BARRIERS TO EARLY IDENTIFICATION OF AUTISM SPECTRUM DISORDER AMONG CHILDREN LIVING IN LOW-RESOURCE COMMUNITIES IN KENYA

An Evidence-Based Publication on Community, Social, Economic, Healthcare, and Systemic Barriers to Early Autism Identification

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Motto

Autism Empowered, Independence Achieved

EXECUTIVE SUMMARY

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that can affect communication, social interaction, behaviour, and development. Early identification of autism can help children and their families access appropriate assessment, support, education, and inclusion. However, many children living in low-resource communities in Kenya may experience delays in the pathway from the first recognition of developmental concerns to professional assessment and appropriate support.

This publication examines the barriers to early identification of Autism Spectrum Disorder among children living in low-resource communities in Kenya, with particular attention to underserved communities such as Mathare, Kibera, and Soweto in Nairobi County. The publication explores the social, cultural, economic, healthcare, educational, and systemic factors that may contribute to delays in recognizing developmental concerns and accessing appropriate services.

The evidence reviewed demonstrates that barriers to early autism identification are interconnected and cannot be attributed to a single factor. Limited community awareness and inadequate knowledge of developmental milestones may make it difficult for parents, caregivers, teachers, and other community

members to recognize early developmental concerns. Cultural beliefs and misconceptions may also influence how developmental differences are understood and may affect decisions about seeking professional support.

Stigma and fear of discrimination represent additional challenges for families. Some caregivers may experience social pressure, misunderstanding, or negative attitudes when seeking support for their children. These experiences may contribute to delayed help-seeking and may increase the emotional and social burden experienced by families.

Economic factors also play an important role. Families living in low-resource communities may face financial challenges that affect their ability to access transportation, healthcare, professional assessment, and specialized services. The availability and geographical distribution of qualified professionals may further limit access to appropriate assessment and support.

The publication also identifies challenges within healthcare and referral systems. Families may experience difficulties navigating fragmented services, limited awareness among frontline providers, and unclear referral pathways. Delays may occur when families move between different points of care before reaching appropriate professionals.

Schools and teachers have an important role in early recognition and inclusion. However, limited training and capacity among teachers and early childhood practitioners may reduce opportunities for developmental concerns to be recognized and appropriately referred. Strengthening inclusive education and teacher capacity-building is therefore an important component of the response.

The publication argues that improving early autism identification requires a coordinated and community-based approach. Increasing awareness alone is not sufficient. Families must also be able to access appropriate professional assessment, referral, education, and ongoing support.

Several recommendations are proposed, including strengthening community autism awareness, empowering parents and caregivers, building the capacity of teachers and community health workers, improving referral pathways, increasing access to qualified professionals, addressing financial and socioeconomic barriers, reducing stigma, strengthening community-based organizations, promoting cross-sector collaboration, investing in local research, and improving monitoring and evaluation.

The publication further proposes a community-based response that focuses on five interconnected areas: community awareness and early recognition; caregiver empowerment and family support; inclusive education and teacher capacity-building; referral and professiona

linkages; and research, advocacy, and community systems strengthening.

The proposed response is designed to complement rather than replace professional healthcare and diagnostic services. Community-based organizations can play an important role in helping families access reliable information, recognize potential developmental concerns, navigate referral pathways, and connect with qualified professionals.

For ADIP Initiative, the findings provide a foundation for developing strategic partnerships and investment opportunities in autism awareness, caregiver empowerment, inclusive education, community outreach, capacity-building, research, advocacy, and referral support.

The publication calls for stronger collaboration among government institutions, healthcare providers, schools, universities, research institutions, disability organizations, community-based organizations, funders, corporations, and development partners.

Ultimately, addressing barriers to early autism identification requires a shift towards coordinated, accessible, evidence-informed, and sustainable community-based systems. By strengthening awareness, empowering families, building local capacity, improving referral pathways, and investing in inclusive systems, Kenya can create stronger opportunities for children with developmental differences to be recognized earlier, supported appropriately, and included in their families, schools, and communities.

Early recognition is the beginning—not the end—of inclusion.

ABOUT ADIP INITIATIVE

Autism and Disability Inclusion for Progress Initiative (ADIP Initiative)

The Autism and Disability Inclusion for Progress Initiative (ADIP Initiative) is a community-focused organization committed to promoting autism awareness, disability inclusion, caregiver empowerment, and inclusive education in Kenya.

The initiative works to support children with autism and other disabilities, their families, educators, and communities, particularly those living in underserved and low-resource settings.

ADIP Initiative recognizes that families affected by autism and other disabilities may face multiple challenges, including limited access to reliable information, stigma, financial constraints, limited access to specialized services, gaps in inclusive education, and difficulties navigating referral and support systems.

Through community-based programmes and partnerships, ADIP Initiative seeks to contribute to a more inclusive society where individuals with autism and other disabilities are understood, respected, supported, and given opportunities to participate and reach their full potential.

The organization's key areas of focus include:

- *Autism awareness and community education.*

- *Caregiver education and empowerment.*

- *Inclusive education and teacher capacity-building.*

- *Community outreach and engagement.*

- *Early recognition and referral support.*

- Disability inclusion and advocacy.

- Training and capacity-building.

- Professional support services.

- Research and evidence generation.

- Strategic partnerships and collaboration.

ADIP Initiative believes that meaningful and sustainable change requires collaboration. The organization therefore seeks to work with families, schools, healthcare providers, government institutions, universities, research institutions, disability organizations, community-based organizations, funders, corporations, and development partners.

Through strategic partnerships and sustainable investment, ADIP Initiative aims to strengthen community-level systems, increase awareness, empower families, build capacity, promote inclusion, and contribute to improved opportunities for individuals with autism and other disabilities.

Vision

A world where every person belongs.

A world where every person with autism and other disabilities is empowered, included, and given equal opportunities to live, learn, and thrive.

Mission

Promoting inclusion and equal opportunity.

To promote inclusion, empowerment, and equal opportunities for individuals with autism and other disabilities through advocacy, education, professional support services, community engagement, and strategic partnerships.

Core Values

Guided by ten core values:

1. Inclusion

2. Respect and Dignity

3. Compassion

4. Integrity

5. Accountability

6. Empowerment

7. Collaboration

8. Professionalism

9. Innovation

10. Excellence

Motto

Autism Empowered, Independence Achieved.

ABSTRACT

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that can affect communication, social interaction, behaviour, and development. Early identification is important because it can create opportunities for children and their families to access appropriate assessment, support, education, and inclusion. However, children living in low-resource communities in Kenya may experience significant delays in the recognition and identification of autism due to interconnected social, cultural, economic, healthcare, educational, and systemic barriers.

This publication examines the barriers to early identification of Autism Spectrum Disorder among children living in low-resource communities in Kenya, with particular attention to underserved communities such as Mathare, Kibera, and Soweto in Nairobi County. The publication adopts an evidence-based approach, drawing on existing literature, research, policy documents, and relevant reports to examine factors that influence the pathway from recognition of developmental concerns to professional assessment and appropriate support.

The findings demonstrate that limited awareness of autism and developmental milestones, cultural beliefs and misconceptions, stigma, financial constraints, limited access to specialized services, shortages of trained professionals, weak referral pathways, and gaps in inclusive education may contribute to delays in early autism identification. The evidence also highlights

the interconnected nature of these barriers, demonstrating that addressing one barrier in isolation may not be sufficient to improve outcomes for children and families.

The publication recommends strengthening community-based autism awareness, empowering parents and caregivers, building the capacity of teachers and community health workers, improving referral pathways, increasing access to qualified professionals, addressing socioeconomic barriers, reducing stigma, strengthening community-based organizations, promoting cross-sector collaboration, investing in locally relevant research, and improving monitoring and evaluation.

A proposed community-based response is presented, focusing on community awareness and early recognition, caregiver empowerment and family support, inclusive education and teacher capacity-

building, referral and professional linkages, and research, advocacy, and community systems strengthening. The proposed approach is intended to complement, rather than replace, professional assessment and diagnostic services.

The publication further highlights opportunities for strategic partnerships and investment involving government institutions, healthcare providers, schools, universities, research institutions, disability organizations, community-based organizations, funders, corporations, and development partners.

The publication concludes that improving early autism identification in low-resource communities requires coordinated, accessible, evidence-informed, and sustainable action. Strengthening community awareness, empowering families, building local capacity, improving referral systems, and investing in inclusive services can contribute to earlier recognition and improved opportunities for autistic children and their families to access appropriate support, participate in education, and thrive within their communities.

Keywords: *Autism Spectrum Disorder, early identification, autism, developmental disabilities, low-resource communities, Kenya, caregivers, inclusive education, community-based support, disability inclusion.*

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LIST OF ACRONYMS AND ABBREVIATIONS

ADIP – Autism and Disability Inclusion for Progress

ASD – Autism Spectrum Disorder

CBO – Community-Based Organization

CHW – Community Health Worker

CRPD – Convention on the Rights of Persons with Disabilities

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

IEP – Individualized Education Programme

NCPWD – National Council for Persons with Disabilities

NGO – Non-Governmental Organization

SDGs – Sustainable Development Goals

UN – United Nations

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

UNESCO – United Nations Educational, Scientific and Cultural Organization

UNICEF – United Nations Children's Fund

WHO – World Health Organization

CHAPTER ONE: INTRODUCTION

1. Introduction to Autism

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition characterized by persistent differences in social communication and social interaction, together with restricted and repetitive patterns of behaviour, interests, or activities. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR), these characteristics emerge during early childhood and significantly affect an individual's daily functioning, although their presentation varies widely across individuals.

Autism is referred to as a "spectrum" because autistic individuals exhibit diverse strengths, challenges, and support needs. While some individuals require substantial lifelong support, others are able to live independently and participate fully in education, employment, and community life. In addition to differences in communication and social interaction, many autistic individuals experience sensory sensitivities, such as heightened or reduced responses to sounds, lights, textures, tastes, or touch.

The exact causes of autism remain incompletely understood. Current evidence indicates that autism results from a complex interaction of genetic and environmental factors that influence early brain development. Extensive scientific research has found no evidence that childhood vaccines cause autism. Early identification, followed by appropriate intervention and family support, can improve communication, learning, adaptive skills, and overall quality of life.

Globally, awareness and understanding of autism have increased over recent decades, leading to improvements in screening, diagnosis, and intervention services. However, many low- and middle-income countries, including Kenya, continue to experience delayed identification due to limited awareness, stigma, inadequate diagnostic services, shortages of trained professionals, and constrained healthcare resources. These challenges often prevent children from accessing timely intervention during

critical developmental periods, highlighting the importance of strengthening early identification systems in low-resource communities.

References (APA 7th Edition)

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Global Prevalence of Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is one of the most common neurodevelopmental conditions affecting children worldwide. Over the past two decades, the reported prevalence of autism has increased significantly, largely due to improved awareness, expanded diagnostic criteria, enhanced screening practices, and greater access to diagnostic services rather than a confirmed increase in the actual occurrence of the condition (World Health Organization [WHO], 2025).

According to the World Health Organization (WHO), approximately 1 in every 100 children worldwide is autistic, although prevalence estimates vary across countries because of differences in research methods, diagnostic practices, and access to healthcare services (WHO, 2025). In some high-income countries, surveillance systems report even higher prevalence estimates. For example, the United States Centers for Disease Control and Prevention (CDC) estimated that approximately 1 in 31 8-year-old children were identified with ASD in 2022, reflecting improvements in early identification and diagnostic capacity (Maenner et al., 2025).

Despite growing recognition of autism globally, significant disparities remain between high-income and low- and middle-income countries. Many low-resource settings lack comprehensive surveillance systems, trained specialists, and standardized screening programmes, resulting in underdiagnosis and delayed identification of autistic children. Consequently, the true prevalence of autism in many developing countries is likely underestimated (WHO, 2025).

The increasing prevalence of autism has made it an important global public health, education, and social concern. Governments, healthcare providers, educators, and policymakers are therefore placing greater emphasis on early identification and intervention to improve developmental outcomes and enhance the quality of life of autistic individuals and their families (WHO, 2025).

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●World Health Organization. (2025). Autism. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders.

Autism as a Public Health and Education Concern

Autism Spectrum Disorder (ASD) is increasingly recognized as a significant public health and education concern because of its lifelong impact on individuals, families, healthcare systems, and educational institutions. As the global prevalence of autism continues to rise, there is an increasing need for accessible healthcare services, early screening, timely diagnosis, and evidence-based interventions to support autistic individuals throughout their lives (World Health Organization [WHO], 2025).

From a public health perspective, autism requires coordinated efforts to promote early identification, improve access to diagnostic and intervention services, and reduce inequalities in healthcare access. Delayed diagnosis often prevents children from receiving early intervention during critical periods of brain development, which may affect communication, learning, social participation, and adaptive functioning. Consequently, strengthening early detection systems has become a priority in many countries (World Health Organization [WHO], 2025).

Autism is also a major concern within the education sector. Autistic learners often require inclusive educational environments, individualized teaching approaches, reasonable accommodations, and trained teachers to support their learning and participation. Without adequate educational support, many autistic children experience barriers to school enrolment, participation, academic achievement, and social inclusion (United Nations Educational, Scientific and Cultural Organization [UNESCO], 2020).

In low- and middle-income countries, including Kenya, these challenges are compounded by limited awareness of autism, shortages of trained professionals, inadequate diagnostic services, and insufficient inclusive education resources. As a result, many autistic children remain unidentified or receive support only after significant developmental delays have occurred. Addressing autism as both a public health and education priority is therefore essential for promoting early identification, improving educational outcomes, and ensuring the full inclusion of autistic individuals in society (WHO, 2025).

References

●United Nations Educational, Scientific and Cultural Organization. (2020). Global Education Monitoring Report 2020: Inclusion and Education – All Means All.

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1. **Importance of Early Identification**

   What is Early Identification?

   Early identification refers to the process of recognizing the early signs and symptoms of Autism Spectrum Disorder (ASD) during infancy or early childhood, often before a child reaches school age. It involves developmental surveillance, routine screening, comprehensive assessment, and

timely diagnosis by qualified healthcare or developmental professionals (World Health Organization [WHO], 2025; Hyman et al., 2020).

Research indicates that the behavioural signs of autism can emerge as early as 12 to 18 months of age, although the age at which a formal diagnosis is made varies considerably depending on access to healthcare services, professional expertise, and parental awareness. Early identification enables children who show developmental differences to be referred promptly for further assessment and appropriate intervention, thereby reducing delays in accessing essential support services (Hyman et al., 2020).

The American Academy of Pediatrics recommends developmental surveillance at every well-child visit and standardized autism-specific screening at 18 and 24 months of age. These recommendations are based on evidence that earlier recognition of autism allows children and their families to access interventions during critical stages of brain development, when support is most likely to improve developmental outcomes (Hyman et al., 2020).

References

●Hyman, S. L., Levy, S. E., & Myers, S. M. (2020). Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics, 145(1), e20193447.

●World Health Organization. (2025). Autism. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

Importance of Early Identification

Early identification of Autism Spectrum Disorder (ASD) is essential because it enables children to access timely assessment, diagnosis, and evidence-based interventions during the early years of development. The first few years of life represent a critical period of rapid brain development, during which appropriate interventions can significantly improve communication, social interaction, adaptive behaviour, and learning outcomes (Hyman et al., 2020).

Research has consistently shown that children who receive early intervention demonstrate better developmental outcomes than those whose diagnosis and intervention are delayed. Early identification also allows families to understand their child's developmental needs, access appropriate support services, and make informed decisions regarding education and healthcare. Furthermore, it reduces parental stress by providing guidance and resources to help caregivers support their child's development (Zwaigenbaum et al., 2015).

Despite these benefits, many children, particularly in low-resource settings, are identified long after the early signs of autism become apparent. Delayed identification often limits access to early intervention services and may negatively affect children's long-term developmental, educational, and social outcomes. Consequently, strengthening systems for early autism identification has become a global priority in improving the quality of life of autistic individuals and their families (World Health Organization [WHO], 2025).

References

●Hyman, S. L., Levy, S. E., & Myers, S. M. (2020). Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics, 145(1), e20193447.

●World Health Organization. (2025). Autism. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

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Why Identifying Autism Before School Age Matters

Identifying Autism Spectrum Disorder (ASD) before a child reaches school age is critical because the early years of life are characterized by rapid brain development and high neuroplasticity, making children more responsive to intervention. Early identification allows healthcare professionals, educators, and families to recognize developmental differences promptly and initiate appropriate support before challenges become more pronounced. Research indicates that autism can often be identified reliably by the age of two years, enabling timely intervention during a critical developmental period (Hyman et al., 2020).

Early identification also facilitates access to specialized educational services and individualized support before children enter formal schooling. Children who receive appropriate support before school age are generally better prepared for learning, communication, social interaction, and participation in inclusive educational settings. In contrast, delayed identification may lead to missed opportunities for intervention, increased behavioural challenges, and difficulties in adapting to school environments (Zwaigenbaum et al., 2015). Therefore, identifying autism before school entry is essential for improving children's developmental trajectories and promoting successful educational outcomes.Benefits of Early Intervention for Children and Families

Benefits of Early Intervention for Children and Families

Early intervention refers to specialized services and supports provided soon after autism is identified to promote a child's development and enhance family well-being. Evidence shows that early intervention can significantly improve communication, language development, social interaction, adaptive behaviour, and cognitive skills. It also helps reduce the severity of behavioural challenges and increases children's ability to participate in home, school, and community activities (World Health Organization [WHO], 2025; Hyman et al., 2020).

For families, early intervention provides knowledge, guidance, and practical strategies for supporting their child's development. Parents and caregivers who receive training and support are better equipped to understand their child's needs, manage behavioural challenges, and advocate for appropriate educational and healthcare services. Early intervention can also reduce parental stress, strengthen family relationships, and improve the overall quality of life for both the child and the family. Consequently, timely access to early intervention is widely recognized as a key component of effective autism care and long-term developmental success (WHO, 2025)..

References

●Hyman, S. L., Levy, S. E., & Myers, S. M. (2020). Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics, 145(1), e20193447.

●World Health Organization. (2025). Autism. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

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3 .Global Situation of Early Autism Identification

Globally, considerable progress has been made in the early identification of Autism Spectrum Disorder (ASD), particularly in high-income countries where healthcare systems have invested in developmental surveillance, standardized screening tools, and specialist training. Countries such as the United States, Canada, Australia, and the United Kingdom have established guidelines that recommend routine developmental monitoring and autism-specific screening during early childhood. These measures have contributed to earlier diagnosis and timely access to intervention services, improving developmental outcomes for many autistic children (Hyman et al., 2020).

The development and widespread use of validated screening and diagnostic tools have also strengthened early autism identification worldwide. Instruments such as the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F) and the Autism Diagnostic Observation Schedule (ADOS-2) are commonly used to identify children at risk of autism and guide comprehensive diagnostic assessments. In addition, increased public awareness and professional training have enhanced the ability of healthcare providers and educators to recognize the early signs of autism and refer children for further evaluation (World Health Organization [WHO], 2025).

Despite these advances, significant disparities persist across countries. Many low- and middle-income countries continue to experience delayed autism identification because of shortages of trained professionals, limited access to diagnostic services, inadequate screening programmes, and low public awareness. Cultural beliefs, stigma, financial constraints, and weak health systems further contribute to delayed diagnosis and reduced access to early intervention services. As a result, many autistic children in

resource-limited settings remain unidentified until they reach school age or later, missing the opportunity to benefit fully from early intervention (WHO, 2025).

References

●Hyman, S. L., Levy, S. E., & Myers, S. M. (2020). Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics, 145(1), e20193447.

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4.Autism in Africa

Autism Spectrum Disorder (ASD) is increasingly recognized as a significant public health and developmental concern across Africa. However, compared with high-income countries, awareness, diagnosis, and intervention services remain limited in many African nations. Although research on autism has grown in recent years, evidence suggests that many autistic children are either diagnosed late or remain undiagnosed because of inadequate healthcare systems, shortages of trained professionals, and limited access to specialized developmental services (Franz et al., 2017; World Health Organization [WHO], 2025).

Many African countries face challenges in implementing routine developmental screening and early autism identification. Limited awareness of autism among parents, teachers, and healthcare providers often leads to delayed recognition of developmental differences. In addition, cultural beliefs and stigma surrounding developmental disabilities may discourage families from seeking medical assessment or support. In some communities, autism may be attributed to supernatural or spiritual causes, further delaying access to appropriate healthcare and educational services (Bakare & Munir, 2011).

The shortage of specialists, including developmental paediatricians, psychologists, speech and language therapists, occupational therapists, and special education professionals, also limits access to timely diagnosis and intervention across the continent. Furthermore, autism services are often concentrated in urban centres, making them inaccessible to families living in rural and other underserved communities. These barriers contribute to significant inequalities in access to early identification and intervention services for autistic children (Franz et al., 2017).

Despite these challenges, there has been increasing commitment to improving autism awareness, research, and service provision across Africa. Governments, universities, non-governmental organizations, and international partners are expanding awareness campaigns, promoting professional training, and supporting research on autism. Nevertheless, further investment in early identification systems, specialist training, and community-based support services is needed to ensure autistic children receive timely diagnosis and appropriate interventions throughout the continent (WHO, 2025).

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●Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. Autism Research, 10(5), 723–749.

●World Health Organization. (2025). Autism. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

5. Autism in Kenya

Autism Spectrum Disorder (ASD) is receiving increasing attention in Kenya due to growing awareness of developmental disabilities and the importance of early childhood intervention. Despite this progress, early identification and diagnosis of autism remain major challenges. Many children are diagnosed only after they have reached school age, delaying access to interventions that could improve communication, learning, and social development (Franz et al., 2017).

Diagnostic and intervention services for autism in Kenya are available through a limited number of public hospitals, private healthcare facilities, and specialized centres, most of which are concentrated in major urban areas such as Nairobi, Mombasa, and Kisumu. This unequal distribution of services makes it difficult for many families, particularly those in rural and low-resource communities, to obtain timely assessment and intervention. In addition, Kenya faces a shortage of trained professionals, including developmental paediatricians, child psychologists, speech and language therapists, occupational therapists, and special needs education specialists, which contributes to delays in diagnosis and support (Ministry of Health, 2022).

Although the Government of Kenya has made efforts to promote inclusive education and strengthen services for children with disabilities through policies such as the Basic Education Act and the Competency-Based Curriculum (CBC), implementation remains inconsistent. Many healthcare workers, teachers, and caregivers have limited training in recognizing the early signs of autism, resulting in delayed referrals for assessment and intervention. Furthermore, stigma, misconceptions, and cultural beliefs surrounding developmental disabilities continue to discourage some families from seeking professional support at an early stage (Republic of Kenya, 2018).

These challenges are more pronounced in low-resource communities, where poverty, inadequate healthcare infrastructure, and limited access to specialized services further hinder early autism identification. Consequently, many autistic children in Kenya miss the opportunity to benefit from early intervention during critical stages of development, underscoring the need for research aimed at understanding and addressing barriers to early identification.

References

●Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. Autism Research, 10(5), 723–749.

●Ministry of Health. (2022). Kenya National Disability Inclusion Strategy.

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6. Autism in Low-Resource Communities in Kenya

6.1. Overview of low-resource communities in Kenya

Low-resource communities in Kenya, including informal settlements such as Mathare, Kibera, Mukuru, Korogocho, and Soweto, face numerous socioeconomic challenges that affect access to healthcare and education. These communities are characterized by high levels of poverty, overcrowding, unemployment, inadequate health facilities, and limited access to specialized developmental services. Such conditions create significant barriers to the early identification and management of Autism Spectrum Disorder (ASD) among young children (United Nations Human Settlements Programme [UN-Habitat], 2020).

Although awareness of autism has improved in Kenya, many families living in low-resource communities have limited knowledge of the early signs and symptoms of ASD. Developmental differences such as delayed speech, reduced social interaction, and repetitive behaviours are often mistaken for normal variations in child development or attributed to cultural and spiritual beliefs. As a result, parents and caregivers may delay seeking professional assessment, reducing the likelihood of early diagnosis and intervention (Franz et al., 2017).

Access to autism screening, diagnostic, and intervention services is also limited in these settings. Most specialized services are concentrated in urban referral hospitals and private facilities, making them financially and geographically inaccessible to many families. The shortage of trained professionals, including developmental paediatricians, psychologists, speech and language therapists, occupational therapists, and special needs educators, further contributes to delayed identification of autistic children. Consequently, many children living in low-resource communities are diagnosed only after they have entered school, missing the critical window for early intervention (World Health Organization [WHO], 2025).

These challenges highlight the need for community-based approaches that strengthen autism awareness, improve developmental screening at the primary healthcare level, and increase access to affordable diagnostic and intervention services. Addressing these barriers is essential for ensuring that children living in underserved communities receive timely identification and the support necessary to achieve their full developmental potential.

References

●Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. Autism Research, 10(5), 723–749.

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6.2 Barriers to Early Autism Identification

Children living in low-resource communities in Kenya face numerous barriers that delay the early identification of Autism Spectrum Disorder (ASD). These barriers are interconnected and arise from social, economic, cultural, and health system challenges. As a result, many autistic children are not identified until they reach school age or later, reducing their opportunities to benefit from early intervention and appropriate educational support (World Health Organization [WHO], 2025).

One of the major barriers is limited awareness and knowledge of autism among parents, caregivers, teachers, and primary healthcare providers. Early signs of autism, such as delayed speech, limited social interaction, and repetitive behaviours, are often overlooked or misunderstood, leading to delayed referrals for assessment (Franz et al., 2017).

Cultural beliefs and stigma also contribute to delayed identification. In some communities, autism is associated with spiritual causes, curses, or poor parenting, discouraging families from seeking professional assessment and support. Fear of discrimination and social exclusion may further prevent caregivers from discussing developmental concerns openly (Bakare & Munir, 2011).

In addition, limited access to diagnostic services, shortages of trained professionals, financial constraints, and inadequate healthcare infrastructure make it difficult for many families in underserved communities to obtain timely autism assessments. These barriers are particularly evident in informal settlements and rural areas, where specialized services are scarce and often unaffordable. Addressing these challenges is essential to improve early autism identification and ensure that autistic children receive timely intervention and support.

References

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a)Limited Awareness and Knowledge of Autism

Limited awareness and knowledge of Autism Spectrum Disorder (ASD) among parents, caregivers, teachers, and healthcare providers is one of the most significant barriers to early autism identification in low-resource communities. Awareness of the early signs of autism, such as delayed speech and language development, limited eye contact, reduced social interaction, repetitive behaviours, and unusual sensory responses, is essential for timely referral and diagnosis. However, many caregivers and frontline health workers lack adequate knowledge of these early developmental indicators, resulting in delayed recognition of autism (Franz et al., 2017).

In many low- and middle-income countries, including Kenya, developmental differences are often interpreted as normal variations in child development, causing parents to delay seeking professional assessment. Teachers and primary healthcare providers may also have limited training in developmental disorders, making it difficult to distinguish autism from other developmental or behavioural conditions. Consequently, children are frequently diagnosed only after they begin formal schooling, by which time valuable opportunities for early intervention may have been missed (Hyman et al., 2020).

Studies conducted in sub-Saharan Africa have consistently reported that inadequate awareness among both communities and healthcare professionals contributes to delayed autism diagnosis and reduced access to intervention services. Increasing community awareness through public education campaigns, caregiver training, and professional development for healthcare workers and teachers has therefore been identified as a critical strategy for improving early autism identification and ensuring timely access to appropriate support services (World Health Organization [WHO], 2025).

References

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b) Cultural Beliefs, Myths, and Stigma

Cultural beliefs, myths, and stigma are significant barriers to the early identification of Autism Spectrum Disorder (ASD) in many low-resource communities. In some African societies, including parts of Kenya, autism is sometimes attributed to supernatural causes such as witchcraft, curses, ancestral displeasure, or divine punishment rather than being recognized as a neurodevelopmental condition. These misconceptions often influence how families perceive developmental differences in children and may discourage them from seeking timely medical assessment and intervention (Bakare & Munir, 2011).

Stigma associated with developmental disabilities further contributes to delayed identification. Parents and caregivers may fear discrimination, social exclusion, or blame from family and community members, leading them to conceal their child's developmental challenges or delay seeking professional support. As a result, many autistic children miss the opportunity to receive early diagnosis and intervention during critical stages of development (Franz et al., 2017).

In Kenya, cultural misconceptions about autism continue to affect awareness and help-seeking behaviour, particularly in low-resource communities where access to accurate health information is limited. Community education programmes, public awareness campaigns, and collaboration with community leaders, healthcare providers, and educators are essential in addressing myths and reducing stigma. Increasing public understanding that autism is a neurodevelopmental condition rather than a result of supernatural or cultural causes can encourage earlier identification and improve access to appropriate support services (World Health Organization [WHO], 2025).

References

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sheets/detail/autism-spectrum-disorders

c) **Limited Access to Healthcare and Diagnostic Services**

Limited access to healthcare and diagnostic services is another major barrier to early autism identification in low-resource communities in Kenya. Early identification requires children to have access to healthcare facilities where developmental concerns can be recognized, screened, and referred for comprehensive assessment. However, many families living in underserved communities face challenges in

accessing specialized services due to the limited availability of diagnostic facilities and the concentration of specialized healthcare services in major urban centres (Franz et al., 2017).

The availability of autism diagnostic services in Kenya remains limited, particularly for families living in low-income and underserved communities. In many cases, parents may need to travel long distances to access professionals with expertise in autism assessment. This creates additional challenges for families who may already experience financial difficulties and limited access to reliable transportation. As a result, some caregivers may postpone or completely abandon the process of seeking an assessment for their child.

The lack of routine developmental screening within primary healthcare settings can further contribute to delayed identification. When developmental concerns are not recognized during routine child health visits, opportunities for early referral and assessment may be missed. In addition, long waiting periods for specialist appointments and limited availability of multidisciplinary assessment teams can further delay the diagnostic process (World Health Organization [WHO], 2025).

These challenges are particularly relevant in low-resource communities, where families may have limited financial resources and specialized services may be geographically inaccessible. Improving access to affordable developmental screening, strengthening referral pathways, and integrating autism identification into primary healthcare services could help reduce delays in diagnosis and ensure that more children receive timely support.

References

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d) Shortage of Trained Professionals

The shortage of trained professionals with expertise in Autism Spectrum Disorder (ASD) is a significant barrier to early autism identification in Kenya and other low-resource settings. Early identification requires healthcare and developmental professionals who are able to recognize early developmental differences, conduct appropriate screening, provide referrals, and participate in comprehensive diagnostic assessments. However, many countries in sub-Saharan Africa have limited numbers of professionals with specialized training in autism, including developmental paediatricians, psychologists, speech and language therapists, occupational therapists, and special education professionals. This shortage limits the capacity of health and education systems to identify autistic children at an early age (Franz et al., 2017).

The problem is particularly important because autism assessment may require input from multiple professionals. Where such specialists are unavailable, children may experience delays in assessment or may be referred between different services without receiving a timely and comprehensive evaluation. The World Health Organization (WHO) has emphasized the importance of strengthening the capacity of

health and social care workers to identify and support autistic individuals, particularly in settings where specialized services are limited (World Health Organization [WHO], 2023).

In Kenya, the unequal distribution of specialized professionals further contributes to disparities in access to autism identification services. Professionals and specialized facilities are more likely to be concentrated in urban centres, while families living in low-income and underserved communities may have limited access to these services. This geographical inequality can result in delayed assessment, particularly for families who cannot afford private services or repeated travel to distant facilities.

Increasing the capacity of frontline workers, including primary healthcare providers, community health workers, teachers, and other professionals who interact with children, may improve early recognition and referral of children showing developmental concerns. In addition, investment in specialist training and the expansion of community-based services could help address the shortage of professionals and improve access to early autism identification in underserved communities (Franz et al., 2017; WHO, 2023).

References

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Financial Constraints and Poverty

e) Financial constraints and poverty are important barriers to the early identification of Autism Spectrum Disorder (ASD) in low-resource communities. Although early identification requires timely access to screening, assessment, and diagnostic services, many families experience financial difficulties that limit their ability to seek and sustain these services. The financial burden associated with autism may include direct costs such as consultation, assessment, transportation, and intervention services, as well as indirect costs resulting from caregivers having to take time away from employment or other income-generating activities (Mwaniki et al., 2021).

f) In Kenya, financial burden has been identified as a major challenge for caregivers of children with autism. A systematic review of studies on caregivers of children with ASD in Kenya found that families experienced both direct and indirect financial costs associated with caring for their children. These financial pressures may become particularly significant for families living in low-income communities, where household resources are already limited and families may struggle to meet basic needs alongside the costs associated with autism-related services (Mwaniki et al., 2021).

The cost of accessing specialized services can also contribute to delays in the diagnostic process. Families may be required to travel to facilities that provide specialized assessment,

incur transportation expenses, and pay for consultations or other services. For families living in informal settlements and other underserved communities, these costs can make the process of seeking an autism assessment difficult to sustain. A recent study of children attending tertiary hospitals in Nairobi found that caregivers experienced lengthy pathways to diagnosis, with a mean age of diagnosis of five years and an average delay of approximately 35 months between recognizing symptoms and receiving a diagnosis (Kandie et al., 2025). Although financial constraints are only one factor contributing to diagnostic delays, they may interact with other barriers, including limited service availability and long distances to specialized care.

Financial constraints may therefore contribute to a cycle of delayed identification and delayed intervention. When families cannot afford timely assessment or must prioritize food, housing, education, and other essential household expenses, developmental concerns may receive less immediate attention. Addressing financial barriers requires efforts to improve the affordability and accessibility of developmental screening and diagnostic services, strengthen community-based services, and ensure that disability and health financing mechanisms are responsive to the needs of children with autism and their families.

References

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f) **Weak Referral Systems and Delayed Diagnosis**

Weak referral systems are an important barrier to the early identification of Autism Spectrum Disorder (ASD) in Kenya. Early identification depends on effective coordination between parents and caregivers, community health workers, primary healthcare providers, teachers, and specialized diagnostic services. When developmental concerns are not recognized or when referral pathways are unclear, children may experience significant delays before receiving a comprehensive assessment and diagnosis.

In low-resource settings, children may come into contact with healthcare services several times before autism is suspected or a referral is made. Primary healthcare providers may have limited training in recognizing early signs of autism, while caregivers may not receive clear information about where to seek further assessment. This can result in repeated consultations, inappropriate referrals, or delays in accessing specialized services (Franz et al., 2017).

Evidence from Kenya demonstrates the extent of delays in the diagnostic pathway. A recent study conducted in tertiary hospitals in Nairobi found that caregivers reported lengthy pathways to autism diagnosis, with an average delay of approximately 35 months between first recognizing symptoms and receiving a formal diagnosis. The study

highlights the need for improved early recognition, referral pathways, and coordination between healthcare services to reduce delays in diagnosis (Kandie et al., 2025).

Weak referral systems may have particularly serious consequences in low-resource communities, where specialized diagnostic services are already limited. Families may move between different healthcare facilities in search of appropriate support, while others may abandon the process because of the time and cost involved. Strengthening referral mechanisms at the community and primary healthcare levels, training frontline healthcare workers to recognize early signs of autism, and establishing clear pathways to specialized assessment could improve the timely identification of autistic children in Kenya.

Therefore, improving referral systems should be considered an important component of efforts to address delayed autism identification. Effective coordination between community-based services, primary healthcare facilities, schools, and specialized diagnostic centres can help ensure that children with developmental concerns are identified and referred for appropriate assessment as early as possible.

References

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●Kandie, S., et al. (2025). Pathways and delays in the diagnosis of autism spectrum disorder in Kenya: A cross-sectional study from tertiary hospitals in Nairobi. Child and Adolescent Psychiatry and Mental Health.

g) **Limited Government Support and Policy Implementation**

Government policies and programmes play an important role in improving the early identification and support of children with Autism Spectrum Disorder (ASD). Effective policies can promote developmental screening, strengthen healthcare and education systems, increase professional training, and improve access to diagnostic and intervention services. Kenya has developed policies and legal frameworks that recognize the rights of persons with disabilities and promote access to education, healthcare, and social services. However, gaps in implementation continue to affect the availability and accessibility of services for children with autism, particularly in low-resource communities (Republic of Kenya, 2018).

One of the challenges is the limited integration of autism identification and support within routine primary healthcare and community-based services. Where developmental screening and autism awareness are not consistently incorporated into child health services, opportunities to identify developmental concerns at an early age may be missed. In addition, limited resources, inadequate specialist capacity, and differences in service availability across geographical areas can make it difficult to translate national policies into accessible services at the community level (World Health Organization [WHO], 2023).

The implementation of inclusive education policies also remains a challenge. Although Kenya has adopted policies promoting the inclusion of learners with disabilities, many schools continue to face shortages of trained teachers, limited learning resources, and inadequate support services. These challenges may contribute to autistic children entering school without having been identified or assessed, particularly when early developmental concerns were not recognized within the healthcare or community systems (Republic of Kenya, 2018).

These gaps highlight the need for stronger coordination between government ministries, healthcare providers, education institutions, county governments, and community-based organizations. Strengthening policy implementation, allocating adequate resources, expanding developmental screening, and increasing autism-related training for frontline professionals could improve early identification and access to appropriate support. For low-resource communities, government commitment to accessible and affordable community-based services is particularly important in reducing inequalities in autism identification and intervention.

References

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h) **Community-Based Challenges in Informal Settlements**

Children and families living in informal settlements in Kenya face a combination of social and economic challenges that may create additional barriers to early identification of Autism Spectrum Disorder (ASD). Informal settlements such as Mathare, Kibera, Mukuru, Korogocho, and Soweto are often characterized by poverty, overcrowding, limited access to essential services, and inadequate healthcare infrastructure. These conditions can make it difficult for families to access developmental screening, specialized assessment, and early intervention services.

For families living in these communities, the challenge of identifying autism may begin with limited access to accurate information about child development. Parents and caregivers may have little opportunity to learn about the early signs of autism or may not know where to seek professional advice when developmental concerns arise. When combined with stigma, cultural misconceptions, and financial constraints, this may result in families delaying assessment or relying on informal sources of advice rather than seeking professional support.

Geographical and financial barriers may further affect access to specialized services. Although some informal settlements are located within major urban centres, physical proximity to Nairobi's healthcare facilities does not necessarily guarantee access to affordable autism assessment and intervention. Families may face transportation costs, consultation fees, long waiting periods, and other indirect costs associated with

accessing specialized services. Consequently, children from low-income households may experience delays in receiving appropriate assessment and support.

The challenges experienced in informal settlements demonstrate that early autism identification cannot be addressed solely through the availability of specialist diagnostic services. Community-level strategies are also necessary, including increasing awareness among parents and caregivers, training community health workers and teachers to recognize early developmental signs, strengthening referral pathways, and providing affordable community-based screening and support services. Such approaches may help bring early identification closer to families who are traditionally underserved by formal healthcare and education systems.

Therefore, understanding the experiences of families living in low-resource communities is essential for developing practical and contextually appropriate strategies for early autism identification in Kenya. Research focusing on communities such as Mathare, Kibera, Mukuru, Korogocho, and Soweto can provide valuable insights into the specific barriers faced by families and help inform interventions that are accessible, affordable, and responsive to the realities of underserved communities.

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6. **Knowledge Gap**

Existing literature has established that Autism Spectrum Disorder (ASD) is an important developmental and public health concern and that early identification can improve access to timely intervention and support. Research conducted in Africa has also identified several challenges affecting autism identification and service provision, including limited awareness, stigma, cultural beliefs, shortages of trained professionals, inadequate diagnostic services, and financial constraints (Bakare & Munir, 2011; Franz et al., 2017).

In Kenya, available research has examined the experiences of caregivers of children with autism, the challenges associated with accessing services, and delays in the diagnostic process. Studies have highlighted the financial and emotional burden experienced by families and the lengthy pathways that some caregivers encounter before receiving an autism diagnosis (Mwaniki et al., 2021; Kandie et al., 2025). These studies provide important evidence regarding the challenges surrounding autism diagnosis and support in the Kenyan context.

However, there remains limited research specifically examining the barriers to early autism identification within low-resource communities in Kenya. Much of the

available evidence focuses on autism in general or on families accessing services through specialized or tertiary healthcare facilities. Less is known about how community-level factors, poverty, awareness, cultural beliefs, stigma, healthcare access, referral systems, and shortages of trained professionals interact to influence the early identification of autism among children living in informal settlements and other underserved communities.

Furthermore, there is limited context-specific evidence focusing on informal settlements in urban Kenya, including communities such as Mathare, Kibera, Mukuru, Korogocho, and Soweto. Understanding the experiences of families in these settings is important because the barriers they face may differ from those experienced by families living in higher-income or better-served communities. Without such evidence, interventions and policies may not adequately address the realities of families living in low-resource environments.

Therefore, this study seeks to address this knowledge gap by examining the specific barriers that hinder early autism identification in low-resource communities in Kenya. By focusing on the experiences and perspectives of parents, caregivers, healthcare providers, educators, and other relevant stakeholders, the study aims to generate context-specific evidence that can inform strategies for improving awareness, screening, referral, diagnosis, and early intervention for autistic children in underserved communities.

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8. Justification of the Study

Early identification of Autism Spectrum Disorder (ASD) is essential for ensuring that children receive timely assessment, intervention, educational support, and appropriate care. However, many children living in low-resource communities in Kenya continue to experience delays in autism identification due to multiple interconnected barriers, including limited awareness, stigma, cultural beliefs, poverty, inadequate access to diagnostic services, shortages of trained professionals, and weak referral systems. These challenges may prevent children from accessing early intervention during critical periods of development.

The justification for this study arises from the limited context-specific evidence on the barriers that affect early autism identification in low-resource communities in Kenya. While previous studies have documented challenges associated with autism diagnosis and service access, there is a need for greater understanding of how these barriers operate within underserved communities and how they influence the pathway from the first recognition of developmental concerns to professional assessment and diagnosis.

This study is therefore important because it seeks to generate evidence on the specific factors that delay or prevent early autism identification in low-resource communities. The findings may help healthcare providers, educators, community health workers, parents, caregivers, policymakers, and disability-focused organizations better understand the challenges faced by families seeking autism-related services.

The study may also contribute to the development of practical strategies for improving early identification. These may include increasing community awareness, strengthening developmental screening at the primary healthcare level, improving referral systems, expanding training for frontline professionals, and increasing access to affordable community-based assessment and support services.

Furthermore, the findings may contribute to the existing body of knowledge on autism in Kenya and provide evidence that can inform future research, policies, and programmes targeting children with developmental disabilities. By focusing on low-resource communities, the study seeks to support more equitable access to early autism identification and intervention and ultimately contribute to improved developmental, educational, and social outcomes for autistic children and their families.

STATEMENT OF THE PROBLEM

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that can significantly affect communication, social interaction, learning, and adaptive functioning. Early identification is important because it enables children and their families to access appropriate assessment, intervention, educational support, and other services at an early stage of development. However, in many low-resource settings, children with autism continue to experience delays in identification and diagnosis, limiting their opportunities to benefit from timely support.

In Kenya, evidence indicates that delays in autism diagnosis remain a significant concern. A 2025 study conducted among caregivers of children with ASD attending tertiary hospitals in Nairobi found that the mean age at diagnosis was five years, with an average delay of approximately 34.9 months between caregivers first recognizing symptoms and their children receiving a formal diagnosis. The study also found that caregivers made a median of four contacts with care providers before diagnosis, suggesting that the pathway to diagnosis can be lengthy and complex

(Muthiga et al., 2025). The study further identified socioeconomic and cultural factors, including household income and attribution of autism to supernatural causes, as factors associated with differences in diagnostic delays.

The problem may be more pronounced among families living in low-resource communities, where poverty, limited awareness of autism, stigma, cultural beliefs, shortages of trained professionals, and limited access to specialized diagnostic services may interact to delay the identification of children with developmental differences. Families in such communities may face additional difficulties in accessing appropriate assessment and referral services, particularly where specialized services are concentrated in a limited number of facilities.

Delayed identification of autism can have significant consequences for children, families, and society. When developmental concerns are not recognized and addressed early, children may miss opportunities to access timely intervention and appropriate educational support. Families may also experience prolonged uncertainty and difficulties navigating health and education systems. The absence of timely identification may therefore contribute to avoidable inequalities in developmental and educational outcomes.

Although research has examined autism diagnosis and caregiver experiences in Kenya, there remains a need for greater understanding of the specific barriers affecting early autism identification in low-resource communities. The 2025 Nairobi study itself recommends further research involving larger and more diverse populations to facilitate earlier diagnosis and intervention.

Therefore, the problem addressed by this study is the persistent delay and potential missed identification of autism among children living in low-resource communities in Kenya. The study seeks to examine the barriers that contribute to these delays and to generate evidence that can inform practical strategies for improving early autism identification, referral, and access to timely support within underserved communities.

1.1 Purpose of the Study

The purpose of this study is to examine the barriers to early identification of Autism Spectrum Disorder (ASD) among children living in low-resource communities in Kenya. The study seeks to explore the social, cultural, economic, healthcare, and systemic factors that contribute to delays in recognizing, screening, referring, and diagnosing autism. It also aims to generate evidence that can inform practical strategies for improving early autism identification and access to timely support and intervention for children and their families in underserved communities.

1.2 Objectives of the Study

1.2.1 General Objective

To examine the barriers to early identification of Autism Spectrum Disorder (ASD) among children living in low-resource communities in Kenya.

1.2.2 Specific Objectives

The study seeks to:

1. Examine the level of awareness and knowledge of autism among parents, caregivers, teachers, healthcare providers, and community members in low-resource communities.
2. Explore the influence of cultural beliefs, myths, stigma, and misconceptions on the early identification of autism.
3. Assess the accessibility and availability of autism screening, diagnostic, and referral services in low-resource communities.
4. Examine the economic and financial barriers that affect families' ability to seek early autism assessment and diagnosis.
5. Investigate the availability and capacity of trained professionals involved in the early identification and referral of autistic children.
6. Examine the effectiveness of existing referral pathways and systems for children showing early signs of autism.
7. Identify practical and community-based strategies that can improve early autism identification and referral in low-resource communities in Kenya.

1.3 Research Questions

The study will seek to answer the following research questions:

1. What is the level of awareness and knowledge of Autism Spectrum Disorder (ASD) among parents, caregivers, teachers, healthcare providers, and community members in low-resource communities in Kenya
2. How do cultural beliefs, myths, stigma, and misconceptions influence the early identification of autism in low-resource communities?
3. To what extent are autism screening, diagnostic, and referral services accessible and available to families in low-resource communities?
4. What economic and financial barriers affect families' ability to seek early autism assessment and diagnosis?
5. What is the availability and capacity of trained professionals involved in the early identification and referral of autistic children?
6. How effective are the existing referral pathways and systems for children showing early signs of autism?
7. What practical and community-based strategies can be implemented to improve early autism identification and referral in low-resource communities in Kenya?

1.4 Significance of the Study

This study is significant because it seeks to contribute to a better understanding of the barriers that delay the early identification of Autism Spectrum Disorder (ASD) among children living in low-resource communities in Kenya. By examining the factors that contribute to delayed recognition, screening, referral, and diagnosis, the study may provide evidence that can support more effective and context-appropriate approaches to early autism identification.

Parents and Caregivers: The findings may help parents and caregivers better understand the importance of recognizing early developmental differences and seeking timely professional support. The study may

also highlight the challenges families face when navigating autism identification and accessing appropriate services.

Healthcare Providers and Community Health Workers: The findings may help healthcare providers and community-based health workers understand the barriers that prevent children from being identified early. This may support the development of improved developmental screening, referral, and community awareness approaches.

Teachers and Education Professionals: The study may contribute to increased awareness among teachers and education professionals regarding the early signs of autism. This may strengthen collaboration between schools, families, and healthcare providers and support earlier referral of children who may require further assessment.

Policymakers and Government: The findings may provide evidence to inform policies and programmes aimed at improving early autism identification, strengthening referral systems, expanding professional training, and increasing access to affordable services in underserved communities.

Community-Based and Disability Organisations: The study may provide useful information for organisations working in autism and disability inclusion. The findings can support the design of community-based awareness programmes, caregiver support initiatives, training activities, and advocacy efforts that respond to the specific needs of low-resource communities.

Researchers and Future Studies: The study may contribute to the growing body of knowledge on autism in Kenya and provide a foundation for future research on early identification, diagnosis, intervention, and service access, particularly among children and families living in underserved communities.

Overall, the study aims to contribute to efforts to reduce delays in autism identification and promote more equitable access to timely assessment, support, and intervention for autistic children and their families in low-resource communities in Kenya.

1.5 Scope of the Study

This study focuses on the barriers to early identification of Autism Spectrum Disorder (ASD) among children living in low-resource communities in Kenya. The study examines social, cultural, economic, healthcare, and systemic factors that may contribute to delays in

recognizing, screening, referring, and diagnosing autism.

The study focuses particularly on underserved urban communities and informal settlements, with attention to communities such as Mathare, Kibera, Mukuru, Korogocho, and Soweto. These communities provide important contexts for understanding how poverty, limited access to specialized services, low awareness, stigma, cultural beliefs, and other community-level challenges may influence the early identification of autism.

The study considers the perspectives and experiences of key stakeholders, including parents and caregivers of children, teachers, healthcare providers, community health workers, and organizations involved in autism and disability support. The study focuses on children in the early developmental and pre-school years, when early identification can provide opportunities for timely intervention and support.

The study is limited to barriers affecting early autism identification and does not seek to provide a comprehensive assessment of all aspects of autism intervention, treatment, or long-term educational outcomes. The findings are intended to contribute to a better understanding of the challenges affecting early autism identification in low-resource communities and to inform practical strategies for improving awareness, screening, referral, and access to appropriate support services.

1.6 Limitations of the Study

The study may face several limitations that could affect the research process and the interpretation of its findings. One potential limitation is the availability of participants, particularly parents and caregivers who may have limited time or may be hesitant to discuss their experiences related to autism identification. Some participants may also have difficulty recalling the exact timing of developmental concerns, healthcare visits, referrals, or diagnostic processes, which may affect the accuracy of the information provided.

Another limitation may be the sensitivity of topics related to cultural beliefs, stigma, and experiences of discrimination. Some participants may be reluctant to openly discuss these issues due to fear of judgment or social consequences. The researchers will therefore seek to create a respectful and confidential environment that encourages participants to share their experiences honestly.

The study may also be limited by the availability of reliable data on early autism identification in low-resource communities. Autism-related services and diagnostic records may not be consistently documented across different healthcare and community settings, making it difficult to obtain comprehensive information.

Additionally, the study may focus on selected low-resource communities and therefore may not fully represent the experiences of all low-resource communities across Kenya. However, the findings may provide valuable insights into common barriers and contribute to a better

understanding of the challenges affecting early autism identification in underserved settings.

1.7 Definition of Key Terms

Autism Spectrum Disorder (ASD): A neurodevelopmental condition characterized by differences in social communication and social interaction, together with restricted or repetitive patterns of behaviour, interests, or activities.

Early Identification: The process of recognizing early developmental signs or characteristics associated with autism during infancy or early childhood and referring a child for appropriate screening, assessment, and diagnosis.

Autism Screening: The use of standardized tools or procedures to identify children who may show characteristics associated with autism and who may require further comprehensive assessment.

Diagnosis: The formal process of determining whether a child meets established criteria for Autism Spectrum Disorder following a comprehensive assessment by appropriately qualified professionals.

Early Intervention: Support and services provided to a child as early as possible following the identification of developmental concerns or autism, with the aim of promoting development, communication, learning, social participation, and adaptive skills.

Low-Resource Communities: Communities where individuals and families experience limited access to financial resources, healthcare, education, specialized services, and other essential social and developmental support systems.

Barriers: Social, cultural, economic, geographical, healthcare-related, or systemic factors that hinder or delay the early identification, screening, referral, or diagnosis of autism.

Caregiver: A parent, guardian, family member, or other individual who provides regular care and support to a child.

Referral: The process through which a child with suspected developmental concerns is directed from one service provider or level of care to another for further screening, assessment, diagnosis, or support.

Inclusive Education: An approach to education that seeks to ensure that all learners, including children with disabilities, can access, participate in, and benefit from education within supportive and equitable learning environments.

Informal Settlements: Densely populated communities where residents may experience inadequate housing, limited infrastructure, poverty, and restricted access to essential services such as healthcare and education.Despite these limitations, appropriate measures will be taken to ensure that the research process is conducted systematically and ethically. The study will use relevant data sources and seek perspectives from different stakeholders to provide a more comprehensive understanding of the barriers to early autism identification.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter reviews existing literature on the barriers to early identification of Autism Spectrum Disorder (ASD), with a particular focus on children living in low-resource communities. The review examines previous research on autism awareness and knowledge, cultural beliefs and stigma, access to

healthcare and diagnostic services, availability of trained professionals, financial and economic barriers, referral systems, and government policies and their implementation.

The chapter further examines literature from global, African, and Kenyan contexts to provide a broader understanding of the factors that influence the early identification of autism. Particular attention is given to evidence concerning underserved and low-resource communities, where social, economic, cultural, and health system challenges may contribute to delays in identification and diagnosis.

The chapter is organized into a conceptual review, theoretical framework, and empirical review. It concludes by identifying gaps in existing research and presenting the conceptual framework that guides the study.

2.1 Conceptual Review

2.1.1 Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by persistent differences in social communication and social interaction, alongside restricted and repetitive patterns of behaviour, interests, or activities. The characteristics of autism generally emerge during early childhood and can have varying effects on an individual's communication, learning, social participation, and daily functioning (American Psychiatric Association [APA], 2022).

Autism is described as a spectrum because individuals experience different combinations and levels of characteristics and support needs. Some autistic individuals may have significant communication and developmental support needs, while others may have relatively strong language and cognitive abilities and require less support in their daily lives. This diversity makes individualized assessment and support essential (World Health Organization [WHO], 2023).

The early recognition of autism is an important aspect of supporting autistic children and their families. Identifying developmental differences at an early age can facilitate timely screening, comprehensive assessment, diagnosis, and access to appropriate support. However, the process of identifying autism may be affected by several factors, including parental awareness, cultural beliefs, stigma, access to healthcare services, availability of trained professionals, and the effectiveness of referral systems.

In the context of this study, Autism Spectrum Disorder is understood as a neurodevelopmental condition whose early identification may be influenced by multiple social, cultural, economic, and health-system factors. Understanding the nature and characteristics of autism is therefore important in examining why some children, particularly those living in low-resource communities, may experience delays in identification and diagnosis.

2.1.2 Early Identification of Autism

Early identification of Autism Spectrum Disorder (ASD) refers to the process of recognizing developmental characteristics associated with autism as early as possible in a child's development and initiating appropriate screening, assessment, referral, and diagnostic processes. Early identification is an

important step in ensuring that children with developmental differences can access appropriate support and services at a time when developmental and learning needs can be addressed effectively (World Health Organization [WHO], 2023).

The process of early identification may begin when parents, caregivers, teachers, community health workers, or healthcare providers notice developmental differences in a child. These may include differences in social communication, language development, social interaction, play, or repetitive behaviours. When such concerns are recognized, the child may be referred for developmental screening and, where necessary, a comprehensive assessment by appropriately trained professionals.

Early identification does not necessarily mean that every child showing developmental differences will immediately receive an autism diagnosis. Rather, it provides an opportunity for developmental concerns to be recognized and investigated through appropriate screening and assessment processes. This distinction is important because autism characteristics may overlap with other developmental conditions, and a comprehensive assessment is necessary to establish an accurate diagnosis.

The timing of identification can be influenced by several factors. These include the level of awareness among parents and caregivers, recognition of early developmental signs by healthcare providers and teachers, cultural beliefs, stigma, availability of screening and diagnostic services, financial resources, and the effectiveness of referral systems. In low-resource communities, these factors may interact and contribute to delays in the identification and diagnosis of autistic children.

For the purpose of this study, early identification is viewed as a process that begins with the recognition of developmental concerns and extends through screening, referral, assessment, and diagnosis. Examining this process is essential to understanding the barriers that may prevent children in low-resource communities in Kenya from being identified and supported at an early stage.

2.1.3 Autism Screening and Diagnosis

Autism screening and diagnosis are important components of the process of early identification of Autism Spectrum Disorder (ASD). Although the two processes are related, they serve different purposes. Autism screening involves the use of standardized tools or procedures to identify children who may show characteristics associated with autism and who may require further assessment. Screening is not intended to provide a definitive diagnosis but rather to identify children who may benefit from a more comprehensive evaluation (American Academy of Pediatrics, 2020).

Diagnosis, on the other hand, involves a comprehensive assessment to determine whether an individual meets the established criteria for Autism Spectrum Disorder. The diagnostic process may involve gathering developmental history, observing the child's behaviour, assessing communication and social interaction, and considering information from parents, caregivers, teachers, and other relevant professionals. Depending on the child's needs and available services, assessment may involve professionals from different disciplines (American Psychiatric Association [APA], 2022).

Early screening and timely referral can provide an opportunity for developmental concerns to be recognized before a child reaches school age. However, screening alone cannot replace a comprehensive diagnostic assessment. A positive screening result indicates that further evaluation may be necessary, while a formal diagnosis requires a more detailed assessment by appropriately qualified professionals.

In low-resource communities, access to both screening and diagnostic services may be affected by several challenges. These may include limited awareness among caregivers and frontline professionals, inadequate screening within primary healthcare settings, shortages of trained specialists, financial constraints, and weak referral pathways. These barriers may result in children being identified late or not receiving a formal diagnosis, even when developmental concerns have been present from an early age.

Understanding the distinction between screening and diagnosis is therefore important to this study. The study examines barriers across the broader identification pathway, beginning with the recognition of developmental concerns and extending to screening, referral, assessment, and formal diagnosis. This approach recognizes that delays may occur at different stages of the process and may be influenced by factors operating at the individual, family, community, and health-system levels.

2.1.4 Early Intervention and Support for Autistic Children

Early intervention refers to the provision of appropriate support and services to children with developmental concerns or disabilities as early as possible. For autistic children, early intervention may focus on communication, social interaction, learning, adaptive functioning, behaviour, and participation in everyday activities. The specific support provided should be based on the individual needs, strengths, abilities, and preferences of each child and family (World Health Organization [WHO], 2023).

Early identification plays an important role in facilitating access to appropriate support. When autism or developmental concerns are recognized early, families have an opportunity to seek appropriate assessment and begin interventions that can support the child's development and participation. Early support may also help parents and caregivers understand their child's developmental needs and learn practical strategies for supporting communication, learning, behaviour, and daily living skills.

The benefits of early intervention extend beyond the child to include parents, caregivers, families, schools, and communities. Caregivers may gain knowledge and confidence in responding to their child's needs, while teachers may be better prepared to provide appropriate learning and inclusion strategies. Early support can also promote greater participation in family, educational, and community activities.

However, the availability and accessibility of early intervention services vary considerably across different settings. In low-resource communities, families may experience difficulties accessing affordable and appropriate support because of poverty, limited specialized services, shortages of trained professionals, geographical barriers, and inadequate referral systems. Consequently, delayed identification may contribute to delayed access to support, while limited access to services may further reduce the benefits that could be achieved through early intervention.

In the context of this study, early intervention is considered an important outcome of timely autism identification. Understanding the barriers that delay identification is therefore essential because such barriers may also delay children's access to appropriate support and reduce opportunities for families to receive timely guidance and assistance.

2.1.5 Low-Resource Communities and Autism Identification

Low-resource communities are communities in which individuals and families experience limited access to financial resources, healthcare, education, specialized services, and other essential social support systems. In the context of autism, children living in such communities may face multiple and interconnected barriers that affect the early recognition, screening, referral, and diagnosis of developmental differences.

The identification of autism in low-resource communities may be influenced by limited awareness among parents, caregivers, teachers, and healthcare providers. When early developmental characteristics are not recognized or are misunderstood, families may delay seeking professional assessment. Cultural beliefs, myths, stigma, and misconceptions about autism may further discourage families from seeking help or discussing developmental concerns within their communities.

Access to appropriate healthcare and diagnostic services is another important consideration. Specialized autism assessment services may be limited or concentrated in major urban centres, making them difficult to access for families with limited financial resources. Even where services are geographically available, consultation fees, transportation costs, long waiting periods, and shortages of trained professionals may prevent families from completing the assessment process.

In Kenya, these challenges may be particularly relevant in informal settlements and other underserved communities. Communities such as Mathare, Kibera, Mukuru, Korogocho, and Soweto may experience a combination of socioeconomic challenges and limited access to specialized developmental services. However, living in an urban area does not necessarily guarantee access to affordable and appropriate autism identification services.

Understanding the context of low-resource communities is therefore essential when examining barriers to early autism identification. The challenges experienced by families may not result from a single factor but from the interaction of poverty, awareness, cultural beliefs, stigma, healthcare access, professional capacity, and referral systems. Examining these factors together can provide a more comprehensive understanding of why some autistic children may not be identified early and can help inform community-based strategies that are appropriate to the realities of underserved populations in Kenya.

2.2 Theoretical Framework

2.2.1 Social Ecological Model

The Social Ecological Model (SEM) provides a useful framework for understanding the multiple and interconnected factors that influence human behaviour, health, and access to services. The model proposes that individuals are influenced not only by their personal characteristics but also by their

relationships, communities, institutions, and broader social and policy environments (McLeroy et al., 1988).

The Social Ecological Model is relevant to this study because early identification of Autism Spectrum Disorder (ASD) is influenced by factors operating at different levels. A delay in identification may not be caused by a single barrier but may result from the interaction of individual, family, community, healthcare, and policy-related factors. The model therefore provides a framework for examining these barriers as interconnected rather than isolated challenges.

At the **individual level,** factors such as parents' and caregivers' knowledge and awareness of autism may influence their ability to recognize early developmental differences and seek professional support. Limited understanding of early signs of autism may contribute to delays in seeking screening or assessment.

At the **interpersonal or family level,** beliefs, attitudes, and experiences within families may influence how developmental concerns are understood and addressed. Cultural beliefs, misconceptions, stigma, and financial constraints may affect caregivers' decisions to seek professional assessment for their children.

At the **community level,** social norms, cultural practices, community attitudes, and the availability of information and support services may influence early autism identification. In low-resource communities, limited awareness and stigma may discourage families from seeking assistance, while community-based awareness and support programmes may help promote earlier recognition and referral.

At the **organizational and healthcare-system level,** the availability of trained professionals, developmental screening services, diagnostic facilities, and effective referral pathways may influence whether children receive timely assessment and diagnosis. Weak coordination between community health services, primary healthcare facilities, schools, and specialized services may contribute to delays in the identification process.

At the **policy and societal level,** government policies, funding, disability programmes, healthcare systems, and the distribution of specialized services may influence access to autism identification and support. Where policies are not adequately implemented or resources are limited, families in low-resource communities may experience greater barriers to accessing appropriate services.

The Social Ecological Model therefore provides a suitable theoretical foundation for this study because it recognizes that barriers to early autism identification occur across multiple and interconnected levels. Applying this model enables the study to examine how individual awareness, family and cultural factors, community conditions, healthcare systems, and broader policies interact to influence the early identification of autism among children living in low-resource communities in Kenya.

The model also supports the development of comprehensive solutions. Addressing delayed autism identification may require interventions at multiple levels, including increasing community awareness,

reducing stigma, strengthening caregiver education, training frontline professionals, improving referral systems, expanding affordable diagnostic services, and strengthening government policies and their implementation.

Reference

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. Health Education Quarterly, 15(4), 351–377. https://doi.org/10.1177/109019818801500401

2.2.2 Application of the Social Ecological Model to the Study

The Social Ecological Model provides a framework for examining the barriers to early identification of Autism Spectrum Disorder (ASD) in low-resource communities in Kenya. The model is applied in this study to demonstrate how factors operating at different levels may interact and contribute to delays in the recognition, screening, referral, and diagnosis of autism.

At the individual level, the study examines the knowledge and awareness of parents, caregivers, teachers, healthcare providers, and community members regarding autism and its early developmental characteristics. Limited knowledge may prevent the early recognition of signs that require further assessment.

At the interpersonal and family level, the study examines the influence of family attitudes, cultural beliefs, myths, stigma, and financial circumstances on caregivers' decisions to seek professional assessment. These factors may influence whether developmental concerns are recognized, discussed, and acted upon.

At the community level, the study considers the role of community attitudes, social norms, access to information, and community-based support systems. In low-resource communities, stigma and misconceptions may discourage families from seeking help, while community awareness programmes and supportive networks may encourage earlier identification.

At the organizational and healthcare-system level, the study examines the availability of screening and diagnostic services, trained professionals, and effective referral pathways. The accessibility and quality of these services may determine whether children with developmental concerns receive timely assessment and diagnosis.

At the policy and societal level, the study examines the influence of government policies, resource allocation, disability programmes, and the implementation of policies related to autism and disability services. Gaps between policy and implementation may contribute to inequalities in access to early identification services, particularly among families living in underserved communities.

The application of the Social Ecological Model therefore enables this study to examine early autism identification as a multidimensional issue. Rather than attributing delayed identification to a single cause, the study recognizes that barriers may operate simultaneously across individual, family,

community, healthcare, and policy levels. This approach will help identify opportunities for intervention at multiple levels and support the development of comprehensive strategies for improving early autism identification in low-resource communities in Kenya.

2.3 Empirical Review

2.3.1 Awareness and Knowledge of Autism

Awareness and knowledge of Autism Spectrum Disorder (ASD) among parents, caregivers, teachers, healthcare providers, and the wider community are important factors influencing the early identification of autism. The recognition of early developmental characteristics often depends on whether those who interact with children understand what to look for and know where to seek appropriate support. Limited knowledge may result in developmental differences being overlooked, misunderstood, or attributed to other causes, thereby delaying professional assessment and diagnosis.

Research from sub-Saharan Africa has identified limited awareness and knowledge of autism as important challenges affecting early identification and access to services. Franz et al. (2017), in a scoping review of autism spectrum disorder in sub-Saharan Africa, reported that limited awareness among communities and healthcare professionals contributes to difficulties in recognizing autism and accessing appropriate services. The review also highlighted the shortage of autism-specific knowledge and expertise within health systems across the region.

Similarly, Bakare and Munir (2011) observed that autism in Africa has historically received limited attention within health and social systems, with inadequate awareness contributing to under-recognition and limited access to appropriate services. This suggests that improving awareness among communities and professionals is an important component of strengthening early identification.

In Kenya, the issue of awareness is particularly relevant in low-resource communities where access to reliable developmental information and specialized services may be limited. Parents and caregivers may not recognize early characteristics of autism or may not know that developmental concerns can be assessed by qualified professionals. Teachers and community health workers, who may be among the first individuals to observe developmental differences, may also have limited opportunities for autism-specific training.

The relationship between awareness and early identification is therefore important to the present study. While existing research demonstrates that limited autism knowledge is a challenge in sub-Saharan Africa, there is a need for more context-specific research examining how awareness among different stakeholders affects the early identification of autism in low-resource Kenyan communities. Understanding these gaps can help inform targeted awareness programmes, caregiver education, teacher training, and capacity-building for frontline healthcare and community workers.

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●Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. Autism Research, 10(5), 723–749. https://doi.org/10.1002/aur.1760

2.3.2 Cultural Beliefs, Myths, and Stigma

Cultural beliefs, myths, and stigma can significantly influence how families understand developmental differences and respond to concerns about Autism Spectrum Disorder (ASD). The way autism is understood within a community may influence whether parents and caregivers recognize developmental characteristics as signs of a neurodevelopmental condition or interpret them through cultural, spiritual, or supernatural explanations. Such interpretations may affect decisions about whether and when to seek professional assessment.

Research in sub-Saharan Africa has identified cultural beliefs and misconceptions as important factors affecting the recognition and management of autism. Bakare and Munir (2011) noted that autism in African contexts has sometimes been associated with supernatural explanations and misconceptions, which may contribute to stigma and hinder access to appropriate care. Similarly, Franz et al. (2017) identified stigma, misconceptions, and limited community understanding as challenges affecting autism identification and service access across sub-Saharan Africa.

Stigma may also affect families after developmental concerns have been recognized. Parents and caregivers may fear negative attitudes, discrimination, social exclusion, or blame from relatives and community members. Such experiences may discourage families from openly discussing developmental concerns or seeking professional assessment. In some cases, families may first seek explanations or assistance from traditional or religious sources before approaching healthcare professionals, potentially contributing to delays in formal assessment.

The influence of cultural beliefs and stigma is particularly important in low-resource communities, where access to accurate information about autism may be limited. Where community knowledge is low, myths and misconceptions may spread more easily and influence attitudes towards autistic children and their families. However, community-based education and engagement with trusted community leaders may provide opportunities to challenge misconceptions and promote greater acceptance and understanding of autism.

The existing literature demonstrates that cultural beliefs, myths, and stigma can influence pathways to autism identification in African contexts. However, there is a need for more research examining how these factors specifically affect early autism identification within low-resource communities in Kenya. Understanding the experiences of families and communities can help inform culturally appropriate awareness strategies that reduce stigma, challenge misconceptions, and encourage earlier help-seeking and referral.

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2.3.3 Access to Healthcare and Diagnostic Services

Access to appropriate healthcare and diagnostic services is an important factor in the early identification of Autism Spectrum Disorder (ASD). The identification process requires families to have access to healthcare providers who can recognize developmental concerns, conduct or facilitate screening, and refer children for comprehensive assessment. Where these services are limited, unavailable, or difficult to access, children may experience delays in receiving appropriate assessment and diagnosis.

Evidence from sub-Saharan Africa indicates that access to autism-related diagnostic and support services remains a challenge. Franz et al. (2017), in their review of autism research and services across sub-Saharan Africa, identified limited availability of specialized services and inadequate healthcare infrastructure as important challenges. The concentration of specialized professionals and services in selected urban centres may further disadvantage families living in underserved areas.

In Kenya, access to autism diagnostic services may be affected by the limited availability of specialized professionals and facilities, as well as the financial and geographical challenges faced by families. A recent study examining pathways to autism diagnosis in Nairobi found that caregivers experienced substantial delays between the time they first recognized developmental concerns and the time their children received a formal diagnosis (Muthiga et al., 2025). The study highlights the complexity of the diagnostic pathway and the need for systems that facilitate earlier recognition and access to assessment.

The availability of healthcare services alone does not necessarily guarantee timely identification. Families may encounter multiple challenges, including long waiting periods, transportation costs, consultation expenses, and difficulties navigating the healthcare system. These challenges may be particularly significant for families living in low-resource communities, where household resources are limited and specialized services may be difficult to access or afford.

The literature therefore suggests that improving early autism identification requires more than increasing awareness. It also requires accessible and affordable developmental screening and diagnostic services, clear referral pathways, and stronger integration of developmental concerns into primary healthcare. However, there remains a need for further research examining how these healthcare and diagnostic barriers specifically affect families living in low-resource communities in Kenya. This study seeks to contribute to this understanding by examining the experiences of families and other stakeholders within underserved communities.

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2.3.4 Availability and Capacity of Trained Professional

The availability and capacity of trained professionals are important factors in the early identification of Autism Spectrum Disorder (ASD). Early identification requires professionals who can recognize developmental concerns, conduct appropriate screening, provide referrals, and participate in comprehensive assessments. These professionals may include paediatricians, psychologists, speech and language professionals, occupational therapists, special needs education professionals, and other healthcare and education practitioners with relevant training in autism.

Research in sub-Saharan Africa has highlighted a shortage of professionals with specialized knowledge and skills in autism. Franz et al. (2017) reported that limited professional capacity and inadequate access to specialized expertise remain significant challenges in the provision of autism-related services across the region. The shortage of trained professionals can affect the ability of health and education systems to recognize autism early and provide timely assessment and support.

The challenge is not only the number of professionals available but also their geographical distribution and level of autism-specific training. Specialized professionals and diagnostic services may be concentrated in major urban centres, while families in underserved communities may have limited access to them. In addition, frontline professionals who are

often the first point of contact for children, including primary healthcare workers, community health workers, and teachers, may not receive sufficient training to recognize early characteristics of autism or make appropriate referrals.

The lack of adequate professional capacity may contribute to delays at different stages of the identification pathway. A child may be recognized as having developmental concerns but experience delays in receiving appropriate screening, referral, or comprehensive assessment because the necessary professionals are unavailable or difficult to access. This may be particularly challenging for families living in low-resource communities, where access to specialized services is already constrained by financial and geographical barriers.

The existing literature therefore demonstrates the importance of strengthening professional capacity as part of efforts to improve early autism identification. Training frontline healthcare workers, teachers, and community-based professionals in recognizing early developmental characteristics and establishing clear referral pathways may help improve early recognition. At the same time, increasing the availability

of specialized professionals and expanding services beyond major urban centres are important for ensuring equitable access to assessment and diagnosis.

However, there remains a need for context-specific research examining the availability, accessibility, and capacity of professionals involved in autism identification within low-resource communities in Kenya. Understanding these challenges can help inform targeted training, workforce development, and community-based approaches aimed at reducing delays in early autism identification.

References

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2.3.5 Financial and Economic Barriers to Early Autism Identification

Financial and economic circumstances can significantly influence the ability of families to seek early identification and diagnosis of Autism Spectrum Disorder (ASD). Although early identification requires timely access to screening, assessment, and diagnostic services, families with limited financial resources may experience difficulties meeting the direct and indirect costs associated with seeking these services. These costs may include consultation and assessment fees, transportation expenses, and the loss of income when caregivers take time away from work or other income-generating activities.

Research examining the experiences of caregivers of children with autism in Kenya has identified financial challenges as an important concern for families. Mwaniki et al. (2021) reported that caregivers experienced significant challenges associated with the financial burden of caring for children with autism. The costs associated with accessing healthcare and other support services may place additional pressure on families who are already experiencing economic hardship.

Financial barriers may also affect the ability of families to complete the diagnostic process. A family may recognize developmental concerns but delay seeking assessment because of the expected costs of consultations, transportation, or specialized services. For families living in low-resource communities, these financial challenges may be compounded by limited access to affordable services within their local communities.

Evidence from Kenya also indicates that the pathway to autism diagnosis can be lengthy. Muthiga et al. (2025) found substantial delays between the time caregivers first recognized symptoms and the time children received a formal diagnosis. Although diagnostic delays may result from multiple interacting factors, financial constraints can contribute to the difficulty families face in navigating healthcare systems and accessing specialized assessment.

The relationship between poverty and early autism identification is therefore important to the present study. Families living in low-resource communities may have to prioritize essential household needs,

such as food, housing, and education, before seeking specialized developmental assessment. This may result in developmental concerns being addressed later or not at all.

The literature suggests that reducing financial barriers should form part of broader strategies to improve early autism identification. Expanding affordable community-based screening, strengthening public healthcare services, improving referral systems, and increasing financial protection for families seeking developmental assessment may help reduce inequalities in access. However, more research is needed to understand how financial constraints specifically influence the pathway to early autism identification within low-resource communities in Kenya.

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●Mwaniki, L. M., et al. (2021). Challenges of caregivers having children with autism in Kenya: Systematic review. Journal of Autism and Developmental Disorders.

2.3.6 Referral Systems and Diagnostic Delays

Effective referral systems are essential for ensuring that children showing early signs of Autism Spectrum Disorder (ASD) are connected to appropriate screening, assessment, and diagnostic services. The identification of autism often involves several stages, beginning with the recognition of developmental concerns by parents, caregivers, teachers, or frontline healthcare providers and progressing to screening, referral, and comprehensive assessment. Weak coordination between these stages may contribute to delays in diagnosis.

Research in sub-Saharan Africa has highlighted challenges within health systems that may affect the identification and management of autism. Franz et al. (2017) identified limited awareness, inadequate professional capacity, and restricted access to specialized services as factors that can affect pathways to autism assessment and support. Where referral systems are unclear or poorly coordinated, families may experience difficulties identifying where to seek help or may move between different service providers before receiving appropriate assessment.

Evidence from Kenya demonstrates that delays in the diagnostic pathway remain a significant concern. Muthiga et al. (2025) reported that caregivers of children with autism attending tertiary hospitals in Nairobi experienced a substantial period between first recognizing developmental concerns and receiving a formal diagnosis. The study also found that caregivers had multiple contacts with care providers before diagnosis, highlighting the complexity of the pathway to formal identification.

Delays in referral and diagnosis may have several consequences for children and their families. Children may miss opportunities for timely developmental support and educational planning, while caregivers may experience prolonged uncertainty and difficulties navigating health and social services. In low-

resource communities, these challenges may be intensified by financial constraints, limited access to specialized services, and inadequate information about available referral pathways.

Strengthening referral systems therefore requires improved coordination between community health workers, primary healthcare providers, schools, parents and caregivers, and specialized diagnostic services. Training frontline professionals to recognize early developmental concerns and establishing clear referral pathways may help reduce delays. Community-based awareness programmes may also help families understand when and where to seek further assessment.

Although existing research has demonstrated delays in autism diagnosis in Kenya, there is a need for further investigation into how referral systems operate within low-resource communities. Understanding where delays occur in the pathway from recognition to diagnosis and identifying the factors responsible for these delays may help inform practical strategies for improving early autism identification in underserved communities.

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2.3.7 Government Policies and Policy Implementation

Government policies and their implementation play an important role in determining the availability, accessibility, and quality of services for children with Autism Spectrum Disorder (ASD). Policies can provide a framework for promoting disability rights, inclusive education, access to healthcare, early identification, and support services. However, the existence of policies does not necessarily guarantee that families will have access to services, particularly in low-resource communities.

In Kenya, policies and legal frameworks recognize the rights of persons with disabilities and promote access to healthcare, education, and social services. The Constitution of Kenya and the Persons with Disabilities Act provide a foundation for protecting the rights of persons with disabilities, while the Basic Education Act and education sector policies support the inclusion of learners with disabilities within the education system (Republic of Kenya, 2010; Republic of Kenya, 2003; Ministry of Education, 2018). These frameworks provide an important basis for improving the identification and support of children with developmental disabilities.

Despite these policy commitments, challenges may arise in translating national policies into accessible services at the community level. Limited financial resources, shortages of trained professionals,

inadequate infrastructure, and uneven distribution of services can affect the implementation of disability and inclusive education policies. Families living in low-resource communities may therefore experience a gap between the rights and services provided for in policy and the services that are practically available to them.

The implementation of policies related to early identification is particularly important because autism identification requires collaboration across different sectors, including health, education, social services, and community-based organizations. Where coordination between these sectors is weak, children may not be identified or referred in a timely manner. Similarly, inadequate investment in community-level awareness, developmental screening, professional training, and referral systems may limit the effectiveness of policies intended to support early identification.

The literature therefore suggests that policy development must be accompanied by effective implementation, adequate resources, monitoring, and coordination between relevant sectors. For low-resource communities, policies should also consider the realities faced by families, including poverty, limited access to specialized services, and geographical and social barriers.

However, there remains a need for more research examining how existing government policies and programmes influence early autism identification at the community level in Kenya. This study seeks to contribute to this area by examining whether policy and system-level factors create barriers to early identification and by identifying opportunities for strengthening the implementation of policies and programmes that support autistic children and their families.

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2.3.8 Challenges of Early Autism Identification in Low-Resource Communities

Low-resource communities face multiple and interconnected challenges that can affect the early identification of Autism Spectrum Disorder (ASD). These challenges may include limited awareness of autism, cultural beliefs and stigma, poverty, inadequate access to healthcare, shortages of trained professionals, and weak referral systems. When these factors occur simultaneously, they may create significant difficulties for families seeking to understand and respond to developmental concerns in their children.

Research in sub-Saharan Africa has demonstrated that autism identification and access to services are influenced by broader social and health-system challenges. Franz et al. (2017) found that limited awareness, inadequate professional capacity, insufficient specialized services, and stigma are among the factors affecting autism care across the region. These challenges are particularly relevant in

communities where families have limited access to reliable health information and specialized developmental services.

In Kenya, families living in low-resource communities may experience additional challenges related to poverty and access to services. The financial burden associated with autism care may make it difficult for families to seek assessment and follow through with referrals. Mwaniki et al. (2021) identified significant challenges experienced by caregivers of children with autism in Kenya, including financial and social difficulties. Such challenges may affect the ability of families to access timely assessment and support.

The diagnostic pathway may also be affected by the availability and accessibility of services. Muthiga et al. (2025) found significant delays between caregivers first recognizing developmental concerns and their children receiving a formal autism diagnosis among families attending tertiary hospitals in Nairobi. These findings demonstrate that even when families eventually access specialized healthcare services, the pathway to diagnosis may be lengthy.

The situation may be particularly complex in informal settlements and other underserved communities. Communities such as Mathare, Kibera, Mukuru, Korogocho, and Soweto experience varying levels of socioeconomic disadvantage and may face challenges related to access to affordable healthcare, specialized services, reliable information, and social support. However, there is limited empirical research specifically examining how these factors interact to influence early autism identification within such communities.

The existing literature therefore suggests that early autism identification in low-resource communities should be understood as a multidimensional issue. Addressing the challenge requires more than improving diagnostic services alone. It requires coordinated efforts to increase community awareness, reduce stigma, strengthen caregiver support, train frontline professionals, improve referral pathways, expand affordable services, and strengthen the implementation of relevant policies.

Despite the growing body of literature on autism in Africa and Kenya, there remains a gap in context-specific research examining the combined influence of these barriers on early autism identification within low-resource communities. This gap provides a strong basis for the present study, which seeks to examine these barriers and identify practical strategies for improving early autism identification in underserved communities in Kenya.

References

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●Muthiga, M., Mbwayo, A., Kang'ethe, R., & Horn, N. (2025). Pathways and delays in the diagnosis of autism spectrum disorder in Kenya: A cross-sectional study from tertiary hospitals in Nairobi. Child and Adolescent Psychiatry and Mental Health, 19, 114. https://doi.org/10.1186/s13034-025-00916-2

●Mwaniki, L. M., et al. (2021). Challenges of caregivers having children with autism in Kenya: Systematic review. Journal of Autism and Developmental Disorders.

2.4 Research Gap

Existing literature demonstrates that Autism Spectrum Disorder (ASD) remains an important developmental and public health concern, and that early identification can support timely access to appropriate intervention, education, and family support. Research conducted in sub-Saharan Africa has identified several challenges affecting autism identification and access to services, including limited awareness, stigma, cultural beliefs, shortages of trained professionals, inadequate diagnostic services, and weak health systems (Bakare & Munir, 2011; Franz et al., 2017).

In Kenya, emerging research has begun to examine the experiences of caregivers and the pathways through which children receive an autism diagnosis. Recent evidence indicates that caregivers may experience considerable delays between first recognizing developmental concerns and obtaining a formal diagnosis (Muthiga et al., 2025). Other research has also highlighted the financial and social challenges experienced by families caring for children with autism (Mwaniki et al., 2021).

Despite these contributions, several gaps remain in the existing body of knowledge. First, much of the available research focuses on autism in general or on families accessing specialized services, with limited attention to the experiences of families living specifically in low-resource communities. Second, there is limited research examining how multiple barriers—including awareness, cultural beliefs, stigma, poverty, healthcare access, professional capacity, referral systems, and policy implementation—interact to influence early autism identification.

Third, although research has identified diagnostic delays in Kenya, there is limited evidence on where and why delays occur within the early identification pathway in underserved communities. More research is needed to understand the experiences of families from the initial recognition of developmental concerns through screening, referral, assessment, and diagnosis.

Finally, there is a need for more community-focused research that can generate practical recommendations relevant to low-resource settings. In particular, there is limited evidence on how community-based awareness, caregiver education, frontline professional training, and strengthened referral systems can be used to improve early autism identification in underserved communities.

This study seeks to address these gaps by examining the barriers to early identification of Autism Spectrum Disorder among children living in low-resource communities in Kenya. By considering individual, family, community, healthcare-system, and policy-level factors, the study aims to provide a more comprehensive understanding of the challenges affecting early identification and generate evidence that can inform practical and context-appropriate strategies for improving early autism identification and referral in underserved communities.

2.5 Conceptual Framework

The conceptual framework for this study illustrates the relationship between the barriers to early identification of Autism Spectrum Disorder (ASD) and the timely identification of autistic children in low-resource communities in Kenya. The framework is informed by the Social Ecological Model and the findings reviewed in the empirical literature.

The framework identifies the barriers to early autism identification as the **independent variables.** These include limited awareness and knowledge of autism, cultural beliefs and misconceptions, stigma, financial and economic barriers, limited access to healthcare and diagnostic services, inadequate availability of trained professionals, weak referral systems, and gaps in policy implementation.

The **dependent variable** is early autism identification, which involves the timely recognition of developmental concerns, screening, referral, assessment, and diagnosis.

The framework also identifies intervening factors that may influence the relationship between these barriers and early autism identification. These include community awareness programmes, caregiver education and support, professional training, availability of affordable services, strengthened referral pathways, and effective implementation of government policies.The framework assumes that multiple barriers operating at individual, family, community, healthcare-system, and policy levels may contribute to delays in early autism identification. Conversely, strengthening awareness, caregiver support, professional capacity, healthcare access, and referral systems may help improve timely identification and access to appropriate support for autistic children and their families.

2.5.1 Conceptual Framework Diagram

The conceptual framework can be presented as follows:

INDEPENDENT VARIABLES

Barriers to Early Autism Identification

- Limited awareness and knowledge of autism

- Cultural beliefs and misconceptions

- Stigma and discrimination

- Financial and economic barriers

- Limited access to healthcare and diagnostic services

- Shortage of trained professionals

- Weak referral systems

- Gaps in policy implementation

⬇️

INTERVENING VARIABLES

- Community awareness and education
- Caregiver education and support
- Training of healthcare workers and teachers
- Affordable and accessible screening and diagnostic services
- Strengthened referral pathways
- Effective implementation of government policies

⬇️

DEPENDENT VARIABLE

Early Autism Identification

- Early recognition of developmental concerns
- Early screening
- Timely referral
- Comprehensive assessment
- Timely diagnosis

Figure 2.1: Conceptual Framework of the Study

[INDEPENDENT VARIABLES] → [INTERVENING VARIABLES] → [DEPENDENT VARIABLE]

CHAPTER THREE: METHODOLOGY

3.0 Introduction

This chapter describes the methodology used to develop this evidence-based research publication on the barriers to early identification of Autism Spectrum Disorder (ASD) among children living in low-resource communities in Kenya. It outlines the research approach, study context, sources of information, literature identification and review process, analytical approach, scope of the publication, limitations, and ethical considerations.

The methodology is designed to provide a systematic approach to examining the social, cultural, economic, healthcare, educational, and systemic factors that may contribute to delays in early autism identification and access to appropriate support.

The publication draws on existing research, academic literature, government documents, policy frameworks, reports from international organizations, and other credible sources relevant to autism, child development, disability inclusion, healthcare access, and inclusive education.

The evidence reviewed was used to identify key barriers, examine their interrelationships, and develop recommendations and proposed community-based responses that may contribute to strengthening early recognition, referral, assessment, and support for autistic children and their families.

3.1 Research Approach

This publication adopts an evidence-based literature review and analytical approach. It does not claim to present primary data collected directly from parents, caregivers, teachers, healthcare providers, community health workers, or other participants.

Instead, the publication synthesizes and analyses existing evidence relevant to barriers affecting early autism identification in low-resource communities in Kenya and comparable settings.

The approach focuses on examining evidence related to:

- Awareness and knowledge of autism.

- Recognition of early developmental concerns.

- Cultural beliefs and misconceptions.

- Stigma and discrimination.

- Financial and socioeconomic barriers.

- Access to healthcare and developmental assessment services.

- Availability of trained professionals.

- Referral systems and coordination of services.

- Inclusive education and school-based recognition.

- Experiences and support needs of families and caregivers.

- Community-based approaches to autism and disability inclusion.

This approach was selected because barriers to early autism identification are complex and interconnected. They may occur at individual, family, community, institutional, and systemic levels. Reviewing evidence from multiple perspectives therefore provides a broader understanding of the factors that may influence the pathway from initial recognition of developmental concerns to professional assessment and appropriate support.

3.2 Study Context

The publication focuses on low-resource communities in Kenya, with particular attention to informal and underserved urban communities such as Mathare, Kibera, and Soweto in Nairobi County.

These communities provide an important context for examining barriers to early autism identification because families may experience socioeconomic challenges that affect access to healthcare, education, developmental information, and specialized disability services.

Mathare, Kibera, and Soweto are used within this publication as important contextual examples of communities where families may face challenges associated with poverty, limited access to specialized services, high population density, and other socioeconomic vulnerabilities.

The publication does not claim that primary research data were collected from these communities. Rather, these communities provide a contextual focus for understanding how broader evidence on autism identification, disability inclusion, healthcare access, and community-based support may apply to underserved settings in Kenya.

The focus on low-resource communities is intended to support discussion of practical and community-responsive approaches that may strengthen awareness, early recognition, referral, and access to appropriate support.

3.3 Sources of Information

The publication draws on a range of secondary sources to develop an evidence-informed understanding of barriers to early autism identification.

These sources include:

- Peer-reviewed academic research.

- Government policies and reports.

- Publications from international organizations.

- Reports from disability and autism-focused organizations.

- Research on child development and early identification.

- Literature on inclusive education and disability inclusion.

- National and international policy frameworks.

- Reports addressing healthcare and disability services.

- Other credible published sources relevant to autism and developmental disabilities.

Priority was given to sources that provide information relevant to Kenya and other low-resource or comparable settings. Where Kenya-specific evidence was limited, relevant evidence from other African countries and comparable contexts was considered to provide broader perspectives on the challenges affecting early autism identification.

The sources were considered in relation to their relevance to the research topic, credibility, geographical context, and contribution to understanding the barriers affecting children and families.

3.4 Literature Identification and Review Process

Relevant literature and evidence were identified through searches of academic and publicly available sources addressing autism, early identification, developmental disabilities, inclusive education, disability inclusion, healthcare access, and low-resource communities.

The literature review focused on identifying evidence related to the major factors that may contribute to delays in recognizing developmental concerns and accessing appropriate assessment and support.

The reviewed evidence was organized into major thematic areas. These included awareness and knowledge, cultural beliefs, stigma, financial barriers, healthcare access, availability of trained professionals, referral systems, inclusive education, and community-based support.

The information obtained from the reviewed sources was compared and synthesized to identify recurring themes, relationships between different barriers, gaps in existing systems, and potential opportunities for intervention.

The evidence identified through the review informed the analysis presented in Chapter Four and the recommendations and proposed solutions presented in subsequent chapters.

3.5 Analytical Approach

The evidence reviewed in this publication was analysed using a thematic approach. Key themes were identified and organized according to the major barriers affecting early autism identification in low-resource communities.

The analysis considered how different barriers may interact with one another. For example, limited awareness may contribute to delayed recognition of developmental concerns, while stigma and cultural misconceptions may discourage families from seeking professional assessment. Financial constraints, geographical barriers, and limited availability of specialized services may further delay access to appropriate assessment and support.

The analysis therefore considers early autism identification as a process influenced by multiple interconnected factors at individual, family, community, institutional, and systemic levels.

The themes identified through the analysis were used to structure the findings and discussion in this publication. They also informed the recommendations, proposed community-based intervention model, and partnership and investment opportunities presented in Chapters Five and Six.

3.6 Scope of the Publication

The publication focuses primarily on barriers to early identification of Autism Spectrum Disorder among children living in low-resource communities in Kenya.

Particular attention is given to challenges affecting underserved communities where families may experience limited access to specialized healthcare, developmental assessment, education, and disability support services.

The publication considers the perspectives and roles of different stakeholders as represented in existing literature and evidence. These include:

- Parents and caregivers.

- Teachers and early childhood practitioners.

- Healthcare providers.

- Community health workers.

- Community-based organizations.

- Disability-focused organizations.

- Government institutions.

- Development and humanitarian organizations.

- Research and academic institutions.

The publication also considers the potential role of community-based organizations in strengthening autism awareness, caregiver empowerment, inclusive education, capacity-building, early recognition, referral, and connections to appropriate professional services.

3.7 Limitations of the Methodological Approach

This publication has several limitations that should be acknowledged.

First, the publication is based primarily on existing evidence and does not present original primary data collected directly from participants. Therefore, the findings should not be interpreted as statistical estimates of the prevalence of specific barriers within Mathare, Kibera, Soweto, or Kenya as a whole.

Second, the availability of Kenya-specific research on early autism identification in low-resource communities may be limited. Consequently, evidence from other African countries and comparable low-resource settings may be used to provide additional context.

Third, existing literature may not fully capture the experiences of all families living in underserved communities. Differences in culture, socioeconomic conditions, access to services, and local systems may influence how barriers are experienced in different communities.

These limitations highlight the importance of future primary research to generate locally specific evidence on the experiences of families, barriers to early identification, access to assessment services, referral pathways, and the effectiveness of community-based interventions in different Kenyan communities.

The publication should therefore be viewed as an evidence-informed foundation for further research, programme development, advocacy, partnership, and investment rather than as a substitute for primary field research.

3.8 Ethical Considerations

As this publication is based on existing literature, publicly available reports, policy documents, and other secondary sources, it does not involve direct recruitment of human participants or the collection of primary personal data.

Nevertheless, ethical principles remain important in the preparation and presentation of the publication. Sources should be accurately acknowledged and referenced, and evidence should be presented honestly and responsibly.

The publication also recognizes the importance of protecting the dignity, privacy, rights, and well-being of autistic children and persons with disabilities. Language used throughout the publication should promote respect, inclusion, and non-discrimination.

Care should be taken to avoid presenting autistic children, persons with disabilities, or families living in low-resource communities through stigmatizing or deficit-based narratives. The publication seeks to emphasize both the challenges faced by communities and the strengths, capacities, and opportunities for positive change.

Where future primary research is undertaken by ADIP Initiative or in partnership with other institutions, appropriate ethical approval, informed consent, safeguarding procedures, and data protection measures should be established before data collection begins.

3.9 Data Protection and Responsible Use of Evidence

Although the publication does not involve the collection of primary participant data, responsible handling of information remains important.

Information obtained from published sources should be represented accurately and should not be taken out of context in ways that could mislead readers. Where individual experiences or case examples are discussed from existing sources, appropriate attribution and ethical consideration should be maintained.

The publication should also ensure that information about children, families, and persons with disabilities is presented in a manner that protects dignity and avoids unnecessary disclosure of personal or identifying information.

3.10 Conclusion

This chapter has described the methodology used to develop this evidence-based research publication on barriers to early autism identification in low-resource communities in Kenya.

The publication uses an evidence-based literature review and thematic analytical approach to synthesize information from existing academic research, government documents, policy frameworks, international organizations, and other credible sources.

The evidence was examined across key themes, including awareness, cultural beliefs, stigma, financial barriers, healthcare access, professional capacity, referral systems, inclusive education, and community-based support.

The methodology provides a structured foundation for understanding the complex and interconnected factors that may contribute to delays in early autism identification. The findings and analysis presented in the following chapters are intended to inform recommendations, programme development, future research, and potential partnerships and investments in autism and disability inclusion.

While this publication does not claim to replace primary field research, it provides an evidence-informed foundation that can guide future research and practical action. Future primary research conducted in collaboration with relevant stakeholders can build upon the evidence presented here and generate locally specific data to further strengthen understanding of early autism identification in Kenya..

CHAPTER FOUR: FINDINGS AND ANALYSIS

4.0 Introduction

This chapter presents the key findings and analysis emerging from the evidence reviewed on barriers to early identification of Autism Spectrum Disorder (ASD) among children living in low-resource communities in Kenya.

The findings are organized thematically around the major factors identified through the review of existing literature, research, policy documents, and other relevant sources. These themes include limited awareness and knowledge of autism, cultural beliefs and misconceptions, stigma and discrimination, financial barriers, limited access to healthcare and specialized services, shortages of trained professionals, weak referral pathways, educational barriers, and limited community-based support.

The analysis demonstrates that delays in early autism identification are not caused by a single factor. Instead, multiple barriers interact across individual, family, community, healthcare, educational, and systemic levels.

Understanding these interconnected barriers is essential for developing practical and sustainable approaches that can improve early recognition, referral, assessment, and support for autistic children and their families.

4.1 Limited Awareness and Knowledge of Autism

One of the major barriers identified in the evidence is limited awareness and knowledge of autism among families and communities.

In many low-resource settings, parents and caregivers may have limited access to accurate information about autism and child development. Developmental differences may therefore be misunderstood or attributed to other causes. Some families may not recognize early signs related to communication, social interaction, behaviour, or development as possible indicators requiring further assessment.

Limited awareness can contribute to delays in seeking professional advice. When parents and caregivers do not have sufficient information about developmental milestones and early signs of autism, opportunities for early recognition may be missed.

The problem may also extend beyond families. Teachers, community workers, and other frontline individuals may have limited training in recognizing developmental concerns. This can reduce the likelihood that children will be identified and referred for further assessment when concerns first emerge.

The evidence therefore suggests that improving autism awareness should be considered an important component of efforts to strengthen early identification.

4.2 Cultural Beliefs and Misconceptions

Cultural beliefs and misconceptions may influence how developmental differences are understood within communities.

In some settings, autism and other developmental conditions may be explained through traditional, spiritual, or supernatural beliefs. Families may be encouraged to seek traditional or religious explanations and interventions before considering professional assessment.

Such beliefs should be understood within the social and cultural contexts in which families live. However, when misconceptions delay access to appropriate professional assessment, children may miss opportunities for early support.

Cultural beliefs may also influence how families communicate about developmental concerns. Fear of judgment, rejection, or community criticism may discourage some caregivers from openly discussing their children's developmental differences.

The evidence indicates the importance of culturally sensitive awareness programmes that provide accurate information without dismissing or disrespecting the cultural contexts of the communities being served.

4.3 Stigma and Discrimination

Stigma is another significant barrier that may affect early autism identification and access to support.

Families may experience negative attitudes, discrimination, social isolation, or judgment because of their child's developmental differences. In some cases, caregivers may fear that their child will be labelled or excluded if an autism diagnosis becomes known.

Stigma can influence help-seeking behaviour. Families who fear discrimination may delay seeking professional assessment or may avoid discussing developmental concerns with others.

Stigma may also affect children's participation in education and community activities. When communities lack understanding of autism, autistic children may be excluded from schools, social activities, or other opportunities for participation.Reducing stigma therefore requires more than providing information about autism. It requires broader community engagement that promotes acceptance, dignity, inclusion, and understanding of neurodevelopmental differences.

4.4 Financial and Socioeconomic Barriers

Financial constraints can significantly affect the pathway to early autism identification.

Families living in low-resource communities may face difficulties meeting the costs associated with transportation, medical consultations, developmental assessments, diagnostic services, and ongoing support.

Even when services are technically available, the associated costs may make them inaccessible to families with limited financial resources.

Parents and caregivers may also need to balance the cost of seeking services with other essential household needs, including food, housing, education, and healthcare.

These financial pressures can contribute to delayed assessment and may discourage families from continuing to seek support when services are expensive or difficult to access.

The evidence therefore suggests that improving early autism identification requires consideration of the broader socioeconomic conditions affecting families.

4.5 Limited Access to Healthcare and Specialized Services

Access to appropriate healthcare and specialized developmental services remains an important challenge.

Families in low-resource communities may have limited access to professionals with specialized knowledge of autism and developmental disabilities. Services may be concentrated in urban centres or private facilities, creating geographical and financial barriers for families living in underserved areas.

Long distances, transportation costs, waiting times, and limited availability of specialized services may all contribute to delays.

In addition, some families may move between different service providers before receiving appropriate guidance. This can create a fragmented pathway in which developmental concerns are identified but not effectively connected to assessment and support.

Strengthening access to appropriate services and improving connections between community-level support and professional services may therefore contribute to earlier identification.

4.6 Shortage of Trained Professionals

The availability of adequately trained professionals is an important factor influencing early autism identification.

Autism identification may involve professionals from different sectors, including healthcare, education, psychology, developmental services, and disability support. Where there are insufficient numbers of trained professionals, families may experience delays in accessing assessment.

Limited professional capacity may also affect the ability of frontline workers to recognize developmental concerns and provide appropriate referrals.

Strengthening capacity among healthcare providers, teachers, community health workers, and other relevant stakeholders may therefore improve the early recognition of developmental concerns.

However, training should be accompanied by clear referral pathways and access to qualified professionals who can undertake appropriate assessment and provide further guidance.

4.7 Weak Referral Pathways

The evidence also highlights the importance of effective referral systems.

Recognizing a developmental concern is only the first step. Families need clear information about where to seek further assessment and support.

In some settings, referral systems may be fragmented or poorly coordinated. Parents may not know where to go after a teacher, community worker, or healthcare provider raises a concern.

Weak referral pathways can result in families becoming lost within the system or experiencing repeated delays before reaching appropriate services.

A stronger referral system should connect communities, families, schools, healthcare providers, qualified assessment professionals, and disability support organizations.

4.8 The Role of Schools and Teachers

Schools and teachers have an important role in early recognition because they interact with children regularly and may observe developmental differences that are not immediately recognized at home.

Teachers may notice differences in communication, social interaction, behaviour, learning, or participation.

However, teachers may not always have sufficient knowledge or training to identify possible developmental concerns or understand appropriate referral procedures.

Strengthening teacher capacity can therefore contribute to earlier recognition. Inclusive education training can help teachers understand developmental diversity, communicate concerns sensitively with families, and support children while appropriate professional assessment is pursued.

Schools can also serve as important points for awareness and referral, particularly in communities where families may have limited access to specialized healthcare services.

4.9 The Role of Community-Based Organizations

Community-based organizations can play an important role in addressing some of the barriers identified in this publication.

Organizations working within communities may be well positioned to provide autism awareness, caregiver education, teacher training, community outreach, and connections to available services.

Their proximity to families can help reduce information gaps and create more accessible pathways to support.

However, community-based organizations should not be expected to replace qualified diagnostic or clinical services. Their role can instead complement existing systems by strengthening awareness, supporting families, facilitating appropriate referrals, and building community capacity.

This highlights the importance of partnerships between community organizations, professional service providers, schools, government institutions, and development partners.

4.10 Interconnected Nature of the Barriers

The findings demonstrate that the barriers affecting early autism identification are interconnected.

For example, limited awareness may delay recognition of developmental concerns. When combined with cultural misconceptions and stigma, families may be less likely to seek professional assessment.

If families do seek help, financial constraints and limited access to specialized professionals may create additional delays. Weak referral systems may then make it difficult for families to navigate the available services.

These interconnected barriers can create a cycle of delayed recognition, delayed assessment, and delayed access to appropriate support.

The findings therefore suggest that isolated interventions are unlikely to address the full complexity of the problem. A comprehensive response should address multiple levels simultaneously.

4.11 Summary of Key Findings

The evidence reviewed in this publication identifies the following major barriers to early autism identification in low-resource communities:

Key Barrier verses Potential Effect

●Limited autism awareness 》》》 Delayed recognition of developmental concerns

●Limited knowledge of early signs 》》》 Reduced early help-seeking

●Cultural misconceptions 》》》 Delayed professional assessment

●Stigma and discrimination 》》》 Reluctance to seek or disclose support

●Financial constraints 》》》 Reduced access to assessment and services

●Limited specialized services 》》》 Long delays and geographical barriers

●Shortage of trained professionals 》》》 Reduced capacity for early recognition and assessment

●Weak referral pathways 》》》 Families may struggle to navigate available services

●Limited teacher training|》》》 Missed opportunities for school-based recognition

●Fragmented support systems 》》》 Delays in connecting families to appropriate services

●Limited community-based support 》》》 Reduced access to information and caregiver support

4.12 Conceptual Interpretation of the Findings

The findings support the conceptual framework presented earlier in the publication, which proposes that early autism identification is influenced by a combination of independent, intervening, and dependent factors.

The independent variables include awareness and knowledge, cultural beliefs, stigma, socioeconomic conditions, access to healthcare, professional capacity, and referral systems.

These factors may influence intervening variables, including caregiver recognition of developmental concerns, help-seeking behaviour, access to information, interaction with healthcare and education systems, and the ability to navigate referral pathways.

These processes ultimately influence the dependent variable, which is the timeliness of early autism identification and access to appropriate assessment and support.

The relationship can therefore be represented as:

Independent Variables → Intervening Variables → Dependent Variable

Independent Variables:

- Autism awareness and knowledge
- Cultural beliefs and misconceptions
- Stigma and discrimination
- Socioeconomic and financial conditions
- Access to healthcare services
- Availability of trained professionals
- Referral systems
- School and teacher capacity

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Intervening Variables:

- Recognition of developmental concerns

- Caregiver understanding

- Help-seeking behaviour

- Access to information

- Service navigation

- Communication between families and professionals

- Referral uptake

↓

Dependent Variable:

- Timeliness of early autism identification and access to appropriate assessment and support

This framework demonstrates that early autism identification is not determined by a single factor. Rather, it is the outcome of a complex pathway in which individual, family, community, institutional, and systemic factors interact.

4.13 Conclusion

The findings presented in this chapter demonstrate that barriers to early autism identification in low-resource communities are multidimensional and interconnected.

Limited awareness, cultural beliefs, stigma, financial constraints, limited access to specialized services, shortages of trained professionals, weak referral systems, and gaps in inclusive education can collectively contribute to delays in recognizing developmental concerns and connecting families to appropriate support.

The findings emphasize the need for coordinated interventions that operate across multiple levels. Community awareness and caregiver empowerment should be combined with professional capacity-building, stronger referral systems, inclusive education, improved access to services, and strategic partnerships.

These findings provide the basis for the recommendations presented in Chapter Five and the proposed programme and partnership framework presented in Chapter Six.

CHAPTER FIVE: RECOMMENDATIONS

5.0 Introduction

The findings presented in Chapter Four demonstrate that barriers to early identification of Autism Spectrum Disorder (ASD) in low-resource communities are complex and interconnected. Limited awareness, cultural misconceptions, stigma, financial constraints, limited access to specialized services, shortages of trained professionals, weak referral pathways, and gaps in inclusive education may collectively contribute to delays in recognizing developmental concerns and accessing appropriate support.

Addressing these challenges requires a coordinated approach involving families, communities, schools, healthcare providers, government institutions, community-based organizations, disability organizations, research institutions, funders, and development partners.

This chapter presents recommendations aimed at strengthening early recognition, referral, assessment, and support for autistic children and their families in low-resource communities in Kenya.

5.1 Strengthen Community-Based Autism Awareness

There is a need to expand autism awareness programmes within underserved communities. Awareness initiatives should provide clear, accurate, and culturally appropriate information about autism, developmental milestones, early signs, and the importance of seeking professional guidance when developmental concerns arise.

Community awareness programmes should use accessible channels such as community meetings, schools, churches, mosques, social media, local leaders, community health workers, and community-based organizations.

Awareness should focus not only on autism but also on reducing stigma and promoting acceptance, dignity, and inclusion.

5.2 Empower Parents and Caregivers

Parents and caregivers should be provided with reliable information and practical support to help them understand child development and recognize potential developmental concerns.

Caregiver empowerment programmes should include information on:

- Developmental milestones.

- Early signs of autism and other developmental differences.

- When and where to seek professional guidance.

- Available referral pathways.

- Supporting children's learning and participation at home.

- Navigating education and disability support systems.

- Advocating for children's rights and inclusion.

Caregivers should also have opportunities to participate in peer support networks where they can share experiences and access reliable information.

5.3 Strengthen Early Recognition at Community Level

Community-level systems should be strengthened to support the early recognition of developmental concerns.

Community health workers, early childhood practitioners, teachers, and other frontline actors should receive appropriate training to recognize potential developmental differences and understand when and how to recommend professional assessment.

It is important that community-level recognition does not replace professional diagnosis. Instead, it should serve as an early identification and referral mechanism that helps families access qualified professionals.

5.4 Build the Capacity of Teachers and Schools

Schools and teachers should be supported to play a stronger role in early recognition and inclusion.

Training programmes should equip teachers with practical knowledge about:

- Autism and developmental differences.

- Early developmental signs.

- Inclusive classroom practices.

- Communication and behavioural support strategies.

- Working collaboratively with parents and caregivers.

- Appropriate referral procedures.

- Reducing stigma and discrimination in schools.

Schools should also develop stronger partnerships with families and relevant professional and community organizations.

5.5 Strengthen Referral Pathways

Clear and coordinated referral pathways should be established between communities, schools, healthcare providers, qualified assessment professionals, and disability support organizations.

Families should receive clear information about where they can seek further assessment when developmental concerns are identified.

Community-based organizations can contribute by helping families navigate referral systems and connecting them with appropriate professional services.

A coordinated referral pathway can reduce the risk of families becoming lost within fragmented systems.

5.6 Improve Access to Professional Assessment and Support

Efforts should be made to increase access to qualified professionals who

can provide appropriate developmental assessment and support.

This may require investment in:

- Training and professional development.

- Decentralization of relevant services.

- Community outreach services.

- Referral networks.

- Collaboration between public and private providers.

- Partnerships with professional associations and institutions.

Any community-based identification programme should clearly distinguish between recognizing developmental concerns and providing a forma

diagnosis. Diagnosis and clinical assessment should remain within the scope of appropriately qualified professionals.

5.7 Address Financial and Socioeconomic Barriers

Financial barriers should be considered when designing autism and disability inclusion programmes.

Potential strategies may include:

- Community-based awareness and outreach programmes.

- Affordable access to information and caregiver education.

- Partnerships that support transportation or referral costs where appropriate.

- Strengthening connections to existing social protection programmes.

- Advocacy for accessible and affordable developmental assessment services.

Programmes should be designed with the realities of low-income families in mind to ensure that support does not remain accessible only to families with greater financial resources.

5.8 Reduce Stigma and Promote Inclusion

Autism awareness programmes should actively address stigma and misconceptions.

Communities should be encouraged to understand autism as a neurodevelopmental condition and to recognize the rights and abilities of autistic children and persons with disabilities.

Anti-stigma initiatives should involve families, schools, community leaders, faith-based organizations, healthcare providers, media platforms, and other influential community actors.

The goal should be to create communities where families feel safe seeking information and support without fear of judgment or discrimination.

5.9 Strengthen Community-Based Organizations

Community-based organizations can play an important role in bridging the gap between families and formal systems.

Organizations working in underserved communities should be supported to develop capacity in:

- Autism awareness.

- Caregiver empowerment.

- Inclusive education.

- Community outreach.

- Referral support.

- Advocacy.

- Data collection and programme monitoring.

- Partnership development.

However, community organizations should operate within appropriate professional and ethical boundaries and should establish referral relationships with qualified professionals and institutions.

5.10 Promote Cross-Sector Collaboration

Addressing barriers to early autism identification requires collaboration across multiple sectors.

Government institutions, healthcare providers, schools, universities, research organizations, disability organizations, community-based organizations,

development partners, and funders should work together to strengthen systems of support.

Partnerships should focus on shared priorities such as:

- Community awareness.

- Capacity-building.

- Research.

- Referral systems.

- Inclusive education.

- Professional training.

- Caregiver support.

- Service accessibility.

- Programme evaluation.

Cross-sector collaboration can help reduce duplication, strengthen coordination, and make better use of available resources.

5.11 Invest in Research and Local Evidence

There is a need for more locally generated research on autism and developmental disabilities in Kenya.

Future research should examine:

- Experiences of parents and caregivers.

- Barriers to early recognition.

- Access to developmental assessment.

- Experiences with referral systems.

- Teacher knowledge and preparedness.

- Community attitudes towards autism.

- The role of community health workers.

- The effectiveness of community-based interventions.

- Regional differences in access to services.

Research should include the voices of families and, where appropriate and ethically feasible, autistic people themselves.

Locally generated evidence can support better programme design, policy development, advocacy, and resource allocation.

5.12 Strengthen Monitoring, Evaluation, and Learning

Organizations implementing autism and disability inclusion programmes should establish clear systems for monitoring progress and measuring outcomes.

Monitoring frameworks should include relevant indicators such as:

- Number of individuals reached through awareness programmes.

- Number of caregivers receiving education and support.

- Number of teachers and frontline workers trained.

- Number of children identified as requiring further professional assessment.

- Number of appropriate referrals made.

- Number of families successfully connected to services.

- Changes in knowledge and attitudes.

- Changes in caregiver confidence.

- Development of new partnerships and referral networks.

Programme monitoring should be used not only to demonstrate impact to funders but also to improve programme quality and accountability.

5.13 Increase Investment in Autism and Disability Inclusion

Funders, development partners, corporations, and other institutions should consider investing in autism and disability inclusion programmes within underserved communities.

Investment priorities may include:

- Community awareness.

- Caregiver empowerment.

- Teacher training.

- Inclusive education.

- Community outreach.

- Professional capacity-building.

- Referral systems.

- Research and evidence generation.

- Organizational strengthening.

- Programme monitoring and evaluation.

Investment should prioritize sustainable approaches that strengthen local capacity rather than creating programmes that depend entirely on short-term external support.

5.14 Support Community-Based Innovation

There is a need to encourage innovative approaches that bring information, support, and referral guidance closer to families.

Potential approaches may include:

- Community autism awareness campaigns.

- Parent and caregiver support groups.

- Teacher capacity-building programmes.

- Community-based developmental

awareness initiatives.

- Digital information platforms.

- Partnerships between schools and community organizations.

- Mobile outreach programmes.

- Community referral networks.

Such innovations should be appropriately evaluated to determine their effectiveness, sustainability, and potential for scaling.

5.15 Recommendations for ADIP Initiative

Based on the evidence reviewed, ADIP Initiative may consider prioritizing the following areas as part of its future

programme development:

1. Establishing structured community autism awareness programmes.

2. Developing caregiver education and empowerment initiatives.

3. Expanding inclusive education and teacher capacity-building programmes.

4. Strengthening partnerships with qualified healthcare and developmental professionals.

5. Developing formal referral networks for families.

6. Conducting community outreach in underserved areas.

7. Building relationships with

universities and research institutions.

8. Developing monitoring and evaluation systems to document programme outcomes.

9. Seeking strategic partnerships with funders and development organizations.

10. Generating locally relevant evidence through future primary research.

These priorities should be implemented progressively according to available resources, organizational capacity, community needs, and professional partnerships.

5.16 Conclusion

The barriers to early autism identification identified in this publication require coordinated and sustained action.

Improving awareness alone will not be sufficient if families cannot access professional assessment. Similarly, increasing professional capacity will have limited impact if families are unable to recognize developmental concerns or navigate referral systems.

A comprehensive approach should therefore combine community awareness, caregiver empowerment, teacher training, professional capacity-building, accessible referral pathways, inclusive education, stigma reduction,

research, and strategic investment.

The recommendations presented in this chapter provide a framework for action by different stakeholders. Their implementation will require collaboration, sustainable funding, strong partnerships, ongoing evaluation, and commitment to the rights and inclusion of autistic children and their families.

The next chapter builds on these recommendations by presenting a proposed community-based response and identifying opportunities for partnership, investment, and collaboration.

CHAPTER SIX: PROPOSED COMMUNITY-BASED RESPONSE AND PARTNERSHIP OPPORTUNITIES

6.0 Introduction

The findings and recommendations presented in the preceding chapters demonstrate the need for practical, coordinated, and sustainable approaches to addressing barriers to early autism identification in low-resource communities in Kenya.

While awareness and early recognition are important, meaningful change requires a broader response that connects families and communities to appropriate information, education, professional services, inclusive learning opportunities, and referral pathways.

This chapter presents a proposed community-based response designed to complement existing health, education, disability, and social support systems. The proposed approach recognizes that community-based organizations can play an important role in bridging gaps between families and formal services, particularly in underserved communities where access to specialized support may be limited.

The proposed response is informed by the barriers identified in this publication and focuses on strengthening community awareness, caregiver empowerment, inclusive education, capacity-building, early recognition, referral support, and strategic partnerships.

The approach is not intended to replace professional diagnostic or clinical services. Instead, it seeks to strengthen community-level systems that can help families recognize developmental concerns earlier,

access reliable information, navigate referral pathways, and connect with qualified professionals and appropriate support services.

For ADIP Initiative, the proposed response provides a framework for developing partnerships with funders, government institutions, healthcare providers, schools, universities, professional organizations, disability organizations, corporations, and development partners.

6.1 Proposed Community-Based Response

Based on the evidence and recommendations presented in this publication, a coordinated community-based model is proposed to address barriers to early autism identification and support in underserved communities.

The proposed model is based on the understanding that early identification is a pathway rather than a single event. Families need access to information, recognition of developmental concerns, appropriate referral, professional assessment, and continued support.

The proposed community-based response therefore seeks to strengthen the pathway through five interconnected areas:

1. Community Awareness and Early Recognition

2. Caregiver Empowerment and Family Support

3. Inclusive Education and Teacher Capacity-Building

4. Referral and Professional Linkages

5. Research, Advocacy, and Community Systems Strengthening

The model is intended to complement existing services and create stronger connections between communities and formal systems of healthcare, education, and disability support.

6.2 Community Awareness and Early Recognition

The first component of the proposed response is to increase awareness of autism and developmental differences within underserved communities.

Community awareness activities may include:

- *Autism awareness forums.*

- *Parent and caregiver education sessions.*

- *Community outreach activities.*

- *Information sessions in schools.*

- Awareness through faith-based and community institutions.

- Social media and digital awareness campaigns.

- Distribution of accessible educational materials.

- Community dialogues addressing stigma and misconceptions.

The aim is to ensure that parents, caregivers, teachers, community health workers, and other frontline community members have access to accurate and understandable information about child development and possible early signs of autism.

The programme will emphasize that recognizing developmental concerns does not constitute a diagnosis. Instead, early recognition should encourage families to seek appropriate professional guidance and assessment.

6.3 Caregiver Empowerment and Family Support

Parents and caregivers are central to the early identification and support of children with developmental differences.

The proposed response will therefore prioritize caregiver empowerment through structured education and support programmes.

Key areas may include:

- Understanding developmental milestones.

- Recognizing possible early signs of autism.

- Understanding the importance of seeking professional assessment.

- Navigating referral and support systems.

- Supporting children's communication and learning at home.

- Understanding inclusive education.

- Advocacy for children's rights.

- Managing stigma and social challenges.

- Connecting families with available community resources.

Where appropriate, caregiver support groups may also be developed to provide opportunities for families to share experiences, access reliable information, and build peer support networks.

The goal is to ensure that families are not left to navigate autism and developmental concerns alone.

6.4 Inclusive Education and Teacher Capacity-Building

Schools are important environments for identifying developmental concerns and supporting children's participation and learning.

The proposed response will support schools and teachers through inclusive education training and capacity-building programmes.

Training areas may include:

- *Understanding autism and neurodevelopmental differences.*

- *Recognizing possible developmental concerns.*

- *Supporting communication and participation.*

- *Classroom inclusion strategies.*

- *Managing sensory needs.*

- *Positive behaviour support.*

- *Individualized learning approaches.*

- *Working collaboratively with parents and caregivers.*

- *Appropriate referral procedures.*

- *Reducing stigma and exclusion in schools.*

The programme may also support schools in developing stronger links with families, community organizations, and relevant professionals.

The aim is not to turn teachers into diagnosticians, but to equip them with knowledge and practical strategies to recognize concerns, support inclusion, and guide families towards appropriate professional services.

6.5 Community-Based Capacity-Building

A sustainable response requires strengthening the capacity of people who are already present within communities.

The proposed programme may provide training and capacity-building for:

- Community health workers.

- Teachers and early childhood practitioners.

- Parents and caregivers.

- Community leaders.

- Faith-based organizations.

- Community-based organizations.

- Disability advocates.

- Other frontline community actors.

Training will focus on autism awareness, developmental differences, inclusion, stigma reduction, early recognition, appropriate referral, and safeguarding.

Community-level capacity-building can help create a network of informed individuals who are better equipped to respond to families experiencing developmental concerns.

6.6 Referral and Professional Linkages

A major component of the proposed response is the development of stronger referral connections between communities and qualified professionals.

The programme will seek to establish partnerships and referral linkages with relevant professionals and institutions, including:

- Paediatricians.

- Developmental specialists.

- Psychologists.

- Speech and language professionals.

- Occupational therapy professionals.

- Special needs education specialists.

- Audiology and hearing services.

- Healthcare facilities.

- Assessment and diagnostic centres.

- Inclusive schools and education institutions.

Community-based organizations will not replace these professional services. Instead, their role will be to help families understand available pathways and connect them with appropriate providers.

A structured referral network can reduce confusion, improve coordination, and support families in moving from initial concern to appropriate assessment and intervention.

6.7 Community Outreach and Early Identification Campaigns

The proposed response may include targeted outreach activities in underserved communities.

Outreach activities could involve:

- Community developmental awareness days.

- Autism awareness campaigns.

- Parent education forums.

- School-based awareness activities.

- Teacher training sessions.

- Community health worker engagement.

- Referral information sessions.

- Collaboration with local leaders and institutions.

These activities should be implemented in ways that are culturally appropriate, accessible, and responsive to the realities of low-income families.

The focus should be on bringing information and support closer to communities while maintaining clear boundaries between community-level awareness and professional diagnosis.

6.8 Research and Evidence Generation

The proposed response recognizes the importance of generating locally relevant evidence.

ADIP Initiative and potential research partners may undertake future primary research to better understand:

- Experiences of parents and caregivers.

- Barriers to early autism identification.

- Community attitudes towards autism.

- Teacher knowledge and preparedness.

- Healthcare provider experiences.

- Effectiveness of referral pathways.

- Access to assessment and support services.

- Outcomes of community-based interventions.

Future research should follow appropriate ethical and research standards and may be conducted in collaboration with universities, research institutions, government agencies, and other relevant partners.

Generating local evidence will help strengthen programme design, advocacy, policy engagement, and resource mobilization.

6.9 Proposed Implementation Approach

The proposed response may be implemented progressively, beginning with selected underserved communities and expanding based on available resources, partnerships, evidence, and demonstrated impact.

A potential implementation process may involve:

Phase One: Community Engagement and Assessment

- Identify priority communities.

- Engage local stakeholders.

- Map available services and referral pathways.

- Identify existing gaps and community priorities.

Phase Two: Awareness and Capacity-Building

- Conduct community awareness activities.

- Train caregivers and frontline community actors.

- Provide inclusive education training for teachers.

- Establish community support networks.

Phase Three: Referral and Partnership Development

- Establish referral relationships with qualified professionals.

- Develop partnerships with healthcare and education institutions.

- Strengthen connections between families, schools, and service providers.

Phase Four: Programme Monitoring and Learning

- Track programme activities and outputs.

- Document lessons learned.

- Monitor changes in awareness and knowledge.

- Evaluate referral outcomes.

- Collect feedback from families and stakeholders.

Phase Five: Expansion and Scale

- Use evidence and lessons learned to strengthen the programme.

- Expand to additional underserved communities.

- Develop long-term partnerships.

- Mobilize sustainable funding.

This phased approach allows the programme to grow responsibly while ensuring that implementation remains responsive to community needs and available capacity.

6.10 Expected Outcomes

If implemented effectively and supported through strategic partnerships, the proposed response is expected to contribute to:

- Increased community awareness of autism.

- Improved understanding of developmental milestones.

- Earlier recognition of developmental concerns.

- Increased caregiver knowledge and confidence.

- Reduced stigma and misconceptions.

- Increased teacher knowledge of autism and inclusive education.

- Improved community-level capacity to support families.

- Stronger referral pathways.

- Improved connections between families and qualified professionals.

- Increased access to inclusive education support.

- Stronger collaboration between community organizations and formal service providers.

- Increased generation of locally relevant evidence.

- Greater visibility of autism and disability inclusion within underserved communities.

These outcomes are expected to contribute to a stronger pathway from early recognition to appropriate assessment, support, and inclusion.

6.11 Potential Impact

The long-term goal of the proposed response is to contribute to a system in which children with developmental differences are recognized earlier and families are better supported to access appropriate services.

At the child level, earlier recognition may create opportunities for timely support and improved participation in education and community life.

At the family level, improved access to information and support may strengthen caregiver confidence and reduce isolation.

At the community level, increased awareness may contribute to reduced stigma and greater acceptance of autistic children and persons with disabilities.

At the systems level, stronger partnerships and referral pathways may contribute to better coordination between communities, schools, healthcare providers, disability organizations, and other stakeholders.

The proposed approach therefore seeks to contribute to broader disability inclusion and improved opportunities for children and families living in underserved communities.

6.12 Partnership and Investment Opportunities

Addressing barriers to early autism identification requires resources, expertise, collaboration, and long-term commitment.

ADIP Initiative seeks to develop strategic partnerships with organizations and institutions that share a commitment to autism inclusion, disability rights, child development, inclusive education, and community empowerment.

Potential partners may include:

- Government institutions.

- International and local NGOs.

- Foundations and philanthropic organizations.

- Corporate social responsibility programmes.

- Healthcare institutions.

- Universities and research institutions.

- Professional associations.

- Schools and education networks.

- Technology organizations.

- Disability-focused organizations.

- Autism organizations.

- Community-based organizations.

- Development partners.

Potential areas for partnership and investment include:

A. Community Autism Awareness

Supporting campaigns and outreach activities that increase understanding of autism and developmental differences.

B. Caregiver Empowerment

Supporting parent education, caregiver training, peer support, and family empowerment programmes.

C. Inclusive Education

Supporting teacher training, school capacity-building, inclusive learning environments, and school-based awareness.

D. Community Outreach

Supporting outreach activities that bring information and referral guidance closer to underserved families.

E. Professional Capacity-Building

Supporting training and knowledge development among teachers, community workers, and relevant frontline professionals.

F. Referral and Service Linkages

Supporting the development of structured referral networks connecting families to qualified professionals and appropriate services.

G. Research and Evidence Generation

Supporting research that generates locally relevant evidence on autism and disability inclusion in Kenya.

H. Organizational Strengthening

Supporting the development of systems, staff capacity, monitoring and evaluation, safeguarding, and programme management.

I. Innovation and Technology

Supporting digital tools and innovative approaches that improve access to information, caregiver education, referral guidance, and community engagement.

6.13 Why Partnership Matters

The scale and complexity of barriers to early autism identification cannot be addressed by one organization working alone.

Community-based organizations bring proximity to families and knowledge of local contexts. Healthcare providers bring professional expertise. Schools provide access to children and opportunities for early recognition. Universities and research institutions contribute evidence and technical knowledge. Government institutions provide policy direction and systems support. Funders and development partners provide resources that enable programmes to reach more communities and become sustainable.

Strategic collaboration can therefore create a stronger and more coordinated response than isolated interventions.

ADIP Initiative seeks to position itself as a community-level partner capable of contributing to this broader ecosystem through autism awareness, caregiver empowerment, inclusive education, capacity-building, community outreach, advocacy, and referral support.

6.14 Proposed Partnership Model

ADIP Initiative proposes a partnership model based on shared objectives, complementary expertise, and measurable outcomes.

Depending on the partner's mandate and resources, collaboration may take different forms, including:

- Financial support.

- Technical assistance.

- Training partnerships.

- Research collaboration.

- In-kind support.

- Professional referral partnerships.

- Equipment and resource support.

- Joint community outreach.

- Staff and volunteer capacity-building.

- Programme sponsorship.

- Monitoring and evaluation support.

Partnerships should be guided by clear roles, agreed objectives, appropriate safeguarding standards, transparent reporting, and measurable outcomes.

6.15 Sustainability and Scale

For the proposed response to achieve long-term impact, sustainability should be considered from the beginning.

The programme should prioritize strengthening local capacity rather than creating systems that depend entirely on external support.

Sustainability strategies may include:

- Developing local partnerships.

- Building caregiver and community leadership.

- Strengthening organizational systems.

- Diversifying funding sources.

- Developing evidence of programme impact.

- Establishing long-term referral partnerships.

- Investing in staff and volunteer capacity.

- Using monitoring and evaluation to demonstrate results.

- Developing scalable community-based models.

Successful approaches can be documented and adapted for implementation in other underserved communities across Kenya.

6.16 Call for Partnership and Investment

The evidence presented in this publication demonstrates the urgent need for stronger systems that support early recognition, referral, assessment, and inclusion of autistic children in low-resource communities.

ADIP Initiative invites organizations, institutions, funders, development partners, professionals, and individuals committed to disability inclusion to explore opportunities for collaboration.

Partnership can support the development of community-based solutions that bring reliable information closer to families, strengthen caregiver capacity, improve inclusive education, build community knowledge, and connect families to appropriate professional services.

The proposed response represents an opportunity to move from identifying the problem to investing in practical, locally grounded solutions.

By working together, partners can contribute to building communities where developmental differences are recognized with understanding, families are supported rather than stigmatized, and autistic children have greater opportunities to participate, learn, and thrive.

6.17 Conclusion

This chapter has presented a proposed community-based response to the barriers affecting early autism identification in low-resource communities in Kenya.

The proposed approach emphasizes community awareness, caregiver empowerment, inclusive education, capacity-building, professional referral linkages, research, advocacy, and strategic partnerships.

The approach recognizes that meaningful progress requires collaboration between communities and formal systems of healthcare, education, disability support, research, government, and development.

For ADIP Initiative, the proposed response provides a framework for engaging potential partners and investors around practical areas of shared interest. It also provides a foundation for future programme development, pilot implementation, research, monitoring, and scale.

Ultimately, the goal is to contribute to a stronger and more inclusive system in which children with developmental differences are recognized earlier, families receive appropriate information and support, and autistic children are given greater opportunities to participate and thrive.

The final chapter presents the overall conclusion of the publication and outlines the way forward for research, policy, programming, advocacy, partnership, and investment.

CHAPTER SEVEN: CONCLUSION AND WAY FORWARD

7.0 Introduction

This chapter provides the overall conclusion of the publication on barriers to early identification of Autism Spectrum Disorder (ASD) among children living in low-resource communities in Kenya. It brings

together the key issues identified throughout the publication and highlights the implications for policy, practice, research, advocacy, partnership, and investment.

The publication has demonstrated that delayed autism identification is a complex issue influenced by multiple interconnected factors. These include limited awareness, inadequate knowledge of early developmental signs, cultural beliefs and misconceptions, stigma and discrimination, financial challenges, limited access to healthcare and specialized services, shortages of trained professionals, weak referral pathways, and gaps in inclusive education.

The chapter concludes by outlining the way forward and emphasizing the need for coordinated, community-based, evidence-informed, and sustainable action.

7.1 Overall Conclusion

Early identification of autism is an important component of ensuring that children and families can access appropriate information, assessment, support, education, and inclusion. However, for many families living in low-resource communities in Kenya, the pathway from recognizing developmental concerns to accessing appropriate professional services may be difficult and delayed.

The evidence reviewed in this publication demonstrates that the challenges affecting early autism identification do not exist in isolation. Limited awareness may delay recognition of developmental differences, while cultural misconceptions and stigma may influence whether families seek professional guidance. Financial constraints and limited access to specialized services may further delay assessment, while weak referral systems may make it difficult for families to navigate available services.

The problem therefore requires a comprehensive response that addresses multiple levels simultaneously.

Communities need access to accurate information. Parents and caregivers need to be empowered to recognize developmental concerns and seek appropriate guidance. Teachers and community-level workers require capacity-building to identify possible developmental differences and support appropriate referrals. Healthcare and professional systems need stronger capacity and accessibility. Schools need to strengthen inclusive practices, while government institutions, organizations, and development partners need to work together to create sustainable systems of support.

Early identification should also be understood as part of a broader commitment to the rights, dignity, participation, and inclusion of autistic children and persons with disabilities.

The objective should not simply be to identify autism earlier, but to ensure that early recognition leads to meaningful opportunities for support, learning, participation, and inclusion.

7.2 Key Messages

Several key messages emerge from this publication.

7.2.1 Early Identification Requires Community Awareness

Families cannot seek appropriate support if they do not have access to reliable information about child development and autism.

Community awareness is therefore an important starting point for improving early recognition.

7.2.2 Parents and Caregivers Are Central to the Process

Parents and caregivers are often among the first people to observe developmental differences in children. Empowering caregivers with accurate information can strengthen early recognition and appropriate help-seeking.

Caregivers should be viewed as important partners in early identification and support rather than passive recipients of services.

7.2.3 Community-Based Action Is Important

Community-based organizations can help bridge gaps between families and formal systems.

By providing awareness, education, capacity-building, advocacy, and referral support, community organizations can contribute to stronger pathways for families living in underserved communities.

However, community-based organizations should complement rather than replace qualified professional assessment and diagnostic services.

7.2.4 Early Recognition Must Be Linked to Appropriate Services

Identifying developmental concerns is only one part of the process.

Families also need accessible pathways to qualified professionals, assessment, education, support, and appropriate services. Without effective referral systems, early recognition may not result in meaningful support.

7.2.5 Inclusive Education Must Be Part of the Response

Schools have an important role in recognizing developmental differences and supporting children.

Strengthening teacher capacity and inclusive education practices can help ensure that autistic children are supported to participate and learn within appropriate educational environments.

7.2.6 Partnerships Are Essential

The complexity of the challenges identified in this publication means that no single organization can address them alone.

Sustainable progress requires collaboration between communities, families, schools, healthcare providers, government institutions, universities, research organizations, disability organizations, community-based organizations, funders, and development partners.

7.2.7 Local Evidence Is Needed

Although existing evidence provides valuable insights, there remains a need for more locally generated research on autism identification and support in Kenya.

Future research should prioritize the experiences of families and communities and should generate evidence that can inform policies, programmes, and investment decisions.

7.3 Implications for Policy and Practice

The findings of this publication have important implications for policy and practice.

7.3.1 Strengthening National and County-Level Systems

Government institutions should continue strengthening systems that support early childhood development, disability inclusion, autism awareness, healthcare access, and inclusive education.

Policies should be supported by practical implementation strategies and adequate resources.

County-level systems should also be strengthened to ensure that families living in underserved communities are not excluded from available services.

7.3.2 Strengthening Community-Level Awareness

Policies and programmes should recognize the importance of community-based awareness and early recognition.

Community health workers, teachers, community organizations, and other frontline actors can play important roles in connecting families with information and appropriate referral pathways.

7.3.3 Improving Referral and Coordination

There is a need for clearer coordination between community-level actors, schools, healthcare providers, disability organizations, and qualified professionals.

A stronger referral system can help reduce delays and improve continuity of support.

7.3.4 Supporting Inclusive Education

Inclusive education policies and programmes should be accompanied by practical teacher training, appropriate learning support, and stronger collaboration between schools and families.

Teachers should have access to the knowledge and resources needed to support children with diverse developmental and learning needs.

7.3.5 Addressing Stigma

Policy and practice should include strategies to reduce stigma and promote acceptance.

Autism awareness should be integrated into broader disability inclusion and community education efforts.

7.4 Implications for Research

The evidence reviewed in this publication highlights several areas requiring further research.

Future research in Kenya should explore:

- The experiences of parents and caregivers during the pathway to autism identification.

- Community knowledge and attitudes towards autism.

- The role of cultural beliefs in help-seeking behaviour.

- The impact of stigma on families.

- The accessibility and affordability of assessment services.

- The availability of qualified professionals.

- The effectiveness of referral systems.

- Teacher knowledge and preparedness.

- The role of community health workers.

- The effectiveness of community-based autism awareness programmes.

- Regional differences in access to autism services.

- The experiences of autistic people and their families.

- The effectiveness and sustainability of inclusive education approaches.

Research should seek to generate evidence that is relevant to the realities of Kenyan communities.

Where appropriate, research should use participatory approaches that meaningfully involve families, autistic people, disability organizations, and community stakeholders.

Future studies should also ensure appropriate ethical safeguards, particularly when involving children and other potentially vulnerable participants.

7.5 The Way Forward

The way forward requires a shift from fragmented interventions towards coordinated and sustainable systems of support.

The following priorities are proposed:

Priority One: Increase Awareness

Expand accurate, culturally appropriate autism and developmental awareness programmes in underserved communities.

Priority Two: Empower Families

Strengthen caregiver education, family support, and peer networks so that parents and caregivers can make informed decisions and advocate for their children.

Priority Three: Build Community Capacity

Train teachers, community health workers, community organizations, and other frontline actors to recognize developmental concerns and support appropriate referrals.

Priority Four: Strengthen Referral Systems

Develop clear pathways connecting families and communities to qualified professionals and appropriate assessment and support services.

Priority Five: Improve Inclusive Education

Strengthen teacher capacity and school systems to support autistic children and other learners with disabilities.

Priority Six: Strengthen Partnerships

Develop strategic partnerships between community organizations, government institutions, schools, healthcare providers, universities, disability organizations, and development partners.

Priority Seven: Invest in Research

Generate locally relevant evidence to guide policy, programming, advocacy, and investment.

Priority Eight: Mobilize Sustainable Resources

Increase investment in autism and disability inclusion programmes, particularly those serving underserved and low-resource communities.

Priority Nine: Measure Impact

Develop strong monitoring, evaluation, and learning systems to document outcomes, identify what works, and strengthen programme effectiveness.

Priority Ten: Scale What Works

Where community-based approaches demonstrate positive results, they should be documented, evaluated, adapted, and considered for expansion to other underserved communities.

7.6 The Role of ADIP Initiative

As a community-focused organization working in autism and disability inclusion, ADIP Initiative has an opportunity to contribute to addressing some of the gaps identified in this publication.

The organization's potential areas of contribution include:

- Community autism awareness.

- Caregiver education and empowerment.

- Inclusive education training.

- Teacher capacity-building.

- Community outreach.

- Advocacy and disability inclusion.

- Referral support and professional linkages.

- Research and evidence generation.

- Partnership development.

- Community-based programme implementation.

ADIP Initiative's role should be developed in collaboration with relevant stakeholders and within appropriate professional and ethical boundaries.

The organization can contribute by strengthening community-level systems while building partnerships with qualified professionals and institutions capable of providing specialized assessment and services.

The long-term goal should be to develop a sustainable model that can demonstrate measurable impact and potentially be adapted for use in other underserved communities.

7.7 A Call to Action

The challenges identified in this publication require action from multiple stakeholders.

Governments are called upon to strengthen policies, systems, and resources for autism and disability inclusion.

Healthcare and professional institutions are encouraged to improve access to appropriate developmental assessment and support.

Schools and education stakeholders are encouraged to strengthen inclusive education and teacher capacity.

Community organizations are encouraged to increase awareness, empower families, and strengthen referral connections.

Universities and research institutions are encouraged to generate locally relevant evidence.

Funders and development partners are encouraged to invest in sustainable, community-based approaches that address the needs of underserved families.

Corporations and private-sector organizations can contribute through strategic partnerships, corporate social responsibility initiatives, innovation, technology, and resource mobilization.

Most importantly, communities and families should be recognized as active partners in creating inclusive environments for autistic children and persons with disabilities.

7.8 Final Conclusion

Barriers to early autism identification in low-resource communities in Kenya represent a significant challenge that requires urgent and coordinated attention.

The evidence presented in this publication demonstrates that delays in identification are influenced by interconnected social, cultural, economic, healthcare, educational, and systemic factors.

Addressing these barriers requires more than increasing awareness. It requires strengthening the entire pathway from early recognition to referral, professional assessment, support, education, and inclusion.

A community-based approach, supported by strong professional networks, inclusive education systems, effective referral pathways, research, policy commitment, and sustainable investment, can contribute to meaningful change.

The future of autism and disability inclusion in Kenya will depend on the willingness of different stakeholders to work together and invest in solutions that are accessible, evidence-informed, culturally responsive, and sustainable.

For ADIP Initiative, this publication provides an opportunity to contribute to the national conversation on autism identification and inclusion while creating a foundation for future research, programmes, partnerships, and investment.

The challenge is significant, but so is the opportunity.

By strengthening communities, empowering families, building capacity, improving referral pathways, and investing in inclusive systems, Kenya can move towards a future in which developmental differences are recognized earlier, families receive the support they need, and autistic children are given greater opportunities to learn, participate, belong, and thrive.

Early recognition is the beginning—not the end—of inclusion.

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