.

### **6.2.5 Intervention of the Social Service Providers**

As the study revealed, it is mainly the hospital, the religious organization, Iddir and the police, which parents used as a source of their support. Therefore, strengthening these service providers to give appropriate support for the parents is one of the areas for social work intervention.

- Provide psychosocial support training for the staff working in the hospitals.
- Provide legal protection trainings for the staffs working in the hospitals so that they can empower and advocate for the rights of those parents, the patient and the family as whole.
- Provide training for the polices so as to identify the symptoms of mental illness, develop better awareness on stigma and discrimination help and protect both the patients including the other family members when threats of right or stigma and discrimination occurred.

- Organize awareness raising programs for Iddirs' Officials so that they can mobilize their members for the care and support of these parents and patients.
- Facilitate linkage with other social service and legal protection providing organizations such as CSOs, NGOs etc.

### 6.3 Advocacy

The other social work intervention that can benefit the parents is intervention through advocacy for the care and support and legal protection of the parents and patients. As it is indicated in the study lack of social service provision is the main challenge therefore, advocating the provision of social services by non-governmental organizations government organizations and different responsible agencies including private clinics can benefit the parents and their children. Advocate for the establishment of rehabilitation and vocational centres for patients themselves is important.

**Implication for Policy:** Mental illness is a problem of significant public health importance. Therefore, the most important steps to tackle the problem of mental illness are through the development and endorsement of mental health policy that gives emphasis on the wellbeing of the patient and their families. Even though, mental health was mentioned in the national health policy of the country, it did not get enough attention. This lack of attention in a country like Ethiopia where, mental illness is more prevalent due to various reasons affects many people and its being neglected has a negative consequence. As a result, the development of the policy that insure the responsibility and accountability of all the concerned bodies is needed. As WHO(2006),reported, sustainable development of a mental health system can be achieved only

if services are based on policy and guided by action plan. Therefore, Ethiopia needs a mental health policy for protecting the family, the patient and the society at large.

**Implication for Further Research:** researchers in Ethiopia are focused on the epidemiological aspect of the illness and on the issues of stigma and discrimination associated to the cultural view of the community. Yet very little is known about the challenges and experiences of parents.

This study explores the different challenges parents encountered and the coping mechanisms used by them towards tackling their challenges. However, the sample size is small and the focus is also limited to the parents of autistic children. Therefore, a compressive study that incorporates the perspectives of other family members including their siblings would help for the better planning of care and support. Researchers that focus on guardians such as parents, sibling guardian and others will also help. The issue of communication, right issues both at work place and to the larger community needs to be addressed through research.

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## Annex 1

### **Informed Consents**

My name is Merhawit Muluberhan, post graduate students in Addis Ababa University School of Social Work. Currently, I am conducting a research as part or requirement of Masters Degree in Social Work. The study is mainly focused on understanding the lived experience of parents caring for their autistic children. Under this, the study will try to address the following activities. These are identifying the challenges in relation to care giving, identifying the emotional and social challenges parents of children with autism encountered, identifying the coping mechanisms used by those parents, understanding the awareness parents have about autism and identifying the possible social work intervention areas.

The finding of this study will also have different benefits. First it provides an insight about the parents experience on care giving for their children with autism. Secondly, it will also serve as a point of reference for the responsible agencies working on the area and for social workers to develop better understanding on the challenges and coping mechanisms of the parents and so as to take appropriate interventions and measures. Besides, this study will serve as a stepping stone for other academicians and practitioners who want to do research on the same area. Finally, I would like to tell you that in participating in this study you will have contribution for the betterment of peoples understanding about parents caring for their autistic children.

In order to conduct this qualitative case study therefore I will use in depth interview as data collection tool. While sorting out the potential responding or those who fulfil the inclusion criteria you have been identified. However, conducting the interview with you in total depends on your willingness. So that, this consent form is organized to formally make sure you are willing to participate.

As I said, your participation is purely based on voluntarism. Therefore, once you agreed to participate you also have a right not to respond for the questions you are not willing to answer and you can also quit this interview any time you want. The data obtained from you will be recorded only in notes and audio recording instruments. The tapes and notes will be all discarded after the final documents has been prepared and approved. All personal information will be altered as much as possible. In other words no particular information will be mentioned. The researcher can assure you that your participation will never affect your service access or status. If you have the concern on seeing the result of the final document of the study it will be given to the organization (Nia Foundation) so that you will get the access to it.

Finally, since the trustworthiness of the research highly depends up on your response for the questions and your response to each question has an importance for understanding the issue explained above, the researcher expects your kind commitment to volunteer and actively participate in the study. Lastly, if you agree to participate in the study, tick in the box “I agree”. If you don’t want to participate in the study, tick in the box “ I do not”. I thank you in advance for your intention and willingness to participate in this study.

I agree

I do not agree

Signature-----

## **Annex 2**

### **Interview Guide for Parents of Children with Autism**

#### 1. Background of information

Sex

Age

Marital status

Educational status

Age of your child

Sex of your child

Educational level of the parent

Educational level of the child within Nia Foundation

Year of stay of your child at Nia Foundation

How do you find out about the diagnosis of your child?

2. How do you describe your first reaction to the diagnosis when you find out? And how was it disclosed?
3. Can you tell me the process before the child being medically diagnosed with autism?
4. Tell me about your child's living situation? Whether she/he lives with both of her/his parents, other family members?
5. What is your role in the care giving process?
6. Can you tell me what you know about autism? Before and after the diagnosis of your child?
7. What do you think the cause for the illness and can you also tell me what you think the treatment is?
8. Tell me about the challenges your child faced in schools before joining Joy Centre?
9. Is there any change after the child diagnosis with autism? If yes what are those changes? (it could be behavioural or medical)
10. Can you tell me what the care giving process is like? What is more challenging?
11. Have you ever experienced emotional challenge or emotional disturbance in the care giving process? If your answer is "yes" can you please tell me more about the challenge?

12. Does the illness of your child affect the family relationship?( parent-to-parent, parent-to-siblings, marital relationships, parent-to-other family members) If your answer is "yes" can you please tell me more about how it affect the family's relationship?
13. Have you come across any social challenges in relation to care giving? If yes what kinds of challenge have you been encountered?
14. Have you experienced any financial difficulties because of your Child's diagnosis?
15. How do you witness the awareness of the society regarding children with autism in Ethiopia?
16. Tell me about the process you have gone through to make your child join Nia Foundation?
17. Tell me about the improvements your child showed after joining the Centre if there are any?

**Focus Group Discussion Guide for FGD Participants**

1. Can you tell me the common/the day to day challenges you face as you find out your child diagnosis for the first time?
2. How does the behaviour of your autistic child affect your life?
3. Among the challenges you come across those past years can you tell me what helps you to cope up?
4. Have you ever thought for outside support? (family members, expended families, friends, neighbours, support groups, religious institutions, traditional healers, hospitals and other social service providers).