ST. MARY'S UNIVERSITY

SCHOOL OF GRADUATE STUDIES

ASSESSING AUTISM CARE, TREATMENT AND SERVICES CHALLENGES IN ETHIOPIA CATHOLIC CHURCH MISSIONARIES

BY

HIRUT EBDO

ID No. SGS/0667/2011A

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ADDIS ABABA, ETHIOPIA.

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ASSESSING AUTISM CARE, TREATMENT AND SERVICE CHALLENGES IN ETHIOPIA CATHOLIC CHURCH MISSIONARIES (BROTHERS)

A Thesis Submitted to School of Graduate Studies, School of social science and humanities, St. Mary's University for Partial Fulfillment for the Requirements of Master of Art in Social Work

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ENDORSEMENT

This thesis has been submitted to St. Mary's University, School of Graduate Studies for examination with my approval as a university advisor.

_____ _____

TilahunTefera (PHD) Signature & Date

St Mary's University, Addis Ababa

DECLARATION

I, the under signed, declare that this thesis is my original work, prepared under the guidance of TilahunTefera (PHD), my thesis advisor. All sources of materials used for the thesis have been properly acknowledged, I further confirm that the thesis has not been submitted either in part or in full to any other higher learning institution for the purpose of earning any degree.

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HirutEbdo Signature & Date
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I have no words to express my special thanks to the almighty God, for his help throughout my life and enable me to go one step up in my academic career.

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List of Abbreviations and Acronym

A.A Addis Ababa

AAC Augmentative and alternative communication

ABA Applied behavior analysis

ABI Antecedent based intervention

ASD Autism spectrum disorder

CBT Cognitive behavior therapy

DSM Diagnostic statistical manual

DTT Discrete trial training

EBA Evidence based approach

ECCM Ethiopia catholic church missionaries

FCT Functional communication training

FGD Focus group discussion

IEP Individualized education program

MFMER Mayo foundation for medical education &research

NIH National institution of health

PDD Pervasive developmental disorder

PECS Picture exchange communication system

PRT Pivotal response training

Abstract

Autism is a complex neurobehavioral disorder that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviors. The main objective of the study was to explore autism care, treatment and challenges in Ethiopia Catholic Church Missionary (Brothers) autism center. To achieve this objective a descriptive design was employed. Both primary and secondary data were used to empirically analyze the issue. The primary data was gathered from both employees of the center and its beneficiaries (9) through semi structured interview. The empirical finding of this research indicates that the center includes autistic from the street and women and children's affairs office. Though there is certain improvement on the awareness of the society, still autistic persons are neglected.

The care services in the center are only feeding, washing, and other external activities. They rarely work on the development of skills towards the children. The activities of the center are more focus on one of occupational therapy which is handwriting skills. But there is limited effort on speech therapy which teaches verbal skills that can help people with autism communicate better. The center's focus on the education provision for the autistics is very little and they are not able to identify the necessary care services for each person. There is weak evaluation on the effect of the medicine.The findings also indicate that the center involvement with key stakeholders is not strong enough.

Therefore, to improve the performance of the center the researcher recommended that it is important to expand the awareness of the society and the center should include more professionals to bring fruitful change in the in the autistics life.

***Keywords**: autism,attitude, spectrum disorder, Center, Care, Treatment, Parents, stigma*

CHAPTER ONE

1 INTRODUCTION

1.1 Background of the Study

Autism spectrum disorder (ASD) is a developmental disorder that affects communication and behavior. Although autism can be diagnosed at any age, it is described as a "developmental disorder" because symptoms generally appear in the first two years of life.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM), a guide created by the American Psychiatric Association used to diagnose mental disorders, people with ASD have: difficulty with communication and interaction with other people, restricted interests and repetitive behaviors, symptoms that affect the person's ability to function in school, work and other areas of life (DSMMD, 2014).

Autism is known as a "spectrum" disorder because there is wide variation in the type and severity of symptoms people experience. ASD occurs in all ethnic, racial, and economic groups. Although ASD can be a lifelong disorder, treatments and services can improve a person's symptoms and ability to function (National Institution of Health 2018).

People with ASD have difficulty with social communication and interaction and have restricted interests and repetitive behaviors. The list below gives some examples of the types of behaviors that are common in people diagnosed with ASD. Not all people with ASD will have all behaviors, but most will have several of the behaviors which can be categorized under like social communication/interaction behaviors and Restrictive/repetitive behaviors (www. Clinical trials Gov.).

Social communication/interaction behaviors which are observed in people with ASD include: making little or inconsistent eye contact, having a tendency not to look or listen to people, being slow to respond to someone calling their name or to other verbal attempts to gain attention, having facial expressions movements and gestures that do not match what is being said, having unusual tone of voice that may sound sing-song, having trouble understanding another person's point of view or being unable to predict or understand other people's actions (ibid).

Examples of restrictive/repetitive behaviors which can be observed on people with ASD may include: repeating certain behaviors or repeating words or phrases (a behavior called echolalia), having a lasting intense interest in certain topics, getting upset by slight changes in a routine, being more sensitive or less sensitive than other people to sensory input, such as light, noise, clothing, or temperature . (Tipton2014).

Children with autism spectrum disorders (ASDs) who were enrolled for intervention programs receiveprimarily (daily living) skill-based interventions rather than structured social, behavioral, and educational interventions. The children were underserved due to a shortage of available professionals, low number of training facilities, and inadequate resources for family support. Whichresults also highlighted on some recommendations like improving the number of in-service educators, giving continuous training programs as well as evaluating the outcomes and failures of existing strategies in schools and agencies for children with ASDs in Ethiopian (Waganesh, 2013).

Services for children with disabilities and community-based rehabilitation programs are primarily given by NGOs and religious charities but their work related with autism services are very limited. In the case of Addis Ababa there are two autism-specific schools which educate children with autism; these are Joy Center which hosts 80 children with 500+ children on a waiting list; and the Nehemiah Autism Center which enrolls 40 children with 250 children on their waiting list. Both centers only serve for children from Addis Ababa and its surroundings (MOLSA, 2010).

Currently available services for children with autism in Ethiopia come from four main types of providers: governmental and private clinics, centers for children with autism, mainstream schools with inclusive education programs, and NGOs and religious charities providing community-based rehabilitation services. Most of those service providers located in the capital city of Ethiopia which is A.A. (Tekola 2016)

1.2 Statement of the Problem

According to Elsabbagh et al. (2012), the median estimate of Autism Spectrum Disorder (ASD and Pervasive Developmental Disorders (PDD) in developed countries is 17/10,000 and 62/10,000 respectively. Caring for children with these disorders is demanding, especially in contexts where access to services and support are inadequate. There is critical lack of awareness among the community and parents about ASD. Once the parents found out that

their child experienced developmental challenge, even without being diagnosed, they consider their child as useless and unworthy of spending resources on him/her. Children with ASD are often denied any rights whatsoever, even the right to see daylight, or the right to participate in society. Such disorders are sometimes even seen as punishment for some spiritual wrongdoing or a tragic incidence. Most parents had no knowledge about ASD and felt that they were not fully empowered with information about autism by professionals before or after diagnosis. Many parents of autistic children also feel lack of support (Miraf, 2015).

In Ethiopia there is lack of knowledge and understanding about ASD. The diagnosis and education provision is very limited. Families of children with autism found in Addis Ababa, face sever psychosocial and practical challenges in caring for their child with autism including stigma and social exclusion (B.Tekola, Y.Bahiretibeb, I.Roth, D.Tilahun, A.Fekadu, C.Hanlon, and R.A.Hoekstra.2016).

There are few researches regarding on ASD in Ethiopia and they are focusing on mostly on parental challenges such as implications of childhood autism on the wellbeing of families (Minasie, 2017), lived experiences of single mothers having autistic children (Roman, 2019), reactions, challenges & coping mechanisms of mothers raising children with ASD (Helen, 2016), and parents' experience & care practice (Miraf, 2015). There is one research which was done by Cleopatra. L, 2018 about care &treatment: services, challenges & promising practices in Ethiopia. This specific research focuses on two prominent autism centers in Ethiopia that is Nia- Foundation Joy Center and Nehmia autism center and assessed care and treatment they are giving for autistics and the organizations services, challenges they are faced and their promising practices. The gap in this research paper is that it only focuses on the two autism centers locally established by Ethiopians and it does not asses the practices and nature of other autism centers established by foreigners with the same objectives.

Therefore, it needs to assess the functions and contributions of Ethiopia Catholic Church Missionary (Brothers) autism center because of its unique features compared with the above mentioned studies. The center is differing from the previous study areas because it is religious based, and also owned and supervised by foreigners.

Eventually this study is going to assess autism care, treatment, and organizational challenges in Ethiopia Catholic Church Missionary (Brothers) autism center for it has not been studied well and to fill a literature gap in this specific study area.

Therefore, this study was intended to fill the gap on lack of studies on the study area and assess challenges which are not studied by previous studies that affect the performance of the center.

1.3 Objectives of the Study

1.3.1 General Objective

The general objective of this study is to explore autism care, treatment and challenges in Ethiopia Catholic Church Missionary (Brothers) autism center.

1.3.2 Specific Objective

The specific objectives include:

- To identify the types of care service provided by Ethiopia Catholic Church missionary(Brothers) autism center
- To explore the types of treatment service provided by Ethiopia Catholic Church missionary(Brothers) autism center
- To investigate the challenges experienced by Ethiopia Catholic Church missionary (Brothers) autism center while delivering the service

1.4. Research Questions:

The study will attempt to answer the following research questions

- How is the Ethiopia Catholic Church Missionary (Brothers) autism centerproviding care servicefor the autistics children?
- How is the Ethiopia Catholic Church Missionary (Brothers) autism center providing treatment services for the autistics children?
- What are the organizational challenges while giving the service for autistics and their families?

1.5. Significance of the Study

The study has practical importance for sharing their evidence based intervention for other related centers. The result of the study will play key role as an input for policy makers and for newly open centers especially for those who are religious based centers and who run their budget by foreign fund which aimed at work on ASD as a guideline. This research also influences the government to contribute its responsibility and to give much attention in this area.

1.6. Scope of the Study

Geographically, this study is conducted in Addis Ababa Ethiopia Catholic Church Missionary (Brothers) autism center. Thematically, the variables under this study include assessment on treatment and care services, provided by the charity organization and the challenges they faced since its establishment in Ethiopia, 1984.

1.7. Limitation of the Study

The researcher has faced limitations with regards to finding studies on the area. To manage this limitation, the researcher has used information from other similar centers and internet.

In interview the respondents did not respect interview schedule due to work load. This was also managed by rescheduling fitting time for them.

The other main constraint is the sudden global pandemic called corona virus (COVID-19). This was also managed by strictly following precaution methods.

1.8.Operational Definitions of Key Terms

- *Autism*: a developmental disorder characterized by difficulties with social interaction and communication, and by restricted and repetitive behavior
- *Autism spectrum disorder*: Persistent deficits in social communication and interactions across multiple contexts that interfere with the development of social relationships and can negatively impact academic or occupational performance (APA, 2013).
- *Brothers*: volunteer care givers for autistics by living in ECCM.
- *Care*: services for autistic focusing on social aspectse.g. giving affection, cleaning, recreational activities, nutrition and education service.
- *Center*: a place where autistics are live.
- *Parents*: those who have children in ECCM.

- *Service users*: autistics who are getting services in ECCM.
- *Treatment*: giving service for autistics according to medical procedure particularly medicine.

1.9. Organization of the Study

The thesis consists of five chapters. The first chapter outlines the introduction part, which comprised background of the study, statement of the problem, the general and specific objectives, the research questions that will be answered in this research, significance of the research, scope and limitation of the of the study, and definition of term.

The second chapter of the study deals with literature review in order to enable readers comprehensively understanding on kaizen. It has theories of kaizen, empirical studies and conceptual framework session.

The third chapter describes the context of the study area, research design, research approach, methodology which includes research design, population, sample size, sampling technique, sampling frame and unit, data collection methods, data analysis and presentation, and ethical considerations.

Chapter four focuses on the important aspect of this research; the data presentation and interpretation. It comprises of the response rate description of the characteristic of respondents, presentation and interpretation of the data pertaining to research one, two and three.

Finally, chapter five focuses on presenting summary of the major findings, the conclusion and the practical recommendations.

CHAPTER TWO

2.REVIEW OF LITERATURE

2.1.Introduction

Literature review provides back ground information to address the problem of the study. It helps to identify the key concepts of about Autism. The conceptual framework is developed based on literature review to emphasize mainly on the relationship of the variables. This chapter presents the review of related and relevant literatures in order to lay down the theoretical, empirical and conceptual frame work of the study.

2.2.Definition and Concept

2.2.1.Autism Definitionand Concept

Autism is a complex neurobehavioral disorder that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviors. A child with autism who is very sensitive may be greatly troubled sometimes even pained by sounds, touches, smells, or sights that seem normal to others. Many people with autism are cognitively impaired to some degree. In contrast to more typical cognitive impairment, which is characterized by relatively even delays in all areas of development, people with autism show uneven skill development. Autism is four times more common in boys than in girls. Autism typically appears during the first three years of life. It knows no racial, ethnic, or social boundaries. Family income, lifestyle, or educational levels do not affect a child's chance of being autistic (Aadil, 2014).

Symptoms of autistic disorder fall under three domains: social relatedness, communication, and behaviors and interests, with delays or abnormal functioning in at least one of these areas prior to age 3 years. To meet criteria for autistic disorder, an individual must demonstrate at least 6 of 12 symptoms, with at least 2 coming from the social domain and 1 each from the communication and restricted behaviors/interests categories (Ozonoff, et al., 2005).

2.2.2. The causes of Autism

Scientists aren’t certain about what causes ASD, but it’s likely that both genetics and environment play a role. Studies of people with ASD have found irregularities in several

regions of the brain. Other studies suggest that people with ASD have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that ASD could result from the disruption of normal brain development early in fatal development caused by defects in genes that control brain growth and that regulate how brain cells communicate with each other, possibly due to the influence of environmental factors on gene function. While these findings are intriguing, they are preliminary and require further study(Pottie, 2008).

2.3 Economic Effects

According to a study in 2005 the expenses for a child with autism was more than triple that of a child without, and for those children that also had a co-occurring condition the costs were even higher. The larger portion of the expense is incurred during adulthood (Sonya & Jessica, 2012).

Costs associated with having a child with autism are not, only, limited to the cost of interventions. Like any other forms of childhood disability, parents of a child with autism often face greater outlays of time and money than they would for a neurologically typical child (Aadil ,et al., 2014).

In a few cases, fathers acknowledged that their child's autism might have encouraged a great commitment to work. In addition, many mothers who worked were often forced to miss work. They performed below average and some eventually worked part-time or ultimately left the workplace altogether (Sonya & Jessica, 2012).

2.4 Psychosocial Effects

Research into families under stress has demonstrated a link between relationship breakdown and poor physical and mental health. The evidence points ultimately therefore to a significant cost to the state in the stress placed on individual careers, and the consequent breakdown in health and family relationships (Fiona, 2001).

Other important factors associated with parental stress in families of children with autism, include, feelings of loss of personal control, absence of spousal support, informal and professional support (Aadil, .et al., 2014).

Parents of children with disabilities experience more marital stress and discord than parents with normal children. Families with autistic children face many stressors and challenges, today's partnership in marriage is more challenging and more difficult than in the past years; especially couples with special needs children (AlHorany, 2013).

Mothers of autistic children have higher parenting-related stress and psychological distress as compared to controls. Outwardly, it might appear as if the psychological stressors exerted specific effects resulting in mental ill-health attributable these stressors (Abdullahi& Samira, 2013).

Positive attitude, social support and faith in God, helped mothers generate psychic energy to cope with the physical, emotional, and financial aspects of care giving and Interventions focused on parents' coping skills have reported positive results (Ashum&Nidhi, 2005).

Siblings of children with autism are significantly more likely to experience depression than the general population. Along with psychological problems, exhaustion may affect siblings who may be responsible for domestic tasks and physical care (Ashum&Nidhi, 2005).

Fear of discrimination and the stigmas surrounding disabilities lead many families to refuse to go to professionals and receive a diagnosis for their children (Aadil.et al., 2014).

2.5 Theories on Autism

2.5.1 Refrigerator Parenting Hypothesis (RPH)

Kanner(1943)had originally suggested that autism was partly the result of 'cold', unemotional parenting, specifically by the mother. However, the prevailing current view is that parent's behavior doesn't initiate or in any way provoke autism (Powell, 1999). Indeed, any difference in parents' behavior towards their autistic child is more likely to be caused by the autism than vice versa (Powell, 1999). Also, autism seems to strike indiscriminately. It is not respecter of social class or family environment: it can affect a child with extremely warm and loving parents (Mitchell, 1997).

2.5.2 Genetic Theories (GT)

Kanner suggested that autism has a genetic component. According to (Rutter, Andersen- Wood, Beckett, Bredenkamp, Castle, Groothues, Kreppner, Keaveney, Lord, & O'Connor, 1999) finding from several independent studies provided compelling evidence for a strong genetic component underlying autism (Richard 2010). If one member of a twin pair is autistic, the probability that the other will also be autistic depends to a significant degree on whether they share all their genes or only half their genes (the same as ordinary siblings). Rutter et al (1999) autism is the most strongly genetically influenced of all multi factorial child psychiatric disorder.

2.5.3 Theories of Mind (TOM) and Mind-Blindness

The most influential theory of autism in recent years maintains that what all autistic people have in common (the core deficit) is mind- blindness (Boron-Coher, 1993). A sever impairment in their understanding of mental states and in their appreciation of how mental states govern behavior. Autistic individuals fail to develop the ability to attribute mental states to other people and this has fundamental implications for communication, where making sense of others' intentions enables the listener to understand what's being said (Baron-Cohen, 1993). The strongest evidence for autistic children's lack of a theory of mind (ToM) and mind-blindness is their consistent failure on false belief tasks by comparison; Down syndrome normal children reliably pass them. Autism individuals may become distressed by changes in their immediate ritualized behaviors: they don't plan to anticipate the consequence of their actions. Executive function deficit is not a sufficient explanation of the specific nature of autism (Lewis, 2003).

2.5.4 Empathizing Systemizing (E-S) Theory

The theory was developed by, Baron and Cohen (1993). According to the E-S theory, Female brain is hard-wired for empathy (E-type), while male brains are hard-wired for constricting system (S-type). These differences are reflected in male /female difference from birth until the adult skills and occupations, according to which the autistic individuals have an extreme male brain.

2.6 Diagnosis of Autism Spectrum Disorder (ASD)

Early diagnosis of ASD is very necessary in order to identify cause and risk factors to provide reliable counseling and treatment by implementing early intervention. For diagnosis of ASD, evaluation is often a two stages process. Stage I entails general developmental screening of all toddlers during their primary health care visits while stage II entails professional evaluation of any cases suspected to have ASD during stage I by a multidisciplinary team that includes a developmental pediatrician, a speech pathologist, an occupational therapist, a child psychologist, and a child psychiatrist. Stage II professional multidisciplinary team assessment has to focus on evaluation of autistic core symptomatology, cognitive and linguistic abilities, and adaptive, sensory, and motor skills For detection of any possible cause and to exclude any differential diagnosis, a battery of laboratory testing and electrophysiological evaluation might be needed. (Cleopatra L. 2018).

2.6.1 Diagnosis in Young adults

Every child should receive well-child check-ups with a pediatrician or an early childhood health care provider. The American Academy of Pediatrics recommends that all children be screened for developmental delays at their 9- 18, and 24- 30-month well-child visits, and specifically for autism at their 18 and 24-month well-child visits. Additional screenings might be needed if a child is at high risk for ASD or developmental problems. Children at high risk include those who have a family member with ASD, have some ASD behaviors, have older parents, and have certain genetic conditions. Parents' experiences and concerns are very important in the screening process for young children. Sometimes the doctor will ask parents questions about their child's behaviors and combine those answers with information from ASD screening tools and with his or her observations of the child (Lewis, 2003).

Children who show developmental differences during this screening process will be referred for a second stage of evaluation. This second evaluation is with a team of doctors and other health professionals who are experienced in diagnosing ASD. This team may include: A developmental pediatrician doctor who has special training in child development, a child psychologist and/or child psychiatrist doctor who has specialized training in brain development and behavior, a neuropsychologist a doctor who focuses on evaluating, diagnosing, and treating neurological, medical, and neurodevelopment disorders, speech-language pathologist a health professional who has special training in communication difficulties. This second evaluation may assess: Cognitive level or thinking skills, Language abilities, and Age-appropriate skills needed to complete daily activities independently such as eating, dressing, and toileting. Because ASD is a complex disorder that sometimes occurs along with other illnesses or learning disorders, the comprehensive evaluation may include blood tests and a hearing test. The outcome of this evaluation will result in a formal diagnosis and recommendations for treatment (WHO 2013).

2.6.2. Importance of Early Diagnoses

Some parents are completely devastated upon learning that their child has been diagnosed with autism. The early diagnosis in turn, leads to early treatment that can offer a child that is autistic a better chance of what society considers a semi normal life. (Sonya, Jessica, 2012).

Children as young as 2 to 3 years, who exhibit behavior associated with a diagnosis can qualify for early intervention services. This alarming rise in the number of children, clearly calls for additional services to meet the needs of these children and their families.

(Ashum&Nidhi, 2005) The diagnosis of autism begins a journey that places profound demands on family human and financial resources for the remaining lifetime of the child (Aadil, 2014).

More than half of school-aged kids were age 5 or older when they were first diagnosed with autism spectrum disorder, the study showed. Less than 20% were diagnosed by age 2. The American Academy of Pediatrics recommends that pediatricians screen children for autism at 18 months of age (Denise, 2012). From birth to at least 36 months of age, every child should be screened for developmental milestones during routine well visits. When such a screening or a parent raises concerns about a child's development, the doctor should refer the child to a specialist in developmental evaluation and early intervention (Aadil, 2014).

There are no diagnostic or educational services in the rural areas, where 85% of the population lives. In these areas autism usually remains undetected because of limited health care, low levels of awareness and stigma. Autism type symptoms are often seen as a punishment for wrongdoing from supernatural forces (Marquis D, 2014).

Getting children early intervention that increases IQ's, social interactions and communication skills will increase the ability for individuals with ASD to gain employment and be able to live independently. This will increase the individual's wellbeing and decrease overall costs. . (Sonya & Jessica, 2012)

2.7 Treatment of autistic disorder

Treatment for ASD should begin as soon as possible after diagnosis. Early treatment for ASD is important because proper care can reduce individuals' difficulties while helping them learn new skills and make the most of their strengths. The wide range of issues facing people with ASD means that there is no single best treatment for ASD. Working closely with a doctor or health care professional is an important part of finding the right treatment program (Fiona, L. 2001).

According to Fiona, Lone of the interventions is applied behavioral Analysis(ABA). It is the process of applying behavioral principles to change specific behaviors and simultaneously evaluating the effectiveness of the intervention. ABA emphasizes both prevention and remediation of problem behavior. Significant attention is given to the social and physical environment, including the antecedent conditions and consequences that elicit and maintain behavior. Numerous empirical studies have documented the effectiveness of ABA with individuals with ASD. These interventions should typically be provided under the supervision

of a trained behavioral psychologist or behavior analyst. Research suggests that the best outcomes occur when ABA is initiated early in development, preferably prior to 5 years of age. ABA mainly helps children with ASD to eliminate behavioral problems. There are different types of ABA interventions listed below: (Fiona, L. 2001).

Discrete Trial Training (DTT): this type of intervention sometimes called "Lovaas therapy" in reference to IvarLovaas at UCLA, who was a strong early proponent of using DTT with children with autism.DTT often incorporates the use of errorless learning, shaping, modeling, prompting, facing, correction, and reinforcement to encourage skill acquisition. It is especially well-suited for skills that can be taught in small, repeated steps. Research indicates that DTT can produce powerful behavioral outcomes in the areas of language, motor skills, imitation and play, emotional expression, academics, and the reduction of self-stimulatory and aggressive behaviors. This type of intervention can be used in all level and ages (Fiona, L. 2001).

Functional Communication Training (FCT): FCT has a strong research base, especially using single-subject research designs, and FCT has been shown to significantly reduce problem behavior and to increase communication and social interaction. This intervention is very effective with young children with limited cognitive and language skills, but it can be used with individuals of all ages. When delivered through weekly training sessions with parents/caregivers and their children, FCT can be a very effective and efficient intervention strategy for reducing problem behavior and increasing communication and social behavior (Fiona, L. 2001).

Pivotal Response Training (PRT): PRT builds on a child's initiative and interests, which makes it particularly effective in developing communication, play, and social behaviors. Research has supported the effectiveness of PRT in increasing motivation and improving language and play skills. It is recommended that PRT be implemented by caregivers and teachers in natural contexts; it is considered cost- and time-efficient. This intervention can be used with preschool-aged children through adults with mild cognitive impairments and with those who have at least a minimal level of receptive and expressive language (Fiona, L. 2001).

Antecedent-Based Interventions (ABI): This type of intervention applies reinforcement or punishment after some behavior occurred and also set up the antecedent to increase the good behavior and to minimize the bad one (Fiona, L. 2001).

Social Skills Training: the main problem of ASD are social interaction. The use of peer-mediated interventions to build social skills is well established as well. There is evidence that specific aspects of social interaction (e.g., eye contact, joint attention, verbal greetings, etc.) can be learned with focused training(Fiona, L. 2001).

Cognitive-Behavioral Therapy (CBT): In fact, CBT is one of the most widely used non-pharmacologic treatments for individuals with mental and emotional disorders, especially depression, and its use with individuals with autism spectrum disorders is growing. CBT focuses on replacing negative or ineffective patterns of thought and behavior with structured strategies that are effective in improving mood and adaptive functioning. This type of therapy helps to manage depression, anxiety and social deficits.CBT is especially appropriate for use with older children and adolescents or adults with Asperger's syndrome or high functioning autism, for which the cognitive demands of the therapy are manageable(Fiona, L. 2001).

Educational programs for autistic children usually try to relieve their symptoms and improve their communication, social skills, and adaptive behavior, so that they can become more independent. Autistic children have several problems that make teaching difficult, however. First, they do not adjust normally to changes in routines, including special events and substitute teachers. Second, their behavior problems and self-stimulatory movements may interfere with effective teaching. Third, it is particularly difficult to find reinforces that motivate autistic children. 'Normal' children (who are not autistic) like to explore and control their surroundings, but not children with autism. For reinforces to be effective with autistic children, they must be explicit, concrete, or highly salient. A widely used method of increasing the range of reinforces that autistic children respond to is to pair social reinforcement with primary reinforces such as food (Lovaas, Koegel, Simmons, & Long, 1973).

From the literature, further problem that often interferes with the learning of autistic children is their over selectivity of attention. When the child's attention becomes focused on one particular aspect of a task or situation, other properties, including relevant ones, may not even be noticed. For example, in sign language training, the teacher often says a word while making its sign in the presence of the referent object or its image. Students, it is assumed, will learn to associate the sign with the spoken word and the object. Children with autism are more likely to attend to only one of the cues (Lovaas et al., 1973).

2.7.1 Psychodynamic Treatment

A very different treatment of autism was developed over many years by (Bettelheim 1967; Bettelheim 1974). Bettelheim argued that a warm, loving atmosphere must be created to encourage the child to enter the world. According to (Davison, 1980) Bethlehem's treatment may contain more direct instruction, systematic reinforcement, and extinction. By the same token, of course, reports of behavior therapists usually underplay the rapport building that undoubtedly provides the context for their programs (Davison, 1990).

2.7.2 Drug Treatment

There is evidence that some autistic children have elevated blood levels of serotonin (Ritvoet. al., 1970). In hopes of reducing their serotonin levels and there by improve behavior and cognitive functioning, investigators administered efflux amine to autistic children.

2.8 Interventions for children with autism

2.8.1 Need for Evidenced-Based Interventions

Identifying effective medical and behavioral treatments for neurodevelopment disorders should be based on a solid foundation of scientific evidence. This tradition of scientific investigation has long been a foundation of modern medicine, and the need for identifying evidence-based treatments has received increasing recognition in the field. In addition, as part of legislation under the "No Child Left Behind Act" (NCLB, 2002), the field of education also requires the use of "effective interventions" to support learning. These interventions can only be validated through "scientifically based research." The call for the use of interventions that have proven their effectiveness is particularly important for the autism spectrum disorder community, which has long been plagued by the use of unsupported and often controversial interventions. In fact, it has been suggested that the uncritical use of unproven "miracle" interventions has encouraged unrealistic, implausible, and unhealthy expectations about treatment results and have ultimately impeded the progress of identifying effective interventions for children and adolescents with autism spectrum disorder (Simpson, 2005).

2.8.2 Identifying Effective Interventions

One major barrier to the adoption of evidenced-based practices for autism spectrum disorder is the lack of consensus on how to identify and evaluate scientifically valid and effective interventions. According to the No Child Left Behind Act of 2001 (NCLB), "scientifically based research" is defined as "research that involves the application of rigorous, systematic,

and objective procedures to obtain reliable and valid knowledge" (NCLB, 2002). For a practice to be judged as scientific, it must meet particular standards, reliably yield positive results, and survive a rigorous peer review process. In addition, scientifically based practices are validated by means of specific "gold standard" research designs that include random samples of subjects that are assigned to control and experimental groups or a series of replications of well-controlled studies using rigorous single-subject designs. However, the scientific method of validation has sometimes been criticized as being too narrow and as having a negative effect on ASD research because of the methodological restrictions that make this type of research difficult to conduct in many real-life settings. The following guidelines (Simpson, 2005) provide a balanced perspective for evaluating ASD interventions:

- Just because a website or brochure lists an intervention as "evidence-based" or "research-based" does not make it true. It may take careful investigation to determine whether a treatment truly has been validated.
- Rigorous methods of determining a treatment's validity can take several forms when conducted appropriately, including but not limited to single-subject design, correlation studies, quasi-experimental design, and randomized controlled trials.
- Information about a treatment's effectiveness that comes from a single source that is not supported by other research, lacks peer review, and comes primarily from testimonials rather than empirical validation should be viewed with extreme caution.
- It is important to consider the match between the needs of the individual with ASD and the focus of the intervention.
- It is important to consider the potential risks (e.g., cost, time commitment, adverse effects, impact on quality of life, etc.) of interventions.
- There is no single universally effective intervention for all children with ASD. The best programs often incorporate several research-based interventions and attend to the individual needs of children with ASD and their families.

2.9 Importance of Care and support

The Autism Specific Early Learning and Care Centers provide early learning programs and specific support to children aged zero to six years with autism spectrum disorders (ASDs) in a long day care setting. They also provide parents with support in the care of their children and give them the opportunity to participate more fully in the community (Fiona, 2001).

Regarding Special Needs program, there are no specifically designed curriculum, syllabus, and/or modules that intend to meet the educational needs of children with autism spectrum disorder in segregated or inclusive classrooms. Although it is based on the country's capacity, this fact is far from the national and international convention of human rights and education for all(AlHorany, 2013).

Greater levels of daily positive mood were associated with more emotional and instrumental support, and less parenting stress and unsupportive interactions. Greater daily negative mood was associated with less emotional support and more parenting stress, unsupportive interactions, and disruptive child behaviors. Emotional support, unsupportive interactions, and disruptive child behaviors moderated the stress-mood relationship. (Pottie, et al., 2008) Environmental risk factors such as lack of services and negative attitudes can also have an adverse influence on the prognosis of the child with autism, the family concerns are difficulty in accessing services, limited involvement in interventions, services that are not effective in meeting the needs of the child or family, and a lack of interagency collaboration(Ashum&Nidhi S, 2005).

2.10. Empirical Review

2.10.1. Historical Development of Autism

Autism was first described by Leo Kanner in 1943 based on the case histories and observation of children who showed a similar pattern of behaviors including language delay, social remoteness, excellent rote memory, obsessive to sameness, oversensitivity to stimuli and delayed echolalia. At that time, the term autism was used to describe early infantile autism or infantile autism. In 1944, Hans Asperger independently described a syndrome which is now known as Asperger Syndrome (AS). The descriptions of Kanner and Asperger shared a similarity in some autistic characteristics such as poor eye contact, stereotyped language and physical movements, resistance to change and narrowed special interests. The important value of the identification of AS was the recognition that autistic-like syndromes can arise in individuals of normal language and cognitive development but who have often shown more subtle abnormalities in communication patterns. With the development of research and clinical practice, more behavioral symptoms were described and categorized as autistic characteristics (Hens and Van Goidsenhoven 2017).

2.10.2. Prevalence of ASD

Recent reviews estimate a global median prevalence of 62/10 000, that is one child in 160 has an autism spectrum disorder and subsequent disability. In Europe, the median rate is 61.9/10,000 (range 30.0–116.1/10,000) and in America, the median rate is 65.5/10 000 (range 34–90/10 000). Autism spectrum disorders account for 0.3% of all disability adjusted life years. Autism spectrum disorders impose a huge emotional and economic burden on families (WHO, 2013).

Although most studies on ASD prevalence reflect the estimates for developed countries, little is known about the ASD /PDD prevalence in low income countries. However, the estimates suggest that it is less that or as high as in developed countries (Nyoni and Serpell, 2014).

Although prevalence studies reflect the prevalence of developed countries and the global rate is adopted for developing countries, chronic problems related to reproductive health, prevalence of diseases like malaria, poverty and food security are assumed to contribute for increased prevalence of ASD and PDD in Ethiopia and other low income countries (Elizabeth et al., 2003).

Studies conducted by different researchers at different region revealed that, the prevalence of all forms of autism combined is estimated to be 1 in 162 individuals (Elsabbagh et al., 2012). Taking the global median estimate, Autism Spectrum Disorder ASD=17/10000 and Pervasive Developmental Disorders (PDD) 62/10000. 5000 and 18500 children and parents/care givers are estimated to suffer from having children with ASD and PDD (Elsabbagh et al., 2012).

If one in every 115 children is diagnosed with autism in the United States, we should fairly be able to say that with Ethiopia's population of more than 80 million, we can estimate that there are at least 530,000 children suffering from autism and related developmental disorders in the country (Nyoni and Serpell, 2014).

Despite the above estimated number of children suffering from ASD and other PDD syndromes, the prevailing lack of prevalence study and diagnostic capacity/setup implies the pervasive lack of attention and awareness. There is lack of awareness among the community and parents about ASD. Usually when parents found out that their child has some kind of mental development problem, even without being diagnosed, they consider him/her as useless. Children with ASD are often denied any rights whatsoever, even the right to see daylight, enjoy sunshine, or the right to in some way participate in society. Such disorders are

sometimes even seen as "punishment for some spiritual wrongdoing or a tragic incidence" (Autism in Ethiopia, 2014).

2.10.3. Autism in Africa

Little is known about autism in Africa: the vast majority of autism research studies to date have been conducted in Western, high-income countries (Durkin et al. 2015), resulting in a research gap concerning studies from low-income countries like Ethiopia. Due to a lack of epidemiological studies the prevalence of autism in Africa is unknown (Elsabbagh et al. 2012). The few autism studies conducted in Africa indicate a lack of knowledge and awareness about autism, inadequate mental healthcare facilities and a severe shortage of trained personnel (Bakare&Munir, 2011). No African country has published policies or good practice guidelines for autism assessment, treatment, education and support (De Vries, 2016). A recent report of an autism meeting attended by 47 delegates from 14 African countries highlighted the lack of available autism services throughout Africa and the need to raise awareness and develop autism screening, training and service strategies on the continent (Ruparelia et al. 2016).

Similar to other African countries, Ethiopia has limited autism service provision. The detection of, and care for, children with autism in Ethiopia is further impeded by stigma surrounding mental health (Shibre et al. 2006) and misconceptions about the causes of developmental disability and mental illness (Alem et al. 1999; Abera et al. 2015). We recently examined the experienced stigma, explanatory models and unmet needs of 102 help-seeking caregivers of children with autism and/or intellectual disability (ID) in Ethiopia (Tilahun et al. 2016). Caregivers provided a mixture of biomedical (e.g. head injury or birth complications) and supernatural (e.g. spirit possession or sinful act) explanations for their child's condition.

Caregivers also reported high levels of stigma, with higher stigma associated with seeking help from traditional institutions, providing supernatural explanations and affiliation to Orthodox Christian faith. The majority (75%) of caregivers reported unmet needs regarding their child's educational provision and many (47%) also indicated an unmet need for support from health professionals. These findings illustrate the great challenges experienced by families with children with developmental disorders in Ethiopia (De Vries, 2016).

In recent years however, Ethiopia's mental healthcare system has become the focus of new initiatives. The National Mental Health Strategy (2012/13–2015/ 16) presents a plan for

scaling up mental healthcare and recognizes children with mental disorders as a vulnerable group. Training of mental health specialists is being expanded, with in-country psychiatrist, Ph.D., Masters and psychiatric nurse training programs, and basic mental health training for rural community based health workers. New initiatives from local nongovernmental organizations (NGOs) also contribute to an increase in autism awareness and service provision in Ethiopia (De Vries, 2016).

Although these developments are promising, existing services for children with autism have scarcely been documented. Moreover, little has been done to explore opportunities and challenges to expand services and the most effective ways for future service development. This paper aims to assess the current health and education service provision for children with autism in Ethiopia. It explores the unmet needs, future opportunities and stakeholders' views of the best approach to further develop services (Tilahun et al. 2016).

2.10.4. Public Awareness on Autism

Autism was not recognized until 1949. It is now highlighted as an "epidemic". In the West, there has been more public attention on ASD due to more advanced autism research and improved awareness in the general population, which could be partly due to a few high profile celebrities and parents lobbying for recognition. The characteristics of ASD are presented in novels and movies which have improved their recognition and acceptance by the society. In Africa including our country Ethiopia, the recognition was much later than the West (Tipton &Blacher, 2014).

Currently, there is little information on the attitudes of the general adult populations towards individuals with autism. There are studies that look at knowledge of autism as a representation for attitude towards people with autism; Campbell and Barger, 2011). Nonetheless, these studies are limited due to the lack of established connection between knowledge and attitude in the area of autism spectrum disorders. Other studies that have looked directly at attitude or comfort ability have been done with either middle school students (Chambres, Auxiette, Vansingle, & Gil, 2008; Campbell, 2007) or with university students (Butler and Gillis, 2011; Nevill& White, 2011). While university students are of adult age, they are typically unrepresentative of the broader adult population. The present study seeks to expand the literature by doing an exploratory study of present attitudes, knowledge, and prior personal experience regarding adults with autism with a representative sample of adults living in a local community.

2.10.5 Parents' awareness

Although knowledge about autism has improved in recent years, Autism in Ethiopia is still surrounded by lack of awareness and stigma. There is a severe lack of diagnostic and educational services for individuals with autism and their families; facilities are non-existent in rural areas. (Marquis, 2014)

Most parents had no knowledge about ASD and felt that they were not fully empowered with information about autism by professionals before or after diagnosis. Commonly parents of autistic children in Ethiopia, particularly mothers, become disabled themselves. Burdened with the full responsibility of care, and likely having very little income, their child's disability directly constrains their ability to work and make a living; to take care of their children and themselves. Often, the exceptional demands of the child's disability also create emotional and financial problems for the parent (Marquis, 2014).

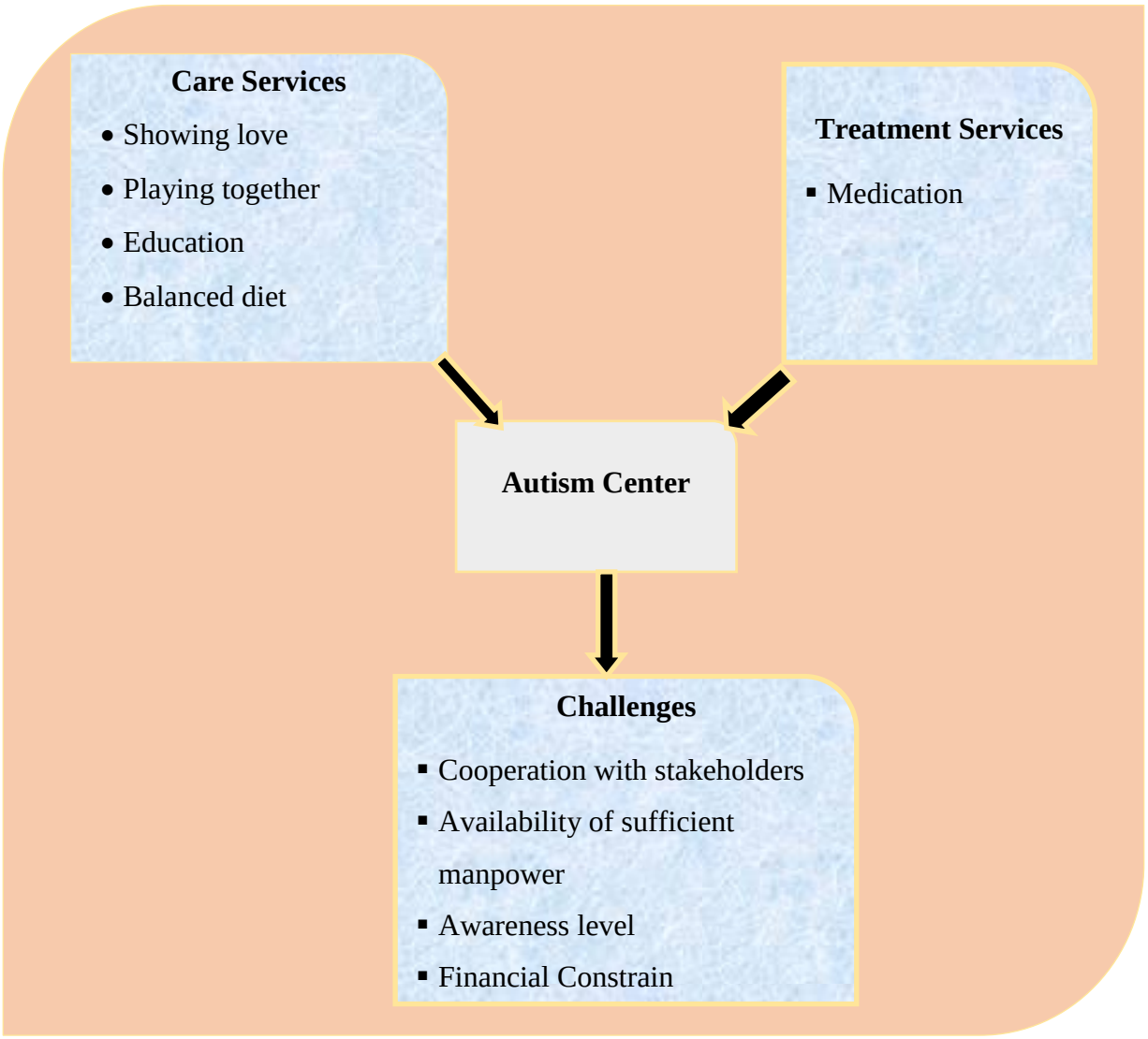
2.11The Conceptual Framework

Conceptual framework tries to show the independent variables of this research which are the care services, treatment services and challenges of autism center and beneficiaries. They directly affect the dependent variable, which is autism center.

The care treatment service which can be given for any person with autism is medication. On the other hand autistic person cannot be treated only by medications; therefore the center provides different care services like showing love, playing together, education and providing balanced diet.

The other independent variable, which is factors which affect the performance of the centre are shown in the diagram. These challenges include lack of cooperation with stakeholders, lack of sufficient manpower, low level of societal awareness and financial constraint.

Figure 2. 1: Conceptual Framework



Source: Own Framework (2020) designed based on readings

CHAPTER THREE

3. RESEARCH METHODOLOGY

3.1. Introduction

This chapter focuses on the research methods, design and other related sub topics. It gives description of the study area, sampling method, type and source of data and method of data presentation and analysis.

3.2.Description of the Study Area

The study area Ethiopia Catholic Church missionary (Brothers) autism center established in 1984 and found in Addis Ababa around *AddisuGebeyaAgipworeda* 7 and currently it gives care and treatment for sixty autistics and orphanage children. It is under mother Theresa charity organization.

In Addis Ababa it is one of the three autism center and the other branches are found in *Asko* and *Arat* kilo with the same mission. ECCM is giving care for victims of polio, autism, and other mental disabilities. In the center there are fifteen employees and two voluntary brothers. The fund is found from India and Europe. The ECCM headquarters is found in India. In addition to those activities, they opened school that gives free education and support for the needy peoples in *Kechene* area. The main reason of selecting this center is it is the one not yet been studied before by its nature of being religious based and funded by foreign fund.

3.3 Research Design

Research design implies the way the study will be conducted, the procedures and techniques employed to answer the research questions (Mcmilan& Schumacher, 1984). It indicates the nature of the study that was conducted. For this study, descriptive research design is used. This method is selected for that it enables the researcher to obtain the information concerning the current status of the phenomenon.

3.4.Research Approach

The purpose of this study is to investigate the care, treatment and services challenges in the Ethiopia Catholic Church missionary (Brothers) autism center. For this reason a qualitative research approach was identified as the most appropriate to meet the research aim. This is due

to qualitative research advances knowledge through a series of detailed, and small-scale studies in general it can add the depth of the study.

3.5.Sample Design

3.5.1.Population

The target population for this study was all employees of the center and parents of autistics. According to the data of the center 2019 report, the numbers of staffs in the center are 17and parents or service users of the center are 65. The total population for the study is 82. It is from this population that the sample research participants were drawn.

3.5.2.Sampling Frame

A list of employees of the center and parents who are benefiting from the center were constitute under this research sample frame.

3.5.3.Sample Size

Among the two sampling frames, the researcher will take 4 samples from employees and 5 from beneficiaries, who get services from the center purposively. The researcher believes that this sample size is suitable for the qualitative research approach which focuses on depth rather than width. The other reason is the researcher believes that this sample size can give a better data for the study and also it can be manageable for the researcher.

3.6. Sampling Technique

To get a qualitative data through interview non-probability purposive/ judgmental sampling were used. It is a technique by which the researcher selects the units to include in the sample. The reason behind selecting this technique it can provide a more accurate and reliable data. It is also possible to use this method if the researcher knows a reliable professional that is capable of providing the relevant data (Dolores, 2007).

By taking the above points into consideration the researcher made an interview with key informants by selecting purposively from staffs and beneficiaries, who get services from the center(9).

3.7.Sources of Data

Both primary and secondary sources of data were used in this study.

The primary source of this study includes information which was obtained from the targeted respondents.

Secondary source of the study includes documents and reports available in the center. In addition, secondary data were obtained from journals, researches, articles and books were also used to substantiate the information secured the primary data sources.

3.8.Data Collection Instruments

Open-ended interview questions were used in this research. The reasons behind is its flexibility in which new question could be forwarded during interview, based on the response of interviewee. This type of interview questions enables the respondents to answer the questions in much detail.

3.9.Method of Data Analysis

According to Kothari (2004), data analysis means to find meaning from the data and a process by which the researcher can interpret the data.

To analyze the qualitative data the researcher, develop and apply codes by open coding, axialcodingand selective coding. By identifying patterns and relationship within responses of sample group members with codes that have been specified in the previous stage, the data were summarized on linking findings with the research objectives. The researcher uses noteworthy of quotations from the transcript in order to highlight major themes within findings.

3.11.Ethical Consideration

To undertake the research, the necessary approval and permission letter were written and obtained from the Saint Marry University. After the researcher has gotten official permit to conduct the study on the specific office, for respondents detail explanation on the overall objective of the study were provided. Moreover, they are informed that any information provided by them was kept secret and was not be transferred to a third party or was not be used for any other purposes. Thus, their participation was based on their consent. Therefore, the researcher made all possible efforts to keep the participants privacy.Finally, the researcher fully acknowledges the works of authors that have been used for this study.

CHAPTER FOUR

4.DATA PRESENTATION ANALYSISAND INTERPRETATION

4.1. Introduction

This chapter contains the critical topics of this study. In this chapter the data which collected from interview are presented and further interpretation of the data is also included. The chapter is organized in a way that answers the research questions and objectives.

4.2. Background of Respondents

In this study, to get the necessary data were used and the characteristics of these respondents are presented below.

Table 4. 1: Characteristics of Respondents

Sample Frame	Respondent	Sex	Age	Level of Education	Experience & Beneficiary (years)
Staff	Care giver	Female	43	Diploma	12
	Doctor	Male	36	Degree	9
	Teacher	Female	40	Degree	10
	Brother	Male	46	Degree	18
Beneficiaries	Parent 1	Female	29	Elementary	7
	Parent 2	Female	25	Elementary	6
	Parent 3	Female	55	Elementary	5
	Parent 4	Female	51	Elementary	9
	Parent 5	Female	45	Elementary	12

Source: Own survey (2020)

4.3.Empirical Results and Discussion

This study had three research objectives and questions that had to be answered by analyzing and interpreting the data gathered. The data gathering methods have been designed in a way

that they will provide important data that will answer these questions and achieve the objectives of the study.

With this regard, the first two research questions are focus on the overall activities of the center related with care and treatment services. Thus, the data gained from interview to answer these questions are presented below through providing analysis on each variable.

4.3.1. Care Services provided by Ethiopia Catholic Church missionary autism center

The data gathered from interview with the center's staff indicated that the first initiation to include autistics in the center comes from the staff workers who experience mental related problems in the street. Others autistics are also joined the center by creating a link with women and children's affairs office. The office gives priority for vulnerable, poor and neglected individuals by their own families. Similarly those who don't have families are the other criteria of the center to include the beneficiaries.

The staff worker tells that they give much attention for the profile of beneficiaries because their aim is helping the one who is neglected, very poor, having no families and those who found from the streets with a problem of autism and related mental problems.

The data gathered from the interview with brothers of the center reveal that the center is for those who are neglected by their parents. He said:

> There are some rich families who don't want to raise their children having mental problem and leave their children outside the center. During that time the center will contact the kebele and gives the necessary care and treatment for the child.
>
> Our impact is very small with regard to autism… recently what our people have started to do is when they know the problem is autism they refer the child saying we don't have the capacity to intervene.

The center experienced these difficulties because of lack of knowledge and understanding about autism in Ethiopia. The Brother justify this idea by briefing his experienced as follow

> When we do our outreach program … many people come to seek help…Some of the children we see have not seen sunshine before….we used to first go door to door and do census before we start our job. When we asked parents whether there are children who have problems in their house, they didn't tell us about their child who has autism. They only showed us their child who has a physical disability. When we said: 'what about this child?' they would say this one is useless."

The teacher stated that

> Some of the families of autistics child can't visit their child frequently, because they are very old. Other parents which visits the center, come and just see their child with distance, they don't give love and care for their child, they just back to their home only by looking them. This is due to lack of awareness and wrong thinking about ASD. They assume ASD as "God punishment". Even though they observe their child from distance, they witness for their children's progress. They said that their child started keeping balance, walking properly, starting playing, having good relationship with others etc.

According to the above interview responses, one can understand that many of the respondents worried about other people perception about autistic child's condition. The society provides spiritual explanations for autistic child's condition for example, attributing autism or developmental delays to a curse on the family or a punishment from God. Spiritual explanations for autism are by no means unique to Ethiopia, but acknowledging it is a key to understanding the treatment parents seek.

Care giver of the center indicated that children with autism were sometimes forced to leave public buses, and taxis were not happy to take them. Parentsindicated that it is difficult for parents to find rental accommodation because as soon as landlords know about their child's condition, they would force them to leave. The informant also indicated that children with autism and their families frequently experience exclusion, stigma and negative judgments from others and even by their own parents.

The doctor indicated that the majority of person with autism remain without any formal diagnosis, due to lack of awareness. Nevertheless, the key informants concurred that because of the gradual improvement on the awareness of the society the number of children receiving an autism diagnosis is gradually increasing but there is still needs further effort to increase the awareness of the society.

Ethiopia catholic church missionary (brothers) staffs members are limited in number in addition to this, they didn't include more professionals, expertise, teachers, psychologists, and psychiatrists for the best service delivery. The discussion with participant's and the researcher's observation show that ECCM focuses on more giving care rather than treatment for autistics.

One of care giver worker at the center described as follows:

> I have been working for long years in ECCM, in this process we try to give balanced foods with the necessary ingredients, we will wash their body frequently, cleaning their room twice a day, washing their cloth and we will go together all the worker and autistics in to vacation twice in a year in order to make them refresh and happy.

The other informant in the center was brothers (monk) they are serving the autistics the whole day and night always by living in the center. They believed that helping autistics have a great value in front of their lord.

The brothers says that

> We try to keep them in spiritual way in different activities like praying together, studying bible, practice them how to pray this is because we think that it help them to out from worries and stress. In addition to this we did different recreational activities with autistics like playing football and basketball. These activities are very effective in order to bring change in their behavior and the autistics like it very much and they are happy. This activity makes them busy instead of fighting, and they know respect and giving chance for others…….....

From the above information and the researcher observation, the center is very clean and attractive, and it is suitable for autistics to move freely and play.

According to data the care givers understand care to mean only feeding, washing, and other external activities. They rarely work on the development of skills towards the children. It can be said that almost all the respondents of this interview did not work on the development of mental and other extra training activities. But one of the respondents mentions that the there is little effort by the center to the development of autistic person skill.

There are different therapies which help for a person with autism to develop some skills. Based on the data, the activities of the center are more focus on one of occupational therapy which is handwriting skills. But there is limited effort on speech therapy which teaches verbal skills that can help people with autism communicate better. In addition to using words correctly, it helps children to improve the rate and rhythm of their speech. For adults it helps to improve how they communicate about thoughts and feelings. The practice related with self-care and fine motor skill like cooking and cleaning is also not practiced by the beneficiaries in the center.

The other key informant the teacher explains the service as follows;

……...Teaching autistic is very difficult and challenging. I am the only teacher for all of them in the center. Due to this the desire out come from teaching is not successful because instead of teaching I spent the time by making them quiet, try to get their attention……within those difficulties I used to teach them by different pictures and materials because it helps to get their attention instead of oral learning.

The curriculum needs to be compensatory developed with an understanding of the inclusion of impairment, sensory processing issues and psychological theories to make it meaningful. "Without these individualized supports across the school environment it is highly unlikely that a person with autism will make the academic and social progress that they should.

Education is a key part of every child's life but too many children with autism in Ethiopia are not getting the education and support they need (Helen, 2016). Research has shown that mainstream schools are frequently neither fully educated nor equipped to deal with the needs of an autistic child and give them the necessary support. The center particularly, tries to give lessons for those autistic persons. This teaching learning system is supported by pictures, songs, music and even they practice drama. In order to make them active participant the teacher also use reinforcement after a good performance.

Children with autism benefit most when teachers and parents are on the same page and efforts in the home and at school (Organization for Autism Research, 2004). The teacher should first meet with parents to discuss the possibility of a class lesson about autism. It is important to get parent input, and if appropriate, input from the student with autism as well. But with regard to the center, there is a gap on working together by the teacher and parents. Therefore it's difficult for the teacher to give appropriate lesson for autistic person.

The number of teacher in the center is only one. The teacher can't address all autistic persons in the center as a result it's difficult to say the center gives adequate educational service for its members.

4.3.2. TreatmentServices provided by Ethiopia Catholic Church missionary autism center

Ethiopia Catholic Church missionaries (Brothers) provide treatment for autistics however the service differs from one to the other based on the severity of their illness.

The service at ECCM center includes giving medication collaborating with Emanuel hospital, teaching them different activities in order to improve their skill and abilities, recreational activities, and keeping them clean. The doctor as a key informant described the services provided in the center as follows:

> We can divide the types of services in to different groups. The first one is giving medication discussing with psychiatrist. This service is given with the collaboration of Addis ketemasub city and Emanuel hospital. The center gives first aid service, but if it is beyond the capacity of the center, the sub city will write a cooperation letter for Emanuel hospital. Most of the time the hospital gives us free medicine but if we can't find the necessary medicine webroughtfrom pharmacies with additional cost. All the autistics have regular medicines based on the nature of their problem and the medication brings a huge change on their medical history in addition with other services.

Based on the finding of the above findings and the researcher observation in the center, the medical room is organized in a good manner. Medicines are found in each child's name column with its amount and it helps to give the medicines for each child by anyone without waiting the doctor. The service user's medical history and progress is also documented effectively.

According to the doctor there is no medication that can cure autism spectrum disorder (ASD) or all of its symptoms. But some medications can help treat certain symptoms associated with ASD, especially certain behaviors. The medicines used by the center are treating for the three core symptoms which are communication difficulties, social challenges and repetitive behavior.

As reviewed in the literature medications might not affect all children in the same way. It is important to work with a healthcare professional which has experience in treating children with ASD. Parents and healthcare professionals must closely monitor a child's progress and reactions while he or she is taking a medication to be sure that any negative side effects of the treatment do not outweigh the benefits (Cleopatra, 2018). But this is not actually observed in the center as understood during interview. There is weak evaluation on the effect of the medicine, there is a problem on healthcare providers and families working together to help ensure safe use of medication. According to the doctor the referral hospital usually prescribe a medication on a trial basis to see if it helps. But some medications may make symptoms

worse at first or take several weeks to work. Therefore the centre is not effective enough due to lack of sufficient doctors to evaluate the progress of the medications and to try different dosages or different combinations of medications to find the most effective plan.

During interview sessions the staffs mentioned that the relationship or cooperation of the center with parents of autistic child is not strong enough due to two major reasons. The first one is most of autistic children parents are not known by the center because they leave their children outside the center. The second reason is even though the parents of these children are known; they are not willing to visit their children and the work of the center.

4.3.3 ChallengesExperienced by Ethiopia Catholic Church missionary (Brothers) autism center while delivering the service

This part of the chapter contains the presentation and interpretation of the data that pertains to research question three/objective three. The third research question focuses on the challenges that affect the activities of the center. The result of the data collected to explain the challenges is presented and interpreted as follows.

The involvement of number of key actors plays a significant role for the improvement of autistics life. This includes hospitals, schools, families, and governmental and non-governmental organizations.

One of brother describes their relation with sub city as follows:

> One of the main supporters of the center is children and women's affair office. The office gives us plot of land by supporting our mission. We have also a good relationship with Addis Ketemasub city in two main points. The first one is if we found autistics children on the street the first thing we do is contacting the sub city as well as the kebele in order to get a detail information about his profile and family background in order to be legal and to get approval to take care of him. The second point is if we need support from Emanuel hospital the sub city gives us a cooperation letter.

Based on the above fact the organization has a good relation with children and women's affair office, Addis Ketema sub city and Emanuel hospital.

But it still there is a gap on supporting the center in financial and other kinds.

This theme describes the challenges the center undergo in the process of seeking crucial services for their children with ASD. The caregivers highlighted their problems in striving for

healthcare, education and other supportive services. One of the respondent explained that the capacity of the center is very limited but there are so many people which ask support from the center. One of the parent stated that she found it extremely difficult to access services for her child. She reported difficulty having to live with the child with ASD and experienced little support from service providers and they assume themselves as very lucky to get the chance from the center.

Participants discussed in detail that the center faced difficulties on expanding its services due to lack of financial support. The fund that provides for the center can't address the interest of the beneficiaries. Therefore there are so many people which wait the call of the center.

The participants raised a lot of issues pertaining to the government agencies and lack of policies aimed at taking care of ASD children's welfare. One of the respondents felt that the government agencies should formulate mechanisms which will ensure the community is well informed on the available services for issues of autism spectrum disorders. In this way, the participant felt that managing of these children would be easier for those responsible for their care, as well as alleviating the communities' negative perception towards these children and their families.

The other respondent or the teacher expressed his concern at lack of skilled professionals who are able to manage children with ASD, particularly in occupational therapy and places of education for children with ASD.

The center faced other challenge which is access to the crucial services to benefit their children. The care of these children is a collaborative effort which includes rehabilitation, schools, support from government and other stakeholders, including facilitation of research in ASD. However, there are shortcomings in accessing skilled health professionals and the meeting of norms and standards which therefore demands fair distribution professionals to needy areas by incorporating the relevant authorities. Occupational therapy practitioners should partner with caregivers to identify ways of providing responsive and fitting services focusing on supportive and conducive environments in which children withASD and their caregivers can participate. Measures should be taken to ensure policies which address issues concerned with the welfare of children with ASD are never implemented, in addition to developing guidelines to address issues pertaining to children with ASD and their caregivers.

CHAPTER FIVE

5. SUMMARY, CONCLUSION AND RECOMMENDATION

5.1. Introduction

This chapter covers conclusion and recommendations. The conclusion gives implication to the key findings and recommendations are made to manage the indicated challenges and improve the service of the center and the beneficiaries.

5.2 Summary

The study findings indicated that, the respondents agreed thatthough there is certain improvement on the awareness of the society, still autistic persons are neglected. The care services in the center are only feeding, washing, and other external activities. They rarely work on the development of skills towards the children. The activities of the center are more focus on one of occupational therapy which is handwriting skills. But there is limited effort on speech therapy which teaches verbal skills that can help people with autism communicate better. The center's focus on the education provision for the autistics is very little and they are not able to identify the necessary care services for each person. There is weak evaluation on the effect of the medicine.The findings also indicate that the center involvement with key stakeholders is not strong enough.

5.2.Conclusions

This study assesses autism care, treatment, and organizational challenges in Ethiopia Catholic Church Missionary (Brothers) autism center. The objective of this study is to explore autism care, treatment and challenges in Ethiopia Catholic Church Missionary (Brothers) autism center. Simple random sampling and purposive sampling methods were used to select a representative sample for the study. The study employed descriptive research design.

The study revealed that the center includes autistic from the street and women and children's affairs office. It mainly focuses on for those who don't have families. This shows that the society is not willing to accept and give the necessary support for the autistics. There is still stigma which affects the life of autistics and their families.

According to the findings, majority of person with autism remain without any formal diagnosis, due to lack of awareness. It is also possible to conclude that there is certain

improvement on the awareness of the society but still needs further effort to increase the awareness of the society.

The findings indicated that, the care services in the center are only feeding, washing, and other external activities. They rarely work on the development of skills towards the children. There is little effort by the center to the development of autistic person skill by providing the necessary care services. The activities of the center are more focus on one of occupational therapy which is handwriting skills. But there is limited effort on speech therapy which teaches verbal skills that can help people with autism communicate better. For adults it helps to improve how they communicate about thoughts and feelings. The practice related with self-care and fine motor skill like cooking and cleaning is also not practiced by the beneficiaries in the center.

Thecentrefocus on the education provision for the autistic is very little. There is a single teacher without formal curriculum or educational plan and on the other hand each child has unique strengths and skills and may require a personalized learning and support plan as a result the progress on the autistic person in the centuries not as expected.

Everyone on the autism spectrum is different and has a unique set of strengths, interests and abilities so to try to understand each person's strengths it needs professional on the field. To understand why people on the autism spectrum behave the way they do for it needs certain knowledge on the issue. With regard to this, the centre is not able to identify the necessary care services for each person. They support their beneficiaries without considering the level of severity of the problem on each person.

Even if there is no medication that can cure autism spectrum disorder or all of its symptoms the center use some medications which can help to treat certain symptoms and behaviors. These medications used to treat three core symptoms which are communication difficulties, social challenges and repetitive behavior. There is a gap to work with a healthcare professional which has experience in treating children with ASD to evaluate child's progress and reactions while he or she is taking a medication to be sure that any negative side effects of the treatment do not outweigh the benefits.

There is weak evaluation on the effect of the medicine, According to the doctor; the referral hospital usually prescribes a medication on a trial basis to see if it helps. Therefore it needs further study on the success of these medicines. On the other hand, the centre is not effective

enough due to lack of sufficient doctors to evaluate the progress of the medications and to try different dosages or different combinations of medications to find the most effective plan.

The findings also indicate that the center involvement with key stakeholders is not strong enough. There is communication with Emanuel Hospital regarding with medication for autistics. The same is true with Addis Ketema sub city to have a legal acceptance to raise children found in the street. The data also indicates that the center is not work with other similar centers which gives service for autistics so it is possible to say the center fail the chance to learn other centers experience.

The other finding indicates that the financial capacity of the center is very limited to address the need of the society. The fund that provides for the center can't address the interest of the beneficiaries. Therefore there are so many people which wait the call of the center. The participants also raised lack of national policies aimed at taking care of ASD person and lack of skilled professionals affect the performance of the center.

5.3. Recommendation

Based on the findings of the study and the conclusion made, the researcher strongly believes that the existing practice of center needs to be improved. For this improvement the researcher recommended the following: -

Social Work policy

- Policy makers should expand their policy and structure that are intended to support autistic and other mental related problem. Formulating and effective implementation of policies, strategies and programs are very crucial.
- The government need to give the problem due attention as one of a public health issues and include it in ministry of health top priority seeking public health problem.
- To enhance the awareness of society, the media should need to give coverage to create awareness on ASD for the public as it is one of the untouched public problems.

Social Work Practice

- For expand the access of the center, the center should try to open similar institutes in other sub cities, and rural areas.
- For a better involvement of the parents, the center should provide information for parents about their child development

- For the effectiveness of the center work, the center should work widely with government and non- government organizations for the better visible out come in the autistics life. The center should create favorable condition for parents, and also should work with schools, health facilities, professional associations, early childhood development centers and others for early detection of ASD and timely intervention.
- The center should include more professionals particularly teachers, doctors, psychiatrists and nurses to bring fruitful change in the in the autistics life.

Social Work Research

- This study has focused only one single center which gives support for autistics. To publicized good practice from other similar centers comparative study should be conducted on practice and challenges of supporting autisticsand social workers should do more researches on this issue.

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Annex

Annex 1 Interview Guide with Parents

Dear respondents!

I am a student from School of social science and humanitiesSt. Mary's University.I am conducting a thesis work on the topic "Autism Care, Treatment and Services Challenges in Ethiopia Catholic Church Missionaries.

I would be very grateful if you could provide me with the following information. You are assured that any information will be treated CONFIDENTIAL.

Thank you for your cooperation in advance!!

A. Background information

Education level of the interviewee----------

Age of the interviewee_____

Sex of the interviewee _____

1. How did you come or hear about Ethiopia catholic church missionary (Brothers)?
2. How many children do u have in Ethiopia catholic church missionary (Brothers)? Please tell us the age and sex of your child. If your answer is more than one did all of them does get the same service?
3. For how long your child had been getting service at Ethiopia catholic church missionary (Brothers)?
4. When your child diagnosed as autistic?
5. What kinds of services is your child getting at the center?
6. Did you have any involvement in the services that are given to your child?
7. Which service do you prefer more than other service deliveries given by the center? Why?
8. How do you evaluate the effectiveness of the service interims of bringing change in your child social, academically, communication skill, controlling body movement and self-regulation?
9. Do you think is there any advantage or disadvantage because of Ethiopia catholic church missionary (Brothers) is funded by foreign aid? How?
10. Do you think is there any advantage or disadvantage Ethiopia catholic church missionary (Brothers) is religious based organization? How?

11. Which services delivered by Ethiopia catholic church missionary (Brothers) needs to be improved? Why?

12. What kinds of services needs to be add in Ethiopia catholic church missionary (Brothers) in addition to the existing services? Why?

13. What challenges do you thinkEthiopia Catholic Church missionary (Brothers) face challenges while delivering the service?

14. How do you think those challenges can be dealt with?

15. Is there anything that you would like to add or tell me?

Annex 2InterviewGuides with Technical Staff

Dear respondents!!

I am a student from School of social science and humanitiesSt. Mary's University. I am conducting a thesis work on the topic "Autism Care, Treatment and Services Challenges in Ethiopia Catholic Church Missionaries.

I would be very grateful if you could provide me with the following information. You are assured that any information will be treated CONFIDENTIAL.

Thank you for your cooperation in advance!!

A. Background information

Position of the interviewee----------

Education level of the interviewee----------

Age of the interviewee_____

Sex of the interviewee _____

1. What is the mission and vision of Ethiopia Catholic Church missionary (Brothers)?

2. What is your educational background?

3. What is your role in the center? Do you think your knowledge and skill is capable in working with autistics.

4. How long you have been working in Ethiopia Catholic Church missionary (Brothers)?

5. What is the main aim of Ethiopia Catholic Church missionary (Brothers)?

6. What are the services provided for autistics?

7. Is there any difference the services given for autistics? If so, what are the criteria of differentiation?

8. Is there any program that links you to work with the parents having autism children in the center for the betterment of service delivery? If so, what are the programs? How do u evaluate the participation of the parents?

9. How do you evaluate the effectiveness of the service interims of bringing change in social, academically, communication skill, controlling body movement and self-regulation?

10. What are the criteria's of accepting service user?

11. Do you think is there any advantage or disadvantage of the center by being helped by foreign aid?

12. Do you think is there any advantage or disadvantage of the center by its nature of religious based? Does it have negative or positive impact on the service user?

13. Which interventions were more effective in bringing about the changes or improvements in the development skills of the autistics? Mention the evidence

14. Does Ethiopia Catholic Church missionary (Brothers) has relationships with other government or non-government organizations? If so, how do you evaluate it?

15. Among all services which one is the best service for bringing change and what kinds of services should be added?

16. What are the challenges that you are faced while delivering the services?

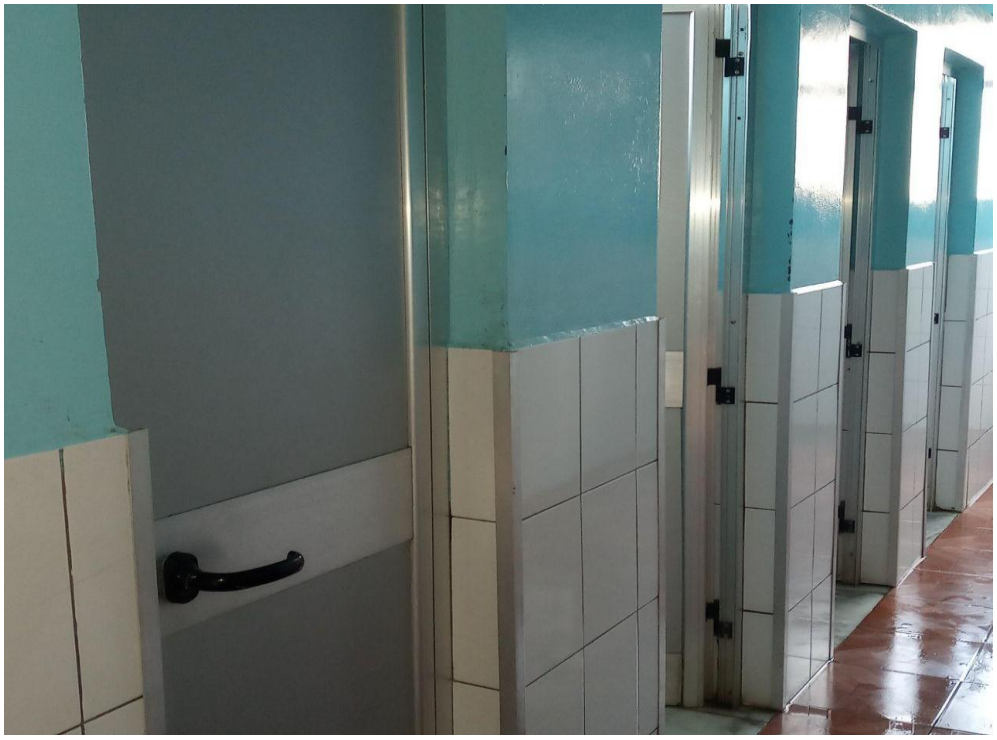
17. What are the remedies that you take to solve the problem?

18. Is there anything that you would like to add or tell me?

Partial view of the center

Service users profile keeping room

Hand wash basin



Toilets

Dining room

Physical compound of the center

Praying room

Source:-Researcher own document (2020)