

AUTISM CARE AND TREATMENT: SERVICES, CHALLENGES AND PROMISING
PRACTICES IN ETHIOPIA



PREPARED BY:

CLEOPATRA LEGESSE

A Thesis Submitted to the School of Graduate Studies of the Addis Ababa University in Partial
Fulfilment of the Requirements for the Degree of Masters of Arts in Special Needs Education

ADDIS ABABA, ETHIOPIA

June 2018

ADDIS ABABA UNIVERSITY
COLLEGE OF EDUCATION AND BEHAVIORAL STUDY
DEPARTMENT OF SPECIAL NEEDS EDUCATION

Autism care and treatment: Services, challenges and promising practices in Ethiopia

A Thesis Submitted to the School of Graduate Studies of the Addis Ababa University in
Partial Fulfillment of the Requirements for the Degree of Masters of Arts in Special
Needs Education

BY:

CLEOPATRA LEGESSE

Under the Advisor ship of Belay Hagos(PhD)

Declaration

I, the undersigned, declare that this thesis is my original work, has not been presented for a degree in any other university and that all sources of materials used for the thesis have been dully acknowledged.

Declared by:

Name: Cleopatra Lesesse

Signature: Cleopatra Lesesse

Date: 06/27/2018

Addis Ababa University
School of Graduate Program
College of Education and Behavioral Study
Department of Special Needs Education

Autism care and treatment: Services, challenges and promising practices in Ethiopia

By: Cleopatra Legesse Gultie

Approved by the examining Board:

Prof. Tirussew Teferra
Chairman, Department Graduate Committee


Signature

Belay Hagos (PhD)
Advisor


Signature

Approval of Examiners:

Name: Tilahun Achaw (Dr.)
Internal Examiner

Signature  June 28, 18

Name: Teka Zewdie (Dr.)
External Examiner

Signature  28-06-18

Table of Contents

Abstract.....	vii
CHAPTER ONE: INTRODUCTION.....	1
1.1 Background.....	1
1.2 Nia Foundation Joy Center	2
1.3 Nehemiah autism center.....	2
1.4 Rationale of the study	3
1.5 Research questions:.....	4
1.6 Scope of the study	5
1.7 Significance of the study.....	5
1.8 Ethical Considerations	6
CHAPTER TWO: REVIEW OF RELATED LITERATURES	7
2.1 Definition	7
2.2 History of autism.....	7
2.3 Causes and Symptoms of Autism	9
2.4 Theories on Autism.....	11
2.4.1 Refrigerator Parenting Hypothesis (RPH)	11
2.4.2 Genetic Theories (GT)	11
2.4.3 Theories of Mind (TOM) and Mind-Blindness	11
2.4.4 Empathizing Systemizing (E-S) Theory	12
2.5 Treatment of autistic disorder	12
2.5.1 Psychodynamic Treatment.....	13
2.5.2 Drug Treatment.....	13
2.6 Interventions for children with autism.....	14
2.7 Autism program quality indicators	15
2.8 What is a “Best Practice”?	17
2.9 Criteria for Selection of “Best Practices”	18
2.10 The nature and magnitude of the problem in Ethiopia: Review of empirical works	19
CHAPTER THREE: RESEARCH METHODOLOGY	22

3.1 Research Design.....	22
3.2 Study population sand sampling frame.....	22
3.3 Sampling technique and sample size	22
3.4 Data collection instruments and data collection methods.....	23
3.5 Validity and reliability of data collection tools.....	23
3.6 Procedures of data collection	24
3.7 Data analysis	25
CHAPTER FOUR: DATA PRESENTATION, ANALYSIS AND DISCUSSION.....	26
4.1 Study participants’ demographic and socio-economic characteristics	26
4.2 Seeking help and Initiation of service delivery.....	26
4.3 Reaction and response of caregivers to diagnosis findings	27
4.4 The nature and process of the services provided	28
4.5 Autistic care and treatment practice.....	31
4.6 Diagnosis, assessment and intervention planning practices at Nia Foundation-Joy center and Nehemiah Autism Center.....	31
4.6.1 Individual evaluation	31
4.6.2 Personnel.....	33
4.7 Partnership and collaboration with community and other actors.....	34
4.8 Methods of teaching and promising practices of Nia Foundation-Joy center and Nehemiah Autism Center	36
4.9 Inclusion.....	39
4.10 Review, monitoring or progress and outcomes- Evidence generation	39
4.11 Challenges experienced by Nia Foundation-Joy center and Nehemiah Autism Center in delivering service to children with autism and their families	40
CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS	43
5.1 Summary and conclusion.....	43
5.2 Recommendations.....	45
Reference	47
Annex I: Data collection tools	52
Annex II: AUTISM PROGRAM QUALITY INDICATORS	56

Abstract

Autistic syndrome disorder is being revealed as one of the major problems in Ethiopia in recent years. Nia Foundation Joy Center and Nehemiah autism center are the major actors in the provision of support for children with Autistic syndrome disorder and their families. This study was conducted to assess autism care and treatment service provision practice of existing service providers in light of widely recommended practices and evidence based programming in Ethiopia. The study adopted a cross sectional descriptive study involving 42 people selected purposively from teachers, professionals, parents and the centers management body. The research was qualitative in nature. The findings of the study revealed that the service packages of the organizations are giving training on the area of autism and treating Autistic children. The centers also provide counseling and training services to parents and family members including skill trainings. However, the services are primarily limited to awareness creation and consultation on major issue based on the initiation from the parents/caregiver. The services are guided by the individual knowledge and experience of the program managers rather than via a standardized manuals, guidelines and curriculum. The physical environment of the centers is good but very limited in terms of technology application and space adequacy. Demonstration, positive reinforcement and use of tangible things in teaching the children were found to be effective. The programs of both centers fail to be inclusive in the sense of facilitating interaction with nondisabled children. Lack of a supportive environment, low level of public awareness about the issue, absence of well proven effective remedies to autism, shortage of knowledgeable and skilled human resource were indicated to be major challenges. Increasing public awareness and advocacy for expansion of service and academic institutions training program, enhancing the involvement of spiritual leaders, leveraging with other actors via partnership and collaboration were suggested for improved impact. Besides, strengthening the review, monitoring and evaluation of the interventions are recommended to come up with evidence based programming.

CHAPTER ONE: INTRODUCTION

1.1 Background

Autism is a neurodevelopmental disorder that challenges families and professionals to find effective interventions that can improve the lives of individuals with autism spectrum disorders. Due to the difficulty in finding interventions that work and that are readily available regardless of geographic location or financial resources, the field has nurtured many popular interventions that lack support from scientific research. At the same time, each child or adult with autism is unique. Nevertheless, the call for the use of interventions that have proven their effectiveness is particularly important for the Autism Spectrum Disorders (ASD) community, which has long been plagued by the use of unsupported and often controversial interventions (Weiss, Fiske, & Ferraioli, 2008).

In Ethiopia Autism has been a neglected issue for long. Developmental disorders such as autism are regarded as an evil-spirit phenomenon in most parts of the country (Sara, 2014). There is no organized data on the number of children with autism. One estimate by Nia foundation in 2002 show the number could be as high as 500, 000 (Mahlet, 2016). Few non-governmental organizations are providing service to children affected by autism. These are Nia Foundation-Joy center and Nehemiah Autism Center. Both are located in Addis Ababa, the capital city of Ethiopia.

A number of reports conducted on these institutions show that the children with autism as well as their family members are benefiting in a number of ways from the services. However, the studies are primarily focused on understanding the challenges in relation to psychological, social, economic, marital and sibling aspects and coping mechanism of families living with a child diagnosed with autism. Studies that deal with the nature and process of the service provision in light of widely recommended practices are in dearth in the literature.

In view of this, this study intended to assess the service provision of the autism centers and identify the challenges and promising practices of the centers. This analysis was undertaken

within the framework of evidence based interventions and practices. The study was instrumental in identifying areas of improvement and promising practices in the general effort of improving the life quality of children with autism and their families. Besides, it will add value to the empirical literature by portraying the autism service practice in Ethiopia.

1.2 Nia Foundation Joy Center

The Foundation's name, "Nia," originally comes from an Arabic word meaning "good intentions." In Tigrigna (one of Ethiopia's major languages), the name of our Executive Director's beauty and modeling school, Niana, means 'our intention.' In Afaan Oromo (another Ethiopian language), the term can be translated as both "let's move ahead" and "I care about you." The Foundation was established in 2002, in realization of the great demand for autism treatment in Ethiopia. It started with four kids at the center. It now accommodates around eighty children with autism (Nia Foundation, 2018)

The goal of the foundation reads as "to move ahead and to do so with the many spiritual, cultural, and progressive meanings that the word itself carries, in all of the languages in which it is found". Embodying the humanitarian senses of the word, Nia, operates with positive purpose and with a vision to move towards the development and the well-being of children and youth; regardless of their different abilities, their disabilities and vulnerabilities (Nia Foundation, 2016).

It promotes a fertile and high quality life for its students, by encouraging them to develop great aspirations for themselves, their families, communities, their country and the world. Through education, rehabilitation, vocational training, and leadership development, Nia Foundation strives to empower and inspire children, youth, women, and men (Nia Foundation, 2016).

1.3 Nehemiah autism center

Nehemiah Autism Center is a non-profit and a non-governmental organization. It has a license from Charities and Societies Agency, which is a concerned governmental office. It started work on Jun 16, 2011. Nehemiah Center aspires to see every ASD child is cared for, parents of ASD children are supported and awareness about autism created in the society. Nehemiah Center's

mission is to provide care, instruction and support for children with autism and related disabilities - promoting cognitive, emotional and relational growth through individualized programs, while providing counseling and support to parents, especially mothers as they deal with these particularly difficult challenges; teaching the parents to become active participants in their child's education and development; and finally, to raise public awareness of the nature and prevalence of Autistic Spectrum Disorders.

At the moment it is giving training and treating Autistic children at its facility in Addis Ababa. The center does not charge a fee for treating children. Out of all the children it accepted which are 40 in number, 60 percent of the autistic children are from poor families. Nevertheless, it accept contributions from parents based on only their willingness. It also provide transportation free of charge for those families who can't afford to send their autistic children to the center due to the reason that it is difficult to use public transport for these kind of children.

1.4 Rationale of the study

Autism as developmental disorder did not receive due attention it deserves in Ethiopia. This could easily be inferred from lack of any policy or program by the government to address the issue. The efforts are very limited to two formally registered non-governmental organizations and ad hoc efforts of individuals. The two prominent actors in this regard are Nia Foundation-Joy center and Nehemiah Autism Centers which mainly operate in Addis Ababa. These organizations are endeavoring to improve the life qualities of autistic children and their families. Yet, the organizations are operating in a context where there is no framework for autism care and treatment in the country. In addition with the current global trend to pursue use of empirically supported effective interventions and best practices, the lack of such research works in Ethiopia makes the practice challenging (Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. ,2016; Merssa, 2014; Aynalem, 2014). The few available studies on autism in Ethiopia did not deal with the issue. The studies mainly are dealing with the prevalence, the challenges and coping strategies of families with autistic children. Very few assessed directly the challenges the children experience in primary school settings. The practice

of the care by the two leading organization in the care for autistic children is not analyzed systematically. This knowledge gap poses a significant challenge in programming for effective interventions aimed at improving the lives of the children affected and their respective families.

1.5 Research questions:

The study attempted to answer the following research questions

- What is the nature and process of the services provided by Nia Foundation-Joy center and Nehemiah Autism Center
- To what extent are the interventions of the Nia Foundation-Joy center and Nehemiah Autism Center informed or aligned with recommended and evidence based interventions for children with autism and their families
- What are the promising practices of Nia Foundation-Joy center and Nehemiah Autism Center?
- What are the challenges experienced by Nia Foundation-Joy center and Nehemiah Autism Center in delivering service to children with autism and their families?

1.5 Research Objectives

1.5.1 General Objective

The general objective of the study is to assess the Nia Foundation-Joy center and Nehemiah Autism Centers service provision in light of widely recommended practices and evidence based programming. The study also intends to identify promising practices and challenges in the delivery of service for children with autism and their family members.

1.5.2 Specific Objectives:

- Identifying the types of interventions and services provided by Nia Foundation-Joy center and Nehemiah Autism Center

- Determine the degree to which the interventions and services the Nia Foundation-Joy center and Nehemiah Autism Center are aligned with recommended and evidence based interventions for children with autism and their families
- Identify promising practices of Nia Foundation-Joy center and Nehemiah Autism Center
- Identify the challenges experienced by Nia Foundation-Joy center and Nehemiah Autism Center in delivering service to children with autism and their families
- Generate evidence for evidence based programming

1.6 Scope of the study

The study was conducted in Addis Ababa. Nia Foundation- Joy center and Nehemiah Autism Center are the only two organizations which have service facilities for children with autism and are providing service as key actors. Consequently, the study covered the two institutions. The study was limited to the interventions and services packages of the organizations, the extent to which their interventions and activities are informed by evidence based interventions, identification of best practices and challenges of working on autism.

1.7 Significance of the study

The study will have practical importance in laying the foundation for evidence based interventions in the general effort of caring for children with autism and supporting their family members. This will be mainly realized via the mapping of the existing interventions and services against the evidence based interventions and identification of new promising practices supported with evidence. The results of the study will also be instrumental as an advocacy input in influencing policy makers including Ministry of Education (MOE), Ministry of women and children and Ministry of Health(MWCMH). Yet, the significance will be the organization working on autism care as an input for their refinement of their programs and appreciation of evidence based interventions.

1.8 Ethical Considerations

The study was conducted in a transparent manner. Approval was sought from the organizations management to undertake the study with a full disclosure of the study process and potential benefits and implications. All participants of the study were informed about the nature of the study and were requested for their consent to participate. This is primarily meant for the parents or caregivers of the children with autism. Only those potential respondents who gave their consent of participation without pressure participated in the study. The data that were collected were only used for the study purpose. Individual identifiers like name were are changed in the report to protect the key informants. The researcher is also committed to report the research findings in a complete and honest fashion, without misleading others about the nature of the findings.

CHAPTER TWO: REVIEW OF RELATED LITERATURES

2.1 Definition

Autism is diagnosed on the basis of abnormalities or impaired development in three areas of expected development milestones. Social interaction, communication, and a severely restricted repertoire of activity and interests, present before the age of 3 (American Psychiatric Association, 2013). Under IDEA, autism is defined as...”a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child’s educational performance. Autism is a neurodevelopment disorder defined by impairments in social and communication development, accompanied by stereotyped patterns of behavior and interest (Landa, 2007). Autism is pervasive developmental disorder characterized by lack of normal sociability, impaired communication and repetitive obsessive behavior such as politeness, turn-taking (Young & Nettlebeck , 2005). Linked to Profound Learning Disability (PLDs) are further impairments in the production of speech. Among these are (i) personal pronouns reversal for instance the use of “I” instead of “you” and vice-versa, (ii) the misuse of such prepositions as “in”, “on”, “under”, “next to” (...), and (iii) the prevalence, in speech, of echolalia formal repetition of other’s utterances (Arron and Gittens, 1999).

Children with autism vary literally in their use of words, (Rutter, 1966). Communication deficiencies may leave a lasting mark of social retardation on the child. The link, between social skills and language is made evident by the often spontaneous appearance of affectionate and dependent behavior in these children after they have been trained to speak (Churchill, 1966 & Hewett, 1965).

2.2 History of autism

The word autism was coined from the Greek word “autos” meaning self. Various scholars used the concept of autism linking it to other mental health issues such as schizophrenia. The term was first used to describe behavior in 1943 by Leo Kanner, a child psychiatrist at John Hopkins University (Ozonoff, Dawson, & Mcpartland, 2002). The study Kanner conducted with children

revealed clinical conditions such as being aloof and having a language difficulty manifested at an early age of 3 which he termed as infantile autism (Kita & Hosokawa, 2010). The term ‘early infantile autism’ was used to describe the unusual patterns of behavior observed in young children that were characterized by severe impairment in social interaction and communication and an intense resistance to change. Infantile autism is identified by Kanner as a distinct diagnostic entity for description of eleven children seen at Johns Hopkins University. All the eleven children were unable to develop normal relationships with people (‘extreme autistic aloofness’). In behavioral categories, they were different from the general child clinical population. With normal physical appearance, the children showed delay in speech development, engaging in repetitive and stereotyped play activity ...etc in very early infancy (Keenan, Dilenburger, Doherty, Byrne, & Gallagher, 2007).

Currently, mental health professionals define autism as per the Diagnostic and Statistical Manual of Mental Disorders (DSM) fifth edition prepared by the American Psychiatric Association. With the emergence of more research about the symptoms of autism, the definition of autism has been revised. The DSM (Diagnostic and Statistical Manual has updated several diagnostic criteria of autism and other mental disorders. The first and second publications of DSM published in 1952 and 1968 respectively classified autism under a mental disorder termed as a schizophrenic reaction of childhood type that is characterized by symptoms such as disturbances in reality, stream of thought and intellectual abilities. The third publication of DSM provided more tangible diagnostic criteria than the previous two publications. This publication categorized autism under disorders of infancy, childhood and adolescence (American Psychiatric Association, 1980). The fifth edition of DSM classifies autism under a group of neurodevelopmental disorders and describes the diagnostic features of autism as impairment in social interactions and communication skills. Impairment in social interactions includes abnormal use of non-verbal behaviors, lack of developing peer relationships, lack of regards for others, etc. Impairments in communication skills involve delay or lack of spoken language development, inability to sustain conversation, use of stereotyped and repetitive language (American Psychiatric Association, 2013). This edition of DSM uses the term autism spectrum disorder. This term is an umbrella term that includes four separate disorders; autistic disorder, asperger’s disorder, childhood disintegrative disorder and the catch-all diagnosis of pervasive

developmental disorder.

2.3 Causes and Symptoms of Autism

The exact cause of autism is unknown by scientists, but gene and environmental factors are suggested by researchers as an important role player (National Institute of Mental Health [NIMH], 2011). Research has shown that autism tends to run in families. Among identical twins, if one child has autism, then the other is likely to be affected 75-90% of the time. Parents who have a child with an ASD have a 2-10% chance of having a second child who is also affected. Some parents worry that vaccines cause autism, but the scientific evidence does not support this theory. There is some evidence that exposure to factors in the environment (such as viruses or infections) may play a role in causing some forms of autism. It is important to recognize that autism is a brain based disorder and is not caused by inadequate parenting; however, parents can play an important role in planning and carrying out interventions after an ASD is identified (Lindgren & Doobay2011).

Although various factors are believed to cause autism, the etiology of autism is not clearly understood. Several theories have been proposed by scholars about the causes of autism in the past. The most widely known theory was termed as “refrigerator mothers theory” that was proposed by Leo Kanner in the 1940s. According to Kanner, autism may be triggered by the lack of maternal attachment that mothers fail to provide to their infant (Cook & Willmerdinger, 2015). Following the foundation laid by Kanner, Bruno Bettelheim provided an explanation for the theory and proposed psychological factors, stating that specifically mothers who are unloving towards their infant are the main cause of autism. Bettelheim also stressed out that providing therapy to both the mother and the child can improve the situation (Martin, 2012). In today’s time, this theory has been discredited in various publications that studied other factors such the biological causes of autism. However, some studies still argue that most of the studies on this topic report mothers as being responsible for the birth of a child with autism.

Connotations such as ‘autism mothers’ has played a widespread role in blaming mothers for the situation of their child (Douglas, 2014). Douglas also argues that the parental blaming approach that started with the “refrigerator mother theory” still continued to create other forms of burdens

and blames on mothers of today.

Children with autism display certain characteristics that are observed as symptoms of autism by parents. Among the characteristics that are mostly observed are impairments in social interactions and communication skills, repetitive patterns of behavior, interests and activities (Blumberg, 2013). According to the publication of National Institute of Mental Health, symptoms of autism may differ from one child to another. However, the generally accepted symptoms can be categorized into social impairment, communication difficulties and repetitive stereotype behaviors (National Institute of Mental Health, 2011). In addition to the characteristics mentioned above, there are cases where autism in children co-occurs with other neurological disorders such as epilepsy.

Tuchman, Cuccaro, and Alessandri (2010) discussed the historical views regarding the co-occurrence of epilepsy and autism. Although there are cases where epilepsy and autism co-occur, providing a clear explanation regarding their association is a challenge. It is still not clearly identified if one disorder causes the other or if there are specific genes responsible for the occurrence of each of these two disorders. Other studies also mention the prevalence of other disorders such as epilepsy and intellectual disability in children with autism. Viscidi (2013) also support that intellectual disability and epilepsy co-exist with autism. In children with autism, the onset of epilepsy was recorded to be higher in the first year of life. With the increment of age, the prevalence of epilepsy in children with autism also increases.

The majority of studies on the causes of autism and the criteria set to identify its symptoms have been documented in developed countries. Only a few studies addressed the causes and symptom of autism in developing countries. Ametepee and Chitiyo (2009) mentioned, that the onset and causes of autism in Africa may not necessarily fit the criteria set in developed countries. They suggest that extensive research should be done to address autism in an African context. There are less studies about the extent of the problem in an African context and studies found in sub Saharan countries are very scarce (Bakare and Munir, 2011). In Africa, Bakare and Munir (2011) mention that traditional herbalists and spiritualists play a major role in treating illness while it is medical professionals that treat illness in developed nations. Such differences in medical

treatment approaches between African nations and developed nations make it a challenge to apply the diagnostic criteria set in developed countries as standard criteria to diagnose children with autism in Africa.

2.4 Theories on Autism

2.4.1 Refrigerator Parenting Hypothesis (RPH)

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

2.4.2 Genetic Theories (GT)

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

2.4.3 Theories of Mind (TOM) and Mind-Blindness

The most influential theory of autism in recent years maintains that what all autistic people have in common (the core deficit) is mind- blindness (Boron-Coher, 1993). A sever

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

2.4.4 Empathizing Systemizing (E-S) Theory

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

2.5 Treatment of autistic disorder

Educational programs for autistic children usually try to relieve their symptoms and improve their communication, social skills, and adaptive behavior, so that they can become more independent. Autistic children have several problems that make teaching difficult, however. First, they do not adjust normally to changes in routines, including special events and substitute teachers. Second, their behavior problems and self-stimulatory movements may interfere with effective teaching. Although the similar behavior of children with other disabilities may interrupt on the teacher's efforts. Third, it is particularly difficult to find reinforces that motivate autistic children. 'Normal' children (who are not autistic) like to explore and control their surroundings, but not children with autism. For reinforces to be effective with autistic children, they must be

explicit, concrete, or highly salient. A widely used method of increasing the range of reinforcers that autistic children respond to is to pair social reinforcement with primary reinforcers such as food (Lovaas, Koegel, Simmons, & Long, 1973).

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

2.5.1 Psychodynamic Treatment

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

2.5.2 Drug Treatment

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

2.6 Interventions for children with autism

2.6.1 Need for Evidenced-Based Interventions

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

2.6.2 Identifying Effective Interventions

One major barrier to the adoption of evidenced-based practices for autism spectrum disorder is the lack of consensus on how to identify and evaluate scientifically valid and effective interventions. According to the No Child Left Behind Act of 2001 (NCLB), “scientifically based research” is defined as “research that involves the application of rigorous, systematic, and objective procedures to obtain reliable and valid knowledge” (NCLB, 2002). For a practice to be judged as scientific, it must meet particular standards, reliably yield positive results, and survive a rigorous peer review process. In addition, scientifically based practices are validated by means of specific “gold standard” research designs that include random samples of subjects that are assigned to control and experimental groups or a series of replications of well-controlled studies using rigorous single-subject designs. However, the scientific method of validation has sometimes been criticized as being too narrow and as having a negative effect on ASD research because of the methodological restrictions that make this type of research difficult to conduct in

many real-life settings. The following guidelines (Simpson, 2005) provide a balanced perspective for evaluating ASD interventions:

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

2.7 Autism program quality indicators

The Autism Program Quality Indicators (APQI) are a compilation of the best practices in educating students with autism, which were developed to serve as a means of guiding quality improvement activities for schools and programs serving children with autism. The APQI are organized into the following 14 areas with the seven categories relating to the specific aspects of the educational process for students, and the seven categories in the right-hand column referring more broadly to program characteristics and supports (New Jersey Department of Education, 2004).

- Individual Evaluation: Thorough diagnostic, developmental, and educational assessments using a comprehensive, multidisciplinary approach are used to identify students' strengths and needs.
- Development of the Individualized Education Program (IEP): The Committee on Preschool Special Education (CPSE) and the Committee on Special Education (CSE) use evaluation results, parent and family concerns, and present levels of performance in developing individualized education programs (IEPs) to meet students' needs.
- Curriculum: The program uses a curriculum that addresses the significant skill deficits of students with autism and relates to the New York State Learning Standards.
- Instructional Activities: The program provides a variety of developmentally and functionally appropriate activities, experiences, and materials that engage students in meaningful learning.
- Instructional Methods: Teaching methods reflect the unique needs of students with autism and are varied depending on developmental appropriateness and individual strengths and needs.
- Instructional Environments: Educational environments provide a structure that builds on a student's strengths while minimizing those factors that most interfere with learning.
- Review and Monitoring of Progress and Outcomes: The program uses a collaborative, ongoing, systematic process for assessing student progress.
- Family Involvement and Support: Parents are recognized and valued as full partners in the development and implementation of their children's IEPs.
- Inclusion: Opportunities for interaction with nondisabled peers are incorporated into the program.
- Planning the Move from One Setting to Another: Parents and professionals work collaboratively in planning transitions from one classroom, program, or service delivery system to another.
- Challenging Behavior: Positive behavior supports, based on a functional behavioral assessment (FBA), are used to address challenging behavior.
- Community Collaboration: The program links with community agencies to assist families in accessing supports and services needed by students with autism

- Personnel: Teachers, teacher aides and assistants, related service providers, school psychologists, administrators, and support staff are knowledgeable and skilled related to the education of students with autism.
- Program Evaluation: Systematic examination of program implementation and impact is conducted, including the aggregation of individual student outcomes and consumer satisfaction.

The items contained within the APQI do not reflect specific instructional strategies or theoretical approaches. Instead, they reflect methods that have consistently been found to be effective in improving learning in children with autism. Additionally, where items reflect practices that are broadly appropriate to educating all children (e.g., involving and supporting families in the educational process), the APQI focus on those aspects most important for educating students with autism (New Jersey Department of Education, 2004).

2.8 What is a “Best Practice”?

A “Best Practice” is commonly defined as “a technique or methodology that, through experience and research, has proven reliably to lead to a desired result Best Practices. (n.d.). The term is used frequently in areas such as health, government administration, the education system, project management, and others. In the context of health programs and services, a practical definition of a “Best Practice” is “knowledge about what works in specific situations and contexts, without using inordinate resources to achieve the desired results, and which can be used to develop and implement solutions adapted to similar health problems in other situations and contexts”.

The use of the word “best” should not be considered in the superlative sense. In other words, the term “Best Practice” is not about “perfection”, the “gold standard” or only elements that have been shown to contribute towards making interventions work or successful (WHO, 2008). Results can be partial and may be related to only one or more components of the practice being considered. Indeed, documenting and applying lessons learned on what does not work and why it does not work is an integral part of “Best Practice” so that the same types of mistakes can be avoided by other programs and projects.

There are several creative and constructive actions by people and organizations in the health sector to improve health outcomes of people. Making knowledge of such actions widely available may prevent the repetition of mistakes and loss of valuable time. Thus, the main rationale for documenting and sharing “Best Practices” is to enable persons and organizations working in the health sector to avoid “re-inventing the wheel”; to “learn in order to improve performance” and; to “avoid the mistakes of others”. Documenting and sharing “Best Practices” affords one the opportunity to acquire knowledge about lessons learned and to continue learning about how to improve and adapt strategies and activities through feedback, reflection and analysis in order to implement larger-scale, sustained, and more effective interventions. A commitment to using a “Best Practice” is a commitment using the body of knowledge and technology at one’s disposal to ensure success.

2.9 Criteria for Selection of “Best Practices”

Identifying “Best Practices” involves judgement. Such judgements require prior analysis using the following set of criteria: effectiveness, efficiency, relevance, ethical soundness, sustainability, possibility of duplication, partnership, community involvement, and political commitment.

Effectiveness: This is a fundamental criterion implicit in the definition. The practice must work and achieve results that are measurable.

Efficiency: The proposed practice must produce results with a reasonable level of resources and time.

Relevance: The proposed practice must address the priority health problems in the WHO African Region.

Ethical soundness: The practice must respect the current rules of ethics for dealing with human populations.

Sustainability: The proposed practice must be implementable over a long period of time without any massive injection of additional resources.

Possibility of duplication: The proposed practice, as carried out, must be replicable elsewhere

Involvement of partnerships: The proposed practice must involve satisfactory collaboration between several stakeholders.

Community involvement: The proposed practice must involve participation of the affected communities.

Political commitment: The proposed practice must have support from the relevant national or local authorities.

By definition, a “Best Practice” should meet at least the “effectiveness”, “efficiency” and “relevance” criteria in addition to one or more of the other criteria. A “Best Practice” needs not meet all the above criteria. This is because a “Best Practice” can be anything that works to produce results without using inordinate resources, in full or in part, and that can be useful in providing lessons learned (WHO, 2008).

2.10 The nature and magnitude of the problem in Ethiopia: Review of empirical works

There are some empirical works on autism in Ethiopia. Wajira (2014) investigated the dominant autistic behavior among the school children in Jimma Town. The study showed that the prevalence of autism spectrum disorder to be 33 out of 10,000 school age children. In the study he used different developmental traits against DSM-5 diagnostic criterion and checked for 1) presence of symptom at early developmental period 2) developmental impairment in three areas, including impairment in social, communication & repetitive behaviors.

Sara (2014) studied the learning problems of children with autism and the challenges in the teaching process. The study was conducted on Nia Foundation-Joy Center for children with autism. The results of the study showed that the children with autism have learning problems related to their social behavior, communication and attention problems and insistence on maintenance of sameness. The study also reveals that the teachers face challenges of managing behaviors of the children, like repetitive and stereotypic behaviors in the teaching process. Lack of parents’ cooperation is also the other challenge the teachers mentioned. The study also shows that the teachers employ reinforcement as the main technique of teaching the children. They also use visual methods of teaching and storytelling.

Aynalem (2014) analysis of challenges of living with a child diagnosed with autism and related coping mechanisms revealed that families of autistic children experience a number of challenges. The finding showed that 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. In her conclusion and recommendation the author calls for the provision of psychosocial support and awareness creation in the area of disabilities particularly autism.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016) study on the stigma experiences, explanatory models, unmet needs, preferred interventions and coping mechanisms of caregivers of children with developmental disorders in Ethiopia showed related findings. The result showed that most caregivers experience stigma: 43.1 % worried about being treated differently, 45.1 % felt ashamed about their child's condition and 26.7 % made an effort to keep their child's condition secret. In connection to this, it was also noted that the stigma did not depend on the type of developmental disorder, the child's age or gender, or on the age or level of education of the caregiver (all $p > 0.05$). Besides, the reported stigma was significantly higher in caregivers who had sought traditional help ($p < 0.01$), provided supernatural explanations for their child's condition ($p = .02$) and in caregivers of Orthodox Christian faith ($p = .03$). The authors indicated as the biggest reported unmet need was educational provision for the child (74.5 %), followed by treatment by a health professional (47.1 %), financial support (30.4 %) and expert help to support their child's development (27.5 %). Most caregivers reported that talking to health professionals (86.3 %) and family (85.3 %) helped them to cope. Many caregivers also used support from friends (76.5 %) and prayer (57.8 %) as coping mechanisms.

Mahlet (2016) explored the experiences of parents raising a child with autism in Ethiopia and found that the major stressors were the lack of awareness about autism in the society and the lack of facilities designed for children with autism. In relation to positive resources, she indicated that Joy center and Nehemiah center were the two organizations with major resources. Some parents participated in the study reported financial stability as being an important resource. In addition to external resources, parents highlighted that full acceptance of their child's situation is the most important resource in their coping process. Several of the participants can be said to have built a

strong sense of coherence, which is related to the strong belief that they will overcome various types of stressors and build a healthy lifestyle.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Research Design

The study applied a cross sectional descriptive type of study. The research design is preferred based on the purpose of the study; describing the organizations interventions, best practices, challenges and the extent to which they apply evidence based interventions. The major purpose of descriptive research is description of the state of affairs as it exists at present. The main characteristic of this method is that the researcher has no control over the variables; he can only report what has happened or what is happening (Kothari, 2014). It was primarily qualitative in approach.

3.2 Study population and sampling frame

The population of the study were Nia Foundation-Joy center and Nehemiah Autism Center. The children getting services from the autism centers and their parents or caregivers as well as the employees were considered as part of the organization and considered accordingly. The same was true for the employees of the organization. In view of this, the sampling frame was the list of employees of the centers and the list of children getting service at the center-as an entry point for the selection of the parents or caregivers as appropriate. Besides, a complete enumeration of the physical facilities and infrastructures of the centers were undertaken.

3.3 Sampling technique and sample size

The key informants were selected purposively i.e. based on their involvement in the management and service provision of the centers. Some types of research design necessitate researchers taking a decision about the individual participants who would be most likely to contribute appropriate data, both in terms of relevance and depth (Paul, 2005). The purposive sampling technique is a type of non-probability sampling that is most effective when one needs to study a certain cultural domain with knowledgeable experts within. Purposive sampling may also be used with both

qualitative and quantitative research techniques. The inherent bias of the method contributes to its efficiency, and the method stays robust even when tested against random probability sampling (Tongco, 2007). The number of key informants was 9 determined by applying the principle of data saturation. On the other hand, convenient sampling technique was used to select the parents and other family members of the children. This is based on the assumption that parents and other family members that come to the center will be informative enough about the service. The size of the sample was determined through personal judgment; budget and the cost of the research may be the good determinant of the sample size (Green et al., 1988). In this research, all of these factors were considered when determining sample size. Sample size of this research for the caregivers or parents was 30 subject to the principle saturation of data and 12 for key informants. The parents or caregivers were selected upon the selection of the children i.e. the parent or caregiver of a child were selected for interview or FGD.

3.4 Data collection instruments and data collection methods

Key informant interview guide, focus groups discussion guide, and observation checklist and were used in the collection of data. The key informant guide was used to collect data from employees and selected caregivers or parents through interview. The data from the parents and other family members were collected using two focus group discussions and individual interviews. The focus group discussion involved 7 people at each organization. On the other hand, the observation checklist was used to collect data on the facility infrastructure, the service delivery process and the children activities in the centers.

3.5 Validity and reliability of data collection tools

Unlike quantitative researchers, who apply statistical methods for establishing validity and reliability of research findings, qualitative researchers aim to design and incorporate methodological strategies to ensure the 'trustworthiness' of the findings. Accordingly, in this study the researcher took actions that were believed to enhance the trustworthiness of the data.

Babbie and Mouton (2011) note that trustworthiness refers to how a researcher can convince the audience that the findings of the study draw their attention. One of the strategies used by the

researcher to enhance the trustworthiness of the study will be collecting data until the researcher reached saturation point. Data saturation is reached when the researcher can no longer get any new insights from continued data collection. According to Babbie and Mouton (2011), and Creswell (2009), these strategies of member checking and ensuring data saturation contribute to the enhancement of the trustworthiness of the study. Cognizant of these facts, efforts were made to assure the trust worthiness of the interview and focus groups participants by clarifying the purpose and value of the study, by diversifying the participants, and application of the principle of data saturation. Patton (2001) states that validity and reliability are two factors which any qualitative researcher should be concerned about while designing a study, analyzing results and judging the quality of the study. This corresponds to the question that “How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?” (Lincoln & Guba, 1985).

3.6 Procedures of data collection

In undertaking the study the following procedure were pursued in collecting the data

- Identification of the appropriate respondents from the staffs of the organizations, parents and caregivers of the children getting the services at the center using the children as sampling unit
- Contacting the parents and caregivers of the selected children to request and secure consent
- Conduct document review of the organizations
- Interview the parents or caregivers of the selected children with autism
- Undertake the interview with the parents and caregivers
- Undertake the focus groups discussions with the parents and caregivers
- Conduct non-participant observation of the facility
- Undertake non-participant observation of the children engaging in different activities at different times
- All interviews and focus group discussions were recorded and transcribed

3.7 Data analysis

The data collected through interview and focus group discussion were coded, grouped in to code families and narrated. Data were analyzed and compiled using a thematic approach by conducting content analysis of the transcripts. Data analysis based on various strategic options was utilized. These include categorization via chronology, key events, settings, relationships, people, processes, and issues. Emerging themes were developed and expanded as a result of the interviews. The qualitative data analysis on the data collected using document review was also analyzed using a narrative approach. As data were collected from the service providers as well as service recipients the triangulation was undertaken via the use of multiple sources of data.

CHAPTER FOUR: DATA PRESENTATION, ANALYSIS AND DISCUSSION

4.1 Study participants' demographic and socio-economic characteristics

Teachers, program management staffs, experts in the area of autism from academic institutions, caregivers of autistic children and the autistic children receiving service at Nehemiah and Joy autism centers participated in the study. The profile of the study participants' show that 6 were teachers at the autism centers, 4 were program management staff, 1 was education specialist, 9 were caregivers and 2 were psychiatrists that work closely with Nehemiah autism center. Almost all of the program management staff and teachers had 5 years and more experience in the centers. Gender wise, most of the teachers were female while all of the program management staff were male. The composition and experience of the staff shows that the study participants are well positioned to provide accurate and reliable data on the subject.

4.2 Seeking help and Initiation of service delivery

The discussion with the center's staff and the caregivers of the children getting service from the centers indicated that caregivers search for help for their children is the starting point for the interaction between the center and the caregivers. The key informant from Nehemiah autism center reported that caregivers come to the service typically following witnessing some kind of symptoms related to ADS. The most commonly mentioned type of symptoms reported by the caregivers were delay in speech and being hyper active. Knowledge of this is mainly attributed to the awareness creation efforts being made by the two centers according to the caregivers participated in the study.

However, all children diagnosed with autism will not get spontaneous acceptance by the centers due to capacity limitation and focus of target groups. Nehemiah autism center focuses on autistic children in the age group of 3-8 years old on the other hand Joy center appear to host more severely affected children. The rationale for such a focus on the part of Joy center is that children with a less server problem are better in coping in the normal environment and priority should be given to those with more severe problem. Depending on availability of space children diagnosed

and found to be autistic will be enrolled while other will be on waiting list. Consequently, services are initiated up on diagnosis and assessment of the children by the center and enrollment based on available spaces.

In connection to seeking help, some of the key informants reported as they believe that still a higher number of people with a family member who is experiencing autism are not seeking medical care. Some say that most people consider it as a result of sin and opt to look for spiritual solutions via holy water or other means. Seeking medical care needs better understanding of the problem and the possible ways of dealing it for a better quality of life for the children as we as the families affected by the case.

4.3 Reaction and response of caregivers to diagnosis findings

The reactions and responses of caregivers differ significantly as reported by the key informants from the two centers. The key informants revealed as they believe the caregivers come to the centers with suspicion that the children might be autistic based on the behavioral changes at home. Yet, their level of preparedness to accept the diagnosis result and related planning on how to deal with the result is very questionable. Most of the caregivers experience shock when they learn their child is autistic while a significantly higher proportion are stunned and lose hope. According to the key informants from the center such reaction is not that much influenced by ones education, sex or financial position. One key factor in such a reaction according to some of the key informants is a function of low level of awareness and the prevailing belief that it is a result of God's punishment, which in turn results in social stigmatization and discrimination. Only very few accept the fact on the spot and try to learn as how they should live with the challenge and help their child. These individuals are mostly people who have made conclusion as their children are autistic.

4.4 The nature and process of the services provided

Nehemiah autism Center and Joy Center of Nia foundation provide different services to children with autism and their families. However, the service packages, manner of service delivery and degree of parental and other key stakeholders' engagement differ in the two centers.

The services at Nehemiah autism Center include giving training on the area of autism and treating Autistic children. Alemnesh a key informant at Nehemia Center described the services and activities of the center in the following manner:

“.....the type of services and activities we have might be grouped in to three. The first one is giving our professional advice for parents and caregivers when they seek professional opinion on the autistic status of the child under their care. Such caregivers usually come to us when they suspect that the children are autistic. In connection to this, we undertake the assessment using standard tools, interview the care givers and conduct observation and make our professional judgment. The second service is providing training and education for those who are accepted by the center. The trainings focus on helping the caregivers deal with the autistic children. We also have training and awareness creation program for the caregivers of the autistic children benefiting from the center service teachers as well as caregivers of children on the waiting list. Some annual awareness training events are also organized and conducted to raise the general public awareness on autism. To this effect, Electronic medias, print medias and different opportunities like workshops and forums are used to reach the public with message on autism.....”

The findings from the discussion with the joy center staffs and observation of the center showed that the organization is actually working to improve the situation of children affected by autism and their families. The organization intervenes at three levels with different approaches:

Individual level, family level, and community and school levels. The individual level intervention focuses helping the children with autism to develop self-help skills, deal with their behavioral challenges and providing them on enabling and supportive environment to learn and spend time. In connection to this, the children learn to cook, express their needs, interact with

others, writing, painting, computer use, use toilet. Withal, they are supported to participate in different events and shopping activities.

The family level intervention is aimed at enhancing the capacity of the parents and siblings of the children with autism in understanding and responding to the care and support needs of the children. Besides, it equips them with the skills and knowledge required to support themselves in coping up with the situation. Thus, it does benefit both the children affected by autism and their family members in creating a better living environment. This is a very important aspect of the center activity as the center does not provide a boarding service i.e. the children spend their time with their family members during off center hours. This is also true at Nehemiah autism center.

On top of the above, the organization works with wider members of the children respective communities and primary schools in Addis Ababa and its surrounding special woredas to raise awareness on the issue and increase the responsiveness of the concerned bodies. Currently, 8 primary schools in Addis Ababa and 5 from the special woredas supporting Addis are working with the center. The role of the foundation in the partnership is to train teachers on autism and helping children with autism whereas the respective schools make sure that children with autism are supported in the school environment. On the other hand, the community level intervention is part of the general effort of the foundation on creating awareness on autism.

The physical observation of the joy center and Nehemiah autism center revealed that the centers are well equipped to provide the services the centers promises. The interaction and observation of the children activity was also indicative of the healthy and friendly environment in which the children are getting the services. Further, the children were interactive, happy and active. However, the adequacy and qualification of the staff remain to be questionable.



Partial view of the facilities

Source (Own study documentation, 2018)

4.5 Autistic care and treatment practice

Autism Program Quality Indicators (APQI) developed by the University of the State of New York's to serve as a means of guiding quality improvement activities for schools and programs serving children with autism in New York. Due to absence of customized indicators, the study adapted the indicators in the analysis of the quality of the service delivery. It is primarily a compilation of the best practices in educating students with autism. The quality dimensions include: Individual evaluation, family involvement and support, development of the individualized education program (IEP), inclusion, curriculum planning the move from one setting to another, instructional activities, challenging behavior , instructional methods, community collaboration, instructional environments, personnel , review and monitoring of progress and outcomes, and program evaluation. Of these, individual evaluation, family involvement and support, development of the individualized education program (IEP), inclusion, instructional methods, collaboration, personnel, review and monitoring of progress and outcomes, and program evaluation are analyzed.

4.6 Diagnosis, assessment and intervention planning practices at Nia Foundation-Joy center and Nehemiah Autism Center

4.6.1 Individual evaluation

The assessment and diagnosis practice of both Nehemiah autism center and joy center appear to be very loose and not that much influenced by prevailing best practices. Yet, there is effort at Nehemiah to apply the current recommended practices of diagnosis and assessment. As noted above, standard assessment tools, observations and interviews are used to assess and determine whether a child is within the spectrum of Autism. The key strength of the assessment at both centers is that evaluations include the examination of the individual skills and strengths of students with autism, as well as their needs. Use of a variety of measures and sources of information including parent and family input and observation is the other strength of the center with some difference between the centers. Nehemiah autism center applies available tools and review progress and functional level. On the other hand, evaluations are not conducted by

multidisciplinary teams made up of personnel who are familiar with the characteristics and response patterns of children with autism. The medical and developmental history review factors specific to autism are not also accounted for. Evaluation reports are not well written in a meaningful, understandable manner and shared to caregivers, teachers and other professionals who work collaboratively with the center and the family of the autistic child.

The key informants including the education specialist at Nehemiah are well aware of the current thinking's related to autism and related interventions. The management recognizes the uniqueness of each child and attempts to intervene based on individualized intervention plans despite the fact that all are autistic. Expressing this one of the key informants said

“actually....all are unique...all are in the same category...in the same spectrum but their skills differ...they differ in their communication skill, gross motor and fine motor skills, sensory processing skill....so we develop individualized education plan based on assessment of skills gap which happen after the child is accepted by the center.....the assessment covers sensory motor processing skills, cognitive skills, social skill and other skills.” This is very commendable for the fact that appropriate treatment of ASD should begin with a careful assessment to determine the child's specific strengths and needs. The literature review discussed in the earlier indicates that assessment of autism spectrum disorder is a vital element of an effective intervention. This is based on the notion that each person with ASD is unique, and intervention plans must be individualized based on the needs of the individual and family.

Though there are no specific medical tests for diagnosing autism, there are genetic tests for some disorders that may be associated with behaviors on the autism spectrum. An accurate diagnosis is based on systematic interviewing, observation, and assessment of the child's communication, social interaction, behavior, and developmental level. In view of this, we can infer that the practice at Nehemiah autistic center approaches the current thinking and practices of autism care and treatment despite its limitations.

The assessment is conducted by the teachers who work at the center and the education specialist in the case of Nehemiah autism center. These assessments are sometimes complemented by the second opinions of psychiatrists and other physicians working with the center with a firm belief

that a team of expertise is better than education specialists. The key informants indicated that they have classified the children in to three levels based on the DSM 5 to lay the foundation for the intervention planning process. Accordingly, the children are classified in to three: level 1, level 2, level 3 and the basic skills for each level is developed by the education specialist. In spite of the claim by the expert, the review of the literature does not indicate the presence of standards set for skill intervention based on the levels.

Although ASD screenings may be completed by a number of different professionals (e.g., primary care physicians, speech pathologists, teachers, etc.), the diagnosis of ASD should typically be made by a psychologist, psychiatrist, or developmental-behavioral pediatrician who has been trained in the diagnosis of ASD which is not the case both at Nehemiah or Joy Center. Observation tools such as the Autism Diagnostic Observation Schedule (ADOS) and structured diagnostic interviews such as the Autism Diagnostic Interview – Revised (ADI-R) are often used to provide additional rigor to the assessment of ASD yet these are also lacking in the case of Joy-center.

The above discussion indicates as the diagnosis and assessment of autism is in short of the best practices. Nevertheless, the procedures used and the leverage with psychiatrists by Nehemiah autism center is commendable compared to Joy Center.

4.6.2 Personnel

Staff are expected to be knowledgeable and skilled in the areas of expertise specific to autism, including characteristics of autism, familiarity with assessment methods, developing IEPs to meet the unique needs of each student, curriculum, environmental adaptations and accommodations, and instructional methods, strategies to improve communication and social interaction skills, classroom and individual behavior management techniques. However, the discussion with the centers management and the staff show that the centers are challenged by the availability of knowledgeable and skilled staff.

Almost all of the key informants reported that there is no higher education institute in Ethiopia that effectively prepares psychologists, teachers, and administrative staffs to be knowledgeable or skilled in the area of autism. In light of this, the centers rely on special short term trainings given to the teachers at the center rather than recruiting ready work force. There are 20 teachers in Nehemiah autistic center and 18 in Joy Center. The teachers' educational background and expertise in the area differ significantly. It ranges from grade 10 to first degree in special needs education and educational psychology.

The centers attempt to improve the knowledge and skills of their staff via trainings designed to further develop their knowledge and skills. There is also mentoring and coaching to the teachers in the centers by the program management and education specialist (in the case of Nehemiah autism center). The study was not able to make judgment on the sufficiency of the available staff to provide quality service in a manner the implementation of individual education plans as in the case of Nehemiah autistic center.

4.7 Partnership and collaboration with community and other actors

Programming related to autistic intervention demands the involvement of a number of key actors that have a stake in influencing the life of the child. This includes the child's family, schools, other experts in the fields and community agencies that may assist families in accessing supports and services needed by children with autism.

The role of coordination with caregivers was emphasized as a pillar in determining the effectiveness of the learning and teaching process. All of the key informants agree that the level of engagement of caregivers influence the pace and direction of skill acquisition by autistic children. Speaking about the partnership one key informant from Nehemiah autism center said

“we closely work with caregivers.....parents as well as family member that spend much time with the children.....unless otherwise we involve them all of our efforts will be a futile exercise.....”.

Building on this, the education specialist of Nehemiah Autism center said

“.....as parental cooperation and level of engagement is a criterion to accept the children as well as to determine the continuity of the service.....if parents and caregivers are not willing to be engaged and be supportive we do not accept the children at the center....”.

The parents/caregivers are informed and knowledgeable about the intervention plan and their expected role in the case of Nehemiah autism center. Mahlet expressed the situation in the following manner “....we are investing a lot of time and effort here at the center...for example I teach a child how to use a toilet.....when I do this I clearly communicate what the parents or caregivers are expected to do at home.....if they do not cooperate and did not reinforce what the child learned at schoolwhen the child returns to school you will be expected to start from the scratch....on the contrary, if they cooperate and fulfill their roles that would make the progress better”. Such practice was not noted in the case of Joy center. Despite the facts discussed above, the centers parent counseling and training services are very shallow. The services are limited to awareness creation and consultation on major issue based on the initiation from the parents/caregiver.

The area of improvement in the autism program in both centers is poor integration with the health care system and early educators. One of the key informants indicated that “..... 24 months can be very helpful in early identification of an ASD by health care providers or early educators. Early intervention can make a significant difference in improving cognitive and social development for children with ASD,early identification is a key to early intervention, which has shown to have a significantly positive effect on long-term outcomes for children with ASD. Early signs of autism are often noticed by 18 months of age, or even earlier. Some early signs may include

- Lack of interest in other children
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects
- Lack of or delay in spoken language
- Poor response to his/her name

- Repetitive use of language
- Little or no eye contact
- Fails to imitate caregivers
- Hand-flapping

However, due to the absence of awareness and referral linkage with health facilities and early educators the opportunity is missed. In addition, assisting parents in accessing services from community agencies would be a vital addition in the centers profile.

4.8 Methods of teaching and promising practices of Nia Foundation-Joy center and Nehemiah Autism Center

Some underlined as starting from the knowledge of the where the child stands with clear identification of its strength and areas of improvement is important in enhancing the effectiveness of the teaching methods. Tayech, one of the key informants, expressed that it is much better and easier to facilitate learning when one starts from where the child is. This is because it helps in creating a realistic expectation from the teacher which in turn will facilitate the application of more effective techniques like repetition.

The program managers as well as the teachers emphasized as they invest time on understanding the children behavior and addressing behaviors that may hinder the overall learning progress of the children in teaching them new skills. One of the key informant clarified this in the following manner

“ ...we try to identify what upsets a child and how she/he reacts to something that upsets her/him.....the knowledge of this will help to prevent possible upsets and develop a mechanism of responding to the child’s reactionin addition, it helps to identify additional skills the child need in dealing with things that upsets her/him.....for example, you may want to help in avoiding negative reactions like scratching, falling on the ground, biting, hitting a wall which may harm the child.....in general knowledge of such issues improves the overall teaching-learning process.”

Some also mentioned that children with autism engage in behaviors like rocking their body, flapping their hands and scratching their friends and teachers in most cases. Most also like to be isolated. According to the key informants, it is usually beneficial to deal with such behaviors so as to create a better learning teaching environment for the children.

Most of the study participants reported that paying attention is one of the key success factors in the teaching learning process. In relation to this, one of the teachers expressed that “.....when you show them some kind of behavior that you want to train them on...they may not notice what you are doingso you have to repeatedly show them so as to get their attention and influence them to perform the instruction.” With regard to the need for repetition, in order to teach something another teacher said “.....repetition in demonstration is very important.....when you teach a new thing for a child at first s/he may not remember a single thinghowever with repeated demonstration from time to time ...s/he will start to practice or adopt the desired behavior”. One interesting such an example reported at Nehemiah was a child who started using toilet with such teaching technique.

A teacher at Nehemiah reinforced the importance of repetition in order to teach new things to children with autism. She stated

“ autistic children could easily be distracted and lose attention while you are teaching them.....this is particularly true when there is some kind of noise or sound around the environment in which you are teaching.....besides they easily forget things ...because of short memories....thus, it is important that one should repeat a given instruction a number of times to help them learn and acquire new skills andadopt new behaviors”

The other most frequently reported effective method of teaching was using visual aids like picture or dolls with modeling. Almost all of the teachers reported that autistic children easily learn or acquire specific skills when such techniques are applied. The teachers and program directors confirmed that it is difficult for autistic children to comprehend abstract concepts. To get an understanding autistic children typically need to learn via real and tangible things. This is much easier to teach as well as easier for the children to learn.

One of the teachers explained the situation saying “ It is not easy to teach autistic children without the use of real or tangible things.....we usually teach them by demonstrating the desired behavior or skill.....for example we teach them bed making, how to dress their cloth.....as part of the self-help program.....in such trainings explaining how to do such things verbally will not bring any result...rather the demonstrations are highly effective in helping the children acquire the skills”

Alemitu a teacher interviewee also stated “ I teach children using models, pictures and movie.....for exempling in helping a child who is afraid of a mouse.....I will show the child a mice picture...familiarize him by touching the pictureand will do the same using models of mice....such methods are effective in encouraging the children to overcome such fears gradually.....though time they model the behavior and may be good in managing the situation in real life scenario.....” One of the participants said “ when we want to teach children to adapt a certain behavior like brushing teeth.....telling them to brush their toothit does not work.....we have practically proved ithowever...when you show them by doing it repeatedly, they are more likely to practice it.”

Some other participants reported that they use stories to teach children to focus. Regarding this Tayitu said “.....we use reading stories as a means of teaching them paying attention.....since their attention span is very short, we ask them questions after reading a certain part of a paragraph...like a sentence.....the questions are actually asked for verbal children.....such methods are good in helping us to learn about the children cognitive abilities andattention.

All the participants confirmed that rewarding is the other effective method of teaching. They explained that when the children perform instructions or do things in a desirable way they are rewarded with things or activities they like most. Reward is our best method of teaching said one of the teachers from Joy Center. For example, they may ask for something they need badly, at that point you tell them in order to get that they need to perform a certain activity, then they perform the desired activity immediately.

If you hug them or appreciate them with a loud voice like ‘good job’ then that is a reward for them says Meseret, who is a teacher at Joy center. She also further stated “by rewarding them you will be able to let them do what they do not want to do. For example, the girl who likes to

play a piano will be allowed to play piano...this is just an example...it is mostly about letting children engaged in a certain kind of activity they like listen.”

4.9 Inclusion

Inclusion refers to including children with autism in general education programs. Inclusion with typically developing peers is recommended once a child can imitate gestures, sounds or words. However, the children benefiting from the services of both Nehemiah autism center and Joy Center are not provided with many opportunities for interaction with nondisabled peers. Opportunities for interaction with typically developing peers needs to be systematically incorporated into the daily activities of the program as recommended by available best practices. Inclusion will help the children with autism to get an opportunity to participate in programs in their community with their siblings, friends and neighbors. It also helps them learn from their peers who serve as role models to help them with social skills and communication and prepare them for adult life in the community. On the other side, it will creating an opportunity for their peers to learn empathy and exposed them to diversity.

4.10 Review, monitoring or progress and outcomes- Evidence generation

The discussion with the study participants and the review of the documents indicates that there is low level of effort in undertaking systematic assessment of the children progress based on the IEP in the case of Nehemiah and intervention plan in the case of Joy Center, documenting progress. There is some level of effort in summarizing and reviewing progress for refinement of instructional program at Nehemeiah. Programmatic evaluation is nonexistent in both cases. This particularly refers to systematic examination of program implementation and its impact, including the aggregation of individual student outcomes and clients satisfaction.

4.11 Challenges experienced by Nia Foundation-Joy center and Nehemiah Autism Center in delivering service to children with autism and their families

Challenge related to the characteristics of autism, behavioral requirements to work on autism, parents and family commitment, and shortage of proven strategies to effectively care and treatment options were raised as major issues by most of the staff and the key informants. The participants from the centers management also underlined as there is awareness and related policy gap in the operating environment.

The teachers described that for children with autism learning takes a longer time than the time we take for typically developing children. Frehiwot also stated that “unlike normally developing children autistic children need to be taught for longer period of time in order to catch something new. They cannot be changed all of a sudden rather they need repetition. Therefore, this is one of the challenges of teaching of children with autism. Most of the key informants reported as it is very challenging and time taking to bring change in the skills of autistic children. All believe that teaching a new skill or making them to develop a certain behavior takes a longer period of time unlike other normally developing children. Describing the situation one of the key informants said

“ there is no defined time frame to know as when an autistic child will acquire a certain skill or adapt a certain behavior.....what you can do is just teach the desired skill based on the individualized plan without losing hope.....the change may happenunfortunately...it might not happen depending on the degree of the problem.....this is one of the key challenge in autism intervention....”

Another major issue raised in teaching autistic children was insistence on sameness. Most of the key informants particularly the teachers reported children are resistant or reluctant to change the environment they are accustomed to. The children may resist any effort to make them change classroom, their chairs and other things they are familiar with.

All participants of the study explained that the behavior of insistence on sameness affects the opportunity of learning new things. In explaining this behavior of children with autism, Alemitu

explained that “children with autism insist on sameness, they even do not want to change the things they are familiar with...they do not want to change their tables, ...their chair..... Even in the selection of games during their time here at the facility....they prefer to repeat the same games. Taferech also added a point with regard to this issue “ as you may see it we have handball facility at the front of the building.....children play the game.....if you install a new game in the facilityit needs effort to make the children to try and play the new game.....I think the contrary if true for other children.....”

Restlessness was the other most frequently reported challenge for teaching children with ASD. Most of the teachers reported keeping children at a certain place for some period of time is very challenging and requires them to sit down for few minutes with significant effort and time. Meseret noted that “...sitting at least for a couple of minutes is important to facilitate the teaching and learning process.thus, it is very important to make sure that children are able to sit for a few minutesthis is best done when progressive target is used as an approach.....rather than targeting 10 minutes....you can start with 5 minutes and work towards longer stay.....only very few children sit for more than 25 minutes at our facility..... “

Getahun said “if you are someone like who loses hope so easily then you are not able to do it. You cannot bring about change at oncee it requires longer time and parents’ meaningful support and engagement. actually we do not expect them understand and acquire the desired skills at once..... children with ASD do not show progress quickly....they respond very slowly .” Another participant said that “ you might be teaching something this week for a child....you may see some progress and be happy by that.....however.....you may not see the sign of the progress you witnessed in the following week for different reasons....may be he was learning something contrary at home during the weekend.....thus, it is important that anybody who deals with ASD children should be patient and assure the involvement of parents and family members.

The other challenge both Joy Center and Nehemiah Autism Center face is related to families’ degree of commitment and ability to fulfill their roles and responsibilities as per the intervention plans. Some families do not have the time or patience to fulfill their roles. This makes our effort very challenging as bringing about change in autistic children significantly demands effective

coordination with parents and caregivers. Seida says “.....the reluctance of some parents to play their role tests ones patience....when parents fail to play their role it discourages us...”

CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS

5.1 Summary and conclusion

There are very few actors engaged in providing care and treatment for autistic children in Ethiopia. The two officially registered organizations providing such services are Nehemiah Autistic center and Joy Center. This study was aimed assessing the centers service provision in light of widely recommended practices and evidence based programming. The study also intended to identify promising practices and challenges in the delivery of service for children with autism and their family members.

The findings of the study revealed that the service packages of the two organizations include giving training on the area of autism and treating Autistic children. The services are guided by the individual knowledge and experience of the program managers rather than via a standardized manuals, guidelines and curriculum. Nehemiah autistic center appear to be better in terms of trying to applying the current thinking and recommended best practices in providing care and treatment. This is well reflected in the fact that their interventions are based in relatively good diagnosis and individualized intervention plans unlike the case of Joy center. Given that Joy center hosts children with more sever ASD, it the comparison on the assessment and use of individualized education plan might not be valid for comparison

The centers provide counseling and training services to parents and family members including skill trainings. This is instrumental in the centers effort of creating an enabling and supportive home environment. However, the counseling and training services are limited to awareness creation and consultation on major issue based on the initiation from the parents/caregiver.

The physical environment of the centers is also good but very limited in terms of technology application and space adequacy. Yet, both are in a poor condition in having sufficient number of knowledgeable and skilled staffs. Nevertheless, the centers facilitate different capacity development trainings to their staff along with mentoring and coaching. Besides, the degree of integration and collaboration with other service providers is limited in both cases.

The instructional methods were found to be effective and well informed by the prevailing best practices. In both cases the teachers deal with difficult behaviors and teach social skills as a starting point. This is based on detailed assessment of the individual child strengths and areas of improvement, particularly in the case of Nehemiah. With the creation of a better environment via such intervention they apply different instructional methods. The most frequently reported effective methods being applied were demonstration, positive reinforcement and use of tangible things in teaching the children. Repetition of demonstration and positive reinforcement were emphasized as pillars for the teaching process effectiveness. However, the programs of both centers fail to be inclusive in the sense of facilitating interaction with nondisabled children.

The major challenges noted in the operation of the centers and teaching learning process were lack of a supportive environment, low level of public awareness about the issue, absence of well proved effective remedies to autism, shortage of knowledgeable and skilled human resource. Besides, the characteristic of children with autism was reported to demand high level of intrinsic motivation. Limited involvement and commitment on the part of some parents and family members was also indicated to be a challenge.

The practice of the centers in the area of systematic assessment of the children progress based on the IEP in the case of Nehemiah and intervention plan in the case of Joy Center, documenting progress and programmatic evaluations are very weak. This has resulted in the inability to generate evidence based promising practices.

To this end, we can conclude that the service packages of the two centers are relatively good but the manners of service delivery are is short of the widely recommended practices and evidence based programming.

5.2 Recommendations

Based on the findings of the study the following directions are suggested to improve the quality of the centers services and

Awareness and advocacy for expansion of service and academic institutions training program

The centers need to invest further on creating awareness on Autism Spectrum Disorder among the general public. This is vital to influence the service seeking behavior of parents and families of children with autism. However, this has to be complemented with increased service delivery capacity via production of knowledgeable and skilled human resource as well as availability of services at the different regions.

Enhancing the involvement of spiritual leaders

The role of religious leaders in traditional societies like Ethiopia is immense in influencing social attitudes and norms. The religious explanation of autism as a punishment of family sin hampers families' effort of seeking help for their children affected by autism and usually results in anxiety and stigma. In view of this, providing training for religious leaders on autism and using the institutional arrangements of major religions in the country with the proper message about autism will be helpful in reducing the social stigma and encouraging affected families to seek help.

Parents' involvement and Psychosocial support for parents

For a better involvement of the parents it would be important to make sure that the parents or caregivers counseling and training services are comprehensive and include providing parents with information about child development, assisting parents to understand the needs of their child, fostering coordination of efforts between school and home, supporting the family in behavior management, and enabling parents to acquire skills to support the implementation of their child's IEP in the case of Nehemiah. Besides, establishing support groups for parents or create opportunities to parents to meet regularly with other parents and professionals in such support groups would be vital. Providing information to parents via regular communication regarding their child's progress and assisting them in accessing services from other agencies

(when available and as appropriate) would also add value in making the support more comprehensive. In addition, assisting parents in accessing services from community agencies would be a vital addition in the centers profile.

Partnership and collaboration

The limited capacity of the two centers and absence of other actors working on the issue necessitates partnership and collaboration for better result and access. Consequently, leveraging with schools, health facilities, professional associations, early childhood development centers and schools among others will be important in early detection of ASD and timely intervention. It will also help to improve the quality of the diagnosis and assessments as well as related interventions.

Inclusion

Facilitating interaction with non-disabled children in both informal and planned interactions would be helpful. In doing so, the autistic children need to be provided with instruction and support to maximize successful interactions. Likewise, it would be important to provide nondisabled peers with knowledge and support to facilitate and encourage spontaneous and meaningful interactions.

Review, monitor and evaluate interventions

The program should evaluate short-term (e.g., weekly or bi-weekly), intermediate (e.g., quarterly), and long-term (e.g., yearly) changes in the children's progress. The programs should incorporate evaluation systems that assess the effectiveness of the programs in the areas of the children's progress toward defined goals and objectives, students' generalization of skills, and student progress toward long-term outcomes. Such program evaluation should include measures of consumer satisfaction with services. And most importantly, information obtained from program evaluation needs to be used for program improvement.

Reference

- Aarons, M., & Gittens, T. (1999) *The Handbook of Autism*. London: Routledge.
- Agency for HealthCare Research and Quality. (2011). *Therapies for Children With Autism Spectrum Disorders*. Nashville, TN: Vanderbilt Evidence Based Practice Center.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington,DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.
- Ametepee, L. K., & Chitiyo, M. (2009). What we know about autism in Africa: A brief research synthesis. *The Journal of the International Association of Special Education*, 10(1), 11-13.
- Aynalem, T. (2014). *Families Living With a Child Diagnosed With Autism : Challenges And Coping Mechanisms Families Living With A Child Diagnosed With Autism : Challenges And Coping Mechanisms*. Addis Ababa University.
- Babbie, E. & Mouton, J. (2001). *The practice of social research*. Oxford: Oxford University Press.
- Bakare, M. O., & Munir, K. M. (2011). Autism spectrum disorders (ASD) in Africa: a perspective. *African journal of psychiatry*, 14(3), 208-210.
- Baron-Cohen, S., Allen, J. & Gillberg, C. (1992). Can autism be detected at 18 months? The needle, the haystack, and the CHAT. *British Journal of Psychiatry*, 161, 839-843.
- Best Practices. (n.d.). Retrieved September 06, 2017, from <http://www.bitpipe.com/tlist/Best-Practices.html>
- Bettelheim, B. (1974). *A home for the heart*. New York: Knopf. *The Person-Centered Journal*, Vol. 13, No. 1-2, 2006
- Bettleheim, B. (1967) *The empty fortress: infantile autism and the birth of self*. New York: The Free Press
- California Department of Developmental Services. (2002). *Autistic Sectrum Disorders: Best*

Practice Guideline for Screening, Diagnosis and Assessment. California: California Department of Developmental Services.

Cook K.A., Willmerdinger A.N. (2015) The History of Autism. Furman University Scholar Exchange Narrative Documents.

Cook, K. A., & Willmerdinger, A. N. (2015). The History of Autism. Retrieved January 2, 2016, from <http://scholarexchange.furman.edu/schopler-about/1>

Creswell, J. W. (2014). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches (4th ed.). California: SAGE Publications, Inc. Dagneu, D. (2014). The Strategic Roles of Social Media Marketing to Build a Strong Brand Equity (The Case of Selected Companies in Ethiopia). Addis Ababa University.

Davidson, J. (1990). Treatment of posttraumatic stress disorder with amitriptyline and placebo. *Archives of General Psychiatry*, 47, 259–266.

Davison, G.C., Neale, J.M. (1980). *Abnormal psychology: An experimental Clinical approach* (4th edition). Chichester: Wiley

Douglas, P. (2014). Autism's "Refrigerator Mothers": Identity, Power, and Resistance. University of Toronto. Retrieved from <http://munkschool.utoronto.ca/cphs/papers/>

Green S. A., Yang Y. (2009). Reliability of summed item scores using structural equation modeling: an alternative to coefficient alpha. *Psychometrika*; 74, 155-67, DOI: 10.1007/S11336-008-9099-3

Kanner, L. (1943) 'Autistic disturbances of affective contact', *Nervous Child*, vol.2, pp.217–50.

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2007). Meeting the needs of families living with Children diagnosed with Autism spectrum disorder. Retrieved from <http://www.peatni.org/uploads/27/22007215234-autismreport.pdf>

Kothari, C.R., 2004. *Research Methodology: Methods and Techniques* 2nd ed., New Delhi: New Age International Publishers.

Landa, R. (2007). Early communication development and intervention for children with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 16-25.

- Lewis, V.(2003). Play and language in children with autism. *Autism*, 7, 391–399.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications, Inc.
- Lindgren, S., & Doobay, A. (2011). *Evidence-Based Interventions for Autism Spectrum Disorders*. Iowa: University of IOWA Department of Human Services.
- Lovaas, O. I., Koegel, R. L., Simmons, J. Q., & Long, J. (1973). Some generalization and follow-up measures on autistic children in behavior therapy. *Journal of Applied Behavior Analysis*, 6, 131-166.
- Mahlet, B. (2016). Resources in raising a child with autism in Ethiopia: parents' perspectives, a thesis submitted to the Faculty of Psychology University of Bergen in partial fulfilment of the requirements for the degree Master of Philosophy in Health Promotion. Bergen, Norway
- Mahlet, B. (2016). Resources in raising a child with autism in Ethiopia : parents ' perspectives. Uniiversitas Bergensis.
- Majira, O. (2014). Assessment of Autistic Behaviors Among School Age Children in Selected Elementary Schools in Jimma, Oromia, Regional State South West Ethiopia. Addis Ababa University.
- Martin, D. M. (2012). The Ever-Changing Social Perception of Autism Spectrum Disorder in the United States. Retrieved March 16, 2016, from <http://thescholarship.ecu.edu/handle/10342/1709>
- Meressa, S. (2014). Learning problems of children with autism and the challenges in the teaching process : the case of Nia Foundation Joy Center. Addis Ababa University.
- Mitchell, P. (1997). *Introduction to theory of mind: Children, autism and apes*. London, England: Edward Arnold Publishers.
- National institute of Mental Health (2011). A Parent's guide to Autism Spectrum Disorder. Retrieved from <http://www.nimh.nih.gov/.../a-parents-guide-to-autism-spectrum-disorder/pare>
- New jersey Department of Education. (2004). *Autism Program Quality Indicators*. New Jersey:

New jersey Department of Education.

Nia Foundation. (2018). Autism in Ethiopia. Retrieved March 2018, from http://www.ethioautism.org/Joy/Autism_in_Ethiopia.html

No Child Left Behind Act of 2001. 20 U.S.C. 70 § 6301 et seq. (2002).

Olani, W. (2014). Assessment of Autistic behavior Among School Age Children in Selected Elementary Schools in Jimma, oromia Regional State South West Ethiopia, a thesis submitted to department of Special Needs Education Addis Ababa University in partial fulfilment of the requirements for the degree of Master of Education in Special Needs Education. Addis Ababa, Ethiopia

Ozonoff, A., Pennington, B. F., & Rogers, S. (1991). Executive function deficits in high-functioning autistic individuals: relationship to a theory of mind. *Journal of Child Psychology & Psychiatry*, 32, 1081–1105.

Patton, M. Q. (2002). *Qualitative research and education methods*. Thousand Oaks: Sage.

Paul A., (2003) - *Journal of family issues*, Sage Publications

Powell, S. D. (1999). Autism. In D. J. Messer, & S. Miller (Eds.), *Developmental psychology*. Cambridge: Cambridge University Press.

Ritvo, E. R. The syndrome of autism: A medical model. *Integrative Psychiatry*, 1983,1, 103-109.

Rutter, M., Andersen-Wood, L., Beckett, C., Bredenkamp, D., Castle, J., Groothues, C., Kreppner, J., Keaveney, L. Lord, C. & O'Connor, T. G. (1999) Quasi-autistic patterns following severe early global privation. *Journal of Child Psychology and Psychiatry*, 40 (4): 537-549

Sara, M. (2014). Learning problems of children with autism and the challenges in the teaching process: the case of Nia Foundation Joy Center, a thesis submitted to department of Social work Addis Ababa University in partial fulfilment of the requirements for the degree of Master of social work. Addis Ababa, Ethiopia

Simpson, R. L. et al. (2005). *Autism spectrum disorders: Interventions and treatments for children and youth*. Thousand Oaks, CA: Corwin Press.

- Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma , explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country : a cross-sectional facility- based survey. *BMC Health Services Research*, 1–12. <http://doi.org/10.1186/s12913-016-1383-9>
- Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: A cross-sectional facility-based survey. *BMC Health Services Research*, 16(1). doi:10.1186/s12913-016-1383-9
- Tongco, M. D. C. (2007). Purposive Sampling as a Tool for Informant Selection, *5*, 147–158.
- Tuchman, R., Alessandri, M., M., & Cuccaro, M. (2010). Autism spectrum disorders and epilepsy: Moving towards a comprehensive approach to treatment. *Brain & Development*, 32, 719-730.
- Weiss, M. J., Fiske, K., & Ferraioli, S. (2008). Evidence-Based Practice for Autism Spectrum Disorders. *Clinical Assessment and Intervention for Autism Spectrum Disorders*, 33-63. doi:10.1016/b978-012373606-2.50004-8
- WHO (2008) Guide for Documenting and Sharing “Best Practices” in Health Programmes, Regional Office for Africa Brazzaville
- Young, R.L., Nettlebeck, T.,(2005). The abilities of a musical savant and his family.*Journal of Autism Dev. Disord.* 25, 231-248.

Annex I: Data collection tools

Key informant interview- Staffs

1. What is the primary purpose/mission of the center?
2. What are the specific services you provide in the center? Probe till all services are mentioned....how do you choose the mix of services and activities ?
3. Are the kinds of services provided different for different children? If so, what is the base for the differentiation of the services?
4. How do you accept children with autism? Probe what is the procedure? Do parents bring their children or? Do you diagnose the children for autism?
5. What are the criteria and diagnostic symptoms you use to identify children with autism?
6. How do you evaluate the staffs knowledge and skill in autism assessment?
7. How do you assure the quality of the assessment process and the overall quality of the services provided at the center? Probe does the organization has any standard manual or quality assurance guideline
8. How do you work with parents of the children with autism? Probe how the parents are involved in the program-planning and service delivery? What kinds of specific interventions do you undertake in relation to parents and family involvement? How cooperative and responsive are the parents/other family members?
9. How and in what areas of collaboration do you work with schools or other institutions in the city/country? Probe with which organization the center works along with the areas of collaboration
10. What are the major challenges you face in relation to human resource, financial resources, equipment and supplies? Probe
11. What are the major challenges you face in relation to your operating environment? Probe about government policy, working with concerned government offices, schools and other stakeholders?
12. How do you think these challenges could be dealt with? probe
13. Is there anything you would like to tell me?

Interview guide for technical staffs

1. What is your role in the center?
2. What trainings and relevant education do you have that relate to the work you do here?
3. How do you evaluate your knowledge and skill in autism assessment and related service?
4. What are the specific services you provide in the center? Probe till all services are mentioned....how do you choose the mix of services and activities ?
5. Are the kinds of services provided different for different children? If so, what is the base for the differentiation of the services?
6. How do you work with parents of the children with autism? Probe how the parents are involved in the program-planning and service delivery? What kinds of specific interventions do you undertake in relation to parents and family involvement? How cooperative and responsive are the parents/other family members?
7. How do you evaluate the effectiveness of the services provided by the center? Seek explanation are there changes in the developmental skills that your intervention may target to increase academic, communication higher cognitive functions interpersonal, learning readiness, personal responsibility, placement, play, self-regulation among other
8. Which interventions were more effective in bringing about the changes or improvements in the development skills of the children? Probe for each positive change reported
9. What are the major challenges you face in delivering the service to the children?
10. How do you think these challenges could be dealt with? probe
11. Is there anything you would like to tell me?

Interview questions with parents

1. How do you hear about joy center/Nia foundation?
2. For how long your child had been getting service at joy center/Nia foundation?
3. When and how was s/he diagnosed as autistic?
4. What services is your child getting at the center?
5. How are you involved in the planning of the kind of services provided to the child as well as in the service delivery?
6. Which services do you most like from the services provided by Nia foundation? Probe why for each service
7. How do you evaluate the effectiveness of the services provided by the center? Seek explanationare there changes in the developmental skills that your intervention may target to increase academic, communication higher cognitive functions interpersonal, learning readiness, personal responsibility, placement, play, self-regulation among other
8. Which of the services out of those provided by the center currently do you think needs to be improved? Probe why and how for each service
9. What services do you think needs to be added in the existing services of joy center/Nia foundation? Probe why for each service
10. What challenges do you think joy center/Nia foundation is facing in proving service to children with autism? Probe
11. How do you think these challenges be dealt with?
12. Is there anything you would like to tell me?

FGD with parents

1. What are the sources of information about Autism in your area?
2. How do you find out about joy center/Nia foundation?
3. What motivated you to seek care and treatment from the centers?
4. When and how did parents like you learn about your child's autistic condition?
5. What are the services being provided at the center? Probe
6. How are caregivers like you involved in the planning of the kind of services provided to the child as well as in the service delivery?
7. Which services are good from the services provided? Probe why for each service
8. How do you evaluate the effectiveness of the services provided by the center? Seek explanationare there changes in the developmental skills that your intervention may target to increase academic, communication higher cognitive functions interpersonal, learning readiness, personal responsibility, placement, play, self-regulation among other
9. Which of the services out of those provided by the center currently do you think needs to be improved? Probe why and how for each service
10. What services do you think needs to be added in the existing services of joy center/Nia foundation? Probe why for each service
11. What challenges do you think joy center/Nia foundation is facing in proving service to children with autism? Probe
12. How do you think these challenges be dealt with?
13. Is there anything you would like to tell me?

Annex II: AUTISM PROGRAM QUALITY INDICATORS

The Autism Program Quality Indicators (APQI) are a compilation of the best practices in educating students with autism, which were developed to serve as a means of guiding quality improvement activities for schools and programs serving children with autism in New York State.

Structure and Content of the APQI

The APQI are organized into the following 14 areas with the seven categories in the left-hand column relating to the specific aspects of the educational process for students, and the seven categories in the right-hand column referring more broadly to program characteristics and supports.

- Individual Evaluation
- Family Involvement and Support
- Development of the Individualized Education Program (IEP)
- Inclusion
- Curriculum
- Planning the Move from One Setting to Another
- Instructional Activities
- Challenging Behavior
- Instructional Methods
- Community Collaboration
- Instructional Environments
- Personnel
- Review and Monitoring of Progress and Outcomes
- Program Evaluation

Each of the 14 areas is described by a single summary sentence, followed by more specific "quality indicators." The items contained within the APQI do not reflect specific instructional strategies or theoretical approaches. Instead, they reflect methods that have consistently been found to be effective in improving learning in children with autism. Additionally, where items reflect practices that are broadly appropriate to educating all children (e.g., involving and supporting families in the educational process), the APQI focus on those aspects most important for educating students with autism. (1)

How should the APQI be used?

The APQI were developed to apply to programs that serve children between the ages of 3 and 21, on the full range of the autism spectrum (including Asperger syndrome and Pervasive Developmental Disorder–Not Otherwise Specified {PDD-NOS}) and ability levels, and in all educational settings. Some items may, therefore, not apply to every program. The purpose of the APQI is to provide a tool for schools or programs to self-

evaluate educational services as a whole rather than an evaluation of services provided to any specific child. A program would rate itself on the degree to which there is evidence supporting that a particular item or practice is in place. In this way, the APQI may serve as a quality improvement tool in which programs note relative strengths and weaknesses. Given the indicators cover such a wide range of educational practices, it is highly unlikely that any program would have clear evidence of every quality indicator.

The APQI were developed to apply to programs that serve children between the ages of 3 and 21, on the full range of the autism spectrum (including Asperger syndrome and Pervasive Developmental Disorder–Not Otherwise Specified {PDD-NOS}) and ability levels, and in all educational settings. Some items may, therefore, not apply to every program. The purpose of the APQI is to provide a tool for schools or programs to self-evaluate educational services as a whole rather than an evaluation of services provided to any specific child. A program would rate itself on the degree to which there is evidence supporting that a particular item or practice is in place. In this way, the APQI may serve as a quality improvement tool in which programs note relative strengths and weaknesses. Given the indicators cover such a wide range of educational practices, it is highly unlikely that any program would have clear evidence of every quality indicator.

Development of the APQI

The APQI were developed over a one-year period by the New York Autism Network (NYAN) at the request of the Office of Vocational and Educational Services for Individuals with Disabilities (VESID) of the New York State Education Department. NYAN is a consortium of four regional centers with a shared focus of promoting effective educational approaches for students with autism. NYAN is funded by the New York State Education Department.

The items on the APQI were derived from a variety of sources including federal and State law and regulations, scientific evidence, and professional experience. The APQI were developed first by examining the professional literature to identify likely dimensions for the scale. The next step was to identify key quality components specific to autism in each of these areas. A preliminary draft of the APQI was field tested with the NYAN regional advisory groups. Information from the advisory groups was compiled into a working draft of the APQI (dated 11/6/00) that was shared with national experts and VESID representatives for their comments. These comments led to a significant re-focusing of the APQI on making it as autism specific as possible. A number of interim versions were shared with NYAN staff, representatives from programs and advocacy groups, national experts, and VESID staff. The resulting document (6/15/01) has been strengthened considerably by the input of these many people.

Scoring the APQI

The APQI uses a four-point rating system, plus a Not Applicable rating, as follows:

Score	Description
-------	-------------

NA	Not applicable. The program is not responsible for this area.
0	There is no evidence of this indicator.
1	There is minimal to no evidence of this indicator, but clear evidence exists that the program is in the process of planning for implementation and/or staff development in this area.
2	There is some evidence of this indicator <i>or</i> there is clear evidence of the indicator for only a portion of students with autism.
3	This quality indicator is clearly evident for all students with autism.

These ratings can be applied to each of the items and a summary rating can be given to each area. A summary table at the end of the scale allows programs to identify areas of relative strength and weakness.

AUTISM PROGRAM QUALITY INDICATORS

Score	Description
NA	Not applicable. The program is not responsible for this area.
0	There is no evidence of this indicator.
1	There is minimal evidence of this indicator, but clear evidence exists that the program is in the process of planning for implementation and/or staff development.
2	There is some evidence of this indicator <i>or</i> there is clear evidence of the indicator for only a portion of students with autism.
3	This quality indicator is clearly evident for all students with autism.

INDIVIDUAL EVALUATION: Thorough diagnostic, developmental, and educational assessments using a comprehensive, multidisciplinary approach are used to identify students' strengths and needs.		Score	Comments
1)	Evaluations are conducted by multidisciplinary teams made up of qualified personnel who are familiar with the characteristics and response patterns of students with autism.	.	.
2)	The medical and developmental history review factors specific to autism.	.	.
3)	Evaluations include the examination of the individual skills and strengths of students with autism, as well as their needs.	.	.
4)	Evaluations use a variety of measures and sources of information, including: a) appropriate standardized, developmental, and observational methods, b) autism-specific measures, c) parent and family input, d) review of recent progress and functional level.	.	.

5)	For both verbal and nonverbal students, speech and language evaluations use standardized measures, parental report, observation, and spontaneous language samples to assess: a) receptive language, b) expressive language, c) speech production, d) communicative intent, e) pragmatics.	.	.
6)	Evaluation reports integrate results from all areas in ways that lead directly to programmatic recommendations for instruction.	.	.
7)	Evaluation reports are written in a meaningful, understandable manner.	.	.
8)	Evaluation reports are shared with the student (if appropriate), parents, educators, and other professionals who work collaboratively with the family.	.	.
Summary Rating for Individual Evaluation		.	.

DEVELOPMENT OF THE INDIVIDUALIZED EDUCATION PROGRAM: The Committee on Preschool Special Education (CPSE) and the Committee on Special Education (CSE) use evaluation results, parent and family concerns, and present levels of performance in developing individualized education programs (IEPs) to meet students' needs.		Score	Comments
1)	The IEP identifies developmental, health, social-emotional, and behavioral needs.	.	.
2)	While the IEP addresses a broad range of developmental and educational needs, it specifically includes the areas of: a) communication, b) social interaction, c) behavior and emotional development, d) play and use of leisure time.	.	.
3)	Goals and objectives: a) relate directly to the student's present level of performance and identified needs, b) reflect parental input and family concerns, c) are observable and measurable, relate to long-term outcomes, d) are selected to achieve long-term outcomes.	.	.
4)	The IEP identifies program modifications, including environmental and instructional adaptations and accommodations, that are needed to support the student.	.	.
5)	"Parent counseling and training" is indicated as a related service as appropriate.	.	.
6)	Augmentative and alternative communication systems are considered for students with limited verbal abilities.	.	.
7)	Opportunities for interaction with nondisabled peers are provided as appropriate.	.	.
Summary Rating for Development of the IEP		.	.

CURRICULUM: The program uses a curriculum that addresses the significant skill deficits of students with autism and relates to the New York State Learning Standards.		Score	Comments
1)	The curriculum contains a written statement of goals and philosophy from which instructional objectives, methods, and activities proceed.	.	.
2)	The curriculum focuses on maximizing independent functioning in home, school, vocational, and community settings.	.	.
3)	The curriculum is adapted to the different ages, abilities, and learning styles of students with autism.	.	.
4)	The curriculum emphasizes the development of: a) attention to social stimuli, b) imitation skills, c) communication and language, d) social relationships, e) symbolic play, imagination, and creativity, f) self-regulation, g) skills to meet the learning standards, h) vocational skills.	.	.
5)	With respect to communication, the curriculum emphasizes the development of a functional communication system for both verbal and nonverbal students with autism.	.	.
6)	With respect to social relationships, the curriculum emphasizes the development of social interaction skills with adults and peers for a range of occasions and environments.	.	.
7)	The curriculum focuses on the maintenance and generalization of learned skills to more complex environments.	.	.
Summary Rating for Curriculum		.	.

INSTRUCTIONAL ACTIVITIES: The program provides a variety of developmentally and functionally appropriate activities, experiences, and materials that engage students in meaningful learning.		Score	Comments
1)	Instructional activities: a) enhance response opportunities, b) are appealing and interesting, c) promote active engagement of the student, d) focus on basic skills before more complex skills, e) provide multiple opportunities for practicing skills identified on the IEP, f) are (whenever possible) embedded within ongoing and natural routines of home, school, vocational, and community settings.	.	.

2)	Activities use a variety of instructional formats—one-to-one instruction, small group instruction, student-initiated interactions, teacher-directed interactions, play, peer-mediated instruction—based upon the skill to be taught and the individual needs of the student.	.	.
3)	IEP goals and instructional methods are compatible and complementary when the program uses components of different intervention approaches.	.	.
4)	Instructional activities are adapted to the range of ages, abilities, and learning styles of students with autism.	.	.
5)	Daily instruction is provided to meet the individual communication needs of students with autism.	.	.
Summary Rating for Instructional Activities		.	.

INSTRUCTIONAL METHODS: Teaching methods reflect the unique needs of students with autism and are varied depending on developmental appropriateness and individual strengths and needs.		Score	Comments
1)	Instructional methods are adapted to the range of ages, abilities, and learning styles of students with autism.	..	.
2)	Instructional methods reflect empirically validated practices or solid evidence that demonstrates effectiveness over time.	.	.
3)	The degree of structure and intensity of teaching are geared to the functional abilities of the student.	.	.
4)	Instructional methods: a) emphasize the use of naturally occurring reinforcers, b) promote high rates of successful performance, c) encourage communication and social interaction, d) encourage the spontaneous use of learned skills in different settings.	..	.
5)	As instruction proceeds, an effort is made to teach students to cope with the distractions and disruptions that are an inevitable part of daily living.	.	.
6)	There is a clear plan showing methods for systematically promoting the maintenance and generalization of learned skills to new and different environments.	.	.
Summary Rating for Instructional Methods		.	.

INSTRUCTIONAL ENVIRONMENTS: Educational environments provide a structure that builds on a student's strengths while minimizing those factors that most interfere with learning.		Score	Comments

1)	Environments are initially simplified to help students recognize relevant information.	..	.
2)	When needed (particularly for younger students), classrooms have defined areas that provide clear visual boundaries for specific activities.	.	.
3)	Environmental supports (e.g., the use of visual schedules) are available that facilitate the student's ability to: a) predict events and activities, b) anticipate change, c) understand expectations.	.	.
4)	Communication toward and with students: a) is geared to their language abilities, b) is clear and relevant, c) encourages dialogue (when appropriate), rather than being largely directive.	.	.
Summary Rating for Instructional Environments		.	.

REVIEW AND MONITORING OF PROGRESS AND OUTCOMES: The program uses a collaborative, ongoing, systematic process for assessing student progress.		Score	Comments
1)	The program provides regular and ongoing assessment of each student's progress on his/her specific IEP goals and objectives.	.	.
2)	Student progress is summarized and reviewed by an educational team.	.	.
3)	Students are assessed and the instructional program is refined when: a) target objectives have been achieved, b) progress is not observed after an appropriate trial period, c) target objectives have not been achieved after an appropriate trial period, d) there is an unexpected change in a student's behavior or health status, e) significant changes occur in the home, school, vocational, or community setting.	.	.
4)	The program routinely reports to the CPSE or CSE when there is a need to consider modifications to the IEP.	.	.
Summary Rating for Review and Monitoring of Progress		.	.

FAMILY INVOLVEMENT AND SUPPORT: Parents are recognized and valued as full partners in the development and implementation of their children's IEPs.		Score	Comments
1)	Parents and family members are supported as active participants in all aspects of their child's ongoing evaluation and education to the extent of their interests, resources, and abilities.	.	.
2)	Parents are informed about the range of educational and service options.	.	.

3)	The program demonstrates an awareness and respect for the culture, language, values, and parenting styles of the families they serve.	.	.
4)	The program makes available "parent counseling and training" services, which: a) provide parents with information about child development, b) assist parents to understand the needs of their child, c) foster coordination of efforts between school and home, d) support the family in behavior management, e) enable parents to acquire skills to support the implementation of their child's IEP.	.	.
5)	Parents are provided with opportunities to meet regularly with other parents and professionals in support groups.	.	.
6)	Parents receive regular communication from the program regarding their child's progress.	.	.
7)	Parents are assisted in accessing services from other agencies (when available and as appropriate) such as respite, in-home behavior support, home health care, transportation, etc.	..	.
Summary Rating for Family Involvement and Support		.	.

INCLUSION: Opportunities for interaction with nondisabled peers are incorporated into the program.		Score	Comments
1)	The program offers opportunities for interaction with nondisabled peers in both informal and planned interactions.	..	.
2)	In their contact with nondisabled peers, students are provided with instruction and support to maximize successful interactions.	.	.
3)	The program provides nondisabled peers with knowledge and support (e.g., peer training) to facilitate and encourage spontaneous and meaningful interactions.	.	.
4)	Training and ongoing support are provided to the general education teachers and staff.	.	.
Summary Rating for Inclusion		.	.

PLANNING THE MOVE FROM ONE SETTING TO ANOTHER: Parents and professionals work collaboratively in planning transitions from one classroom, program, or service delivery system to another.		Score	Comments
1)	All aspects of planning include the student (whenever appropriate), parents and other family members, current and receiving professionals, and other relevant individuals.	.	.

2)	Transitional support services are provided by a special education teacher with a background in teaching students with autism.	.	.
3)	Transition planning: a) begins while the student is in the current placement, b) provides the student and family with the opportunity to visit the new setting (i.e., meet teachers, view classrooms).	.	.
4)	Planning integrates considerations of future placements (i.e., skills needed in the next classroom or school setting) with the student's current program.	.	.
5)	Planning includes teacher preparation and other supports to ensure success of the student in the new classroom, school, or work site.	.	.
Summary Rating for Planning the Move from One Setting to Another		.	.

CHALLENGING BEHAVIOR: Positive behavior supports, based on a functional behavioral assessment (FBA), are used to address challenging behavior.		Score	Comments
1)	The program has a school-wide behavioral system that: a) defines expectations for appropriate behavior in all instructional settings, b) uses proactive approaches to managing behavior, c) has established strategies for crisis intervention, d) provides training for staff in recommended behavioral strategies.	.	.
2)	A FBA is used to direct intervention planning for persistent challenging behaviors.	.	.
3)	Multiple methods (e.g., direct observations, functional analysis, rating scales, and interviews) are used in conducting the FBA.	.	.
4)	The FBA identifies both immediate (e.g., request to perform a task) and more distant (e.g., poor sleeping habits) factors that increase challenging behaviors.	.	.
5)	The FBA identifies one or more functions for the challenging behaviors.	.	.
6)	Environmental accommodations and adaptations are used to prevent or minimize occurrences of the problem behavior.	..	.
7)	Instruction in alternative, appropriate skills (e.g., communication, social, or self-regulatory skills) is routinely incorporated into behavior intervention plans.	.	.
8)	Behavioral interventions are based on positive supports and strategies.	.	.
9)	Behavior intervention plans focus on long-term outcomes (e.g., making new friends, participating in extracurricular activities).	.	.
Summary Rating for Challenging Behavior		.	.

COMMUNITY COLLABORATION: The program links with community agencies to assist families in accessing supports and services needed by students with autism.		Score	Comments
1)	The program develops links with different community agencies that provide the comprehensive services often needed by students with autism.		
2)	The program assists parents in defining their child's outside-of-school needs, such as respite, in-home behavior support, home health care, transportation, etc.		
3)	Parents are assisted in accessing services from community agencies.		
Summary Rating for Community Collaboration			

PERSONNEL: Teachers, teacher aides and assistants, related service providers, school psychologists, administrators, and support staff are knowledgeable and skilled related to the education of students with autism.		Score	Comments
1)	Staff are knowledgeable and skilled in the areas of expertise specific to autism, including: a) characteristics of autism, b) familiarity with assessment methods, c) developing IEPs to meet the unique needs of each student, d) curriculum, environmental adaptations and accommodations, and instructional methods, e) strategies to improve communication and social interaction skills, f) classroom and individual behavior management techniques.	.	.
2)	Staff participate in continuing professional development (e.g., consultation, workshops, conferences) designed to further develop their knowledge and skills.	.	.
3)	Staff are available in a ratio sufficient to provide the support necessary to accomplish IEP goals.	.	.
4)	Teachers and related service providers have access to students' IEPs and are informed of their responsibilities for implementation.	.	<="">.
5)	Paraprofessionals receive specific and direct instruction and supervision regarding their IEP responsibilities to the student.	.	<="">.
6)	Ongoing support and technical assistance are available to resolve concerns related to learning and behavior.	.	<="">.
Summary Rating for Personnel		.	<="">.

PROGRAM EVALUATION: Systematic examination of program implementation and impact is conducted, including the aggregation of individual student outcomes and consumer satisfaction.		Score	Comments
1)	The program incorporates evaluation systems that assess program-wide effectiveness in the areas of: a) students' progress toward mastery of IEP goals, b) student performance on State and districtwide tests (including, as appropriate, student performance on the State Alternate Assessment) c) students' generalization of skills, d) student progress toward long-term outcomes.	.	.
2)	The program evaluates short-term (e.g., weekly or bi-weekly), intermediate (e.g., quarterly), and long-term (e.g., yearly) changes in student progress.	.	.
3)	Parents regularly receive feedback on their child's progress toward meeting IEP goals and objectives.	.	.
4)	Program evaluation includes measures of consumer satisfaction with services.	.	.
5)	Information obtained from program evaluation is used for program improvement.	.	.
Summary Rating for Program Evaluation		.	.