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THE PRACTICE OF DIAGNOSING AUTISM SPECTRUM DISORDER: THE CASE OFNEHEMIAH AUTISM CENTER

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A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES OF ADDIS ABABA UNIVERSITY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE MASTER OF ARTS DEGREE IN DEVELOPMENTAL PSYCHOLOGY

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This is to certify that the thesis prepared by Samrawit Werkneh, entitled *The Practice of Diagnosing Autism Spectrum Disorder: The Case of Nehemiah Autism Center* and submitted in partial fulfillment of the requirements for the Degree of Master of Arts in Developmental Psychology complies with the regulation of the University and meets the accepted standards with respect to originality and quality.

Signed by the Examining Committee

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2. Internal Examiner

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3. External Examiner

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Declaration

I declare that The Practice of Diagnosing Autism Spectrum Disorder: The Case of Nehemiah Autism Center is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of reference and that the work has not been submitted before any others degree at any other institution.

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ACRONYMS AND ABBREVIATIONS

ASD – Autism Spectrum Disorder

NAC – Nehemiah Autism Center

NGO - Non Governmental Organizations

ICD – International Classification of Disease

DSM – Diagnosis statistical Manual

STAT – Screening tools for Autism Toddler

CSBS – Communication and Symbolize Behavior Scale

ADI-R – Autism Disorder Interview- Revises

DISCO – Diagnostic Interview for Social and Communication Disorders

3DI – Developmental, Dimensional and Diagnosis Interview

ADOS – Autism Diagnosis Observation Schedule

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ABSTRACT

*The purpose of this study was to assess the practice of diagnosing Autism spectrum disorder in the case of **Nehemiah Autism Center**. To do this, a case study research design was employed in qualitative approach. Data were gathered from the center. The researcher availed herself to employinterviews and reviewing documents; Developmental psychologist and BA Psychologists were interviewed to obtain the necessary data. Thematic data analysis was used, findings of the study revealed that there is a limited professional support in order to diagnose ASD. Diagnosing ASD was made by the two psychologists and both are used different instrument to diagnose children with ASD. Observation of children with ASD at the Nehemiah Autism center practice with general experience there is no standardized observation tool use in order to observing the children with ASD. Following the finding and the conclusions, it is recommended that those professional who diagnose ASD children at Nehemiah Autism Center must make sure to used standardized instrument for the diagnosing process. Hence, if the processes of diagnosing ASD are not correctly interpret then it hard to get a successful interpretation result.*

CHAPTER ONE

1. INTRODUCTION

1.1 Background of the Study

Autism Spectrum Disorder (ASD) is widely recognized for many decades, yet there are no definitive or universally accepted diagnostic criteria (Volkmar, State andKlin, 2009). Most diagnostic systems and measures consider ASD to be a 3-symptom cluster disorder with varying severity and etiology. This is reflected in the diagnostic systems of Diagnostic and Statistical Manual of Mental Disorders- IV Text Revision (DSM-IV TR) and International Classification of Diseases-10 (ICD-10), as well as the various measures that evolved from them (ICD-10, 2002 and APA,2000)

The first description about Autism was made in the 1940 by Leo Kanner. In the past 20 years, the understanding of the social and communication deficits in individuals with ASD has become increasingly refined. In the DSM-IV (APA, 1994) and the ICD-10 (WHO, 1990), social and communication impairments in Autism are conceptualized as separate entities. Existing criteria distinguish the communication deficits in Autism, such as severe delays in expressive language level, as a separate symptom domain from social impairments. The 2013 DSM-5 divided Autism into two social skill and communication skill into one and restricted and repetitive behavior similarity.

Another hallmark of ASD is restricted and repetitive behaviors and interests (RRBs). Based on the proposed DSM-5 criteria of ASD (APA, 2010), RRBs include a very broad category of

behaviors such as intense preoccupations and interests. For instance, having very specific knowledge about vacuum cleaners, adherence to specific, nonfunctional routines which insisting on taking a certain route to school, repetitive motor manners (such as hand flapping and preoccupation with parts of objects).In the version of DSM-5(APA, 2013), unusual sensory responses and repetitive/stereotypic behaviors are considered distinct, yet both are subsumed under the restricted and repetitive symptom grouping for the diagnostic classification of ASD. Similarly, researchers have suggested (Schaaf and colleagues, 2011) that unfamiliar spaces made sensory behaviors more pronounced and problematic, and alternately, familiar contexts made performing everyday activities easier for the child and the family.

However, research on the behavioral manifestation of ASD highlights several communication impairments in ASD, such as limited engagement in social chat, difficulties in reciprocal conversation, and limited gestures, which are both social factors and communication (Snow et al., 2009). Moreover, several recent studies have also shown that it is more valid and parsimonious to think of the social and communication symptom domains as a single factor rather than being separate (Gotham et al., 2007; Kim & Lord, 2011). In addition, there are several aspects of the communication impairments in ASD which go beyond speech/language delays. Language delays in individuals with ASD are not compensated by other modes of communications, such as eye contact, gestures, and facial expressions, as one would expect to see in other populations (for example, thought with hearing impairments). Problems with speech quality have been also noted in individuals with ASD. For instance, unusual prosody and rhythm as well as a tendency towards using repetitive speech patterns such as stereotyped speech or

delayed echolalia for example, repeating music from movie(Gotham et al., 2007; Kim & Lord, 2011).

Diagnosing children with ASD during the first year or two of life show delays or failures to achieve various social communication milestones. As infants, children diagnosed with ASD often show difficulties such as following another person's shift in gaze, smiling at someone who smiles or vocalizes at them, and vocalizing 'back' to someone who is talking to them (Baranek, 1999). As they become older and more verbally fluent, children and adolescents with ASD show impairments in reciprocity while conversing with others, such as building on what the other person says or listening to how someone else feels about a particular experience. Other conversational deficits include difficulties initiating and maintaining meaningful conversation for instance, the individual not responding to others' leads or questions.

The developmental age and pattern of onset, in order to detect the symptoms recognized, manifest during the second year of life between 12 and 24 months but may be seen earlier than 12 months if developmental delays are severe, or noted later than 24 months if symptoms are more subtle (Baranek, 1999). In addition, the behavioral features of ASD first become evident in early childhood, with some cases presenting a lack of interest in social interaction in the first year of life. Some children with ASD experience developmental plateaus or regression, with a gradual or relatively rapid deterioration in social behaviors or use of language, often during the first 2 years of life. Such losses are rare in other disorders and may be a useful "red flag" for ASD (DSM-5, 2013).

However, obtaining a detailed developmental history may be difficult when an individual diagnosis is late. Some individuals come for first the diagnosis in adulthood, perhaps prompted by the diagnosis of Autism in a child in the family or a breakdown of relations at work or home.

As it indicated indifferent guidelines while diagnosing Autism Spectrum Disorder all professionals involved in diagnosing ASD in children, young people or adults consider using different tools such as; current version of either ICD-10 or DSM-5, ADOS,ADI-R,DISCO and 3DI. The classification system used for diagnosis recorded in the patient's notes. The timing of the diagnosis is important to see the differential diagnosis for preschool children displaying an absence of age appropriate developmental features (Scottish Intercollegiate Guideline Network, 2016). Practically, in the USA and Canada to diagnosis ASD instruments were used by combined Autism Diagnosis observation schedule and Autism Disorder Interview-Revises. Combining the two instrument recommended to improve the interpretation and the result at the end of the diagnosis process. (Lord,Rutter,DiLavore,Risi, 1999)

Various experts can make this diagnosis, including some psychologists, pediatricians and neurologists, Speech& Language Pathologists, Occupational Therapists, Physical Therapists, Behavior Specialists, Psychiatrists and Special Education Teachers and Psychologists (including neuropsychologists, who specialize in the relationship between the brain and human cognitive, behavioral and emotional functioning) are often involved in the diagnostic process. It is important that the expert making the diagnosis has extensive experience working with the wide range of symptoms associated with ASD (APA, 2013).

In the diagnostic practices of Canada show that no uniform ASD diagnostic requirements to make an ideal setting to explore varying diagnostic practices and their impact on wait times.

Three sections were chosen for survey distribution based on their likelihood of participating in ASD diagnosis: developmental pediatrics, community pediatrics, and mental health. Current members of these sections who were practicing pediatrics in Canada and who were able to complete the survey in English were eligible to participate (Wendy, 2018).

To diagnose ASD there are different criteria have to consider by the professionals. According to APA(2013), Autism Spectrum Disorder diagnostic criteria are a persistent deficit in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behavior, interests, or activities. Additionally, it specifies the severity in three levels based on social communication impairments and restricted, repetitive patterns of behavior as Level 3: "Requiring very substantial support", Level 2: "Requiring substantial support" and Level 1: "Requiring support" (APA, 2013).

The purpose of this study is to assess the practice of the diagnosing Autism Spectrum Disorder at Nehemiah Autism Center. Nehemiah Autism Center was established in June 16, 2011 by a small group of parents of children with ASD who could not obtain either a proper diagnosis or effective intervention for their children.

1.2Statement of the Problem

Diagnosing autism spectrum disorder (ASD) can be difficult, since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child's behavior and development to make a diagnosis (Lord C, et al., 2000).

Since the diagnosis of ASD in Ethiopia has only recently developed, with services often being provided by private centers, having a clear understanding of the diagnosis process is critical to ensure children receive the most appropriate care.

Despite the consensus that ASD diagnoses occur more frequently today, researcher continue to debate whether this is a result of new cases or simply the availability of better diagnostic measures. In the early 1940s, Kannercharacterized11 children included social aloofness, insistence on sameness, and language delays or oddities (Kanner, 1943). At about the same time, Hans Asperger described four children whom he called **''little professors"** who showed social awkwardness and circumscribed interests, with intact even advanced abilities in vocabulary and syntactic aspects of language (Hans Asperger, 1944).Later, Frith compared these different descriptions of ASD, which have formed the basis for conceptualizations of ASD until now (Frith, 1989).

According to pediatricians' developmental study as first birthday videotapes of children who were diagnosed with Autism were reviewed with the reviewers being blind to the diagnosis and the pediatricians were able to classify correctly 82 percent of children based on four variables. This shows that while diagnosis is challenging, it can be standardized to a relatively high degree with the appropriate skills and knowledge. In the context of Europe, diagnoses are still a big

problem with advocates calling greater resources for early detection. Research shows that the average age the first concerns about autism are identified is at 25.3 months, while on average, diagnosis does not happen until 44.4 months – 19 months later (Manuel, 2018).

Children diagnosed with Autism later displayed fewer joint attention and social behaviors such as pointing, orienting to name, showing of objects and looking at the face of another(Osterling and Dawson, 1994).This show diagnosing children with ASD are not an easy task and it is difficult to observe differences in the observed children with regard to their physical, social, language and communication skills.

As child psychiatrists and pediatricians observe children particularly girls, ASD diagnosis is tragically missed until late in their development and schooling. According to the American Psychiatric Association (1994) diagnostic criteria for pervasive developmental disorders specify that impairment must be interpreted relative to the child's developmental areas. In addition, diagnosing ASD below the developmental age 12-18 months is hard, as it is difficult to detect the disorder because children under this age are not strong in developing their social and communication skill. The infant is socially developing skills of approaching, following, clinging, and signaling. Therefore, detecting the diagnosis of ASD in infants of 12-18 months old in their social and cognitive ability is difficult.

As studies indicate that discrepancies between areas of development in young children make it difficult to identify specific social deficits as opposed to more generalized developmental delays, particularly when nonverbal skills are below a year in development stage. When skills and behaviors are consistent with the child's mental age, other diagnoses may be more accurate than

ASD (Lord et al. 1997). In addition to Lord study children with Autism at age 2 display deficits in joint attention, social referencing and interest in other children. They also attended less to voice and have difficulty understanding and using nonverbal gestures. Diagnosis of children with ASD before at the age of 2 years is not an easy task since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child's behavior and development to conduct the diagnosis process (Lord, 1995).

However, misdiagnosed children with ASD can result unnecessary stigma and reduced expectations of self and others and therefore precautionary over-diagnosis ought to be avoided (Gould, and Ashton-Smith, 2011). Misdiagnosis might result in the neglect of another, accurate, diagnosis or result in discrimination for the child who was misdiagnosed. As a result, it is critical that the correct knowledge and skills are available in order to correctly diagnose children with ASD.

In other hand, those professionals who conduct the diagnosis process may not accurately diagnose children, if there is no use of appropriate tools to diagnose diagnosing Autism Spectrum disorder is difficult at any age. It is complex if there is no multidisciplinary team of expert involvement in the diagnosis process. It makes misdiagnosis if professional do not used proper instruments.

In addition, the limitations faced by professionals in diagnosing, the tools have changed over time, which specify how diagnosis is to occur. According to the DSM-5 (2013) ASD has more specificity but also more limited sensitivity. Owing to the changes to the DSM and the lessening of sensitivity, there is the possibility that individual who was diagnosed with Autism Spectrum Disorders using the fourth revision DSM-4 will not receive the same diagnosis with

the DSM-5. The DSM is the most widely used tool internationally, and these changes are critically important, as their utilization may be result in different diagnoses.

This study was focused diagnosing Autism Spectrum Disorder with a special emphasis on the experience of Nehemiah Autism Center (NAC). Nehemiah Autism Center has been providing diagnosis and intervention services for the last seven years. However, so far, only eight children have been able to move into the mainstream school for inclusive education. The capacity of the center is limited to accommodate more than fifty children; as a result, hundreds of children with Autism are on waiting lists to get service. This has a consequence that children with a diagnosis are unable to access appropriate intervention. As a result, children become regressed in their development meaning that there is no progress manifested by the children. Although, if there is a problem in diagnosing children with ASD this also affects the ability to provide the right services to the children that need them. Without proper diagnosis there is another consequence which result in misguiding the interpretation this also makes the intervention wrong.

In order to assess the practice of diagnosing Autism Spectrum Disorder, the following basic research question was raised in the study:

1.3 **Research Questions**

1. What is the practice of Nehemiah Autism Center in diagnosing ASD?
2. What is the knowledge and skills of professionals' involved in diagnosing ASD at Nehemiah Autism Center?
3. What kinds of tools does Nehemiah Autism Center use to diagnosis ASD?

1.4 Objective of the study

1.4.1 General objective of the study

The general objective of the study was to find out the practice of diagnosing children with ASD at Nehemiah Autism center.

1.4.2 Specific objectives

The specific objectives of this study include:

1. Assess the practices of Nehemiah Autism Center in diagnosing children with ASD.
2. Assess the knowledge and skills of professionals who involves in the diagnosis of ASD at Nehemiah Autism Center.
3. Assess the appropriateness and availability of tools that Nehemiah Autism Center is using to diagnose children with ASD.

1.5 Significance of the study

This study will contribute to the improvement of diagnosis and service provision for children with Autism. It will contribute critical information concerning the appropriate uses of instrument for diagnosing Autism Spectrum Disorder in NAC. Furthermore, the study may inspire other researchers and NGO‟s who are interested to undertake further study and work in the area.It may also provide information for health professionals and NAC to think about multi-professional involvement to diagnose ASD.

1.6 Delimitation of the Study

This study was delimited to one local organization called Nehemiah Autism Centre. The participants of this study were purposive samples of five facilitator teachers employed in the center as well as the psychologist in the center.

1.7 Limitations

The study has limited use of instrument and limited in addressing the problem as country wise. Therefore the finding of this study can't address other Autism center in Addis. It would have been better if other center were included. The limitation was due to time and resource which made it impossible to include other Autism centers in Addis Ababa.

Definition of Terms

Autism Spectrum Disorder: a developmental disorder of variable severity that is characterized by difficulties in social interaction and communication and by restricted or repetitive patterns of thought and behavior.

Assessment: In this research refers the action of checking the practice of diagnosing Autism Spectrum Disorder practice.

Diagnosis: Identifying specific developmental disorders that are affecting a person suspected of having an ASD.

Practice: the actual application or use of an idea and method, as opposed to theories relating to it.

CHAPTER TWO

2. LITRATURE REVIEW

This chapter provides four parts which overview about the practice of diagnosing Autism Spectrum Disorder which briefs the understanding ASD from historical concept and the process of diagnosing ASD. In the second part it reviews about diagnoses tools for ASD which has describe tools that were used to diagnose ASD. Part three is prevalence and context of ASD. Part four reviews about professional involvement to diagnose ASD.

2.1 The practice of diagnosing Autism Spectrum Disorder

2.1.1 Understanding of Autism Spectrum Disorders (ASDs)

The term Autism was first used by a Swiss psychiatrist called EugenBleuler. The term describes in Latin as Autismus which describes symptoms of schizophrenia and also the term is originated from Greek word which is autos meaning that self and the English translated as Autism. According to Gallo (2010) a Latin term autismus was first used by a Swiss psychiatrist called EugenBleuler in describing some symptoms of schizophrenia. The term autismus is originated from the Greek word autos which mean self and the English translation is autism (Ibid). From this understanding, 'Autistic', as for Kanner, referred to the children's aloneness and self-absorption, while by 'psychopathy' Asperger meant a psychiatric disorder affecting the personality. Asperger highlighted important features in common with Kanner's case studies, yet the children he described seemed less disabled than Kanner's group, generally having fluent speech and vocabulary, even if they used it oddly. They tended to talk at length about their

favourite topic or interest. Rather than seeming unaware of the existence of others, their reactions to others appeared strange and antisocial. Asperger's work was for many years not widely known outside Austria. It was only in the 1980s that psychiatrist Lorna Wing highlighted the remarkable similarity between Asperger's and Kanner's clinical observations and 'Asperger syndrome' was recognised as a diagnostic sub-type of autism. Wing also introduced the term 'autism spectrum' to reflect the variation on the core symptom profile.Fromthis we can understand that the meaning of autism describes one of the symptoms of autism that is being alone or in their own world. Then in 1943 Leo Kanner wrote a paper with a title "Autistic disturbances of affective contact" almost all the characteristics observed by Kanner are the same as the current characteristics of autistic children

In 1944 in Austria, Hans Asperger published a paper with the title "Autistic psychopathology" in which he explained about four boys who have difficulties in making friends, two sided conversation and do not have the ability to understand others (Gallo, 2010).

Kanner's description of Asperger's have many similarities including the term "autistic" they use to name their patients, the preference of the term shows their common belief that the child's social problems were the most significant and typical attributes of the disorder (Happe, 2009).

2.1.2 Diagnose process of Autism Spectrum Disorder

The inclusion of standardized cognitive and developmental testing, as well as an assessmentof language, is particularly important to differentiate ASD from other developmentaldifficulties. These tests, which if carefully selected and carried out by professionalsexperienced in assessment of children with developmental disabilities, should provideinformation about the child's overall level of ability and functioning in both verbal

andnonverbal areas, thereby providing a crucial starting point for the clinician to make a best estimate of a clinical diagnosis (Marisela, 2012).

The separation of verbal and nonverbal estimates offunctioning is particularly important because many children with ASD show much strongernonverbal skills than one might expect from their language level or play. Standardizedscores from a skilled examiner allow the clinician to consider such questions as intellectual disability and/or language delay explain the difficulties in social interaction. The ability observed difficulties in communication and social behavior. The term "multidisciplinary" has often been used to describe best practice diagnosticevaluations. At some clinics this has meant that an autism evaluation is performed by multi-member diagnostic teams (Marisela, 2012).

However, this is not always feasible, and in some cases can beoverwhelming for parents. Instead, "multidisciplinary" should be interpreted to mean thatmultiple areas of functioning should be considered during a diagnostic evaluation. Thougha physician should always be available to provide a medical evaluation, it is most important that these multi-faceted evaluations be completed by clinicians with extensive experience inthe standardized testing of children with particular expertise in assessment of ASD.In addition to covering multiple domains, diagnostic evaluations should considerinformation from multiple sources (Braiden, 2010).

A comprehensive evaluation must, at minimum, includea parent interview and an observational assessment of the child's current functioning by anexperienced clinician in a context in which social-communicative behavior and play or peerinteraction can be observed. For the diagnosis of ASD, diagnostic specificity is much worse if only one or the other is

performed.The clinician's observation provides the opportunityto put the child's behavior into the context of knowledge about other children, butinformation from caregivers provides a broader context needed in understanding the child'sday to day behavior in a wide range of situations, his or her history, as well as familyexpectations, resources and experiences and other important contextual factors (Marisela, 2012).

Childtesting and parent interviews should be viewed as complimentary and necessary componentsof the diagnostic evaluation. Ultimately, it is the job of the clinician to integrate information across the various sources ofinformation. Although, clinician can take into account that a caregiver was veryuncomfortable saying anything negative about his or her child or, as a new parent,unfamiliar with typical development or that a child was so hyperactive or tired or shy thathis or her behavior in the office was not likely representative of other times.In some cases, diagnostic clarity is not easily obtained despite access to formal testingresults. Research on the early diagnosis of ASD suggests that for diagnostically complexcases, best practices are to adopt a surveillance approach that is recursive, meaning repeatedscreening and assessment. Such a strategy may be particularly appropriate for very youngchildren when formal estimates of functioning may not always remain stable, for childrenwith very difficult behaviors (e.g., aggression, self-injury) where there are very pressing dayto day concerns and for children with the very mildest difficulties where diagnosis may beless accurate (Marisela, 2010).

2.1.2.1 Assessment of Autism Spectrum Disorder

Once the presence of an ASD is suspected the child shouldbe referred for a multi- disciplinary assessment, in which all members of the team should have some ASD training and at least one member should be trained in the assessment and diagnosis of ASD using standardized assessments. The multi-disciplinary team should have access to input from psychologists, educationalists, language therapists, pediatricians and/or child psychiatrists, occupational and physio-therapists and social services support. For the purposes of assessment the individual should ideally be observed in a number of different settings, both structured and unstructured (e.g. in clinic, home setting, nursery/schools, day care centre etc.) Videos may be used if direct observations on site are not possible.

There are a number of specialized assessment instruments. It is important to ensure that diagnostic assessment covers the main areas related to ASD. Interviews must be as systematic and structured as possible.Standardized autism specific assessment among the best validated of such assessments are the Autism Diagnostic Observation Schedule; the Autism Diagnostic Interview revised; the Diagnostic Interview for Social and Communication Disorder; and the Developmental, Dimensional and Diagnostic Interview. Other assessments include the Behavioral Summarized Evaluation and the Childhood Autism Rating Scale (CARS) (Autism Europe, 2000).

It is recognized that not all services will have access to these specialized instruments. The cost and time involved in completing such assessments may also be impractical for some hard-

pressed services. However, having at least one staff member trained in the use of such instruments is important in ensuring that the diagnostic assessment covers the principal areas related to ASD (communication, social and repetitive/stereotyped behaviours) and that interviews are conducted in as systematic and structured way as possible (Catherine et al., 2000). Cognitive assessment a variety of different tests is available depending on the child's age and ability level. The best standardized assessments include the Wechsler tests (WPPSI, WISC, WAIS, and WASI which span the age ranges of 3 to 60+). For younger children the Mullen Scales of Early Learning or the Bayleyscales may prove useful. When direct testing is not possible for any reason the Vineland Adaptive Behaviour Scales can provide detailed information, based on parental report, on the individual's communication, social and adaptive behaviour skills. In other hand, language assessment tests assess a relatively circumscribed area of language and it is important to include assessments of comprehension, expression and pragmatic use of language in order to obtain a full assessment of the individual's functional communication skills. Assessments of play ability may also provide valuable information on the child's "internal language" or imaginative ability (Autism Europe, 2000). In addition, physical and medical assessment test is a test for each child undergoes thorough medical examination. This should include assessment of visual and auditory acuity; height, weight and head circumference. Information about eating, sleeping, bowel and bladder control and possible epilepsy should also be obtained.

However, diagnosing Autism Spectrum Disorder should only be made on the basis of a thorough clinical assessment, conducted by professionals with training in the field of autism and with a range of skills (medical, psychological, educational, and social). This is difficult in a country like Ethiopia, which lacks sufficient trained personnel. The reason why this

isimportanttheassessment is not only to establish, with as much certainty as possible whether or not an individual meets criteria for ASD, as well as ensure that this process leads to appropriate behavioral intervention and educational programmers for both child and his or her family (Catherine, Joaquin, Patricia &Rutger, 2000).

2.1.2.2 Screening for Autism Spectrum Disorder

Screening has been defined by the UK National Screening Committee as "a public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by a disease or its complications, are asked a question or offered a test, to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications" (Tebruegge ,Nandini& Ritchie ,2004). Any screening test must have a known specificity (analogous to the risk of false positives) and sensitivity (analogous to the risk of false negatives) within the population to which it is being applied (SIGN, 2007).Moreover, (SIGN, 2007) don't recommended screening population for ASD. This false positive or false negative result from inappropriate use of screening test may delay correct diagnosis meaning that the professional should be careful in screening ASD to get a correct diagnosis. Child health surveillance takes a broad clinical approach involving partnership between parents, children and health professionals. Child health surveillance can contribute to the early recognition and diagnosis of ASD (Malhi&Singhi ,2003).

Surveillance for ASD should follow general developmental surveillance and should be considered by all professionals working with children and young people. Responding to concerns raised by parents has a role in surveillance, and healthcare professionals should be aware that

parental concerns about the absence of normal developmental features are as important as the presence of abnormal features (Tebruegge et al., 2004, Malhi et al.,2003).

Therefore, structured instrument are used to identify young children with possible Autism Spectrum Disorder. This is Checklist for Autism in Toddlers (CHAT) which designed to identify 8 month old children at risk of ASD. It has been tested in a general population setting and was found to have acceptable specificity, but the sensitivity was too low for it to be used in total population screening (Baron-Cohen et al., 2000).

2.2Prevalence and the study of ASD in different country

Autism was once considered a relatively rare condition. Recent epidemiological data have radically altered this perception. Based on large surveys in the US, the Centers for Disease Control and Prevention (CDC), estimates the prevalence of ASD as 1 in 88 children, occurring in all racial, ethnic and socioeconomic groups, although it is five times more common among boys (1 in 54) that girls (1 in 252). The CDC website also offers data from numerous studies in Asia, Europe and North America showing an average prevalence of ASDs of about 1%. A recent survey in South Korea, which screened children in the schools, reported a prevalence of 2.6% (3.7% among boys and 1.5% among girls) (Kim et al, 2011). Another study in England estimated a prevalence of ASD at almost 1% in adults (Brugha et al, 2011). However, epidemiological studies are difficult to compare.

According to National Health Statistics report (2013) based on parent reported autism spectrum disorder in school aged U.S children the prevalence of autism spectrum disorder in 2011-2012 among school children between the ages of 6-17 was estimated to be one in fifty. And the same

report shows that school aged boys were reported to have autism more than four times as likely as school aged girls.

As to Center for Disease Control and Prevention(CDCP, 2014) in 2010, the general prevalence of Autism among the Autism and Developmental Disabilities Monitoring (ADDM) sites of USA was 14.7 per 1000 one in sixty eight children aged eight years.

In Ethiopia there is no statistical evidence as to the extent and prevalence of the disorder. However, according to Nia foundation (2012) estimation it is expected that there is the same prevalence with other countries because autism is found in all without differences in race, ethnicity, social status and other criteria, so in USA if one in every 115 children is diagnosed with autism in Ethiopia with a population of 80 million it is estimated that there are around 530,000 children with autism.

2.2.1 The study onAutism Spectrum Disorder in the Europe

Autistic Spectrum Disorders (ASD) is severe early-onset neurodevelopment disorders characterized by significant difficulties in social communication, as well as restrictive interests and repetitive behaviours that critically affect daily living activities (APA, 2013).

A review of epidemiological studies published between 1996 and 2001, and conducted in the United Kingdom, United States and in Scandinavia and Japan, indicated that the prevalence was likely to be within the range of 30–60 cases per 10,000 (Rutter, 2010). The estimates are as high as 1 in 68, based on 8-year old children in the United States (CDC, 2010). However, a combination of the broadening of diagnostic criteria previously discussed, and the methodology

employed in epidemiologic surveys, including changes in the assessment process, response rates, and differences in sample size, publication year, and geographic location, suggests that it may not be informative to estimate trends over time (Fombonne, 2005).

ASDEU tested three methods to estimate ASD prevalence, screening in two phases – teachers nominating children via a form, then a parent questionnaire, screening in a single phase with parent questionnaire only and looking at data from national registries (Manue, 2018).

Diagnosis Autism Spectrum in Europe is a big problem and more resources are needed to facilitate early detection: Research showed that the average age first concerns about autism are identified is 25.3 months, while on average, diagnosis does not happen until 44.4 months – 19 months later. Most parents (68.8%) indicated delays of more than six months to access a diagnostic service. Only 44.8% of families reported that professionals informed them about their child's specific needs and 20% of families said they did not receive any information at the time of diagnosis. Families evaluated detection services negatively in terms of the attention professionals gave to parents' concern (Manuel, 2018).

2.2.2 The study on Autism Spectrum Disorder in Africa

ASD was thought to occur mostly in Western cultures and countries with high technological development. Occurrence of ASD in Africa was then a subject of debate (susan, 1984).

Studies provided information on diagnosis of ASD among African children, as it relates to symptom presentation and co-morbid disorders (Belhadj, 2006 &Bakare, 2008).

However, awareness and concern regarding the prevalence of autism spectrum disorders (ASD) has increased worldwide (Malcom et al., 2013&Frank-Briggs, 2012). In high resource countries, this has led to an increase in funding for ASD research and the inclusion of ASD in health policies. Despite an increase in research on ASD in Africa in the last decade little is known about its prevalence on the continent (Chamberset al., 2017 &Bakareet al.,2014). In part, research in Africa suggests that the prevalence of individuals living with ASD is greater than was previously perceived and may be increasing (Bakareet al.,2014&Wetherby et al.,2014).

In other side, there is no epidemiological data on ASD for many African countries, including South Africa (Grinaker et al., 2012). However, in a study of 355 Cape Town children (6-18 years) attending special schools for intellectual disability, 9.4% had a diagnosis of Autism (Molteno et al., 2008). Even though epidemiological data for ASDs in South Africa is not available, prevalence studies in various countries have provided similar rates to each other. Thus, assume that South Africa has similar rates to the rest of the world, (Baird et al., 2006; Robins, 2008) especially as ASD is a neurodevelopmental disorder. As it link to studies in the prevalence of ASD there is no clear epidemiological date in the Africa continent.

A study on diagnosis of ASD in Africa is usually made when children reach school age, if at all.Since early diagnosis helps the children and their families may the adjustments needed to maximize later success, this is concerning. The delay in screening and diagnosis has been attributed to several factors. These include not limited to lack of knowledge of ASD among communities, care givers and professionals in the health and education sectorsas well as stigma. The financial expense of diagnostic procedures and a lack of culturally appropriate screening measures are also attributing factors (Wannenburg&Niekerk, 2018).

The age for diagnosingAutism Spectrum Disorder should occur before the age of three years, if possible so that early interventions can be implemented tt help the child achieve his or her maximum potential and will impede the progress of development delays (Wannenburg&Niekerk, 2018).

In addition, in Africathere is lack of trained diagnosticians and affordable culturally appropriate screening tools, as well as feasible interventions. Therefore, the individuals with ASD living in Africa and their care givers face problems with diagnosis, intervention, delayed help seeking as a result of stigma and misconceptions about the cause of ASD symptoms.

Thus symptoms at presentation aside from the core symptoms of ASD in the areas of impairment in social interaction, communication and restricted, repetitive repertoire of behavior, one common symptom presentation that was found in over fifty percent of the cases reported in the literature was lack of expressive language (non-verbal cases). Studies reported about non- verbal case of ASD prevalence shows that 1.2%. In the other studies 71% of non-verbal cases of ASD but they quickly concluded that this observation might be as a result of local diagnostic practices (Belhadj et.al,2006;Mankoski et., 2000).

Furthermore, diagnosis ASD is a difficult task to detected the ASD therefore, since ASD had common associated disorder with intellectual disability and epilepsy this make difficult for the professionals to detect the disorder(Belhadj, 2006).

2.2.3 The study on Autism Spectrum Disorder in Ethiopia

The study on autism spectrum in Ethiopia was so minimal and the researcher observed some of the studies as follows assessment on multi-cultural intervention for autistic children: The case of Joy, Nehemiah and Ryan Autism Centers (Abdulhakim, 2016) His qualitative study was

conducted to examine issues related with multiculturalism to effectively intervene with autistic children found in care centers of autism. The study focused on three autism centers namely Joy center for children with autism and related developmental disorders, Nehemiah autism center and Ryan autism center. This study has essentially examined those interventions that are helpful when working with multicultural children diagnosed with autism spectrum disorder the clandestine affecting such interventions. Data was collected through nine semi-structured interviews with professionals who work with these autistic children inside the three autism treatment centers.

Additionally, 22 open ended questioners were distributed to practitioners in the treatment centers with the rational of maximizing acquired data. Grounded theory methods and open coding were used in this study to analyze codes in the data and recorded common themes from the collected data. Findings of this study produced themes separated into three categories: language, accessibility and culture as barriers affecting multicultural intervention. Additionally in terms of helpful interventions for multicultural children, Participants of this study recommended interventions developed under the model of Applied Behavioral Analysis (ABA) to be more helpful while treating these autistic children with diverse background applying individualistic treatments depending on specific needs using speech therapy, occupational therapy, social interaction enhancement therapy, and picture exchange therapy while teaching them self-help skills like toilet training.

According to AynalemTadess (2014) study about families living with child diagnosed with Autism expressed that families are facing a number of challenges in raising a child with developmental disability. Though there are different types of developmental disabilities, autism is one of the most important developmental disabilities to be studied. The functional family

system is experiencing a challenging situation due to caring a child with autism which further affects family members and the community at large. The main objective of the study was to understand the challenges in relation to psychological, social, economic, marital and sibling aspects and coping mechanism of families living with a child diagnosed with autism. A qualitative approach particularly a case study was used in this study. The tool for collecting primary data was in depth interview to gather detailed information about family challenges. Six families whose children are enrolled at Joy Center for Children with Autism and Related Developmental Disorder were involved in the study. The finding from the study confirmed that study participant families living with a child diagnosed with autism are facing psychological, social, and economic challenges. Stress, anxiety, social isolation, discrimination, limitation in labor market participation and financial burdens are the main challenges. Families have employed various coping mechanisms to minimize the magnitude of these challenges. In addition, the result of the finding has implication to social work practice. Provision of psychosocial support and awareness creation has to be addressed with different stakeholders in health and social sector. In addition, research works in the area of disabilities particularly autism has to be encouraged.

Daniel (2014)studiedabout the psychosocial impacts of autism and the support systems to families of children with autism. To do this, a narrative research design was used for the study and qualitative approach was employed. Data were gathered from Joy Center Nia Foundation for Autistic children in Addis Ababa, Ethiopia. First, the researcher availed himself to employ observation session. Then, using interviews focus group discussion and observation; three teachers, including one head of teachers, five parents have participated in the study to obtain the

necessary data. Findings of the study revealed that these parents were getting the support they needed even though there were a number of support systems yet to be accomplished. Experience and educational level of families appeared to have significant relationship with the provision of the support system and its application.

In addition, psychological problems such as depression, exclusion, anxiety, fear, etc had also been their major problems. Caregivers are also found to get subsistence amount of money which negatively affect the support system as better trained and more costly personnel can't be identified and retained. Following the findings and conclusions drawn, it was recommended that the government and other pertinent bodies should work in collaboration with the management of the center in areas where families can benefit a lot and ameliorate their current problems. It is also recommended that the center should do it's very best to make the center a conducive research place for all who come to carry out their studies.

During the same year Helen (2016) studied about reactions, challenges and coping mechanisms of mothers raising children with ASD. The study indicated about Autism Spectrum Disorder is a complex neurological disorder which causes impairments in multiple areas of development including social interaction, communication, and behavior. There is clear evidence that parents of children with autism face many challenges in dealing with their children's difficult behaviors that can lead to negative psychological outcomes, including exhaustion, stress and depression. Moreover, it is evident that parents encounter social challenges such as problems on family relationship and lack of understanding attached to the disorder by society that lead to discrimination not only of the autistic child but also of the family as a whole.

However, despite the many challenges parents of children with autism usually identify coping strategies that will work for them. This study therefore aims to explore the lived experiences of mothers raising children diagnosed with autism on the psychological and social challenges they faced as well as coping mechanisms they found effective in dealing with those challenges. A qualitative phenomenological research design guided the data collection and analysis which included six deep interviews that were recorded. The results that were conceptualized under the four research questions containing fourteen themes indicate that raising a child with autism is characterized by many psychological and social challenges such as mothers lack of information and support during the time of diagnosis, worry about child‘s future, stress from managing a child with autism, not having a time for oneself, effect on family, difficulty finding education and treatment for their children and lack of understanding followed by negative comments from the society (Helen Berhane, 2016).

SelamTassew, (2016)studyfocused on the knowledge and attitude of nurses towards childhood autism. The Objective of her study was to assess knowledge and attitude of nurses towards childhood autism at selected governmental hospitals in Addis Ababa, Ethiopia, from March to June 2016. The Method used for the study was Hospital based cross-sectional study design was used. Sample size was calculated by using single population proportion sample formula and the final sample size was 360. Final study subjects were selected by using systematic random sampling method. Data were collected using structured self-administered questionnaires and it was coded and entered to Epi-data version 3.1and exported to SPSS version 21 for analysis. Descriptive statistics such as frequency and percent was carried out and analysis of variance was carried out to compute the association between the dependent and independent variables. P-value

less than 0.05 at 95% CI was indicated presence of association between dependent and independent variables. P-value less than 0.05 at 95% CI was indicated presence of significance meandifference between dependent and independent variables. Independent t test was also done to see the association between dependent variables and independent variable with two means result- The mean score for knowledge related question was 8.79 ± 0.44. .In this study out of 331 nurses 180 [54.35 %] had good knowledge, Age of respondents [F-Ratio = 2.8, P-value = 0. 04], level of education [F-ratio = 13.97, P–value = 0.000] and work experience [F-Ratio = 3.07 P–value = 0.017] had significant association with knowledge of nurses towards childhood autism. Regarding attitude of nurses 178(53.8 %) and have favorable attitude. Conclusion and recommendation- knowledge deficiency was found in this study which could deprive the quality of care that is given for autistic children. This result can be taken as the predictor of the need to improve knowledge and attitude of nurses towards childhood autism, which could ultimately enhance the quality of care that is given to autistic children.

Therefore, awareness about Autism Spectrum Disorder in Ethiopia is limited and there is lack of clinics to diagnosis ASD. There are only two state-funded child mental health clinics where a formal diagnosis can be made. Both clinics are in Addis Ababa inaccessible to most Ethiopians, who reside in dispersed rural communities. Furthermore, Autism school are limited the one which exist have and a long waiting list. The vast majority of children with autism remain undiagnosed, with no access to intervention or appropriate education.

2.3 Diagnoses of Autism Spectrum Disorder and Tools

A quick review of the current literature on ASD reveals an abundance of available diagnostic instruments. The best practice diagnostic tools assess social functioning in a developmental context and they should take into account the variability of behavior across settings. Following these criteria, a useful child testing tool in autism evaluations continues to be the Autism Diagnostic Observational Schedule (Lord et al, 1999).

Recent revisions to the ADOS have improved its accuracy and expanded its clinical utility to include an indicator of severity (Gotham et al., 2007). Another development has been the toddler version of the ADOS, which employs a surveillance model of classification for very young children. The Screening Tool for Autism in Toddlers and Young Children (STAT) and the Communication and Symbolic Behavior Scales (CSBS) are also recommended for use in young children (Wetherby et al., 2001). A particular strength of all of these instruments lies in the fact that they are standardized in their administration and coding, ensuring careful assessment of something as complex as social behavior (Lord, 2000).

For the parent interview, the ADI-R has been established as a useful diagnostic tool in the assessment of ASD. For use with very young children, toddler versions of the ADI-R diagnostic algorithm were recently created. Importantly, though the ADI-R is quite useful for diagnosis, it is a lengthy instrument that requires significant training. Alternative methods of collecting parent report are needed. Currently, the use of the Social Communication Questionnaire (SCQ) in conjunction with the ADOS appears to be are reasonable replacement when it is not possible to do an ADI (Corsello, 2007). An emerging area of research involves validating ASD diagnostic instruments that have been translated into a number of different languages. However, the cultural equivalence of these translated instruments has not yet been established. In fact, for some instruments, there is emerging evidence that certain items function differently for non-English

speaking parents. For example, the restricted and repetitive behaviors on the ADI-R tend to be under-endorsed by Spanish-speaking caregivers compared to their English-speaking counterparts (Overton, 2007).

Screening instruments function to identify children in need of further monitoring or diagnostic evaluation.

At that point, standardized autism diagnostic instruments are often employed to structure the information-gathering from both parents and identified children within a diagnostic assessment. The existence of an ongoing improvements to such measures are associated with more accurate diagnosis of ASD, including the ability to reliably describe milder and younger cases, as well as increased comparability of research findings, based on better agreement as to "caseness" across research teams. However, as with screening tools, diagnostic instruments are often limited by inadequate power to correctly identify individuals with and without ASD.

Further, the estimates of such performance validity for each particular measure are necessarily limited by the absence of an absolute test for ASD, and as such are influenced by clinical experience in diagnosing ASD, training and experience in using the diagnostic measure, and evolution within the field in terms of what is recognized and labeled "ASD." Four commonly used autism diagnostic instruments are reviewed briefly below in terms of intended purpose, administration and scoring, and psychometric properties. Instrument parameters of these measures based on the largest available samples are briefly summarized in. For more detailed psychometric information, see the National Institute of Clinical Excellence guidelines (NICE, 2011).

The diagnosis process of autism varies from institution to institution from professional to professional. The diagnostic process includes all of the activities in which a clinician engages in

trying to understand the nature of an individual's difficulty (Volkmar, 2005). Diagnosis process categorize in two stages. The diagnosis process begins with general developmental screening with a pediatrician or early childhood care provider.

Children identified with developmental problem in first stage are referred to second stage of evaluation for diagnosis of a child with autism and other developmental disorder (NIMH, 2011). (Nejman, 2009) also argues the requirement of trans-disciplinary assessment team based on the needs of the child.

There is a wide agreement that, once the presence of ASD is suspected, the child should be referred for a multi-disciplinary assessment in which all members of the team should have some ASD training and at least one member should be trained in the assessment and diagnosis of ASD using standardized instruments. Also, it is recommended that the child should be ideally observed in several different settings, both structured and unstructured. It needs to be recognized, however, that the vast majority of child and adolescent mental health services worldwide do not have the state-of-the-art instruments used in specialized clinics in wealthy countries such as the Autism Diagnosis Observation Schedule, the Autism Diagnostic Interview, the Diagnostic Interview for Social and Communication Disorder or the Developmental, Dimensional and Diagnostic Interview. This highlights the need for dissemination, training and development of multi-cultural, multi-language, cheap, reality-oriented, user-friendly, instruments.

The essential features of autistic disorder are the presence of markedly abnormal or impaired development in social interaction and communication and a restricted repertoire of activity and interests. (American psychiatric association, 1994)

Cutgno(2009) describes Autism Spectrum Disorder(ASD) as a neurologically based disorder which has an impact on growth of social, behavioral and language/ communication area. He also explains that Autistic Disorder, Asperger's Disorder (AD) and Pervasive Developmental Disorder- Not otherwise specified (PDD-NOS) are included under Autism spectrum Disorder it being categorized under Pervasive Developmental Disorder (PDD). The Diagnostic and Statistical Manual for Mental Disorders fourth edition(DSM-IV) classifies Autistic Disorder, Asperger's Disorder, and Pervasive Developmental.

According to Cutgno (2009) Childhood disintegrative disorder are related with step by step loss of functioning and other skills that have formerly been gained within the first few years of life and also with serious mental retardation. Autism spectrum disorder is also defined as an enduring developmental disability that effects on how people understand what they hear, see or sense which in turn impairs social interaction communication and behavior (Alberta learning,2003).

There are two major diagnosticclassification systems is use which is the International Classification of Diseases (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5).They have similar symptom criteria for diagnosis, based on a triad of impairments, with the behaviors being discrepant from the individual's mental age:Such as social impaired, deviant and delayed or a typical social development, especially interpersonal development. Language and communication are one of the similar symptoms for the diagnosis this impaired and deviant language and communication, verbal and non- verbal. In the other hand, thought and behavior is link to the similar symptom criteria for ICD-10 and DSM-5. This impaired imagination play and it rigidity the thought and behavior and impoverished social

imagination and so on (DSM-5, 2013).With regard to diagnostic criteria the DSM-5 puts it in the following manner: Diagnostic criteria for autistic disorder (APA, 2012). Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text): First, deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions. Second, deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures: to a total lack of facial expressions and nonverbal communication (APA, 2013).

Third, deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers. Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text): First, stereotyped or repetitive motor movement use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, and idiosyncratic phrases). Second, insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

Fourth, highly restricted, fixated interests that is abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). Fifth, hyper- or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior. The symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Furthermore, there are many tools to assess ASD in young children, but no single tools should be used as the basis for diagnosis. However, diagnostic tools usually rely on two main sources of information such as parents' or caregivers' descriptions of their child's development and a professional's observation of the child's behavior.In some cases the primary care provider might choose to refer the child and family to a specialist include neurodevelopmental pediatricians, developmental behavioral pediatricians, and early intervention program that provide assessment services. As articles suggest about the selected diagnostic tools such as; Autism Diagnosis

interview revised. It is a clinical diagnostic instrument for assessing autism in children and adults. The instrument focuses on behavior in three main are: reciprocal social interaction, communication, and language; and restricted and repetitive stereotyped interests and behaviors. The ADI-R is appropriate for children and adults with mental age about 18 months and above (Lord, Rutter and Couteur, 1994).

2.3.1 The Autism Diagnostic Interview-Revised (ADI-R)

The Autism Diagnostic Interview-Revised is astandardized, semi-structured interview that is administered by a trained clinician to a parentor caretaker familiar with the developmental history and current behaviour of the individualbeing evaluated. Scoring is based on the interviewer's judgment of the behaviouralreportsobtained, rather than on the informant's judgment and the administration and scoring of thisinterview takes approximately 1.5–3 hours in a face-to-face setting (Lord, Rutter, & Le Couteur, 1994). The ADI-R versionpublished by Western Psychological Services (WPS) can be used to assess those with mentalages above 24 months (Rutter, Le Couteur, & Lord, 2003); newly-created algorithms extendthe use to children aged 12–47 months and down to nonverbal mental ages of 10 months.The ADI-R is comprised of 93 items focusing on Early Development, Language/Communication, Reciprocal Social Interactions, and Restricted, Repetitive Behaviors andInterests. Most items includes distinct current and historical scores, the latter based either onthe period between the individual's 4th and 5th birthdays ("Most Abnormal 4–5") or thepoint in the individual's lifetime at which the behaviour in question was regarded as mostatypical ("Ever"). Scores are assigned on a 0–3 scale; higher numbers indicate more definite presence or greater severity of symptoms.

The diagnostic algorithms for children aged 2:0 to3:11, or 4:0 and older are based on sums of specific item scores across the domains notedabove. Algorithm cut-offs for all domains must be met or exceeded to achieve the instrument classification of "autism." Current Behaviour algorithms exist but do not yieldclassifications.In two large independent samples aged 3 and older (N=960 American; N=232 Canadian),the ADI-R correctly identified 89–95% of children with ASD, however it yielded a non-spectrum classification for only 56–59% of children with non-ASD disorders (Risi et al.,2006).

When used in combination with the Autism Diagnostic Observation Schedule (ADOS), this specificity improved to 77% and 75% by sample. This supports therecommendation by de Bildt and colleagues (2004) that the ADI-R and ADOS are mostvaluable in combination. WPS ADI-R diagnostic algorithms have been found to be over-inclusive for individuals with nonverbal mental ages below 18 months and those with severeto profound intellectual disability (Lord, et al., 1993; Nordin and Gillberg, 1998; Risi et al., 2006); In general, interpreter reliability was found to be very good in a sample of 20 children with autism orintellectual or language impairments (Lord et al., 1994), as well as in larger sample of 94preschoolers (Lord et al., 1993). A later study of seven reliable examiners rating oneadministration reported well to perfect agreement on 87% of items (Cicchetti et al., 2008). Original test-retest data were available for six children:with blind interviewers administering the measure 2–3 months later, exact agreement exceeded 83% for all but 6 items (Lord et al., 1994).

2.3.2 Diagnostic Interview for Social and Communication Disorders (DISCO)

The Diagnostic Interview for Social and Communication Disorders (DISCO; Wing,Leekam, Libby, Gould, &Larcombe, 2002), now in its 11th version, is a semi-structured,standardized

interview used in ASD assessment for diagnosis and educational and/ortreatment planning. Like the ADI-R, the DISCO is administered face-to-face by a trainedexaminer interviewing a parent or close caregiver of an individual with suspected ASD.

However, ratings on the DISCO can be based on any available information, including direct observation of the individual or reports from teachers or other caregivers.

The instrument is intended for individuals of all chronological and mental ages, although published data on the diagnostic validity of the measure in special populations (such as very young children or those with above average or impaired intellectual ability) are limited.The DISCO takes approximately 2–4 hours to administer (including scoring). Itencompasses 362 items covering domains of social interaction, communication,imagination, and repetitive behaviours, as well as domains assessing developmental levelsand daily living skills, and non-ASD-specific behaviours, such problems with attention,overactivity, sexual or psychiatric difficulties, and other challenging behaviours.Developmental items are rated on a 3-point scale of "delay," "minor delay," or "noproblem"; atypical behaviour items receive separate ratings based on current behaviourandmost atypical behaviour ever, with a scale of "severe," "minor," or "not present." The DISCO was originally intended to assist in clinical assessment and treatment planning for an individual rather than to yield a categorical diagnosis, however computerized diagnostical gorithms for research use have been created (Leekam, Libby, Wing, Gould, & Gillberg,2000; Leekam, Libby, Wing, Gould, & Taylor, 2002). These include two algorithmsoperationalizing the ICD-10/DSM-IV criteria for autistic disorder and Asperger's Disorder,a 5-item algorithm based on Wing and Gould (1979) criteria for autism spectrum disorders,and an algorithm based on Ehlers and Gillberg (1993) criteria for Asperger's

Disorder.In a DISCO-9 validity study of children aged 3–11 years (Leekam et al., 2002), all 36children with ASD were correctly identified by either Wing & Gould or ICD-10 autism algorithms, however 10 out of 17 with intellectual disability and 4 out of 14 with languagedisorders were also identified as "ASD." In a study using the Swedish translation of theDISCO-10, the ICD-10 autism algorithm identified 42 out of 51 individuals with an ASDdiagnosis and incorrectly identified 1 individual out of 6 without ASD (Nygren et al., 2009).Another Swedish study reported that 89 adult longitudinal participants with an ASD were correctly identified by the DISCO as having an autism spectrum condition by either ICD-10autism or atypical autism algorithms (Billstedt and Gillberg, 2007). Inter-raterreliability of the DISCO-10 was assessed in 33 children (aged 2.5–15) and 7 adults (20–38years), with over 90% of items showing good or excellent inter-rater reliability and themajority of algorithm items showing at least moderate reliability (Nygren et al., 2009).

2.3.3 Developmental, Dimensional, and Diagnostic Interview (3Di)

The 3DI is apparent caregiver interview administered face-to-face by a trained examiner using a laptopcomputer. Prior to the interview, parent/caregivers complete questionnaires that are entered into the software and used to tailor the order and wording of questions asked in the in-person interview(Skuse et al., 2004). Parent responses are entered directly into the software in the moment, and immediately following the 90–180 minute interview, a computer-generated report, including algorithm scores and classification, is available to the clinician. In addition, a spreadsheet of up to 1300 3Di variables is automatically created. The 3Di was developed primarily to assess ASD symptoms in children with average-range abilities and to differentiate ASD and non-spectrum conditions in a general population; the authors suggest it may also be used in populations with moderate to severe intellectual disability (Skuse et al., 2004).The 3Di is

comprised of mandatory modules covering autism spectrum symptoms (266items), optional modules on comorbid symptoms (291 items), and 183 items concerningpatient demographics, family background, developmental history, and motor skills. A short53-item form of the 3Di has also been piloted (3Di-sv; Santosh et al., 2009). On both theoriginal and short forms, response options vary within 3-point scales.

Computer-generate dalgorithms weight and sum responses within domains, though published reports are not clear as to which domains are represented in the algorithm, how items were chosen for algorithm in collusion, and which classifications are produced.In the former report, the measure discriminated between 27 children with ASD,60 typically developing children, and 33 with unreported diagnoses with 100% sensitivity and 98% specificity. In the latter report, sensitivity of the short form ranged from .90 to .96and specificity ranged from .85 to .96 by domain in an independent sample of 439 children,58% of whom had ASD (Santosh et al., 2009).

2.3.4 Autism Diagnostic Observation Schedule (ADOS)

The Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) is a semi-structured, standardized observation of children and adults referred for ASD. With the recentaddition of a Toddler module (Luyster et al., 2009), the ADOS has five development- andlanguage-dependent modules, which are 30–60 minute protocols of activities that are basedon talking and/or play-based interaction. Trained examiners choose the appropriate modulefor the individual's age (from 12 months through adulthood) and verbal level (from nowords to fluent speech), and follow that protocol of activities using standardized materials(e.g., books, toys), for a semi-structured social interaction. An adapted ADOS module to address diagnostic needs in older individuals with minimal language is currently undergoing validity testing (Lord et al., 2000).

Like its companion measure, the ADI-R, the ADOS was created by operationalizing DSM-IV criteria for autism. Item scores on a 0–3 scale, with higher scores indicating greater symptom severity, are assigned immediately after completing the administration. Specificitems from Communication, Reciprocal Social Interaction, and Restricted and RepetitiveBehaviour domains comprise algorithms, which yield a classification of "autism," "autismspectrum disorder," or "non-spectrum".

In 2007, revised algorithms were created with thesame number of items and of similar content across modules 1–3 (Gotham et al., 2007), and in 2009, two algorithms were created to correspond to the Toddler module(Luyster et al., 2009). In these seven new algorithms, raw scores of algorithm items from a"Social Affect" and a "Restricted Repetitive Behaviour" domain are summed and applied toone set of cut-offs to yield the instrument classification.

In addition, Toddler algorithm totalscan be located within three "ranges of concern," in order to discuss the scores dimensionallyrather than applying a cut-off score. For the original algorithm still in use for Module 4 (forolder adolescents and adults with fluent speech), separate cut-offs exist for Communication,Social Interaction, and the combination of those two totals; all three sets of cut-offs must exceeded to achieve an "autism" or "autism spectrum" classification.Both original and revised diagnostic algorithms have strong predictive validity against bestestimate clinical diagnoses, with the revised set of algorithms showing minimal associationbetween ADOS totals and chronological age.

Generally, decreased association betweenADOS total and verbal IQ when compared to the original algorithms, and improved sensitivity in lower. ADOS performs better in autism clinic samples in which the information gainedfrom the measure is directly used in clinicians'

diagnostic decisions; in samples in which theADOS examiner is not the primary diagnostician (Risi et al.,2006, Molloy, Murray, Akers, Mitchel, 2011), the predictive validity of the measure tends to be significantly lower. Inter-rater reliability, internal consistency, and test-retest reliability of the measure were found to be good to excellent in the original ADOS reliability sample of 98 individuals and12 reliable examiners, as well as in updated data on the revised algorithms (Luyster et al., 2009).

2.4 Professional involvement to diagnosis ASD

Diagnosis is more reliant on the expertise of professionals in interpreting the results of standardized observations and assessments (NICE, 2011; 2012).

The Australian adviser board on ASD (2013) point out in the guideline about the number of professionals involvement in the assessment process including pediatricians', psychiatrists, psychologists, speech pathologists, occupational therapists, audiologists and neurologists. A diagnosis of ASD in children is often conducted by a multi-disciplinary team of health professionals over a number of sessions. These health professionals will be experienced in the assessment of ASD and they will gather comprehensive information on cognition (knowledge and understanding), communication (language and non-verbal), and social, behavioural and adaptive skills. There are a number of public and private practitioners and teams that specialize in the assessment and diagnosis of ASD. To ensure the quality of the diagnostic process, expertise from several perspectives needs to be integrated: that of the individual, their family, and the professionals (De Clercq and Peeters, 2007).A goal for professionals is to reduce the (often lengthy) waiting times for an autism diagnosis, whilst also providing a high-quality diagnostic service that adheres to best-practice clinical guidelines (Rutherford et al. 2016).

Studies about professionals involvement reported that all professionals used diagnosing criteria and standardized tools to aid the diagnostic process, perceiving them to be very helpful. Professionals who were experienced in multi-disciplinary teams (MDTs) advocated this way of working, reporting that it was advantageous for a holistic assessment (Moh and Magiati, 2012). However, constraints were acknowledged regarding time, obtaining enough information, conflicts of opinion, parent involvement and case complexity.

Professionals need to communicate the realities (positive and negative) of the ASD diagnosis with the individual and their parents openly and effectively. Diagnosing professionals need to have wider knowledge of ASD e.g., of more subtle presentations. Health professionals specializing in diagnosing ASD may use any number of standardized tests. Those are Childhood Autism Rating Scale (CARS), Autism Diagnostic Interview-Revised (ADI-R), Autism Diagnostic Observation Schedule (ADOS) and Developmental, Dimensional and Diagnostic Interview (3DI) (Moh and Magiati, 2012).

Furthermore, in related to post diagnosis Professionals express a desire to offer long-term support, but this is not possible for many services and Professionals felt services were fragmented and disjointed and that services needed to work together to provide the best possible support for an individual and their family (Rogers, Goddard, Hill, Henry, and Crane, 2015).

2.5 Theoretical framework

Autism theory of LeoKanner

Leo Kanneran Austrian-born immigrant to the USApioneered the application of psychiatry to psychological problems in children. In 1943, he made case studies of 11 children referred to his

clinic. He identified language problems; atypical use of non-verbal communication, such as eye gaze and gesture; narrowly restricted interests and a desire for sameness; and atypical reactions to sensory stimuli. The children's apparent aloofness and isolation from the human world led him to coin the phrase 'autistic aloneness'. 'Autism' comes from the Greek word 'autos' for self, and means being absorbed into oneself. Kanner shared features of behaviour suggested a syndrome, a specific disorder with a characteristic set of symptoms (observable characteristics-that may indicate a clinical problem or disorder).

However,these daysthevariedprofileandseverityofkeysymptomsbetweenindividualsisconsideredto represent a spectrum of problems rather than a single unified syndrome. Kanner describes many of the children had been diagnosed with Autism Spectrum disorder and schizophrenia at one point. He differentiated the two disorders, however, stating that a person with schizophrenia steps outside his or her world and departs from already existing relationships, whereas the children he described had never established such relationships, experiencing an extreme aloneness from very early on. While Kanner's diagnosis children he used observation and interviewing parents. The initial interview was includes the children's family members led the field in subsequent directions. He found that how parent was destructive and unsupported notion of parental responsibility for autism. In is observation of autism spectrum disorders which describes as a single disorder. Early infantile autism was distinct from all other disorders appears unjustified in the context of current thought. Kanner immediately became concerned with differentiating this disorder from other forms of childhood psychopathology (Blacher and. Christensen, 2011).

Summary of literature

Autism is a neuro-developmental disorder first described by the American psychiatrist Leo Kanner (1943). Children with this disorder are extremely unresponsive to others, uncommunicative, repetitive, and rigid. Their symptoms appear early in life, typically before 3 years of age. In 1943 Leo Kanner wrote a paper with a title "Autistic disturbances of affective contact". Kanner described about the cases of eleven children who have difficulties of social interaction and language (Ibid).

In 1944 in Austria Hans Asperger published a paper with the title "Autistic psychopathology" in which he explained about four boys who have difficulties in making friends, two sided conversation and do not have the ability to understand others (Gallo, 2010).

The prevalence of ASD in the USA was 14.7 per 1000 one in sixty eight children aged eight years. In Africa continent there is no clear epidemiological data about the prevalence of Autism Spectrum Disorder.

There are many different diagnosis instrument are used to diagnosis Autism Spectrum Disorder. Those are DSM-5, ICD-10, STAT, ADI-R, DISCO, 3DI AND ADOS. Those instruments were used to diagnosis and screening Autism Spectrum disorder. The tools used into different setting. For instance, ADI-R is standardize instrument used for parent or caregiver who is familiar with developmental history and current behavior, DISCO used to assess diagnosis and educational treatment plan, 3DI is caregiver interview used to administered face to face trained examine used a laptop or computer.

CHAPTER THREE

3. RESEARCH METHOD

This chapter presents the design used, the sampling techniques employed, the data collection instruments used, and the procedure of the study and the method of data analysis.

3.1 Research Methodology

This study used a qualitative methodology. According to Chisaka (2011) qualitative research focuses on studying phenomena in their natural setting, thus enabling the researcher to draw theoretical insights and conclusions from academic debate rather than positivism which tends to stay with theoretical positions which are then supported by the research data. It uses corroboration and triangulation to produce more in-depth and comprehensive information.

3.2 Research design

A research design is a plan, structure and strategy of investigation conceived as to obtain answers to research question or problems. Hence, the design used in this particular research was qualitative, specifically case study. This is because it is useful to obtain in-depth data from the center psychologist and teachers. According to Stake (2005) case study research is not a methodology but a choice of what is to be studied (as cited in Creswell, 2007).

3.3 Study Area

Ethiopia is one of the African countries and Addis Ababa town serves as a capital city. Addis Ababa lies at an elevation of 2,200 metres (7,200 ft) and is agrassland biome, located at 9°1′48″N 38°44′24″E. Addis Ababa has 10 sub cities with a total population of 2,976,425.Bole sub city is the largest and Kirkoseis the third smallest sub cities of the town.

Moreover, all Ethiopian ethnic groups are represented in Addis Ababa because it is the capital of the country, the largest groups include the Amhara (67.04%), Oromo (19.00%), Gurage (16.34%).

3.5 Study Site

The study was conducted at Nehemiah Autism Center (NAC), found around Goteraarea, Addis Ababa City. NAC is a non-governmental local organization established for providing services for children with ASD in 2011.

It also offers a family support group in addition to holistic rehabilitation services for children with autism spectrum disorders. It has also experience with parents and staff from other center related to the diagnosis and intervention related to Autism. It is now develop its work to allow more children with Autism Spectrum Disorders to obtain professional services. The center provides services in three levels (level1: self-help skills, level 2: receptive skills, and level 3: expressive skills) by accommodating 50 children with ASD and facilitated by 20 teachers.

Nehemiah Autism Center is an NGO and has a license from Charities and Societies Agency, which is a concerned governmental office, and has rented a house to receive children with ASD. The center started work on June 16, 2011 after it got its license on 31 August 31, 2010. It functions on a non-profit basis, for example by providing transportation free of charge for those families who cannot afford to send their children with ASD to the center due to the reason that it is difficult to use public transport for these kinds of children with ASD.

Nehemiah Center aspires to see every ASD child cared for, hence the parents of ASD children are also given awareness about ASD and taught ways to best support their children in order to help maximize their children's functioning. This fits into the Nehemiah Autism Center's mission, which is to provide care, instruction and support for children with Autism and related disabilities by promoting cognitive, emotional and relational growth through individualized programs. NAC's holistic approach is evidenced by the fact that they are also providing counseling and support to parents, especially mothers as they deal with these particularly difficult challenges. They teach parents to become active participants in their child's education and development. Finally, they aim to raise public awareness of the nature and prevalence of ASD.

They are now trying to reach to so many children with ASD who are deprived of their rights for education and rehabilitation because of shortages of schools and society's lack of awareness. They first started with 6 children with ASD. In those beginning days, due to lack of funds the Board Members were forced to discuss about the center sitting on the floor. They were in shortage of funds to pay salaries for the caregivers.

3.4 Approaches

In conducting the study, qualitative approach was used as the approach will give high degree of flexibility to understanding the case in its qualitative nature. The qualitative approach was helped me in gathering subjective information and other related issues such as the qualification and skills of professional involvement, the practice of NAC in diagnosing ASD and the availability of tools use to diagnose.

3.5 Population

Population is described by Yin (2001, *accessed on line 13 April 2010),* as the entire number of subjects under study which is the whole. Gall et al (2007) go on to say that; population in a study can be found in two types that is target population and accessible population. Target population includes all the members of a real or hypothetical set of people, events or objects to which researchers wish to generalize the results of their research (Burns & Groove, 2005). In this study the target population referred to teacher and psychologist in one Autism center.

3.6 Sample

According to Burns & Grove, (2005) a sample is a subset of the population that is selected for a particular study. Gall et al (1996) say a sample is a part of a whole. Data are generally collected from a sample rather than the entire population because using a sample is more practical and less costly than collecting data from the entire population (Polit and Hungler, 2003, *accessed on line 8 August 2011).* However, as Patton (2002) pointed out that the sample can be a disadvantage if it does not reflect the characteristics, behaviors or beliefs of the population which were 8 participants was selected as a sample.

3.7 Participants of the Study

The researcher used two psychologist who are directly involved in the diagnosis process and working with ASD children at Nehemiah Autism Center. Six teachers of the center, two from each level were identified and took part in the study. Both psychologist and teacher of participants were selected using purposive sampling technique. The criteria of the purposive sampling technique help for the target of the participants' direct relationships between the children with ASD.

This research targeted on investigating the practice of diagnosis children with ASD at Nehemiah Autism Center. Mainly the investigation was conducted with personnel who are directly involved in the diagnoses process. However, the investigation was also further included few staff who have direct relation to diagnosing children with ASD. The general characteristics of the respondents are discussed here below:

Demographic Characteristics of Psychologist and teachers

No	Name	Sex	Age	Educational level
1	A	Male	31	Diploma in IT
2	G	Male	51	Developmental psychologist
3	Z	Male	26	Completed 12
4	W	Female	25	BA in psychologist
5	M	Female	30	Diploma in Nursing
6	B	Female	28	BA in psychologist
7	F	Female	40	Completed 12
8	B	Female	23	Completed 12

3.9 Data collection instruments

The study has been classify the research questions that are needed to be addressed in the scientific study and to make decisions who should be studied, what source of file should be involved and what kind of tools should be employed to diagnose ASD. In order to get the desired and relevant information of the practice for diagnosis children with ASD, the researcher gathered the data were obtained from both primary and secondary sources.

The primary data sources have been prepared semi structure interview using open ended questions. The primary data sources have been prepared and checked within piloting by semi structure interview. By piloting the interview question to see how valid the questions are interview first piloting the interview with teacher who had related experience with ASD then after applied to the participants of this study. The interview questions were used as open ended this provide a good opportunity for participants to freely share their views attribute to their experiences.

The open ended questions were developed in English and then translated into Amharic. The items was classified in two three parts the first part was include question about how diagnosing ASD practice at NAC and the second part include how professional qualified and skillful to involve in diagnosing ASD and third part it include the availability and appropriateness of tools to diagnose ASD. In other hand, secondary data were relevant document analysis and child profiles.

3.9.1 Validity

According to Kumar, T. (2008)validity is the ‘integrity of the conclusions that are generated from a piece of research’ and reliability is believed to mean dependability of consistency’ and that qualitative researchers' use a variety of techniques (interviews, participation, documents) to

record their observations consistently' (Polit& Beck, 2004). Validity in qualitative data techniques was reached through transcribing, corroborating and triangulating information from semi-structured interviews and observation from different groups of participants.

3.9.2 Measures to ensure trustworthiness

Whilst verifiability of qualitative research is assessed in terms of its reliability and validity, qualitative research is accurately assessed according to trustworthiness through credibility, transferability, dependability and conformability (Baxter & Jack, 2008, *accessed on line 11 December 2009)*. In this study I used piloting the questions to see how the interview questions are understood by others and the participants.

3.9 Data Collection Procedure

The data collection process was as follows. First, a letter of permission was taken from school of Psychology of Addis Ababa University obtain approved from the center to conducted in this study. The letter was submitted to the heads of at Nehemiah Autism Center associations and then agreement was arrived on the objective of the study and thereafter they became willing to inform participants for the study.

Then, participants were selected for the study and necessary rapport was established with frequent visits of the researcher and through phone calls. Next, after agreement of using tape recorder was assured, interviews sessions were made with each respondent. The interviewees were made free to arrange the time and place of the interview session and as a result as itwas very comfortable for them. If the interviewee has difficulty answering a question or provided only a brief response, the interviewer used prompts to encourage the interviewee to consider the question further. The interviewer also had the freedom to probe the interviewee to elaborate on

the original response or to follow a line of inquiry introduced by the interviewee. The item was address regarding the objective of the study. Items were classified in to three parts. Such as questions that address the practice of diagnosing ASD, professional involvements in terms of their qualification and skills and the availability of tools use to diagnose ASD.

Furthermore, the interview processed by using a tape recorder notes were as recorded using a note book during an intensive interview held with each case privately.

Then, data instruments were triangulated in the finding process. After that the findings discussed. Finally, the result was summarized, the study concluded and recommendation arrives at based on the findings and discussions.

3.10 Data analysis

Data were analyzed through thematic analysis. In this study, the process of analyzing commenced right after every interview and also after all the information collected. The analysis process started Interim analysis with organizing notes and then transcription of audio records collected from in depth interview of study participants in Amharic language. Transcriptions of audio record were followed by compiling note taken in the interview session with transcribed audio record. After the interview were translated to English and transcribed into written form. The data was summarized into cleaning then thematic and interpreting.

3.11 Ethical consideration

To gain support from participants a qualitative researcher conveys to participants that they are participating in a study, explains the purpose of the study and doesn't engage in deception about the nature of the study (Creswell, 2007). Accordingly, participants were given clear information about the purpose of the study before they engage in any kind of interview. Berg (2005) defines confidentiality as the effort of making the study participants unknown in the study record and

anonymity implies making the participants stay unnamed. As Berg explains in most qualitative research anonymity cannot be maintained since the researcher knows the name of the participants and due to there being few research participants in the study. To address this, the research ought to ensure the confidentiality of the participants.

CHAPTER FOUR

4. DATA PRESENTATION AND ANALYSIS OF THE FINDING

4.1.The practice of diagnosis at Nehemiah Autism Center

4.1.1 Information and understanding about autism and Diagnosing ASD

The diagnosis process starts from parent obtaining information and an understanding about Autism and diagnosing ASD. There are different ways that parent received information about the diagnosis service as well as interventions, such as from online resources that related to Autism Spectrum Disorder. Other informational materials that parents got information from include the media, flyers, via reference from professionals and from other parent who had children at the center (i.e. parent to parent shared information).

According to Dillenburger (2013), awareness of autism has been growing, with most people in the general population being aware of autism or knowing someone on the autism spectrum (Dillenburger, 2013).It is important to focus research efforts on exploring early knowledge seeking behaviors amongst parents, particularly since caregivers often rely on the media, conferences and other parents to find out more about autism (Rhoades et al. 2007).

Parents get information from different kinds of sources. As the psychologist discusses about ASD with parents, their level of understanding of NAC services regarding diagnosing ASD improve. For example, one explained:

"While interviewing parent I ask about how they get information about NAC and their understanding of ASD. From my experience interviewing a lot of parents, usually, parents get the information about NAC from different source those who can access internet, they find about Nehemiah Autism center through searching the website and visiting our face book pages. However, most of parents have the information by recommended clinical doctor for intervention purpose and from other people."

From a parent of teacher who had a son that was provided the intervention service stated that:

> *"I have a son who is taking the intervention service in this center. From my experience when I have seen a change with my son. I had no idea where to take this child, then one of my neighborhoods gave me a suggestion to take my son to the center so that the child could get intervention. I had no idea that my son needed diagnosis. Then, after I came to Nehemiah, I got the understanding and intervention process."*

Therefore, parents who came based on a reference from a neurologist get the information from the clinic and those parents who do not have any understanding about the diagnosis came straight to the center without consulting physicians.

> As the response of BA psychologist: "*While I am interviewing parents for the first time, those parents who came at the center referred by neurologist have lack of awareness about autism and even the fact that their children are difference. Even if they know the*

result with the referred paper, they want their children to get assessed again because they don't trust the result they had, and they want to make sure its Autism and they want to know more about the case."

Furthermore, those parents who are directly referred by the neurologist for further assessment and intervention to the center were confused about autism and had difficulty accepting the result. From the response of teacher who had a son at the center response:

"*Before I took my son to the center and hospital, both the doctor and the person who diagnosed my son asked me if I know about autism and my answer was no. Even after they explained about it, I was still confused with the result because my son was smart in doing some activities and I can't imagine that he becomes this. So, I am sure that every parent doesn't have understanding about autism until they are clear about what is different about their children. I stated this because I was there. But, after a very clear information given by the psychologist, here I am now. I understand about autism and how to help my son."*

NAC provided information about Autism Spectrum Disorder for parents who lacked an understanding about Autism after assessing the diagnosis process by explaining the change that the children showed and the difference from those children that has strong communication and language skill and so on.

4.2.2 Appointment Process

According to the literature, when concerns arise that a child may have ASD, a referral should be made to an interdisciplinary team for a comprehensive diagnostic evaluation. It is important that

these teams or individuals demonstrate expertise in evaluating children with ASD. Referral of children with ASD is a major hindrance to screening and identification of children with ASD. Insufficient processes can create confusion surrounding the referral process. Many service providers do not know where children with developmental problems should be seen or how to initiate the referral. This needs a resource directory that lists the geographic location served, contact information for individual within the team, an explanation of the referral process, insurance plans that are accepted, and services rendered (CDDS, 2002).

From the practice of NAC, when parents visit the center for the first time with their children to get service they come to both to diagnose the children and receive interventions after the diagnosis process. Those parents follow a procedure which is provided by the NAC. Practically, when parents come to the center the first procedure is started by contacting the secretary and then the secretary asks the parent if they have a referral paper from the hospital. After reviewing the paper, parents are asked to wait for the diagnosis service. On the other hand, children who already had the diagnosis service, and if there any confusion with the result, then the person who conducted the diagnose process refers the children for another service.

The analysis from interview the developmental psychologist response quoted that:

> ‘‘W*hile I am working with the children, my responsibility is to work with the diagnosis process and facilitating the intervention. From my experience, there is a case I have had a hard time to diagnose one of the children who came for the first time. I was assessing a 14 years old girl. She had an eye contact with me and with the parent she came with. The parent told me that they came to NAC recommend by a doctor. Based on the information I got from the parents, they took their daughter to the hospital then, the doctor stated that*

she was an autistic and she had seizure too. Then, the parents wanted to get her intervention immediately. Here at the NAC, intervention was made for the new child by assessing her behavior through reviewing her history and observation from my experience. Then, when I reviewed the result, it showed that the girl could speak. She had good eye contact. She understood with whom she came. The assessment I made for the 14 years old girl was beyond the criteria of the instrument I used. Therefore, since the result didn't meet the criteria, I then recommended the parent to take the girl for better clinical diagnosis especially for neurologist."

If children need more tests, the next step is to be given appointment, probably to check the children with a team of ASD specialists, including as: child psychologist, speech-language pathologist, and occupational therapist and for further more diagnosis children meets developmental pediatrician and a neurologist. This evaluation is usually to check things like the child's cognitive level, language abilities, and other life skills like eating, dressing themselves, and going to the bathroom then for an official diagnosis, the children must meet the standards of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published by the American Psychiatric Association (Web MD, 2019).

NAC gives the appointment before and after the diagnosis process and if there any confusion with the diagnosis process then the psychologist refers the children to another clinic or hospital especially referred for better neurological assessment.

For parents who were listed on the waiting list, the appointment day is given for every Thursday. As a result, every Thursday is a registration day to diagnosis children with ASD. Without have this process every Thursday, parents could not get the service as easily. However, in the case that a parent needs an emergency diagnosis, the children may be given the chance based on specific circumstances. As teacher of psychologist explained:

"While am working at this center I have a chance to observe the diagnose process. From my experience, I have seen the psychologist when she diagnosis children with ASD. What she does is first she looks the parents' referral paper and then she listed them into waiting for appointment. In other hand, some parents came without taking any referral paper during this time the person then secretary let the parent to talk to psychologist. After the psychologist done the assessment, she start refer to the clinical doctor for further diagnosis."

In the case of children most referrals to secondary care trust services to general community pediatrician services. This might follow referral from Health Visitors, Speech and Language Therapists, general childcare social services or occasionally referral from parents. Initial referral may also be to other services including child & adolescent mental health and Speech and Language Therapy services (Lord M, 2008).

The appointment process practiced at Nehemiah Autism Center:After assessing the diagnosis, either the child is autistic or not and if it is beyond the psychologist assessment and there is a practice that the children was recommend for further diagnoses service.

4.2.3 Counseling Service

Giving proper counseling for parents is helpful for professional service, and a requirement of the one who had the responsibility for diagnosing ASD. When parents feel free to give information about the child's history, then the diagnosing result is most likelyto be successful. At NAC, when parents came to the center for the first time, they get frustrated about what to do and what kind of information they support to give for the person who conducts the diagnoses process. The

findings revealed that parents struggled to accept that their children are autistic. Some are frustrated and confused with what to do and how they support their children.

For the centers that provide ASD diagnosing service, there need to be a professional counselor. The role for the counselor is to assist children, parents, and families of children with autism. Knowing the symptoms of each disorder is necessary, but there are other foundational components of which to be aware. Specifically, it is critical for the counselor to debunk unhelpful myths and misperceptions about autism spectrum disorder in to identify the needs and wants of children with ASD and to identify the individual strengths of children with an ASD and to be familiar with the common struggles experienced not only by children on the autism spectrum. It is also to discuss the struggles experienced by their parents so as to offer a strengths-based approach to serving the child and family (Moyson and Roeyers, 2011).While most parents and siblings of a child with ASD adjust to and accommodate the issues involved, some struggles may continue. One outcome for parents and siblings is the discomfort resulting from onlookers' actions and words (Moyson and Roeyers, 2011).From the response of developmental psychologist express:

> *"During the interview time before we star interviewing, most parents are frustrate. At that time, I always had a hard time to get relevant information from the parents. Since the center doesn't have a counselor, I try to support the parents by advising how to support their children at home. But, during the diagnosis process, if parents aren't calm, it is hard to get the information I need. After parents know the result then, they become very emotional specifically single mothers. Since NAC don't have professional counselor or a department to do specifically counseling service for parents, I advise the parents by*

informing about what Autism are how they support their children and the support they get from the center too."

As it indicated in other studies, for professionals, taking the time to explain the way the autism diagnostic process occurs is helpful to highlighting the challenges that autistic children, young people and adults face which could provide important context to why difficulties are the main focus of the assessment (Laura Crane, 2018).

Nehemiah Autism Center lacks a professional counselor that provides counseling for parents before the diagnosing ASD. Practically, counseling was given by the general experience that the person who diagnoses the children and counseling is more traditional.

4.2.4 Diagnosis Procedure

Diagnosis procedures were made at Nehemiah Autism Center by first looking into doctor referral of the children which was written to the center. Then either a BA degree psychologist or developmental psychologist cross checks the result through diagnosing the children. From the practice of NAC, the diagnosing procedures were made first by checking the referred paper then interviewing with parent conducted during the interview time observation was follow by the psychologist.

The procedures were made first by taking a detailed history from primary caregiver then a medical history of the developmental, behavioral and family history, it also important to see physical examination in the growth parameters of the children and head circumference, general examination with special attention to skin and neurological findings in inspection for any dimorphic features. Observation of the child is a part of procedure that the professionals observes the children social interaction, response to name, joint attention, play skills, use of language and

presence of atypical behaviors or stereotypes. It is important to see the developmental or psychometric testing, speech/language testing as well (Macferran and Fussell, 2011).

From my document analysis of children, the information was provided and it includes the family history, medical history and behavioral history. The thematic analysis of participant response:

> *"When we interview parents, we use general question to ask about the children development. Besides interviewing the parent, we checked the child activity by giving toys if he/she plays with it. When we observed the child, we cross check the child verbal communication and their movement over all."*

Therefore, the procedure was made at NAC by interviewing parent about the children back history and observation of the children activities in their verbal, communication and movement area.

In the analysis of NAC practice, the formats were used for diagnosing children with ASD and had its own process. Before an assessment was made, it takes time to process the diagnosis. As a result, NAC has a procedure before diagnosing process children was listed out in the waiting list. Waiting for to have diagnosis service can take long time until the center gets fundraised to register and accept new children with ASD. Therefore, this result as one of the procedures that followed by NAC and NAC after reviewing the referral of those under the waiting list children then they start interviewing with the parents to get information. As many participants' response:

> "*Before we apply diagnose process, we use formant that can help us to start the process. The format as it practices in our center is for the first time when both parent and children came to the center, we first review referral paper then, we do observation what the child can do. If the child has had repeated behavior, we ask the parent further information. For*

further information, parent are asked about their children past experience to get relevant information."

Diagnosing procedure that practices at NAC procedure was followed as its own step. First reviewing the referral paper, and then listing out the name of children, then appointment was given. After the appointment, children start getting the diagnosis service by interviewing the parent and observation about the children activity.

4.2.5 Duration of Diagnosis

Early diagnosis is highly desirable, as early intervention has been shown to help improve social and communication skills. To diagnosis ASD it takes an ample time and it is more important to assess the children age.

To diagnose ASD as it indicated NICE, diagnosing children with ASD take about 3 months between referral for specialist assessment following general developmental assessment and first appointment (NICE, 2016). From the practice of Nehemiah Autism Center the time that took in the process of diagnosing children with ASD about 30 minutes minimum and 1 hour maximum. The process was more successful when parent had the referral paper. This also makes the assessment quite easy. Whenever the process took more than an hour the psychologist referred the children to other clinical service.

4.2.6 Transparency of Diagnosis Process

As is practice at Nehemiah Autism Center, clarifying the procedure of diagnosis ASD is limited on the person who provides the diagnosis. Form the participant response about the understanding

of diagnosis and the process. A teacher response about the clarity of diagnosis procedure of diagnosis Autism Spectrum Disorder replied;

> *"I study psychology but I have no idea how the psychologist diagnose children with ASD even at this center, but I didn't get any chance to observe how the diagnosis process is going. The only thing I know about is the intervention applying into the children. Children after they get assessed by the psychologist, and then children assign to the different levels according to the diagnosis result."*

The result is that, the teacher who had the knowledge in psychology has not had a chance to engage in the diagnosing ASD at the Nehemiah Autism Center this result that the center to lack to use the resource the center had in hand.

4.3 Professionals knowledge and skills in the involvement of Diagnosing ASD

4.3.1 Team of Experts

To diagnose Autism Spectrum Disorder, it is important to have professionals who are qualified in diagnosing ASD and qualified in using tools. Therefore, from the finding revealed that professional who coordinates diagnosing service for children with ASD at Nehemiah Autism Centerare not qualified. With numbers, there are two psychologists involve in the diagnose process. Particularly, the background of the psychologists is full time psychologists and one part time developmental psychologist was involved in diagnosing children with ASD. While diagnosing, the psychologist don't involve at the same time. This reveals to diagnosing ASD, all members of the multidisciplinary assessment team should come from different professional disciplines. Therefore, NAC don't involve multidisciplinary teams of experts. In particular, team of experts were including as the practice of Europe country, occupational therapist those who can

assist the individual with their sensory process, fine and gross motor skill, self-care and social skill. Speech pathologist needs to involve working individual with ASD in their respective and expressive language. In addition, pediatrics psychiatrists, pediatricians, psychologists and rehabilitation professionals and should involve professionals who are experienced and specifically trained in neuro-developmental disorders and other childhood disorders, and not only in ASD. Those experts need to have experienced in the assessment of ASD and they gather comprehensive information on cognition (knowledge and understanding), communication (language and non-verbal), and social, behavioral and adaptive skills. There are a number of public and private practitioners and teams that specialize in the assessment and diagnosis of ASD (Haute santé, 2018).

At the Nehemiah Autism Center both psychologists have the experience into diagnosing children with ASD. As literature support the idea, diagnosis coordinators must have appropriate operational knowledge of and experience diagnostic evaluation process and functional and support Needs Assessment process.

Those professional needs to scheduling appointments with flexibility to accommodate and collating relevant background information professional have to communicatingwith autistic individuals and their caregivers using a variety of mediums(Evans, Eapen, and Prior, Wray, 2017).

To diagnoses ASD it is critical to involve multidisciplinary professional teams of experts trained in the diagnosis process. Therefore, as it practices at the NAC professional are limited in number as well as in their skill. As it included from literature to ensure the quality of the diagnostic process, expertise from several perspectives needs to be integrated: that of the individual, their family, and the professionals (De Clercq and Peeters, 2007). In addition professional have to

demonstrate at least four years fulltime equivalent of postgraduate experience that is directly relevant to ASD diagnostic evaluations, obtained through university qualifications, formal training programs and formally supervised work experience (Evans, Eapen and Prior, Wray, 2017). The Nehemiah Autism Center professional are qualified with the BA degree have 1 year experience and MA degree with psychology and they have 3 years experience in diagnosing children with ASD.

4.3.2 Recommendation for further diagnosis

As it practiced at Nehemiah Autism center, diagnosis was made for additional information children with ASD. Therefore, for further diagnosis service, parentshave come to the center as they are referred by the doctors then the person who diagnoses children with ASD at NAC applied the diagnoses assessment.

The thematic Analysis highlighted that to send parent for further diagnosis service first children were assessed with the process of diagnosing them. A developmental psychologist says:

> *"When parents came to the center first, they see the secretary then the secretary asks parents if they have referral paper. If they don't have the paper, then we assess the child. If the diagnosing process beyond our knowledge and experience, then we referred the parent as a recommend to government hospital who work specifically in diagnosing ASD like Powlos and Yekatit Hospital and they also recommend for those parent who can afford to private clinic which is called Yewibishet Clinic."*

In addition, a parent who is a teacher at the center sates:

> "*From my experience, for the first time when I brought my child to the center, the psychologist observed my son and I asked about my son developmental experience. When*

he got the diagnosis service, my son was 5 years old, but his eyes were not right when he saw someone and objects. During this time, the psychologist recommended me to take my son to eye doctor. After the result of the eye examination, I came to the center and the psychologist review the

Referrals for children who have been diagnosed with ASD will require re-evaluations periodically, particularly at times of transition. For instance, transition to prior to the start of primary school. A child who receives a diagnosis of ASD at age 2 or 3 should receive testing the following year, sooner if any test results were suspect. Reevaluations need not be as comprehensive as the initial diagnostic testing, but they are important over time, children with ASD change, not so much in diagnosis, but in their needs, strengths, and difficulties (Lord et al., 2006).

In addition, in the study, professionals were asked where they referred children with ASD if they need further diagnoses. A participant answer:

"while I assess the children in looking at whether the child is an autistic or not, if there any confusion like if the child has had physical movement problem and if there is seizer problem, then I recommend parents to take the child to Black lion Hospital."

Other respondent states:

"When parents came to the center without taking their child for diagnosis to the hospital, we recommend the parent to the children to the hospital. However, we don't have that much contact with the clinical doctor, but we referred the children to clinic or hospital"

As it is practiced at the NAC center, when the diagnosis process makes a confusion for the person who conduct the diagnoses process referred children with ASD if there any related sign of disorder and if there any needs of further medical check for the children.

Nehemiah Autism center had a good practice to diagnose children with ASD. However, if parent came to the center with referral paper to get the service, then further diagnosis was made. When result for diagnosing process not satisfied or don't meet with the criteria, then the professional who diagnoses the children refer the children to other profession working at government Hospital or clinics.

4.4 Standardized Tool used to Diagnose ASD at Nehemiah Autism Center

4.4.1 Instrument for parent interview

Interviewing parent is important process to get relevant information about children with ASD. Te interview must be standardized and structured in use. The interview information includes history of the child or young person's pre-natal and developmental history which includes social and emotional factors up to the patient's age at assessment and this should include a detailed enquiry into evidence of any problems at home, school or in other social relationships (SIGA, 2007). To support the information from parents ADI-R (Autism Autism Diagnostic Interview – revised) interview were used by the professional who conduct diagnosing ASD process (SIGA, 2007). The thematic analysis of participant who directly conduct with diagnosing ASD don't use instrument for parent to get strong information about children with ASD. As it practiced by NAC, interviewing parent was made by experience and as a general question. This result that professional who diagnoses ASD lacks the understanding about tool uses for parent interview.

Professional was interviewed about the kinds of tool they used and how familiar they are with the tool. One of the respondents says:

> *"I understand that there are different tools to diagnosis Autism Spectrum Disorder. Practically at this center, I use DSM-4 to diagnosis children."*

The other psychologist responded that DSM-5 was also used by this professional to diagnose ASD. As a result, DSM-4 defined autism and related disorders as 'pervasive developmental disorders' (PDDs). This definition has been replaced in DSM-5 by the term 'autism spectrum disorders' (ASDs)'. In the DSM-4 Autism classified by the category of pervasive developmental disorders included five different subtypes of autism and DSM-5 has replaced four of these subtypes with one central diagnosis, 'autism spectrum disorder' (ASD). Rett syndrome is no longer included in the DSM (Volkmar&Reichow, 2013)

As the finding reveled DSM-4 was used to diagnosis the children. Both professional who involves in the diagnosis used similar tool as it indicate the finding the kinds of instrument used in the practice of Nehemiah Autism center was DSM-5. One of the psychologists who diagnosis ASD children at Nehemiah Autism Center are not skilled in using DSM-5 this revealed that professional must have well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder used this instrument to diagnosis Autism Spectrum Disorder (KCE, 2014). Furthermore, in using both DSM-4 and DSM-5 professional should consider the influence of diversity such as ethnicity, culture, gender, sexuality, religion, socio-economic status, and geographical location (INSiGHT, 2014). In interviewing with the participant at NAC, the thematic analysis question about the uses of instrument as the context of Ethiopia or as it is. From my document analysis the instrument of DSM-4 was used as it is but a small track change was made.

4.4.2 Instrument used for Observation

Observation check list is critical and important to diagnosis ASD this made by professional who provide diagnosing process. Trained professionals used different observation check list to assess

children with ASD behavior. For instance, ADOS (Autism Disorder Observation Schedule) used to observe children with ASD trained professional choose the appropriate module for the individual's age (from 12 months through adulthood) and verbal level (from no words to fluent speech), and follow that protocol of activities using standardized materials(e.g., books, toys), for a semi-structured social interaction (ADOS; Lord et al., 2006). At the NAC observation was made through experience, but those psychologists don't use observation instrument. However, from the response of the participant answer the interview question about if there is any observation used at NAC. A participant of the study states:

> "*Observation made through day to day experience that we had to assess the children activities. We observe the child as a general when he/she actively engages playing with toys, their eye contact and if they had stereotyped behavior and repetitive behaviors."*

The process of assessing a child or adult usually involves a diagnostic instrument tool, designed to ensure consistent application of the diagnostic criteria themselves. To diagnosis Autism Spectrum Observation Schedule(ADOS), was practical in the Europe country this helps comprising'modules' for assessing children of different age groups (Lord et al., 2006).

As the finding of this study, even though those psychologists don't use observation instrument, standardized material is used. This result the strength of NAC practice while observing children with ASD using standardized material is the best methods to follow the children activist and response.

As it is practiced at NAC, observation was made through experience of the psychologist meaning that there is no use of observation instrument to check the children behavior, motor activity and so on.

4.4.3 Nehemiah Practice of using Tools

At Nehemiah Autism Center, instrument that was used to diagnose children with ASD had limited in using different tools and limited in having team of experts. As it is practiced at NAC DSM-4 and DSM-5 was used to diagnose children with ASD. One of the psychologists talks about how she diagnoses children with ASD.

> *"When the child fully shows that behavior as in Autism, then we interpreted that the child is autistic. Then, we look at which level he/ she listed then, we asset the child spastically to the level they supposed to be. Once the child is already set into the level, that means the intervention process is started. For instance, earlier case I had experience with 3 year and ½ came to the center to diagnosis and to get the service. I asked the parent the main concerns of the parent about their child.The parent related to in the lack of social responsiveness including poor eye contact and failure to respond to his name. Since age 3½ years, he has not acquired new vocabulary words or expanded his repertoire of phrases. The child is older than his two sisters. There are no extended family members diagnosed with ASDs or other related disorders. He was born full-term after an uncomplicated pregnancy, labor, and delivery."*

As the response of the psychologist experience in diagnosing ASD, she expressed well about the child's behavior but there is more specificity of the child behavior that needs to be diagnoses through using available and standardized instrument either to interview parents or to observe the children. Hence, the primary purpose of a diagnosis is to provide guidance for intervention. Therefore, professional at NAC doesn't review the instrument they used to diagnosis ASD. The instrument must be revised and needs to contextualize.

CHAPTER SIX

SUMMARY, CONCLUSION, AND RECOMMENDATION

6.1 Summary

In this chapter the finding were addressed in the three main research questions and specific objectives.

- What is the practice of Nehemiah Autism Center in diagnosing ASD?
- What is the knowledge and skills of professionals' involved in diagnosing ASD at Nehemiah Autism Center?
- What kinds of tools available at Nehemiah Autism Center use to diagnosis ASD?

This study has mainly aimed at assessing the practices of Diagnosing ASD at Nehemiah Autism Center. For this purpose, the sample have been drawn from one of Autism center in Addis Ababa from non profit and a nongovernmental organization located at Addis Ababa, Kirkose sub city around Gotera. NAC has a license from Charities and children with ASD. The center has started working since 16th June, 2011 after it got its license on 31th.

The research was a qualitative approach, case study design; the data were collected through semi-structured interview and document analysis, which were analyzed qualitatively using the thematic analysis. Two psychologist were selected those directly involved the diagnosis process. Six teachers were selected for triangulation. From those, two of them had Bachelor degree in psychology.

The finding of the research indicated that Nehemiah Autism Center practice in diagnosing children with ASD practically. There is teacher psychologist who didn't get the chance to involve in the diagnosis process. This result as lack of professional and team of expert to conduct the diagnosis and those who conduct the diagnosis assessment was not qualified in using DSM-4 and DSM-5.

In addition to these, the availability of tools especially observation tools was not found at NAC and parental interview instrument was not available to conduct interview with parent of children with ASD. While the psychologist interviewing parents to get relevant information about their children development, most parents were lack to give the information because of frustration and because of lack of professional counselor not available at the center. In addition to procedure to diagnose children with ASD at NAC reviewing referral were made but not for all children applied.

Finally, based on the result of the study, major conclusion were made and important recommendation were made.

6.2Conclusion

The study targeted on investigating the practice of diagnosing children with ASD at Nehemiah Autism Center. Mainly, the investigation was conducted with personnel who are directly involved in the diagnoses process. On the other hand, this study also indicated the parental understanding and information about the diagnosis process of the place. The practice of diagnosis for children with ASD at Nehemiah Autism Center was revealed showing that there is a good practice, but using two instruments lacks to see the result at the end of the diagnosis. The

study was found that the combine uses of DSM-4 and DSM-5 than single uses of DSM-5 this despite the fact the DSM-4 exhibited more limited diagnostic accuracy than DSM-4.

The process for diagnosing ASD was taking more than 30 minutes while assessing children with ASD. Observation was used to check the child's milestone development through experience. Therefore, standardized instruments for using observation check lists were not practical at Nehemiah Autism center. In the finding of professionals' involvement the practice of Nehemiah Autism Center was involved by two professionals. This study demonstrated the number of professionals who could be involved in the assessment process include pediatricians, psychiatrists, psychologists, speech pathologists, occupational therapists, audiologists and neurologists. Moreover, in this study it was found that medical professionals were involved in the diagnosis process and for further assessment and intervention children were sent to the center and then the center triangulates the result from the medical doctor by assessing the children.

Additionally, the finding of this study indicated that the practice of Nehemiah Autism Center in announcing the parent after the process of the diagnosis end was found that there is no professional counseling provided. Therefore, parents were helped through the experience of the person who does the assessment. As this study analyzed literature to look at other practices it mentioned that the announcement of the diagnosis must be associated with indications for development of a personalized plan of educational and therapeutic intervention. On example of this is that, parents need to be supported during this transition period between the end of the diagnostic process and the effective implementation of the intervention plan co-developed with families.

Generally, this study concluded by assessing the strengths and limitations of the practice of diagnosis of ASD at Nehemiah Autism Center. By using the resources they had the center has helped many children. According to its capacity, it has used professionals in the assessment of diagnosing children, and was found as strength in its practice. The limitation this study found is that the center not using standardized written observation check list.

6.3 Recommendation

Based on the findings of the research and the conclusions made, the following recommendations are forwarded. The center uses of instrument for diagnosis ASD is limited in to DSM-4 and DSM-5. For observation it used through experience which they don't used standardized tool. Therefore, there is different observation check list can use to assess ASD. It recommended using those observation instrument and interview instrument. Autism Diagnosis Observation Schedule (ADOS), Autism Diagnostic Interview, Diagnostic Interview for Social and Communication Disorder or the Developmental, Dimensional and Diagnostic Interview. This highlights the need for dissemination, training and development of multi-cultural, multi-language, cheap, reality-oriented, user-friendly, instruments. It is advisable that the professionals must understand the different tool to diagnosis ASD. In addition, the center provides counseling for parent through experience they don't have professional counseling. Therefore, it is more advisable for Nehemiah Autism Center to provide proper counseling for parent before and after diagnosis. Furthermore, It is recommended that to include multiple professional involved in the diagnosis process so that the professional get clear result. Time duration is a very important to look carefully while diagnosing children with ASD. It recommended that to don't take long waiting time to get the diagnosis service

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APPENDIX A

Addis Ababa University

School of Graduate

College of educational and behavioral studies

Department of developmental psychology

Interview guide

Dear participants, the following interview questions are designed to collect data for MA thesis study on the Practice of Diagnosing ASD at Nehemiah Autism Center. Therefore,1 would like to thank you in advance for your kind cooperation.

Thus, I need to ensure you that the data collected from you will be used to achieve these objectives, not for other purpose. Therefore, your responses are the valuable input to improving the quality of the research study.

Objectives

1. To assess the practice of Nehemiah Autism Center in diagnosing children with ASD.

1. How do parents know about Nehemiah Autism Center and come for the diagnosis service?
2. Do the parents come after they already know that their children have autism or the come without knowing it?
3. When parent came to the center how do they take an appointment for the diagnosis?
4. Do you have a counselor who provides counseling service? If no, how do you treat those parents who feel frustrated after knowing that their children are diagnosed with autism?
5. What procedures do you follow to provide the diagnosis for children with ASD?
6. How long does it take to diagnose a child?
7. Do you have defined or clearly stated the procedures that everyone knows (including the staff) about what to do?

2. **To assess the qualification and skills of professionals involvement in diagnosing of ASD at Nehemiah Autism Center.**

1. What is the professional background or specialty of the staff that are involved in the diagnosis process?
2. When the children come to the center which kinds of professional they see first?
3. If there need further diagnosis where do you referred the children?
4. What kind of format are you using to follow the children's diagnosis?
5. How do you inform the parent that their children have autism?
6. Do medical professionals involve in the diagnosis?

3. To assess the availability of tools that Nehemiah Autism center use to diagnose children with ASD.

1. Do you know the different kind of tools that are applied to diagnose ASD?
2. What kind of tool are you using to diagnose?
3. Why do you choose this tool?
4. Do you contextualize it or using as it is?
5. Do all the professionals use the same tool?
6. How do you interpret the results?
7. Do you apply observation in the diagnosis process?
8. What instruments (tools) do you use to diagnose while observing the child?
9. What do you tell to parents about the results if the diagnosis is not ASD?

APPENDIX B

Addis Ababa University

School of Graduate

College of educational and behavioral studies

Department of developmental psychology

እኔ የአዲስ አበባ ዩኒቨርስቲ ትምህርት ክፍል እና የባህሪ ጥናት ውስጥ የእደገት ሳይኮሎጂ የድህረ ምረቃ ተመራቂ ተማሪ ስሆን በአሁን ስዓት የ መመረቂያ ጽሁፌን በ ማዘጋጀት ላይ እገኛለሁ፡ ፡
የ ጥናቴርዕስ አቲዝምን የ መመረመርሊመድበ ነሂሚያ አቲዝምመፅ ከል፡ ፡
እርሶ ምበዚህ ጥናት እንዲሳተፉተመርጠዋል፡ ፡
እርሶ የሚሰጡትትክክለኛውመረጃ የ ጥናቱውጤታማነ ትአስፈላጊመሆኑን በ መግ ንዘ ብጥያቄዎቹን በ ጥን ቃቄአን ዲ መልሱአጠይቃለሁ፡ ፡ ተሳተፎበእርሶፈቃድላይየ ተመሰረተነ ው፡ ፡
በ መጨረሻምየ ሚሰጡትመረጃሚስጥራዊነ ቱየ ተጠበቀእና የ ዘህ ጥና ትአላማብቻእን ደሚውልአረጋግጣልሁ፡ ፡

ዓላማዎች

1. **የነህምያ አቲዝም ማዕከል አቲቲም ልጆችን የመመርመር ልመዳቸውን ለመገምገም::**

   - **ወላጆች ስለ ነህምያ አቲዝም ማዕከል □እና ስለሚሠጠው የምርመራ አገልገሎት□እንዴት አውቀው ይመጣሉ?**
   - **ወላጆች ልጆቻቸው አቲዝም □እንዳላቸው አስቀድመው አውቀው ነው የሚመጡት?**
   - **ወላጆች ወደ ነህምያ አቲዝም ማዕከል ሲመ□□እን□ትነው ለምርመራ ቀጠሮ የሚይዙት?**
   - **በነሂሚያ አቲዝም ማዕከል ውስጥ የምክር አገልግሎት የሚሰጥ አማካሪ አለዎት? አይደለም ከሆነ ልጆቻቸው በኢቲዝም መያዛቸውያወቁ ወላጆች □እንዴት ነው የሚታገዙት?**
   - **አቲዝም ልጆችን ለመመርመር ምን አይነት ሂደቶትን ትከታተላላችሁ?**
   - **አንድ ልጅ ለመመርመር ምን ያህል ጊዜ ይወስዳል?**
   - **ሰራተኞች የሚወስዳቸውአሰራሮች በትክክል ገልጸዋል ወይም ግልጽ አድርገዋል?**

2. **በነህምያ አቲዝም ማዕከል ያሉባለሙያዎች በ አቲቲም ምርመራ ላይ ያላቸው ተሳትፎ ለመ□□ም::**
   - **በምርመራው ሂደት ውስጥ የሚሳተፉ ሰራተኞች ሙያዊ ዳራ ወይም ልዩ ሙያ ምንድን ነው?**
   - **ልጆች ወደ ማዕከሉበሚመጡበት ጊዜ በመጀመሪያ የሚያዩትባለሙያ ምን ሙያ አለው?**
   - **ለተጨማሪ ምርመራ ልጆችን ወዲት ይላከሉ?**
   - **ልጆችን ለመመርመር ምን አይነት ሙያዊ ቅርጽ ይ□ዉ□የተጠቀሙ ነው?**

- እንዴት ነው ለወላጆች ልጆቻቸው ኢቲዝም □እንደሆኑ የሚያሳውቋቸው?
- የሕክምና ባለሙያዎች በምርመራው ውስጥ□እንዴትጁሳተኛሉ?

3. በነህምያ ኦቲዝም ማዕከል ውስጥኦቲቲምልጆችን ለመመርመር መደበኛ የሆነ ለምርመራ የሚጠቀሙት መሳሪያ ለመገምገም::

- እንደባለሙያ ተግባራዊ የሆኑ የተለያ የኦቲቲም መመርመሪያ መሳሪያዎች ያዉቃሉ?
- በምርመራው ክትትል ውስጥ ልጁን ለመመርመር ምን አይነትመሳሪያዎችን ይመቀማሉ?
- ይህን መሳሪያ ለምን የመርጣሉ?
- የሚጠቀሙት መሳሪያ በአግባቡ ይረ□ል ወጁስእንዳምጣጡ ነው የሚጠቀሙበት?
- በማዕከሉ ያሉ ሁሉም ባለሚያዎች ተመሳሳይመሳሪያ ይመቀማሉ?
- የምርመራውን ውጢት □እንዲት ትተረጉሙታላችሁ?
- በምርመራው ሂደት ውስጥበምን አይነት መንገድ ክትትል ይደረጋል?
- የምርመራው ውጤት ኦቲዝም ጸልሆነ ስለ ውጤቱ ለወላጆች ምን ይነግሯቸዋል?

APPENDIX C

Addis Ababa University

School of Graduate

College of educational and behavioral studies

Department of developmental psychology

Key point for Document review

1. Referral paper of children from the hospital

2.Personal profile of children on their diagnosis

3. Educational background and filed of specialization of teachers and the diagnosis and assessment providers.