

**ASSESSMENT OF CHALLENGES AND SUPPORT NEEDS OF PARENTS
OF CHILDREN WITH AUTISM AT NEHEMIAH AUTISM CENTER IN
ADDIS ABABA, ETHIOPIA**

MASTRRS OF SOCIAL WORK DISSERTATION RESEARCH PROJECT

REPORT

(MSWP-001)

MASTEWAL ABERA

Enrolment No. 099110886

INDIRA GANDHI NATIONAL OPEN UNIVERSITY

SCHOOL OF SOCIAL WORK

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ADDIS ABABA, ETHIOPIA

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Enrolment No. 099110886

PROJECT SUPERVISOR

SEBSIB BELAY (Mr.)

INDIRA GANDHI NATIONAL OPEN UNIVERSITY

SCHOOL OF SOCIAL WORK

DECLARATION

I hereby declare that the dissertation entitled, ASSESSMENT OF CHALLENGES AND SUPPORT NEEDS OF PARENTS OF CHILDREN WITH AUTISM AT NEHEMIAH AUTISM CENTER IN ADDIS ABABA, ETHIOPIA, submitted by me for the partial fulfillment of MSW to Indira Gandhi National Open University (IGNOU) in Addis Ababa, is my original work and has not been submitted earlier, either to IGNOU or to any other institutions for the fulfillment of the requirement for any other program of study. I also declare that no chapter of this manuscript in whole or in part is lifted and incorporated in this report from any earlier work done by me or others.

Place: Addis Ababa, Ethiopia

Signature: _____

Date: November, 5, 2013

Enrolment NO.: 099110886

Name: Mastewal Abera

Address: Addis Ababa Ethiopia

Email: nanu_abya@yahoo.com

CERTIFICATE

This is to certify that **Miss Mastewal Abera** who is a student of MSW from Indira Gandhi National Open University in Addis Ababa was working under my supervision and guidance for her project work for the course **MSWP-001**. Her project work entitled **ASSESSMENT OF CHALLENGES AND SUPPORT NEEDS OF PARENTS OF CHILDREN WITH AUTISM AT NEHEMIAH AUTISM CENTER IN ADDIS ABABA, ETHIOPIA**, which she is submitted her genuine and original work,

Place: Addis Ababa, Ethiopia

Signature: _____

Date:

Name: Mr. Sebisib Belay

Address of the supervisor:

School of Graduate Studies

St. Mary's University

Phone No: +251- 911165264

Dedicated to all Ethiopian parents of children with autism who are struggling to manage their lives with the most challenging disorder.

Table of Contents

DECLARATION	iii
CERTIFICATE	iv
ACKNOWLEDGEMENT	xi
ACRONYMS	xii
LIST OF TABLES	xiii
ABSTRACT	xiv
CHAPTE ONE	1
INTRODUCTION.....	1
1.1 Statement of the Problem	6
1.2 Research Questions	9
1.3 Objectives of the Study	10
1.3.1 General Objective	10
1.3.2 Specific Objectives	10
1.4 Definition of Concepts	10
1.5 Limitation of the Study	11
1.6 Chapter Plan of the Thesis	12
CHAPTER TWO	13
REVIEW OF RELATED LITERATURE	13
2.1 Autism: Definition and Characteristics	13
2.1.1 What is Autism?.....	13
2.1.2 Characteristics of Autism.....	15
2.1.1.1 Impaired Social Development.....	15
2.1.1.2 Impaired language and communication	16
2.1.1.3 Flexibility Impairment or Resistance to Change	17
2.1.2 Causes of Autism	18
2.1.3 Diagnosis.....	19
2.1.4 Prevalence	20
2.1.5 Some Early Mistakes about Autism.....	21

2.2	Challenges of Raising Autistic Children.....	22
2.2.1	Diagnosis as a challenge	23
2.2.2	Getting Social or Professional Support as a Challenge	24
2.2.3	Autism Characteristics as a challenge.....	25
2.2.4	Family Strain.....	25
2.2.4.1	Marital.....	26
2.2.4.2	Siblings	26
2.2.5	Stigma	27
2.2.6	Stress	27
2.3	Support Needs of Parents of Autistic Children.....	28
	CHAPTER THREE.....	31
	RESEARCH DESIGN AND METHOD	31
3.1	Background Information of the Study Site	31
3.2	Research Design and Methods	32
3.3	Universe of the Study.....	33
3.4	Sampling Methods.....	34
3.5	Data Collection: Tools and Procedures.....	34
3.6	Data Processing and Analysis	36
	CHAPTER FOUR.....	38
	RESULTS OF THE FINDINGS.....	38
4.1	Data on Parents Interviews	38
4.1.1	Challenges	38
4.1.1.1	Social Challenge.....	38
4.1.1.1.1	Diagnosis.....	38
4.1.1.1.2	Getting Professional Help.....	41
4.1.1.1.3	Impact on Family life.....	43
4.1.1.1.4	The Public Understanding.....	45
4.1.1.1.5	Personal life	48
4.1.1.2	Economic Challenge	49
4.1.1.2.1	Financial Strain	49
4.1.1.3	Psychological Challenge	50

4.1.1.3.1	Parents Understanding and Attitudes towards Autism	50
4.1.2	Need Specific to Parents of Children with Autism	52
4.1.2.1	Professionals’ Support.....	52
4.1.2.2	Social support.....	54
4.1.2.3	Future Concern and prospect	55
4.2	Staff Interview Report.....	57
4.2.2	Major Activities of the Center and Future Plan	57
4.2.2.2	Intervention Plan, Implementation and Assessment Procedure.....	57
4.2.2.3	Public Awareness creation and advocacy	58
4.2.2.4	Communication With Parents	59
4.2.2.5	Relationship and Affiliations with others	60
4.2.2.6	Support service for Parents	60
4.2.3	Constraints and Challenges of Nehemiah Autism Center	61
4.2.3.2	Government Support	61
4.2.3.3	Parents’ Involvement	62
4.2.3.4	Financial Constraints	62
4.2.3.5	Professionals on the area.....	63
4.3	Document review Report	64
4.3.2	Child enrolment file	64
4.3.3	Child progress file	64
4.3.4	Parent communication booklet and Report	65
4.3.5	Meeting and Training Reports.....	65
4.4	Data on Observation at the Center	65
4.4.1	The Physical Environment of the Center	65
4.4.2	Reception (Giving information).....	66
4.4.3	Class Rooms	66
	CHAPTER FIVE	67
	FINDINGS AND DISCUSSION.....	67
5.1	Discussion of the Findings on Parents Interview.....	68
5.1.1	Challenges of Raising an Autistic Child	68
5.1.1.1	Social Challenge.....	69

5.1.1.1.1	Diagnosis.....	69
5.1.1.1.2	Getting Professional Help.....	70
5.1.1.1.3	Impact on Family Life	71
5.1.1.1.4	The Public Understanding.....	72
5.1.1.1.5	Effect on Personal life.....	74
5.1.1.2	Economic Challenge	75
5.1.1.2.1	Financial Strain	75
5.1.1.3	Psychological Challenge.....	76
5.1.1.3.1	Parents Understanding and Attitude	76
5.1.2	Needs Specific to parents of children with autism.....	78
5.1.2.1	Support Needs	78
5.1.2.1.1	Professional Support and Service	78
5.1.2.1.2	Social support.....	79
5.1.2.1.3	Future Concerns and Support need.....	80
5.2	Finding and Discussion on Staff Interviews	81
5.2.1	Strengths and Constraints of Nehemiah Autism Center.....	81
5.2.1.1	Major activities and Future plan	82
5.2.1.1.1	Intervention Plan, implementation and assessment procedure	82
5.2.1.1.2	Public Awareness Creation and Advocacy	83
5.2.1.1.3	Communication With Parents.....	83
5.2.1.1.4	Relationship and Affiliations with others	84
5.2.1.1.5	Support service for Parents	84
5.2.1.2	Constraints and Challenges of Nehemiah Autism Center	84
5.2.1.2.1	Government Support.....	84
5.2.1.2.2	Parents' Involvement	85
5.2.1.2.3	Financial Constraints	86
5.2.1.2.4	Professionals on the Area.....	86
5.3	Discussion on Document Review	87
5.3.1	Child Enrolment File.....	87
5.3.2	Child Progress File.....	87
5.3.3	Parent Communication Booklet and Report	87

5.3.4	Meeting and Training Reports.....	88
5.4	Discussion on Observation at the Center.....	88
5.4.1	The Physical Environment of the Center.....	88
5.4.2	Reception (Giving information).....	89
5.4.3	Class Rooms.....	89
CHAPTER SIX		90
CONCLUSION AND RECOMMENDATIONS.....		90
6.1	Conclusion.....	90
6.2	Recommendations.....	94
6.2.1	Recommended Social Work Interventions.....	96
REFERENCES		98
Appendices.....		102
Annexure I: Interview Guide for Parents of Children with Autism.....		102
Annexure II: Interview Guide for Staff Members		105
Annexure III: Observation Schedule		107
Annexure IV: Document Analysis Template.....		108

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ACRONYMS

ABA	Applied Behavioral Analysis
ASD	Autism Spectrum Disorder
PDD	Pervasive Developmental Disorder
VB MAPP	Verbal Behavior Milestones Assessment and Placement Program

LIST OF TABLES

Table 5.1 Background information of Participants

Table 5.2 Background Characteristics of Children of Participants

ABSTRACT

The purpose of this study was to assess the challenges of parents of children and their support needs in raising an autistic child. To attain this objective, a qualitative research approach was implemented. In this qualitative study, four parents of autistic children at Nehemiah Autism Center were interviewed regarding their experiences in having autistic children and the challenges encountered and their support need. In addition, two staff members were also interviewed. The researcher utilized semi-structured, in-depth, face-to-face interviews as a qualitative research method of data collection using interview guide. As the finding of this study indicated that, parents of autistic children experienced many challenges. Together with many other social, emotional and economic challenges these parents facing, lack of professional and institutional support were the major ones. The finding of the study also showed that parents and the public including health workers have limited awareness and information about the disorder. Therefore it can be concluded that the lack of information and awareness about the disorder is the biggest challenge this parents facing. As the public lacks awareness it also affects the service available to the autistic children and their parents. It is recommended that the concerned professionals and institutions main focus should be working on awareness creation.

CHAPTE ONE

INTRODUCTION

Autism is one of the five primary developmental disorders called Pervasive Developmental Disorders (PDD). Pervasive Developmental Disorders is a general term which includes a wide range of social and communication disorders, such as Autistic Spectrum Disorders, Childhood Disintegrative Disorders, Rett's Disorder, Asperger's Disorder and PDD-not Otherwise Specified (PDD-NOS) Disorders. These disorders show similar range of symptoms, but they differ in terms of when the symptoms start, how fast they appear, how severe they are, and their exact nature (Volkmar & Wiesner 2009, p. 25).

Autism is one of the five developmental disabilities of childhood included under the umbrella term 'Pervasive Developmental Disorder (PDD)'. It was first described by a psychiatrist named Leo Kanner at Johns Hopkins Hospital in Baltimore in 1943. He based the term on the Greek word *autos* which means self, for the children who showed such symptoms are seemingly locked inside themselves and detached from the world (William, 2000, p. 124). Many professionals now use the term 'autism spectrum disorders (ASD)' instead of PDD. Autism Spectrum Disorders refer to a complex group of related disorders marked by impaired communication and socialization and by a limited (and often unusual) range of interests.

Autism is a neurological and developmental disorder that usually appears during the first three years of a child's life. It is as a severe developmental disability marked by impairment of communication, social and emotional functioning. Other characteristics often associated with

autism are engagement in repetitive activities and stereotyped movements; resistance to environmental change or changes in daily routines and unusual responses to sensory experiences (Volkmar&Wiesner 2009, p.25).

According to the report of National Research Council (2001), autistic children often have problems in communication, avoid eye contact, and show limited attachment to others. A child with autism appears to live in his/her own world, showing little interest in others, and a lack of social awareness. The focus of an autistic child is a consistent routine and includes an interest in repeating odd and peculiar behaviors

Experts estimate that three to six children out of every 1,000 have autism. According to scholars in the field, boys are affected four times more than girls. As US Centers for Disease Control and Prevention (2011)stated, in the U.S.A, one 1.16in every 100 children is diagnosed with autism. This reported prevalence is substantially higher than that of a decade earlier. Similar increases have been noted in the UK, Europe and Japan (Landrigan 2010,p. 219). The reason is not known why there has been such a rapid increase in autism. Autism affects all children regardless of colour, race and gender. However, a lot is still not known on the possible risk factors for and causes of autism. Scientists think that both genetic and environment play a role.

Regarding the prevalence of disabilities there appeared lack of appropriate information in Ethiopia. Issue of developmental problems, delays and disorders are not very well researched. According to the World Report on Disability (2011), there were 15million people with disability in Ethiopia. However, the available data do not provide sufficient evidence on the type and the prevalence of persons with disabilities by degree and specific category of *impairment*. This is because of the reason that the public associate developmental problems with spiritual evil and

caused by ones sin most people do not let disabled persons to go out in public. This stereotypic attitude also forces families to hide disabled family members which in turn lead to inaccurate information and statistics on disabilities (Tirusew, 2005).Thus, statistical evidence on the extent and prevalence of autism in Ethiopia is not sufficiently available at the moment.

Although it is difficult to know the number and the prevalence of autism in Ethiopia, it is estimated that 600,000 people throughout the country (Getnet, 2013).This is also confirmed by the Annual Report of Nehemiah Autistic Center, as it is stated:

Since Autism is found throughout the world and amongst all nations, nationalities and social classes, Ethiopia is not an exception. If one in every 100 children are diagnosed with autism in the U.S.A, we could fairly say that with Ethiopian's population of more than 80 million, we can estimate to have over 600,000 children suffering from autism and related developmental disorders, with no access to rehabilitation, education and training (Nehemiah Autistic Center,2012).

As explained by Nehemiah Autistic Center, there are currently 800 children on waiting list of Joy Center for Children with Autism and Related Disorder (J-CCARD).Though there is lack of official data on autism in the country, it is believed that prevalence rates are increasing rapidly

According to 2006Report of UNICEF, Ethiopia did not have centers for autistic children, until 2002.One parent who had discovered her son had the disorder decided to build her own after facing a lot of challenges and struggles to find an appropriate support in Ethiopia. She began the centre by the name 'Joy Center for Children with Autism and Related Developmental Disorder. The Joy Center's work was unique for it dared to operate for a disorder that neither received any

medical attention nor specialization in Ethiopia at that time. Medical practitioners' knowledge on the disorder was insufficient and those who knew about it treated it as one of psychiatric cases or simply told the patients' parents to treat their children better than the previous time (J-CCADD, 2005).

Currently, there are two autism centers that give care and support for children with autism in Ethiopia. These are Joy Center for Children with Autism and Related Developmental Disorder, and the other is Nehemiah Autistic Center which opened recently. The two centers are opened by parents with autistic children. The centers are located in Addis Ababa and are currently limited in giving services to the area. Even if these centers are contributing a lot in creating awareness and giving service, unfortunately the majority of the public including professionals who are living in Ethiopia still lack awareness of the problem. According to the report of Joy center of autism (J-CCARD)(2005), parents of autistic children also lack information about the nature and the symptoms of autism. Because of this reason as well as others stated above, many parents will continue to suffer in silence until more parents, like Zemi and Rahel, who are founders of the Autism Centers in Addis Ababa, can be found with the time and the sacrifice to lead these children to a brighter future.

Considering the described limitations, social stigma and lack of awareness in Ethiopia, developmental problems in general and autism in particular can be considered as one of the most important issues that social workers need to address in the country. As social workers have a responsibility to promote social justice and inherent worth and dignity of all people it is important and necessary to study challenges and support needs of parents of children with autism.

The researcher's motivation for the choice of this topic through social work perspective is both personal and Professional. The personal interest for this study arises after having an autistic student in the researcher's class room while teaching at one preschool and meeting his parents. The situation is that the pupil is not getting any appropriate support and his family struggle to get professional help made the researcher to realize that there may be many children and parents in different sub cities of Addis Ababa struggling to cope with the problem and to get appropriate professional supports.

The professional motivation is to assess the challenges and support needs of parents of children with autism in Ethiopia. The aim is to inform helping professionals and social workers to develop effective and efficient intervention models and counseling programs that are sensitive to the unique needs of the identified target population in Ethiopia.

Therefore studies on autism, what it is, its symptoms and characteristics are well represented throughout the available literature. However, the challenge of this disorder on parents is investigated only by few researchers with different capacity. This is also confirmed by a study undertaken by Wnoroski,(2008)on uncovering the stigma in parents of children with autism. As Wnoroski further explained information and study on autism have exploded in recent years however, the effect of this disorder on parents and other family member is investigated only by few studies. The researchers of this study similarly reviewed studies conducted on autism in Ethiopia. Nevertheless to date, there have been limited studies on this area in general.

Quoting Mauk Reberand Batshaw, Argaw(2010), in order to cope up with the challenges of raising an autistic child parents need professional's advice ,information and social support. This is also substantiated by study conducted by Meron, (2006) on Autism and the Family: Prospect

and coping with the disorder, in Ethiopia *"Almost all parents agreed on working together with professionals in different areas."* She further explained in her findings, to cope up with the challenge parents make connections and seek help from family members, professionals and autistic center. The parents also started communicating to and building friendship with other parents of autistic children as a coping mechanism. However, Meron was not specific which coping mechanism is widely used by the parents and why they use it. However, there should be a need for outlining the kind of coping mechanism parents usually utilize for this will indicate what kind of professional help or assistance these parents would need. Any successful professional intervention plan has to be tailored specifically to the parents' individual needs.

In conclusion, previous studies reviewed for this study are limited in their scope, as well as inconclusive regarding supports need. In addition, only few studies were undertaken on autism in the Ethiopian context due to the fact that there are no institutions that may produce reliable information. Thus, it is important to study autism, autistic children, their parents challenge and support needs from relevant professionals. This study seeks to investigate the social, psychological, emotional and economic challenges the parents of autistic children undergo and the means of support they need in order to further their child's development and their family well-being. Therefore this study aims to assess challenges and support needs of parents of autistic children in Addis Ababa, Ethiopia.

1.1 Statement of the Problem

Being a parent is one of the most rewarding, challenging and difficult task one can ever undertake. This is because the role requires a continuous lifetime commitment, no matter how old our children get. Even if parenthood is a rewarding experience realizing that a child has

disability can be one of the most painful experiences of a parent. Having a child with developmental disability is the most challenging and demanding task for parents. Among other disabilities autism is unique and challenging in many ways. Problems with communication, emotional expression and antisocial behaviors rank autism as the most stressful childhood developmental disabilities. Among childhood pathologies, autism is the most challenging one due to its severity, duration and impact on the family (Gray, 2002,p.215).

Autism is a developmental disorder which is often characterized by extremely disruptive antisocial behavior like tantrums, self-destructive acts and other forms of inappropriate public behavior. Like other disabilities (e.g. mental retardation, deafness, blindness, and aphasia) this disorder has no clear biological marker and definitive medical tests. Its diagnosis is full of uncertainties. These unclear situations make it extremely difficult for parents to accept the child's condition (Gray, 2002, p.214).

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

One of the challenges faced by these parents is social isolation. Friends and family members may not understand the special needs of a child. Thus, those people in such social networks may not be able to provide the child-care support often available to families with more typical young children (Gray 2002, p. 216). Gray further explained the general public still lack awareness when it comes to autism. Parents of autistic children still suffer from social stigma, criticisms and insensitive treatments when the autistic child misbehaves in public. These negative reactions further delineate the physical, mental and emotional challenges of parents with autistic children,

further exacerbate the struggles of the parents and the family in general(Gupta &Singhal, 2005, p. 63)

In Ethiopia, this situation is even more tragic and severe due to the failure of the community in general to understand and to accept the person with the disability. As Tirusew(2005) stated, the birth of child with disability in Ethiopia has been viewed as the source of shame, disagreements as well as divorce among some families. Moreover the FDRE 2002 Country Profile on Disability,(2002) also explained the situation as:

Ethiopia is characterized by stereotypes and prejudice, based on traditionally held views that link disability with immorality, punishment and curses. Labeling people according to their disability is still common, and disabled children and their parents are stigmatized.

Besides, to that there are still major problems concerning developmental problems (like, lack of public understanding, insufficient information on the number and status of disabilities, shortage of basic needs, such as vocational training placement, health facilities etc) inaccessibility to assistive devices (FDRE, 2002).

It is common to misdiagnosed and misunderstand mental health disabilities and developmental disorders in Ethiopia. However, when compared with other developmental problems, (like intellectual disability) the complexity surrounding the life-long autistic disability are rarely understood. As reported by J-CCARDD,(2005) and also confirmed by a study undertaken by Meron(2006), the majority of the public, including professional and parents themselves are still unaware about the problem and also its impact on individuals and family life. Due to this most children with autism in Ethiopia are deprived of their rights for education and rehabilitation because of lack of awareness as they are considered to be useless and unworthy to invest on.

In the worst cases, these children are subject to neglect and abuse because of their unacceptable behavior. J-CCARD (2005) report stated that the founder of the center saw an autistic girl who was kept with her hands tied behind her back in a dark room. Many people still think affected children are possessed by the devil because of their parents' sins thus most parents hide their autistic children.

The other problem is, that there are only two official institutions in Ethiopia that have been giving care and support for such children and their families. These centers are located and are working only in Addis Ababa for a limited number of families due to lack of the required resources and funds. These centers are established by those individuals who have had autistic children.

In this framework, the present study is designed to assess multidimensional challenges being faced by parents of children with autism and their support needs at one of the two autistic centers in Ethiopia, namely Nehemiah Autism Center.

1.2 Research Questions

The basic research questions in the study to address the aforementioned aims of the study are:

- What are the social, emotional, and psychological challenges are being faced by the parents of autistic children?
- What are the social, psychological, and emotional as well as personal demands that parents of autistic children have?
- What types of experience do the parents have regarding handling their autistic children?
- What are the greatest challenges in raising an autistic child?

- What are the major support needs of these parents?
- What are the strengths and constraints of the intervention?
- What are the possible social work intervention strategies for these parents?

1.3 Objectives of the Study

1.3.1 General Objective

The general objective of the study is to assess challenges encountered and support needs of parents of children with autism at Nehemiah Autistic Center in Addis Ababa, Ethiopia.

1.3.2 Specific Objectives

- To identify support needs specific to parents of children with autism
- To assess the social, psychological, emotional and economic challenges being faced by parents of children with autism at Nehemiah Autistic Center; and
- To identify the strengths and constraints of Nehemiah Autistic Center.

1.4 Definition of Concepts

Challenge: refers to the situations that are difficult for parents of children with autism in raising their children and to cope with the disorder.

Support need: is the material, financial, psychological and social assistance, aid and service that parents of children need to cope with the disorder and the challenge of raising an autistic child.

Parent: is a person who is a father, a mother or a legal guardian of an autistic child and who is living and raising the child with autism and provides care and support for that child.

Pervasive Developmental Disorder (PDD): PDD is a category of disorders that involve impairments in, social interaction skills, communication skills, and the presence of stereotypical behaviors, interests and activities. There are five disorders under this umbrella term; Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder (CDD), Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

Autism: is one of the most complex and life-long pervasive developmental disorders that can impact how people understand, see, hear and sense the world around them. It is characterized by qualitative impairment in social interaction, qualitative impairment in communication and restricted, repetitive and stereotypic patterns of behavior, interests and activities.

1.5 Limitation of the Study

The sample size was originally intended to be 10 parents of children with autism at Nehemiah autism center as a case informant and 4 staff members as key informant. However there were only 4 parents and 2 staff members had the time and the willingness to participate in the study. This study is also limited to one institution this is because there are only two institutions that give care and support for parents of children with autism in Ethiopia, of these institutions only one was willing to cooperate for this study.

1.6 Chapter Plan of the Thesis

The MSW thesis consisted of five chapters. The first chapter is an introduction of the theme of the present study. This chapter described the concept of autism and how it is a social problem. It also provides a brief rationale for the particular study is worth pursuing. It further presented the statement of the problem, the research questions, the objectives of the study, and the definition of key terms, the limitations of the study and the organization of the thesis. The second chapter reviewed related conceptual, theoretical and empirical latest and classical literatures. The third chapter stated about research design and method of the present study. The fourth chapter presented the result of the data. In fifth chapter the findings will be discussed. The final chapter will pack up the major findings of the study in order to draw conclusions and forward recommendations in the light of social work perspective.

CHAPTER TWO

REVIEW OF RELATED LITERATURE

This chapter presents an extensive review of the available literature and research related to the study. It also has three sections. The first section dwells on definitions of autism, its characteristics, prevalence, causes, treatments and misconceptions about the disorder. The second section discuss about the challenges of raising an autistic child. The last section presents the review of related empirical studies and researches on the prospective support needs that the parents of autistic children needs elsewhere in the world

2.1 Autism: Definition and Characteristics

2.1.1 What is Autism?

Autism is a most common pervasive, neurologically based developmental disability which causes severe learning, communication, and behavior disorders with age of onset during infancy or childhood. It is marked by qualitative impairments of problems with verbal and nonverbal communication, social and emotional functioning which makes it difficult for autistic people to understand the world around them. (American Psychiatric Association,1994)

It belongs to the class of developmental disorders called pervasive developmental disorders. It is an umbrella term consists of a group of five disorders called: Rett's disorder; Childhood Disintegrative Disorder (CDD); Asperger's Disorder; Pervasive Developmental Disorder Not Otherwise Specified (PDO-NOS) and finally Autism. Autism has been detected four times more

in males than in females. In conventional cases, autism gets usually diagnosed in children below three years of age (Volkmar & Wiesner, 2009, p.26).

Autism was first described in 1943 by a child psychiatrist Dr. Leo Kanner. He called the case as “*an inborn disturbance of affective contact*” meaning, a child born without the usual interest in other people. According to Kanner’s earliest diagnoses on eleven children with autism, the children particularly exhibited resistance to change. He described resistance to change as insistence on Sameness or routine, like requiring or taking the same route, wearing of the same kind of clothes, eating the same kind of food, etc. He also used the term resistance to change to refer some of the unusual behaviors frequently seen in autism like, stereotype purposeless motor behaviors such as, body rocking, hand flapping, toe walking, unusual staring etc. Another characteristic reported by Dr. Kanner was the unusual language development like not having the proper tone, echolalia or pronoun reversal (Volkmar & Wiesner 2009, p.26).

All people with autism exhibited difficulties in social interaction and since they respond to sensory stimuli in an unusual manner they show atypical, odd and repetitive behavior such as body rocking, spinning, hand flapping etc. However, the extent and type of difficulty and behavior of each child may vary. For instance, some individuals may be very withdrawn, while others may be overly active and approach people in peculiar ways, some may even demonstrate unusual use of objects and attachment to objects. Despite sharing some behavioral similarities, people with autism have different characters. Consequently, the pattern and extend of difficulties may also change as individuals grow. (Columbia Ministry of Education, 2003)

2.1.2 Characteristics of Autism

When Karner first reported his finding about autism, he stated that the main features for the diagnosis of autism are social isolation and insistence on sameness. Other succeeding studies and researches also include communication problem as an important element in the diagnosis of autism. In 1980, the American Psychiatric Association published an official guideline on the diagnosis of autism. It was intended to serve as diagnostic criteria (Volkmar & Wiesner 2009, p.27)

In spite of the fact that all individuals with autism are unique, there are still some common characteristics that these people encounter. These features also serve as a hallmark to diagnose the disorder. There are three distinguishing characteristics that all professionals in the field use, however a fourth feature can be considered though it is not as salient as the first three. These features are; impaired social development, impaired language and communication, flexibility impairment or resistance to change.

Special need teachers take learning behavior as the fourth characteristic of autism though other professionals usually base their diagnosis on the first three features especially if the diagnosis is for children under three years old (Columbia Ministry of Education, 2003).

2.1.1.1 Impaired Social Development

Impaired social interaction is one of the hallmark features of autism. Children with autism have difficulties of interacting both with peers and adults. From infancy to age years 3 they exhibit lack of social skills such as, disinterest in social games, having little attention for family

members, having abnormal eye contact or limited attention to other people, poor playing skills, etc. Children with autism demonstrate rigidity and limitation in social interaction and have problems establishing relationships. This is because they are unable to process social information properly and to use appropriate social skills to create and maintain relationships (Columbia Ministry of Education, 2000)

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

Additionally, since they have trouble understanding others people's feelings or talking about their own feelings, they have difficulties in making friends and show significant difficulty with any interaction that requires knowledge of other people and what they think or know. Consequently, autistic children have impaired ability to initiate or sustain a conversation. Some children with autism show difficulty in noticing people who are talking to them and others might be interested in people but do not know how to talk, play or relate to them. (Ruble & Gallagher, 2004)

2.1.1.2 Impaired language and communication

About 40% of children with autism does not talk at all and others have echolalia or repeating what was said by others. Even if they can communicate, autistic children's communication skills

are limited to getting needs met rather than information sharing or complex interaction with other people. An individual with autism shows considerable difficulty in using languages as faculties of communication and interaction and information gathering and dissemination. This can include delayed development of spoken language, difficulty holding a conversation or repetition. (Ruble & Gallagher, 2004)

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

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

2.1.1.3 Flexibility Impairment or Resistance to Change

Demonstrating unusual and distinctive behavior is one characteristic of autistic children. These stereotypic and unusual behaviors are typically exhibited through repetitive behavior like restricted range of interest and preoccupation with specific interest or objects or parts of objects (spinning of fan, turning of wheels on toys, etc), stereotypic and repetitive motor mannerisms,

such as hand flapping, finger flicking, rocking, spinning, walking on tiptoes, spinning objects. Autistic children might repeat actions over and over again. They might want to have routines where things stay the same so they know what to expect. (Gray, 2000)

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

2.1.2 Causes of Autism

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

More recent studies reported that children with autism were more likely have had problems either before birth or during and other reported associations of autism with a number of medical conditions that can affect brain development. Currently, there is growing evidence that autism is a genetic condition, and that there are likely several different genes involved (Ruble & Gallagher, 2004). Environmental factors such as viral infections, metabolic imbalances, and

exposure to environmental chemicals and harmful substances ingested during pregnancy are currently gaining wide attention in the causes of autism as well (Landrigan, 2010). Various studies have been done to identify the cause of the disorder and multiple theories have been proposed to date. However, the absolute cause of autism remains unknown.

2.1.3 Diagnosis

Getting a diagnosis for autism is not an easy task. *“There is not a simple blood or laboratory test to determine who is autistic”* (Volkmar & Wiesner 2009, p.26). Since the exact cause of autism is not known, the diagnosis mostly relies on observation and history. In order to diagnose autism accurately, the child should have a comprehensive evaluation by professionals in the fields of language development, behavioral, social, and cognitive skills in young children. Autism is thus diagnosed by multidisciplinary team which consists of psychologists, neurologists, psychiatrists, speech therapists, social workers and other professionals (Ruble & Gallagher, 2004, Columbia Ministry of Education, 2000)

Medical doctors will often use a questionnaire or other screening instrument to gather information about a child's physical, mental, emotional and behavioral development. Some screening instruments rely solely on parent observations while others rely on a combination of parent and doctor observations. Medical doctors rely on main characteristics, such as, manifestations of qualitative impairments in social, communicative and imaginative development to alert them to the possibility of diagnosis of autism (Jardine, 2008). The American Psychiatric Association (1994) also specified three criteria that are used to make diagnosis for autism. These criteria are composed of the main distinctive characteristics of autism and include the following:

- Social interaction- severe abnormality of reciprocal social relatedness,

- Communication- severe abnormality of communication development, and
- Behavior- restricted, repetitive behavior and interest.

The above stated criteria are used by most professionals and most authors also agreed up on them. However, there are also other features that some professionals use as diagnosis criteria together with the above criteria. These are early onset of signs and symptoms and abnormal response to sensory stimuli. (Balfuor, 2007)

2.1.4 Prevalence

Autism is one of the developmental problems that affect everyone regardless of race, culture, religion, level of income and education. It is also a lifelong disability with no known cure. Early studies on the prevalence of autism among children show that in every 10,000 child births, 10 are affected by autism. However recent literatures are estimating the prevalence to be 1 in every 150 births and in the USA, it is estimated to be 1 in every 100 births. (National Research Council 2001, Columbia Ministry of Education, 2000)

Although autism affects both sexes, empirical studies found out that males are highly likely to be autistic than females. Studies also reveal the ratio range from 4: 1 to 5:1. Autism has a spectrum of severity which range from severe to mild. The severely autistic needs institutional care while the mildly autistic may be very intelligent and can live independently. However, approximately only one quarter of people with autism can function in the intellectually normal range a small number may make significant improvements with relative weaknesses in social and communication skills. (Balfuor, 2007) According to the American Psychiatric Association

(1994), two out of three children remain severely impaired and unable to lead independent lives. The majority of children with autism are also mentally retarded.

The main treatments for autism are educational and behavioral approaches. Other treatment approaches such as medication and alternative methods may be used in combination with these approaches (Swanepoel, 2003). “There is no specific treatment and medication for autism. However behavioral interventions which include teaching a language, social skill and decreasing maladaptive behavior are used as a therapies and treatments.” (National Research Council 2001, Columbia Ministry of Education, 2000) Early detection is also important for early interventions, particularly special needs education is found to develop positive outcomes to the autistic children’s future well-being (Swanepoel, 2003).

2.1.5 Some Early Mistakes about Autism

Karner’s (1943) first descriptions of autism led to more scientific inquiry regarding the disorder. However, the results he published about autism also proved to be misleading. He stated on his report that children with autism had normal intelligence because the children did rather well on some parts of intelligence test and quite poorly on the other part. However, current studies suggest that almost half of children with strictly defined autism function within the range of intellectual disability (Volkmar & Wiesner 2009, p.26).

Another misconception about autism is the belief that people suffering from the disorder possess extraordinary talents and skills. Findings show that only around 10 percent of autistic people had special abilities like idyllic memory, musical and mathematical prowess and artistic talents (Volkmar & Wiesner 2009, p.27). According to a study undertaken by Taylor in 2006 70% of autistic children have learning difficulties. This misconception can also be attributed to the

movie a movie called “Rainman” which is about an autistic man who had an extraordinary memory. Unfortunately, this film contributed to the common perception of autistic children as savants with extraordinary talents in calculation, music or drawing.

Karner’s findings on the primary causes of autism were also misleading. In his study, ten out of eleven participants of the research were highly educated and successful and the children and parents had less interaction. This leads to the idea that educated and successful parents are somehow ignorant and did not treat their children. This in turn, contributes for the cause of autism. This leads to a belief that autism spectrum disorders are caused by cold, distant parenting, and the mothers were particularly led responsible for the social and emotional abnormalities their children exhibit (Swanepoel, 2003). Even if the cause of autism is still unknown, it has been empirically demonstrated that parents of children diagnosed with autism do not differ from parents of typical children.

2.2 Challenges of Raising Autistic Children

Having a child with developmental problem is a challenging task for parents due to the constant extra attention that the child needs. However, as most studies and researches mentioned, rearing an autistic child is more challenging than rearing children with other developmental disabilities. According to Gray (2006), due to problems with communication, emotional expression and antisocial behaviors, autism gives tremendous stress for the families. *“Autism occupies an extreme position among childhood pathologies in terms of its severity, and impact on the family.”* (Swanepoel, 2003)

Autism is unique in most aspects than other developmental disabilities. Most of the challenges arise from its nature and characteristics. Autism is a problem that causes impaired

communication and social interaction which in turn makes intimate familial relationships extremely difficult to develop. An autistic child may have self-injurious behaviors which make a parent feel frightened and helpless. According studies, parents of children have high risk of developing psychiatric disorders such as major depression and social phobia which may be directly related to the stress and burden of living with and caring for an autistic child or adult (Gray, 2002).

According to a research, parents of children with autism typically report higher levels of parenting stress and higher affective symptoms when compared to parents of typically developing children and parents of children with other disabilities (Davis & Carter, 2008).

2.2.1 Diagnosis as a challenge

Due to the lack of more appropriate diagnostic criteria, the process of obtaining an accurate diagnosis and an appropriate form of treatment for autism is often a long and frustrating experience for parents. *“While the symptoms of autism are usually manifested early in childhood, it is usually several years before the disorder itself is diagnosed. This process is complicated by the absence of a biological marker”* (Gray 2003). Most of the time examiners will use various methods to ensure that the result is valid. There are many reason that makes autism diagnosis challenging. One is that it is misdiagnosed most of the time. Autism is misdiagnosed because the disorder shares a number of features with others which are commonly known as disabilities like intellectual disability, hearing impairment and other speech and language disorders. For instance, both intellectual disabled and autistic children exhibit low IQ and both may also show stereotypic body movement. Gray also supported this; *“because of the difficulty in accurately*

diagnosing the disorder. It is likely that many autistic children are misdiagnosed as retarded, and, consequently, never receive appropriate treatment” (Gray, 2002).

Another reason that makes autism diagnosis challenging, is the tremendous range of variability in levels of functioning within and between children. No two children with the disorder behave the same way. Additionally, autistic children may exhibit behavioral problems that can complicate the process and also the child may not cooperate due to lack of social interest. These problems can all be devastating for parents and may also lead to depression (Gray 2003; Swanepoel, 2003).

2.2.2 Getting Social or Professional Support as a Challenge

Having a child with autism imposes an extra demand on parents as their children have specialized and reutilized needs. In order to deal with the stressful situation parents then require considerable formal and informal support. Parents need professionals and social support starting from the time of diagnosis until the intervention planning period (Gupta & Singhal, 2005). The absence of such support may lead to the child staying at home, a situation that would only cause more stress to the parents. According to a study undertaken by Jardine (2008), having an autistic child can not necessary be the source of stress in the families, although lack of appropriate service or insufficient special education provision can be an external stressor.

2.2.3 Autism Characteristics as a challenge

Autism is a disorder that is characterized mainly by impairing a child's communication and social interaction, and causes the development of stereotypic or repetitive behaviors or interests. These characteristics impose a great challenge as fundamental rewards of parenthood such as forming attachments and showing affection are not available to them. (Gray, 2002) Autistic children also exhibit behaviors that are difficult to understand and manage. They similarly exhibit socially inappropriate and aggressive behavior which leads parents of autistic children to have high levels of anxiety, depression, and everyday stress from parenting. In addition, these antisocial behaviors cause stigma to parents (Swanepoel, 2003).

2.2.4 Family Strain

As studies on the family strain revealed, raising an autistic child is the most challenging and demanding task that has a serious impact on family life. A diagnosis of autism presents significant challenges to parents; this is because there are no specific diagnosis criteria for autism. Mostly autism misdiagnose as there is no clear biological marker like other disabilities such as mental retardation, deafness and blindness. Regarding to family strain the following experts say this:

After the onset of autism, parents experience an intensely stressful period as their child's problems grow more pronounced and they struggle to obtain an accurate diagnosis and treatment for their child. The process of obtaining an accurate diagnosis and an appropriate form of treatment is often a long and frustrating experience Gray (2002).

Autism also makes intimate familial relationships extremely difficult to develop as autism is a disorder that impaired social and communication skill .This inherently changes the parent-child relationship and intimacy. The child's self-injurious and disruptive behaviors may also make a parent feel frightened and helpless (Wnoroski, 2008).

2.2.4.1 Marital

Autism causes difficult marital relationship. The stress of living with such an individual can affect the psychological well-being of family members as well as generate conflicts among them According to a study undertaken by Grey (2003), most parent emotional well being had severely affected by the disorder. Many parents had experienced distress and required psychotherapy and medication. Parents of disabled children are particularly vulnerable to stress. High levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children. Parents of autistic children also found to be at a higher risk for depression, social isolation and marital discord. A study conducted by Balfour (2007) illustrated that a child with autism put marital relationship under stress which in turn pull the relationship apart. Swanepoel (2003) argued that extreme demands on time and energy which the autistic child made on caregivers gave them little or no time to spend as a couple. This in turn causes marital conflict as the other partner feels neglected.

2.2.4.2 Siblings

As the core nature of autism makes extreme demands on parents' time and energy they devote less parental attention to normal developing siblings. As Gupta and Singhal (2005) reported,

Many siblings have felt that their parents perceived their needs as being secondary, with more time and attention given to the child with autism. Whilst they may have a

deep love for their sibling, they may also harbor feelings of resentment at the amount of time their parents are spending with the child with autism, and feel that they are being treated unfairly.

The study conducted by Gray also explained that, in addition to the feeling of getting less attention, siblings of autistic children were also at risk of bearing the psychological and emotional brunt of growing up alongside a child with behavioral difficulties. Along with psychological problems, exhaustion may affect siblings who may be responsible for domestic tasks and physical care (Gray 2003).

2.2.5 Stigma

As most studies on the stigma conducted in different parts of the world revealed, families of children with autism experienced stigma from the outside world. This is because of socially inappropriate and aggressive nature of autistic behavior families. Such families often find that public reaction to them is stereotypical and negative (Gray, 2002). The same author further explained that the parents of autistic children frequently encounter hostile or insensitive reactions from the public when their children behave inappropriately. This problem may be exacerbated by the contrast between the children's appearance, which shows no signs of disability, and their behavior, which is perceived as abnormal and "strange". Swanepoel (2003) also stated that families of autistic children lose family friends or isolate themselves because of public criticism and inappropriate behavior of the autistic child in public places.

2.2.6 Stress

A number of studies have demonstrated that parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children (Pisula 2010,

Davis & Carter 2008). The feelings of loss of personal control, absence of spousal support, informal and professional support are found to be the major source of stress in parents and caregivers of children with autism. Other important factors associated with parental stress in families of children with autism, include, adjustments to the reality of the child's condition, housing and finance. Studies have also demonstrated that families with aggressive or violent children and had few resources in terms of treatment or residential placement to deal with their situation experienced high levels of stress (Guptha & Singhal 2005).

Other study undertaken by Pisula (2010) revealed that child characteristics, lack of adequate professional support and limited access to medical and educational services for the child and social attitudes towards individuals with autism and lack of understanding to be the major groups of factors that contribute to elevated stress in parents of children with autism.

2.3 Support Needs of Parents of Autistic Children

Any form of developmental disabilities causes a serious challenge, for both the afflicted individual and families. Parenting autistic child though is the most demanding and challenging task which creates physical and emotional exhaustion. Many parents greet the news with shock and denial and keep looking ways to prove it is not true. At the same time they often experience tremendous guilt anger.

After passing the first stage parents cope with the situation differently. One parent may cope by giving every attention for the child and others may become avoidant or depressed (Volkmar & Wiesner 2009, p.28). According to Batshaw (2010) (cited in Argaw 2010), to cope with the challenges of raising an autistic child parents need professional's advice and information and also

social support. This issue also supported by Meron(2006), parents of children with autism needs professional support to cope up with the disorder positively.

The majority of parents will need a range of supports in order to cope up with the demands of caring for a child with a developmental disability. The type of support needed may vary according to child's behavioral problems, motor impairments, parents' gender, parenting roles, parents' socioeconomic background and parents' attitudes to childrearing. However, according to experts in the field, most parents of autistic children support needs are; information, support, social support, access to professionals services, respite care and financial support (Guptha & Singhal 2005).

In Ethiopia finding professionals for support is difficult due to the fact that there are no such professionals in the field. This also confirmed by Argaw (2010), on a study of parental involvement at the intervention program of Joy center for children with autism. As he stated there is a lack of professionals that can give individual based support and also guide parents through their involvement in the intervention program. All parents interviewed for the researched stated this as a problem

According to Meron (2006) Most parents of children with autism in Ethiopia did not have clear idea and understanding of autism and its nature in general. Although some people give their own explanation, it is far from the concept and definition given by professionals. For instance, The Autism society of America defines autism as severe life-long developmental disability marked by impairments of communication, social and emotional functioning. However according to Meron, some parents believed it is mental illness, some thinks it is caused by evil eye which can be cured by prayer and some rituals, and others still don't understand what it is, how it affects people. In connection with this Meron has stated that "parents are still unaware of autism and do

not have the information on how it affects people”. Further Meron, also stated that there is also limited public knowledge and understanding of the disability in general. As the respondents mentioned, neighbors do not allow their children to play or be with their kids. Some also believed that the children are acquired the disability due to their parents sin.

CHAPTER THREE

RESEARCH DESIGN AND METHOD

3.1 Background Information of the Study Site

Nehemiah Autism Center is one of the two centers in Ethiopia that are providing service to children with autism. It is an indigenous non-governmental and non-profit organization which was established in August, 2010 by a mother of an autistic child who was tired of waiting at the long waiting list of the only center providing service for such children in the country at that time. Nehemiah is the second autism center in the Ethiopia.

Nehemiah Autism Center is located in Addis Ababa, Ethiopia, in Bole Sub City around 'Megnagna' district. It is giving service in a small rented house situated in a residence place. The center comprises of eight class rooms, one office and two toilets. Currently it has 16 teacher and 4 supportive staffs. The teachers who are presently working at the center are 16. 3 males and 13 females of these one has autistic child. All the teachers took different training which enables plan intervention program and gave different education and training for the children. Regarding qualification there are 4 psychologists and the rest members of the staff are college graduates in different fields.

Regarding student population, when the Center for the autistic commenced its services there were only two children. However, within the last three years the number of autistic children has dramatically risen and currently it has 33 children who are receiving school based intervention and 140 children in the waiting list. Among these, 26 are males and 7 are females. The major

areas of the services provided by the Center are; self help skill development, social skill development, occupational therapy, cognitive skill, communication skill and others. The center has been also providing care training and education for parents.

3.2 Research Design and Methods

In this study the researcher was employed non-experimental research design. A qualitative research approach was identified as the most appropriate to meet the aim of the research in assessing the challenges of parents raising a child with autism and support needs. The central guiding question is “What are the challenge and support needs parents of autistic children at Nehemiah Autistic Centre?” This existential question was answered with a qualitative research approach which was conducted at the centre in Addis Ababa.

The research approach was chosen by the fact that qualitative research method offers the researcher the opportunity to understand individual’s situation the way it appears naturally. This in turn, helps the researcher to understand what it means to them, within their social reality, to live with a particular condition or be in a particular situation. It is also through an in depth interviews of qualitative research method that one can better gets answer to questions of why, how and in what way? It then allows the investigator to go deep and to generate an intensive data which are useful for intervention.

Qualitative research is also concerned with the opinions, experiences and feelings of individuals thereby producing subjective data. It describes social phenomena as they occur in their natural settings (Biggerstaff& Thompson,2008). With regards to answering the central question of this study, the qualitative research methods prove to be the most efficient as it can provide direct

answers to the question of the events people undergo in their daily routine of lives and how they are affected by them.

To this end, qualitative research methods, such as case study method which involves in depth-interviews with case informants, semi-structured interviews with key informants, observation of setting of the center, related published and unpublished documents, research and case studies in the centre was reviewed to triangulate the research problem completely and also to get background information about the autistic centre. In qualitative research approach and method reviewing relevant documents, progressive reports and records which help the researcher to get the necessary background of the situation and insights into the dynamics of everyday functioning of the parents, autistic children and the Centre. Documents, reports and records also give the researcher to have access to pieces of information that would otherwise be unavailable.

3.3 Universe of the Study

The universe of this study was composed of parents of children with autism at Nehemiah Autistic Centre. Nehemiah Autistic Center is one of the two centers in Addis Ababa, Ethiopia. It is located and operating only in Addis Ababa. Currently it is providing care and support for more than 20 autistic children. It also provides training and support to a group for parents. The study used cross-sectional data which was collected during the academic year of 2012/13.

The main target group for this study was parents of children with autism at Nehemiah Autistic Centre who were willing to disclose pieces of information about their daily lives and how they are dealing with their autistic children. The sample was selected from Nehemiah Autism Center. The sample size was consisted of 4 parents who have children with autism and come to the

center to seek for professional help. Generally the total sample size was 4 key informant parents and 2 people from other stakeholders.

3.4 Sampling Methods

The sampling method to select case informants and key informants in the study was purposive sampling of non- probability sampling method which was entirely dependent on the willingness of the informants to answer the interview questions. Even if it was based on their willingness, the following study participant inclusion criteria were also considered:

- all participants will have child/ children diagnosed by physician as autistic;
- who were willing to share their experience with the researcher;
- who reside in Addis Ababa; and
- were able to speak Amharic or English in answering those qualitative questions in a research tool(s)/ instruments.

The sampling method for the institution was also purposive. Since autistic centers are the best places to find parents of autistic children who are directly related to the study topic and can share firsthand information on the parents' experiences. In addition, there are no other well organized social institutions that provide care and support for autistic children and their parents in Addis Ababa, Ethiopia.

3.5 Data Collection: Tools and Procedures

The researcher was employed research methods, such as semi-structured, in-depth and face-to-face interviews under qualitative research methods as methods of data collection. These methods

were used since they are the best fitted method for such qualitative research undertaking with small number of informants.

According to Longfield (2004), Semi-structured interviews give the flexibility to explore different topics in-depth with different informants and also facilitate the collection of new information. Open-ended questions encourage informants to determine the direction of the response and encourage them to reply at length. The major advantage of using open ended questions is that they reveal what is on informants' minds, as opposed to what researchers suspect is on their minds. The questions were formulated keeping in mind the objective. Thus, the researcher was held in-depth interviews with case informants who are parents with autistic children using interview guide consisting of semi-structured open ended questions for about 90 minutes.

Such in depth interviews through probing was needed more than one interview sessions, the researcher was held with those case informants accordingly. This was to ensure that if one interview does not go well, the researcher still has another interview with the same type of informant from whom to collect qualitative data. This measure was taken by the researcher to ensure the reliability and validity of the data in the study

Based on consent all the interviews were recorded using the tape recorder. Audio-recordings of the interviews were made with the informed consent of all participants. Informants were informed about the purpose of using a tape recorder. Confidentiality was also maintained for the sake of protecting the informants from unforeseen circumstances by changing their personal names and it will be only accessible if needed for professional purpose after the researcher has got consent from the respective informants. All participants in the study were informed at each

interview session that they can refuse to answer any question, or end the interview session whenever they wish in the process of the actual face to face interview.

3.6 Data Processing and Analysis

If data are collected using audio tape recorder; one should prepare written verbatim transcripts the interviews. Later analysis can be done, but notes should still be recorded immediately after being in the field (Dey, 1993; 2005). Taking this into account, the interviews made using audio tape recorder was transcribed and noted on a paper right after the interviews. Then was translated from Amharic in to English by making sure that the actual statements were repeated and meanings are clear to readers in order to identify patterned categories of issues and themes. The collected data should be labeled according to each category of issues, theme and in the light specific objectives of the study because it enables the researcher to manage data by labeling, storing, and retrieving it according to the codes (Dey, 1993; 2005). After the completeness of data collection, the researcher read the transcripts again and again till the data were understood. Then, the data were categorized by identifying the major and essential themes. In what follows, these themes were again divided into categories and then the categories were divided in to sub categories as required. The data were further categorized until all the relevant themes were identified. Then after, the researcher was identified connection between and within categories of issues and was interpreted the data qualitatively.

Narrative and thematic qualitative data analysis methods were employed for this study. Narrative analysis is one of qualitative data analysis methods which seek to understand human experience and/or social phenomena through the form and content of stories narrated by individuals (Reissman, 2005). Of the different models of narrative data analysis, the researcher was used

thematic model of narrative data analysis. It is the model which focuses on the content of a text. In other word it emphasis on “what” is said more than “how” it is said(Reissman,2005)As the aim of this study is to assesses challenges of parents autistic children and their support needs from what they said; this model was selected. This identified and categorized major issues, as well as themes were putted in different labeled folders and then drawn to be used while writing up the MSW thesis.

CHAPTER FOUR

RESULTS OF THE FINDINGS

The chapter presents results of the data analysis and discussion of the results of the study and their interpretation process. The themes and categories that resulted from the data analysis were grouped into two broad themes. These include: challenges and needs specific to parents of children with autism. These themes are again categorized and subcategorized accordingly.

4.1 Data on Parents Interviews

The analysis was done based on the following themes; challenges, support need and strength and constraints of Nehemiah Autistic Center. Then these themes again divided into categories and the categories further divided in to sub categories as needed.

4.1.1 Challenges

Having an autistic child is the most challenging situation one can face. All respondents experienced so many challenges before and after coming to the center seeking help. The challenges were explained under the following categories and subcategories.

4.1.1.1 Social Challenge

4.1.1.1.1 Diagnosis

Getting diagnosis for autism by itself is challenging. This is due to the fact that, diagnosis needs time and different professionals working as a team. According to researches, receiving a

diagnosis is a complex process that frequently begins when parents recognize that there is something 'different' about their child and their behavioral development (Kirsten, 2008). All participants in this study described recognizing that there was something different about their child and wondering and doubting what it was. From this theme the following sub categories were identified.

I. Recognizing the problem and searching for an answer

Parents with autistic children have different experiences. Parent 1 for example has recognized her child was different since she was eight months old. She was told by a physician that her child is not sitting properly like typical children of her age. However, she explained that, "*I thought she was fine and I even used to say that all kids are not the same and my daughter will sit in her own time, so I left her alone*".

This mother continued and stated that she spent most of her time searching for what the problem was but it took her four years to discover what was wrong.

Some other parents had various ways of recognizing autism. Parent 2 recognized her son's situation because of his behavior. As she explained "*He had such a difficult behavior. He didn't use to sleep well; he used to cry and disturb us a lot.*" She said that she used to spend most of her time praying about her child's situation. Parent 2 knew her son was autistic after four years.

In addition to the child's behavior, problem in speech can be taken as another evidence on autism. Parent 3 is a case in points, as he said was able to detect his son's disability because he had a speech delay. "*We thought that the problem was only speech delay. When we took him to a physician, we got the same response.*"

As parent 3 explained they were not able to find out soon that their child is autistic right away, even with the physician's help. That was because of professional misdiagnosis. *"The other physician told us that there was blood clot in the child's brain and he prescribed medicine for him."*

Parent 4 also identified the problem on the part of her child because the differences became evident as her child was displaying difficulties interacting with his environment. *"I used to compare him with his elder and younger brothers and told a physician that he was different. But I didn't get any solutions just by saying that."* As this parent continued to explain, she found out her child's exact problem after she had watched a documentary on television about one autistic child and she compare her child to him. The mother recalled *"My child had similar character with the child on TV,. I called one doctor I know and told him about my discovery."*

II. After diagnosis: Searching for professionals help

All parents with autistic children first got their respective child and diagnosed. Afterwards, they looked for professional help.

Parent1 explained her reaction when she first knew her child has autism as *"It was so difficult to accept that. I used to talk alone while walking. Once, a car was about to hit me while I was crossing road having been filled with this thought."*

She said that it was her husband understanding about autism that gave her strength. She had no idea about the disability. She used to ask physicians' help for every single matter and talked to everyone about it for she thought that people might give her solution to her child's developmental problem.

Parent 2 explained her feeling back then as “*scared*”. She had never heard about autism before and she got her strength back through prayer.

Parent 3 was in denial. Even if he knew what autism was, it was not easy for him to accept the fact that his child is autistic. He said, “*It is difficult to handle when it come to you.*”

When Parent 4 realized his child’s disabilities, “*I cried a lot and asked God why that happened to my child.*”

Parent 4, said that she was aware of the fact that her child is different from typical children of his age and after she saw a documentary on television about autism she knew that her child had the same problem too. However when the doctor told her that her child is autistic she was very sad and desperate.

4.1.1.1.2 Getting Professional Help

Once parents know about the situation they pass through an emotional adjustment till they accept the problem and seek for help. However, finding help was as complex and challenging for the parents as identification and recognition of the disability.

Parent 1 was told by a physician to go to one of the only autistic centers in the country, but it was closed for admissions due to overcapacity. She said,

I went to ‘J’, but I didn’t get a place for admission. When I saw the autistic children there, I thought my child was not like them; and hence, I didn’t give much attention to follow up and lost motivation in admitting my child there.” I never got professional support. I have lived searching for a convenient school that suits her, but I found none.

For Parent 2, however, the situation was different for she did not know how to proceed after discovering that her child was autistic. No one informed her for the procedures and interventions she has to take as a parent. When she stated: *“The physicians didn’t tell us anything about where to take our child after that, they had no idea.”*

Even if her husband finally got the information about the only autistic Center in the country at that time, it was also closed for new admittance. This situation has its negative impact as she reflected *“That hurt me so badly. The fact that he couldn’t go to other regular schools hurt us more again.”*

Parent 3 explained that he was denying for a long time so he sent his son to a conventional school where he paid extra for the guards to keep an eye on his son not to run out of the compound. However as he noticed he got no help there so he went to a doctor that made him believe that his child problem is autism. Then he took his child to the autistic center. He said that: *“I wouldn’t be able to secure a place for my child even if I waited for four years while the child was learning in community school.”*

Parent 4 also experienced the same challenge. Like the other parents she also went to ‘J’ Autistic Center as recommended by the doctor. This parent added *“What the doctor told me was that my child wouldn’t be fine; you don’t expect such response from a doctor. What he told me made me desperate of my child’s health”.*

When she got back in her feet again she went to the autistic center. She disclosed,

I took him to ‘J’ Center and got registered. I was the 400th something person to be registered. I didn’t even know that I was in the waiting list. There were many people crowded there and weeping. I saw an old man weeping and telling the registrar officer that he had been waiting for the previous 5 years’ time when I asked why they are doing this with no service she said ‘do you know how many people are

before you?’ I said ‘I don’t know’. She asked for my registration number and when I told her she said that it is a waiting list.

Like other parents this parent also didn’t enrolled her child and gets professional support at the Center.

4.1.1.1.3 Impact on Family life

Having an autistic child has a negative impact on family life; because once a diagnosis has been made, the family with an autistic child faces yet another challenge. According to Gray (2000), families of children with autism have to learn to adjust to and cope with the needs and multiple demands of their child. In addition they need to balance the situation with siblings, marriage and some financial strains. From the above theme the following categories were identified.

I. Marriage

Parent 1 described that having an autistic child didn’t cause any impact on her marriage. She said that *“My husband gives much focus on our daughter and takes every care for her. He helps her a lot as he understands the matter more than me. There had never been any problem that has arisen in our marital life due to our autistic child.”* Parent 1 explained that she coped with her grief because of her husband’s understanding and support.

Parent 2 also had the same experience regarding her marriage and autism. As she stated, *“My husband is so busy, and he frequently goes for field work. So it is me who stay most of the time with the child. My husband, however, helps me a lot in all his presence here. It is just because I have some good things with my husband that we are bound together. We would have been separated had it not been our close understanding of each other.”*

However Parent 3's marriage was greatly affected by having an autistic child. As his wife is still grieving, their marriage is not like it was before, when he expressed; *"As my wife couldn't accept the problem, she usually gets depressed, upset and in tears. Whenever he shows unusual character, she weeps. So, this has created some gap between me and her."*

Parent 4 also described that her marriage is not affected by autism. She said that it is their understanding and support kept them strong, as reflected: *"I am so grateful; God is great, we understand the situation well. It is our understanding towards the problem and my husband's strength keeps us like this."*

II. Siblings

Parent 1 described that she spent more time with her autistic child, however as she said the others are old enough to understand the situation. *"I spend much of my time with her. The others focus on their education, they are not that demanding, they understand me, as they are her elders, they help her very much"*.

Parent 2 also explained that she gave more attention and time for her autistic child. As she aired *"I am biased to him. He needs my whole attention. The others understand why I do that. They know that he can't go here and there independently and can't communicate his needs properly. So, they don't complain if I spend more time for him. Nowadays, as they have known about autism, they stay with him most of the time."*

Parent 2 also said that since they understood the problem, they started to play with him and he has shown physical improvement. She also acknowledged how the situation was difficult and

disturbs her family members. She continued, “*We sometimes go to sleep without dinner seeing his unfavorable situation. When my children see me crying, they will also feel so bad.*”

However, when her autistic child’s behavior is better, Parent 2 considered it that she spent time with her other children.

Parent 3 also described that he gives much time for his autistic child. He also said that his autistic child’s younger brother is too young to understand the situation.

Parent 4 also spent much time with her autistic child as he demands a lot. But, she said that the elder one slowly understands the situation though the younger one is too young and also required her attention. She said her elder child use to resent her, as she uttered “*The eldest one has grown and become able to differentiate things. He used to tell me ‘you don’t like me’ when I fed my autistic child. The youngest one still wants my care. If Dani (the autistic child) sits on my lap, he also wants to do that.*”

4.1.1.1.4 The Public Understanding

Parent 1 explained that the urban population had a better understanding of autism now than before.

Since this place (Addis Ababa) is a city, I suppose that the public has understood about it. When we go out for an invitation or recreation, we won’t face serious problems. They tell me that God will heal her and reveal his power. I talk about it with everybody who comes to me. I do this thinking that I will get mental relief. I also think that people will give me better ideas on how to handle the problem if I am open to them. When people come to my store and if there is a discussion about our children I tell them about my child’s situation. I do think that people might have some information where I can get help.

Parent 1 also mentioned that sometimes she gets negative comment in public places. She remembered one that incident that hurt her, as she said *“Once we were in Sodere (a recreation center) and my daughter took someone’s glass and drank what was in it. The lady who was using the glass poured out the remaining drink and washed it. She was not even satisfied with washing that, and she brought another glass to use as if my child had any other communicable disease. It really hurts.”*

Parent 2 thinks that the public does not have awareness and understanding about autism yet. When she stated

Most people don’t have the understanding. I myself came to know about it just because it happened to my child. The physician, who, at the beginning, told us about our child, didn’t even inform us where to take him for education or any other help. Even sometimes when we take him to hospital for other checkups, the doctors and the nurses themselves don’t have the awareness about autism and they just take their own judgment and comment that we should discipline him when he misbehaves.

She also mentioned that people passed negative comments and judgments.

People talk many things about it. Sometimes when we go somewhere far, he shouts after going some distance. I will feel bad if people turn back because of the child’s screams. Once he was sick and we took him to a health center for medication. While going here and there for laboratory, he was screaming and people were saying how undisciplined he is. I was not actually surprised with that since I had also heard bad experiences from other parents of autistic children.

However, this parent mentioned that things are starting to change now.

Parent 3 explained that the educated ones in Addis Ababa have better understanding.

While walking on the street or going by taxi, some people ask me why he doesn’t talk as his face doesn’t indicate he is autistic. I explain it to them. There are also people who know well about autism, some, even if they have no idea what it is

they pretend that they understand you they don't want to bother you. Anyway, there is some positive change nowadays.

However, he said there is still a problem with the uneducated ones, as he expressed: *"They think the child has got some kind of evil spirit. They also think that it is contagious. When I came from Dilla, I was looking for a house of rent and seeing my child the land lord refused to rent his house to me."*

Parent 3 also described that he received negative comments. When he stated, *"Once we took him to a dentist to get his teeth pulled out. The dentist did that with the help of two other guys with a lot of difficulty. Then, the dentist told us 'how have you raised him up to be rude like this?'"*

Parent4 disclosed that, *"Most people have not understood it, yet. But, there is better awareness now as compared to before. Here in Addis is better. We hear about autism on the media more frequently. There are many people that at least know there is a disability called autism."*

She also responded that there is a huge gap in understanding the main causes of the problem.

Some still thinks that it is something evil and caused by your sin. Some confuses it with retardation. Let alone the ordinary people some professionals whom you think know a lot don't have the awareness. That is why they don't even tell you that there is the possibility that it might be autism. Most parents only know of the disability a lot later. I came to know about it by myself late. In fact, lot of things should be done immediately. While teaching in the church once, a pastor told me to close my door, stay at home and pray to God to be forgiven instead of going out to the public to open a school.

4.1.1.1.5 Personal life

Having an autistic child affects the parents' personal life in many ways. Parent 1 described the way that her personal life changed. As she shared her experience,

I quit my job for her. Wherever I go, I take her with me. Sometimes I take her to social gatherings (Mehaber) if she doesn't have disturbing behavior, but she may unexpectedly stare at you. She touches you, picks up something, and so on. When she does these, people won't say anything; but I get disturbed. For this reason, I don't have friends whom I invite them to come home.

Parent 2 related and said that *"I spend most of my time with him. I don't have my own time. If there was some institution that I can trust I could have at least have sometime for myself. I am happy working here and I love my son, I really love him. Sometimes I feel guilty for not giving much attention for my other children."*

She also said that as her child does not enjoy going to places, she avoided going to any social gatherings except the church.

Parent 3's personal life was also affected in many ways, when he argued, *"I left my job and came here to help him, though by chance, I got a job here easily. I had begun doing my PhD but due to him I couldn't proceed, and had to quit. I sometimes think that there is no use whether I learn or not."*

Parent 3 responded that his social life is not affected as his wife. Then he reflected,

I can say that he has affected my social life a little bit. My wife however, is very much refrained from that. As she can't tolerate things, she gets easily disturbed when he does something in the presence of others. She doesn't even like it when people stare at him. Her friends don't come home due to this. Therefore, I can say that it has affected her social life a lot.

Parent 4, however, described having an autistic child affected her personal life both positively and negatively mixed experience. She explained:

I was a good Christian and I use to pray before, after my mother died I stopped everything. No church, no praying, I was disappointed with God I guess, but He called me again through my child. Not only I, but even my aunts also- we all renewed our relationship with God. It is my child who brought me to spiritual life again.”

She said that her personal and social life also affected negatively, as she aired,

It alienates me from social life, you don't even have sufficient time to get your hair done let alone going out for wedding and invitations. Once or twice, I tried to go to a birthday party with him, but he himself didn't enjoy it. He doesn't like to go to someone's house that he doesn't know. Hence, I don't usually take him to such places.

4.1.1.2 Economic Challenge

4.1.1.2.1 Financial Strain

Regarding finance, the participants had different experience. Parent 1 reported that having an autistic child didn't affect her financially. However this mother mentioned that when she was looking for a school she was asked a great deal of money that she could not afford. As expressed

What I spend for her is the same as what I spend for the others”. “I went to some schools that give special classes for such children, but what they asked me to pay was too much. Even if I sell all my properties, I still couldn't be able to cover it. Even if I dare to pay there is no guaranty that they really help my child, for how long am I able to pay that amount of money? They don't even consider this.

Parent 2 reported that having an autistic child causes her some financial strain but not that much. In the same framework but through different windows; Parent3, however, said that having an autistic child doesn't affect him financially: *"I pay tuition fee for him just like the amount anybody pays for a normal child."*

Parent 4 responded regarding financial strain, *"Medication costs a lot and, initially, it strained our budget. After the medication though, there's not really any other expenses incurred from having an autistic child."*

4.1.1.3 Psychological Challenge

4.1.1.3.1 Parents Understanding and Attitudes towards Autism

I. Parents Understanding

Parent 1 is still unable to fully comprehend the root cause and consequences of autism. Her predicament as a parent of an autistic child still makes her uncomfortable.

I used to be worried how it happened to me and I didn't even know what it was. I had inquired from a physician about it but they didn't tell me anything.... there was nothing different when I gave birth to her except that I had taken labor pills. Due to this, I sometimes doubt that the physicians might have overdosed me with pills which may have created an impact on the child..." Even if she was puzzled by the situation she still believed that her daughter will heal, *"God is sacred, and what I know and believe is that my child will be relieved from this problem. I don't know how it can happen or I have never had any idea about it, but I have the belief that my child will be normal in the future."*

Parent 2 viewed autism as:

It is the worst type of disease. A devil should not even deserve to have it. It makes you lose social life. I have no words to explain about it. It is a disease human beings should not deserve to get it. Oh can I get a word to explain how difficult it is? I don't know how it happened to me but the time that I used to feel bad has ended.

Parent 3 had awareness about autism before however he still explained it as:

Most challenging, it is so challenging despite my awareness. It is such a difficult matter. You can't recognize their interests and needs. It is difficult to know what they want, what is disturbing them. It is the most challenging thing I have faced in my life. I don't know how it happens.

He also explained that through reading and personal research on the disorder, he is able to have a better understanding and knowledge on how to cope with his child's behavior.

However, Parent 4 said she understood autism as autism, as the science describes it. *"Despite the fact that it's challenging I understand it well."* She believes that her understanding is the reason why her has acted quickly when she knew that her child was suffering from the disorder.

II. Parents Attitude

Parents described their attitude towards their children's situation and beliefs regarding leading an independent life.

Parent 1 wanted to find her child's unique talent and help her develop it. When she stated, *"People say that autistic children have some extraordinary talent. I think if we can find that gift in her and it's developed through our support, she can be effective in her life. I have a strong faith in God, my child will be fine."*

Parent 2 thought that having a better service would help her child to improve.

If there is a better service, change will come. God has done a lot of things for me. My child has gone through a lot of changes. And there will be something more tomorrow. I believe that God

will do much more things. If there is better service than which is now it will minimize the problem.

Parent 2 believed that being autistic by itself has problems but the problems had been exacerbated by the lack of professional help and facilities that could aid her child's development.

Parent 3 wanted to know his child's unique talent. As he stated; *"If I get the opportunity of taking him abroad, I believe that I will get to know his unique natural talent. And, if he develops that, I suppose that he will be effective. Anyways God knows everything about it."*

He also said that there is a problem that his child facing and will face just by being autistic especially in Ethiopia. However, like Parent 2, Parent 3 also believed that improvement in his child's well-being will be faster if professional facilities and services are available, affordable and accessible.

Parent 4 had a complete conviction about her child's future and his ability to lead an independent life. *"My child will be an engineer. God is super. I have a huge trust in this."* She explained that there are existing problems right now but she believes that there is also resolve for improvement.

4.1.2 Need Specific to Parents of Children with Autism

Having an autistic child is the most demanding task one can have. Parents have different needs to cope with the disorder. The following categories were identified from the finding of the study: professionals' support, social support, future concern and prospect,

4.1.2.1 Professionals' Support

Parent 1 wished if she could get support to discover her child's special talent. As she stated,

I would be happy if there are any help from others that could work on detecting talents of autistic children. I wish there could be special needs schools according to the level of mild autistic children. I have been worrying about where to take my child for education. A regular school is not suitable for her. She needs to be in a special school for her previous school was not convenient for her. The autistic children there were in worse condition than her. Their behavior was different from hers. The school where she is learning now does not also fit her. She has started screaming and disturbing nowadays. She was not like this before.

Parent 2 described the institution with professionals as her support need. When said;

It will make situations easier and better if there is a better service. I will also be relieved if such things get established. Well-trained and committed professionals can bring positive changes if an institute will be set up. I am doing this job now giving up a lot of other things just to make sacrifice for my child.

Parent 3 also explained that having professionals would make things easier, as she explained

Things will be better if there is an institute where these children get help. There is no sufficient number of professionals. Those who work here are always with check lists to tell you something insignificant. There is no team work and they inform you what any educated person can read and understand easily. I suggest that the government be involved in establishing a special school, arranging and providing transport access to the autistic children.

Parent 4 shared the idea of having professional support. As she stated in the following answer,

If the government gives emphasis and makes governmental schools incorporate special needs in the curriculum, it will make things better. It has been started, but it is always challenging in the beginning. We don't have professionals. It is mandatory to have a speech therapist, and that is the problem we have here. We parents have to raise our voice. Nobody understands the situation better than us so we have to push the government and other people and NGOs to work on the problem.

4.1.2.2 Social support

Regarding social support all parents, except Parent 3 explained that they got support from their spouses and the rest of the family other than other extended family or friend.

Parent 1 related that, *“Owing to my husband’s help and better understanding, I have passed all those sufferings and become well like this now. But I dare not to say that I have just understood about it well, too.”* She said that her daughter also is a great support for her autistic sister.

However, this mother has never been in any support group and has never discussed about her life with her autistic child with other parents who also have autistic children.

Parent 2 said she got support from her family, as she expressed,

Nowadays, as they have known about autism, they stay with him most of the time. They play football with him; especially they youngest one plays ‘hide and seek’ with him. They take care of him as much as they understand about his problem. Hence; his body has become stronger and able to move properly. He was not able to do that before.

She also said that she is a member of a social support group which is formed by parents of children with autism. She argued

After I started working in the school here, I have been discussing with parents, sharing ideas and praying together as most of us are Christians. It is good; it helps us to support one another, as we have the same burden. We take trainings together. We discuss about our children’s progress, their behavior and our general experience with them. It relieves us from the burden of keeping things in. You know sometimes we laugh about some of our reactions towards our children’s behavior or peoples comments.

Parent 3 said that, *“As I am also working on the same issue, I discuss with parents who have autistic children. It is helpful, we have common concerns.”*

Parent4 related that,

Here, we discuss about our children with parents of autistic children. We meet regularly for trainings and if there is anyone who is interested, we pray together. It is really helping us and it gives us relief. We support and encourage one another. When we meet we share experiences and new information. In addition, the problem is not something you talk about with anyone; most parents are not comfortable to discuss it, actually I don't blame them because the public lacks awareness. When we meet it is like oh, you share your burden, no fear of judgment or being misunderstood.

Parent 4 also explained that,

My husband helps me a lot. He used to go to gym before. Then, he stopped saying here after my gym is my son. Coming back from his work, he helps him at home. We help each other very much. That is why many things have become easier for me. My husband said to me, the problem had already come to our house and we should accept it and made me accept it, too. We even go to religious institutes and teach about it.

4.1.2.3 Future Concern and prospect

Parent 1 explained that she will do whatever it takes as long as she is alive. Her fear and concern is who will look after her daughter if she fails to do so.

Who will look after her? I am afraid of this thing when I think about her future; nevertheless, nothing will happen to her as long as I am alive. I have a strong faith in God that my child will be fine. After I pray I always go and look and touch her, hoping that it is gone. I sometimes complain why God is taking his time, but he has a reason, I believe I would be happy if there could be a place where my child can be in a better situation without my presence.

This mother has other concerns when she thinks about the future. "As she is a female, I am always worried that she could go with someone and get abused. She likes to go with anyone. She

may start menstruation soon, and that scares me. What is she going to do with that? You know being female has a problem by itself let alone with such situation.”

Parent 2 did not want to think about the future but she explained that she has a strong faith that her son would get a healing from God. She thus reflected

There is a long gap between the problem that exists and the service that is rendered. Nevertheless, I believe that my child will get healing from God. I think there will be some changes in the future. Perhaps a school might be built where these children can independently learn and do something better. But I don't want to think about the future right now. Things are somehow better than before. I heard that there are some health professionals who are trying to work in a team. But God will find a way that is my hope. I wish my child could speak and tell me even just a word. I wish people had a better understanding of autism and had the opportunity of getting a better public service so that autistic children could learn how to support themselves and live independently.

Parent 3 believed that his child has improved since he came to the Center and he has hope he will do much better in the future. However he still believes that if he could take him abroad his child would be even much better. As he stated:

If I get the chance and take him abroad for medication, it will be good. As autistic children have extraordinary natural talent, we may get a chance of identifying that capacity which could help him a lot. Sometimes when I think about his future, I become pessimistic and so I rather not think about it. I do what I have to do now. When you think about the future based on the current situation, it looks frightening.

Parent 4 explained that she has concerns for the future but her hopes outweigh such concerns.

She aired:

There are still so many challenges though I have great hope that things will be better. You know we still don't have professionals in the area. If professionals from other countries come here, we will get training and support for the children. The government trained four speech therapists but as this time none of them are here for they went abroad. We need a speech therapist because it is necessary for

autistic children. Some health professionals have started to work as a team to diagnose autism. This is a big step at least they don't tell like previous times just by some check list they read on the internet. However, above all this challenges I can see a bright future ahead of us.

4.2 Staff Interview Report

4.2.2 Major Activities of the Center and Future Plan

The center has been working on different activities towards supporting the autistic children and their parents. To improve the service has been provided and also to reach out as many parents as it can, the management team has also future plans. This is discussed under the following categories: intervention Plan, Implementation and Assessment Procedure, awareness creation, communication with parents, relationship and affiliation, support service for parents.

4.2.2.2 Intervention Plan, Implementation and Assessment Procedure

The Center planned and implemented intervention plan for the autistic children using ABA method. Key informant 1 stated as,

We use the strategy called applied behavior analysis (ABA) which has wide applicability to various student groups and settings. We took so many trainings on this area. We plan our intervention based on the ABA method. The method has very basic things for the autistic children. It will enable us to assess their progress and development level. Our intervention plan focuses mainly on life skill training as the major aim is to enable children lead independent life. After we achieve the life skill goal we proceed with academic training. We focus mainly on the three major areas that autistic children impaired. We prepare individual based intervention and group them based on their severity level and age. The recommended way of implementing the intervention is one to one; however, as we have no capacity to do that we use one to two way; that is one teacher for every two children. We assess children using VB MAPP (Verbal Behavior Milestones Assessment and Placement Program). We assess them based on the milestone and

the target of the intervention program for a specific child. There is daily assessment the teachers record the implemented intervention, the target and the student progress in each session. So it is an ongoing progress assessment.

Key informant 2 also explained,

We use ABA method to plan, implement and assess the intervention. ABA method is the widely applicable method for autistic children. We use different strategies to implement the ABA based intervention plan as per the goal of every child. Our first focus is self –help trainings, like using toilet, self dressing up, and self feeding. The teachers decide which strategy to use as per each child capacity and severity of the disorder. They may use verbal request, modeling or visual approach etc to train the desired skill. In some cases, several trials targeting the same skills may be implemented. They also evaluate and assess the student progress according to the goal set. All children had never had any kind of training before they come to the center. Here, there are autistic children who are 12 and 15 years of age. We have become unable to help them improve. Their parents didn't do anything to help them know something prior to this age. If it was known earlier, lots of things would be done to help them. We have to train them basic independency skills. According to the target we implement and assess the progress. The assessment will be recorded every day using assessment milestone.

4.2.2.3 Public Awareness creation and advocacy

Regarding the center activity on public awareness and advocacy Key informant 1 explained,

We use the media, now days we hear a lot about autism on media. We educate people in religious institution about the disorder. We sale t-shirt during the April foot marching, as it is autism month. We also teach parents of autistic children to educate others whenever they got chances. Our focus right now is creating public awareness. If the public has better awareness advocacy will be easy as more people know the depth of the problem we can use and mobilize the available resource and we can have more funds and can reach more people. There are many parents who still hid their children the society has to be educated before advocating in their behalf.

Key informant 2 stated,

Since this center is opened of the many activities we have done awareness creation is the major one. We use media well. We even go to religions institutes and teach about it. We had street foot marching program to create public awareness. We go to different school and teach parents when there is parent conference. This year we had fund raising programs, we were invited ministers

and higher officials. We have elected one person as autism ambassador. He is a famous artist; our future plan is to educate the public more. We just ask the government working place other than that we have never done advocacy. However once we have insured our sustainability it is our future plan. We want parents to raise their voice. Nobody understands the situation better than parents so we have to push the government and other people and NGOs to work on the problem for this parent need to have better understanding and has to believe they can make a difference. The government has to work on the policy implementations. More schools and centers have to be opened. Parents have more voice than the center. We want them to enforce the government for that we have to first educate the public.

4.2.2.4 Communication With Parents

The center communicates with parents mostly through the daily communication booklete. Key informants 1 explained this,

We have two ways of communication parents ask information and pass their comment and we also communicate with parents regularly about their children progress and to discuss about the disorder. We send communication book every day. It has information about the child's day at the center The communication book has the daily activity report, progress and if there is any information or needs from parents we attach a letter. Further we held a regular meeting monthly.

Key informant 2 stated that the in addition to the information booklet the center also held regular meeting with parents.

We have regular meetings it is mandatory. We discuss about the intervention program and exchange information with parents. We also held conference to discuss about child progress report and transition to the next level. During the conferences and meetings parents ate expected to raise question and share their experience. However parents don't attend meetings and conferences. We made a sanction if any one misses a conference or a meeting will pay 50 birr. They are not happy with that but attending the meeting is important for the success of the intervention program. As we communicate with parents about their children and what is expected at home they have to be there. The 50 birr is the only controlling way. We also have communication booklet that is send every day home. If it is urgent and important we call for parents too.

4.2.2.5 Relationship and Affiliations with others

Key informant has said the following about relationship and affiliations with others, “*Currently we are working closer to ministry of women’s, children and youth. It has started supporting us we are one of the beneficiaries of the income from the great run.*”

Key informant 2 also answered;

We have relations with different organization. They donate money sometimes. Last year we were about to close the center as we had no money to operate any more, it is Oak Foundation which release money and we survived. Now we have members organizations like Commercial Bank of Ethiopia they contribute money annually as a membership payment. Currently we are affiliated with Ministry of Women’s’, children and Youth.

4.2.2.6 Support service for Parents

Support service available for parents was explained by Key informant 1as;

We prepare training and education when ever specialists come from abroad. We may hold such event two to four times a year. We don’t have formal counseling for parents, however whenever parents communicate their concern we will try to help. There are parents who have formed their own support group. We facilitate meeting place if they asked. If someone has personal problem like, death of family member we facilitate and collect money from parents and give to that person. We provide the intervention plan for free; no one will pay except some parents pay for transportation service we provide.

Key informant 2 aired the service provided for parents by the center, as she explained

The center prepares training and education for parents. Professionals come from abroad, most volunteer to train and educate parents about the disorder. For holiday people from abroad send money and cloths for parents and children, we distribute that according to their economic status. We assist parents on how to precede the intervention program for the children at home.

4.2.3 Constraints and Challenges of Nehemiah Autism Center

The center has been facing many challenges while providing support for parents. Lack of government support, limited parental involvement in the intervention plan, financial constraint and lack of professionals in the area were mentioned by respondents from the center.

4.2.3.2 Government Support

Key informant 1 responded that the government support is limited. As he said,

Government is giving special education in government schools however there will be one teacher for more than 20 students in that case the program will not be effective. Here the center has no support from the government. This year Ministry of Women's, children and youth is supporting us. However the autism is becoming one of the biggest problems. There are a lot of children on waiting list at one of the autistic center. We already have 140 children. Government at least has to teach health professionals about the disorder at list they can diagnose properly in addition early intervention are good for the autistic children development.

Key informant 2 also viewed the government controlling than supporting. She reported,

We have no support from the government instead it controls us. We need to add more classrooms and one real estate promised to construct that for free but the "Kebele" officials (district officials) did not permit the construction. We are giving service- social service, which is also the government's responsibility. Parents are hiding the problem. They have to advocate and demand the government to allocate resources. However, parents are still hiding their children. Only a few dare to come to us. Those who came to us have so many burdens. They need to work to support their lives and they don't have the time and energy to advocate the issue regarding their children, so how can the government see the depth of the problem?

4.2.3.3 Parents' Involvement

Key informant 1 viewed parent's involvement in their children intervention program as limited.

Parents lack understanding and attitude regarding the disorder. Most parents still believed that autism caused by evil spirit. In addition most parents who came here are from low economic class, most are uneducated, they don't have enough time and understanding to help their children at home. They have to run for daily bread, as the intervention has no continuity the children development will not go as expected. As most don't have time they don't attend meeting and trainings. Those who are from middle economic class, even if they have the awareness and understanding they gave up on their autistic children and don't want to spend time.

As Key informant 2 explained parent's involvement in the intervention program as,

The intervention we planned for the children should be repeated at home. We train the parents what and not to do. Doing things spontaneously will hinder the children's development and the intervention needs to be repeated exactly as specified. If the children could only get support here but it is necessary to have equal support at home so the intervention can be effective. Parents' involvement is important. Parents have to work to earn for living, I don't blame them because it's an economic problem. They are already tired and they have to support the other family members with household activities. When the children get back home they want them to sleep. Most parents think that their autistic child is a burden and useless so they don't want to invest on them. They want us to work over the weekends so we can take care of their children. If we prepare trainings and meetings to discuss their children's progress only few participate.

4.2.3.4 Financial Constraints

Key informant 1 stated the financial problem is the major constraint the center had.

Finance is our biggest problem. We need different educational material to teach the children. One puzzle is so expensive here. The locally made ones are not comfortable for children. We always struggle to pay office rent. Staff turnover is also high as we can't pay them enough. People give money but it is not enough we need sustainable source of money. We are working on that, this year we are one of the beneficiaries of the income from the Ethiopian Great Run.

Key informant 2 also explained the situation as

We get money from individual donors most of the time, we have financial problem. Last year, we were about to close the center because we didn't have money to pay for house rent. We have to go to ask organization and individuals for money all the time, we prepare fund raising campaign frequently but it is not enough, our office rent expenses is big. We have staffs turn over because we don't pay good money. This year we have found member organizations, they give us specific amount of money as a membership payment that at least can cover our house rent. However it can't insure our sustainability. We are working towards that. We already have 140 children on our waiting list. We are operating only in Addis Ababa and only in specific district. We are not reaching as many families as we want to. Currently we need to have 15 branches only for Addis Ababa; however, sadly our only center sustainability is under question mark. If the government give us working place it will be a great support.

4.2.3.5 Professionals on the area

Key informant 1 reported that there lack appropriate professionals in the field. He stated the situation as,

There are no professionals in the area here, most come from abroad. The government is training in masters and degree program in special need education but there is no special training for autism. There is no speech therapist in the country which is basic for autistic children. Even the existing medical practitioners don't work in team they just diagnose with some check list. Some children diagnosed autistic when they reach 15 or 16 years which is difficult to change them. I have seen many children who still don't have potty training by the age of 16. If we have professionals it will minimize such problems, the children can get early intervention before parents give up on them and the program also help them to develop in to independency.

Medical workers viewed by as having limited awareness and information Key informant 2

We require parents to have diagnosis paper given from doctors before we register their children. However, the doctors misdiagnose the children. We have one child here who has no social and communication problem, he also speaks very well but they said he is autistic, he is not ,I don't know their diagnosis criteria. They can at least see the accepted criteria for diagnosis. The problem is deep but the understanding is still far. We need speech therapist, I remember few years before the government trained four speech therapist none are here now, and they all went abroad. For autistic children speech therapy is mandatory. Most medical practitioner diagnosis just by asking few questions from parents and label them as autistic.

4.3 Document review Report

4.3.2 Child enrolment file

The child enrolment is a kind of document that holds child and parents profile including contact address, pictures, diagnosis report, and any prior intervention report and date of enrolment at the center. The children and parents information was filed in a box file with different folder. Each folder contained full information about each child.

4.3.3 Child progress file

This file holds the type of the intervention program and the child progress in each intervention in daily basis. The file holds different children folders. In each folder the intervention implemented and child's performance and progress in each session was documented. The document has different formats according to the type of intervention and child's performance and the way the teachers implemented. The center uses VB MAPP and ABLLS in order to assess the progress of each child and they all were included in the file. In the folders there are progress assessment kits

according to the goal of the intervention. The intervention progress assessment kit contained the implemented intervention (e.g. concentration on task, self dressing up etc), how it implemented, how the child responded. Each kit has different objective, activity started and date.

4.3.4 Parent communication booklet and Report

Children daily activity communicated to parents through communication book. Teachers sent the communication book after feeling the daily report. Formal headed letter were also sent for parents attached on communication including notice for monthly meeting, training and payment request for school bus(for those who pay). Unusual behavior on children and any concern or if there is a request for special meeting with specific parent letters were sent.

4.3.5 Meeting and Training Reports

Minutes of regular meetings and reports on training and education for both staff and parents were kept in this file. Reports on training given include the topics of the training, the individual or organization delivered the training.

4.4 Data on Observation at the Center

4.4.1 The Physical Environment of the Center

The center is located in a residence places which is far from the main road. It is a rented house with big compound. There is a billboard 50 kilometers before the center and at the main gate of the center. It has the name and address and motto of the center. There are no other signs or information about the center or the disorder written or posted outside and inside the compound. It

has big compound with safe play ground. Half of the class rooms and the office are inside the house; the other class rooms are at the back yard. It has eight class rooms and one office and bath room.

4.4.2 Reception (Giving information)

The reception and the main office of the manager are in the same room. There were no posters or written information about the disorder in the office. They provide brochures for any guest and give clear and appropriate information according to the demand of the individual. They handle clients well. However one has to knock for several minutes before the main gets open.

4.4.3 Class Rooms

The class rooms have different visual aids hanging on the wall. There one shelf, one table and chairs equivalent to the number of individuals in that class room. The seating arrangements were different according to the day lesson. Each child was placed based on their severity level. There were two teachers in each classroom for four children. There were also different supplementary materials in each class rooms like, puzzles, Lego, blocs and toys. The teachers had positive interaction with the children. As they are helping them to be independent they give instructions repeatedly.

CHAPTER FIVE

FINDINGS AND DISCUSSION

The purpose of this study was to assess multi-dimensional challenges being faced by parents of children with autism and their support needs at Nehemiah Autism Center in Addis Ababa. The aim of this chapter is to present the key findings from the analysis of the qualitative data. It comprises detailed discussion of the results of the data analysis. The findings of this study will be presented in the light of to the basic research questions and objectives of the study as well as the subsequent themes.

Background Information of Participants

Table 5.1

Participants	Gender	Age	Marital Status	Educational Status	Number of Children
Parent 1	Female	Above 40	Married	College Degree	4
Parent 2	Female	Above 35	Married	High school Education	3
Parent 3	Male	Above 35	Married	Master's	2
Parent 4	Female	Above 35	Married	High school Education	3

Background Characteristics of Participant's Children

Table 5.2

Participants	Child's Gender	Age	Age at Diagnosis	Birth order in the family
Parent 1	Female	12	At 5(Autism) & at 10 Mild Autism	4 th
Parent 2	Male	7	4 years	3 rd
Parent 3	Male	8	4 years	1 st
Parent 4	Male	7	4 years	2 nd

5.1 Discussion of the Findings on Parents Interview

5.1.1 Challenges of Raising an Autistic Child

Under this theme different categories are presented to discuss the challenge faced by parents of autistic children while raising an autistic child. The categories will have subsequent sub-categories as needed.

5.1.1.1 Social Challenge

5.1.1.1.1 Diagnosis

The two periods, before and after the diagnosis are the most challenging periods for the parents to cope with autism. Making sense of the symptoms of autism represents the initial part of the parents' discovery of their child's developmental disability. This began with recognizing that something is wrong with their child. According to this study, all parents recognized that their children have problems early on. However, they did not find out what exactly it was as early as they recognized the problem. This is because of lack of knowledge from the parents and unavailable professional services.

We thought that the problem was only speech delay. When we took him to a physician, we got the same response; the other physician told us that there was blood clot in the child's brain and he prescribed medicine for him. We brought the medicine from abroad and got the child to take it for a year time.

As one parent also responded *"I used to compare him with his elder and younger brothers and told a physician that he was different. But I didn't get any solutions just by saying that."*

The above example revealed that even if parents seek professional help, the medical practitioners themselves lack sufficient knowledge about the disorder thus further delaying the detection process. This in turn created more strain for the parents because they did not have sufficient knowledge about what their child has and what means of help they can provide for their child. Parent 3 and 4's children were misdiagnosed and Parent 1 and 2 were not able to fully comprehend the cause of their children's behavioral differences. This led to a delay of diagnosis

and parents only knew of their children's predicament years after first recognizing the disabilities.

Even after their child was diagnosed with autism the mere knowledge about the problem was not a relief to itself. All parents had an emotional experience, passing through a process of denial, frustration and depression before they were able to accept the truth. The health professionals were unable to help the parents to understand the disorder and they were also unable to provide instrumental support for parents to access the available support.

The above reasons in turn caused delay for early intervention for the autistic children. According to the American Academy of Pediatrics (2010), early diagnosis is important for immediate implementation of consistent and appropriate intervention, which has shown improved outcomes in the development of autistic children compared to those who were not diagnosed early. The development of an autistic child could be seriously hindered if the diagnosis is delayed for even just six months to a year.

5.1.1.1.2 Getting Professional Help

The study revealed that after passing through intense emotional adjustment, the parents subsequently looked for professional support for their autistic children. However, finding professional help proved to be more difficult than accepting their child's diagnosis. The major constraints after diagnosis were the health practitioners' failure to help parents to understand the problem and cope with it well, and the lack of access to appropriate professional help and support.

All parents were frustrated and desperate by the fact that they were not able to get support for their children. This made the challenge worse because there was only one institution that was known to give support for children with autism but they were not able to get admission. Thus, going through the emotional hurdles of knowing about the child's disability was not the most extreme of challenges parents of autistic children faced, but rather, the fact that there is no professional help and support available to intervene in their child developmental disorder.

As this study shows, support for parents was inadequate during and immediately after the diagnostic process. This indicates that getting professional support was another fundamental challenge parents have to face in having an autistic child. According to researchers, lack of adequate professional support is one of the most significant causes of stress experienced by parents of children with autism (Pisula, 2010). As most parents have no idea of the existence of the disorder before, they did not know how to deal with the situation. Hence, not getting any professional support makes the challenge even worse.

5.1.1.1.3 Impact on Family Life

I Marital

Most studies indicated that having an autistic child in the family affects the family interactions and relationships, including husband and wife, sibling to sibling and children to parents' interconnections. Participants of this study also believed that the disorder is difficult and can put their relationships under stress. However, this study revealed that despite the strain of having an autistic child, all respondents except one were able to maintain a healthy relationship with their

spouses. They also described that understanding and supporting one another was their source of strength.

II Siblings

This study regarding parental relationship with other siblings indicates that parents devote less parental attention to normal developing siblings due to the extreme demands of their autistic children. One participant reported of being guilty and regretful that she is not giving enough support and attention for her other children. Although some respondents disclosed that siblings of autistic children are becoming more understanding and supportive as they mature, this study has revealed that the parents' relationship with their normal developing children are affected by having autistic children.

5.1.1.1.4 The Public Understanding

According to the parents interviewed for this study, the public understanding of autism is changing. However, they all mentioned that even though the disability is widespread, A gap between public awareness and the frequency of the disorder's occurrence still exists. As the finding revealed, people in public places still pass negative and express negative attitudes towards the parents and their autistic children. These attitudes can be either directed to the parents or to the children.. Consequently, the parents also mentioned that even most medical practitioners lack the basic information about autism and attribute the autistic child's behavior directly to the parents.

Most people don't have the understanding. I myself came to know about it just because it happened to my child. The physician who, at the beginning, told us about our child didn't even inform us where to take him for education or any other help. Once he was sick and we took him to a health center for medication. While going here and there for laboratory, he was screaming and people were saying what a misbehaved he was. I was not actually surprised with that since I had also heard that bad experience from other parents of autistic children I will feel bad if people turn back and see us hearing the child scream.

The above example illustrates that the public has still little knowledge and awareness about autism. All respondents mentioned that they received negative comments due to their child's behavior. The health professionals' failure to understand and guide parents through the disorder comes from lack of knowledge and understanding. According to Gray (2006) and Pisula (2010), parents of children with autism must cope not only with problems resulting from their child's developmental disability and challenging behaviors, but also with distressing responses of others to the child's behavior, as well as general lack of knowledge about autism. Participants of this study also mentioned that they are negatively affected by the public attitude towards their autistic children.

This study also shows that there is a better understanding of autism in Addis Ababa than anywhere else in Ethiopia and there are more people who at least know of its existence. The respondents of this study also mentioned that there is a difference between the behaviors of educated individuals to the disorder to that of uneducated ones.

The educated ones have better understanding about it. While walking on the street or going by taxi, some people ask me why he doesn't talk as his face doesn't indicate he is autistic. I explain it to them. There are also people who know well about autism, some, even if they have no idea what it is they pretend that they understand you they don't want to bother you. Anyway, there is some positive change nowadays.

Autism is however a disorder which can affect all human beings regardless of race, social, economic and educational status. Ethiopia is a country with 85 million people, more than 80 percent of which live in rural areas. Even if the public's awareness and understanding in Addis Ababa is changing, when compared to vast population living outside of Addis, the study revealed that there is still a gap in public awareness.

5.1.1.1.5 Effect on Personal life

With regards to personal life, the study indicated that the parents' personal life is affected negatively by having an autistic child. Respondents reported that they quit their jobs and other important things of life to help and look after their autistic child. Since autism is among the most stressful and demanding developmental disorder parents responded that they gave up so many things. Two parents explained the situation as, *"I left my job and came here to help him, though by chance, I got a job here easily. I had begun doing my PhD but due to him I couldn't proceed, and had to quit."* The other parent also stated the effect the disorder imposes on her life as *"I spend most of my time with him. I don't have my own time. If there was some institution that I can trust I could have at least some time."*

This explains that how having an autistic child affects parents' personal life. As the disorder is demanding most of their time parents forced to give up their personal life, this in turn can cause more stress and strain on the parents. Experts on this area also reported that parents of disabled children are particularly vulnerable to stress and parents of children with autism typically report higher levels of parenting stress and higher affective symptoms when compared to parents of typically developing children and parents of children with other disabilities. This is due to

additional demands over typical childcare duties. This in turn makes parents tired and unavailable to perform other tasks to satisfy their personal and family needs. This also has direct effects on employment choices, nearly 40 percent of parents of children with autism claimed that problems associated with childcare significantly affected their employment decisions and professional careers (Pisula, 2010).

Parents also reported giving up their social life as well. As they said,

I quit my job for her. Wherever I go, I take her with me. Sometimes I take her to social gathering (Mehaber) she doesn't have disturbing behavior, but she may unexpectedly stare at you. She touches you, picks up something, and so on. When she does these, people won't say anything; but I get disturbed. For this reason, I don't have friends whom I invite them to come home.

As the finding illustrates parents spend most of their time taking care of their autistic child. This gives no time for their personal need including having friends and attending social gatherings which is one of the most important aspects of life in Ethiopian culture this in turn can restrict parents from getting the most common social support provided by the society and participating in different social events.

5.1.1.2 Economic Challenge

5.1.1.2.1 Financial Strain

This study found that having an autistic child does not have significant effect regarding finances. All respondents explained that they are only spending money for school which is the same amount that they spend with their typical children. However, before they come to Nehemiah Autism Center they all responded that the disorder caused financial strain in different ways.

Parent responded that the financial strain was mostly at the initial time during diagnosis. One parent reported that he used to pay extra money for guards at a conventional school to keep an eye on his son while he was at the school. Another parent was also reported that she was asked a lot of money to send her child to a special school.

I went to some schools that give special classes for such children, but what they asked me to pay was too much. Even if I sell all my properties, I still couldn't be able to cover it. Even if I dare to pay there is no guaranty that they really help my child, for how long am I able to pay that amount of money? They don't even consider this.

However, because of the limitations in professional care and services, the parents did not have to invest any financial resources for specialist support. Their only choice is to enroll their children in schools that provide limited services to students with special needs which currently cost the same as they would have paid in a conventional school. This indicates that finance was not such a challenge for these parents.

5.1.1.3 Psychological Challenge

5.1.1.3.1 Parents Understanding and Attitude

As the finding of this study indicates, the parents' understanding about autism is still limited. This limited understanding affects their views and attitudes towards the disorder and also their future expectations regarding their child's developmental process. Two respondents believed that autistic children have extra ordinary talent and they were seeking help in finding that. They also explained their child will be successful if their talents are identified and development. According to scholars, the vast majority of people diagnosed with autism spectrum disorders do

not possess genius abilities and the belief that all autistic children possess extra ordinary talent is a just myth (Wiesner. & Volkmar 2009, p,25).

However, as Parent 3 disclosed, *“If I get the opportunity of taking him abroad, I believe that I will get to know his unique natural talent. And, if he develops that, I suppose that he will be effective.”*

Moreover, all respondents showed strong faith that their children will be healed. *“God is sacred, and what I know and believe is that my child will be relieved from this problem. I don’t know how it can happen or I have never had any idea about it, but I have the belief that my child will be normal in the future.”*

This revealed that parents have still limited understanding and awareness about autism. Since the parents are the children’s first and most important teachers who provide fundamental emotional and social support, their understanding of their children’s disorder can affect both the children’s development and their own coping strategies. Additionally, their attitude towards autism could further exacerbate the limitations of the disorder or can further the developmental success of their children.

5.1.2 Needs Specific to parents of children with autism

5.1.2.1 Support Needs

Parents of autistic children have various support needs not experienced by parents of typical children. Based on the study, the respondents' main concerns included the security of their children's future, specifically on how their children will manage the pressures and responsibilities that adulthood entails.

5.1.2.1.1 Professional Support and Service

As the finding revealed the major need of parents of autistic children is having professional support and better services. Apart from professional support they also mentioned a better transport service. Parents also explained that government and NGO involvement will be essential in finding adequate professional and institutional support for their children. As one parent Indicated, speech therapy is necessary to improve a child's speech development, yet there is not even one professional speech therapist in the country. These are significant indicators of the importance of getting proper support for though the problem is widespread and needs immediate intervention, the solutions, particularly professional help and services available are practically non-existent. This shows that it is an area that needs social work intervention through different methods including advocacy. According to the study, these parents are currently getting help from one autistic center, however as their responses illustrated, the available service is not enough. One parent explained the situation,

I wish there could be special need schools according to the level of mild autistic children. I have been worrying about where to take my child for education. Regular

school is not suitable to her. She needs to be in a special school. The school where she was learning before was not convenient for her. The autistic children there were in a worse condition than her. Their behavior was different from her. The school where she is learning now is also not fit to her. She has started screaming and disturbing nowadays. She was not like this before.

The above example is a good indicator of parents' dissatisfaction of the service available since it is not based on the child's need and level. It also explained that there is a need for appropriate and reliable individual-based intervention.

5.1.2.1.2 Social support

The study revealed that the support from spouses and immediate family members remain fundamental to how parents overcome the challenges of having an autistic child. Although other relatives, friends and neighbors give out their support to these parents, their basic needs could only be supported within the nuclear family. Two parents explained the situation as, "*Owing to my husband's help and better understanding, I have passed all those sufferings and become well like this now. But I dare not say that I have just understood about it well, too.*"

My husband helps me a lot. He used to go to gym before. Then, he stopped saying here after my gym is my son. Coming back from his work, he helps him at home. We help each other very much. That is why many things have become easier for me.

According to the parents interviewed for this study, social support groups are also essential in helping them cope with the challenges of parenting an autistic child. Social support groups were able to provide these parents a means of outlet and a safe environment wherein they are heard and understood. In addition to the psychosocial support these parents are giving one another, the

support group is also helpful in sharing new information regarding the support available and other helpful information about the disorder. One parents argued, “...*the problem is not something you talk about with anyone; most parents are not comfortable to discuss, actually I don't blame them the public have no awareness. When we meet it is like oh, you share your burden, no fear of judgment or being misunderstood.*”

The above example illustrates that the social support group is a place where parents cope from their stress.

5.1.2.1.3 Future Concerns and Support need

The parents described their needs and concerns regarding their autistic children. The presence of professional support was mentioned as a kind of support needed by all parents in the future. Respondents explained that their children were not going to be independent unless better professional services are provided. The parents argued,

Who will look after her? I am afraid of this thing when I think about her future; nevertheless, nothing will happen to her as long as I am alive. I would be happy if there could be a place where my child can be in a better situation without my presence. It will make situations easier and better if there is a better service. I will also take relief if such things get established. Well-trained and committed professionals can bring positive change if an institute is set up. I am doing this job now giving up a lot of other things just to make sacrifice for my child.

The above example showed that having professional and reliable care and support for their children is not only parents' current challenge and demand but it is also one of their major concerns for the future. Parents concerned that if the situation regarding professional and institutional support is not improved their children will be their life time burden.

Additionally, one parent also indicated that gender is a cause of concern as well.

As she is female, I am always worried that she could go with someone and get abused. She likes to go with anyone. She may start menstruation soon, and that gives me fear. What is she going to do with that? You know being female has a problem by itself late alone with such situation.

The above example justified the concern of a parent of a female autistic child. The challenges of being female with developmental disorders might have severe consequences to the individual as she experiences the biological changes that happen to a female body. Not being able to take care of herself means that she will have difficulty coping with menstruation and might become susceptible to sexual abuse. This is an area that highly needs social work intervention.

In general, parents of autistic children are hopeful that things will be better in the future. However, after careful analysis of the respondents view, only one parent showed strong optimism for the future. Two of the respondents believe that their children will be healed by God and another one sees relocation abroad as the most efficient way to discover his child's gifts. All in all, the parents of autistic children are worried and anxious because of the current challenges and hindrances in providing adequate help and support for their children's developmental needs.

5.2 Finding and Discussion on Staff Interviews

5.2.1 Strengths and Constraints of Nehemiah Autism Center

The aim of this session is to present the key findings from the analysis of strength and constraint of Nehemiah autism center. The discussion will be presented using to major themes, major

activities and future plan and constraints. These themes will be categorized and sub categorized as needed.

5.2.1.1 Major activities and Future plan

5.2.1.1.1 Intervention Plan, implementation and assessment procedure

As the finding of this study demonstrated Nehemiah autistic center plan intervention program for children with autism using ABA method. As experts in the field explained, the standard interventions for autism spectrum conditions in childhood are Applied Behavioral Analysis, or ABA, speech therapy and special education. (Columbia Ministry of Education,2000). They use the method to plan and also assess children progress. As the finding revealed most of the intervention plan focuses on life skill training. The intervention programs are individual based. The information argued, *“Our first focus is self–help trainings, like using toilet, self dressing up, and self feeding. The teachers decide which strategy to use as per each child capacity and severity of the disorder.”*

As the above example illustrated different strategies are used to plan intervention and the strategies and methods vary based on the children severity level and support need. The child progress assessment has also procedures. As the finding demonstrated the center has daily assessment for each child according to the goal sated. They use a standard assessment kit called VB MAPP. They stated

We assess children using VB MAPP (Verbal Behavior Milestones Assessment and Placement Program). We assess them based on the milestone and the target of the intervention program for a specific child. There is daily assessment the teachers record the implemented intervention, the target and the student progress in each session. So it is an ongoing progress assessment.

5.2.1.1.2 Public Awareness Creation and Advocacy

According to the finding of this study the center done activities to create public awareness. They went to religious places and schools parent day where a large number of individuals can be found. Media is one of the great means to address large number of people, as the finding revealed the center uses media well to educate people about the disorder. However, regarding advocacy the study showed that the center has not done much activity. As the respondent argued,

Our focus right now is creating public awareness. If the public has better awareness advocacy will be easy as more people know the depth of the problem we can use and mobilize the available resource and we can have more funds and can reach more people.

The above example supported that the center had limited activity on advocacy. This can show that the resource constraint that the center has been facing can also be resulted from the limited activity on advocacy.

5.2.1.1.3 Communication With Parents

Parents and teachers of autistic children have to communicate beyond the traditional parent-teacher interview modes. Parents and teachers need to work together to develop an effective intervention plan. For this regular communication is necessary. (National Research Council. 2001) Regarding communication with parents the current study revealed that the center has regular communication with parents regarding their children in daily basis. Daily communication book, letters and regular meetings were the meanness of communication with parents. This is one the indicators that the center is implementing good intervention program

which can give a chance for parents to involve and also help them to proceed the intervention program at the home in the same manner.

5.2.1.1.4 Relationship and Affiliations with others

According to the finding of this study the center is not affiliated and related with many organizations that are working in the same area. Only few organizations were mentioned by respondents. According to respondents however recently the center is working cooperatively with one government institution and also the Minister Office will release fund and also has few member organizations. Relationship and affiliation with organization is important for awareness creation and also mainly it would help the center to overcome the constraint in finance and resource. This is also an indicator of the reasons that the center is facing regarding financial problem. As the respondent explained the Center is one of the beneficiaries of the income from Ethiopian Great Run as it is now affiliated with Ministry of Women's, Children and Youth. This indicates more relationship and affiliation with other organization is important for the center to overcome the constraints and to reach more families.

5.2.1.1.5 Support service for Parents

The major support available for parents from the center was found to be education and training about the disorder and how to help their children at home. The study demonstrated that the center has no formal counseling and professional lead social support group for parents.

5.2.1.2 Constraints and Challenges of Nehemiah Autism Center

5.2.1.2.1 Government Support

From the finding of the study the center has constraints and challenges. The lack of support from government was revealed to be one. As the respondent explained the government lacks support

in using the available resource and giving education for the public and health professionals about the disorder. This is one of an indicators that the center giving service to a limited number of children.

5.2.1.2.2 Parents' Involvement

The other challenge the center encountered was parents less participation on the intervention program of their autistic children. Parents viewed by the center staff as lacking understanding awareness, giving up on their children and not having the proper time to participate in their children intervention program as they have other family to support. The study indicated that;

The intervention we planned for the children should be repeated at home. We train the parents what and not to do. Doing things spontaneously will hinder the children's development and the intervention needs to be repeated exactly as specified. If the children could only get support here but it is necessary to have equal support at home so the intervention can be effective. I don't blame them because it's an economic problem. They are already tired and they have to support the other family members with household activities. When the children get back home they want them to sleep. Most parents think that their autistic child is a burden and useless so they don't want to invest on them. They want us to work over the weekends so we can take care of their children. If we prepare trainings and meetings to discuss their children's progress only few participate.

As the above example explained parents involvement is important for the autistic children development and for effectiveness of the intervention plan. The limited parental involvement can be an indicator of the parents' lack of awareness about the disorder. This in turn can affect the children development and the effectiveness of the program.

5.2.1.2.3 Financial Constraints

Financial problem was found to be the major constraint and challenge of the center. The respondent explained that to reach out many people the center need sustainable source of income. The financial constraint can impact the center activity in providing appropriate support and making available the service for more autistic children.

5.2.1.2.4 Professionals on the Area

Having no appropriate professionals was also the other challenge for the center. According to the finding of this study the lack of proper professionals was both in the center to implement proper intervention and also outside the center during diagnosis.

We require parents to have diagnosis paper given from doctors before we register their children. However, the doctors misdiagnose the children. We have one child here who has no social and communication problem, he also speaks very well but they said he is autistic, he is not ,I don't know their diagnosis criteria. They can at least see the accepted criteria for diagnosis. We need speech therapist, I remember few years before the government trained four speech therapist none are here now, and they all went abroad. For autistic children speech therapy is mandatory. Most medical practitioner diagnosis just by asking few questions from parents and label them as autistic.

As the above example demonstrated that there is a gap in professionals who diagnose autism and also the center lacks professionals to plan and implement proper intervention program for autistic children. This in turn can affect the intervention program as the right information about the children problem is important and also each child's need is deferent.

5.3 Discussion on Document Review

5.3.1 Child Enrolment File

It is a kind of document that filled by parents or and staff of Nehemiah Autism Center when the child was enrolled. It has all information about the child and also the diagnosis result given from doctors was attached with each child file. However the documentation style was not orderly with pattern which would make is easy to access.

5.3.2 Child Progress File

Intervention program and the child progress in each intervention was recorded and kept in different folders in this file. The center has form to assess child progress. The child assessment and performance in everyday activities were recorded by the teacher on these forms. This documentation will enable parents and other professionals to see the intervention and the child performance and progress clearly. The assessment formats were prepared based on VB MAPP ABLLS (Assessment of Basic Language and Learning Skills). This format will make it easy to further plan individual based education and also in making placement decisions in transferring the autistic child to another program. As the intervention and the child performance clearly presented it is easy for anyone to understand.

5.3.3 Parent Communication Booklet and Report

Teachers communicate with parents daily using the communication book which was sent home every day. The objective of the daily communication is to help parents proceed the intervention program at home for enhancing the development of the child and also to have information about

their children day at the center. The communication book will be helpful for parents to see their child's progress as it holds daily report. In addition parents can help their child at home accordingly.

5.3.4 Meeting and Training Reports

Minutes of regular meetings and reports on training and education for both staff and parents were kept were also filed and documented. Such files are helpful for new individuals at the center to have some information about the center activities.

5.4 Discussion on Observation at the Center

5.4.1 The Physical Environment of the Center

As the center is located in a residence area it is free from noises that can disturb the autistic children, as some autistic children are sensitive to noise. The compound has enough space for children to play out door games which is helpful for both their gross and fine motor development. There is a billboard 50 kilometers before the center and at the main gate of the center. It has the name and address and motto of the center. However there were no sign at the main road so it was a bit difficult to get the center. There were no signs or posters by the outside wall or gate to create awareness to the nearby community. Posters and other information written on the wall can be one way to educate and create awareness to the surrounding community. The size of the class rooms are enough for the existing number of children.

5.4.2 Reception (Giving information)

The staff has a welcoming face. They provide information well. They handle clients well and provide brochures for any guest and give clear and appropriate information according to the demand of the individual. There were no posters and written information about the disorder to teach anyone who stop by the office. The guards at the gate were not active and informed.

5.4.3 Class Rooms

“The most strongly recommended approach for teaching students with autism is to use visual aids. One of the advantages of using visual aids is that students can use them for as long as they need to process the information.” (Columbia Ministry of Education, 2000) There were different visual aids hanging on the wall related to the lesson. The pictures and the other materials were colorful. Teachers change the seating arrangement according to the day lesson. However as one of the character of an autistic child is sameness in things or activities teacher were changing only their seat. Children develop their fine motor skill, social skill, communication skill through play, in the class room there were materials to support this us, puzzles, Lego, blocs and toys, however the number of the material were not enough. The student teacher ratio was one to two.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The overall objective of this study was to investigate, describe and analyze the social, psychological and economic challenges being faced by parents of children with autism, and their support needs. This goal was attained by conducting an in depth interview with four parents of autistic children who are attending Nehemiah Autism Center, two staff member of the center, document review and observation. From the study the following conclusions were drawn.

Parents of autistic children faces so many challenges starting from the time they realized that there are developmental abnormalities in their children. The time before and after diagnosis was the most challenging for parents. It is because of not knowing their children problem as autism is a disorder with no biological marker and taste. Apart from having no clear biological markers for autism, health practitioner didn't have the awareness about the disorder. Low level of awareness among health workers was the reason for misdiagnosis and late diagnosis for autistic children. Early diagnosis is important for autism as most interventions are successful when they implement at early ages. From this it can be concluded that even if the Center is planning appropriate intervention as most children diagnosed late it will be difficult to have the expected outcome of the program.

After diagnosis, getting services and professionals for education and intervention was the most challenging experience that parents faced. As the study revealed there were no supports for

parents before and after the diagnosis regarding the problem and how to cope with it positively. Together with the psychological turmoil parents encounter due to the disorder and having limited understanding of autism knowing that they are not going to get any support make their life more complicated.

From the finding it is evident that autism has influence on different areas of family life. Parents don't give enough time and attention to their normally developed children due to the extreme demand of time and energy from their autistic child. However, apart from the strain and challenge the disorder imposes, three of the participant explained that their marital relation is less affected; instead the support they get from their spouse is useful to cope with the disorder. One parent however said that his marriage is affected negatively. This shows that the support available within the family members is more important for parents to cope with the disorder positively.

Diagnosis required more monetary resources for parents; however, having no professionals and adequate service in the area, parents are spending money only for school and this cause less financial strain. This clearly shows that if there were appropriate service available financial issues might be the other burden for parents.

As the study revealed, parents lack awareness about autism. Most participants believed that their children get healing from God. They also believed that autistic individuals have extraordinary talent. Even if hope and faith helps to cope with autism positively, parents need to have the right information about the disorder, how it affects, how the children should get help. This affects how to work with the individuals with autism and participating in the intervention program and also choosing the right intervention plan for their children. According to the interview with staff members parents' involvement in their children intervention program is also low and the

intervention of most autistic children has no continuity at home. This can be an indicator of parents' lack of understanding and awareness. If parents understood autism well they will choose the appropriate intervention for their children on the right time which in turn enhance children's development. From these it can be concluded that even if parents come to seek help they don't still understand autism well. This has negative impact both on the service and the children development as well.

Even if the public understanding is changing it is clear that there is still a limited awareness about autism in the country. There are still health professionals who don't have the information about the disorder. Health centers are the first places that parents go and seek information about their children's developmental concern. The understanding and awareness of health professionals is great in assisting and guiding parents. Health professionals can be the first sources of information where to get support and can help parents to understand and cope with the disorder positively.

The public awareness and understanding is the key factor for a better support and service for individuals with autism and their parents. Currently The Center is only giving service for 33 children and there are 140 children on the waiting list. This is a clear indicator of the limited service available in the country. When there is more knowledge and information it will initiate other NGO's and individuals to provide support, in addition parents also will raise their voice towards using available resource and implementing better policy for such children. From the above it can be concluded that the lack of public awareness is one of the key factor it is hindering the service available for autistic children and their parents.

In addition to the above, as the study revealed the public awareness is viewed as changing only in Addis Ababa mostly among the educated ones. However there are more than 85 million

people living in Ethiopia of that 80 percent are living in small town and rural areas. From this one can conclude that there still a huge lack of awareness among the public. Further there are only two autistic centers in Ethiopia. It has been more than ten years since the first autistic center opened in Ethiopia but most parents are still waiting to be registered their due to limited space. Now other autistic center has opened after ten years and it is opened by one parent who has an autistic child. As both centers are opened by parents who have autistic children and both centers are giving service for a limited number of children. Currently the estimated number of people living with autism in Ethiopia is around six hundred thousand of that below 150 children are getting support. This clearly shows that how the public awareness has impact on the service and support available for parents. Since parents have to deal with their emotions it will be difficult to accept the problem easily and take such huge action. So other professionals and institutions should involve in making support available.

Consequently, aside from the current day-to-day challenges that parents are facing in raising autistic children, they are also concerned of their children's future. Throughout this study, the finding illustrated that the parents' main need is having professionals services and facilities that can support their children to improve their academic, social and communication skills which in turn will enable them to lead an independent life or be less of a burden for their parents.

Autistic children in Ethiopia are deprived of getting appropriate services and support because of the lack of professionals and medical facilities that can help in their development. It is not only the autistic children who are affected by this but as the study indicates the parents' personal and social lives are also affected negatively. Parents gave up their life and dreams due to the intense demands in time and energy.

As the finding demonstrated the center has no formal social support group and also it has no counseling service. However, few parents form their own social support group and as they explained it is helpful in sharing everyday experiences and challenges these parents have. It is also a good strategy in coping with the challenge the disorder imposes. Parents need professional support not only for their child they also need support to cope with the challenges faced by raising an autistic child. So, social workers can use the support group to increase parents understanding about the disorder, to give psychosocial support, to train and also to help them advocate in mobilizing the available resource and also creating public awareness.

As the study revealed all participants did not get a place at one of the only center in the country by that time due to limited places. Parents were waiting four to five years, which limits getting early intervention programs that could greatly affect the children's development. As observed during the study, Nehemiah Autism Center is working to its best even with the challenges and limited resources. However, it has many constraints including finance and working place. This shows that there is a need for the government, non-governmental organizations (NGOs), other concerned bodies and professionals like social workers to provide immediate services to meet the needs of these children and their families. As developmental problem is one of the social problems, it is one of the crucial areas in our country that needs immediate social work intervention.

6.2 Recommendations

In order to overcome the challenges surrounding parents of children with autism as well as to enhance the support need of these parents and their children, the following points and areas of social work interventions are recommended.

Parents' knowledge and understanding about the disorder is crucial for the development and improvement of autistic children's life. So it is recommended that the center has to work on education and awareness rising for the parents.

As the number of children diagnosed with autism is increasing overtime, health professionals' especially general medical practitioners and pediatrics should improve their knowledge of autism so as to identify the early symptoms of autism. This enables them to refer parents to the right specialists which in turn help autistic children get early intervention. This is crucial not only to parents but also to the children since early intervention has been successful in the development of these children.

There has to be a better assessment procedure for autism. Specialists who are working in the area should come together and work as a team in order to assess and diagnose autism properly other than using some check lists. They have to make up to date information available for parents like instrumental support including to access service available like social support group, training, school place etc.

As autism is new in our country the service available is limited, so parents coming together and forming associations is recommended. This is one way to increase public awareness and empathy for the unique challenges that families with autistic children encounter. It is also helpful for parents in raising their voices to get appropriate support from the government and other concerned bodies. The center can play a great role in empowering parents to raise their voice. To do so social workers should work with autism centers to empower parents and change their current understanding of the disorder to better cope with the challenges it poses.

Parents of autistic children can benefit from professionally run support groups where they can share challenges, experiences and leanings in the difficult task of raising children with autism. In addition to the social support the center also has to provide counseling service for parents as the disorder imposes emotional and psychological disturbance. So social workers involvement is needed.

Autistic centers should prepare appropriate intervention program according to the level of autistic children. There should be more services available for mild autistic children.

The government has to give more attention towards implementing the policy for education and support for disabled children in general and autistic children in particular.

6.2.1 Recommended Social Work Interventions

Since one of social work values is promoting social justice, equality and inherent worth and dignity of all people. As developmental problems are one of social problems that need social work intervention, the following intervention areas are recommended from the study.

- The Center should engaged in consulting parents about the service and support available and also on how to raise an autistic child
- Nehemiah Autism Center should teach both the public and parents to better understand autism
- It should providing social and professional support for parents and their children.
- The Center should provide counseling service parents
- The Center together with stakeholders at deferent level should engage in advocacy

As autism is new in our country very few studies have been done in the area. Researchers in our country may explore more in this new area. The themes and categories in this study could still serve as individual research topics. However, the author of this study highly recommends that a study concerning the life of female autistic children should be done.

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Appendices

Annexure I: Interview Guide for Parents of Children with Autism

Back ground information about parents

1. Sex: M _____ F _____
2. Age _____
3. Marital Status: Married _____ Single _____ Divorced _____
Widowed _____ have
4. Relation with the child: Mother _____ Father _____ Other (specify)

5. Educational Level: Literate _____ Primary education _____ Secondary
education _____ Collage and above _____ Illiterate _____
6. The standard of living of the family to accommodate the child _____
7. Occupation:
 - a. Employed at governmental organization _____
 - b. Employed at private or NGO _____
 - c. Daily laborer _____
 - d. House wife _____
 - e. Business person _____
 - f. Others (specify) _____
8. How many Children do you have? Do you have other child with developmental
problem?

Back ground information about the child with autism

- Sex: M _____ F _____
- Age _____
- Birth order _____
- Age when first diagnosed with autism _____

Parents understanding and attitude of autism

- Did you have any idea about autism before?
- What do you think of your child situation? How do you explain it? What do you think is the cause?

- How do you explain autism?
- Do you feel comfortable to discuss about your child with other person?
- How does your child spend his/her time in the house?
- Do you think there are problems that your child will face in life only because of her/his developmental problems?
- Do you hope that your child can get employment after some qualification like the other people?
- Did relatives and neighbors use to visit your child when they knew he/she has developmental problem? If so, what did they use to say about the problem?
- What kind of concerns do you have for your child?
- What are your thoughts on the future care of your child?
- Do you believe that a child with developmental problem can be as effective as the normal ones if necessary support is given?

Parent's experience of living with autism

- When did you know that your child has Autism? How did you know?
- What was your first reaction when you know that your child has a special need? What did you feel when you first know? What did you say? What did you do?
- Did you tell for someone when you first know about your child? If yes for whom? What was their reaction? If not why?
- After you know, what was the first institution you went for help?
- Since your child has developmental problem is there any help you get from different bodies? If any specify. Is there any organization that helps your child to enable him educated and be a better person? If any, mention the name of the organization, and what it did to your child
- Have you ever receive instrumental support from professionals to access service available like social support group, training, school place to buy things which is supportive for your child
- Have you ever have a discussion about your child's educational and overall growth with other parents who have children with autism? How was the discussion? What advantages did you get?
- With whom do you discuss freely regarding your child?
- Have you ever done an advocacy for your child for educational access or other service?
- How do you help your child at home?
- Do you communicate with the center regarding your child progress?
- Do you work as team at your home with other family members to make the program consistent?

Siblings

- Do you spend equal time with your children?
- Does your other child understand their siblings problem. Have you ever discussed properly with them about the situation
- Do they play or spend time with him/ her together

Marriage

- How do you manage helping your child with your spouse? In what kind of support does he /she involves
- Which one of you spend more time concerning about your child?
- Do you think having an autistic child has an impact in the family unit?
- How do you support as a couple

Challenges of Having a Child with Autism

- Do you think the public understand autism well now than previous time?
- Have you ever received negative comment from people? What kind of comment? What was your reaction?
- Does your child situation cause isolation from some social gathering?
- Have you ever feel misunderstood by others?
- What was the most challenging time that you wish it wouldn't happen to anyone the way it did to you?
- How do you communicate with your child? Does it need much more effort to play and spend time with your child?
- Do you take your child to any social gathering (wedding, to visit friends or relatives, religious places)? Which places you frequently take him/her? why?
- Is there any negative impact your child's developmental problem caused upon your social life? Could you mention them? For example
 - ❖ In work places, social activities, etc.
 - ❖ In your neighbor-hood
 - ❖ In your relationship to kinships
- Have you ever feel that your child is acting or behaving the way he does purposely like because he needs it? Especially showing some behaviors that he/she did it before right?
- Does having an autistic child affect your marriage or your family?
- What kind of things do you think makes having an autistic child challenging than other problems?
- Does having an autistic child affect you financially? how

Specific needs of parents

- What was is your concern for child and what is it now and in the future
- What kind of services do you think will make things somehow easy if available?
- What do you find to be the most important source of support?
- What do you like to do if you can regarding your child?

Annexure II: Interview Guide for Staff Members

Background information

Age _____ Sex _____

Educational Level _____

Profession _____

Year of Services (relation to the intervention) _____

Skill and training background _____

Information on the center

How many autistic children do you have enrolled currently? boy/ girl/ _____

How many staff do you have? Their profession? _____

Behavioral specialist _____

Occupational Therapist _____

Physical therapist _____

Speech, language pathologist _____

Psychologist _____

Major Activities of the Center and Future Plan

- How do you communicate with parents?
- Do you have professionals in different areas for the intervention?
- Do you have parent conference or meeting? If yes how frequently do you do that? What are the major topics you discuss mostly?
- Do you have staff empowerment? If yes what kind of empowerment?
- Do your staffs have up to date information about autism?
- Did you do advocacy? If yes what was the objective? Did you achieve your goal? If not why

- Are you related/affiliated to other organization? If yes what kind of organization are affiliated with?
- What kind of activities have you done regarding public awareness creation and education, resource mobilization and uses?
- Do you teach the public? What are your means to reach and educate the public?

Intervention Plan and procedures for Autistic children

- How do you plan your intervention?
- Do you have individualized intervention plan?
- Do parents work closely with the center? Are parents' parts of the intervention program planning process of the program?
- Do you have different strategies to teach different skills?
- What are the procedures adopted in assessing and screening the children development
- Who plan the intervention?
- What are your check list to label the children autistic? Do you diagnose? If yes Are you eligible? What is your eligible source to know if the child is diagnosed with autism?

Service and Support Available For Parents

- Do you have training or parent education program? If yes what are the areas of education and training? How frequently you give training?
- Do you have social support group for parents?
- Do you have counseling program for parents?
- Do you help and empower parents to advocate and use and mobilize the available resources?

Challenges and Constraints

- What are your constraints?

Source of support (For the center)

- What are your sources of income?
- Does the government Support you? If yes in what way

Annexure III: Observation Schedule

- Geographical location
- Class rooms' arrangement
- The way they deliver service
- The school environment
- Play ground

Annexure IV: Document Analysis Template

Background of the organization

- Year of establishment
- Founders
- Number of staff
- Number of beneficiaries

Major activities of the center (report)

Recorded review

- Child progress file
- Assessment and evaluation kit(how do they evaluate autistic child(check list))
- Social support meeting report
- Parent communication report