Service gaps among children with autism spectrum disorder (ASD) and their families in selected sites of Addis Ababa

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May 2024

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A thesis submitted to School of Social work

Presented in Partial fulfillment of the requirement for the

Degree of Master of Social Work

Addis Ababa University

Addis Ababa, Ethiopia

May 2024,

Addis Ababa University

School of Graduate Studies Program

This is to certify that this thesis, prepared by Marta Teklie, titled ‘Service gaps among children with autism spectrum disorder (ASD) and their families in selected sites of Addis Ababa’ and submitted in partial fulfillment of the requirements for the Degree of Master of Social Work (MSW), complies with the regulation of the University and meets the accepted standards with respect to originality and quality

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Acknowledgement

First and foremost, I would like to express my deepest gratitude to my advisor, Dr. Tenagne Alemu, for his unwavering guidance, support, and mentorship throughout this research. Your expertise, constructive feedback, and encouragement have been invaluable in shaping the direction and quality of this thesis. I am truly grateful for the opportunity to work under your supervision and learn from your wealth of knowledge.

I would also like to thank the staff of Betemihret, the director and special needs teacher at Kokebe Tsibah primary school, and the speech therapist at Yekatit 12 hospital, for their valuable insights, thoughtful discussions, and collaborative efforts during this research. Your willingness to share your perspectives and expertise has greatly enriched my work.

To my dear friend, Beli, thank you for your unwavering emotional support and intellectual stimulation. You have been a source of strength and inspiration during the challenges of completing this thesis.

I also appreciate the support that my colleagues Girma and Mergitu have provided. If not for your understanding and flexibility with my circumstances during this process, I would not be finishing my research.

Finally, I would like to express my heartfelt gratitude to my family, especially my husband, for their unconditional love, encouragement, and understanding throughout this journey. Your support has been the foundation upon which I have been able to pursue my academic aspirations.

Above all, I am grateful to God Almighty and My Kidanemihret; without them, none of my strength, courage, or devotion would be possible.

Abstract

Autism Spectrum Disorder (ASD) is a growing public health concern in Ethiopia, with limited research on the availability and accessibility of specialized services for affected children and their families. This research aimed to investigate the critical service deficiencies faced by children with ASD and their caregivers in Addis Ababa. A qualitative, cross-sectional research was conducted in Addis Ababa, involving in-depth interviews with six parents/caregivers of children with ASD, a key informant interview with one healthcare professional, one education specialist, and one service provider for the ASD population. Observation was also integrated into the deployed methods to better understand the daily activities of parents and caregivers and the situation of the services provided. The findings revealed significant gaps and challenges in the ASD service at the selected sites in Addis Ababa. Key issues included: limited availability of specialized ASD diagnostic, therapeutic, and educational services; shortage of trained professionals and therapists; high out-of-pocket costs for ASD-related services; low public awareness; and slowly progressing government support with loose follow-up in the implementation. The research emphasizes how critical it is to develop a thorough, multi-stakeholder strategy to address the inadequate services for children with ASD in Addis Ababa and throughout Ethiopia. The creation of integrated, family-centered support networks, community-based awareness campaigns, policy changes, increased government funding, and the strengthening of the healthcare and education systems' capacities are all suggested interventions. The quality of life and developmental outcomes for Ethiopian families with children with ASD can be greatly enhanced by filling in these crucial gaps.

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Acronyms

ABA: Applied Behavior Analysis

ASD: Autism Spectrum Disorder

APA: American Psychiatric Association

CBT: Cognitive Behavioural Therapy

CDC: Center for Disease Control and Prevention

CSA: Central Statistics Agency

CwDs: Children with Disabilities

DD: Developmental Disorder/delay

KG: Kinder Garten

OT: Occupational Therapy,

UAE: United Arab Emirates,

Chapter One

Introduction

1.1. Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects individuals' social communication and interaction skills. It is a global public health concern, with an increasing prevalence worldwide (CDC, 2024). While research and awareness about ASD have grown extensively in developed countries, there remains a significant gap in understanding and addressing the needs of children with ASD and their families in developing countries (Uwaezuoke, 2015) . Autism Spectrum Disorder (ASD) affects individuals worldwide, but there are significant disparities in the availability and quality of services for children and their families. Developing countries often face resource constraints, such as limited financial resources, healthcare infrastructure, and trained professionals, which can hinder the provision of comprehensive services (Tekola et al., 2016) .

Studies have indicated that providing early intervention and support to individuals with autism can significantly enhance their outcomes. As a result, there is now more focus on early diagnosis and screening, as well as on creating interventions that are specifically designed to meet the needs of each individual. The goal is to create a more accepting and helpful society for everyone while also acknowledging and addressing the special abilities and difficulties faced by those with autism (Towle et al., 2020). However, limited awareness and understanding of ASD among healthcare professionals and the general public can lead to delayed diagnoses and inadequate support. Cultural and linguistic factors also influence the perception and acceptance of ASD, impacting the availability of evidence-based interventions. Stigma and social isolation can exacerbate the challenges faced by families in accessing appropriate services (Mandell & Novak, 2005).

A variety of therapeutic modalities are employed for autism spectrum disorder (ASD), with the goal of enhancing social skills, behaviour control, and communication. A customised approach is frequently advised because every person with ASD may react differently to different therapies (Anagnostou et al., 2014) From the different studies, it has been indicated that speech therapy, motor skill training, social skills training, applied behavior analysis (ABA), and occupational therapy (OT) are the prominant ones.

Even if demands can be similar, policy frameworks and governmental support for ASD services can vary significantly between developed and developing countries. Addressing these issues can guide the development of targeted interventions, capacity building programs, and policy changes to promote equitable access to services for children with ASD in resource-limited settings.

This research has aimed to explore and identify the deficiencies in services for children with ASD and their families in Addis Ababa city by visiting three selected sites; Yekatit 12 Hospital, Kokebe Tsibah Primary and Secondary School, and Bete Mihret holistic service providing center. The two public sites were selected to understand the service provision and the initiatives of the government, while the third center is selected from the available private centers in order to get diverse perspectives. The research also conducted indepth interviews with six parents, with a focus on understanding the unique challenges they face in accessing appropriate care, support, and interventions. By shedding light on these deficiencies, this research seeks to contribute to the development of effective strategies and interventions to improve the lives of children with ASD and their families in resource-limited settings. Understanding the current state of services for children with ASD in developing countries is crucial for advocating for policy changes, resource allocation, and capacity building to ensure equitable access to quality care and support for this vulnerable population.

1.2. Statement of the Problem

The prevalence of autism spectrum disorder (ASD) has been increasing globally, and it affects individuals across various age groups, cultures, and socioeconomic backgrounds. Despite the growing recognition and understanding of ASD, there are significant challenges that persist in addressing the needs of individuals with ASD and their families. This statement of the problem aims to identify and highlight the identified issues and gaps that exist in relation to ASD, with a focus on demands, availability, and provision of the service in developing nations.

Given the ongoing rise in the occurrence of autism spectrum disorder (ASD), Amit et al. (2024); in the study conducted on early prediction of autism spectrum disorder using developmental surveillance data, indicated the essentials of having efficient early screening methods in order to promptly implement therapies and enhance results. A different study by Hyman et al. (2020) found that to provide great healthcare for children, we need to set up systems that allow accurate and early detection, quick and accurate diagnosis, immediate implementation of interventions based on strong evidence, involvement of the patient and their family in collaborative decision-making, and efforts to reduce differences in access to care for all children and teens with autism. Elder et al. (2017) studied the clinical impact of early diagnosis and indicated that there is an increasing amount of data that shows the importance of diagnosing and treating individuals with ASD early on using interventions that are based on evidence. These interventions can greatly enhance the quality of life for individuals with ASD, as well as for their families and caregivers.

Chu et al. (2018) in their study, showed that an increase in public knowledge about autism spectrum disorder (ASD) and the establishment of structured support groups for ASD could provide parents with beneficial tools and may assist them in overcoming these obstacles through further assistance. In another study conducted in 2016, Taylor Downey at Eastern Illinois University indicated that even though families with children with different special needs face different problems and coping mechanisms depending on the type and situation of their children, their emotions, feelings, and problems seem to be similar. This study examined the family unit of a child with special needs, exploring stressors and emotions. Families may experience similar emotions and characteristics depending on their child's diagnosis, despite different experiences. On the other hand Sadeghi et al. (2022) looked at how parents of children with ASD felt about their quality of life. The results showed that because there are many different factors that affect the quality of life of parents of children with ASD, it is important to take a broad approach and include everyone in the planning, creating, and implementing of future interventions.

Garry Hornby (2015), in his study about inclusive special education, has tried to find a synthesis of both inclusive education and the procedures and strategies of special education. He suggested the development of inclusive special education to design better policies and guidelines for meeting the educational needs of children with special needs. Johnson et al. (2020), on the other hand, studied school counselors interprofessional educational partnerships in school settings for the support of children with special needs. This study just tried to understand the role counselors can play in these teams and the outcomes of these team based approaches, with suggestions for further studies on these collaborations. On the other hand, the study conducted by Georgiadi et al. (2012) about children's attitudes towards peers with intellectual disabilities found that students in inclusive education schools were more positive about children with intellectual disabilities and concluded that social acceptance could be better achieved through promoting inclusive education. There are also studies undertaken to assess the situation of children with special needs in the Ethiopian context. Yoshiko Tonegawa (2019), in his assessment conducted in three selected schools on the policy and practice of inclusive education from the perspective of parents of children with disabilities and the teachers' side, found that studying together with children without disabilities has benefits for children with disabilities. The frustration that families of children with disabilities and teachers have with the practice of inclusive education is also indicated. Tefera et al. (2015) in the study conducted on the education of children with special needs in Ethiopia, indicated that the Ethiopian government has shown commitment to the Millennium Development Goals and Education for All (EFA) through ratifying international conventions and implementing them in domestic laws, policies, and programs. However, there is limited progress in implementing these legal instruments, particularly in the education of children with special needs. The study also showed that the education of these children is alarmingly low, and proper inclusion is less likely.

In their scoping review, Adugna et al. (2020) found that children with disabilities (CwDs) in the Sub-Saharan African countries they looked at; face a lot of problems, including social stigma and negative attitudes, poverty and limited resources, bad policy implementation, physical barriers like not being able to get to places, not having access to transportation, not having privacy, and healthcare professionals who are not properly trained to deal with disabilities. Tekola et al. (2022) studied cultural and religious beliefs that played a role in the types of delays or differences in a child's development that parents noticed early and the kinds of support they sought.

Tekola et al. (2019) explored the perspectives of Ethiopian caregivers, professionals, and other stakeholders to inform adaptation and implementation of the World Health Organization's Caregiver Skills Training in Ethiopia. The study by Zeleke et al. (2017) autism service providers report: found that children with autism spectrum disorders (ASDs) in Ethiopia receive ad hoc skill-based interventions, which are underserved due to a lack of professionals, limited training facilities, and insufficient family support. It underscored the need for educators' training and documentation of strategies used in Ethiopian schools and agencies for ASD children.

In general, the above studies have given due emphasis to different issues like inclusive education for children with special needs, early diagnosis, and the quality of life of families of children with ASD. Some tried to find out the perception of families, the contribution of special needs education, and the inclusion of children with disabilities in other school systems. Much has been said about the involvement of these children in different school systems.

Considerable discussions have taken place around the inclusion of children with special needs, specifically those with autism spectrum disorder (ASD). When examining the study on the accessibility of services for children with autism spectrum disorder (ASD) and their families, particularly in poor countries, there is a notable lack of information. The existing studies just suggest that there is a significant disparity that needs to be addressed. Therefore, this research study aimed to primarily investigate the service gaps between children with autism spectrum disorder (ASD) and their families. It also examined the accessibility and affordability of these services, as well as any government initiatives aimed at addressing these difficulties.

1.3. Research Questions

1. What available services do we have to diagnose children with suspected ASD cases in Addis Ababa?
2. Is there an early intervention program to support children with ASD in Addis Ababa?
3. What are the educational services available for ASD children in Addis Ababa?
4. What are the therapeutic services available for ASD children in Addis Ababa?
5. What do the support system and resources for families of ASD children look like?

1.4. Objectives of the Study

1.4.1. General Objective

This research's general objective is to provide a comprehensive understanding ofthe current service gaps and challenges faced by children with autism spectrum disorder (ASD) and their families in Addis Ababa, with the aim of informing the development of targeted interventions and policies to improve their access to appropriate and effective services.

1.4.2. Specific Objectives

1. Assess the availability and accessibility of diagnostic services for children with ASD in Addis Ababa.
2. Investigate the availability and quality of early intervention services for children with ASD in Addis Ababa.
3. Explore the educational support available for children with ASD in Addis Ababa.
4. Identify the availability, affordability, and accessibility of therapeutic services, such as speech therapy, occupational therapy, and behavioral therapy, for children with ASD in Addis Ababa.

5. Assess the support system and resources available for families of children with ASD, including parent training programs, support groups, counseling services, and access to information and resources on ASD in Addis Ababa.

1.5. Scope of the study

This research is conducted in Addis Ababa, targeting parents of ASD children at Betemihret Holistic Development Organization, Kokebe Tsibah Primary and Secondary School, and Yekatit 12 Hospital. It focuses on identifying the deficiencies in services for children with autism spectrum disorder (ASD) and their families.

In addition, I have included the perspectives of the service providers at Bete Mihret, Kokeb Tsibah primary and secondary schools, and Yekatit 12 Hospital. This has helped me gain a comprehensive understanding of the existing services, barriers, and challenges faced by families in accessing ASD services in Addis Ababa.

1.6. Justification of selection and Overview of the Centers

The selection of the three sites was done based on the presence of specialized services for children with ASD and their families or caregivers. The two public sites were selected to understand the service provision and the initiatives of the government, while the third center was selected from the available private centers that was willing to provide the necessary data in order to get diverse perspectives to address the research questions effectively.

Yekatit 12 Hospital

It is located around the Addis Ababa University main campus (6 kilo). The hospital provides different services through the different departments that are established to support children with ASD and their families therapeutic needs. There is a speech therapy section, a psychiatry department for behavioral therapeutic needs, and a physiotherapy department for occupational and motor skills. The speech therapy centre serves as the primary hub connecting various services for children diagnosed with ASD. Only one of the two experts assigned to the service is functioning at the moment; the other has been assigned to a task involving further education. There is a social worker room as well, but the person assigned to it is now on maternity leave, therefore, it is not in use.

Kokebe Tsibah Primary and secondary school

The school is located on the road to Megenagna before the Russian Embassy. The special needs and inclusive education service at Kokebe Tsibah was established around 1988 with an individual’s initiative. The kindergarten school provides inclusive education to children with ASD and other developmental disabilities. The primary school has four different classes that serve special needs students based on their level of educational capacity. Currently, 62 students with different developmental disabilities who are enrolled in the four classes are getting specialised education. Ten students out of those are children with autism spectrum disorder/ASD. There are 13 teachers in this department, and eight of them are assigned to support children with developmental delays. All are graduates of special needs education, holding diploma or BA degrees. The school provides skill based training and primary self care training for students with special needs, including ASD.

Bete Mihret comprehensive service center

Missionaries founded it and had it recognised as an international nonprofit organisation 25 years ago. It is located around Ferensai, near Blocket Market. At first, it was used as a creche for kids with special needs as well as an orphanage. However, the centre had to deal with the difficulty of having to cease operations before six years since missionaries had made the decision to depart the nation. The centre was kept open and converted into a local non-governmental organisation thanks to its small but dedicated personnel. It currently provides services to fifty (50) children with various developmental disabilities, including autism spectrum disorder.

1.7. Significance of the Research

This research can be a basis for understanding the unmet needs of ASD children, which is an important first step in advocating for improvements. It can also inform policy decisions and guide the allocation of public and private funding to address the most pressing needs of the ASD community. It can contribute to the understanding of service access challenges for the ASD population and advance the broader field of research on ASD interventions and service delivery models as well.

1.8. Definition of Key words

Autism Spectrum Disorder (ASD): ASD is a lifelong neurological condition that affects how a person communicates with and relates to other people. It is called a "spectrum" disorder because the type and severity of symptoms can vary greatly from person to person (Niu et al., 2020).

Service gaps: refer to the unmet needs or lack of available services for children with autism spectrum disorder that include access to diagnosis, early intervention services, evidence-based treatments, family support, etc. (Brown et al., 2012) .

Service needs: refers to the various types of support, resources, and interventions required to meet the developmental, educational, therapeutic, and social needs of individuals with Autism Spectrum Disorder (ASD) (Moodie-Dyer et al., 2014)

Early intervention: Early intervention in the context of Autism Spectrum Disorder (ASD) refers to the provision of specialized services and therapies for young children, typically from birth to age 3 or 5, to address developmental delays and support their growth and learning (Stahmer et al., 2005)

Epilepsy: a neurological condition involving the brain that makes people more susceptible to having recurrent, unprovoked seizures. It is usually defined as a sudden alteration of behavior due to a temporary change in the electrical functioning of the brain. (APA)

Down Syndrome: is a condition in which a person has an extra copy of chromosome 21 that changes how their body and brain develop. This can cause both physical and mental challenges. (CDC)

Severity Levels of ASD:

Level 1 (Requiring Support) - Need some support for social communication and interaction challenges, and/or inflexible behaviors

Level 2 (Requiring Substantial Support) - Marked deficits in social communication and interaction, and inflexible behaviors

Level 3 (requiring very substantial Support) - Severe deficits in social communication and interaction, and inflexible behaviors. (https://www.verywellhealth.com/what-are-the-three-levels-of-autism-260233)

Chapter Two

Review of Literatures

In this chapter, I have attempted to address key topics regarding the research issue, autism spectrum disorder (ASD). Understanding what has been found through the many studies undertaken and what is known about ASD has been the primary emphasis of the review. It provided insight into the meaning, risk factors, diagnosis, people's perceptions, and service requirements of families and children with ASD.

2.1. Understanding Autism Spectrum Disorder /ASD

Autism spectrum disorder (ASD) is a developmental disability caused by differences in the brain. Some people with ASD have a known difference, such as a genetic condition; other causes are not yet known (CDC, 2023). Autism spectrum disorder (ASD) is a condition marked by restricted and repetitive behaviors along with impaired social communication. Since it affects the normal pattern of child development, causes chronic signs and symptoms that typically appear in early childhood and may have long-term effects, and is linked to neurologic changes that may start in prenatal or early postnatal life, it is classified as a neurodevelopmental disorder. The spectrum runs from mild to severe (Deborah Christensen, 2020).

According to scientists, ASD is caused by a combination of factors that alter the typical manner in which people grow. There is still a lot we don't know about these reasons and how they affect individuals with ASD. People with ASD may exhibit distinct behaviors, modes of communication, interactions, and learning from most other people. Frequently, there is nothing unique about their appearance that makes them stand out from the crowd. People with ASD might have a wide range of abilities. For instance, while some people with ASD may be nonverbal, others may possess sophisticated conversational skills. While some people with ASD require extensive support in their everyday lives, others are able to work and lead normal lives with little to no assistance. (CDC, 2022).

ASD usually starts before the age of three. Within the first 12 months of life, some children exhibit symptoms of ASD. Others may not experience symptoms until they are 24 months old or older. Around 18 to 24 months of age, some children with ASD stop learning new abilities or lose the talents they previously had. Until then, they continue to meet developmental milestones and acquire new skills. When kids with ASD grow into teenagers and young adults, they could struggle to make and keep friends, interact with peers and adults, or figure out what kinds of behaviors are appropriate at work or in the classroom. Healthcare professionals may become aware of them if they also suffer from disorders like anxiety, depression, or attention-deficit/hyperactivity disorder, which are more common in those with ASD than in those without it (Boat, 2015). Children may speak more slowly than is typical, not recognise their names, or exhibit no interest in the people around them. It's possible that they struggle with emotional regulation. These children frequently have a tendency to lose control and become irrationally angry. When a child is upset, they may participate in "self-injurious behaviors like head banging, hair pulling, or self-biting." (CDC, 2022).

Research has shown that early intervention and support can greatly improve the outcomes for individuals with autism. This has led to an increased emphasis on early screening and diagnosis, as well as the development of tailored interventions to support the specific needs of each individual. The focus is on understanding and accommodating the unique strengths and challenges of individuals with autism and promoting a more inclusive and supportive society for all (Towle et al., 2020).

2.2. Prevalence rate of ASD

When the first studies on the prevalence of autism were published in the 1960s and 1970s, it was estimated to be four to five instances per 10,000 children (CDC, 2016). By 2002, estimates of the prevalence of autism in the United States were in the range of 6 to 7 per 1,000 children, more than a 30-fold increase from the first studies of autism prevalence (Boat, 2015). On the other hand, the CD has conducted extensive research into the prevalence of autism spectrum disorder and has found that it is four times more prevalent in boys than in girls.

The prevalence rate of autism spectrum disorder in Ethiopia has not been specifically studied or reported. A study conducted by Teshome et al. aimed to estimate the prevalence of ASD in two regions of Ethiopia and found a prevalence rate of 9 in 1,000 children, which is higher than the global average. Given the WHO's 10% prevalence estimate of disability in a population, it can be said that out of the estimated 47,146,457 million children aged 6 to 18 years (CSA, 2008), nearly 4.5 to 5 million children are expected to have disabilities of one kind or another in Ethiopia. However, based on the available sources, it is clear that there is a substantial need for large-scale clinical, training, and research programs to improve the lives of people living with ASD in Sub-Saharan Africa, including Ethiopia (Franz et al., 2017).

2.3. Risk factors for ASD

Research into the possible factors contributing to the development of autism spectrum disorder is ongoing. Scientists have been investigating a variety of potential causes, including genetic, environmental, viral, metabolic, dietary, and neurological factors.

Despite a great deal of research, the cause of ASD is still unknown. In less than 10 to 12% of cases, the precise etiology is known (Ng et al., 2017).

It is suggested that certain gene mutations and variations can increase the risk of developing ASD. However, there is no single gene that is solely responsible for ASD. Rather, it is believed that a combination of multiple genetic variants contributes to the risk. Having a family history of ASD or related conditions increases the likelihood of having a child with ASD. Even though it is widely accepted that there is a major genetic component to ASD, the underlying genetic reason is unknown in at least 70% of cases (Yasmin H. Neggers, 2014).

Other studies have found that both maternal and paternal age at the time of conception can be associated with an increased risk of ASD. Advanced parental age, especially in fathers, has been linked to a higher likelihood of having a child with ASD. The reasons for this relationship are not yet fully understood (Sandin et al., 2012).

Other investigations linked autism to a range of illnesses that can impact brain development. Certain prenatal factors have been associated with an increased risk of ASD. These include exposure to certain medications (such as valproic acid), maternal use of certain drugs during pregnancy, maternal obesity and diabetes, prenatal infections and complications during pregnancy or childbirth (Ng et al., 2017).

Environmental causes of autism are also receiving a lot of attention these days, including viral infections, metabolic disorders, exposure to chemicals in the environment, and toxic substances consumed during pregnancy (Landrigan, 2010). Although the exact environmental factors contributing to ASD are not well understood, some studies have suggested that prenatal and early-life exposures to certain environmental factors may increase the risk of ASD. These factors include exposure to air pollutants, certain chemicals, pesticides, heavy metals (e.g., lead), and maternal exposure to toxins during pregnancy (Lam et al., 2016).

Understanding the underlying causes of autism is crucial for developing effective interventions and treatments for individuals affected by the condition. While there is still much to learn, progress in this field offers hope for improved support and care for those living with autism (Christensen & Zubler, 2020). However, the absolute cause of autism remains unknown.

2.4. Perception of families about Autism Spectrum Disorder (ASD)

The perception of families with autism spectrum disorder varies greatly and is influenced by factors such as cultural beliefs, societal attitudes, personal experiences, and access to resources (Low & Zailan, 2016). The journey of understanding and accepting a diagnosis of ASD can be complex and emotional for families as well. From the initial stages of noticing developmental differences to seeking a formal diagnosis, the impact on the family can be profound. The lack of knowledge about ASD can create significant challenges for families as they navigate the healthcare system and access appropriate interventions for their child (Chu et al., 2018). Moreover, the societal stigma and lack of understanding surrounding ASD can further complicate the experiences of families. They may encounter misconceptions and discrimination, leading to feelings of isolation and frustration. (Abolkheirian et al., 2022)

Some of the important factors affecting the perception of families with ASD, as indicated in different studies, are the following:

Educational Experiences: Research has shown that the level of education of parents or caregivers can significantly impact their perceptions of autism spectrum disorder and influence the way they approach seeking interventions and support for their child. Higher levels of education are often associated with increased knowledge and awareness about ASD, leading to more positive and inclusive attitudes towards individuals with ASD. This can result in more informed decision-making when it comes to seeking appropriate services, therapies, and educational accommodations for children with ASD (Hodgetts et al., 2014). Individuals with higher education levels also have better advocacy skills, empowering them to navigate systems and advocate for their children's needs effectively. Lastly, higher education can provide diverse social networks that offer emotional support and acceptance for families with ASD children, reducing feelings of isolation (Vogan et al., 2014). In contrast, families with lower levels of education may face additional challenges in accessing accurate information about ASD and may encounter barriers in advocating for their child's needs within educational and healthcare settings. In conclusion, the level of education of parents or caregivers can have a significant impact on their ability to understand and navigate the challenges of autism spectrum disorder (Vohra et al., 2013).

Cultural Perspectives: Cultural beliefs, values, and norms can influence families' perceptions of ASD. Cultural factors may shape families' understanding of the causes of ASD, their help-seeking behaviors, and their attitudes towards treatment options. For instance, in some cultures, there may be stigma associated with developmental disorders, leading to feelings of shame or isolation for families with a child diagnosed with ASD. Furthermore, cultural factors can also influence the types of support and interventions that families are willing to consider for their child with ASD. It is important to consider cultural diversity and tailor interventions and services to be culturally sensitive and inclusive (Mandell & Novak, 2005).

Access to resources and support services: this significantly shapes the perception of families with ASD children. The availability of specialized educational programs, therapy services, and community support groups can greatly impact the well-being of both the child and the family. Families with access to comprehensive resources and services may feel more supported and empowered in their journey of raising a child with ASD, while those with limited access may experience additional stress and feelings of isolation. Navigating the healthcare system, advocating for their child's needs, and managing the emotional and behavioral aspects of ASD can be overwhelming for these families (Sim et al., 2017).

Families in Ethiopia face significant psychosocial challenges that include stigma and discrimination from the broader community, as well as feelings of isolation and stress within the family unit. The limited available sources highlight that families in Ethiopia face practical and psychosocial challenges related to raising a child with ASD. It is also crucial to recognize the cultural and societal factors that further impact their experiences. In Ethiopia, there may be limited awareness and understanding of ASD, which can contribute to the stigma and discrimination faced by these families. Furthermore, the cultural expectations and norms surrounding child-rearing and disability in Ethiopia can significantly influence the way families perceive and address ASD.Understanding and addressing the multifaceted challenges faced by these families requires a holistic approach that considers both the practical barriers and the cultural and societal context in which they exist (Tekola et al., 2016).

2.5. Diagnosis of Autism Spectrum Disorder (ASD)

The early detection of neurodevelopmental disorders in children, such as autism spectrum disorder, is one of the major health concerns of the twenty-first century. Since there is no medical test, such as a blood test, to detect autism spectrum disorder (ASD), diagnosis can be challenging. In order to diagnose a child, doctors consider their behavior as well as their developmental history. When a kid or young person receives a late diagnosis, they are deprived of the chance to comprehend how they react in various circumstances. It also suggests more stress for the families, a longer time for other co-occurring disorders to be diagnosed, and more expenses for the family and society financially (Zwaigenbaum et al., 2019).

In the American Psychiatric Association (APA), it is stated that before a child turns one year old, parents, caregivers, or pediatricians may discover early signs of this disorder. However, by the time the child is 2 or 3 years old, symptoms usually become more consistently apparent. Sometimes an autistic child has a moderate functional impairment that is not noticeable until the child enters school. Once in school, the child's deficiencies may become more noticeable when compared to their peers (CDC). Although there is currently no singular test or medical instrument available for diagnosing ASD, various strategies are employed to detect early signs of ASD in children. The following methods are commonly employed:

2.5.1. Developmental Monitoring

The process of actively observing a child's development and promoting dialogue about a child's skills and abilities between parents and caregivers is known as developmental monitoring. Keeping an eye on your child's growth and determining whether they are meeting the normal developmental milestone skills that most kids acquire by a specific age in terms of playing, learning, speaking, acting, and moving is known as developmental monitoring. Developmental monitoring is a collaborative effort between early childhood educators, parents, grandparents, and other caregivers (León et al., 2015).

2.5.2. Administer screening test

Screening is the process of using specialized tests or examinations to identify previously undetected disorders. Developmental screening does not lead to a formal diagnosis but instead highlights areas where a child's development deviates from the expected norms for their age. Consistent and frequent screening is more probable than a solitary test to detect issues, particularly in abilities that mature later, such as language. (Lipkin PH, Macias MM, 2020)

During the 9-month checkup, a screening is conducted to assess the child's motor skills, visual acuity, and hearing capabilities. Communication skills begin to develop at an early stage, and signs of autism spectrum disorder (ASD), such as a lack of eye contact, responding to one's name, or pointing, may be noticeable during the first year of life. (Lipkin PH, Macias MM, 2020)

It is advisable to do a developmental assessment during the 18-month check-up, as delays in fine motor skills, communication, and language development are frequently noticeable by this age. Additionally, previously unnoticed deficits in gross motor skills may also become apparent. Medical treatments for motor problems have been proven to be successful in infants who are 18 months old. Additionally, there are effective early interventions available for children with delayed language development (McQuiston & Kloczko, 2011).

The 30-month visit offers an extra chance to detect motor, linguistic, and cognitive issues, including more subtle delays. It also serves as another opportunity to identify children who have delays that make them eligible for early intervention programmes. An early intervention programme additionally aids the child and family in transitioning to a school-based programme, if necessary. (Michael J. Guralnick, 2016)

2.5.3. Physical Examination and Routine Developmental Surveillance

Surveillance is the continuous and organized gathering of data that is pertinent to the identification of a disorder over a period of time by a unified health system. Developmental surveillance is an ongoing process where experienced healthcare professionals discover children who may have developmental issues. It is characterized by its flexibility, longitudinal nature, continuity, and accumulation of information. It is advisable to pay extra attention to monitoring during the 4- to 5-year well-child visit before starting basic education. Screening should be conducted if there are any concerns (Lipkin and Macias, 2020).

2.5.4. Complete Medical Evaluation

It is necessary to do a medical diagnostic evaluation to determine the underlying cause when there are concerns about a child's development or when a delay has been proven. This assessment should take into account biological, environmental, and known risk factors that may contribute to delayed development (Jee et al., 2010). A complete medical evaluation for children with autism spectrum disorder (ASD) typically involves a comprehensive assessment to gather information about the child's medical history, developmental milestones, behavioral characteristics, and any associated medical conditions by a multidisciplinary team that may include pediatricians, neurologists, psychologists, and speech therapists. A detailed medical history is collected from the child's parents or caregivers, including prenatal, birth, and early developmental histories. Additional medical tests may be recommended based on the child's medical history and clinical presentation. The healthcare team provides feedback to the child's parents or caregivers, offering recommendations for interventions, therapies, and support services (Hyman et al., 2020).

Looking at the situation in developing nations for diagnostic and care options, it seems devastating for ADS children and their families. The shortage of qualified human resources is one of the main challenges to increasing the service supply for families and children with developmental disorders or delays (DD), including autism. This deficiency is most evident in Ethiopia, where there is presently just one child psychiatrist with formal training practicing there, along with twenty clinical psychologists who are not trained in child mental health. Because services for children with developmental disabilities are primarily limited to Addis Ababa, the nation's capital, most people (85%) who live in rural regions cannot access them (Tekola et al., 2019).

The scarcity of professionals with the expertise to provide specialized care and support can lead to long waiting lists and limited access to essential services. Additionally, it can result in a lack of early intervention, which is crucial for children with autism and developmental delays. This shortage creates a disparity in the quality of care available to affected families, highlighting the urgent need for initiatives to address this issue (Tekola et al., 2016) .

2.6. Therapeutic Approaches for Autism Spectrum Disorder (ASD)

There are several therapeutic approaches used for autism spectrum disorder (ASD) that aim to improve communication, social skills, and behavior management. It's important to note that each individual with ASD may respond differently to various therapies, so a personalized approach is often recommended. Here are some commonly used therapeutic approaches for ASD: (Anagnostou et al., 2014)

Speech Therapy: Many individuals with ASD experience difficulties with language and communication. Speech therapy aims to improve communication skills, including verbal and nonverbal communication, speech clarity, and understanding social cues. Techniques may include picture communication systems, sign language, and social skills training (Brignell et al., 2018). Speech therapists work closely with individuals with ASD to address the unique challenges they face in social interactions and understand social cues. In addition to the techniques mentioned, speech therapy often involves tailored interventions that focus on pragmatic language skills, such as turn taking, understanding sarcasm and humor, and interpreting non-literal language. Speech therapists also collaborate with other professionals involved in the individual's care, such as occupational therapists and behavioral therapists, to ensure a holistic approach that addresses the individual's specific needs comprehensively. (Oliveira et al., 2018).

Social Skills Training: Social skills training focuses on teaching individuals with ASD appropriate social behaviors and interactions. It may involve structured group activities, role-playing, and direct instruction to enhance social understanding, perspective-taking, and friendship skills (Matson et al., 2007) By honing these skills, individuals with ASD can feel more confident and comfortable in social settings, ultimately leading to improved social integration and a greater sense of belonging. In addition to the practical aspects of social skills training, it also provides a supportive environment where individuals with ASD can learn from each other and build a sense of community. This inclusive approach fosters a sense of acceptance and understanding, creating a space where individuals can practice their newly acquired social skills in a safe and nurturing setting (Ke et al., 2017).

Applied Behavior Analysis (ABA): ABA is a widely recognized and evidence-based treatment for ASD. It focuses on teaching and reinforcing desired behaviors while reducing challenging behaviors. ABA interventions are typically individualized and structured, using positive reinforcement and prompting techniques to teach new skills. In addition to focusing on teaching new skills, ABA also places emphasis on generalizing these skills across different settings and situations, ultimately promoting greater independence and success for individuals with ASD. The principles of ABA can be applied across the lifespan, addressing a wide range of behaviors and skills that are important for daily living, social interactions, and vocational success (Kasari and Lawton, 2010).

Occupational therapy (OT): it helps individuals with ASD develop and improve skills necessary for daily living, such as fine motor skills, self-care routines, and sensory integration. OT interventions may include activities that promote sensory regulation, motor coordination, and adaptive behavior (Gee et al., 2018). By promoting sensory regulation, occupational therapy can help individuals with ASD learn to cope with sensory overload and engage more comfortably with their environment. Through targeted activities, OT can also support the development of motor coordination, enabling individuals to participate in daily tasks with greater independence and confidence. Additionally, by focusing on adaptive behavior, OT interventions can assist individuals with ASD in acquiring crucial life skills that will enable them to navigate various social and practical challenges. These interventions are designed to address the specific needs of each individual, taking into account their unique sensory sensitivities, motor challenges, and adaptive behavior goals (Gee et al., 2018).

Cognitive Behavioral Therapy (CBT): CBT helps individuals with ASD identify and modify negative thoughts and behaviors. It can be particularly useful for managing anxiety, improving emotional regulation, and addressing challenging behaviors. CBT often involves teaching coping strategies, problem-solving skills, and promoting self-awareness (Storch et al., 2013). In CBT, therapists work closely with individuals with ASD to develop coping strategies and problem-solving skills by promoting self-awareness. This self-awareness can be transformative for individuals with ASD, enabling them to navigate social interactions and daily challenges with greater confidence (Wood et al., 2017).

Motor skill training: Motor skill training for children with autism spectrum disorder involves activities and exercises aimed at improving coordination, balance, strength, and overall motor skills. These training programs often focus on enhancing gross motor skills, such as running, jumping, and climbing, as well as fine motor skills, including hand-eye coordination and dexterity. The training is typically tailored to each child's specific needs and may involve various activities such as sensory integration therapy, occupational therapy, and physical therapy. The goal of motor skill training for ASD children is to help improve their overall physical abilities and support their participation in daily activities and social interactions. (Yu et al., 2018).

Given the diverse treatment modalities and the distinct characteristics of each individual with Autism Spectrum Disorder (ASD), it is strongly advised that collaborating with a team of experts, such as psychologists, speech therapists, occupational therapists, and educators, is crucial in order to create a customized treatment plan that effectively targets the unique requirements and abilities of individuals with ASD.

Based on the above identified basic therapeutics and my search for the context of available services, according to the sources provided, there is limited information available on specific therapeutic approaches for ASD in Ethiopia. However, the need for training and support for professionals working with children with ASD is highlighted, suggesting that therapeutic approaches may be limited or not well-developed (Zeleke et al., 2017). Additionally, the lack of available professionals, the low number of training facilities, and inadequate resources for family support contribute to the under-servicing of children with ASD in Ethiopia. The limited availability of trained professionals and resources for family support can significantly impact the quality of therapeutic interventions for children with ASD. This lack of infrastructure and support systems may lead to gaps in the implementation of evidence-based practices and tailored interventions for individuals with ASD. It is essential to further explore and address the specific barriers that exist within Ethiopia's healthcare and educational systems to enhance therapeutic approaches for ASD and ensure better outcomes for individuals affected by the condition. Despite the limited information available, it is clear that there is a need for improved training and support for professionals working with children with ASD in Ethiopia (Tekola et al., 2016).

2.7. Service Demands of ASD children and families

Children with autism spectrum disorder (ASD) and their families often have unique service demands that can vary depending on the individual's needs and circumstances. Here are some common service demands associated with ASD:

Early Intervention Services: Early intervention is crucial for children with ASD. Families often require access to early intervention programs that provide specialized services for infants and toddlers at risk for or diagnosed with ASD. These services may include developmental assessments, speech therapy, occupational therapy, behavior therapy, and parent training. This team collaborates to create comprehensive and individualized treatment plans that address the specific communication, sensory, and behavioral needs of each child (Elder et al., 2017).

Special Education: Many children with ASD require specialized education services to support their learning and development. This may include individualized education plans (IEPs), classroom accommodations, and support from special education teachers or aides. Families may need assistance navigating the special education system and advocating for their child's needs. Special education teachers and aides play a crucial role in providing tailored support to ensure that children with ASD can access a meaningful education (Kurth & Mastergeorge, 2009). Building a strong partnership with the school and district can ensure that children receive the appropriate services and accommodations to thrive academically and socially (Trainor, 2008).

Inclusive Education: Inclusive education refers to the practice of integrating students with disabilities, including ASD, into mainstream educational settings. Some families may have positive experiences with inclusive education, where their child with ASD is welcomed and supported in a regular classroom alongside their typically developing peers. This inclusive educational approach has been shown to have numerous benefits for students with ASD, including improved academic and social outcomes, increased opportunities for peer interaction and friendship building, and enhanced self-esteem and confidence (Low et al., 2019). In addition to ASD children, all students in inclusive classrooms develop empathy, understanding, and acceptance. The positive impact of inclusive education reaches far beyond academic and social outcomes, contributing to the creation of a more inclusive society as a whole (Dyer, 2022).

Specialized Interventions: Families may seek specialized interventions and therapies to supplement their child's educational experience. These interventions can include applied behavior analysis (ABA), speech and language therapy, occupational therapy, social skills training, and sensory integration therapy, among others. As in other services for ASD children, in specialized interventions, it's important to take into account the specific needs and challenges of the child. Applied behavior analysis is a well-established therapy that focuses on improving behaviors and developing new skills. Speech and language therapy can greatly benefit children who struggle with communication, and occupational therapy is essential for those who need support with everyday tasks and activities. (Makrygianni et al., 2018)

Behavioral Interventions: Challenging behaviors are common in children with ASD, and families may need support in managing and addressing these behaviors. Applied Behavior Analysis (ABA) therapy is often utilized to teach adaptive skills, reduce problem behaviors, and enhance communication and social skills. By gaining insight into the triggers and maintaining factors of challenging behaviors, parents and caregivers can develop effective intervention strategies. These interventions focus on enhancing emotional regulation, problem-solving skills, and social interactions, offering full support for children with ASD and their families (Soorya et al., 2013).

Speech and Language Therapy: Communication difficulties are a hallmark of ASD. Children with ASD may require ongoing speech and language therapy to improve their communication skills, including speech articulation, expressive and receptive language, and social communication. Families may need access to qualified speech therapists who specialize in working with individuals with ASD. Speech articulation, expressive and receptive language, and social communication are areas that can be specifically targeted in therapy sessions. Speech therapists also collaborate closely with families to ensure that communication strategies and support techniques are effectively implemented at home and in other settings Kasari et al., 2014).

Mental Health Services: Individuals with ASD are more likely to experience mental health challenges, such as anxiety, depression, and attention difficulties. Families may require access to mental health professionals who have experience working with individuals with ASD and can provide appropriate assessment, counseling, and support. These professionals can provide not only assessment and counseling but also invaluable support for both the individual with ASD and their family members. Moreover, they can guide families in developing strategies and interventions that are well-suited to the individual's strengths and challenges, ultimately enhancing their overall well-being.(Becerra et al., 2017)

Respite Care and Parent Support: Caring for a child with autism spectrum disorder can be an all-encompassing task that takes a toll on parents and caregivers. It's important to acknowledge that the unique needs and challenges of a child with ASD can be overwhelming at times. Respite care services can provide crucial temporary relief for parents and caregivers, allowing them to take a much-needed break while ensuring their child's care needs are still being met. These services can be a lifeline for families, offering them the opportunity to recharge and rest (Cooke et al., 2020). In addition, joining parent support groups and accessing available resources can be immensely beneficial. These groups provide a sense of community and understanding, allowing parents to connect with others who are going through similar experiences. Furthermore, accessing resources such as educational materials, workshops, and online forums can equip parents with the knowledge and skills necessary to provide the best care for their child. (Catalano et al., 2018)

It is crucial to delve into the existing support services and interventions tailored for ASD children and their families in Ethiopia. This includes examining the quality and availability of therapies, educational programs, and community support networks that aim to address the specific needs of individuals with ASD and their families in the Ethiopian context. By thoroughly exploring these aspects, a clearer picture can be drawn of the service demands and gaps that exist in providing comprehensive support for ASD children and families in Ethiopia. Exploring the economic and infrastructural barriers that affect the delivery of services for ASD children is crucial. This includes looking into the affordability of therapy and interventions, as well as the geographical accessibility of support services in both urban and rural areas of Ethiopia (Tekola et al., 2016)

It's important for families to have access to a range of services that address the specific needs of their child with ASD, as well as support for their own well-being. Collaboration with healthcare providers, educators, and community organizations can help ensure that these service demands are met effectively.

2.8. Available services for ASD children in developing nations

Children diagnosed with autism spectrum disorder face unique challenges, and it's essential for developing nations to offer appropriate services to support their needs. In developing countries, such as Ethiopia and other nations, the availability of services for children and families affected by autism spectrum disorder is often limited and inadequate. This is mainly due to various factors, such as a lack of awareness and understanding of ASD, limited funding for research and intervention programs, a scarcity of trained healthcare professionals, and a lack of government prioritization (Franz et al., 2017).

In Ethiopia, while the government has shown commitment to international conventions and domestic laws regarding education for all, the ground reality indicates limited progress in the implementation of these legal instruments for children with special needs. The findings of this analysis reveal the complexities and challenges surrounding the education of children with special needs in developing nations like Ethiopia. The need for a more nuanced and community-focused approach to education for children with special needs is evident, and further research and collaboration are required to address these issues effectively (Tefera et al., 2015).

Another study has shown that early intervention can significantly improve outcomes for children with ASD. By providing early screening and intervention services, developing nations can make significant strides in supporting the developmental needs of ASD children. Furthermore, creating community-based support networks can also be instrumental in providing ongoing assistance to families. These networks can offer a platform for sharing experiences, resources, and emotional support, ultimately fostering a sense of belonging and understanding for families of children with ASD. In addition to addressing the immediate needs of ASD children, it is essential to focus on long-term planning for their transition into adulthood. Developing vocational training programs and creating job opportunities for young adults with ASD can help promote independence and self-sufficiency (Jónsdóttir et al., 2018). Moreover, it is essential to address the societal attitudes and stigma surrounding ASD in these regions. Awareness campaigns and advocacy efforts can play a significant role in changing perceptions and fostering acceptance and inclusion for individuals with ASD. By promoting understanding and empathy within communities, it is possible to create an environment that is more supportive and accommodating for children with ASD and their families.

Parents of children with ASDs reported a lack of available services and skilled providers, indicating the need for an increased supply of appropriate services with qualified providers in developing nations (Montes et al., 2009). Additionally, programs that help families find appropriate local services and daytime activities for their ASD children can be particularly beneficial in these countries (Vohra et al., 2013). In the absence of an adequate adult service system, it becomes even more imperative to empower and equip parents with advocacy skills to access and develop support and community activities for their children as they grow into adulthood (Smith et al., 2012). As a result, families in these countries often struggle to access appropriate diagnosis, intervention, and support services for their children with ASD. In order to bridge the gaps in the availability of services for ASD children and families in Ethiopia and other developing nations, it is crucial for governments to prioritize the funding and development of comprehensive and sustainable service provision (Tekola et al., 2016).

In conclusion, it is evident that there is a pressing need for improved services and support systems for ASD children in developing nations. The challenges faced by these children and their families cannot be overlooked, and it is essential to prioritize the allocation of resources and the training of qualified professionals to address these needs. It is crucial to continue exploring ways to enhance the quality and accessibility of services for ASD children in developing nations, ultimately aiming to improve their overall well-being and quality of life. By delving deeper into the specific challenges and opportunities for growth in providing services for ASD children in developing nations, we can work towards creating sustainable and effective support systems that prioritize the well-being and quality of life for these children and their families.

While there has been significant research conducted on autism spectrum disorder (ASD), there are still some gaps and areas that could benefit from further investigation. Research on available services for children with autism spectrum disorder in developing nations is crucial for understanding the support systems in place and identifying potential areas for improvement. Therefore, exploring the availability and effectiveness of services such as early intervention programs, specialized education, therapy options, and community support initiatives is the major focus of this research study. Understanding the landscape of available services and the associated challenges can lay the groundwork for developing targeted interventions and policies to better support ASD children and their families in these settings.

Chapter Three

Research Methods

3.1. Research Design

I utilized an exploratory, cross-sectional, qualitative research approach for this study. In the case of studying the deficiencies in services for children with ASD and their families in Addis Ababa, a qualitative method with in depth interviews and involving key informants has been employed to explore the complexities and nuances of the topic. These methods allowed for capturing the diverse range of experiences, perspectives, and contextual factors that influence service provision in a specific setting. This research has tried to explore the service gaps that families who have a child with ASD face through qualitative, exploratory research. I engaged a sufficient sample of participants in individual interviews selected using the purposive sampling method. I have reached out to respondents through a snowball sampling technique subsequent to the initial interview. To respond to my research questions, I used indepth interviews, key informants, and observation.

3.2. Methods of Data collection

In-depth interview

My research questions through the designed indepth interview guiding tool were answered by the in-depth interviews conducted with parents, and caregivers of ASD children. There were six interview participants selected from Bete Mihret, and others through a snowball technique. These interviews helped me to capture the lived experiences and challenges faced by parents and caregivers in accessing and utilizing services for children with ASD. The snowball method was used to approach parents of children with special needs and solicit their participation in the research. The interview guiding questions were translated, and the interview was conducted in the local language (Amharic) to better facilitate and create interactive communication so that detailed information can be obtained from participants. The interviews of four participants were voice recorded using the equipment I provided and kept on my laptop, to which I have exclusive access. Two of the interview participants were not comfortable with having the records of the interview; hence, I only took notes on the responses. The major issues discussed through the indepth interview have helped me explore the service demands of children with ASD and their parents, the gaps in accessing those services, and the challenges that families face during the process of caring for a child with ASD.

Key informant interview

To respond to my 2nd and 3rd research questions and enhance my understanding of the delivery, affordability, and quality of services, a key informant interview was used with school teachers and healthcare providers of children with ASD in Kokeb tsibah and Yekatiut 12 hospital. This interview was held with the aim of exploring the available services at the centes, how accessible they are to the beneficiaries, what challenges they face during service delivery, and how its provided. It has helped to explore their experiences, and challenges related to ASD services from the provider's perspective.

Observation

The observational method of directly witnessing the day-to-day experiences of children with ASD and their families and service providing centers has offered me valuable insights into the practical challenges parents and caregivers encounter in accessing and utilizing services for their children with ASD. I have conducted observations of parents and caregivers at Bete Mihret for two days while giving their children to the center, during their stay in the center, and taking them out and back home. My observation at Yekatit 12 Hospital was conducted for four days. The office was closed during my three days. I visited Kokebe Tsibah primary and secondary schools once. The observation checklist annexed to this paper provides details of what has been done in this regard.

3.3. Sampling and sample size

A purposive sampling approach was used to select participants who have direct experience or expertise in providing or receiving services for children with ASD in Addis Ababa. It was entirely voluntary for them to take part in the research. The sample includes families of children with ASD, healthcare professionals specializing in ASD, educators, and non-governmental organizations involved in supporting individuals with ASD. A diverse range of perspectives and experiences were sought to capture a comprehensive understanding of the deficiencies in service provision. I engaged five parents and one caregiver for this research. Three of them were selected from Bete Mihret, and the other three were approached through a snowball method that I get contacts from the first three participants. For the key informant one speech therapist at Yekatit 12 Hospital, one special needs teacher from Kokebe Tsibah, and the executive director of Bete Mihret holistic development centers took part.

Upon the individuals' agreement to participate, I determined whether they fit the parameters for the study. The parameter of this study was having a child with a developmental disability, especially autism spectrum disorder. The interview continued until the research reached data saturation. From my indepth interview with the six parents and caregivers, I have reached the desired data saturation and have completed having additional interview participants.

3.4. Data Analysis

Deductive thematic analysis was used to analyze the qualitative data collected from interviews. Deductive, or prior, analysis generally means applying a kind of “top-down” approach to data analysis, which often means applying predetermined codes to the data (Bingham, A.J. 2023). The codes were developed from five research questions that I proposed for my research. Based on this, the thematic analysis, used a six-step system to help establish clarity. The six steps are: familiarization, generating codes, generating themes, reviewing themes, defining and naming themes, and creating the report. The data was transcribed, coded, and categorized to identify themes, patterns, and deficiencies in the services for children with ASD and their families (Nowell et al., 2017). The analysis involved comparing and contrasting the perspectives of different stakeholders to gain a comprehensive understanding of the deficiencies in service provision in Addis Ababa. I have been regularly comparing fresh interview data to pre-existing categories as I conduct each interview in order to either support or eliminate categories. Then, qualitative information gathered through interviews and categorizations was described in words. Based on the specified objectives, the results gathered using the data collection tools were triangulated before being interpreted. In order to get a trustworthy presentation, the interpretation's outcomes were finally debated and compiled.

3.7. Ethical Considerations

Ethical guidelines, including informed consent, confidentiality, and voluntary participation, were strictly followed throughout the research. The necessity for voluntary and impartial involvement was properly communicated to the research participants. They were told that there is no risk of participating, and the consent form that was included makes it clear that they have the choice to withdraw. Based on the information provided, two of the indepth Interview participants were not voice recorded. The information they provided was kept personal and anonymous. The permission forms further state that participation is not subject to compensation or other perks.

3.8. Limitations of the study

The small sample restricts the representation of diverse perspectives and experiences within the population of interest. In addition, the potential loss of interest from families due to repeated interviews by different researchers limited expanded discussion.

The research was also limited by time and resource constraints, which could have an impact on the depth and breadth of the data gathered.

Chapter Four

Findings

The findings presented in this section form the core of the research conducted in this thesis. Through rigorous analysis and interpretation of data, this study aims to provide insights and contribute to the existing body of knowledge on the availability of services for parents and caregivers of ASD children. The findings presented herein shed light on key aspects and address the research questions and objectives outlined in the earlier chapters. This chapter delves into the findings obtained, organized thematically or by research question, to facilitate a comprehensive understanding of the findings. By examining the data through this lens, we can identify patterns, relationships, and trends that contribute to a deeper understanding of the research topic.

4.1. Basic information of participants

This exploratory research involved five parents and one caregiver of ASD children, one executive director of a service providing center, one special needs education teacher, and one speech therapist. I have used indepth interviews, key informants, and the observational method to capture the different views of research participants and respond to the five research questions.

Table 1. Parents/caregiver participants in the indepth interview

S.No	Name of parent/ or caregiver	Status	Age	Child's Name	Age	Sex	Communicationn	Diagnosis	Severity
1	Tsigereda	Parent	32	Kebron	12	Male	Non Verbal	Autism + Eplipsy	Level 3
2	Alem	Parent	28	Selma	11	Female	Non verbal	Autism	Level 2
3	Etsegenet	Parent	34	Wongel	7	Male	Non Verbal	Down syndrem	
4	Mergitu	Caregiver	42	Yike	5	Male	Non	Autism	level 1

							verbal		
5	Haile	Parent	38	Alazar	8	Male	Non Verbal	Autism	level 2
6	Belaynesh	Parent	37	Issac	6	Male	Verbal	Autism	level 1

Table 2. Service center participants for the key informant interview

S.No	**Name**	**Center**	**Role**
1	Tigist	Bete Mihret a holistic development organisation	Executive director
2	Tigist	Kokebe Tsibah secondary school	Special education teacher
3	Akalu	Yekatit 12 Hospital	Speech Therapist

4.2. Parents experience accessing Diagnostic Service for ASD children

The first step in starting treatment for ASD children is the diagnosis. Though no laboratory or blood test is available to confirm the situation of a child with ASD, a physician assessment is essential to confirm the situation and understand the different spectrums that the child is having. Looking for a confirmed diagnosis was almost impossible for my respondents due to a lack of specialty centers and/ or skilled professionals to undertake the diagnosis.

Tsigereda, said that "*looking for a physician to identify the situation of my child was the hardest part of my journey. At the age of 1.3 years, due to a repeated seizure and his developmental delays, I went to a neurologist and confirmed that my child has epilepsy. I was trying to find a solution to that and suspected that my child had additional problems. At the age of 3, he hasn't started talking, he doesn't respond when we call his name, and no eye contact was seen while with people around him. When I told his neurologist, he just told me what he suspected and referred me to a doctor. However, there was no proper diagnosis to identify my child's case.* "

Another caregiver, Mergitu, informed me that her sister's son was living in the USA when he was diagnosed with ASD. The diagnosis was not as easy as it is believed to be in the developed world. The health care system and the insurance policy have made it a very difficult process for her sister to diagnose her son’s developmental delay. There isalso a very long waiting list in the registry for the diagnosis. Hence, her sister has decided to bring her child back to Ethiopia because the situation was devastating for her.

The executive director of Bete Mihret has indicated that many parents came with unconfirmed cases of their child’s developmental delay. “*For us as an institution providing support for children with developmental delays, we need a confirmed diagnosis indicating the level of their delay to categorise them in our class. However, parents didn’t get an appropriate health center to provide such a diagnosis. The pediatricians in different clinics just try to understand the child's case from the discussion with their parents to confirm that the child has developmental delays.”*

Belaynesh, who has been living abroad and understands her child’s developmental delays,. Her search for a diagnosis ended up in two cancellations after the registry due to long waiting and the incident of COVID, which forced her to get a very late diagnosis for her child after a repeated registration in her residence. She mentioned that the diagnosis was done through a virtual consultation with the pediatrician, and they just provided her with a long list of checklists to confirm her child’s situation from his daily activities. Identifying the different actions and behaviours was the work she did to come up with the confirmation of her child’s ASD.

Alem, on the other hand, mentioned that: "*I just feel the difference that my child has in her early stages. However, there was no place for diagnosis as I was living in the UAE, and I wasn't able to pay for specialised centers. When she started to grow up and her behavioural problems were high, I just returned to Ethiopia since it was impossible to take care of her and work there."*

Haile had shared a similar story with the other parents: *"My child didn't get the proper diagnosis for his developmental delays at an early age. We just suspected the differences, and when he started to grow up, these things were not showing progress with his age. Since he also has behavioral challenges, we were convinced to accept his ASD."*

4.3. Availability of early intervention Service for the demands of ASD children

Early intervention is targeted to help a child with ASD befor turns in to three years to acquire basic skills in his/her speech delay, motor skills, behavior, and social skills. This early intervention is more related to the diagnosis services since understanding the situation of the child and having confirmation of the developmental delay is key to the intervention strategy.

According to Tsigereda, having a child with ASD and a seizure caused by epilepsy was a very difficult situation for finding early intervention services. As indicated in the above discussion, the diagnosis of her child for ASD was delayed due to a lack of attention to it, given more to his epilepsy, and a lack of special professional support. Due to this fact, it was almost too late for her son to find services that were meant for early intervention.

Alem, on the other hand, said that "*after coming back to Ethiopia with my daughter, I just tried to register at Yekatit 12 Hospital for early intervention on her communication delay that my child needs. However, it has already been more than five years waiting for the hospital to call* *me, which didn't actually happen. I was also looking for a private service provider to support my child, which ended up being beyond my financial capacity. It wasn't affordable to get any intervention at affordable prices. "*

Etsegenet, who is the mother of a 7 years old child with different developmental delay (Down syndrom), informed me that: : "*the doctor who was seeing my child, after I understood his delay, informed me that my child wouldn't walk his entire life. There is nothing they can do to help my boy improve his situation other than maintain the status quo, and he advised me to accept it as it is."*

Haile has also added a point on this: "*my child hasn't had a proper diagnosis, and because of that, we were not able to find him the appropriate early interventions for his behavioural and communication problems."*

Belaynesh and Mergitu's situation is no different than others because the diagnosis was delayed for both of their children. It is important to identify the child's situation at its very early stages, probably while it is a toddler, to propose an early intervention strategy; however, the case of my respondents showed a very late and not appropriate diagnosis, mostly after their children were four and above.

The key informant interview also supports this finding in that people seeking early intervention services are forced to register for a very long waiting list. The only therapist at Yekatit 12 Hospital confirmed that: service is not provided for children upon their arrival since there are around 2800 registered children waiting for different services. So we just registered for a call and made a call when their service date arrived. This may take more than two years.

I have also witnessed that while I was waiting to conduct this interview, a mother was waiting for the therapist to seek service for her child, and I heard she had been waiting for almost five years after the registry, but still she just didn't get her turn for the service.

The case of all parents with ASD in my interview is similar regarding early intervention services. The more the diagnosis is late, obviously, the child is not getting the early intervention services that were key to making better progress and increasing the chance of improvement in social, communication, and behavioural skills.

4.4. Findings on the availability of educational Service for ASD children

Kokebe Tsibah is the school where I conducted my key informant interview to capture the educational service provision for ASD children. According to the special needs teacher: Tigist, there is a specialized education service at Kokebe Tsibah KG, primary and secondary schools, that has existed for more than 3 decades. Currently, 62 students in different sections/ grades are getting specialised education. 10 students out of the total number are children with ASD. There are 13 teachers in this department, and eight of them are assigned to support children with developmental delays. All are graduates of special needs education, holding diploma or BA degrees. The educational service provided in Kokebe tsibah is a specialised education for children with developmental delays. Except for the KG, children in this school system are assigned to different sections by differentiating their developmental levels. They are provided with a basic skill set that is important for their life experiences.

According to special needs teacher Tigist, Tigist: "*in as much as we want children with ASD to be in inclusive education classes, it is not easy due to their different behavioural* *challenges. Hence, we have arranged for the school to have convenient space for the specialised education class. We provide skill based training, mainly focusing on self care. "*

Most parents believed, and their wish, on the other hand, is to see their children with ASD in inclusive classes, interacting with children of their age without developmental problems. They consider it a method of therapy, especially to develop social and communication skills.

Tsigereda mentioned that: "*since the government has signed different international agreements and adopted laws for implementation, education is a human right, Education for All (EFA), to which Ethiopia is committed also Ethiopia ratified the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD), which recognizes the right of PwDs to inclusive education at all levels of the education system. We need to see our ASD children treated equally as human beings and included in the education provided in a supportive environment to interact with children without developmental problems."*

The other center providing holistic support for children with developmental delays is Bete Mihret. There are around 50 children with developmental delays in the center, categorized into different groups according to their age and level of understanding. Even if we cannot consider the center a school, some segments of the service include education in their program. I have observed the different techniques used to teach children with ASD's primary mathematics, hygiene, and social science.

Belaynesh affirms that *children with autism are not intellectually disabled. Instead, they have a different view of doing things, understanding, and being able to have education. The key to educational programs for ASD children should start with identifying their special capacities. The best version of the child should be the priority concern. Support tailored to enhance the* *identified capacity should be the focus of education for children with ASD. And we cannot think of having similar interventions for different children as their skills are so specific. However, once we identify their special talents, we can consider sending them to inclusive classes for those identified subjects.*

She also shared her experience related to this: one of her friends children with ASD is brilliant in mathematics, even outperforming students without developmental delays. Her son is also good at geometry and sporting activities. She believed that if there are schools that can work hard to identify the talents of these children, it will be easier to support the kids on their stronger side and not waste time on what is not working for them. This is key, as children with ASD are focused on some areas and can contribute a lot if properly utilised.

Other families involved in the interview, were able to understand that they are sending their children with ASD to school so that they will have time to do their businesses. They don't clearly understand that their children have different skills. This could be related to their literacy level, which is influenced by the attitudes that the community has towards their children.

On the other hand, Tigist from Bete Mihret confirmed that these children, "*if a proper assessment is conducted, have different skills that can even help them join the labour force in their specialties. Educating children with ASD needs special consideration and inclusion based on assessments."* She also mentioned that there are two young boys with ASD who are employees in their organisation who received proper training during their childhood in the center and showed very good progress. They are the most loyal and hardworking staff in the center, and their deliverables are always excellent because they are so focused to the work assigned to them. They don't feel tired until the work is done.

Mergitu’s view regarding education promoted inclusive classes. *“My sister's son is sent to an inclusive class. We hired a special needs teacher to support him during his stay at the school. She helps him do things at the school, including going to the bathroom, during his break time, and during feeding times. We have seen him enjoy going to school. I believe inclusive education with little support from assistant teachers is the best approach for children with ASD.”*

On the other hand, Tigist from Bete Mihret mentioned that schools that are open to inclusive education need to have assistant teachers who are assigned to support ASD children. If additional teachers are not available in inclusive classes, the special needs child can’t get necessary support in between classes, and this will be a failure to meet the inclusive class requirement.

4.5. Parents Perspectives on the Availability of Therapeutic services for ASD children

My findings from the key informant interview at Yekatit 12 Hospital revealed that the hospital has different departments that can support ASD children’s therapeutic needs. There is a speech therapy section, a psychiatry department for behavioral therapeutic needs, and a physiotherapy department for occupational and motor skills. On the other hand, parents are expected to register for a lengthy wait, and the service is provided by very few qualified specialists.

From my observation of the speech therapy department, it is not well equipped, the space is not suitable for the services, and the office location is not convenient for children with ASD. The therapy space is not quiet; located on the first floor without disability friendly stairs, it exposes them to different risks. Looking at the speech therapy department, which is the major department providing service to ASD children in the hospital, I found out that there are two speech therapists in the hospital, and only one of them is currently delivering the service. He provides therapy for about 7 -12 children per day. With a waiting list of more than 2800 ASD children coming from different parts of the country, we can not say the hospital is using its full potential for this service.

According to Etsegenet, it is hopeless to wait for Yekatit 12 speech therapy service since she has been waiting for more than three years. "*I have been trying to register multiple times for my daughter: they said they would call me when my turn arrived, but they didn't."*

Tsigereda also mentioned that: *"I was trying to find the best behavioural and speech therapist for my child in private clinics. Their payment is so expensive, and I quit after a few trials without seeing any progress for my son."*

Belaynesh's perspective is a bit different: "I just send my child to therapeutic centers and even hire a private therapist so that I can learn what they do to him. After looking at their techniques, I do repetitive actions for my child's behavioural therapeutic needs. Depending on professional support will not help you reach the desired changes for your child. Parents involvement is essential, and you can see that therapy centers have short serving hours per day, which can't help your child progress in a short period of time."

Mergitu's view is no different from Belaynesh's: Since his mother lives in the USA, she is paying a lot of money for her son's speech therapy at a private clinic. The therapy seems to demand a long period of time for the child to improve his speaking abilities. *"To support that, we are trying to practice what has been done by the therapist at home. The progress is still slow, and I believe caregivers play a significant role in this regard."*

Haile, on the other hand, mentioned that: *“I didn’t find the speech therapy provided in a private clinic to be successful for my son. What worked well in terms of developing his social skills was the school involvement. My son is happy going to an inclusive class and interacting with children there. I prefer paying a lot more for the schools than therapeutic centers.*”

Tigist from Betemihret responded to this as follows: *We try to include therapeutic services for children in our center based on their specific demands with the support of staff that receive short term training. The role of centers like ours is significant in addressing the therapeutic needs of ASD children. We have established a network of organisations that are working in the area of ASD child and family support. Children with ASD were still being restrained from their homes by ropes if it weren't for these self-organized organisations and the services they offered. In fact, we think there are still a lot of kids who are trapped in their homes and yearn to get outside.*

4.5.1 Spiritual support for therapeutic needs

My indepth interview with parents of ASD children showed that most of them went to spiritual solutions for their child’s situation.

Tsigereda mentioned that when her child's behavioural problems aggravated and the frequency of his seizures increased, she always looked for spiritual support. *He just got some relief after frequent spiritual support. I even got stronger after spending time in Tsebel and a continuous church attendance.*

Etsegenet has also mentioned that *when the doctor was hopeless about her son’s walking problems, she just went to a spiritual solution, mentioning that her son started to walk right after that.* She strongly believes he will also start to speak through her spiritual intervention one day.

Alem has mentioned that: *when we attend church prayers, I feel relieved. Even my daughter felt secure. Even if occasionally others don't want to be around us, prayers are my favourite time to calm her.*

Belaynesh said: my baby loved attending church programs. *For him, attending religious services and praying are actual forms of therapy. He even likes music with a spiritual theme. When I often consult with priests and other church workers, my strength even increases.*

4.6. Parents and Caregivers support systems

It is understandable that parents of ASD children face many challenges throughout their lives. Their life struggle is different from other families in diverse ways. One of the major challenges is having a strong support system to vent their inner feelings and share different experiences. During our conversation, the participants in the in-depth interview attested to the fact that parent support groups, counseling, or therapies does not exist in the circumstances of our country.

Alem mentioned that not even the community but her parents didn't understand the situation of her ASD daughter. They avoid her at many social gatherings so as not to be disturbed by her child with ASD. "*My mother sometimes told me that my daughter's voice was so annoying that she didn't want her in her house. My sick child is bad luck, according to a neighbour, so I should avoid crossing the road through the Iddir with her. At that time, I felt so offended that I had to fight with the older women."*

Tisigereda, on the other hand, said: **"***I have a supportive husband; I don't feel the burden either. Even people from my neighborhood are interested in accompanying me. I have strong communication skills, and I engage in different establishments that support ASD children and epilepsy. It just opened up a space for me to see the different experiences."*

Belaynesh also added a point on this: *"I always look for families that have experiences like mine. I believe interacting with people gives you the perspective that you are not struggling alone. Even social media groups can help you see a broader view."*

Mergitu also stressed the need for a parent support system: *My sister's marriage was in danger while she was dealing with this alone. After she brought him to us, I became a member of different social media support groups. It is helping me gain information and learn from the different experiences that families share. I am becoming a master of ASD through the different support systems and resources shared there. The frustration that my sister was facing came from her loneliness related to the lifestyle in the USA.*

Etsegenet also mentioned that *if not for her family support and the good neighbours she has, it wouldn't have been easy for her to go through this journey. She shared the experience of another mother who lived in a rental house and tried to interact with neighbors; the discrimination forced her to leave that house. She was so hurt and decided to live in isolation with her son.*

Tigist from Bete Mihret has shared with me the story of one of their beneficiaries. She is a single mother who runs her life with daily labour and washing clothes by going to people's houses. Because she doesn't have support from anyone, she ties her ASD boy to herself while doing her job. However, many people avoided her from their houses due to her ASD child until Bete Mihret accepted him. Many mothers who have to work in the informal sector and have children with ASD have similar stories to tell.

Chapter Five

Discussion, Conclusion and Implications to Social Work

5.1. Discussion

The main aim of this research was to explore the service deficiencies of ASD children's parents and caregivers. In this section, I will present the main findings of each research question in line with related literature.

5.1.1. Assessing the available services to diagnose children with suspected ASD

The result of my research indicates that diagnostic services for ASD children in Addis Ababa at the public hospitals are almost nonexistent. The long waiting list, doubled by a few professionals, worsens the service of diagnosing children with ASD. Parents may find a privately owned health care center that can assist in identifying a child with a suspected ASD case, but the price is not affordable for most middle class families. Similar research indicates that because services for children with developmental disabilities are primarily limited to Addis Ababa, the nation's capital, most people (85%) who live in rural regions cannot access them. The scarcity of professionals with the expertise to provide specialized care and support can lead to long waiting lists and limited access to essential services. (Tekola et al., 2019). According to another study, a complete medical evaluation for children with autism spectrum disorder (ASD) typically involves a comprehensive assessment to gather information about the child's medical history, developmental milestones, behavioral characteristics, and any associated medical conditions by a multidisciplinary team that may include pediatricians, neurologists, psychologists, and speech therapists. (Hyman et al., 2020) Looking at the results of my research on diagnostic service provision and the findings from previous researchers, we can understand that more attention is needed to improve this sector. Efforts to expand the services are still progressing very slowly compared to similar studies conducted at different times. Government facilities are still underequipped and provide services at their minimal capacities. The service might be improved by integrating it with the paediatric department and forging strong partnerships with other specialty departments.

5.1.2. Exploring the early intervention program to support children with ASD

It appears that without early diagnosis, thinking about early intervention programs is impossible. My research revealed that diagnosis in the public sector demands years of waiting, which in turn affects intervention plans. Other researches has also supported this, When a kid or young person receives a late diagnosis, they are deprived of the chance to comprehend how they react in various circumstances. It also suggests more stress for the families, a longer time for other co-occurring disorders to be diagnosed, and more expenses for the family and society financially (Zwaigenbaum et al., 2019). Diagnosis and early intervention are interlinked. It can play a significant role if both start early. However, the practice on the ground showed in my research and other previous studies confirmed that parents are struggling to find appropriate services in Addis Ababa.

5.1.3. Assessing the Educational services available for ASD children

The result of my findings showed that educational services for ASD children have two approaches. Specialized education and inclusive education systems both practices are available at the school where I have tried to explore the services. Both approaches are preferred by parents for different reasons. Parents supporting specialized education strongly stress the capacity differences of children with ASD and the need to identify the stronger side of the child to work on it. Here, my result indicated that children with ASD have a different way of seeing things, and the support in education has to be in line with their way of understanding.

Supports of inclusive education affirm the benefits of interacting with peers for ASD children. Previous research on this also indicated that an inclusive educational approach has been shown to have numerous benefits for students with ASD, including improved academic and social outcomes, increased opportunities for peer interaction and friendship building, and enhanced self-esteem and confidence (Low et al., 2019). The availability of the services is one thing to consider, but the quality of the services is still in its infant stage. The curriculum needs to include proper capacity assessment and work on enhancing the abilities of ASD children to be productive.

5.1.4. Assessing the therapeutic services available for ASD children

Children with ASD require a variety of therapy demands in order to operate effectively. The main types of services that parents were looking for for their ASD children were social skills, occupational, behavioural, and speech therapy. Being able to access these services entitles their children with ASD to participate in the various arenas of the world. However, my research found that many parents are struggling to find those services. A lengthy waiting list, a shortage of professionals, and a narrow skill set were some of the main causes of the limited access. Previous studies also revealed that the lack of infrastructure and support systems may lead to gaps in the implementation of evidence-based practices and tailored interventions for individuals with ASD. It is essential to further explore and address the specific barriers that exist within Ethiopia's healthcare and educational systems to enhance therapeutic approaches for ASD and ensure better outcomes for individuals affected by the condition (Tekola et al., 2016). In another study, it was indicated that it is important to understand that each individual with ASD has different therapeutic demands and may respond differently to various therapies, so a personalized approach is often recommended (Anagnostou et al., 2014). It is also indicated in another study that parents of children with ASDs reported a lack of available services and skilled providers, indicating the need for an increased supply of appropriate services with qualified providers in developing nations (Montes et al., 2009). In a country with limited resource availability, it may be difficult to think of fulfilling every single need of these children. However, it is imperative that the therapeutic needs of these children be the primary concern of every stakeholder involved in this. If not for the many excuses, the unfulfilled demands of children with ASD are denied human rights, a breach of the several international agreements that the government promised to uphold.

5.1.5. Investigation on the support system and resources for families of children with ASD

According to the findings of the respondents, there is no structured support system for families with ASD. Resources to create better understanding and support families in the process of helping their children are not also available unless with individual efforts. Families are finding it difficult to participate in informal income-generating activities due to a lack of awareness in the community. In a different study, it was mentioned that the societal stigma and lack of understanding surrounding ASD can further complicate the experiences of families. They may encounter misconceptions and discrimination, leading to feelings of isolation and frustration. (Abolkheirian et al., 2022). Temporary relief and childcare assistance for families through respite care services, either in-home or at specialized centers, are crucial to alleviate caregiver burnout and allow parents to recharge and attend to their own wellbeing (Cookie et al., 2020). Additionally, programs that help families find appropriate local services and daytime activities for their ASD children can be particularly beneficial in developing countries (Vohra et al., 2013). From this discussion, we can conclude that counseling and mental health services tailored to the unique needs of ASD families address issues like stress, anxiety, depression, and psychological support as a core component and an integral part of the overall care and treatment plan.

5.2. Conclusion

This research was conducted to assess the service deficiencies faced by children with ASD and their families in Addis Ababa, with the goal of informing policy, guiding resource allocation, and catalyzing the development of comprehensive, inclusive, and accessible support systems. The research emphasizes how critical it is to develop a thorough, multi-stakeholder strategy to address the inadequate services for children with ASD in Addis Ababa and throughout Ethiopia. The creation of integrated, family-centered support networks, increased government attention, and the strengthening of the healthcare and education systems' capacities are all suggested interventions. The quality of life and developmental outcomes for Ethiopian families with children with ASD can be greatly enhanced by filling in these crucial gaps. Implementing these will also contribute to the broader goal of achieving inclusive and equitable development in the country. Sustained commitment and collaboration among policymakers, service providers, and the community at large are essential to creating a brighter future for individuals with ASD in Addis Ababa and beyond. As a result of this research, more recurrent problems can now be investigated in order to better understand problems associated with ASD in adolescents, young people, and adults.

5.3. Implications to Social Work

Based on the findings of my research, I found that the following points should have implications for social work.

For practice in micro level

- Facilitate peer support groups and connect families to community-based networks for mutual learning and emotional support to be undertaken by service providing center in collaboration with the social workers.
- The government launches nationwide public awareness campaigns to educate the public about ASD, dispel myths, and reduce the stigma surrounding the condition.
- Integrate routine ASD screening into standard child health checkups, the primary healthcare system, and mainstream education system for better continuity of care.

Education and training

- Collaborative social work interventions and short term training in health care can be supportive of expanding the service demands of children with ASD.

Policy advocacy and implementation

- Establish a national ASD taskforce or commission to coordinate efforts across different government ministries and stakeholders.
- Develop a clear policy related to different people's developmental delays with the aim of addressing their specific needs.

Research for further exploration

- It is highly underresearched that adolescent and adult people with ASD, reproductive health demands, and employment areas need further exploration.

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Annexes

Consent Form for Research Interview Participation

Research Title: Service gaps among children with autism spectrum disorder (ASD) and their families in selected sites in Addis Ababa

Researcher: Marta Teklie

Purpose: To provide a comprehensive understanding of the current service gaps and challenges faced by children with autism spectrum disorder (ASD) and their families in Addis Ababa, Ethiopia.

Participant's Rights: Your participation in this research is voluntary. You have the right to withdraw from the study at any time without penalty.

Research Procedures: If you agree to participate, you will be staying with the researcher for a halfan hour discussion to explore your thoughts on challenges while trying to find services for your child with ASD based on the interview guiding questions.

Confidentiality: Your confidentiality and privacy will be strictly maintained throughout the research. All information collected during the interview will be anonymized and stored securely. Only the researcher will have access to the data, and any identifying information will be removed during the analysis and reporting process. Your personal information will not be disclosed or published without your explicit consent.

Data Use and Publication: Data from this research may be used for research purposes, scholarly presentations and publications. However, your identity will remain confidential, and any data presented or published will be aggregated and anonymized to ensure your privacy.

Contact Information: If you have any questions or concerns regarding this research or your rights as a participant, please contact Marta Teklie- 0910124457.

Voluntary Participation: Your decision to participate or not participate in this research is entirely voluntary. You may refuse to participate or withdraw from the interview at any time without any negative consequences. By signing below, you acknowledge that you have read this consent form, understood its contents, and voluntarily agreed to participate in this research interview.

Participant's Signature: _____________________
Date: _____________________

Researcher's Signature: _____________________
Date: _____________________

Interview Guide for Parents and Caregivers

Thank you for participating in this research on autism spectrum disorder (ASD) service gaps. I am conducting this research to gain a better understanding of the challenges and gaps that families with children with ASD face when accessing services. Can you please take a few minutes to have a discussion on the following questions?

Title: Autism Spectrum Disorder – Interview Guide

Participant Information

Participant (parent, caregiver) Name: _______
Age: _______
Gender: _______

Diagnostic History

Age of Diagnosis of the child: _______
Diagnosis type: _______
Diagnostic Assessment Tool Used: _______
Professional(s) Involved in Diagnosis: _______

Educational and Occupational History for the parents or Caregiver

Highest level of education completed: _______
Are you currently employed? If yes, please provide job details.
Have you received any specialized education or training related to ASD?

Interview guide for research question 1

How did you first become aware that your child might have ASD? Can you describe any early signs or behaviors that concerned you?
What was the process like for getting an official diagnosis for your child? Did you face any challenges or obstacles along the way?
How do you describe the availability, quality, and affordability of the diagnostic service?

Interview guide for research question 2

Service Demand

1. Have you sought any services or interventions related to your child's autism spectrum disorder (ASD)? If yes, please specify the types of services received and their duration.

Service Availability

2. What kind of early intervention services have you accessed for your child?
3. How has this support helped your child's development and overall well-being?
4. Were these services easily accessible and affordable?
5. Did you encounter any challenges in accessing services for your ASD child? If yes, please describe the difficulties faced

a. Diagnostic assessments for ASD
b. Early intervention programs
c. Behavioral therapy
d. Speech and language therapy
e. Special education programs

Interview guide for research question 3

6. How easy or difficult was it for you to navigate the education system for your ASD child?
7. In your opinion, is inclusive education the best method for your ASD child? or is it the specialised education services?
8. From inclusive or specialized educational services, which one is easily available?
9. Have you experienced any barriers in accessing educational services for your child with ASD?

Interview guide for research question 4

10. Were you looking for therapeutic services for your child with ASD?
11. What were the reasons for seeking services? (Check all that apply.)

Social interactions and communication difficulties
Behavioral challenges
Education and academic support
Occupational or vocational support
Other (please specify): _______

12. Were you successful in finding one for your therapeutic demands?
13. Have you encountered any difficulties in finding specialized care providers for your child with ASD?
14. What were the specific limitations or challenges you have faced when trying to access therapeutic services for your child with ASD.

Interview guide for research question 5

15. How do you manage the emotional and psychological impact of raising a child with ASD?
16. Are there any self-care strategies or support systems you find helpful?
17. Do you feel that there are enough community-based programs and activities tailored for children with ASD and their families in Addis Ababa?
18. In what ways do you think the community support system could be improved or expanded to better meet the needs of families with ASD?
19. Lastly What changes would you like to see in the availability and accessibility of services for individuals with ASD and their families?

Please feel free to provide any additional comments or suggestions regarding the services you have accessed or the overall service system for your child with ASD.

Interview guide for Key Informants- the health care providers

Therapeutic services

1. Can you provide an overview of the specific therapeutic services that are currently in demand for individuals with ASD?
2. How do you collaborate with other professionals, such as speech therapists, occupational therapists, and psychologists, to provide comprehensive care for individuals with ASD?
3. Are there any specific therapeutic approaches that have been found to be particularly effective for individuals with ASD? If so, can you describe them?
4. How do you involve parents and caregivers in the therapeutic process to ensure continuity of support outside of formal sessions?
5. What training and qualifications do your staff members possess to deliver effective therapeutic services for individuals with ASD?
6. Have you seen any challenges related to providing therapeutic services? what are your recommendations for improvement?

Interview guide for Key Informants-Educational services

1. Can you provide an overview of the educational services that are currently in demand for individuals with ASD?
2. Are there any specific educational approaches that have been found to be particularly effective for individuals with ASD? If so, can you describe them?
3. Can you discuss any recent advancements or emerging trends in ASD educational services that have the potential to improve outcomes for individuals with ASD?
4. How do you involve parents and caregivers in the educational process to ensure continuity of support outside of formal sessions?
5. What training and qualifications do your staff members possess to deliver effective educational services for individuals with ASD?
6. Have you seen any challenges related to providing educational services? what are your recommendations for improvement?

Observation check list

1. Considerations for the Hospital

Need for quiet spaces,

Visual schedules,

Communication approaches

Availability of specialized ASD-trained staff or resources within the hospital

Availability and use of accommodations or assistive technologies

Infrastructural accessibility

2. Consideration for the special needs education

Check out Disability friendly class

Anything related to skill training materials

Infrastructural accessibility

3. Family/Caregiver Involvement

Communication strategies used between the centers and families

Coordination of care between hospital staff and family/caregivers