



African Population and
Health Research Center

Autism Spectrum Disorders: Evidence on Education, Therapy, and Support Services in Kenya

2025



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ACKNOWLEDGEMENTS

We gratefully acknowledge the financial support provided by the African Population and Health Research Center (APHRC) for the pipeline idea that made this study possible. We also extend our sincere appreciation to the Arthur's Dream Autism Trust (ADAT) for their fruitful collaboration throughout the entire research process, unwavering support from the study's inception through data collection and the stakeholder engagement meetings.

Our heartfelt thanks to the parents of children with autism who co-created the evidence with us by participating in focus group discussions and completing the questionnaire. We are equally grateful to the Curriculum Support Officers for Special Needs Education (CSO-SNE), teachers of children with autism, and officers from the Ministry of Education – Directorate of Special Needs Education (MoE-DSNE) and the Kenya Institute of Special Education (KISE) for their participation in this study.

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ACRONYMS

ABA	Applied Behavior Analysis
ADL	Activities of Daily Living
AMREF	African Medical and Research Foundation
APHRC	African Population and Health Research Center
ASD	Autism Spectrum Disorder
CAPI	Computer Assisted Personal Interview
CBE	Competency-Based Education
CSO	Curriculum Support Officer
DSNE	Directorate of Special Needs Education
EARC	Educational Assessment and Resource Center
EIBI	Early Intensive Behavioral Intervention
ESRC	Ethics and Scientific Review Committee
FGDs	Focus Group Discussions
KIIs	Key Informant Interviews
KISE	Kenya Institute of Special Education
MoE	Ministry of Education
NACOSTI	National Commission for Science, Technology, and Innovation
NCPWD	National Council for Persons with Disabilities
NIH	National Institute of Health
SHA	Social Health Authority
SHIF	Social Health Insurance Fund
SNE	Special Needs Education
SRC	Scientific Review Committee

EXECUTIVE SUMMARY

Background

Children with Autism Spectrum Disorder (ASD) may behave, communicate, interact, and learn in ways that are different from most other people. ASD manifestations vary from child to child. Some children avoid eye contact, do not respond when their names are called, exhibit excessive fear, and engage in limited interactive or social play. They therefore have service needs in behavioral, educational, health, leisure, and family support needs, among others. This study sought to explore the available care and support services, education programs for children with ASD, and social support for their parents/caregivers.

Objectives

The purpose of the study was to generate evidence on access to educational and professional care and support services for children with autism, as well as psychosocial support and coping strategies for parents/caregivers to inform policy, practice, and further research. Specifically, the study sought to respond to three research questions: (1) What is the availability, accessibility, and effectiveness of education programs for children with autism spectrum disorder (ASD) in Kenya? (2) What are parents'/ caregivers' experiences with care and support services and therapies for children with ASD in Kenya? (3) What kinds of psycho-social support are available for parents/caregivers of children with ASD in Kenya?

Methods

This was an exploratory mixed-methods study that was conducted in Nairobi and Kiambu counties in Kenya. The study targeted parents/caregivers and teachers of children with autism, curriculum support officers in charge of special needs education (CSO-SNE), and officers from the Kenya Institute of Special Education (KISE) and the Ministry of Education-Directorate of Special Needs Education (MoE-DSNE). Quantitative data were collected from parents and/or caregivers using a structured questionnaire. Qualitative data were collected through parent FGDs and Key informant interviews (KIs) with teachers of children with ASD, CSO-SNE, and officers from KISE and MoE-DSNE. Quantitative data were analyzed using the STATA statistical package, version 17, while qualitative data were analyzed thematically using NVIVO.

Summary of Findings

Children with autism are increasingly enrolled in schools, mostly in inclusive settings, where their progress tends to be better in social skills than in academic learning. Therapy services, particularly speech and occupational therapy, are commonly recommended but remain out of reach for many families due to high costs, long distances, and limited availability, leading to greater dependence on home-based interventions. Parents and caregivers experience substantial emotional, social, and financial strain, relying primarily on prayer and informal peer networks for support, while access to formal counselling and financial assistance remains limited.

Conclusions and Policy Recommendations

There is a growing number of children with autism in Kenya and, therefore, a need to strengthen support services related to their education, therapy, and care for their parents and caregivers. The study has six key recommendations:

- i) Expand county-level therapy services, integrate therapy services in school programs, and subsidize costs through the Social Health Insurance Fund (SHIF).
- ii) Invest in teacher training for inclusive, stage-based instruction;
- iii) Strengthen accreditation of therapy providers;
- iv) Support and formalize parent networks;
- v) Establish accessible counselling and psychosocial services; and
- vi) Strengthen partnerships between parents and local NGO and faith groups for holistic support.

1.0 INTRODUCTION

1.1 Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that presents difficulties in social communication/interaction and restrictive and repetitive behavior patterns (Hyman et al., 2020; Okoye et al., 2023). It is rated as the fastest-growing neurodevelopmental disorder globally, with approximately 67 million individuals affected worldwide and a global prevalence of 1/100 in the general population (Bonnet et al., 2017; Zydun, 2022; Elsabbagh et al., 2012). This accounts for about 0.6% of the global population, with 1% in Africa and America and 1.7% in Australia (Salari et al., 2022).

Children with ASD may behave, communicate, interact, and learn in ways that differ from those of most other people. ASD manifestations vary from child to child. Some present avoidance of eye contact, lack of response to names, excessive fear, and lack of interactive and social play (Hyman et al., 2020). They therefore have diverse service needs in behavioral health, education, health, leisure, family support, and other areas. In addition, early identification of these symptoms by caregivers and healthcare providers facilitates the need for diagnosis and appropriate interventions. It is therefore important for parents to become aware of the various ways in which ASD presents itself for early identification.

The abilities of children with ASD can vary significantly. For example, some may have advanced conversation skills, whereas others may be nonverbal; some need a lot of help in their activities of daily living (ADL), while others can work and live with little to no support (Lord et al., 2020). As children with ASD become adolescents and young adults, they may have difficulties developing and maintaining friendships, communicating with peers and adults, or understanding what behaviors are expected of them (Hyman et al., 2020). This wide variability means that no single approach can meet every child's needs, making support and management more complex and requiring individualized assessment.

A narrative review of current knowledge on autism in Africa (Aderinto, Olatunji, and Idowu (2023) noted that the prevalence of autism in Africa is estimated to be similar to that in other regions. However, diagnosis and treatment access remain limited due to various challenges, such as a shortage of specialized healthcare professionals and resources, a lack of awareness and understanding of ASD among healthcare providers, and cultural stigma surrounding mental health and developmental disorders. Alternative therapies are commonly used alongside conventional therapies, but their effectiveness is often unproven. The current study will therefore explore what works in care, support, and therapy services in the Kenyan context.

The impact of ASD on the lives of families and caregivers in Africa is significant, with many facing challenges in accessing care and support services for their children and coping with the high burden of care (time/economic) associated with raising a child with ASD (Shattnawi et al., 2021; Patel et al., 2022). Generating evidence on the availability of psychosocial support and parents' coping strategies when faced with this high burden of care will inform policy and practice, which will help alleviate the psychological and social distress experienced by parents/caregivers.

In African countries such as Kenya, there is a greater need for establishing care and support services and systems for both children with ASD and their parents/caregivers. The emotional, social, and economic burden of ASD on parents/caregivers is overwhelming because of several challenges associated with full-time care, including the high cost of medication and therapy services, among others (Cloete, 2019). This study sought to explore existing support mechanisms for parents/caregivers of children with ASD to inform policy and support evidence-informed decision-making to strengthen existing systems and establish new ones as needed.

Evidence shows that ASD has been on the rise in the recent past globally (UNICEF, 2021; Olusanya et al., 2022). While the prevalence of ASD varies significantly across geographical contexts, Zeidan et al. (2022) reports that there is an increase in measured autism prevalence globally. Increased awareness of the condition has seen improvements in related interventions, especially in high-income countries. However, the availability and access to care and support services for both children with ASD and their caregivers remain a challenge in the African context (Masaba et al., 2021). Since ASD presents in a diverse range of ways, caring for children with autism may be challenging due to their broad spectrum of needs (Tathgur & Kang, 2021). Parents/caregivers, who spend most of the time with a child with ASD before school age, often experience fatigue and stress due to the associated high burden of care (Patel et al., 2022), including limitations on where and when to seek social support for their own psycho-social well-being. This contributes to delays in developmental milestones during the early years due to limited parental support. These limitations, coupled with limited research evidence on the effectiveness of education programs and on what works in care and support for both the child and caregiver call for the targeted generation of research evidence to inform action, especially in Kenya and sub-Saharan Africa at large. This study sought to narrow the existing evidence gap by exploring the available care and support services and education programs for children with ASD, as well as the social support available for the parents/caregivers in their journeys of raising a child with ASD.

It is anticipated that the insights from this study would inform policy and practice regarding care and support services for both the child with ASD and their parents/caregivers. Specifically, the findings of this study are useful to the Ministry of

Education as well as the State Department of Social Protection and Senior Citizen Affairs under the Ministry of Labor and Social Protection to inform ways of improving existing education programs, care, and support services, and in designing more targeted interventions to support both the child with ASD and their families.

1.2 Objectives and Research Questions

General Objective

The purpose of the study was to generate evidence on educational and support services for children with autism, as well as psychosocial support and coping strategies for parents/caregivers in order to inform policy, practice, and further research.

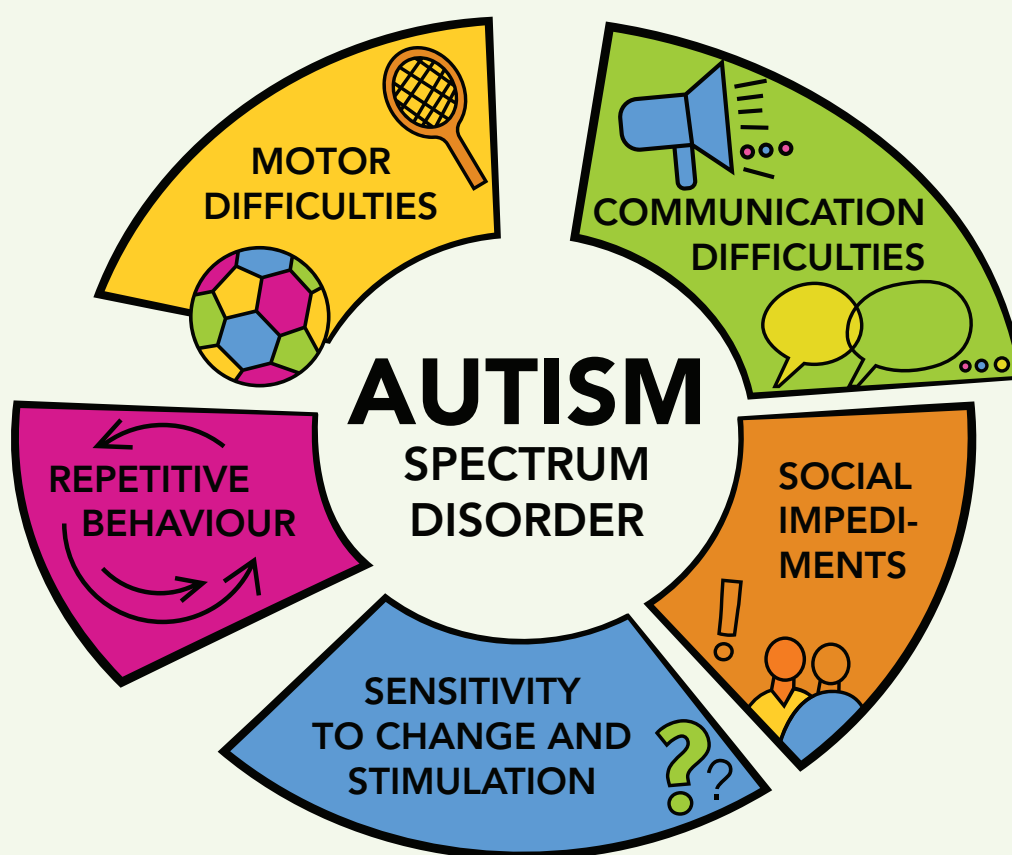
Specific Objectives

1. To explore the availability, accessibility, and effectiveness of education programs for children with autism spectrum disorder (ASD) in Kenya.
2. To establish the therapy services available for children with ASD in Kenya.
3. To examine the kinds of psycho-social support available for parents/caregivers of children with autism in Kenya

Research Questions

The study sought to respond to the following research questions:

1. What is the availability, accessibility, and effectiveness of education programs for children with autism spectrum disorder (ASD) in Kenya?
2. What are the therapy services available for children with ASD in Kenya? How accessible are they? How effective are they?
3. How is the psycho-social support for parents/caregivers of children with autism in Kenya? Are they accessible? Are they useful?



2.0 LITERATURE REVIEW

2.1 Theoretical Framework

This study is grounded in Bronfenbrenner's Ecological Systems Theory (1979). This theory remains relevant in understanding the developmental experiences of children with autism and the support structures available to them. Although developed decades ago, it continues to be widely applied in ASD and public health research because it emphasizes the crucial role of physical, social, institutional, and cultural environments in shaping children's outcomes (Moschetti, 2024; Nešić, 2023; Nyoni, 2022; Predescu, 2018). Bronfenbrenner's ecological perspective is core to this study based on its tenets. For instance, at the heart of the theory is the idea that a child's development is influenced by multiple, interacting environmental systems. By applying this model, this study situates the experiences of children with ASD and their caregivers within broader layers of social organization, policy structures, and cultural contexts. This ecological approach helps reveal how gaps or supports at different levels shape the availability, accessibility, and effectiveness of ASD services in Kenya.

Macrosystem encompasses broader socio-cultural and policy contexts, including societal attitudes toward autism, national education and disability policies (such as the Persons with Disabilities Act 2025), resource allocation decisions, and cultural beliefs surrounding disability. For Kenya, macrosystem factors strongly determine the structure, funding, and prioritization of ASD-related programs, as well as public perceptions that influence stigma, inclusion, or exclusion within schools and communities.

The exosystem includes external environments that affect the child indirectly, such as the availability of trained therapists, the organization of professional services, administrative procedures, and institutional practices within bodies such as KISE, MoE-DSNE, and county-level education offices. This level helps explain systemic constraints such as long therapy waiting lists, shortages of trained professionals, inconsistent service delivery, and the limited reach of government support structures.

The mesosystem refers to connections between microsystems, such as how parents relate with teachers, therapists, and school administrators. This level is crucial for understanding the coordination (or lack thereof) between schools and therapy providers, communication flows between caregivers and professionals, and collaborative decision-making regarding the child's education. In the Kenyan context, mesosystem interactions also include linkages between families and parent support groups, which influence how caregivers seek information and access services.

The microsystem comprises the child's immediate environments such as home, school, therapy settings, and daily caregiving interactions. In this study, microsystem analysis helps illuminate how children with ASD experience education programs, the quality of classroom practices (including special units and integrated programs), interactions with teachers, and the direct forms of therapy they receive. For parents, this level highlights daily caregiving tasks, stressors, and coping strategies, which are essential for understanding psycho-social support needs.

The chronosystem captures changes over time, including evolving policies, shifting societal attitudes, and transitions in service delivery systems. Within this study, it helps frame ongoing developments in Kenya such as the expansion of inclusive education policies, gradual improvements in therapy training, and increased awareness of ASD. It also considers changes within individual families over the ASD journey, such as how needs shift from early childhood to adolescence.

These ecological layers offer a holistic lens through which to interpret the availability, accessibility, and effectiveness of education programs, therapy services, and psycho-social support. Applying Ecological Systems Theory enables the study to identify system-wide barriers and opportunities, highlight gaps across multiple levels, and propose integrated, sustainable solutions to improve services for children with ASD and their caregivers in Kenya.

2.2 Education Programs for Children with Autism

Research evidence on education programs for learners with ASD emphasizes the importance of individualized approaches and effective teacher training. Individualized Education Programs (IEPs), for example, have been shown to significantly enhance academic and social outcomes for students with ASD by tailoring goals and accommodations to each child's unique needs (Odom, Collet-Klingenberg, Rogers, & Hatton, 2010, George, 2018, Findley et al., Findley, 2023). Early Intensive Behavioral Intervention (EIBI) and Applied Behavior Analysis (ABA) are also highly effective, with EIBI demonstrating improvements in cognitive, language, and social skills (Dawson, 2013; Lang, Hancock, & Singh, 2016), and ABA being widely endorsed for reinforcing positive behaviors and enhancing communication skills (Anderson & Carr, 2021; Roane, Fisher, & Carr, 2016). Despite these promising results, challenges such as resource availability and the need for specialized teacher training persist, as highlighted by Johnson, Soares, and Gutierrez de Blume (2021), who emphasize the need for ongoing professional development to ensure the successful implementation of these programs.

In addition to traditional teaching and learning approaches, recent technological advancements and inclusive education offer new avenues for supporting learners with ASD. Technology-enhanced interventions, including educational apps

and digital tools, provide personalized learning experiences and aid in communication and social skills development (Chambers, 2020; Valencia, Rusu, Quiñones, & Jamet, 2019). The integration of Artificial Intelligence (AI) and Large Language Models (LLMs) in autism spectrum disorder (ASD) education is gaining traction, offering personalized learning experiences and aiding communication and social skills development (Jiran, 2024). AI-driven interventions, such as virtual reality and chatbots, have shown promise in improving social interactions for individuals with ASD (Kandalaft et al., 2013; Mishra, 2024; Jiran, 2024). Examples of AI-enhanced ASD apps include Moshi and InnerVoice. Educators report increased engagement and personalized learning opportunities with AI tools (Li, 2024).

Meanwhile, inclusive education practices that integrate students with ASD into general education classrooms have shown promise in improving their social interactions and academic performance, provided adequate support is in place (Mason et al., 2022). However, the availability of educational resources and other support services remains uneven, with significant disparities based on geographic location and socioeconomic status (Mello, Goldman, Urbano, & Hodapp, 2016; Nguyen, Krakowiak, Hansen, Hertz-Picciotto, & Angkustsiri, 2016). Parental involvement is another critical factor; active parental participation in educational planning and implementation has been shown to enhance program success and outcomes for children with ASD (Kurth, Love, & Pirtle, 2020; Licona, Bush, Chavez, Dillon, & Wainer, 2022). These findings highlight the need for a holistic and context-sensitive approach to education for learners with ASD, considering the interplay of individual needs, environmental factors, and systemic support.

2.3 Professional Care and Support Services for Children with ASD

Access to professional care and support services for children diagnosed with ASD remains a challenge for most parents and families (Lamba et al., 2022; Wallace et al., 2023). Research has continuously reported the burden experienced by parents, caregivers, and families of children with autism (Tathgur & Kang, 2021; Minatel & Matsukura, 2014), including the unavailability of care and support services in its management.

Evidence by Marsack-Topolewski and Weisz, 2020 shows that care and support services for children with autism are inconsistently accessible, difficult to obtain, and inadequate. In addition, there is an inadequacy of trained social workers and health care professionals to provide and coordinate services for children with ASD. Parents usually face challenges in accessing and using mainstream health services for their children with ASD (Boshoff et al., 2021).

Parents have been found to be apprehensive about the quality of care and support services provided, thus affecting the parent-professional relationship (Ramachandran, 2020). While some parents report positive experiences with healthcare professionals, others find healthcare professionals to be vague in giving explanations and advice and not interacting with children sufficiently during the consultation (Goh et al., 2021).

Evidence suggests that low-and middle-income countries face significant challenges regarding the availability and adequacy of professional care and support services for children with autism (Pervin & Hagmayer, 2022; Scarpa et al., 2020; Shilubane and Manganye, 2020; Obaigwa & Cloete, 2019)

Care and support service provision is an important aspect of the achievement of developmental milestones for children with autism. It is therefore imperative to study care, support and therapy services and the associated enablers as well as challenges in order to provide an evidence base to inform policy and practice (Papadopoulos, 2021). The current study seeks to explore the situation in the provision of professional care and support services in a Kenyan context.

2.4 Psychosocial Support for Parents of Children with ASD

Understanding psycho-social support for parents of children with ASD in sub-Saharan Africa is shaped by cultural, economic, and healthcare system factors. Studies show that ASD awareness and acceptance are limited, leading to stigma and isolation for families (Gona et al., 2016; Owen, & McCann, 2018). Access to diagnostic services and early intervention is severely constrained, placing immense emotional and financial burdens on parents (Bello-Mojed & Omigbodun, 2016).

Qualitative research highlights the importance of community-based and peer support networks to help parents cope. Parents report needs for psychoeducation, stress management, and respite care (Khusaifan & El Keshky, 2021). However, formal support services are scarce, with heavy reliance on informal networks of family and community (Tilahun et al., 2017).

Innovative models leverage existing community structures, traditional healers, and religious institutions to provide psycho-social support. These approaches emphasize building awareness, reducing stigma, and empowering parents as advocates for their children (Onaiwu & Hamdallah, 2015). While progress is slow, studies demonstrate the efficacy of culturally tailored interventions in improving parental well-being and family outcomes (Dada et al., 2018).

Additionally, online support networks offer several potential advantages, including overcoming geographical barriers to accessing in-person support, providing a safe space for parents to share experiences and seek advice, leveraging the

reach and scalability of digital platforms, and fostering a sense of community and mutual understanding among parents (Miller, 2021). However, the literature also highlights some key limitations and challenges in effectively leveraging online support groups in these contexts, such as uneven digital access and literacy, language and cultural barriers in cross-national online communities, concerns about the quality, reliability, and privacy of information shared online, and the potential for online support to replace, rather than complement, face-to-face interactions (Bakare & Munir, 2016).

The literature points out the critical need to strengthen the conceptual and empirical foundations for accessible, sustainable educational, professional care, and psycho-social support systems for families of children with ASD in sub-Saharan Africa.

2.5 Policy Review

In Kenya, the right to education is guaranteed in Article 53(b) of the Constitution (2010), which provides for free and compulsory primary education for every child. Article 54 further affirms that persons with disabilities are entitled to accessible and appropriate education. The Basic Education Act (2013) reinforces this mandate by requiring all children with disabilities to attend free and compulsory education. In addition, the Persons with Disabilities Act (2025) and the Children Act (2022) contain disability-inclusive provisions that promote fair access and reasonable accommodation in public schools. Collectively, these legislative frameworks guide education stakeholders in improving the quality and relevance of education, strengthening early detection and assessment, and ensuring that children with disabilities have equal opportunities to attend school.

The Kenya Sector Policy for Learners and Trainees with Disabilities (2018) aims to include students with disabilities in the education system at all levels. It focuses on teacher training, caregiver training, assistive devices, and school grants. The National Care Reform Strategy of Kenya (2021) emphasizes the need to prioritize children with disabilities in all care reform initiatives. Additionally, services for these children and their caregivers should be comprehensive, including respite care, inclusive daycare programs, peer support groups, enhanced cash transfers, and specialized community-based rehabilitation and healthcare services. Moreover, improving social workers' competencies in disability is essential to support these efforts effectively.

Despite these robust policies available in Kenya, implementation remains a challenge. Children with disabilities and their families face significant challenges, relating to education, care, and support services, among others, some of which this study aims to focus on.



3.0 RESEARCH METHODOLOGY

3.1 Study Design

The study employed a concurrent mixed-methods exploratory design, combining qualitative and quantitative research approaches to generate evidence on educational and support services for children with autism and on psychosocial support for their parents/caregivers. The quantitative component targeted parents' experiences with the education programs, care and support for children, and psychosocial support for parents/caregivers. On the other hand, the qualitative component provided in-depth insights into responding to the three research questions under study.

3.2 Study Location

The study was conducted in two counties in Kenya: Nairobi and Kiambu, conveniently selected for budgetary and logistical considerations. Nairobi county is a diverse and cosmopolitan County that represents the urban setting. It has both the urban formal and informal settlement making a good target County for the study. On the other hand, Kiambu County has a blend of both semi-urban and rural settings. A blend of these two Counties provides a contextual lens during data analysis.

3.3 Population and Sampling

The population for this research comprised parents/caregivers of children diagnosed with ASD, living in Kiambu and Nairobi counties, teachers from special units (specialized classrooms within mainstream schools designed to support learners with disabilities) or integrated programs (educational arrangements where learners with disabilities learn in regular schools alongside their peers, with added support tailored to their needs) for children with autism within Kiambu and Nairobi counties, Curriculum support officers-SNE from the two counties, and officers from Kenya Institute of Special Education (KISE), Ministry of Education-Directorate of Special Needs Education (MoE-DSNE).

Parents of children with ASD were targeted since they have experienced raising a child with ASD and have been present when seeking education and care and support services. The involvement of teachers provided insights on the education provided to learners with autism. Curriculum support officers in charge of special needs education, who are also responsible for providing assessment and placement advice to learners with disabilities were critical in sharing information in response to the three research questions based on their interactions with the parents, the child with ASD and the school.

Officers from KISE provided insights especially on care and support for the child with ASD as well as psychosocial support for the parents. This is because these officers interact with parents and children during functional assessment and therapy sessions. In addition, assessment officers at KISE provide advice to the parents on education placement options.

The Ministry of Education officers from the directorate of special needs education were involved in the study since they are in charge of the education of learners with disabilities in the country and therefore are knowledgeable about the specific education programs, the related curriculum, and support services available at the school level.

3.3.1 Quantitative Sampling

Drawing on national disability surveys such as the Kenya National Survey on Children with Disabilities and Special Needs in Education conducted by the Kenya Institute of Special Education (KISE, 2018), census data from the Kenya Population and Housing Census (KNBS, 2019) and published prevalence estimates of autism in Kenya (e.g., NCPWD, 2023), the population of parents or caregivers of children diagnosed with ASD in Nairobi and Kiambu counties can be approximated at around 700, with Nairobi contributing close to 500 and Kiambu roughly 200. Note that these values represent synthesized estimates derived from the cited sources rather than exact official statistics. This study adopted the Yamane (1967) formula for calculating sample size when the population size is known as follows.

$$n = \frac{N}{1 + N.e^2}$$

Where;

N = population size

e = level of precision

n = estimated sample size

Using this formula with N = 700, and setting the precision level at 5%, the estimated sample size for the study will be;

$$n = 700 / (1 + 700 * 0.05^2)$$

$$n = 255$$

Accounting for a 10% non-response, a random sample of 281 respondents was used. We used proportional sampling to determine the sample for Nairobi and Kiambu as follows:

$$\text{Nairobi: } (500/700) * 281 = 201$$

$$\text{Kiambu: } (200/700) * 281 = 80$$

3.3.2 Qualitative Sampling

For the qualitative component, participants were recruited using purposive sampling to ensure representation across relevant categories such as gender, geographic location, and role in supporting children with autism. To ensure gender balance, male and female parents/caregivers were included in focus group discussions (FGDs) where applicable. Parents and caregivers for the FGDs were recruited through WhatsApp support groups for parents of children with ASD in Kenya. The researchers collaborated with the group administrators to identify and invite potential participants. Key informants were purposively selected to capture diverse perspectives from education stakeholders, as presented in Table 1.

Table 1: Participant Summary

Participant Category	Recruitment Source/Criteria	Number (n)
Parents/Caregivers (FGD)	Through the Roof parents' network	16
Teachers (KII)	Schools with special units or integrated programs	8
Curriculum Support Officers–SNE (KII)	County TSC offices	4
MoE Directorate of Special Needs Education (DSNE) Officials (KII)	Ministry of Education	2
KISE Officials (KII)	Kenya Institute of Special Education	2

3.4 Recruitment and Training

Six field staff and two field supervisors were recruited in December 2024 from the two target counties. Training field interviewers was conducted from 10th to 12th February 2025. The trainees were taken through the study objectives, research ethics, qualitative and quantitative data collection tools, disability etiquette, and data collection skills. The training also involved role-play activities to equip trainees with relevant field scenarios and ensure the capturing of high-quality data. Interrater reliability scores were computed as the trainees continued practicing until a score of 90.78 was achieved on the quantitative tool.

3.5 Data Collection Tools

A structured questionnaire was used to collect data from parents of children with ASD on therapy services, education programs and on psychosocial support for parents/caregivers of children with ASD.

Focus group discussions (FGDs) guides were conducted with parents in order to gain deeper insights from parents' experiences on education provision and care, support and therapy services for their children with autism, as well as their personal experiences on psychosocial support and how they cope.

Key informant interviews (KIIs) guides were conducted with teachers of children with autism, CSO-SNE, and officers from KISE, and MoE-DSNE. These KIIs collected additional data bringing in the different points of view on the three aspects under study (education programs and therapy services for children with ASD, and psychosocial support for parents).

3.6 Data Collection Procedures

Data were collected between 12th - 20th February 2025. For the parents' surveys, the questionnaire was loaded into SurveyCTO, and a trained field officer completed the questionnaire through a one-on-one Computer Assisted Personal Interview (CAPI) with the parent. The field staff explained to the parents about the study and guided the parents through the consenting process.

Key informant interviews were conducted in a quiet space within the participants' environment. During the KII sessions, participants were briefed about the study and the informed consent sought. The interviews then proceeded for the participants who granted consent. To collect data from CSO-SNE, and officers from KISE and MoE-DSNE, an appointment was booked to get an appropriate time slot for KII.

Two focus group discussions were conducted with parents of children with ASD (one FGD per county). Each FGD had a minimum of six participants, a maximum of 10 participants and lasted up to one hour. The FGDs were conducted in an environment within the proximity of the parents. The focus group discussions were moderated by special needs education specialists while the field research assistants took notes and recorded. After the climate setting, participants were briefed about the study and asked to provide consent. The special needs education specialists conducted a debrief session with parents after the FGD.

3.7 Data Analysis

3.7.1 Analysis of Quantitative Data

Upon completion of fieldwork, data cleaning was conducted to identify and resolve inconsistencies, missing values, and potential outliers. The cleaned dataset was managed and analyzed using Stata 17.0. The analysis began with exploratory descriptive statistics to characterize the study sample, focusing on socio-demographic variables such as the age and gender of parents/caregivers, as well as the profile of their children diagnosed with ASD. Results were summarized using frequencies, proportions, means, and standard deviations. Analytical outputs were presented using tables and graphs to facilitate interpretation.

3.7.2 Analysis of Qualitative Data

Qualitative data from the FGDs and KIs were analyzed using a thematic analysis approach. NVivo 14 (trial version) supported the management and organization of qualitative materials. The analysis began with a verbatim transcription of all audio-recorded interviews. Transcripts from Swahili interviews were translated into English. The research team reviewed all transcripts to ensure accuracy and familiarized themselves with the data. The first cycle of coding involved general-level coding to label broad segments of the text, followed by open coding to capture emerging concepts aligned with the research questions. In the second cycle, axial coding was used to cluster initial codes, identify relationships, and organize them into broader themes. Coding checks and theme reviews were performed by qualitative experts and team leaders (Wawire et al., 2023) to ensure consistency and analytic rigor. Final themes were compared with existing literature to strengthen interpretive validity. NVivo-generated coding reports supported the presentation of findings. The credibility of the qualitative analysis was strengthened through multiple strategies: data triangulation across interviews and focus groups; progressive aggregation of analytic units from significant statements to broader meaning units (Creswell, 2013); thick descriptions derived from participant narratives; and member checking, in which participants reviewed preliminary themes to verify interpretive accuracy.

3.7.3 Triangulation of Quantitative and Qualitative Data

Triangulation was an integral part of the analysis to enable convergence and complementarity between quantitative and qualitative findings. The purpose of triangulation was to enhance the validity, depth, and interpretive power of the results by integrating insights from multiple data sources and methodological approaches (Ndanu & Syombua, 2015).

The triangulation process involved several steps:

- i) Quantitative descriptive statistics were examined alongside qualitative themes to identify areas of agreement, divergence, or elaboration.
- ii) Key findings from surveys were validated against perspectives from FGDs and KIs, strengthening confidence in recurring patterns.
- iii) Qualitative data were used to explain or contextualize quantitative trends. For example, clarifying reasons that may explain numerical patterns in school attendance or service access.
- iv) Both datasets informed the interpretation of results, with qualitative narratives offering depth to numerical trends and quantitative data providing scope and prevalence to qualitative insights.

3.8 Ethical Considerations

The study protocol was submitted to the APHRC Scientific Review Committee (SRC) for review to ensure it met scientific rigor and ethical principles. After this, the study protocol was submitted for review by the African Medical and Research Foundation's Ethics and Scientific Review Committee (AMREF-ESRC) and was approved under protocol Ref. No. AMREF - ESRC P1767/2024. The research team then obtained a research license from the National Commission for Science, Technology, and Innovation (NACOSTI) to conduct the study.

Information about the study was explained to the respondents, consent was sought, and consent forms signed before data collection. The principle of anonymity was applied. We also ensured that all the investigators had completed the - National Institute of Health (NIH) web-based course on protecting human research participants. In addition, all the field staff received training in research ethics, disability etiquette and the APHRC guidelines for working with study participants.

Participation in the study was voluntary, and no coercion was used. In addition, the risks and benefits of the study were described to the study participants. Moreover, all interviews were conducted privately, and all data sets were anonymized to protect the identity of respondents. The information shared during FGDs was kept confidential according to an agreement and code of conduct within the group. All these ethical requirements were emphasized during the training of field staff.

4.0 STUDY FINDINGS

4.1 Demographic Characteristics

Table 2 presents the demographic information of parents and caregivers of children with ASD. The table shows the role, gender, age bracket and employment status of the parents/caregiver who participated in the study.

Table 2: Demographic Information

Characteristic	Category	Freq.	Percent
Role	Parent	187	96.0
	Caregiver	8	4.1
Gender of Parents	Male	11	5.6
	Female	184	94.4
Gender of Children	Boys	137	70.3
	Girls	58	29.7
Age	20–30 years	19	9.7
	31–40 years	94	48.2
	41–50 years	68	34.9
	51–60 years	12	6.2
	Over 60 years	2	1.0
Employment status	Self-employed	92	47.2
	Employed – Casual	16	8.2
	Employed – Formal	30	15.4
	Unemployed	57	29.2

Most of the participants were parents of children with ASD (96%), while caregivers accounted for 4%. Among all parents and caregivers, 94.4% were female and 5.6% were male. In terms of age, nearly half (48.2%) were aged 31–40, followed by those aged 41–50 (34.9%). Regarding employment status, the largest proportion (47.2%) was self-employed, followed by the unemployed (29.2%). Those in formal or casual employment represented the smallest proportion of parents and caregivers.

Most of the children with ASD, whose parents participated in the study, were boys (70.3%) compared to girls (29.7%). Parents in the FGDs sometimes hinted at this imbalance, noting that schools and services “expect” more boys than girls in their units. Teachers, too, tended to speak of children with ASD in masculine terms, often defaulting to “he” when describing classroom challenges. This finding aligns with previous research. For example, after examining 71 studies comprising 99 prevalence estimates, Zeidan et al. (2022) reported that males consistently outnumber females, although the male-to-female ratio varies widely from 0.8 to 6. Overall, the demographic patterns paint a picture of mothers in their thirties and forties, many of them self-employed or unemployed, carrying the primary responsibility for children with autism.

4.2 Education Programs

Table 3 shows the current school attendance of children with autism whose parents participated in the study. Most of the children (about 74%) were reported as attending school, while just over a quarter (26%) were not.

Table 3: School Attendance and Reasons for Non-Attendance

Does your Child go to School	Freq.	Percent
No	51	26.2
Yes	144	73.8
Reasons for Non-Attendance (Multi Response)		
Does homeschooling	2	3.9
Has not attained school-going age	5	9.8
Has not benefited from school in the past	4	7.8
I cannot afford	22	42.2
School is not safe for the child	6	21.6
Completed school	2	3.9
Other conditions, such as being physically disabled, deaf	5	9.8

At first glance, this seems encouraging; however, if more than one in four children (or 26%) with autism are not in school at all, it is striking, particularly in the context of Kenya's constitutional promise of universal basic education. Parents in the focus groups often explained this absence in personal terms. Some children were "not ready" for school, headteachers turned others away, and still others could not cope with the classroom environment. One mother said:

"I tried, but after two weeks, they said he was disturbing other children. I had to take him back home." Parents FGD.

Teachers' interviews add context. They admitted that, while many schools now have special units, resources are stretched, and staff are unprepared to meet the diversity of needs. One teacher said:

"Sometimes we are forced to tell a parent to wait, because we don't have space or enough teachers. It's not that we don't want the child, but we can't manage all of them." Teacher interview.

Curriculum support officers often stresses that the Ministry encourages placement in inclusive settings. Yet the reality of living appears to lag behind policy. The 26% non-attendance figure, when read alongside parents' narratives, suggests that availability does not necessarily guarantee access.

Regarding reasons for non-attendance at school by children with ASD, financial constraints stood out most strongly: 42.2% of parents who kept their children at home cited inability to afford to pay school levies. This suggests that cost may include aspects of tuition, transport, uniforms, or the hidden extra costs, such as paying for a shadow teacher remains the most significant barrier. In FGDs, some parents explained how they had to choose between therapy sessions and school fees, often sacrificing one for the other. One parent said:

"Even if there is a unit, if you don't have the money, it's like the school does not exist for you." Parents FGD

Safety concerns were another prominent theme, mentioned by about one in five parents (21.6%). Parents worry that their children might be bullied, neglected, or physically harmed in unsupervised school environments. One caregiver described how her son was left alone in the playground and returned home with injuries: ***"The teacher said he just fell, but I knew it was because nobody was watching him."*** These fears often led to withdrawal, even when schools were technically available.

A smaller but still meaningful proportion of parents (9.8%) said their child was not yet of school-going age, while another 9.8% cited additional disabilities (such as being deaf or physically disabled) as reasons for staying out of school. This highlights the compounding effect of multiple challenges: when autism intersects with other conditions, parents may feel overwhelmed and reluctant to send their child into an already overstretched school system. Some parents also pointed to negative past experiences (7.8%), saying their child had not benefited from previous school placements. For these families, trying again felt pointless: ***"I took him for one year, but he just came back worse, so I stopped."***

Teachers' accounts shed light on some of these reasons. They acknowledged that schools sometimes send children home because they "cannot cope" or because the school lacks staff trained to manage behavioral challenges. Teachers also empathized with parents' financial struggles, admitting that even in public schools, the burden of levies and extra support falls heavily on families. Table 4 shows school placement and curriculum pathways for children with ASD.

Table 4: School Placement and Curriculum Pathways for Children with Autism

Variable	Outcome	Freq.	Percent
Type of School	Inclusive/integrated	95	66
	Special unit for children with autism	12	8.3
	Special unit for children with different disabilities	6	4.2
	Special school for children with autism	20	13.9
	Special school for different disabilities	11	7.6
Curriculum Pathway	Age based	83	57.6
	Stage based	61	42.4

The majority of children (66%) were enrolled in inclusive or integrated schools, meaning they attended regular schools alongside typically developing peers, often with varying levels of support. This finding is noteworthy because it reflects the government's long-standing policy push toward inclusive education. Yet parents' accounts suggest that **"inclusive"** in practice is not always as supportive as policy implies. Several parents described their children being **"in the classroom but not really learning,"** often sidelined because teachers lacked training or time. One mother explained:

"Yes, he is in an integrated school, but most of the day he just sits at the back." Parents FGD

Only 8.3% of children were placed in special units designed specifically for autism, while another 4.2% were in special units catering to other disabilities. This small share highlights the scarcity of autism-specific units, especially considering the scale of need. Parents frequently commented on this gap, with one saying,

"If there was a unit for autism near me, I would take him tomorrow, but here there is nothing." Parents FGD

Teachers echoed this concern, noting that most units in public schools are general special needs units, mixing children with diverse needs. Results show that 13.9% of children attended dedicated special schools for autism, and 7.6% were in special schools for other disabilities. These figures, though relatively modest, indicate that some parents do opt for segregated schooling when such schools are available and affordable. A few parents even preferred these settings, believing their children were safer and better understood. One of the parents had this to say:

"In the special school, nobody laughs at him. He is free." Parents FGD

At the same time, others worried that such settings isolate children from broader society. From teachers' perspectives, the dominance of inclusive schools is both an achievement and a challenge. Teachers tended to point out that integration is only meaningful if classrooms are equipped, class sizes are smaller, and staff are trained. One teacher describes that in such cases as **"It becomes dumping, not inclusion."** Curriculum support officers, in policy documents, emphasize integrated schooling as the norm. Still, the lived reality presented by parents and teachers suggests that the system may be stretching inclusivity without ensuring effectiveness.

These findings highlight a critical policy gap that, while placement in inclusive settings is high, the quality of support within these schools often falls short of policy expectations. Parents' and teachers' accounts suggest that children may be physically present but inadequately supported, raising concerns about meaningful inclusion. The implication may be that, while promoting inclusive education is essential, its implementation needs strengthening. Table 6 presents the curriculum pathways adopted for children with autism.

Regarding the curriculum pathway, results show that most children (57.6%) were in the age-based classes, while 42.4% were in stage-based pathways. During interviews with parents and teachers, this trend was highlighted as a mismatch during interviews. This can be understood in the context of the Competency-Based Education (CBE) explicit provision for stage-based pathways that did not previously exist. Parents tended to view age-based placement with frustration. Some described how their child was **"just put with others the same age,"** regardless of ability, which led to disengagement and, in some cases, withdrawal. Teachers admitted that resource constraints often forced them into age-based grouping, even when they knew it was not ideal. Managing diverse needs in overcrowded classes left them little room to consistently apply stage-based principles. As one teacher explained:

"I can be teaching ten classes of learners because they are not the same, but officially they are all in one class by age." Teacher interview

Parents were asked to reflect on their children's development since joining school, focusing on both academic and social aspects, and the results presented in Figure 1.

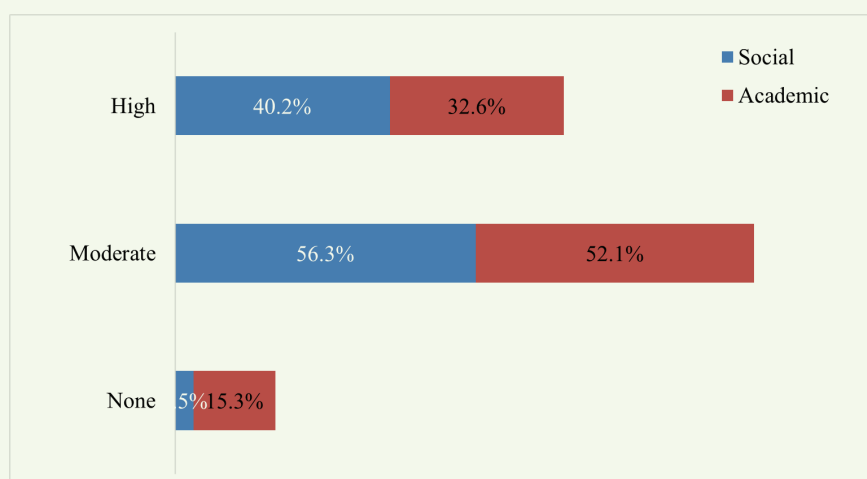


Figure 1: Developmental Achievement of Children Since Joining School

Results show that a majority reported moderate achievement in both domains - 56.3% for social development and 52.1% for academic development. This was followed by the proportion of parents who reported “high achievement,” while a smaller group reported non-achievement in both academic and social aspects. It is, however, important to note that the proportion of parents who reported moderate or high achievement was higher in social aspects compared to academic, while the proportion of parents who reported no improvement was higher in academic compared to social aspects. This contrast was clear during focus group discussions with parents and teachers. Some parents described seeing improvements in their children’s ability to interact and adjust to routines once they entered school. One mother from Nairobi explained:

He can now greet the teacher, he knows how to stand in the parade, he is calmer. Before school he could not sit, even five minutes.” Parents FGD

One teacher argued that ***“school changes a lot... even if you don’t teach them, they learn social skills... they socialize so that we can learn with others.”*** Another emphasized how integrating learners with autism into assemblies, songs, and group activities gave children with ASD opportunities to practice communication: ***“When I am on duty, I always make sure they read like others... lead in songs. They also get role models from their peers.”*** These teacher accounts help explain why parents see more visible social gains than academic ones.

On the other hand of academic performance, some parents expressed disappointment, describing that ***“the child is in the classroom but not really learning.”*** One parent recounted: ***“I took him for one year, but he just came back worse, so I stopped.”*** Similarly, some teachers acknowledged that academic progress is harder to secure. Teachers said that without autism-specific curricula, they fall back on Activities of Daily Living (ADLs) and communication skills, which, while valuable, do not directly translate into reading, writing, or numeracy outcomes. One teacher put it this way:

The ministry has not even designed a curriculum for autism... Sometimes autism is under intellectual disability... we teach ADLs, Communication Skills.” Teacher interview

This helps explain the survey finding that academic non-achievement was more than four times higher than social non-achievement. Based on this, one may speculate that education programs for children with autism are most likely to succeed in providing socialization opportunities but struggle to deliver equivalent academic progress. Table 5 summarizes what parents reported liking most about their children’s schools.

Table 5: Aspects that Parents Like About their Child’s School

What parents like about their child's school	Freq.	Percent
The way teachers treat children with Autism	120	51.7
Accessibility	37	16.0
School Routine	35	15.1
School Administration	31	13.4
Extra-curricular activities	7	3.0
Facilities available (Safety, environment)	6	2.6
Therapy services available	3	1.3

Results show that more than half of parents (51.7%) liked the way teachers treat children with autism. This emphasis on teacher behavior resonates with parents’ sentiments during FGDs, where it was noted that what made the difference was not just whether a school had a special unit, but whether teachers showed patience, care, and understanding. One parent described how her son was “now calmer” because ***“the teacher knows how to change the sitting arrangement and doesn’t shout.”***

A second tier of what parents liked clustered around accessibility (16%), school routine (15.1%), and administration (13.4%). In this context, accessibility may refer to both physical proximity and schools’ openness to enrolling autistic learners. Parents in FGDs sometimes contrasted welcoming schools with those where headteachers asked, “What is autism?” and rejected their child. Where schools did open their doors, parents noticed and valued that accessibility. The appreciation of school routines reflects parents’ recognition that predictability benefits their children with autism. Teachers, too, highlighted routine as therapeutic, saying that even without direct instruction, children learn social skills through repetition of daily activities. School administration (13.4%) was also valued by parents, though much less than teacher behavior. In the FGDs, parents described supportive headteachers who championed inclusion or helped link them to resources as crucial allies. Conversely, uncooperative administrators often became barriers to access.

By contrast, very few parents mentioned facilities (2.6%), extracurricular activities (2.9%), or therapy services (1.3%). This may be in support of frequent complaints in FGDs about the lack of sensory rooms, therapy gaps, and limited materials. One interpretation could be that parents have adjusted expectations downward: they no longer expect fully equipped facilities or regular therapy, and instead, they focus on what makes a tangible daily difference. This suggests that families recognize the scarcity of specialized resources but value personal commitment over material provision. From a policy point of view, these results imply that parents’ primary measure of a “good school” for children with ASD is teachers’

attitudes and relational practice, rather than infrastructure. While facilities and therapies are undoubtedly necessary, what parents consistently experience and remember is whether their child is treated with respect, patience, and inclusion. For CSOs and policymakers, this may suggest that investment in teacher training, professional development, and school culture could yield more immediate and widely felt improvements than focusing narrowly on physical facilities.

Challenges Experienced in the Education Journey of Children with Autism

a) High Cost of Education

The most cited education related challenge by most parents was the high cost of education for their children with autism. Most parents cited being required to pay extra fees for the child with disability. Other costs related to expensive resources and paying for a shadow teacher or a personal teacher. Parents highlighted that good schools that can accommodate children with autism are quite expensive.

"It is expensive since you need to employ a shadow teacher." - Parent open ended survey.

"Getting a school that is affordable for the child and teachers who can be able to handle a child living with autism is challenging" Parent open ended survey.

"Paying school fees is a challenge, without medicines he can't learn". Parent open ended survey.

"There are extra costs to make sure that the child is accommodated." "Schooling materials are expensive." Parent open ended survey

"the child is at home most of the time because of lack of school fees" Parent open ended survey

b) Nonspecialized Teachers for Autism

The second most reported education related challenge was teachers not trained to handle learners with autism. Adequacy of trained teachers was also pinpointed.

"Teachers are not trained on how to handle autistic children." "Most teachers don't understand/know on how to deal with autistic children" Parent open ended survey

c) Inclusivity of Schools

Parents stated that most schools are not inclusive and are lacking specialized care, personnel, resources and attention for learners with autism. Parents consistently reported major challenges in securing appropriate schooling for their children with autism, including schools unwilling to admit them, teachers lacking skills to support them, unsafe or poorly maintained learning environments, frequent school changes due to unmet promises, and limited specialized resources or dedicated caregivers. One of the parents had this to say:

"Not easy to find a school that accepts children with autism, the school is far away, most teachers don't understand/know on how to deal with autistic children" Parent open ended survey

d) Accessibility of Schools

The other cited challenge by parents in the provision of education for learners with autism was the accessibility of schools.

The school is quite a distance, so I have to organize how to drop him in school." Parent open-ended survey

e) Learner Characteristics

Another main challenge relates to the child's characteristics, such as hyperactivity, severity of disability, and academic limitations.

"Getting a good school for my child is not easy because my child's case is severe." Parent open ended survey

"The child gets bruised a lot in school because he is hyperactive" Parent open ended survey

"child doesn't like maths, sometimes doesn't like homework she even tears her books if forced" Parent open ended survey

f) Other Challenges

The other cited challenges regarding the education of children with autism were: diverse curriculum needs of children with autism, unmet special diet needs, stigma at school and community levels, or lack of awareness and support, the child not making any academic progress, and being overwhelming to the parent. Parents' accounts indicated that children with autism face systemic educational barriers. This includes rigid curricula that do not accommodate their interests or learning needs, low expectations from schools, limited access to exams and programs, lack of dietary or physical accommodations, social stigma, and logistical challenges for families. These barriers contribute to poor academic progress, fear for the child's future, and emotional and physical strain on parents. One of the parents had this to say:

"School assumes she is of low intellect; the curriculum imposes subjects on them which they are not interested in rather than focusing on what the child really likes." Parent open ended survey

4.3 Therapy Services for Children with Autism

This section presents results from the study on therapy services for children with ASD. Table 6 compares therapy services recommended by health professionals reported as actually available for their children, while Figure 2 presents weighted Z-scores of unmet needs (the weighted gap/difference between what is recommended and what is available) in therapy.

Table 6: Therapy Services Recommended by a Health Professional Vs Available

Care and therapy services recommended by a health professional vs available	Recommended	Available		
	Freq.	Percent	Freq.	Percent
Occupational therapy	138	38.66	99	31.9
Sensory integration	26	7.28	15	4.9
Speech therapy	126	35.29	77	24.8
Hydrotherapy	31	8.68	30	9.7
Pharmacotherapy	29	8.12	26	8.4
Music therapy	7	1.96	6	1.9
Home-based therapy	-	-	43	13.9
I don't know (Not aware)	12	3.25	14	4.5

The most recommended therapies were occupational therapy (38.7%) and speech therapy (35.3%). These were incidentally the most widely available by proportion, but still do not match the available demand (see Figure 2). Similar trends were observed for sensory integration and speech therapy, where what was recommended (demand side) was less than the available (supply side). On the other hand, home-based therapy, music therapy, pharmacology, and hydrotherapy seem to project a different trend (at least statistically) of everything being okay; however, narratives during focus group discussions paint a different picture, a picture of deficiencies in all the therapy services.

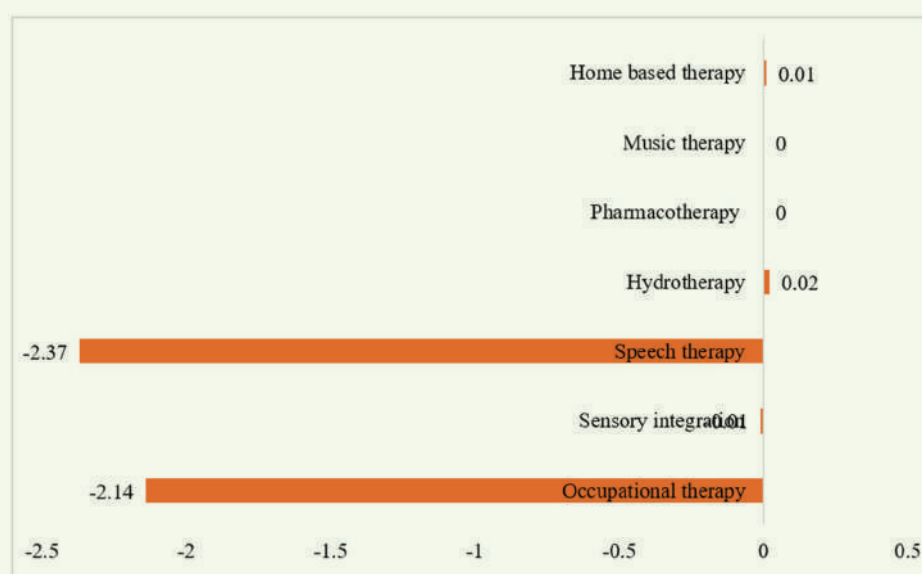


Figure 2: Weighted Z-Scores of Unmet Needs in Therapy

Results presented in Figure 2 suggest that the biggest gaps exist in speech and occupational therapies (below 2 standard deviations) followed by sensory integration. The gaps between recommendation and availability underscores the everyday frustration many parents voiced in the focus groups. One parent remarked:

“The doctor said he needs speech therapy, but in our area, there is nothing. I was told to go to Nairobi, but how often can I afford that?” Parent FGD.

For families outside urban centers, the service gap often translated into complete absence of therapy. Teachers echoed this concern. For instance, some teachers reported that they often ended up trying to play the role of therapist because professional services were missing. As one put it;

“We improvise... sometimes you just try to help with speech in class, even though you are not trained.” Teachers Interview

This improvisation highlights both teachers’ commitment and the systemic gap in specialist provision. Sensory integration therapy was recommended for 7.3% of children, yet only 4.8% had access. Again, this aligns with parents’ laments about the lack of facilities. One mother described how she had read about sensory rooms but found none locally: ***“They told me my child needs sensory integration, but where? Even the unit has no balls, no swings.”*** Teachers confirmed this, admitting they used “sacks and blankets” as makeshift sensory tools.

While hydrotherapy seemed like a good match for the needs, some parents mentioned churches or private centers offering swimming as therapy. Additionally, teachers and CSOs questioned whether these services were consistent or well-supervised. One CSO noted that activities labeled as hydrotherapy “may simply be swimming sessions without proper therapeutic oversight.” In terms of pharmacotherapy, the availability of prescribed medications generally aligns with recommendations, indicating that parents can usually access the necessary drugs, though sometimes at a significant financial burden. Still, in FGDs, a few parents expressed hesitation, saying they feared side effects or could not sustain long-term treatment. Music therapy was the least recommended (2%) and almost equally scarce in availability (1.9%). This aligns with teachers’ accounts that while they used songs and rhythm in classrooms, it was not structured therapy. Parents did not mention it often, except in passing as part of church-based programs.

Home-based therapy, which was not professionally recommended, was reported by 13.9% of parents. In FGDs, parents often described ***“doing what they could”*** at home, using, for example, speech drills, physical exercises, or copying routines observed from YouTube videos. One mother explained: ***“I just do it myself, because waiting for therapy means he will lose time.”*** This finding may suggest that parents are stepping into the therapy gap when formal services are inaccessible or unaffordable. Teachers occasionally encouraged this, advising parents to reinforce skills at home. Yet CSOs noted with caution that unsupervised home therapy risks inconsistency and may not always follow evidence-based practice.

It was observed that a small but significant proportion of parents (about 3–4%) reported not knowing which therapies were recommended or available. This lack of awareness reflects both the information gap and possible denial among some parents. Teachers reported that a few families avoided discussions of therapy altogether. Parents were asked about the accessibility of therapy services for their children, and the results presented in Figure 3.

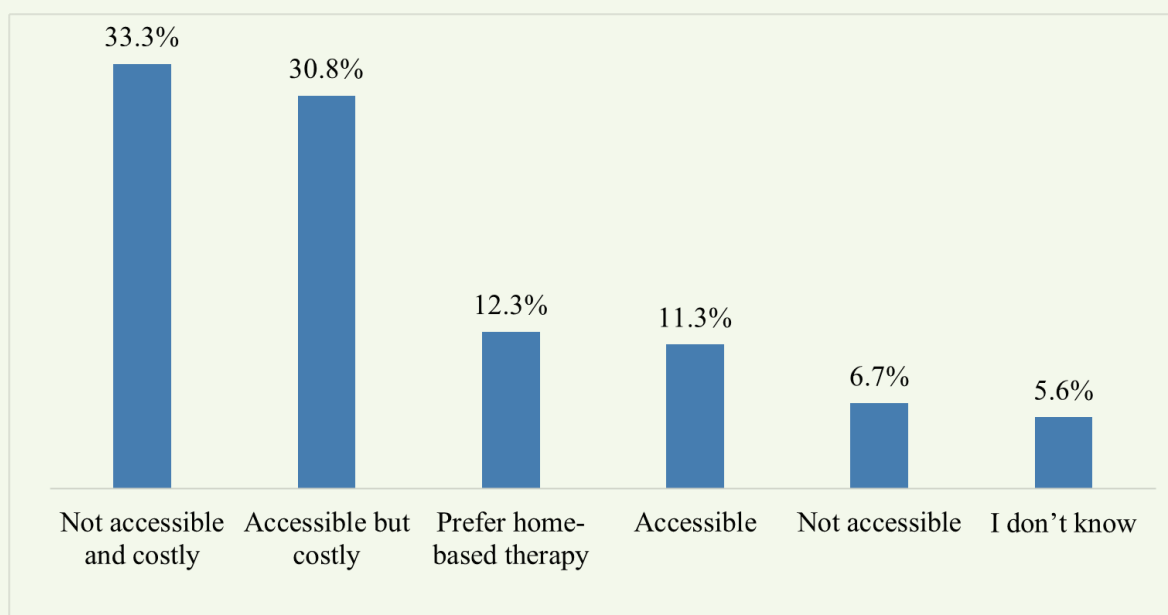


Figure 3: Accessibility of Therapy Services

Roughly a third of respondents (33.3%) said services were “not accessible and costly”, while another 30.8% described them as “accessible but costly.” Taken together, these two categories suggest that, for most parents, cost is the decisive barrier, even when services are physically available. During one of the FGDs with parents, one mother in Nairobi explained:

“The doctor told me to take him for speech therapy twice a week. Even once is impossible. Where will I get that money?”

These results reflect the gap dynamics shown in Table 6 and Figure 3, where recommendations for speech therapy far exceeded its availability. The situation is then further complicated by cost to the already scarce service. Another 6.7% of parents reported that therapy was “not accessible,” without even mentioning cost. This category likely reflects geographic exclusion, particularly for families in Kiambu or peri-urban areas, who repeatedly described having to travel into Nairobi for specialized services. One parent said:

“We are told only Kenyatta [Hospital] can do that therapy. To go there, you leave at 4 a.m. and maybe you are not even seen.” Parent FGD

Teachers confirmed this reality by noting that some parents ***“just stop coming”*** after a few referrals because the distance and queues become overwhelming.

Results show that 12.3% of parents said they prefer home-based therapy. This resonates with the earlier finding from Table 8 where 13.9% of families reported providing therapy at home despite not being formally recommended. Parents often framed this choice as both pragmatic and protective. One mother described how she ***“copied exercises from YouTube”*** and felt it was better than nothing, while another emphasized that home therapy shielded her child from the stigma they sometimes encountered in public clinics. Teachers occasionally endorsed this approach, encouraging parents to “continue at home what we started in class.” Still, curriculum support officers raised caution that unstructured home interventions may lack consistency or evidence-based grounding.

Only 11.3% of parents reported therapy as “accessible” without qualification. This small proportion may suggest that while services exist, very few families experience them as straightforwardly accessible. Even those who do may be a select group with better financial resources, closer proximity to urban centers, or strong networks. The 5.6% who said “I don’t know” suggests lack of awareness. In focus groups, some parents admitted they were unsure what therapy their child needed, or even what autism-specific therapy was. One caregiver said: ***“They just told me he is autistic, but no one explained what comes next.”*** Teachers also pointed out that some parents avoid therapy discussions due to denial or fatigue: ***“We tell them about occupational therapy, but they say, ‘Madam, I have no money, don’t tell me those things.’”***

Figure 4 presents parents’ perceptions of how useful the therapy services their children received had been.

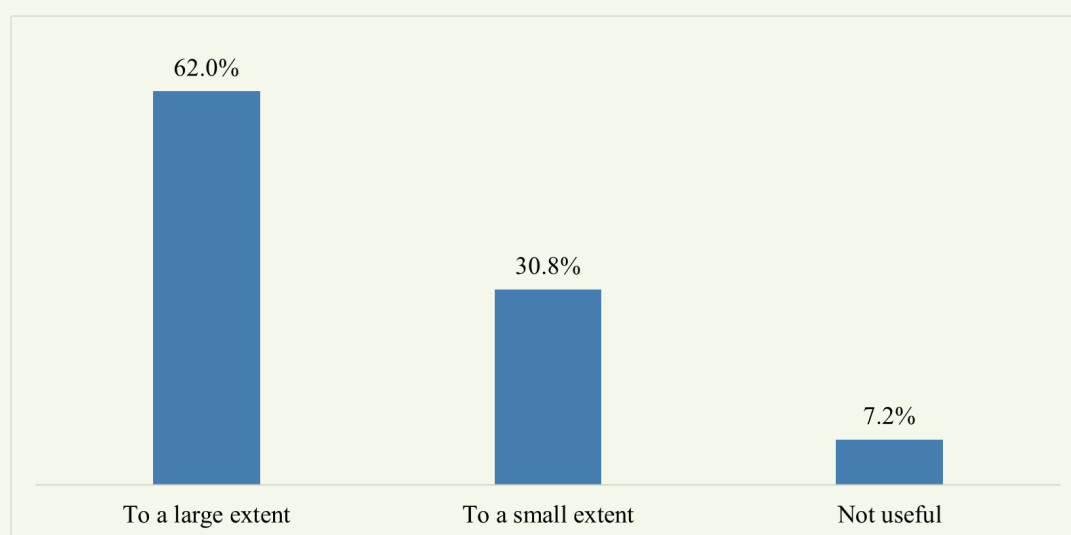


Figure 4: Extent of Usefulness of Therapy Services Received

A majority (62%) reported that therapies were beneficial “to a large extent,” while nearly a third (30.8%) said they were useful “to a small extent.” Only a small minority (7.2%) described therapies as “not useful.” On the surface, these results might suggest a positive picture: most families who managed to access therapies saw some benefits. Parents in focus groups often spoke of therapy as transformative when it was consistent and professionally delivered. One mother from Nairobi explained how, after several months of occupational therapy, her son ***“can now hold a spoon and eat by himself. That alone reduced my stress so much.”*** Another described speech therapy as a breakthrough: ***“Before, he was just crying. Now he can say ‘water.’ It feels like a miracle.”*** These testimonies align with the large group of parents who felt therapy was helpful in a great extent.

However, usefulness was often tempered by concerns about irregularity and sustainability. Parents who placed therapy in

the “small extent” category commonly cited gaps in continuity. One caregiver noted: ***“We start, then after two months I stop because I can’t pay. Then he loses the progress.”*** Teachers also observed that children sometimes regress when therapy is interrupted. A teacher in Kiambu recalled: ***“When the parents bring them after missing months, we have to start all over again.”***

The small group (7.2%) who described therapies as “not useful” frequently voiced frustration with poorly tailored interventions. Some felt that therapists applied a one-size-fits-all approach, failing to adjust methods to the child’s specific needs. One parent complained: ***“They just gave him the same exercises every week, and he hated it. Nothing changed.”*** Others doubted the qualifications of providers, particularly in informal or private centers. Teachers, too, worried about quality: ***“Some people open therapy centers, but they are not trained. Parents pay money, but the child is just playing.”*** Similarly, CSOs defended the usefulness of therapies in principle but acknowledged systemic challenges. One officer argued that therapies under the Ministry’s framework were effective when properly delivered but conceded that gaps in training and supervision limited their impact.

Challenges Experienced when Seeking Therapy Support Services

a) High Cost

The most pressing challenge cited by most parents was the high cost of therapy and medical care for their children with autism. The high cost was exacerbated by the need for several therapy sessions. This high cost made some parents stop taking their children for therapy even though they needed it. Transport to the therapy centers increased the associated cost since using public transportation with the child was challenging. Nutrition for the child with autism also added to the high cost.

“The medicines I need are expensive.” “The therapy sessions are expensive and are not covered by health insurance.” Parents open ended survey

“Costly in terms of medication and therapies and even transportation since you can’t use public means...it is hectic when boarding matatus/ buses with the autistic child” Parent open ended survey

b) Availability and Accessibility of Therapy Services

The second most cited challenge was the accessibility of the therapy centers, with the majority of parents indicating that the available therapy centers are limited and very far away.

“Inadequate therapy centers” “Difficulty in finding centers that offer the recommended therapy services” “Limited facilities that offer therapy service” Parent open ended survey

“Accessibility to the health facilities is quite challenging especially when using public transportation” Parent open ended survey

c) Limited Qualified Health Professionals

The third most cited challenge was limited qualified health professionals and therapists for children with autism. Trained speech therapists were especially difficult to get. Parents’ responses indicate a critical shortage and limited quality of professional services for children with autism. Challenges include insufficient numbers of trained therapists (particularly speech and language specialists), difficulty in accessing appointments, professionals with limited knowledge or creativity, and instances of unprofessional or unethical conduct. In addition, encounters with fake/quack/unprofessional doctors were highlighted by the parents. One of the parents had this to say:

“Lack of enough trained professionals who can handle autistic children” Parent open ended survey

“Limited trained speech therapists” “Speech and language acquisition therapists aren’t available” Parent open ended survey

“The therapists are not creative they keep repeating the same said process ever since the child started the sessions, very few professionals” Parent open ended survey

“Unprofessional doctors who take advantage of the parents” “Fake doctors who have no knowledge on Autism” Parent open ended survey

d) Overwhelming and Time Consuming

The other reported challenge experienced by parents and caregivers regarding care and therapy support services for children with autism is the high burden of care. Specifically, parents stated that it was both overwhelming and time consuming to care for a child with autism.

"It is physically exhausting to take the child to the therapy center" Parent open ended survey

e) Societal Stigma

Parents also cited societal stigma associated with having a child with autism as another challenge reported by a number of parents.

"Discrimination from the society due to lack of information." "stigmatization from the society" Parent open ended survey

"Acceptance from the society and family." "The public doesn't understand these children" Parent open ended survey

f) Child Hyperactivity

Finally, the child being hyperactive and uncooperative during therapy was cited by a few parents as a challenge in the acquisition of care and therapy support services.

"My child is hyperactive and calming her down takes a while" "The child takes a while to get comfortable in a new environment." Parent open ended survey

"Child is stubborn sometimes and doesn't want to be touched." "The child refuses therapy and cries a lot during therapy" Parent open ended survey

4.4 Support Services for Parents and Caregivers

Raising a child with autism is deeply tied to the emotional, psychological, and financial well-being of families. Parents in the study sample spoke about the struggles of caregiving and their search for support. This section explores parents' expressed need for psychosocial support. When asked whether or not they required psychosocial support, the majority (94.9%) of parents reported that they need psychosocial support, with only 5.1% saying otherwise. This suggests that nearly every parent in our study recognized a gap in the support structures available to them as caregivers. The FGDs echoed this demand. Parents described caregiving as emotionally exhausting, socially isolating, and often financially draining. One mother had this to say:

"Sometimes you feel like you are alone in this world. Even family does not understand. They say, 'you are the one spoiling the child.'"

Another parent confessed to moments of despair:

"There are days I just cry... I even thought of leaving the child and running away."

Such statements perhaps illustrate why almost all parents said they needed psychosocial support. Teachers also observed this caregiving strain. A teacher in Kiambu said:

"When we call parents for meetings, some just break down. You see the stress they are carrying."

One of the CSOs reported that while policies emphasize inclusive education for learners, little parallel attention is paid to caregiver well-being: **"We talk about the child, but who talks about the parent?"** This gap helps explain the near-unanimous demand for psychosocial support. However, it's worth noting that the Persons with Disabilities Act 2025 formally recognizes the economic burden of caregiving. However, some work is needed to operationalize the act. For instance, section 57(3) mandates that the Cabinet Secretary develop regulations to operationalize these caregiver benefits. Figure 5 below compares the types of psychosocial support parents said they required against what they reported was available.

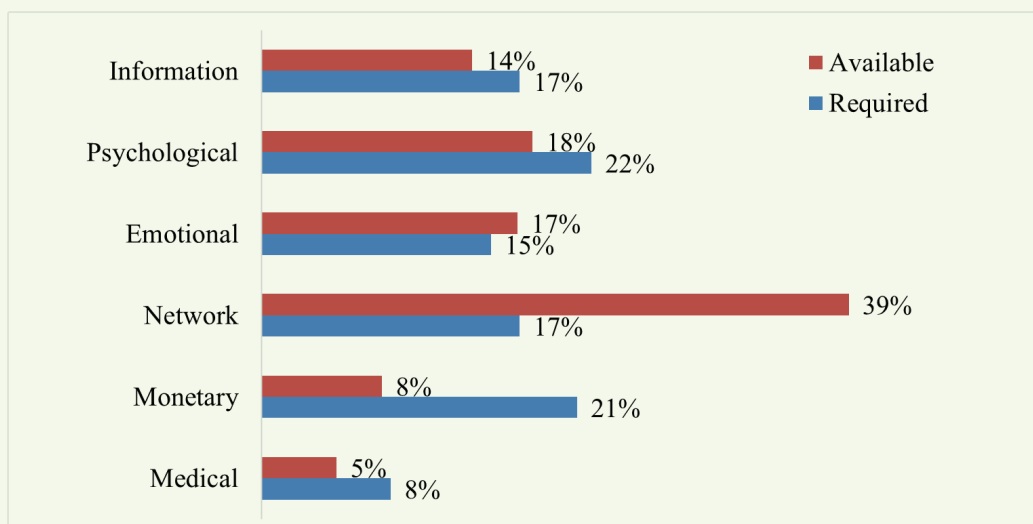


Figure 5: Kinds of Support Required Vs Available

Results show that the highest mismatch was found in monetary support. While 21% of parents said they required financial help, only 8% reported that any financial help was available. Parents in FGDs frequently described the crushing costs of school fees, therapy sessions, and transport. One parent from Nairobi had this to say:

“We have to choose: do I buy food, or do I pay for therapy? You can’t do both.” Parents FGD

A similar gap was evident in medical support (8% required vs 5% available) and information support (17% vs 14%). Parents often reported being “left in the dark” after diagnosis. One caregiver said:

“The doctor just told me: autism. Then I was on my own. I didn’t know where to go.” Parents FGD

Teachers confirmed this lack of guidance, pointing out that they themselves often became the first point of information for parents, despite not being specialists. For emotional support, 15% of parents explicitly required it, while 17% said it was available. Emotional support here often came from teachers, pastors, or extended family. One parent said:

“When the teacher calls me and tells me, ‘Your child has improved,’ I feel encouraged.” Parents FGD

Teachers, for their part, saw themselves as providing this kind of informal encouragement:

“We counsel the parents too, not just the children.”

Regarding psychological support (22% required, 18% available) emerged as a high-priority area. Many parents wanted access to trained counsellors or mental health professionals, but availability lagged slightly behind. Parents in FGDs spoke about the stigma of seeking counselling, and yet at the same time admitted the need. One said:

“Sometimes you feel like you are going mad. If there was someone to talk to, even just once a month...” Parents FGD

The gap here suggests that psychological services, though more present than financial support, remain underprovided relative to demand.

On a different note, network support shows the reverse pattern compared to other support for parents and caregivers of children with ASD. Results show that more parents reported it as available (39%) than those who initially said they required it (17%). This may reflect the rise of informal parent support groups and WhatsApp networks that parents are joining after realizing their value. In the FGDs, some parents spoke with pride about these networks:

“We now meet every month, we share stories, even if there is no money, just talking helps.” Parents FGD

Teachers sometimes facilitated these networks, encouraging parents to connect with each other after meetings. This explains why availability outstrips initial demand: parents may not have known they needed peer networks until they experienced them. Parents were asked about the challenges they experience raising a child with autism and responses summarized in Table 7.

Table 7: Challenges Faced by Parents raising a Child with Autism

Challenges/burden of care	Freq.	Percent
Stressful	149	19.6
Costly	160	21.1
No burden	2	0.3
Emotionally challenging	132	17.4
Physically Exhausting	111	14.6
Socially Isolating	97	12.78
Time consuming	98	12.91
Stigma/Discrimination	10	1.32

The most frequently cited challenge was that caregiving is costly (21.1%), closely followed by being stressful (19.6%) and emotionally challenging (17.4%). This triad of financial, psychological, and emotional strain captures the heart of parents' burden. Parents' voices starkly illustrate these categories. On cost, one parent said:

"I cannot even explain... every shilling goes to this child. School fees, therapy, transport. We eat last."

On stress, another parent confessed:

"Sometimes I feel like my head will explode. You are running up and down, and still nothing changes."

Emotional challenges were described in terms of heartbreak and helplessness. A parent shared:

"You see other children reading, playing, and your own is still not talking. It pains you daily."

Physical exhaustion (14.6%) was also a recurring theme in conversations with parents. Many of them talked about sleepless nights, managing meltdowns, or carrying older children who were hyperactive or non-verbal. One had this to say:

"He doesn't sleep, so I don't sleep. Then in the morning I go to the market. My body is finished."

Social isolation (12.8%) and time consumption (12.9%) also featured prominently. Parents said they often felt cut off from extended family and friends. One parent explained:

"You are not invited anywhere because they fear your child. Even church, people move away."

Teachers observed similar patterns:

"Some parents stop coming to parents' meetings because they feel ashamed or judged."

While stigma and discrimination (1.3%) appeared low in the quantitative data, many parents in FGDs spoke about stigma, sometimes indirectly. Some claimed neighbors call their child "mad" or relatives blaming mothers for "bewitching" the child. One parent said: **"People say you are cursed. They laugh."** Only 2 parents (0.3%) in our study sample reported experiencing "no burden". This small proportion of parents who were comfortable/no burden underscores how nearly all families perceive raising a child with autism as challenging. Since the majority of our respondents had at least a challenge to deal with, we asked them about their coping strategies, and the results are summarized in Table 8.

Table 8: Coping Strategies by Parents/Caregivers

Coping Strategies	Freq.	Percent
I share my worries with other parents of children with autism	59	30.26
Praying	52	26.67
I seek support from my family/Friends	21	10.77
I don't do anything	19	9.74
I avoid thinking about it	10	5.13
Music/Singing	6	3.08
I talk to a counsellor	5	2.56
Exercise	5	2.56
Isolation	5	2.56
I post my worries on social media	4	2.05
Crying	4	2.05

The most common coping strategies were sharing worries with other parents (30.3%) and praying (26.7%). Together, these account for more than half of parents' strategies. This highlights peer support and faith as the backbone of resilience in this context. During FGD sessions, parents spoke warmly about connecting with others in similar situations. One parent said:

"When we meet as parents, you see you are not alone. You even laugh about things."

These informal networks often emerged after school meetings or through WhatsApp groups, reflecting the earlier finding (Figure 5) that network support is more available than parents initially realized. Teachers facilitated some of these connections, encouraging parents to talk to each other.

Prayer, on the other hand, was described as a personal anchor. Parents often said faith helped them find meaning or strength. *"When I pray, I feel lighter,"* explained one. Another added: *"Only God understands this child."* Teachers confirmed that parents frequently invoked spirituality during meetings, sometimes framing their child's progress as divine intervention.

Other coping strategies were less common. For example, about one in ten parents relied on family or friends (10.8%), while a similar share admitted they did nothing (9.7%). A smaller group described avoidance (*"I don't think about it"*), exercise, music, or simply crying as outlets. One parent confessed: *"Sometimes I just lock myself and cry. Then I continue."*

Talking to a counsellor (2.6%) was rare, despite the earlier finding that many parents wanted psychological support (22% required, 18% available in Figure 5). This gap suggests that while counselling is valued in principle, in practice it is either unavailable, unaffordable, or socially stigmatized. Teachers echoed this, saying: *"We don't have counsellors in the schools, so the parent carries the burden alone."* A few parents admitted isolation (2.6%) as a coping strategy, deliberately withdrawing from others to avoid stigma or questions. One parent explained: *"If I stay home, nobody asks me why my child is like that."*



5. DISCUSSIONS OF FINDINGS

This chapter discusses the findings of the study, organized in order of the three research objectives:

1. Availability, accessibility, and effectiveness of education programs for children with ASD in Kenya,
2. The therapy services available to these children, and
3. The psycho-social support systems accessible to parents and caregivers.

The discussion integrates quantitative and qualitative results and situates them within the existing literature on ASD, inclusive education, therapeutic interventions, and caregiver well-being. This chapter offers insights into the systemic factors that shape services and support for children with ASD and their families in the Kenyan context.

5.1 Education Programs for Children with Autism

The findings suggest that while many children with autism are enrolled in school, their educational experiences are diverse, with varying milestones in social and academic domains. Parents described both pride in their children's ability to adjust socially and frustration at the lack of meaningful academic progress. The finding that children with autism in this study made greater progress in social skills than in academic learning aligns with global evidence showing that inclusive schooling often emphasizes peer interaction and behavioral adjustment more than mastery of academic content (Fletcher-Watson et al., 2019). This is not inherently negative, but it raises questions about whether academic ambitions for children with ASD are being lowered in the long run.

Kenya's push toward inclusive education under the CBE aligns with international commitments, such as the Salamanca Statement and Framework for Action on Special Needs Education (1994). Yet, the reality on the ground appears uneven. Teachers admitted that overcrowding and lack of resources push them to group by age. The result is that learners with autism may be either under-challenged or overwhelmed, depending on how their developmental profile fits the class. Similar tensions have been reported in South Africa and India, where inclusive education policies outpace teacher training and classroom resources (Donohue & Bornman, 2014).

Parents consistently highlighted teacher attitudes as the factor they valued most. This resonates with literature from the UK and US showing that teacher empathy and willingness to adapt are stronger predictors of positive inclusion outcomes than the presence of facilities alone (Symes & Humphrey, 2012). In Kenya, where specialized resources are limited, it makes sense that parents place their trust in teachers' character and commitment. It is worth noting, however, that dependence on goodwill risks inconsistency. A supportive teacher can make a world of difference, but when that teacher transfers or burns out, parents and learners may be left vulnerable.

Most children were in integrated or inclusive schools, with only a minority in autism-specific units. This is not a unique case in Kenya. Globally, debates continue over whether learners with autism thrive better in specialized environments or mainstream settings with support, with available evidence suggesting a mixed picture (Kasari & Smith, 2013). Findings from our study echo this ambiguity: some parents preferred special schools for safety and a sense of belonging, while others feared isolation.

5.2 Therapy Services for Children with Autism

When it comes to therapy, the findings show a familiar paradox: health professionals recommend a range of therapies, but availability lags far behind. Speech and occupational therapy were the most frequently prescribed, yet parents often struggled to find or afford them. This gap is not unique to Kenya. Studies from low- and middle-income countries regularly highlight shortages of trained therapists and high out-of-pocket costs as the main barriers to consistent intervention (Durkin et al., 2015). The findings of our study demonstrate this global pattern, with parents often improvising therapy at home when formal services were out of reach.

Home-based therapy deserves a closer look. On the one hand, it reflects resilience, with parents not being passive but actively searching for ways to help their children. Some drew on YouTube, others copied exercises observed in clinics, and advice from other parents. Yet on the other hand, it may signal systemic neglect. Without structured guidance, home-based efforts risk inconsistency or even harm. In wealthier countries, parent-mediated interventions are often carefully designed and supported by professionals (Oono et al., 2013). In Kenya, families are shouldering this role largely alone, which may deepen inequities between those with access to information and those without.

Findings on accessibility underscored cost as the overwhelming barrier. Even when therapies exist, sustaining them financially was beyond many families. Parents described starting therapy only to stop after a few sessions, eroding progress. This aligns with teacher observations of children regressing after long absences. It appears that the usefulness of therapies was undermined by affordability and continuity. Globally, studies show that intensity and duration of therapy matter as much as type; sporadic therapy tends to yield minimal outcomes (Reichow et al., 2018). Teachers reported that some therapy centers operate without qualified staff. In contexts where regulation is weak, families may waste scarce resources on services that look like therapy but lack evidence-based methods. CSOs acknowledged gaps in supervision.

5.3 Support Services for Parents and Caregivers

The findings show parents are recipients of care. At least 94% of parents said they needed psychosocial support. That near-unanimity may reflect the intensity of caregiving, but it also reveals a neglected policy space: while most autism programs center on the child, far fewer address the parent.

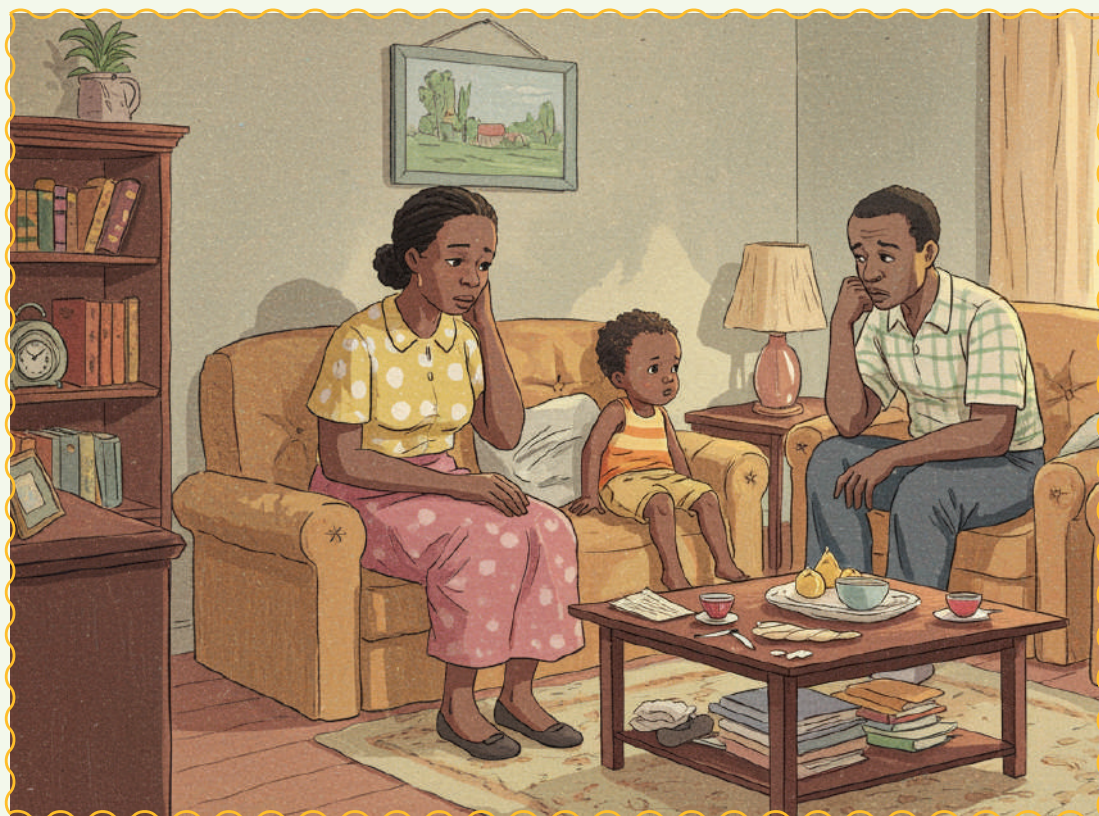
Parents spoke of stress, exhaustion, and social isolation. These are not new findings in autism research. Globally, caregivers of children with ASD report higher levels of depression and anxiety than parents of typically developing children (Hayes & Watson, 2013). What stood out in our study is the layering of financial strain, weak social safety nets, and persistent stigma. The result is a caregiving role that is both emotionally heavy and financially costly. Teachers reported seeing parents break down in meetings, while parents themselves admitted to moments of despair, crying, or avoiding social spaces.

Yet amidst this, parents also identified coping strategies. Peer support groups and prayer emerged as the most common. This reliance on informal networks and faith mirrors findings from other African contexts, where formal counselling services are scarce and community-based or spiritual supports fill the gap (Atilola et al., 2020). The finding that parents often discover support networks only after joining them suggests untapped potential, as these peer groups could be strengthened and developed into structured associations with formal training and resources.

Although many parents wanted psychological support, only a handful reported talking to a counsellor. This points to both availability and stigma. In countries where mental health services are more developed, parent training and counselling are considered essential components of autism intervention packages (McConachie & Diggle, 2007). Kenya's absence of such services leaves parents to improvise.

Financial aid was the most demanded but least available, while network support was more available than parents initially expected. This indicates that while parents are building informal solidarities, structural support, financial, medical, and psychological support systems remain weak. CSOs, while emphasizing inclusion for learners, offered little evidence of systemic caregiver support, which may reflect the narrow framing of education policy around the child rather than the family.

Globally, there is a growing recognition that supporting parents is not a luxury but a necessity (Lancaster et al., 2023; Loucaides et al., 2024; Savari et al., 2023). Parents' well-being directly influences the consistency of care, the child's school attendance, and the uptake of therapies. In Kenya, where extended families are no longer as reliable as they once were, formal structures may need to fill the gap. Subsidized counselling, structured peer support groups, and targeted financial assistance could be starting points. One might say the parents in this study are doing what parents everywhere do: carrying more than they can reasonably manage, hoping systems will eventually catch up. The difference is that in Kenya, the distance between aspiration and provision remains wide.



6 CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

Education programs for children with autism appear to be doing reasonably well at opening the school door, but less well at making what happens inside meaningful. Many children are enrolled, often in inclusive settings, and parents see progress in social adjustment. Yet academic outcomes lag. This contrast may suggest that inclusion, while symbolically powerful, still relies on social participation rather than tailored instruction. One can sense a tension: parents value kind teachers and welcoming routines, but they quietly worry whether their children are learning.

Therapy services tell a story that is both hopeful and frustrating. Health professionals recommend therapies that can make a real difference, and when families manage to access them, many find them useful. The difficulty lies in the gap between recommendation and reality. Costs, distance, and questionable quality mean that therapies are often irregular or improvised at home. The picture that unfolds is not of parents unwilling to seek help, but of systems that make sustained access nearly impossible.

Support services for parents themselves are both urgently needed yet absent. Nearly every parent admitted to needing psychosocial support, and they were open about the stress, exhaustion, and isolation they face. What they rely on most is fragile: peer networks and prayer. Counselling is scarce, financial help is even scarcer, and stigma still lurks in the background. These voices remind us that autism interventions cannot stop with the child; the well-being of parents is part of the package.

6.2 Recommendations

Education Programs

1. The MoE to invest in teacher training and classroom support. Teachers need preparation to implement inclusive education that goes beyond physical placement, focusing on stage-based learning and individualized instruction.
2. Professional development for teachers on care and support services for learners with autism including aspects of professional therapy such as speech therapy, music therapy, hydrotherapy among others.
3. The MoE should employ learner support assistants to help with toileting, feeding, and behavioral management for children with severe autism, easing parents' burden and promoting regular school attendance.
4. Involvement of a multidisciplinary team including special educators/teachers, therapists, parents, and learner support assistants among other officers found at school to design and implement an individualized education program for the learner with autism.
5. Strengthen Educational Assessment and Resource Center (EARC) centers to enhance screening, placement, and follow-up services for learners with autism enrolled in schools

Therapy Services

1. Expand therapy services at county and school level. Therapy services could be integrated into school programs to enhance access for school going children.
2. Strengthen and support home-based therapy services through the Community Health Promoters (CHPs) and parent's capacity building.
3. Subsidize the cost of support services. Autism therapies need to be covered under the Social Health Authority (SHA) to prevent families from discontinuing the beneficial service based on cost.
4. Strengthen regulation of therapy providers. Accreditation and monitoring systems should be developed to ensure that therapy centers and therapists meet minimum standards and to protect families from poor quality or exploitative services.
5. The Ministry of Social Protection in collaboration with the national council for persons with disabilities to support parent-driven networks and groups with grants, recognition, and technical training on homebased therapy services.
6. The ministry of social protection in collaboration with the national council for persons with disabilities and the Kenya Institute of Special Education to come up with community resource centers that can offer mobile therapy, caregiver workshops, and psychosocial support in underserved areas.

Support for Parents/Caregivers

1. Formalize and support parent networks. The informal groups that parents already create, such as WhatsApp groups and church gatherings, could be strengthened by providing meeting spaces, trained facilitators, and small grants.
2. Provide structured counselling and psychosocial services. Counsellors could be placed within special units or county education offices so that parents have accessible outlets for managing stress, anxiety, and emotional fatigue.

Further Research:

Further research is recommended to understand the finding why there are more boys (70%) compared to girls (30%) affected by Autism in the study.



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2025



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