ADDIS ABABA UNIVERSITY

COLLEGE OF EDUCATION AND BEHAVOURAL STUDIES

The Lived Experience of Mothers Having Children with Autism Spectrum Disorder, in Addis Ababa

By

DAGMAWI ALEMNH

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Department of Special Needs and Inclusive Education

Approval of Board of Examiners:

1. Advisor:

_____ _____ _____

Date Signature

2. Internal Examiner:

_____ _____ _____

Date Signature

3. External Examiner:

_____ _____ _____

Date Signature

Declaration

I the under signed, declared that this thesis entitled “The Lived Experience of Mothers Having Children with Autism Spectrum Disorder, in Addis Ababa” is my original work and has not been presented the award of the degree in any other university and that all sources of materials used for this thesis have been duly acknowledged.

Name: Dagmawi Alemnh

Signature _____

Date _____

This is to certify that the thesis entitled “The Lived Experience of Mothers Having Children with Autism Spectrum Disorder, in Addis Ababa” is the original work of Dagmawi Alemnh, done under my close guidance.

Name: Dr. Abebe Yehulawork

Signature _____

Date _____

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ABSTRACT

Autism Spectrum Disorder is a complex neurological disorder which causes impairments in multiple areas of development including social interaction, communication, and behavior. In Ethiopia mothers of children with autism have conventional responsibility and challenge in taking care of their children with autism compared to other members of the family. The study investigates the lived experience of mothers having children with autism spectrum disorder (ASD) regarding the Mothers' reaction after the detection of autism in their children, mothers main challenges in nurturing and caring their children with ASD, the mothers' with ASD children support from the community and schools and the mothers feeling about the future life career of their children with autism. Qualitative research method on particular emphasis on phenomenological research design was employed to conduct the study. Semi-structured interview was used as a data collection instrument. The targeted institutions were six regular schools and one autism center. A total of fifteen mothers having children with ASD were selected purposively as key informants. The data analysis was carried out based on the thematic areas organized in interview guides as leading questions. In addition, as a part and parcel of the study two coherent case stories were prepared. The finding shows that majority of respondent mothers/guardians did believe that they have been overburdened in taking care of their children with autism. They further confirmed negative attitude of the people and non-availability of specialize service coupled with the scarcity of trained human power seriously aggravated their challenge and complicated their duty and responsibilities in taking care of their children with autism. Based on the finding of the study, the involvement of the concerned federal ministries in promoting and coordinating interventions needs to be available for mothers/ guardians and their children with autism have been recommended.

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LIST OF ACRONYMS

APA: American Psychiatric Association

ASD: Autism Spectrum Disorder

DSM: Diagnostic and Statistical Manual

MoE: Minister of Education

MoH: Ministry of Health

PDD: Pervasive Developmental Disorder

UN: United Nation

UNSCO: United Nations Educational, Scientific and Cultural Organization

WHO: World Health Organization

Unit One

1. Introduction

1.1. Background of the Study

Autism Spectrum Disorders (ASDs) is also referred as Pervasive Developmental Disorders (PDDs), currently encompass several disorders, most notably Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified American Psychiatric Association fact sheet (2013). ASDs are characterized by deficits in verbal and nonverbal communication, social interaction and repetitive or restricted interests and behaviors (National Institute of Mental Health, 2008).

Compared to other developmental deviations such as intellectual impairment, autism manifests itself not in developmental delays but rather in striking deviations in development (Beauchesne & Kelley, 2004). Although the onset of symptoms for most children with autism occurs during late infancy, some children may not display any symptoms until 2 years of age after a period of relatively typical development (Rachel, 2015).

Children diagnosed with an ASD are not the only people being affected by these disorders; their families of these children experience enormous struggles on a daily basis that often go unrecognized. Parenting a child diagnosed with an ASD has been shown to be more stressful than parenting a child with any other disability and mothers of these children are more likely to suffer from depression than the general population (Davis & Carter, 2008).

The challenges of caring children with autism can result in pronounced psychological distress for mothers (Davis & Carter, 2008), not only in the impact of diagnosis, but as well as in the specific and on-going psychosocial, developmental and behavior challenges in the process (Eisenhower, Baker & Blacher, 2005). There is the acknowledgment of potential loss of self and family image and livelihood, which implies a unique parenting experience with different expectations, hopes and dreams for the child and family (Woodgate, Ateah & Secco, 2008) to what they had anticipated.

In developing countries autism awareness is low, particularly in sub-Saharan Africa. In Africa the prevalence of autism is unknown because of autism research conducted in Africa has been infrequent and unrepresentative of all African nation Bakare, wuest and todd, (2011). The same is true for Ethiopia currently there is no studies made on the prevalence of autism in Ethiopia however according to the estimation made by Nia foundation (2015), there could be about 530,000 children with autism and related developmental disorder in Ethiopia. However, so far, there are only two centers for children with autism in Ethiopia Joy center and Nehemiah and both centers are established by the mothers of children with autism (www.ethioautism.org, 2016).

From the researcher point of view in Ethiopia mothers raising children with autism spectrum disorder (ASD) conveys a complex and extremely challenging life compared to the developed world, because of the awareness from the community, shortage of professional care and scarcity of material to support those children. The purpose of this study was to attempt to understand the lived experience of mothers having children with autism spectrum disorder (ASD). Using a phenomenological approach, Semi-structured interviews was conducted with fifteen mothers of children with autism regarding their lived experiences of Mothers 'concerning the following areas mothers' reaction after the detection of autism in their children, their main challenges in nurturing and caring their children with ASD, the mothers' with ASD children support from the community and schools and the mothers feeling about the future life career of their children with autism.

1.2. Statement of the Problem

Parenting starts when there is a plan for it because it can change how people define themselves and shift their priorities in fundamental ways. Thus, before their baby is born, many parents prepare themselves for making a lifelong commitment by putting a lot of expectation about the baby they are expecting, This expectation includes having a child who is completely without disability but according to American Psychiatric Association fact sheet (2013), about 1 in 68 children are diagnosed with autism spectrum disorder in America.

Parenting is in itself a challenging experience and could be even more difficult when raising a child with autism. Previous research on families caring for children with autism has focused on the impact parents have on the child, not the child's effect on the parents. More recently, studies

have focused on the challenges that parents face in raising a child with autism and the different adjustments in family life they have to make to accommodate the special needs of these children .Thus, parents of children with autism face unique demands in raising and supporting their children. Therefore an understanding of the experiences of parents of children with autism is crucial in providing the necessary support and facilities.

Mothers make the most intense adjustment to a child's developmental disability and they are at a higher risk of long term stress than fathers. Mothers appear to be the most affected and to experience psychological distress because the mother tends to have the first role in caring of child with autism spectrum disorder and they endure greater psychological pressure than other family members in balancing children needs with their normal life .

Mother's experiences raising a child with autism spectrum disorder (ASD) conveys a complex and extremely challenging life. As a challenge to the mothers, autism must rank among the most stressful of childhood developmental disabilities. Problems with communication, emotional expression and antisocial behaviors, all combined to place tremendous stress on the mothers of children with autism. 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.

In most cases mothers become closer to the child with autism while father works harder to earn money consequently; the farther becomes irritated at the demands of the mother to interact with a children and mothers become frustrated at the lack of involvement of their partners. The absence of informal and professional support, feelings of loss of personal control, and lack of awareness in society are some of the factors associated with mother's challenges in families of children with autism.

The lack of awareness of autism in society at large, which led them to believe that the majority of people do not understand the behavioral manifestations of autism that made them feel judged on how they manage their child's behavior.

In western countries the community is more aware about autism because of increased media coverage and an expanding body of knowledge published in professional journals. Relatively insufficient attention has been given to autism in sub- Saharan Africa. Although a few documented studies have examined the relationship between autism and the stress on mothers, there is virtually very little on this subject in sub- Saharan Africa.

In Ethiopia, caring of a child with ASD can be daunting and overwhelming for mothers, due to the services for children with disabilities in general, and services specifically designed for children with ASD. In Ethiopia the services for children with autism are minimal. Children with ASD and their families face the likelihood of poor health, social care, mental health service, rehabilitation, lack of special education and access to equal opportunities.

Few studies address the lived experience of mothers having children with autism spectrum disorder in Ethiopia. In Ethiopia there is also lack of awareness in autism spectrum disorder these makes the challenges more difficult for mothers. Therefore, the aim of this study is to explore the lived experience of mothers having children with autism deathly.

1.3. Research Questions

1. How do mothers react when their children are detected with autism?

2. What are the main challenges of mothers in nurturing and caring for their children with autism?

3. Do mothers having children with ASD have adequate support from the community, schools and organizations?

4. What do mothers expect about the future life career of their children with autism?

1.4. Scope of the Study

The study is on mothers of children with autism spectrum disorder. The study select sample from Bete Fiker School, Yekatit 23 School, Kokebetshiba School, Edeget school, Bashewam primary school, Gulele Fana school and Nia Foundation. Therefore, mothers of children having children with autism from other schools were not included. Mothers of Children with autism and their

respective children who are not enrolled in school or at center are not included in the study. The study is not considering specific autism type due to lack of organized documentation.

1.5. Significance of the Study

It is important to study the Lived experience of mothers of children with ASD, nationally and internationally, in order to inform the policy and legislative process (Cicirelli, 2004). It is believed that the support services for mothers of children with autism could be provided with the help of such data. Researches directed at understanding what it is like to be a parent of a child with autism. The results of the study are helpful to mother of having new diagnosis children as ASD to learn from other mother's experience. As well as it is helpful for special needs educators and other professionals in understanding the unique experience, struggles and needs of mothers. The research also may help for the professionals to give them different perspective and guide the way in which they plan treatment when working with mothers of children having a child with an ASD.

These research gives additional insight for schools and autism center so that they can employ various means and options to encourage parents and professionals to come together to work on the gaps and insufficiencies that they have. It also serves as reference for governmental organization, non-governmental organization, program developers, organizations like policy makers, international organizations, autism centers and schools to facilitate opportunities for the parents regarding awareness rising, counseling and providing income generating activities. This study will also serve as a stepping stone for other academicians and practitioners who want to conduct research on the same area.

1.6. Conceptual Definitions

Autism Spectrum Disorder (ASD) – a range of complex developmental problems manifested by either atypical behaviors in social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior.

Biological Mother- mother who has conceived rather than adopted a child and whose genes are therefore transmitted to the child.

Guardian- mother who are engaged in adopting, guarding and raising a child.

Children- a group of young person's aged between infancy and adolescence

Special educational needs- refer to the specific need or learning style of children with autism emanated the type and nature of their impairment.

Impairment- refers to factual absence or loss of functioning in a body part that notifies the physical condition of a person and results in activity limitation.

Disorder- is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning.

Disability- refers to the interaction between persons with impairments and attitudinal and environmental barriers that hinders there full and effective participation in a society on an equal basis with others.

Unit Two

1. Review of Related Literature

2.1. Definition and Basic Concepts of Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication, and restricted/repetitive behaviors, the effects of ASD and the severity of symptoms are different in each person (American psychiatrist association, 2013).

ASD is usually first diagnosed in childhood with many of the most-obvious signs presenting around 2-3 years old, but some children with autism develop normally until toddlerhood when they stop acquiring or lose previously gained skills. Studies disclosed that the occurrence or prevalence of autism higher on man rather than female accordingly in accordance with the research conducted American psychiatrist association in (2013), Autism spectrum disorder is also three to four times more common in boys than in girls, and many girls with ASD exhibit less obvious signs compared to boys. Autism is a lifelong condition. However, many children diagnosed with ASD can live independent, productive, and fulfilling lives.

2.2. Diagnosis of Autism Spectrum Disorder

There is a shift in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) from a previous multi category model to a single diagnostic category of ASD. DSM is the handbook used by health care professionals in the United States and much of the world as the authoritative guide to the diagnosis of mental disorders. DSM contains descriptions, symptoms, and other criteria for diagnosing mental disorders. It classifies ASD as a neuro developmental disorder with core deficits in two domains social communication and social interactions as well as restricted repetitive pattern of behavior, interests, or activities. Although these symptoms are often present in the early years of a child's life, as the child grows the symptoms may manifest in varied ways with associated comorbidities and a child's capacity to manage social demands. According to the diagnostic criteria for ASD, the symptoms that cause significant impairment in various areas of child functioning cannot be explained by intellectual disability or global developmental delay. DSM-5 has eliminated the categories Autistic Disorder, Rett's Disorder,

Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified and replaced them with Autism Spectrum Disorder, (i.e., with intellectual or language impairment), another neuro developmental disorder, and known genetic or environmental factors have been added. Furthermore, DSM-5 has also included sensory disturbances such as hyper or hyposensitivity to sensory stimuli (e.g., excessive smelling or touching and visual fascination with objects) in its criteria. Different levels of severity, based on support needed, have also been mentioned in the new classification. In addition to ASD, a new category of Social Communication Disorder has been created in DSM-5 in Social Communication Disorder; there are persistent difficulties in the social use of verbal and nonverbal communication.

According to the American Psychiatric Association DSM-5 (2013) to be diagnosed as autism a child should show the following criteria clearly atypical and they must be presented across multiple contexts:-

A1. Deficits in social emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.

A2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated verbal and nonverbal communication, through abnormalities in eye contact and body language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.

A3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.

B1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypes, echolalia, repetitive use of objects, or idiosyncratic phrases).

B2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior or excessive resistance to change such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes.

B3. Highly restricted, fixated interests those are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed interests).

B4. Hyper- or hypo- reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

C. Symptoms must be present in early childhood (but May not become fully manifest until social demands exceed limited capacities)

D. Symptoms must together limit and impair everyday functioning. (American Psychiatric Association (DSM-5), 2013)

2.3. Mothers' Reaction to Child's Diagnosis with Autism

Mothers pass through challenging moments and react in various ways when discovering that their child has autism. The stressful period of time that parents go through can lead them to blame themselves for giving birth to a child affected by autism. (Lutz, Patterson, and Klein, 2012) conducted their study in United States focusing on mothers' responses to their child's diagnosis with autism, According to their findings, reactions of mothers to their child's diagnosis with autism were grouped into four major groups; grief & anger, disease and relationship, guilt and doubt, and disappointment and sacrifice (Lutz et al., 2012). The most common initial reaction of mothers at the time of diagnosis is feeling of sadness and anger highlighted by self-blaming.

Mothers also experienced psychological problems such as fear and anxiety during the initial stages of learning about their child's situation. The reaction of denial was reported by some parents as their first reaction to their child's diagnosis with autism while others reported experiencing feelings of shame when sharing the news of their child's situation to others

(Dababnah & Parish, 2013). In research conducted by (Samadi, McConkey, and Kelly, 2012) parents' immediate reaction after their child's diagnosis with autism was shock and devastation.

2.4. Challenges of Mothers in Nurturing and Caring Children with Autism

As research facts on autism indicates parents face challenges in nurturing their respective children with autism spectrum disorder (Bilgin & Kucuk, 2010). Autism is considered by many as the most severe childhood disorder with the most complex developmental patterns (Chamak, Bonniau, Oudaya & Ehrenberg, 2011). Caring for a child with autism can be challenging, extremely demanding and a severe stressor on family life (Gray, 2002). Such stressors could be the result of the ambiguity of the diagnoses, the severity and the duration of the disorder and the child's lack of adherence to social norms.

Studies on parent's wellbeing shows that parents who have a child with autism report higher levels of parental stress and psychological distress than parents of children without autism (Baker, 2000). Several factors have been proposed to account for the higher levels of stress of parents with a child with autism, including the uncertainty surrounding autism diagnosis, the long-term prognosis of individuals with autism, the stressful nature of autistic symptoms and associated behavior problems, and the lack of public understanding and tolerance for the behavior of children with autism Giallo, Wood, Jellett & Porter, (2011).

The findings of such studies show that most parents experience intense confusion before, during and after the period of diagnosis. Although the quest to help their child with ASD may alleviate some negative feelings, the stress increases when parents realize that there is no cure for autism (Altiere & Von Kluge, 2009). Hartley et al. (2010) have also found that parents of children with ASD experienced a prolonged period of vulnerability to divorce which in part is attributed to the constant high level of parenting demands and stress and subsequent lack of attention to one's spouse when raising a child with autism. "The significant higher prevalence of divorce among parents of children with autism is (23, 53%) than among parents of children without a disability (13, 81%)" (Hartley et al., 2010 p.143).

2.5. The Significance of Parental Participation in Treatment of Children with Autism

Bennett (2012) pinpoints the best treatment for children with autism is the need for parental participation. The importance of parental participation is shown in both policies and research. Traditionally, schools are considered as authorities in education. Nevertheless, The Salamanca Statement (UNESCO, 1998, p.37). states 'the education of children with special educational needs is a shared task of parents and professionals' Hence, it is not solely schools' but also parents' responsibilities to shared task with respect to support pupils with special needs. Bennett (2012) also indicates lack of parental participation could be harmful to autistic children's development due to incapability to support or meet the needs of children with autism.

Bilgin & Kucuk, (2010) mention over the years, numerous studies have shown that parental attitudes towards and involvement in their children's learning activities in the home and at school have an influence on children's level and quality of learning, development and attainment at all ages. Parental involvement undoubtedly has the significant impact in early years to shape a child's character and development; and the influence may continue to adult years. As Bennett (2012) points out parental participation has a positive effect on increasing developmental skills and progress in an early intervention program. A study by Baker (1997) illustrates the importance of parental involvement, highlight as many different opinions and perspectives as possible, and builds on the theory and practice regarding strengthening school-home partnerships.

Research has shown the benefit and influence of parental participation on both children with SEN and children without SEN. Researches over researches shown that the earlier and more parents are involved, the better and longer effects on children's development last. The advantages of parental participation are numerous. Firstly, from the perspective of development, it is beneficial and significant toward children's development. 'The involvement of parents in their children's education is now widely accepted as desirable and even essential to effective schooling' Kirsten Marie Jardine (2008) p 45. Academically, the influence of parental involvement in children's development has been demonstrated by different researches, for instance Kreuger and Neuman (2006) P. 68noted that "parental participation influence children's acquisition of reading has potentially great importance'.

Another study by the National Literacy Trust (McCoy & Cole, 2011) supports the viewpoint that 'Parental aspirations and expectations on their children's achievements have a strong impact on children's school results.' Secondly, parents generally have a better understanding than anyone else of issues affecting their children.

Parental involvement is beneficial for the pupils with special needs to clarify their learning as well as future paths. Keyser (2001) pinpoints that families know about family issues including family history, culture, or health whereas school has the knowledge of the school setting, development, and curriculum. Keyser (2001) states parents have the key information and play a significant role in children's education. Parents have the knowledge and experience to support their children; therefore, it would be more effective for both professionals and parents to include parental perspectives of their children's developments especially to children who have special educational needs. Furthermore, schools are not the only education provider. There is no doubt that schools are the places provided with well- equipped facilities and trained teachers to educate pupils yet school education takes solely a certain period of time whereas family's influence is lifelong particularly the period of the early childhood development. A study by Kellaghan, Alvarez & Bloom (2010) shows that before pupils reach eighteen years old, they spend thirteen per cent of time learning in school and the rest of the time about eighty seven per cent is influenced by family (Cited,2007). These figures suggest that only a small percentage of children's learning takes place in school and mostly the learning takes places in non-school settings.

2.6. Community Attitudes towards Children with ASD

Attitudes can be described as a "relatively enduring organization of beliefs, feelings and behavioral tendencies towards socially significant objects group's events or symbols" (Hogg & Vaughan, 2011 p.45).

In the past, individuals with disabilities such as autism have faced discrimination, isolation and segregation (Fazio, Sanbonmatsu, Powell, & Kardes, 2014). However, today, the national policy emphasizes that the individuals with disabilities should be treated equally by giving them access to education, employment, and community living.

Positive attitudes towards individuals with disabilities are critical to succeed in all aspects in the society. Public attitudes have the potential to encourage interactions between individuals with disabilities and the general public (Ryan, 2013).

A study conducted by Marsena Williams, (2012).found that although 95% of respondents recognized the name of autism, schizophrenia and bipolar disorders, however, less than 70% can report specific characteristics. This study also indicated that most public attitudes and behaviors towards different disorders appear to be based on assumptions rather than knowledge or evidence. The study highlighted that the stigmatization of individuals with mental disorders can be changed with certain alterations in mental health literacy Marsena Williams Webb, (2012).

In another study Individuals were given an explanation of autism, or simply told that the individual they were responding to had an autism disorder, they had a more positive response Sameroff, A. J., & Fiese, B. H. (2000). On the other hand, university students showed high levels of stigmatization towards individuals on the spectrum, which consistently increased as the severity of the autistic behaviors increased (Campbell, 2007).

There are several factors that affect the attitudes of people towards individuals with disabilities. Among the factors highlighted by Tiffany Wiggs, (2010), in his study is the perceived causality of the disability, gender, age, education and social desirability. Source of information is also important to offer more accurate information about autism.

However, not all the attitudes towards autism are so positive. It is common that the disorders of any kind such as autism will have certain stigma (Marsena Williams Webb, 2012).Like autism, since the autistic children look like ordinary people, therefore, people who could not understand them often see these children as selfish, slow and odd (Mailick Seltzer, 2010). Study conducted by Anthony, J. H. (2009) Discovered that there is a big lack of awareness about autism among people and something needs to be done to raise this awareness.

2.7. Special Educational Needs for Children with Autism

In the educational setting, children diagnosed with an ASD needs support services to help them interact with others both socially and academically when it is determined that their ASD is affecting their learning.

Historically, children with disabilities have been educated apart from the rest of their peers and excluded from the society as adults (Karagiannis, Stainback & Stainback, 1996). The last couple of decades this segregation has followed a decreasing course and more and more students with disabilities, in general, and with ASD, in particular, have been included within the mainstream classrooms, together with their non-disabled peers. This turn in the educational practices was the result of progress in the field of education, as new evidence for the effectiveness of more inclusive methods, came to light (McDonnell, 1998).

The advantages for the children with ASD, when they are taught in inclusive classes are manifold and are concentrated in two main categories: 1) the cognitive/academic category and 2) the adaptive/social category (Ferrraioli & Harris, 2011). Children with ASD have showed significant development in their IQ level, in their communication and socialization skills, as well as in their play expertise. Moreover they achieve more advanced goals in their individualized educational plans, than their peers who continue their studies in segregated classrooms (Harrower & Dunlap, 2001). Improvement in their adaptive skills and social competence were also reported for the children with ASD studying in the inclusive classrooms. Their social interaction length was increased, their play and conversation initiative was boosted and they displayed high language engagement and joint attention (Ferrraioli & Harris, 2011).

Another component that contributes greatly on the success of the inclusion of the pupil with ASD in the general education environment is the use of appropriate instructional methods (Boer S. R., 2009). According to Boer, there are proven teaching techniques, intervention methods, and curriculum and environmental accommodations that can be used to enhance the ability of a pupil with ASD to receive and learn from instructions provided in the general education classroom. Boer explains that these are pupils who are first and foremost needed to “learn how to learn” in order to function appropriately in the general education classroom. Therefore, the teacher and the

Para-educator need to understand the types of teaching methods that have been used successfully in the special education classroom to enable the pupil to learn and progress more easily.

Within the school setting, an IEP is developed for a student with autism when it is demonstrated that the student's disability is affecting his or her learning and ability to achieve academically without supports. The Individualized Education Plan (IEP) for students with autism must address needs as identified by the team which may include, as appropriate, the verbal and nonverbal communication needs of the child; social interaction skills and proficiencies; the child's response to sensory experiences and changes in the environment, daily routine and schedules; and, the need for positive behavior supports or behavioral interventions (Harrower & Dunlap, 2001).

Some services that a child with autism may receive in the school are assistive technology. Assistive technology service is defined as "any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device"(Harrower & Dunlap, 2001, p.81). An assistive technology device is defined as an "item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a child with a disability" (Harrower & Dunlap, 2001,p.45)

When a child with autism is in need of services as determined by the school, the determination needs to be made as to which type of services and how much of those services are appropriate. Autism support services can be carried out in the general education setting exclusively, in both the general education classroom and autism support classroom combined, or the autism classroom only Boer. S (2009). These autism support placements can be itinerant, supplemental, or full time. Itinerant support consists of special education supports and services that are provided by special education personnel for less than 20% of the school day.

Special education resources should be protected and continually provided for pupil with ASD who is being included in the general education classroom. Boer. S (2009), explains that the special educator, who is designated as case manager for a particular pupil with ASD, must have time to do the following; observe the pupil in the class; meet with the general education teacher and the Para educator; develop materials the pupil with ASD may need; and assist in making accommodations and modification to the curriculum in general education classrooms. This

research explores the lived experience of mothers regarding the response of the schools/ foundation towards the special educational needs of children with autism.

2.8. Relevant International and Domestic policy, Legal and Programmatic Instruments that promote the Basic Needs and Rights of Children with Disability

2.8.1. International Frameworks

According to the United Nations (UN, 2007) estimates, there are more than 600 million persons with disabilities throughout the world, 70% of them in developing countries. Disability is caused by diseases, malnutrition, incorrect treatment or non-treatment, physical or mental violence and war, accidents due to inadequate protection at the work place and in traffic situations, and, increasing, age-related diseases.

Today, we live in a world of constant change: everyday life demands an ever- increasing knowledge base and ability to master new technological and technical skills. Education and training are thus becoming more and more necessities and therefore should be intrinsic rights of citizens. The basic interrelated ideas of education included or outlined in international policy documents, declarations, conventions, framework of actions, forums all confirm these rights to education:

The Universal Declaration of Human Rights (1948): States that everyone has the right of equal access to public services in general and education in particular, and establishes the principle of free basic compulsory education for citizens to support the full development of human personality, and to strengthen respect for human rights and fundamental freedoms.

The Convention on the Rights of the Child (1989): Recognizes special needs. It establishes extended assistance, free basic education, and effective access to basic services, education, preparation for employment and recreation opportunities for children and youth with special needs in a manner conductive for the children and youths to achieve the fullest possible social integration and individual development.

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993): Recognizes the principle of equal primary, secondary and tertiary educational opportunities for children, young people and adults with special needs in an integrated setting; the education of

persons with special needs as an integral part of the education system. It establishes appropriate, adequate and accessible support services to accommodate educational provisions for persons with special needs in an inclusive setting.

The Salamanca Framework for Action (1994): Focuses on the right of all children including those with temporary and permanent needs for support and educational adjustment to attend schools in their home community in inclusive classes. Above all, it emphasizes the right of all children to participate in a quality education that is meaningful to all, at inclusive schools using a pedagogically sound learner-centered approach, to provide the enrichment and benefits that could be derived through implementation of inclusive education.

The World Education Forum (2000): This is about making the right to education a reality as it is enshrined in the 'Universal Declaration of Human Rights, 1948'. It is the extension of 'Education for All' movement.

The Convention on the Rights of Persons with Disabilities (CRPD) in (2006): Fundamental rights for all people with disabilities, education and employment are regulated in Articles 24 and 27 of the CRPD and are key areas for the social inclusion of persons with autism.

The UN Convention on the Rights of Persons with Disabilities (2007): This Convention endeavors to elaborate in detail the rights of persons with disabilities and set out a code of implementation.

2.8.2. Domestic Frameworks

According to the Education and Training Policy (1994) children and students with disabilities are among the disadvantaged groups entitled to receive special support. The Policy, however, lacks clarity in terms of special needs education and, therefore, special needs education has not been included in the ESDP. The Special support mentioned in the policy requires strategic planning, definition of priorities, objectives and responsibilities to be realized in practice. (MOE, 2004)

There are no reliable data available on inclusion or exclusion of disadvantaged groups in education. Until now, planning, data collection and statistics have failed to consider a large minority- that of children and students with disabilities or learning difficulties. According to international estimates 10- 20% of any school age population has special educational needs (ILO,

2004; Peters 2003; Wiman & Sandhu, 2004). In a school age population of over 15 million in Ethiopia (MOE, 2004), there may be 1.5 to 3 million children who have disabilities; or gifted and talented students who require special attention.

In order to achieve the objectives of the Education and Training Policy (1994) special attention has to be paid to children and students who are at risk of repetition and drop out, have learning difficulties or disabilities. Along with the increasing enrolment rates, but remaining and increasing dropout rates, it is high time to include special needs education as an essential component in the overall education sector development. Other African countries have successfully started in doing this, being committed to changes from policy to practice, e.g. Uganda, Zambia. (Daniel, 2003)

The Transitional Government of Ethiopia (TGE) ratified the United Nations Convection on the Rights of the Child in (1989) and The Constitution of the Federal Democratic Republic of Ethiopia (FDRE, 1995) stated that all international agreements ratified by Ethiopia are an integral part of the law of the land (Article 9 (4)). In order to address the right to education, the FDRE has developed an Education and Training Policy in 1991 (FDRE, 1994) which stated the nature of education and training in Ethiopia. The Government continued its effort to educate children by committing itself to the international and national declarations, policies, legislations and strategies. The Education for All, (UNESCO, 1998; 2000), the United Nation‘s Millennium declaration on Millennium Development Goals (UNESCO, 2000) and the Ethiopian Government Education Sector Development Programs (ESDPs I, II, III, IV, V) are worth mentioning

Today, in many countries the rights of children with disabilities have acceptance in the human right code, which allows the right to education without discrimination. For example, in most developed countries, a manual of special needs education regulation and policy requires that each school board to provide appropriate educational services in the least restrictive environment (Winzer. 2005). Moreover, Melcher cited in Boone, (2005) explained that legislation should provide by law for establishment of district schools which shall be free to all children or young people. For instance, in the American public law 94-142, the education for all “children with disabilities’’ act is the most comprehensive educational legislation, which guarantees free education for every child with disabilities. In the Ethiopian situation access of special needs education requires more effort and commitment though, the new education and training policy

(MoE, 1994) is committed to address universal Basic education by the year 2015 (ESDP IV, 2010/11)

All schools (centers) are required to operate within the parameters of the national educational goals to overcome problems at "implementation stage. Government in a given country should play main role in the formulation and monitoring of the implementation of educational policies. Particularly the ministry of education is legally mandated to illuminate the existence of diverse educational need cooperating with non-government organizations. Concerning this, the Ethiopian Education and Training policy (MoE, 1994) clearly explained the need for the provision of education for all children with special needs. Moreover, this policy confirms the importance of early childhood (Pre-school) for all- round development of children and in preparing for formal schooling (Education structure 3.2.1). Thus, the policy has confirmed to address the needs of children with disabilities to provide special education and training in this level.

To fulfill an individual with special needs education, effective educational program management according to local conditions either by decentralizing planning or by delegating wide authority in implementation programs is crucial to attain intended goals. For example, in United States of America legislative policies require that each state and local educational agency to ensure an individual based program for each child with disabilities (Lawson, 1991). However, this situation is very difficult in Ethiopian context because of scarce resources.

Unit Three

3. Research Method

3.1. Research Design

This study explored Lived experience of mothers having children with autism. Qualitative research method is selected for this study aimed at acquiring "in-depth understanding about a certain phenomenon through exploration instead of measurement" (Bernard, 2008 P.69). The focus of qualitative research is to find explanations for questions such as 'what', 'how' or 'why' of an occurrence (Green & Thorogood, 2014, p. 5-25). Qualitative research investigates a phenomenon considering the context of people's everyday lives. It attempts to understand and explain the world from participants' points of view (Draper, 2004). Qualitative research does not intend to obtain absolute objective findings from the study (Swift & Tischler, 2010).

One of the approaches in qualitative research is phenomenological approach. Phenomenological research design was implemented for this study. The reason why this approach is chosen for the purpose of this study is due to the fact that the lived experiences of individuals as a phenomenon will be described by the individuals themselves (Creswell, 2014). In other words, this approach is suited for the study that intends to acquire the experiences of mothers having a child with autism as viewed by the mothers themselves.

As confirmed by Creswell (2007), a phenomenon in a phenomenological study is a variable which is experienced directly, rather than being conceived in the mind as some abstract concept or theory that stands in need of explanation. Therefore, the reaction of mothers in one hand, the response of schools, the attitude of the community and siblings treatment on the other in terms of the views of study participant mothers were assessed as phenomena (variables) that are in need of explanation as experienced directly by the mothers of children with autism and the conclusions about these phenomena were presented in this study.

3.2. Description of Research Site

The study was conducted in seven purposively targeted foundation/regular schools where relevant care and support services for children with autism and/or special needs education units are operational respectively. These are Nia Foundation, Bashewam kindergarten school, Betefiker Kindergarten School, Kokeb Thebha primary school, Gulele Fana primary school,

Yekatit 23 Primary School and Edeget Primary school. The reason why these institutions were selected for the study was that specialized service for children/students with autism spectrum disorder have been made available for a years. In addition, Nia foundation and the other regular schools stated above succeeded relatively in enrolling a number of children with autism spectrum disorder compared to other regular schools. Among these regular schools; Kokebthebha primary school, Gulelefana primary school, Yekatit 23 Primary School and Edeget Primary school are government schools. Bashewam kindergarten school and Betefiker Kindergarten School are privately owned schools and also have preschool educational services. The targeted foundation/schools are situated in the following 5 sub cities of Addis Ababa Administration: yeka sub city, Kolfekeranio sub city, Addis Ketema sub city, Bole sub city and Nifas Selklafto sub city.

3.3. Research Participants

The only legitimate informants in phenomenological research are those who have lived the reality or those who passed through the experience related to the targeted thematic issue of the study (Creswell, 1998). Hence, the recruitment process was directed at selecting individuals who had lived experience of being a mother of a child with autism. The study illustrated the Lived experience of mothers having children with autism. Therefore, the target participants were identified based on the following criteria:

- Biological mothers having children with autism spectrum disorder;
- Guardian mothers of children with autism spectrum disorder;
- Mother or Guardians having “preschool age” and above children with autism spectrum disorder;
- Mothers or Guardians having children with autism spectrum disorder who sent their children to school;
- Mothers or Guardians who are willing to be part of the study and share their experience;
- Mothers or Guardians having diagnosed children with relevant professional as autism.

3.3.1. Sampling

Purposive and snowball sampling were employed to identify the respondents who have been living the experience in caring their children with autism spectrum disorder. As confirmed by (kreuger and Neuman, (2006 P.34) "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".

The other sampling used in the study was Snowball sampling. This sampling mechanism was applied while asking the participants purposively recruited to identify more individuals that could also be information-rich by possessing same experiences for the study's interest. It is believed that using this type of approach to sampling enables researchers to identify a greater number of individuals affected by the phenomenon and also yields rich information about the social networks, grassroots of the individuals involved in sampling (Noy, 2007).

This has been accomplished by accessing participants through Nia foundation and regular schools where the relevant support service is operational. This has been found the easiest and more effective method of finding mothers having children with autism spectrum disorder.

3.3.2. Sampling Size

Sample sizes in qualitative studies are often determined on the basis of theoretical saturation (Englander, 2012). It is believed that small sample sizes are the norm in phenomenological research design as the analysis of large data sets may result in the loss of potentially subtle tones of meaning (Collins & Nicolson, 2002).

In addition, phenomenological studies are not interested in 'how many?' who have had a particular experience, but how many times the phenomenon makes its presence in the description (Giorgi, 2009). Hence, for the purpose of this research, a total of 15 mothers and guardians having children with autism spectrum disorder were recruited and participated as key informants.

These mothers or guardians were required to be the ones who sent their child with autism spectrum disorder to targeted schools or foundation where special needs education units or relevant services are made available respectively. The intention of these criteria is to probe the

opinions of the respondents on the inclusiveness of the learning environment of the targeted foundation and school.

3.4. Data Collection Tools and Procedure

The Data used for the purpose of the study was collected using various data collection tools. Accordingly, face to face interview was employed to garner information from key informants. Semi structure interview guide was prepared with a view to maintaining the consistency of the interview. The approach of phenomenological research itself facilitates the interviewees to be active participant and expert in their own life, validating their knowledge and contributing to the research process (Gill & Liamputtong, 2009).

The interview was intended to be semi structured due to the following relevant reasons.

- Semi-structured interviewing allows the researcher and participant to engage in a dialogue whereby initial questions are modified in light of the participant's responses.
- The investigator will be able to probe interesting and important areas which arise from the discussion.
- It facilitates rapport/empathy.
- It allows a greater flexibility of coverage.
- It allows the interview to go into novel areas, and it tends to produce richer data (Smith and Osborn, 2007).

The interview conducted with all key informants was recorded by digital recorder and it was translated into text to facilitate the process of compilation and analysis of the information gathered from the interviewees. The questions postulated in the semi structured format were carefully organized in 5 thematic/focus area.

The interview guide was originally prepared in English and translated into Amharic for the convenience of the conduct of the interview assuming that interviewees will not be English speakers. Thereafter, back translation from Amharic to English was also carried out with an objective to ensuring the clarity of the questions used for the interview.

Respondent Mothers were asked to give responses on questions related to:

- Demographic data of their respective child and themselves such as gender, current age, age of child when diagnosed as autism, occupation, academic qualification and socio economic status/ background; and
- Their lived experiences of raising and taking care children with autism and the challenges they encountered in integrating their children with the local communities and schools.

The interview conducted with two mothers having children with autism among 15 interviewees was selected and used to prepare case story with a view to resonating the lived experience of mothers/guardians of children with autism in the context of Ethiopia.

3.5. Data Analysis

The analysis was carried out based on the thematic areas organized in interview guides as leading questions in reference to the response of respondent mothers. Accordingly, the responses of interviewees was described under each thematic area using descriptive approach which is highly relevant for interpretative phenomenological data analysis method as stated in the research design section of the research.

With regard to these approaches, Joana and Alison (2016 p. 130) indicated that "phenomenological analysis is an appropriate method of analysis where an issue is personal and it is able to contribute to understanding an area of interest through a deeper, more personal, individualized analysis".

The discussion points or questions were clustered into 5 themes and addressed by the participants of the study and illustrated with exemplify extracts from the interviews on participants own words followed by analytic comments from the researcher in writing the results.

According to Creswell (2007, p. 74), "using interviewees own words to illustrate themes enables the reader to assess the pertinence of the interpretations, and it retains the voice of the participants personal experience."

This is a process of getting the essence of the meaning expressed in a word, phrase, sentence, paragraph or significant non-verbal communication in which crystallization and condensation of what the participant say was done by still using as much as possible the literal words of the study participants.

In addition, in this study, two coherent case stories were prepared with a view to finding all possible meanings, commonalities and divergent perspectives. With regard to these Green, & Thorogoo, (2014, p. 5-25) Indicated that "A case story helps to investigate a problem, examine the alternative solution and propose the most effective solution using supportive evidence".

3.6. Ethical Issues

Ethical standards were maintained in the course of the research paying careful attention to issues of consent, confidentiality, anonymity, potential vulnerability, and sensitivity. As (Rubin 2005, p.78) says "researchers should carefully study codes of ethics and cases of unethical behavior to sensitize him/her to situations in which ethical commitments become particularly important". The study participants were adequately informed about the purpose of the study and it was on the basis of their informed consent that all interviewees were engaged in the interview. According to Draper (2004), obtaining informed consent for a research study requires open and honest communication between the researcher and the study participant. In this study, the participants were notified about their 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.

Furthermore, the interviewees were well informed about the confidentiality of the information they provided and the fact that their privacy is fully respected. In accordance with Janet Boddy (2013, P. 54), "The confidentiality of information supplied by research subject and the anonymity of respondent must be respected". Concerted effort was made to respect and facilitate the privacy of the participants. To this effect, the researcher did not call names during the interview and the participants of the study were not allowed to describe their name while responding to the question and the names mentioned on the research document are pseudo names. In addition, all information recorded on the digital recorder was deleted after the research document has been accepted and approved.

Chapter Four

4. Results

This study aims at exploring the lived experience of mothers having children with ASD. Accordingly, this chapter presents the main research findings obtained from the semi structured interview process with the mothers to discover the lived experience of the participants, which was combined with the researcher's data analysis or exploration of their experiences. The key findings of the study have been presented by three sections:

- The profile of the participants
- The mothers lived experience categorized in five thematic areas and
- Two case stories

Table 1 Profile of the informant

No	pseudo name of interviewees	Parental Status	Marital Status	Age	Level Academic Qualification	Mother's Occupation	Child Age	Child diagn-ostic age	Child Sex	Child Grade	Number of Sibling		Name of School/ Center
1	. Hareg	Biological mother	Married	33	BA Degree	Accountant	4	3	Male	Kg 1	Male Female	1 0	Betefiker School
2	Bertukan	Biological mother	Married	36	Elementary school complete	Cleaner	10	3	Male	2	Male Female	0 2	Yekatit 23 School
3	Yemsrach	Biological mother	Married	41	Illiterate	Boiled Coffee seller	7	3	Female	Kg 5	Male Female	2 1	Betefiker School
4	Ewket	Biological mother	Single	31	Certificate	Chef	5	3	Female	2	Male Female	1 1	Kokebetshiba School
5	Belaynesh	Biological mother	Married	34	Elementary school complete	House wife	7	3	Female	1	Male Female	0 1	Edeget School
6	Meskerm	Biological mother	Married	39	High school complete	Merchant	13	3	Female	4	Male Female	1 1	GuleleFana School
7	Yenenesh	Biological mother	Married	43	BA Degree	Designer	10	4	Female	2	Male Female	0 2	Bashewam School
8	Kidst	Guardian mother	Married	37	Diploma	Nurse	8	3	Female	1	Male Female	2 1	Yekatit 23 School
9	Zeynba	Biological mother	Single	35	High school complete	Singer	7	2	Male	1	Male Female	1 0	GuleleFana School
10	Bethalem	Biological mother	Married	39	High school complete	Merchant	6	4	Female	Prep	Male Female	2 0	Bashewam School
11	Helen	Biological mother	Married	36	Elementary school complete	Housewife	11	3	Female	3	Male Female	1 3	Kokebetshiba School
12	Hewot	Biological mother	Single	35	Bachelor Degree	Hotel manager	9	4	Male	2	Male Female	0 1	Bashewam School
13	Hana	Biological mother	Single	40	MA Degree	Bank Manger	17	5	Male	5	Male Female	2 1	Kokebetshiba School
14	Roman	Biological Mother	Married	34	Diploma	Tailor	10	3	Male	2	Male Female	1 1	Nia Foundation
15	Maceda	Guardian Mother	Married	34	High school complete	Merchant	13	3	Male	3	Male Female	1 1	Nia foundation

4.1. The lived Experience of Mothers Focused in Five Thematic Areas

4.1.1. Mother's Reaction for Diagnosis of their Children with Autism

The first organically linked questions delivered to the interviewee mothers were directed towards exploring the information about when and how they observed strange behavior on their respective child that urge them to take action, and their feeling and reaction to the detection of autism spectrum disorder in their children.

In their response, a total of 11 respondent mothers noted that they observed bizarre behavior on their children which was not familiar for them that enabled them to suspect something wrong near to be diagnosed by physicians. They further explained that they recognized how their children behaved or responded to his/her environment differently compared with their peers without disabilities. These respondent mothers confirmed that they were able to be aware of such strange behavior of their respective child at the age ranging from 12 to 18 months to as late as 2-years-old or 24 months. A total of ten respondent mothers confirmed that they were the first in identifying the odd behavior of their child and took initiative and address the problem through taking their child to the health centers for further diagnoses. However, the rest five respondent mothers acknowledged that the problem of their children was identified by others such as fathers, teachers and friends. It was on the basis of the information gained from their partners that these mothers were able to take their children to the health centers seeking the remedy for their children.

All Mothers demonstrated a range of emotions immediately following the diagnosis, the most salient feeling experienced by mothers was despair, sadness and being overwhelmed by the news. After they receive the diagnosis report 13 respondents confirmed that they didn't receive support from professional from the hospitals. As the mothers stated they didn't get useful information, direction and guidance about how they should handle their child behavior, where to go and what to do. One of these respondent mothers, Hareg explained the situation how she observed, or be aware of unfamiliar behavior on her child and her reaction after the diagnosis and the approach of the professionals in the hospital as follows:

While my child was 2 years old, I have detected strange behavior on my child which was different from his siblings. I have tried to share my concern to my husband regarding the problem that I have observed on our child. Unfortunately, my husband couldn't share my worry arguing that he is kid that he may exhibit such strange behavior which is a common characteristic of young children. Regardless of such argument of my husband, I have decided to take our child to the health center and find out the appropriate response and support for my worry and the problem of my children respectively from the right physician. The result of the diagnosis depicted that my child has ASD. When I was informed by the doctor about the real problem of my child, I was totally found in dilemma on the way forward. I understand that I had suspicions about the problem of my child before the diagnosis, but when I was informed by the doctor about the situation of my child, it was really painful and difficult to accept the reality. We had a diagnosis but we had nothing else, absolutely nothing else. We weren't being referred on to anywhere else. We were just being told our child had this condition and that was it. And they couldn't tell us how it was going to progress. They couldn't tell us how they were going to treat it.

4.1.2. The Main Challenges of Mothers in Nurturing and Caring Children with Autism

The other question rendered to respondent mothers was directed towards challenges of mothers in nurturing and taking care of children with autism spectrum disorder. In their response, respondent mothers underscored that they have come up with several challenges related to nurturing their children with autism including managing the day to day activities of their children through providing necessary care and support for them.

The respondent mothers unanimously confirmed that nurturing children with ASD is complicated and challenging. Among the study participant mothers, 11 interviewees concerned that the condition that they were required to over protect their children with autism forced them to have tight schedule and pass through hectic life being overburdened by extra responsibility's and duties needs to be fulfilled for the sake of the safety of their respective child with autism. These Mothers further illustrated the situation that they were always found in state of anxiety and fear due to the inability of their children with autism to respond to their environment properly.

They had strong fear that their children with autism might have been abused by home servants and even the siblings at home and members of the local communities including their peers without disabilities due to their strange behavior. Among those study participant, 4 mothers having children with autism witnessed that they were forced to reach a decision to leave their job and stay at home with an intention to taking care of their respective child with autism. They further reported that this situation isolated them from engagement in community life and work that adversely affected their interpersonal/ social interactions and income or economic status respectively. They still believe that their children require intensive care and mothers naturally closer to them even other than the other members of their families.

In addition, a total of 12 respondent mothers illustrated another aspect of the challenge related to their children with autism that they could not pay proper attention to their husband and the remaining children without disabilities due to the reason that they have been urged to give more time to take care of their children with autism. As a result, 4 interviewee mothers reported that they were forced to get divorced without their willing and consent. However, 3 of them argued that they didn't encounter such challenge from their family including their husband. All respondent mothers employed the specific question whether they enjoyed appropriate support from their respective husband in the process of taking care of their children with autism. In their response, 9 respondent mothers reported that they didn't obtain support and encouragement from their respective husband. Whereas, the remaining 6 interviewee mothers acknowledged that they significantly benefited from the support of their respective husband in the course of provision of care and treatments for their respective child with autism.

Likewise, a total of 13 respondent mothers express their feeling and observation that their siblings didn't have positive attitude towards their sisters/brothers with autism that complicated and aggravated the challenge of these respondent mothers.

4.1.3. The Mothers' with ASD Children Social Support from the Community

The other question delivered to the informant focused on the social support from the community towards children with autism spectrum disorder. The answer of the respondents indicated that the societal response to at least targeted children with autism was both negative and positive.

Accordingly, 7 participant of the study did feel that they experienced positive response from the community towards their children with autism. They further argued that the community they lived in consistently show sympathy and love to their children with autism spectrum disorder. They did believe that the treatment of the community in favor of their children with disability through various cultural norms had a positive message to them against the existing negative attitude of the society towards the disability. Among these respondents, Bethalem firmly explained the situation as follows:

> *I didn't face serious challenge that the community didn't offend me in relation to the situation of my daughter with autism. My friends, relatives, colleague and the like are not aware of the impairment of my daughter: however, no one negatively treated my daughter or affected my feeling and emotion advertently or inadvertently. Especially my neighbors were highly cooperative in assisting and encouraging me in the last 5 years in treating my daughter with autism. They even played a leading role in integrating my daughter with their children without disabilities and play with her peers in harmony and a sense of intimacy. Finally she confirmed that this situation enabled her to develop confidence and hope on the future career of her daughter with autism.*

With regard to the other aspect of the response/attitude of local community's towards children with autism, the remaining 8 respondent mothers argued that they have been experiencing painful discrimination and exclusion of their children with autism with the local community they live in. These mothers further reported with intense feeling that they have forced to pass through traumatic experiences of social exclusion regarding their children with autism. However, they did believe that the exclusion of their children and its adverse effect was attributed to negative attitude of people towards children with autism in particular that seriously adversely affected the life and stability of families of these children.

These mothers pinpointed that the exclusion their children by the society was manifested through different ways, directly and indirectly as described in the case story one. One of these respondent mothers explained that the impact of these negative attitudes of the community affected not only the behavior their children with autism, but also it forced the families of children with autism mainly mothers to keep their children with autism at home.

Helen reported that she often assume that people may mistreat her child with autism, and for this reason she prefers to keep her child at home. She further explained that she had never given opportunity for her child to attend social events with her for fear of negative response and prejudice of the community to disability in general.

The other respondent mother, Yenenesh reported that:

> *Within the general public, autism and "Intellectual disability" are understood as the manifestation of abnormality. I did feel that almost all member of the community consider the unique behavior of my daughter with autism as deviate without regarding the impact the impairment to her unique behavior. Most of the advises forwarded by my friends, neighbors and relatives were intended to urge me to take my daughter to witchcrafts or holy water for healing and remedies considering her impairment as insanity. Even though such opinion of people is annoying, I have understood that these approach of the community is the typical example of traditional belief and practice entrenched within the widen part of the society. It has been heartbreaking experience to me that some people systematically avoided and repulsed my daughter not to be integrated and play with their children without disabilities assuming that the impairment of my daughter is contagious. The other painful challenge that I have encountered was that one of my intimate friends unscrupulously told me that my daughter with autism was the result the punishment of God against my wrong deeds or sin.*

4.1.4. The Mothers' with ASD Children Support from Schools

Education is a major concern for mothers of children with autism especially in relation to their enrollment and continuation of their study at preschool and primary grade levels respectively.

Hence, a question was delivered to the targeted informant mothers what they experienced in facilitating their children with autism to access education. In their response, 13 respondent mothers reported that they encountered serious challenge in finding public and privately owned schools where special needs education units having teachers trained in special needs education are operational.

They further noted that even in the schools where special needs education unit are operational, the situation for the enrollment of children with autism was difficult and challenging. These respondent mothers explained that there are a number of responses that obstructed the enrollment of their children with autism in schools where appropriate and relatively better facilities such as small class size, neat compound, qualified teachers etc. are available. These include:

- Limited financial capacity of families having children with autism to afford the school fee and other related costs;
- Attitudinal and institutional barrier that disregarded the special educational of learners in general and children with autism in particular; and
- High competition among new entrants due to the scarcity of space in the schools where better facilities are available.

Alongside with those general problems, these respondent mothers further reported that they have been obliged to hire personal assistant for their respective child with autism as a requirement and commitment for the enrollment of their children in the regular school. It is obvious that these procedure of the schools resulted in financial constraint that seriously disturbed the effort of parents to facilitate their children with autism to get access to education. It is possible to infer that these problems did exist due to lack of appropriate service and support on the part of the government in regular school system.

The other question out brought for the study participant mothers was which educational modality they prefer for their children with autism spectrum disorder. In their response, 2 respondent mothers preferred to send their children with autism to regular school where special education units are operational. The other 5 respondent mothers also had a choice for their children with autism to join special schools where specialized services are available. The remaining 8 study participant mothers preferred their children with autism to be integrated in general class settling and attend their study with their peers without disabilities. As part of their choice the modalities stated above, the study participant mothers explained the reasons why they preferred those approaches as follows:

Mothers who preferred special schools and regular schools where special needs education units are operational for the placement of their children with autism argued that their children will have special unit class are the right place for learners with special educational needs in general due to the availability of specialized services and teachers trained in special needs education and adaptive skills. But, they unanimously acknowledged that their children may be poor in their social communication skill.

One of these respondent mothers, Maceda presented her past experience as concrete evidence which she used to justify her argument why she preferred special school to her child with autism as follows:

> *I have found difficulty to get my child in regular school system attend his study with his peers without disabilities. My child started his academic career in integrated class attending his study with his non-disabled peers. However, shortly his non-disabled peers could not understand his unique behavior, and finally marginalized and accused him as a disturber of the class. As a result his class mates unanimously applied to the school management requesting my child to leave the class and if possible the school too. Thereafter, I was forced to admit my child to the other nearby private school. Unfortunately, the same challenges that he experienced in the past forced him to leave the school within 6 months. Finally, I was able admit him in special school called Nia foundation established to provide specialized service for children with autism As of his admission to this center, my child has been enjoying special care and support responsive to his unique or specific need. Hence, I feel that special schools having relevant support services including qualified professionals are far better to accommodate the special educational need of children with autism.*

Likewise, respondent Mothers who preferred integrated class for their children with autism argued in different ways. They did believe that regular schools where integration as an approach for teaching of students with disabilities is applied would provide better opportunity for children with autism to develop gradually their social communication skills in the course of their academic career and interaction with their non-disabled teachers and peers respectively.

They farther argued that the more children with autism are facilitated to enroll in separate or special schools; they will get excluded within the community they live. In fact, these respondent mothers acknowledged that the non-availability of professional support in integrated class settings might affect the academic performance of their children with autism.

One of these participants mother's, Ewket explained her lived experience as a wittiness for their argument is presented below:

> *It was on the basis of mutual consent reached between me and my husband and conviction that our child with autism was admitted in regular school to attend her study with her non-disabled peers in integrated class setting. I personally believe that inclusive learning environment is preferable for my child with autism who is in need of support and love from her non-disabled peers. Before joining the school, my child had no opportunity to play with non-disabled peers. As a result, she was not willing to be integrated with non-disabled children due to their negative response to her impairment. It was after joining the school that my child showed progress in avoiding her former loneliness being gradually able to interact with her classmate. Even though my choice is inclusion, I am highly disappointed with the non- availability of professional support and appropriate concern on the issue of disability in general in regular schools where students with autism and other impairments have been attending their study in integrated class settings. No one, including SNE professionals invited me to discuss about the situation of my child.*

4.1.5. Mothers Expectation about the Future Life Career of their Children with Autism

The final general question delivered to respondent mothers focused on investigating their insight about the future life career of their children with autism spectrum disorder. The response of study participant mothers indicated that although their children with autism are too young in their age, they deeply worry and ponder about the implication of the disorder of their children in relation to their future life career.

In the interview conducted with the respondent mothers, the researcher tried to explore the overall insight of mothers about the future final academic achievements of their children with autism raising relevant and probing questions. In their response a total of 10 study participant

mothers having children with autism did believe that their children will be functionally literate. However, these respondent mothers reflected their strong doubt that there is no feasible possibility for their children to be educated and then professional due to the impact of their impairment. These mothers further believed that educational empowerment of their children with autism being literate would enable them to lead their independent life in the future.

In contrary, the remaining 5 respondent mothers did believe that their children with autism have a capacity and potential to succeed in their academic career at secondary, preparatory and even tertiary grade levels. The academic success achieved so far by their children was used as evidence for the point of argument of these mothers.

Finally, all study participant mothers were asked about their aspiration regarding the future life of their children with autism. Among the study participants, 3 mothers did hope that the impairment of their children will be cured by spiritual remedy including miracle and the use of holy water. They further did aspire that their children will get married and have children through leading their independent life.

The majority study participants, (12 mothers having children with autism), however, did hope that their children will be integrated into community life they live in through improving their daily functional skills including the enhancement of their interpersonal and social interactions through supporting them to pass through various hard on experiences and therapies.

One of these respondent mothers, Zeynba presented her aspiration concerning the future life of her child with autism as follows.

> *Currently, my child has been attending his study at grade 1 level. In fact, he is not yet able to appropriately read and write alphabet. But his progress on developing his skill and knowledge in reading and writing of alphabet is encouraging. I can imagine that he may not join secondary school or higher education due to the severity of his impairment but I would like him to be literate in reading and writing and developing functional daily living skills mainly interpersonal and social interaction abilities. Because, presently I am taking care of him, but I will no longer be with him in the future. it is obvious that when I am getting old, my child will be left alone without my assistance. Hence, I wish for my*

child to be capable in leading his independent life at his early age and exercise it with confidence and the spirit of self -reliance.

4.2. Case Stories

The following cases stories are prepared with an intention to present additional and concrete information/evidence for the thematic issues discussed in relation to the lived experience of mothers/guardians having children with autism.

4.2.1. Case Story One

Yemsrach Endalkeshew, was born in 1978 in Addis Ababa City Administration. Her father was a carpenter and her mother was a school cleaner. Yemsrach faced drop out from schooling after completing her study at grade 7 due to the reason that she was forced to be engaged in world of work to earn income for her family. In her early age, 22, Yemsrach married and got birth to children without disabilities. In 2012 Yemsrach got birth another and the third child. Unfortunately, she lost her husband by car accident after 6 month of the birth of the child. It is obvious that, following the death of her husband, Yemsrach was forced to overcome the economic problem of her family through earning income being engaged in daily labor work. Hence, she started traditional cooked coffee vending.

As Yemsrach reported, she noticed strange behavior on her daughter (the third child) shortly after the second birthday of her young daughter. She observed that her daughter delayed in developing social communication skills such as playing independently with her kindred peers. Yemsrach farther more detected that her daughter becomes overwhelmed with loud noise and crowd. But the observation of Yemsrach was not accepted by any one; rather she was considered as crazy by others including her relatives, regardless of the complication and disarray of the situation that Yemsrach encountered in relation to unfamiliar behavior of her daughter and the response of her relatives opposed to her observation, Yemsrach insisted in her position and ultimately decided to bring her daughter to Yekatit 12 hospital for seeking appropriate answer for her suspicion through medical diagnosis. After intensive diagnosis conducted by two physicians, the finding of the process of screening disclosed that her daughter was born with ASD.

Yemsrach confirmed that following the detection of the problem of her daughter, her reaction was overwhelmed with shock and dismay thinking about the adverse effect of the impairment on the future life of her daughter. The other challenge that seriously disturbed her was that she was not aware of the exact cause or reason of the impairment of her daughter. As Yemsrach confirmed, she received no professional support from the hospital except the diagnosis on the way forward that is a guideline what she has to do next and how take care of her daughter. She did believe that this situation seriously aggravated her challenge due to her ignorance about autism.

She did remember that the first two years, after diagnosis were challenging for her even to have appropriate communication and understanding with her daughter. In fact, she was committed to search the ways how she can communicate with her daughter through trial and error. One of the mechanisms that Yemsrach exercised and developed in course of time to establish communication with her daughter was creating eye to eye contact and facilitating her daughter to understand at least simple command and messages. As a result, after two years relentless exercise, Yemsrach started to observe progress on the communication skills of her daughter. These encouraging success enabled Yemsrach to continue her endeavor persistently with an objective to enhancing the overall capacity of her daughter as well as advocating the issue of autism.

Yemsrach reporting that being a mother of a child with autism is challenging due to the reason that the intrigued negative attitude of the community towards autism adversely affect the emotion and integrity of mothers having children with autism. These is due to the fact that most of the local community members did believe that having a child with autism is the result of a punishment of God against the sin committed by parents particularly mothers.

While her daughter became 6 years old Yemsrach decided to send her daughter to school. However it was not easy to get appropriate school having specialized service for children with autism. Financial scarcities as well as school community attitudinal and institutional barriers were also the other challenges that Yemsrach faced to facilitate the enrolment of her daughter in the school.

Finally, even if the school didn't have specialize service for children with autism, Yemsrach decided to enroll her daughter in Betefiker Kindergarten School which is situated in the nearby of her home. Regardless of the non-availability of the specialized service, the school management accepted her daughter and as confirmed by Yemsrach her child surprisingly showed eye catching progress on her study behavior and social skill within a short period of time.

Based on this improvement of her child Yemsrach developed confidence that her daughter will be easily integrated into the community life and capable in enhancing her reading and writing skills.

4.2.2. Case Story Two

Roman Hailu, aged 34 was born in Asebe Teferi town in Oromia region. As she reported Roman had enjoyed stable life with her sisters and brothers. Regarding her academic career, Roman completed her secondary school and joined general Winget poly Technic College by securing the requirement score of grade 10 national exam. In 2007 she earned certificate in garment specializing on design and pattern.

While she was teenager, she was excited and ambitious to get married and form a family. To be specific, she had a dream to have successful destiny being professional and effective in her over all life career. As per her aspiration, she got married at the age of 24. Her husband was professional in accounting and financial management. Roman reported that even though she was highly enthusiastic to get a child, her medical diagnosis proved that she had to obtain medical treatment or assistant to conceive a child due to her low infertility status. As a result, it was after intensive medication and care of 9 months that she succeeded in getting birth in 2009.

Roman reported that during his infancy (until 24 months) her baby was strong and handsome having smiling face. After the age of two however, Roman started to observe unfamiliar behavior on her child. She understood that her child gradually lost some vocabularies such as mam and dad that he had learned and used in his baby hood. She was shocked and worried with unexpected retardation of her child observed on his language skill. Finally, she brought him to Ring rode medium clinic to get medical assistance for her beloved child. The physicians who involved in the process of diagnosis advised roman to wait and see the situation of her child in

patience at least for the coming one year. But Roman observed no change on her child even after one year of the first diagnosis conducted Ring rode medium clinic.

Considering the regression or delay of the language development of her child, Roman brought him to another clinic Addisu Mikael higher psychiatry clinic for further and additional diagnosis and medication. Unfortunately, the finding of the diagnosis revealed that her child was born with autism spectrum disorder. Roman reported that the detection of the problem of my child was extremely shocking to me but at the same time I got relief for the reason that the difficulty of my child which was highly strange and odd to me was medically identified.

She acknowledged that the support of the psychiatrist of the clinic was so positive that enabled her to accept the challenge that she encountered in relation to the impairment of her elder child. Finally, the psychiatrist of the clinic advised Roman to bring her child to Nia Foundation where specialized service is available. Based on the advice of the psychiatrist Roman succeeded in admitting her child to Nia Foundation where he started to receive specialized service and support.

Regardless of her success to overcoming the critical challenges stated above, she was forced to confront another provoke related to the impairment of her child. These were; the problem of feeding of her child the only preference food of her child were milk and egg; and the negative attitude of the local community that adversely affected her emotion and social skill of her child.

Finally Roman expressed her aspiration to her child to be fully and effectively integrated into the community where he live in and lead his independent life without any sort of discrimination and stigma.

4.3. Summary of the Major Findings

The study investigates the lived experience of mothers having children with autism spectrum disorder (ASD) regarding the Mothers' reaction after the detection of autism in their children, their main challenges in nurturing and caring their children, The mothers' with ASD children support from the community and school and the mothers feeling about the future life career of their children with autism. The study indicated that majority of respondent mothers were the first among members of families of children with autism becoming concerned with the developmental delay of their children and the unfamiliar behaviors observed on children are language delay, hyperactivity, picky eating, not responding to their own names, limited socialization and repetitive behaviors. As per the response of the study, most participant mothers reactions' to the detection of autism on their children came as a complete shock that they got overwhelmed with frustration and the feeling of hopelessness and worry about the future life and career of their children with autism. Mother's raising children with autism spectrum disorder (ASD) lead a complex and extremely challenging life. As the study finding confirmed the most common challenges that mothers of children with ASD faces are Having tight schedule as a result they undergo hectic life and overburdened with extra responsibilities and duties, Difficulty to manage their children's with autism behavior, The mothers were always found in states of anxiety and fear due to inability of their children with autism to respond to their environment properly, Mothers are isolated from engaging in communal life and work that adversely affect their interpersonal/ social interactions and economic status and Mothers were not pay proper attention to their husbands and their other children without disabilities. Mothers of children with autism experience negative response from community, schools and organization. As the finding depicted mothers of children with autism faces Painful discrimination and exclusion, Community members consider ASD children's mothers had sinned to bring the condition on their children and Negative reaction of regular school teachers and school management staff towards disability in general and autism in particular. The finding of the study on Mother's Insight about their Children with ASD Future Career indicated unanimously participants hope that their children with autism would overcome barriers and lead their functional independent leaving being integrated in the life local communities.

Chapter Five

5. Discussion, Conclusion and Recommendation

5.1. Discussion

As stated in the presiding section of the research document, five research questions were posed to address the key thematic areas of the study crafted based on the overall objective of the study. These leading questions focused on the Mothers' reaction after the detection of autism in their children, their main challenges in nurturing and caring their children, the mothers' with ASD children social support from the community, schools and organizations and the mothers feeling about the future life career of their children with autism.

5.1.1. The Reaction of Mothers after the Diagnosis of Autism in their Children

The first research question focused on the reaction of mothers after diagnosis of ASD in their children. The question was delivered to specifically understand mothers' experiences before the conduct of child diagnosis as ASD, the early developmental concerns leading them to seek an evaluation for a diagnosis and to explore their reaction after the detection of autism in their children.

As confirmed by the finding of the study, the age range of the targeted children when the concerns of mothers on the strange behavior of their respective children noticed was from 6 to 24 months. These finding of the study has been proved by the researchers conducted by different scholars having relevant expertise and experience on the issue for instance (Chamack, Bonniau, Oudaya, & Ehrenberg, 2011), indicated "The age range when autism sign first noted by mothers or others are from 6 month to 2 years".

The result of the study further depicted that the majority of respondent mothers were the first among the members of the families of children with autism becoming concerned with development delay of their children and bring them to the hospital with an intention to knowing the cause of the phenomena. Some respondent mothers, however, reported that it was teachers, friends and their relatives who initially observed the strange behavior of their children and brought attention to notice the developmental delay of their respective children.

The result of the study clearly assured that the unfamiliar behaviors observed on the children of respondent mothers such as language delay (the most common), hyperactivity, picky eating; not responding to their own name, limited socializing and repetitive behaviors awaked the attention of mothers and others to notice the developmental delay of the targeted children.

This finding is compatible with the facts discovered by different researchers in the area. For instance, (Samadi, McConkey, & Kelly, 2012 p, 123) noted "The most common symptom that mothers first noticed are difficulty in communicating, not responding for their name, problem with eye contact and motor mannerism/ repetitive behavior".

As per the response of the study participant, the reaction that most of respondent mothers showed to the detection of the impairment (autism) on their children through diagnosis was shocking that they overwhelmed with frustration and the feeling of hopelessness and worry about the future life career of their children with autism. (Bayat, 2007 P, 74), indicated that "feelings of despair, sadness, or being overwhelmed by mothers upon first hearing of their children's diagnosis and a period of bereavement".

5.1.2. The Main Challenges of Mothers in Nurturing and Caring for Their Children with Autism

The other research questions were out brought to respondent mothers with a view to exploring the challenges of mothers in nurturing and caring their children with ASD.

The response of the majority study participant mothers concurred that they passed through hard on experience which was full of stress and frustration due to their hectic engagement in managing the misbehavior of their children. They were also required to act as therapist to arrest the deterioration of the severity of odd behavior of their children. They were also forced to get committed in with standing isolation they encountered due to the negative reaction of the society towards disability. (Mailick Seltzer et al., 2010, p. 112) noted that "Mothers of children with autism have higher levels of challenges than are having typical among mothers". As the finding of the research confirmed, nurturing a child with ASD is a stressful experience for mothers due to the reasons related to:

- Lack of appropriate and adequate knowledge or awareness on autism;
- Financial constraint to meet the requirements connected with opportunity costs;
- Lack of skill to manage the strange behavior of a child;
- Limited opportunity to access support and service from professionals.

The study finding further demonstrated another aspect of the challenge of the problem that impacted the life of mothers having children with autism. Mothers of children with autism are found in a difficulty in paying limited attention advertently or inadvertently to their husbands and siblings. As a result, some respondent mothers reported that they faced divorce as soon as the impairment of their children was detected through diagnosis. Sadly, the stress of being a parent to a child with disability takes a massive toll on families, with an increased risk of divorce compared to couple of children without a disability (Farrugia, 2009).

5.1.3. Mothers' with ASD Children Social Support from the Community

In the course of the study relevant questions were delivered to the study participants with an objective to investigating the understanding of respondent mothers of children with autism regarding the attitude of the local community towards children with autism.

As confirmed by the finding of the study, almost half of respondent mothers did believe that most of the members of the local communities where they live in exhibited positive response towards their children irrespective of their impairment. These respondent mothers explained that the positive response of the local communities was manifested through sympathy and love given to their children.

However, the remaining respondent mothers argued that the reaction of local communities towards children with autism was negative and disappointing. The fact that children with autism are isolated and mistreated by their peers without disabilities and the other members of the local community's was mentioned as the living evidence by the respondent mothers for their critiques and rational. Negative attitude from the community about ASD was reported by different researches. Mothers lived in cultures that believed something the mother had done a curse of some sort of upon the family causing their child's disability (Riccio, 2011).The Researcher has found that mothers of children with ASD experience significant levels of fatigue because of the negative attitude of the community.

5.1.4. The Mothers' with ASD Children Support from Schools

The leading research questions were postulated to dig out what response schools towards the needs of children with ASD looks like. As the summarized finding of the study revealed, the respondent mothers unanimously reported that they faced unnecessary and painful challenges associated with lack of access to special education support for their children with ASD, owing to the following reasons:

- Negative reaction of regular teachers and school management staff towards disability in general and autism in particular;
- Limited number of regular schools where specialized service which is responsive to special educational needs of children with autism is operational;
- Financial constraint to afford the school fee of privately owned schools where relatively better specialized service is available;
- Lack of teachers specialized in teaching and rehabilitating of children with autism.

These finding of the study has been proved by the researchers conducted by different scholars having relevant expertise and experience on the issue. As (Samadi, McConkey, & Kelly, 2012) described, students with autism in developing countries are not getting sufficient special education support because of the readiness of the school, limited ability of teachers to meet the special educational needs of children with ASD and shortage of qualified professionals in the area.

Nonetheless, the UN Convention on the Rights of the Child Articles 2 of 1989 stipulates that member states allocate the necessary resources and other support so that children with disability can access education.

As part and parcel of the issue dealt with the research, almost half of respondent mothers preferred regular schools as convenient institution for the schooling of their children, while the remaining study participant mothers choose special school setting.

5.1.5. Mothers Expectation about the Future Life Career of their Children with Autism

Finally, questions were delivered to the study participants aimed at assessing the insight of respondent mothers' about the future career of their children with ASD. In their response most of the respondent mothers explain their aspiration for their children to be literate in reading and writing skills and develop good communication skill through improving the frequency and quality of their language.

Additionally, most of respondent mothers did believe that their children with autism would overcome barriers and lead their functional independent living being integrated in the life of local communities. Whereas, two respondent mothers did wish to get their children cured and lead their "normal" life. These aspirations are very similar to multiple reports from other researchers including by (Merawi, 2013) and (Helen, 2016) as their finding confirmed mothers did report that their hope to make their child 'normal' by using different religious coping mechanisms.

5.3. Conclusion

As per the central theme of the study, the finding of the research presented preliminary information or facts related to the lived experience of mothers/guardians having children with autism spectrum disorder. The objective of the research was constructed on investigating the existing veracities attributed to the main focus areas of the study:

- The reaction of mothers after the detection of autism in their children;
- The main challenges in nurturing and caring their children with ASD;
- The mothers' with ASD children support from the community and schools
- The mothers expectation about the future life career of their children with autism

It has been proved that almost all respondent mothers/guardians were not aware of the sign and typical characteristics of autism except observing strange behavior on their children in different occasions. As a result, when the problem of their children/autism was detected through diagnosis, they were overwhelmed with shock, confusion and dilemma. These situations was aggravated and complicated due to the fact that they could not get appropriate support and guidance/counseling from the professional who involved in the process of the conduct of diagnosis of the children.

With regard to the challenge that the respondent mothers/guardians encountered in nurturing and caring their children with autism spectrum disorder, the response of the study participants concurred that the mode of life of the families of those mothers was gradually changed. Consequently, they were forced to pay more attention and spend time on providing care and support for their respective child with autism. It is possible to infer that these situation inadvertently affected the harmonious interaction between mothers and their siblings without disabilities.

The finding of the research showed that regardless of the progress being observed on the creation of positive attitude within the general public, the existing negative attitude of people towards disability in general and autism in particular adversely affected the socio – emotional makeup of the targeted mothers/ guardians. These mothers/ guardians reported that the society did believe that having a child with autism for a given mother is due to the consequence of the punishment of God against her wrong deeds or sin.

Regarding the existing response of regular schools towards the special educational needs of children with ASD, the finding of the research depicted that mothers/ guardians have been obliged to be engaged in relentless struggle to find out appropriate schools that accommodate the special educational needs of their children with autism. It has been found that the preference of respondent mothers on the type or modalities of teaching approach or schools is not the same, due to their respective reasons. Respondent mothers who preferred regular schools argued that the learning environment of such schools created friendly opportunity for their children with autism to develop and improve their social interaction and communication skills. The other respondent mothers, however, preferred special schools or foundations established for children with autism owing to the availability of adaptive technologies and human power trained in relevant specialization with experienced proficiency.

Finally, the study explored the insight of mothers/ guardians of children with autism about the future life career of their children. Most of the study participant mothers aspired their children with ASD to be literate in reading and writing skills and lead their independent life being integrated in the society.

5.4. Recommendation

Based on the key findings of the study, the following recommendations are identified and suggested with an objective to providing researched facts as valuable input about lived experience of mothers/ guardians of children with autism and related issues for professionals and relevant institutions who are engaged in delivering intervention and services to children with autism. It is believed that the findings of the research would enable professionals/ practitioners and researchers to identify their gap and conduct further study on the issue respectively to enrich the quality of the proposed recommendations.

1. Federal Ministry of Health in collaboration with regional health bureaus is required to establish screening units in selected health centers and hospitals equipped with specialized professionals and devices for the conduct of diagnosis and early intervention on anticipated children with autism.

2. Based on the experience that the ministry passed through in the other health - related public services such as HIV/AIDS, the national manual to serve as a guideline document should be

developed for the provision of pre-and-post diagnosis counseling for mothers/ guardians of suspected children with autism. The post diagnosis counseling should give particular emphasis on coping mechanisms and care need to be available for children with autism.

3. The Federal Ministry of Health should develop and apply national strategy to create link between the service of specialized health institution and schools where children with autism are attending their study with an objective to enhancing the progress of children with autism in their overall personality and academic development taking the involvement and contribution of parents into account.

4. Federal Ministry of Health in collaboration with the Federal Ministry of Labor and Social Affairs should facilitate and encourage parents of children with autism to establish associations with the view to meeting their common interest including experience sharing through organizing consultative platforms. The associations of parents of children with autism may involve in advocacy works focusing on autism and the task of educating their member parents about the typical characteristics and special needs of their children with autism.

5. Conduct further study on the overall situation of children with autism and enhance the capacity of higher education institutions to incorporate the issue of autism in their respective curriculum designed to produce professionals trained in special needs education.

Reference

Altiere, M. J., & Von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. Journal of Child and Family Studies, 18, 83-92.

American Psychiatric Association, (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

American Psychiatric Association, (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing [fact sheet].

Anthony, J. H. (2009). Towards inclusion: Influences of culture and internationalization on personhood, educational access, policy and provision for students with autism in Ghana. Retrieved from http://sro.sussex.ac.uk/2347/

Baird, G. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. Arch Dis Child, 83(6), 475-480.

Bakare, M. O. (1997). Excess of non-verbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa - a trend possibly resulting from late diagnosis and intervention. South African Journal of Psychiatry, 17(4), 118-120.

Bakare, Wuest and Todd, (2011).Excess of non-verbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa - a trend possibly resulting from late diagnosis and intervention. South African Journal of Psychiatry, 17(4), 118-120.

Baker, M. J. (2000). Incorporating the thematic ritualistic behaviors of children with autism into games increasing social play interactions with siblings. Journal of Positive Behavior Interventions, 2(2), 66–84.

Bayat, M. (2007).Evidence of resilience in families of children with autism.Journal of Intellectual Disability Research.

Beauchesne, M., & Kelley, B. (2004).Evidence to support parental concerns as an early indicator of autism in children. Pediatric Nursing, 30(1), 57-67.

Behrman, Kliegman and Janson. (2000). Technical report: The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. Pediatrics, 107(5), e85, 1-18.

Bello-Mojeed, MA. (2013). The relationship between the pattern of impairments in autism spectrum disorder and maternal psychosocial burden of care. OA Autism 2013 Mar 01;1(1):4

Bennett, L. (2012). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. Journal of Autism and Developmental Disorders,

Bernard, A. (2008). Social research methods. Oxford: Oxford University Press. P. 69

Bilgin & Kucuk. (2010). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. Journal of Autism and Developmental Disorders, 39, 350-362.

Boer, S. R. (2009). Successful Inclusion for Students with Autism. San Francisco: Jossey- Bass.

Boone. F (2005).Phenomenology the method. In P.L. Munhall (Ed.), Nursing research: A qualitative perspective (3rd. ed., pp. 93-122). Sudbury, MA: Jones and Bartlett.

Campbell, W. (2007). Parents of children with special health care needs who have better coping skills have fewer depressive symptoms. Maternal and Child Health Journal, 14, 47–57.

Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011).The autism diagnostic experiences of French parents. Autism, 15, 83-97.

Cicirelli, V. G. (2004). The longest bond: The sibling life cycle. In L. L'Abate (Ed.), Handbook of developmental family psychology and psychopathology (pp. 44–59). Oxford, England: John Wiley & Sons.

Cite, L (2007). Expectations and the Post Transition of Young Adults with an Autism Spectrum Disorder to Post-Secondary Education. A Dissertation Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy. ARIZONA STATE UNIVERSITY

Collins, K., & Nicolson, P. (2002). The meaning of „satisfaction" for people with dermatological problems: Reassessing approaches to qualitative health psychology research. Journal of Health Psychology, 7, 615–629. coping mechanism. (n.d.).

Creswell, J. W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage.

Creswell, J. W. (2014). The selection of research approach Research Design. California: Sage.

Creswell, J.W. (2007). Qualitative inquiry & research design: Choosing among five approaches, 2nd Ed. Sage Publications. Thousand Oaks, CA 91320.

Dababnah, S., & Parish, S. L. (2013). "At a moment, you could collapse": Raising children with autism in the West Bank. Children and Youth Services Review, 35(10), 1670-1678.

Daniel. J (2003). Education for All: Is Africa on track? Association for the Development of Education in Africa Newsletter 15, 2-3.

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. Journal of Autism and Developmental Disorders, 38, 1278-1291.

Draper, A. K. (2004). The principles and application of qualitative research. Proceedings of the Nutrition Society, 63(04), 641-646.

Englander, (2012). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. Journal of Special Education.

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatization of parents of children diagnosed with autism spectrum disorder. Sociology of Health and Illness, 31, 1011-1027.

Fazio. M, Sanbonmatsu. B, Powell. L & Kardes. A. (2014). Psychiatric disorders in parents of individuals with infantile autism: A case-control study. Psychopathology, 40, 166- 171.

FDRE Ministry of Education. (2015). Education Sector Development Programme V (ESDP V) 2015/16 - 2019/20. Addis Ababa

FDRE Ministry of Education.(1994). Education and Training Policy. Addis Ababa: St. George Printing Press.

FDRE.(1995). Constitution. Addis Ababa: Brihaneselam Printing Press.

Ferrraioli, S. J., and Harris, S. L. (2011).Effective educational inclusion of students on the autism spectrum. Journal of Contemporary Psychotherapy, 41, 19-28.

Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2011 July 25). Fatigue, wellbeing and parental self-efficacy in mothers of children with an autism spectrum disorder. Autism.[Epub ahead of print].

Gill, J., & Liamputtong, P. (2009). Walk a mile in my shoes: Researching the lived experience of mothers of children with autism. Journal of Family Studies, 15, 309-319.

Giorgi, R. (2009). What in the world is autism? A cross-cultural perspective. Zero to Three, 5-10.

Gray, D.E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. Sociology of Health and Illness, 24(6), 734-749.

Green, J., & Thorogood, N. (2014). Qualitative methodology and health research Qualitative research methods for health research. California: p. 5-25

Harrower, J. K., and Dunlap, G. (2001).Including children with autism in general education classrooms: a review of effective strategies. Behavior Modification, 25(5), 762–784.

Hartley .et al (2010).Parents' constructions of the ‘problem’ during assessment and diagnosis of their child for an autistic spectrum disorder. Journal of Health Psychology.

Helen berhane. (2016). Reactions, Challenges and Coping Mechanisms of Mothers Raising Children with Autism Spectrum Disorder (ASD): The case of Addis Ababa City. Unpublished manuscript, Addis Ababa University, school of graduate studies. 89-94

Hogg. S &Vaughan . (2011). Helping by siblings of children with mental retardation. American Journal on Mental Retardation, 110(2), 87–99.

Hossein Ebrahimi, Ayyub Malek, Jalil Babapoor and Nafiseh Abdorrahmani (2013).Empowerment of Mothers in Raising and Caring of Child with Autism Spectrum Disorder. International Research Journal of Applied and Basic Sciences Vol, 4 (10)

ILO. (2004). Employment of People with Disabilities: The Impact of Legislation. National report. Ethiopia Country Profile

Janet Boddy. (2013, April 5). Parents' experience of the diagnostic process for autistic spectrum disorders.

Joanna and Alisonn .(2016). Qualitative methods in social work research. Thousand Oaks, CA: Sage.

Karagiannis, A., Stainback, S., & Stainback, W. (1996). Historical overview of inclusion. In S. Stainback & W. Stainback (Eds.), Inclusion: A guide for educators (pp. 17-28). Baltimore: Paul H. Brookes.

Kellaghan. S, Alvarez. F & Bloom.M (2010).Career contributions of the consummate developmental scientist. In: Bronfenbrenner U, editor. Making human beings human. Thousand Oaks, CA: Sage;.pp. ix–xxvi.

Keyser. P (2001).Encyclopedia of human rights. Washington, DC: Taylor & Francis inc Schmid, R. and Nagata, M.(1983).Contemporary issues in special education: serious in special education. London: McGraw-hill.

Kirsten Marie Jardine. (2008). What Meaning does raising a Child with Autism have for Parents? A Qualitative Exploration. The University of Edinburgh, 62, 112-117.

Kreuger and Neuman (2006). Family needs after brain injury: A quantitative analysis. Journal of Heat Trauma Rehabilitation.

Lawson, F (1991). Parent advocacy in the face of adversity: Autism and families in the People's Republic of China. Focus on Autism and Other Developmental Disabilities, 22, 39-49.

Lutz, H. R. (2012). Coping with autism: A journey toward adaptation. Journal of pediatric nursing, 27(3), 206-213.

Lutz, H. R., Patterson, B. J., & Klein, J. (2012).Coping with autism: A journey toward adaptation. Journal of Pediatric Nursing, 27, 206-213.

Mailick Seltzer et al. (2010). The role of culture in families' treatment decisions for children with autism spectrum disorders. Mental Retardation and Developmental Disabilities Research.

Marsena Williams Webb. (2012). A study of churches as a source of support for families with children on the autism spectrum. A Dissertation Submitted to the Faculty of the University of Tennessee at Chattanooga in Partial Fulfillment of the Requirements for the Degree of Doctor of Education

McCoy & Cole. (2011). The importance of parent-to-parent support among families of children with autism in the People's Republic of China. International Journal of Disability, Development, and Education, 55, 303-314.

McDonnell, J. (1998). Instruction for students with severe disabilities in general education settings. Education and Training in Mental Retardation and Developmental Disabilities, 33, 199-215.

Merawi, A. (2013). Autism and Family: problems, prospects and coping with the disorder. Unpublished manuscript, Addis Ababa University, School of Graduate studies. 67-71

National institute of mental health Center.(2011). A Parent's Guide to Evidence-Based Practice and Autism. National institute of mental health Center. Randolph, Massachusetts 02368.

Nia Foundation.(2016). Autism in Ethiopia. Retrieved March 10, 2015, from http://www.ethioautism.org/Joy/Autism_in_Ethiopia.html

Nisha V. and Susan K. (2010). Stress and Coping in Mothers of Autistic Children. Journal of the Indian Academy of Applied Psychology , Vol.36, No.2, 245-248

Noy, C. (2007).Sampling knowledge: The hermeneutics of snowball sampling in qualitative research. International Journal of Social Research Methodology, 11, 327-344.

Peter, K. (2003). Experiences of Parenthood and the Child with an Intellectual Disability. University of Gothenburg, 2012. Printed in Sweden by Ale Tryckteam

Rachel, B. (2015). Dilemmas, diagnosis, and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. Journal of Clinical Child Psychology and Psychiatry.

Riccio, A. (2011). Autism in Kenya: A social, educational, and political perspective. ISP Collection. Paper 1203. Retrieved from http://digitalcollections.sit.edu/isp_collection/1203

Rubin.S (2005).From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. Journal of Applied Research in Intellectual Disabilities.

Ryan. T (2013). Child health-related cognitions of parents with autistic children: A cross-national exploratory study. In: U. P. Gielen & A. L. Communian (Eds.), Family and Family Therapy in International Perspective (pp. 461-483), Trieste: Edizioni LINT (Italy).

Samadi, S. A., McConkey, R. & Kelly. (2012). Autism in Developing Countries: Lessons from Iran. Autism research and treatment.doi: http://dx.doi.org/10.1155/2011/145359

Sameroff, A. J., & Fiese, B. H. (2000). Transactional regulation: The developmental ecology of early intervention. In J. P. M. Shonkoff, Samuel J (Ed.), Early Childhood Intervention. New York, NY: Cambridge University Press.

Smith and Osborn. (2007). Qualitative Interview Design: A Practical Guide for Novice Investigators. The Qualitative Report Volume 15 Number 3

Swift, J., & Tischler, V. (2010). Qualitative research in nutrition and dietetics: getting started. Journal of Human Nutrition and Dietetics, 23(6), 559-566.

Tiffany Wiggs. (2010). Stress Levels and Development: A Phenomenology of Autistic Children and Their Parents. A Senior Thesis submitted for the graduation in the Honors Program, Liberty University.

UNESCO. (1994). The Salamanca Statement and Framework for Action on Special Needs Education. Paris: Author.

UNESCO. (2000). The Dakar Framework for Action, Education for All: Meeting Our Collective Commitments. World Education Forum, Dakar, Senegal, 26–28 April 2000. UNESCO, Paris.

UNESCO.(1998). World Declaration on Education for All and Framework for Action to Meet Basic Learning Needs. Jomtien, Thailand. March 5–9.

United Nations. (1989). The Convention on the Right of the Child. New York: Author.

United Nations. (1993). The Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

United Nations.(1948). Universal Declaration of Human Rights. New York: Author.

United Nations.(2006). Convention on the Rights of Persons with Disabilities. New York: Author.

Wiman. R, & Sandhu. U(2004). Explaining and selecting treatments for autism: parental explanatory models in Taiwan. Journal of Autism and Developmental Disorders, 40, 1323-1331.

Winzer, M. (2005).Children with exceptionalities: A Canadian perspective (2nded.). Scarborough: prentice – Hall Canada Inc.

Woodgate, R. L., Ateah, C., & Secco, L. (2008).Living in a world of our own: The experience of parents who have a child with autism. Qualitative Health Research, 18, 1075-1083.

Appendix 1

Addis Ababa University

College of Education and Behavioral studies

Department of Special Needs Education

Date _____

Consent letter

My name is Dagmawi Alemnh. I am a post graduate student of special needs and inclusive education at Addis Ababa University. This research is conducted to fulfill the requirements for the degree of masters in special needs and inclusive education. This interview guide is prepared to collect data from mothers having children with autism.

The objective of this research is by exploring the lived experiences of mothers having children with autism: to give input for professionals working in the area of autism, to contribute for concerned institutions in the area, to share experience for mothers having newly diagnosed children with autism and sharing the finding for the community.

The researcher would like to thank you for your willingness and want to inform that you are not obligated to continue giving any sort of information and can quit at any time of the process as the questions is relay to get your experience dealing with the matter.

I would like to tell you that the interview may take one hour and the information you may give me will be recorded. There might be questions which may be disturbing you and create discomfort. However I would like to ensure you that your identity will not be revealed and the information you provided will be kept secretly and the recorded data will be deleted as soon as the research is completed.

First, I want to express my utmost respect and thanks for your willingness for the interview.

Interview guide

Part1. Profile of the interviewee

- Parental status

☐ Biological mother

☐ Guardian

- Marital status

☐ Single

☐ Divorce

- Age_____
- Academic qualification_____
- Mother's occupation _____
- Child age_____
- Child diagnostic age _____
- Child sex_____
- Child grade level _____
- Number of sibling's_____

☐ Male

☐ Female

- Name of school/ center where the child is attending his /her study_____

2. Queries related to lived experience of mothers

2.1. Questions developed to assess the reaction of mothers to the diagnosis that detected the presence of autism on their children.

2.1.1. When and how you observed strange behavior on your child and then what you did to address the problem?

2.1.2. Who observed the strange behavior on your child?

2.1.3. At what age of your child that the problem was observed?

2.1.4. Where and how your child first received professional support due to his/her unusual behavior?

2.1.5. Have you brought your child to the hospital for diagnosis after observing eccentric behavior? If yes is it due to your initiative or the concern/ encouragement of others that you did admit your child to the hospital?

2.1.6. What kind of service your child gained from the hospital?

2.1.7. What was your reaction or felling towards the detection of autism on your child?

2.1.8. Have you been informed about autism before the diagnosis of your child?

2.1.9. What kind of service you obtained from the professionals of the hospital apian the compilation of the diagnosis and the detection of the problem?

2.2. Questions developed to investigate the challenges of mothers in nurturing and caring of their children with autism.

2.2.1. Have you been facing day today challenges in nurturing your child with autism? If yes, please explain it briefly?

2.2.2. Have you ever faced problem, dismay and stress attributed to the situation of your child is yes explain it briefly?

2.2.3. Do you believe that you have been overburdened in providing special care and support to your child with autism? If yes what is your opinion regarding the reason why you faced such problem?

2.2.4. If your answer is yes for question no 2.2.3, do you believe that the situation or your special responsibility on your child with autism has adverse impact on your work? If yes , please explain briefly the consequence of the adverse effect of the problem

2.2.5. Do believe that the impairment of your child with autism resulted in adverse effect on your life

2.2.6. Have you experienced visible challenge in your family related to the impairment of your child? If yes explain it briefly?

2.2.7. Have you enjoyed support from your husband in providing care and support for your child with autism? If yes or no explain each briefly.

2.2.8. What you observed regarding the response and treatment of siblings to the situation and impairment of your child with autism

2.3. Questions developed to appraise the status in the attitude of local communities towards children with autism.

2.3.1. In your opinion what is the response and treatment of members in local communities to children having autism?

2.3.2. Have you encountered problem in reference to the relationship between your child with autism and his/her peers without disability?

2.3.3. What was the reaction of your neighbors for the diagnosis that detected the status of autism of your child?

2.3.4. Do believe that members of the local communities are aware of the causes of autism? If yes what cause is believed by the community for the occurrence of autism?

2.4. Questions developed to assess the existing responses of regular school towards the special educational needs of children with autism.

2.4.1. Did your child get access to education? If yes or no how and why?

2.4.2. If your answer yes for 2.4.1 where your child is attending his/her schooling? In inclusive class setting, or in special school or special needs education units in regular school?

2.4.3. Which one of those modalities of teaching of children with autism is preferable for you? Why?

2.4.4. What are the special supports that your child has been receiving from the school system?

2.4.5. Do you believe your child is receiving professional support in his /her study? If yes what kinds of professional support that your child enjoyed?

2.4.6. Do you believe that the regular schools are accessible friendly for children with autism? If yes or no how and why?

2.5. Questions develop to assess the insight of mothers about the future life career of their children with autism.

2.5.1. What do you think about your child's future final academic achievement?

2.5.2. What is your thought about your child's future career including marital life?

2.5.3. What is your aspiration regarding your child?

2.5.4. Is there anything you would like to mention other than what I have asked you?

Appendix 2

አዲስአበባዩኒቨርስቲ

የትምህርትእናባህሪጥናትኮሌጅ

የልዩፍላጎትእናአካቶትምህርትክፍል

ቀን.....

መግቢያ

ዳግማዊአለምነህእባላለሁ፡፡
በአዲስአበባዩኒቨርስቲበልዩፍላጎትእናአካቶትምህርትክፍልየድህረምረቃተማሪነኝ፡፡
ይህንጥናትየምሰራውለማስተርስዲግሪመመረቂይማሚያነው፡፡
ይህቃለመጠይቅየተዘጋጀውኡቲዝምያለባቸውንህፃናትለሚያሳድጉወላጆችእናአሳዳጊዎችነው ፡፡

የዚህጥናትአላማኡቲዝምያለባቸውልጆችያላቸውእናቶችያሳለፉትንየህይወትተሞክሮበማጥናትለተለ ያዩባለሙያዎች፣
ተመሳሳይልጆችላላቸውወላጆች፣ጉዳዩለሚመለከታቸውየተለያዩተቋማትእናለማህበረሰቡመረጃውንበ ማካፈልበዘርፉየተሻለውጤትእንዲገኝአስተዋያማድረግነው ፡፡

የጥናቱንአላማተረድተውቃለመጠይቁንለመስጠትፍቃደኛበመሆኖበቅድሚያእያመሰገንኩ፤ቃለመጠ ይቁንለመመለስየማይገደዱመሆኑንናከቃለመጠይቁበፊትምሆነመሃከልላይቃለመጠይቁንለማቋረጥከ ፈለጉሙሉበሙሉየሚቻልመሆኑንእንዲሁምየምጠይቅዎትጥያቄዎችአላማየእርስዎንተሞኩሮለማ ወቅብቻመሆኑንልገልጽእወዳለሁ፡፡

ይህቃለመጠይቅበመቅረፀድምፅየሚቀዳእንዲሁምአንድሰዓትሊፈጅየሚችልናበቃለመጠይቁወቅትአን ዳንድግላዊወይምምኞትየማይሰጡጥያቄዎችሊኖሩእንደሚችሉበቅድሚያእያሳወኩይህንንጥናትእርስ ዎበሚሰጡኝመረጃላይተመርኩገፅስጽፍየእርስዎስምየማይጠቀስመሆኑንናየሚነግሩኝመረጃበሚስጥ ርእንደሚያዝእንዲሁምከጥናቱመጠናቀቅበኋላየተቀዳውመረጃሙሉበሙለእንደሚሰረዝአረጋግጥሎ ዎታለው፡፡

በመሳተፍዎእናለቃለመጠይቁፍቃድዎንስለሰጡኝበቅድሚያከልብየመነጨምስጋናዬንእየገለፅኩለጥና ቱስኬትለሚኖሮውአስተዋፅኦከፍተኛአክብሮቴንእገልፃለሁ፡፡

የቃለመጠይቅቅፅ

ክፍል 1- የቃለመጠይቁተሳታፊግለሁኔታ/ማንነትመረጃ

- ✓ **የወላጅነቶአይነት**

☐**ወላጅእናት**

☐**አሳዳጊእናት**

- ✓ **የጋብቻሁኔታ**

☐**ያገባ**

☐**ያላገባ**

- ✓ **እድሜ** _____
- ✓ **የትምህርትዝግጅት** _____
- ✓ **የወላጅወይምያሳዳጊየስራሁኔታ** _____
- ✓ **የልጅዎእድሜ** _____
- ✓ **ልጅዎየኡቲዝምምልክትታይቶበትምርመራየተደረገለትዕድሜ**_____

_

- ✓ **የልጅዎየታ** _____
- ✓ **የልጅዎየትምህርትደረጃ** _____
- ✓ **የህፃኑልጅዎእህትወይምወንድምብዛት**_____

☐**ወንድ**

☐**ሴት**

- ✓ **ህፃኑትምህርቱን/**

የቅድመትምህርትእንክብካቤየሚያገገኘበትትምህርትቤት/ተቋም_____

_____

ክፍል2.የእናቶችንየህይወትተሞክሮለመዳሰስየቀረቡጥያቄዎች

2.1.

እናቶችልጆቻቸውንባካሄዱትየመጀመሪያምርመራሂደትኡቲዝምእንዳለባቸውበታወቀወይምበተነገራቸውጊዜለ ክስተቱየሰጡትምላሽንበተመለከተሁኔታውንለመዳሰስየቀረቡጥያቄዎች;

2.1.1. በልጆምላይመቼእናእንዴትያልተለመደባህሪተመለከቱ? ይህሲሆንበወቅቱየሰጡትምላሽምንነበር?

2.1.2. ይህንያልተለመደፀባይበልጅምላይለመጀመሪያጊዜያስተዋለውማንነበር?

2.1.3. በስንትአመቱይህያልተለመደ/ እንግዳፀባይበልጅምላይመታየትጀመረ?

2.1.4. ልጅምለዚህእንግዳባህሪመቼእናየትየባለሙያእገዛአገኘ?

2.1.5. ይህያልተለመደፀባይበልጅምላይሲታይወደሆስፒታልወስደውትነበር ?
መልሶአዎከሆነልጅምንወደሆስፒታልየወሰዱትበራስምተነሳሽነትወይስበሌሎችግፊት?

2.1.6. ልጅምምንአይነትአገልግሎትከሆስፒታሉማግኘትቻለ?

2.1.7. ልጅኡቲዝምእንዳለበትከምርመራውውጤትሲሰሙየነበሮትስሜትምንነበር ?

2.1.8.
ልጅምኡቲዝምእንዳለበትበምርመራውወቅትከመስማትምበፊትስለኡቲዝምሰምተውያውቁነበርወይምመረጃውነ በርምት?

2.1.9.
ምርመራውተጠናቅቆልጅምኡቲዝምእንዳለበትካወቁበኋላምንአይነትሙያዊድጋፍከሆስፒታሉተደረገለት?

2.2.

ኡቲዝምያለባቸውህፃናትእናቶችእነዚህንህፃናትበሚያሳድጉበትወቅትያጋጠማቸውንተግዳሮቶችለማጤንወይ ምለመርመርየተዘጋጁጥያቄዎች፡

2.2.1. በዕለትተዕለትኑሮኡቲዝምያለበትልጅምንሲንከባከቡናሲያሳድጉያጋጠምዎትችግርነበርን?
መልሶአዎከሆነበዝርዝርስለሁኔታውይግለፁ?

2.2.2. ኦቲዝምካለበትልጅዎሁኔታጋርበተያያዘተስፋመቁረጥናጭንቀትገጥምዎት

ያውቃልን?መልሶአዎከሆነስለሁኔታውበዝርዝርይግለፁ?

2.2.3.

ኦቲዚምላለበትልጅዎየተለየእንክብካቤእያደረጉበመሆኑበህይወትዎላይጫናተፈጥሮብኛልብለውያም ናሉን? መልሶአዎከሆነይህየሆነበትንምክንያትበተመለከተበዝርዝርይግለፁ?

2.2.4. በተራቁጥር/2.2.3/

ለተቀመጠውጥያቄመልሶአዎከሆነለልጅዎየሚያደርጉትየተለየድጋፍበስራይላይጫናአሳድሮብኛልብ ለውያምናሉን? መልሶአዎከሆነየችግሩንአሉታዊውጤትይግለፁ?

2.2.5. የልጅዎአካልጉዳተኛመሆንበህይወትዎላይአሉታዊውጤትአምጥቷልብለውያምናሉን?

2.2.6. በልጅዎአካልጉዳተኝነትምክንያትበቤተሰብዎውስጥየተለየተግዳሮትአጋጥሞዎታልን?

2.2.7. ልጅዎንበሚንከባከቡበትእናበሚያሳድጉበትወቅትከባለቤትዎዘንድድጋፍአግኝተዋልን? መልስዎአግኝቻለሁወይምአላገኘሁምከሆነበዝርዝርይግለፁ?

2.2.8.

ኦቲዚምላለበትልጅዎእህቶቹእናወንድሞቹለሁኔታውወይምለአካልጉዳተኛልጅዎየሰጡትንምላሽይግ ለፁ?

2.3. ኦቲዚምላለባቸውህጻናትየአካባቢውህብረተሰብያለውንምልከታለመመዘንየቀረቡጥያቄዎች፡

2.3.1.

በእርስዎአስተሳሰብየአካባቢውህብረተሰብአባላትኦቲዝምላለባቸውህፃናትያለውእይታእናእንክብካቤም ንይመስልዎታል?

2.3.2.

ኦቲዝምባለበትልጅዎናበአቻዎቹመካከልባለግንኙነትከልጅዎአካልጉዳተኝነትምክንያትጋርበተያያዘየገ ጠምዎችግርነበር?

2.3.3.

ልጅዎበሀኪምምርመራአማካኝነትኦቲዚምእንዳለበትበታወቀጊዜለሁኔታውየጎረቤትዎምላሽምንይመ ስልነበር?

2.3.4.የአካባቢውህብረተሰብየኦቲዝምመነሻምንእንደሆነያውቃሉብለውያምናሉን?

መልሶአዎከሆነየአካባቢውህብረተሰብየኦቲዝምመነሻምክንያትምንድነውብሎያምናል ?

2.4.

ኦቲዚምላለባቸውህፃናትከልዩየትምህርትፍላጎትጋርበተያያዘትምህርትቤቶችያላቸውንዝግጁነት/ ወቅታዊምላሽንበተመለከተምዘናለማካሄድየተዘጋጁጥያቄዎች፡

2.4.1. ኦቲዝምያለበትልጅዎየትምህርትእድልአግኝቷልን? መልሶአዎከሆነእንዴትእናየት?

2.4.2.

በተራቁጥር2.4.1/ለቀረበውጥያቄመልስዎአዎከሆነበየትኛውየትምህርትስርዓትትምህርቱንበመከታ ተልላይይገኛል፤በአካቶየትምህርትስርዐት፤ በልዩትምህርትቤት፤ ወይስበመደበኛትምህርትቤትውስጥበተቋቋሙየልዩፍላጎትትምህርትክፍል?

2.4.3. ከነዚህየማስተማርስርዓቶችየትኛውንይመርጣሉ? ለምን?

2.4.4. ልጅዎእየተማረበትካለውትምህርትቤትምንአይነትልዩድጋፍበማግኘትላይይገኛል?

2.4.5. ልጅዎበትምህርትቤትደረጃሙያዊድጋፍበማግኘትላይይገኛልብለውያምናሉን? **መልሶአዎከሆነምንአይነትሙያዊድጋፍበማግኘትላይይገኛል?**

2.4.6.

መደበኛትምህርትቤቶችኦቲዝምላለባቸውህፃናትወይምተማሪዎችተደራሽናቸውብለውያምናሉን?መ ልስዎአምናለውወይምአላምንምከሆነእንዴትእናለምን?

2.5.

ኦቲዝምያለባቸውልጆችእናቶችስለልጆቻቸውመፃይእድልያላቸውንምልከታለመመዘንየተዘጋጁጥያቄዎች፡

2.5.1. **ስለልጅዎመፃይትምህርትስኬትያለዎትእሳቤምንድንነው?**

2.5.2. **ስለልጅዎመፃይስኬት/የትዳርሁኔታንጨምሮያለዎትእሳቤምንድንነው?**

2.5.3.**ስለልጅዎመፃይእድልያለዎትተስፋእናእሾትምንድንነው?**

2.5.4. **እኔያልጠየኮትግንመነሳትአለበትየሚሉትነገርካለሀሳብዎትንቢገልፁልኝ?**