Research Report

September 2025

An Investigation of the Educational Experiences of Children with Autism in Kenya

Advantage Africa
pathways out of poverty

AUTISM SOCIETY OF KENYA
A BRIGHTER FUTURE FOR OUR CHILDREN

Lancaster University

Acknowledgements

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Abstract

This study explores the educational experiences of children with Autism Spectrum Disorder (ASD) and their families in Kenya, highlighting key challenges and opportunities for improvement. Employing a qualitative research design, the study gathered data through semi-structured focus group discussions and a timeline tool during a two-day research workshop. Participants included 6 young people with autism and 12 parents or guardians, selected through purposive sampling to ensure representative perspectives.

Findings reveal a critical lack of autism awareness, with many parents failing to recognise early signs or struggling to access professional guidance. This gap contributes to severe psychological distress, stigma, and family strain, exacerbated by misinformation and traditional beliefs wrongly attributing autism to curses or divine punishment. Financial barriers further limit access to essential healthcare, therapy, and quality education, leaving many families without viable support options.

In the education sector, significant obstacles prevent children with autism from accessing suitable schooling. The majority of parents reported difficulties due to a lack of clear guidance, unaffordable school fees and inadequate government-funded alternatives. Teacher attitudes, insufficient training, and limited resources in special schools and units further hinder learning outcomes. Schools often fail to provide individualised support, resulting in stagnation and minimal academic progress. Additionally, negative experiences with medical services, including misinformation, malpractice and neglect, compound the challenges faced by families.

To address these issues, the study recommends a multi-pronged approach. Key interventions include increasing autism awareness, improving early diagnosis and parental support, expanding access to affordable and specialised education, enhancing teacher training, and strengthening school resources. Policy changes, increased government oversight, and greater community engagement are also recommended to ensure that children with autism receive the education and support they deserve. By implementing these recommendations, Kenya can create a more inclusive and supportive learning environment. These actions can also improve the

long-term outcomes for children with autism in line with the educational commitments stated in the Kenyan Constitution and the UN Convention on the Rights of Persons with Disabilities.

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Methodology

This study was conducted through a three-way partnership between Lancaster University, Advantage Africa, and the Autism Society of Kenya (ASK). It adopted a qualitative research design to gain an in-depth understanding of the educational experiences of children with autism and their families in Kenya. A qualitative approach was selected as the most suitable means of exploring lived experiences and generating rich, detailed narrative data from a relatively small sample.

Purposive Sampling

A total of 18 participants were recruited through purposive sampling: 12 parents or primary guardians and six young people with autism. Although the sample size was modest due to resource constraints, it allowed for meaningful, in-depth exploration. Participants were primarily identified through ASK's extensive membership networks, most of whom are based in or near Kiambu County, central Kenya. The existing trust between ASK and its members facilitated recruitment, with invited families showing enthusiasm to participate once the research aims, expectations, and safeguards were explained.

Families were eligible if they had a child with autism aged between 14 and 20 years, ensuring they had sufficient experience navigating the Kenyan education system. Sampling sought diversity across gender, economic background, and autism severity levels. As is common in Kenya, many families affected by disability, including autism, face lower incomes and are often single-parent households, with mothers or grandmothers as primary caregivers. These factors were reflected in the sample as far as possible.

Including the perspectives of young people with autism was considered essential. Six were invited to participate, accompanied by their parents or guardians. Participants were selected based on their ability to engage meaningfully and comfortably without anxiety or distress, meaning that those with the most severe autism were represented indirectly through their parents. Accommodations were made at the workshop venue to support their welfare and participation.

Data Collection Procedures

The main data collection took place during a two-day research workshop at a residential guest house in Kiambu County, providing accessible and uninterrupted time for participants. Data collection tools included a timeline exercise (Appendix 2) and semi-structured focus group discussions (FGDs) (Appendix 1).

The research team, comprising three ASK staff (Muthiru Chege, Anastacia Murugi, and Erastus Njoroge), the principal researcher Rob Aley (Advantage Africa), and local research consultants Dr. Alice Gathoni and Dr. Remi Orao, convened in advance to align on research tools and facilitation methods.

The workshop began with rapport-building, informed consent, and language translation was provided throughout the workshop as required. Participants first completed the timeline exercise, designed to capture each family's educational journey from birth, including key influences such as school availability, significant milestones, and external factors affecting access to education. Assistance with scribing was provided where required. Participants then joined three focus groups (parents/guardians and young people) for semi-structured discussions. Facilitators guided the sessions, which were audio-recorded and documented with detailed notes. These FGDs elicited in-depth narratives, individual stories, and case studies which also supplemented and triangulated the timeline data.

Data Analysis

FGD transcripts, timelines, and related materials were collated and manually analysed using a thematic approach. Data were reviewed in detail, coded, and grouped into key themes, which were refined to capture the main patterns emerging from the study. These themes form the structure for the findings presented in this report.

Ethical Considerations

Ethical approval was obtained from the National Commission for Science, Technology, and Innovation (NACOSTI) in Kenya before data collection. All participants were fully informed about the study's objectives, procedures, and intended use of findings. Safeguarding and confidentiality measures were observed throughout. Participation was voluntary, and individuals retained the right to withdraw at any stage.

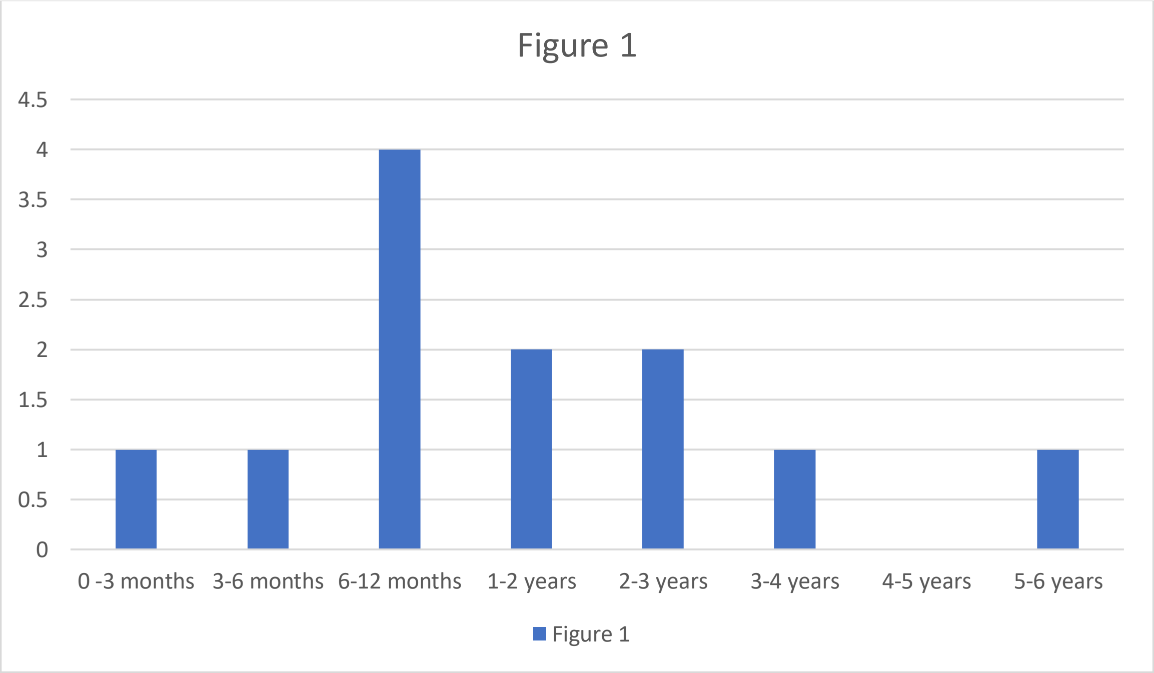
Findings

Early Years

1. Age at which differences in children were identified

The study first examined the age at which parents or guardians became aware of differences in their child compared to peers of the same age. Among the 12 respondents, half reported noticing a difference before their child reached 1 year of age, while the other half identified a difference after their child was over 1-year-old. The earliest reported age at which a difference was noticed was before 3 months, while the latest was at 5 years. In the case of the child identified at 5 years, the mother explained that she had initially been advised to be patient, as others said some children develop more slowly than others. However, after 5 years, she recognised that the differences were persistent and indicative of a lasting condition.

Figure 1. Age at which parents or guardians became aware of differences in their child's development



2. Types of differences identified

Parents / guardians reported noticing a range of early developmental differences in their children. The most commonly observed differences included:

- **Diminished responsiveness in infancy** – such as rarely crying, excessive sleepiness, and difficulty with breastfeeding.
- **Delays in speech development** – including late language acquisition and prolonged echolalia (repeating words or phrases spoken by others).
- **Delays in physical development** – such as difficulty with head and neck control and delayed crawling.
- **Health-related concerns** – including convulsions, frequent illnesses, and heightened fear or anxiety.
- **Unusual social interactions** – such as avoiding eye contact, displaying aggression, and being overly possessive of belongings.

3. Emotional effects on parents when differences were noticed

The parents were asked to summarise their emotional state after realizing their children had significant differences to other children. While all responses emphasized negative emotions, certain key feelings emerged:

- **Confusion** – not knowing what to do next, bewildered given that disability did not run in the family.
- **Pain** – feeling low, depressed, alone
- **Anger** – searching for something to blame (such as the hospital).
- **Shame** – being labelled a bad mother.

Experiences of medical care

The parents / guardians were asked to recall details of their interactions with medical professionals, specifically related to the treatment of their children. All 5 of the responses suggested some element of malpractice, even to the point of a dangerous lack of knowledge when dealing with children.

3 of the responses directly related to the knowledge of autism in hospitals, with misinformation resulting in emotional harm and incorrect surgical procedures.

‘*I was told at a highly regarded private hospital that autistic children die at age 15*’

2 other examples exposed the practices of medical professionals as harmful and abusive, particularly during labor. This included the nurses ‘*abusing’* the mother and recommending a surgery that resulted in severe blood loss.

Only 1 of the responses offered a positive element – in this case the child’s mother had an older brother working as a doctor. He was able to provide support due to his prior knowledge of children with disabilities.

4. Knowledge about what might be causing the differences

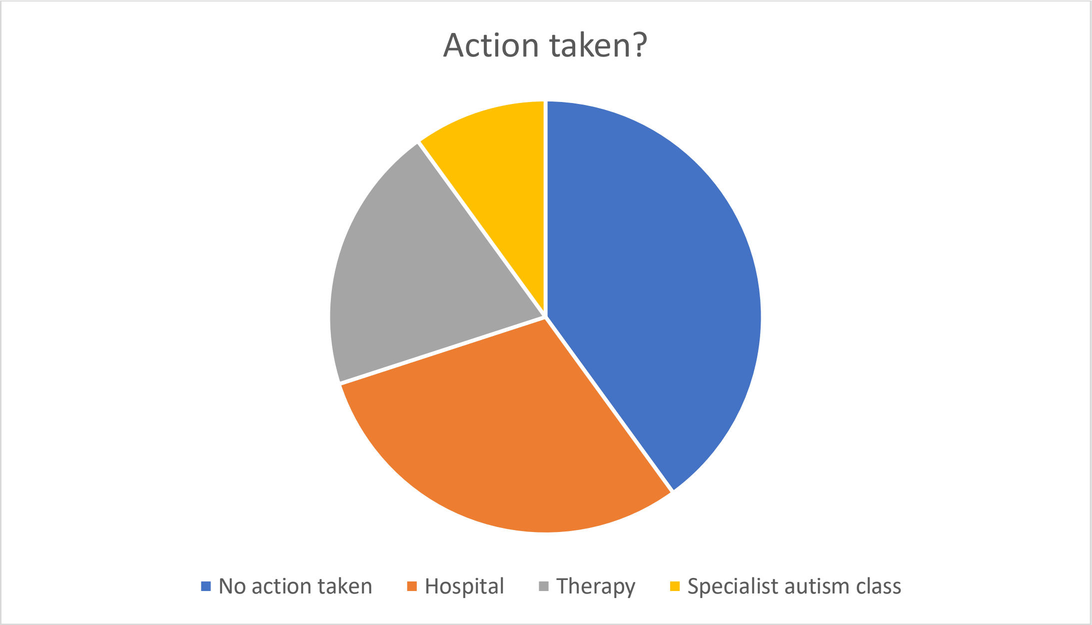
Among the 12 respondents, 10 answered that they had no knowledge about what was causing the differences (while the remaining 2 did not respond), with none of the parents able to recognize autism at first. When expanding on other explanations, some of which were extracted from other responses, common themes emerged:

- **Birth-related issues** – stemming from difficult labor, emotional strain during pregnancy, conceiving the child too soon after the previous pregnancy.
- **Curse** – an unspecified superstitious explanation e.g. witchcraft. This was most often a belief of a family or extended family member, or one imposed by the wider community, causing social stigma and isolation, particularly of mothers.
- **Unknown illness** – the idea that it is normal for children under 5 to get *‘sick’*.

5. Action taken by families when differences were first noticed

Parents / guardians were asked whether they took any particular action when they first noticed the differences. 4 of the parents / guardians answered that they did not take any actions, with 2 of these expanding that they thought the differences were temporary, or a delay.

Figure 2. Family responses after noticing childhood differences.



Expanding on this, the children were taken to hospital for different reasons. One response specified that their child was given an electroencephalogram (EEG) while another parent / guardian explained that they took their child to the hospital to check for a curse.

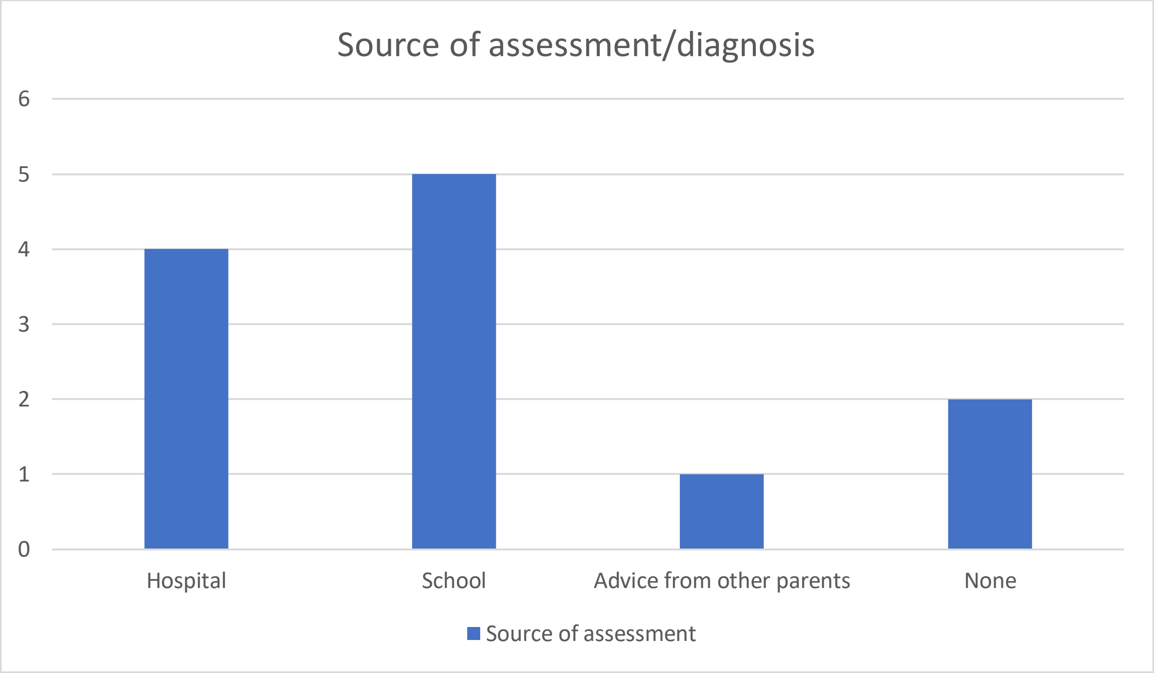
6. Seeking information, advice and support

Parents / guardians were asked whether they had sought information or further advice or support relating to their child's condition. Half the respondents (6 out of 12) sought information and advice from hospitals. Within this, the type of support varied greatly, including medical diagnoses and also referrals to special education facilities. It should also be noted that one parent wanted to take their child to a specialised hospital but was unable to do so due to a lack of money. Moreover, 3 parents communicated that they received support from schools such as an educational assessment. 2 parents received no further information / advice / support from anywhere. Other sources of support included family, traditional healers and the internet.

7. Assessments and diagnosis

The parents / guardians were asked if they received an assessment or diagnosis for their child, and if so, where from? This included both formal assessments and diagnoses as well as informal advice from other parents.

Figure 3. Source of assessment/diagnosis



Assessments at school took multiple forms. One was carried out by visiting doctors. Others were conducted by dedicated bodies such as KISE, EARC, ASK.

8. Responses of others when children’s differences became apparent

The parents were asked about the responses and reactions of other people, such as family, friends, neighbours and members of the wider community, when their children’s differences became apparent. The reactions of others were overwhelmingly negative and often led to extreme consequences, especially for mothers, such as abuse and marriage breakdowns. These are best illustrated with the following direct quotes, beginning with the most common response that parents experienced:

Stigma / isolation – (6 out of 12 responses)

- ‘Neighbours told their children not to play with our child’.

- ‘*Discriminated against even by his (the autistic child’s) own grandfather… who refused to have him take his name’.*
- *‘Rejection by neighbours’.*

Family breakdown / conflict – (5 of 12 responses)

- My husband left the both of us ‘*without warning’*.
- *‘Disability led to the breakdown of the marriage’*.
- *‘Husband started being physically and emotionally abusive… even threatened to shoot them’*.

Curse / bewitched – (4 of 12 responses)

- *‘I was told that my child was bewitched’.*
- *‘Friends advised prayers’.*
- *‘Blamed for everything wrong that happened in family/neighbourhood’*.

Abuse – (1 of 12 responses)

- *‘Neighbours were beating my son in the corridor between our apartments’*.

9. Parents’ thoughts about their child’s condition and the effect on their future

This part of the study sought to grasp how the parents / guardians viewed the prospects of their children, producing both general answers that signalled an emotion and more complex answers focused on areas such as unemployment.

Firstly, 6 of the 12 the parents / guardians expressed a more negative view of their child’s future, describing themselves as distraught, worried and / or confused. Many of the parents were worried about the educational prospects, which subsequently lead into fears surrounding employment. This was clearly compounded by issues such as a lack of money to fund their schooling. The anxiety that some parents expressed about the future had significant detrimental impacts on their mental health, in some cases even amounting to ‘suicidal thoughts’.

3 of the parents responded with a more ambivalent outlook, suggesting that they had not had many solid thoughts about how their child’s condition may affect their future, or that they were simply trying to address each challenge as it came.

4 of the responses were optimistic in nature, expressing confidence that the impact of their child's autism was either negligible or could be managed. 2 were optimistic that their child would *'get better with time'*. 1 parent highlighted employment, expressing some hope that their child could help to run a shop in the future.

Primary Years

1. Support or advice specifically about education

Parents provided a wide range of answers to the question concerning support and advice they received which was specific to their child's education. No clear consensus centred around a single source of support. The various responses were as follows:

- **No advice** – both due to a lack of advice from others and fear of bad / misleading advice.
- **Medical advice** – from sources such as Kenyatta National Hospital.
- **Other parents / family** – e.g. a community group of parents with autistic children.
- **Therapist** – private therapy.
- **School** – referrals from teachers to special schools.

2. Was there a school available that was suitable for your child's needs?

The parents / guardians were asked whether there was a school that was suitable for their child's needs. Reponses were largely given as yes or no answers but additional comments included; *'Unfortunately private schools are only interested in money… not in the interest of education or wellbeing'* and '*The school didn't do much - even toilet training, I did it by myself'.*

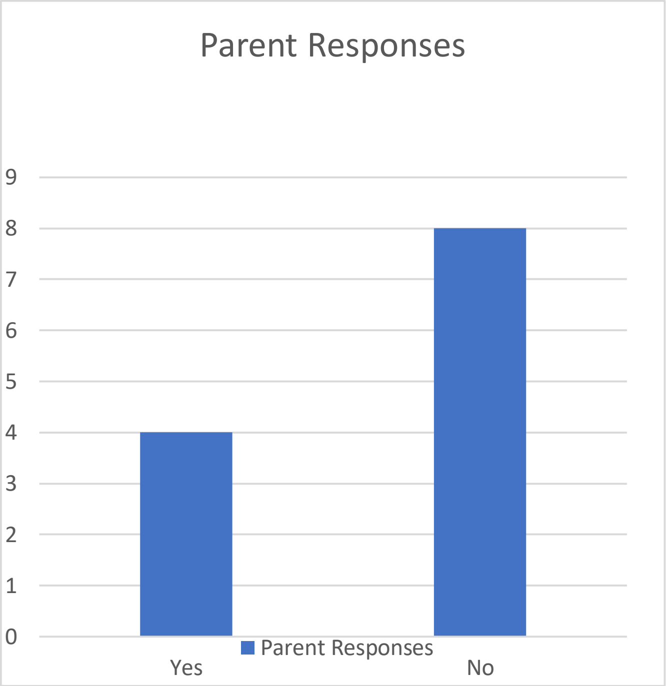


Figure 4. Availability of a suitable school.

3. Barriers to accessing a suitable school

Following a similar theme to the previous question, the parents were asked to list any particular barriers they faced when accessing a suitable school for their children.

Suitable availability of schools was the largest challenge with cost also a significant barrier. Negative attitudes and lack of advice were also identified as constraints. However, 1 in 4 respondents reported that they found no significant barriers to accessing a suitable school.

Figure 5. Table of responses regarding barriers to securing education.

Barrier	**No significant barrier**	**Cost**	**Lack of advice**	**Availability of suitable school**	**Negative attitudes towards their children**
Number of Responses	**3**	**3**	**1**	**4**	**2**

4. Parents feelings concerning access to school for their children

Parents were asked about the emotional impacts of trying to secure an education for their autistic children. The responses were divided into 3 categories: no big problems, negative emotions, a combination of negative and positive emotions.

8 of 12 parents recalled extremely negative emotions, for example:

- '*I felt like nobody else had a disabled child'*
- *'Overwhelmed and at times very angry with society'*
- *'Let down by the education system'*
- *'Initially angry with society to the point of wanting to commit suicide'*
- *'Almost reached a point of giving up getting a school'*

4 of 12 parents communicated a mix of positive and negative emotions, for example:

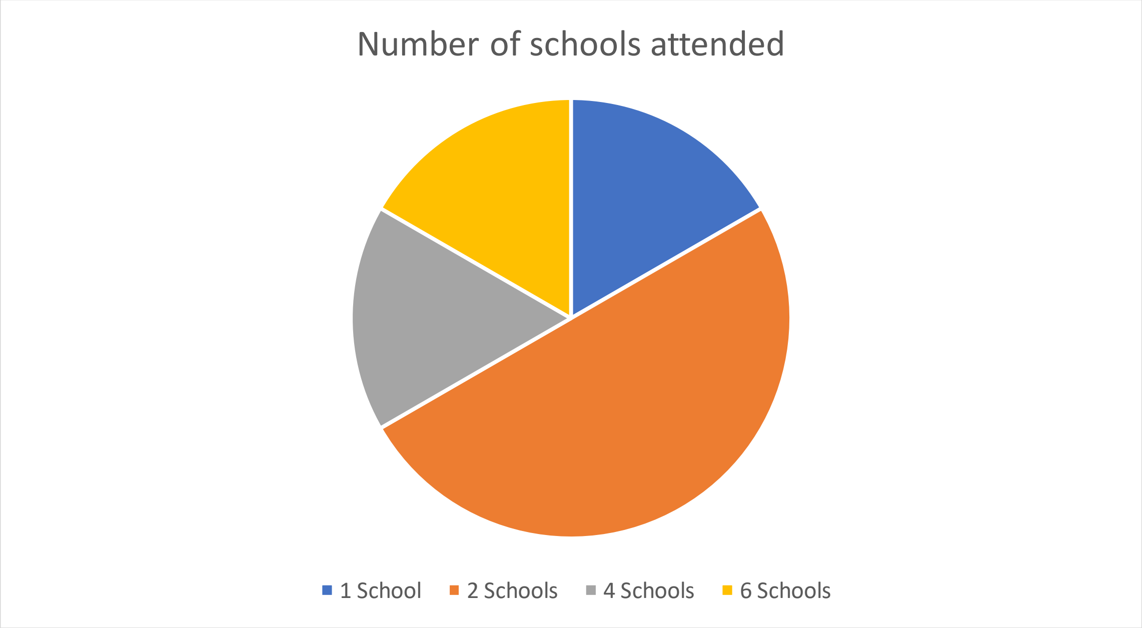
'Initially disturbed but turned to faith in God and accepted the child's diagnosis'.

1 parent answered that there were no big problems.

5. Number of schools children attended?

The parents / guardians were asked about the number of schools that their children attended over their time in education.

Figure 7. Pie chart depicting the number of schools attended by the children.



6. Children’s experiences of education

The parents were asked to describe how their children got on during their time at school. This was asked in a broad manner in order to capture a diverse range of viewpoints, hence some parents may have interpreted the question in a specifically academic or social sense.

- **Travel issue** – long distance to school, worried about the security of girls on the transport, children cannot walk by themselves. Specific safety issues surrounding boda bodas given as an example.
- **Bullying** – initial progress stemmed by bullying from adolescent peers.
- **Stagnation** – stuck in the same class for multiple years, remaining at the beginner’s level of primary education.
- **Lack of achievement** – struggling with academic activity, slow language development.

5 of the 11 parents / guardians pointed to a lack of achievement while 2 of the 11 answered with academic stagnation, showing how a majority of responses centred on academic struggles.

Only 1 of the 11 responses was at all positive, explaining that their child ‘*got on well at the beginning’* although this was subsequently limiting by bullying.

Travel issues also emerged as a key theme, with 3 of the 11 parents / guardians citing issues of distance and safety.

7. School staff knowledge

Parents / guardians were asked about the level of school staff’s knowledge with regard to their child’s specific special needs.

3 of the 12 parents answered ‘yes’, suggesting that the teachers generally had a positive attitude and a degree of knowledge which enabled them to work with their children. However, the comments did not suggest any specific areas of excellence, pointing to only ‘some knowledge’ – that they seemed ‘somehow knowledgeable’. Therefore, these responses imply that teachers could meet the bare minimum but were not excelling in their interaction with the children.

However, 8 of 12 the parents / guardians answered ‘no’, significantly outweighing the more positive outlook. Respondents stated that the quality of the teaching was ‘*only just better than the children being at home*’, with a lot of ‘*guess work’* on the child’s needs. As a result, the children ‘*don’t improve’* from the input of staff which is largely limited to ‘*just babysitting’*.

8. The attitude of the schools towards children with autism

Continuing with the focus on the assessment of the schools’ capacity to deal with children with special needs, the parents were asked whether they witnessed a generally positive or negative attitude from the school towards their child.

3 of 12 experienced a generally positive attitude, with the staff being friendly and supportive to their child.

Most respondents (9 of 12) experienced negative attitudes, providing a range of anecdotes to exemplify:

- Poor facilities provided – toilets in poor condition and shared by the whole school.
- Impersonal attitude – teachers do not put any effort in to get to know / support the children.
- Judging – assuming that disruptive behaviours characterised the children.
- Bullying.
- Low educational expectation of the children.

9. Teaching strategies, expertise or techniques for inclusion and learning

Parents and guardians were asked if schools had teaching strategies, expertise or techniques to assist their child with inclusion and learning. This question sought to develop the understanding of the schools’ specific actions (or inactions) as witnessed by the parents.

Amongst the 12 respondents, 9 observed that there were not any effective teaching strategies, expertise or techniques. One mother strongly criticised the teaching, saying *‘There are no strategies. It’s just babysitting’*.

Another common theme emerged regarding school resources which were considered to be insufficient and inadequate – ‘*everything is destroyed’*. This applies not just to learning equipment such as building blocks, with '*one pack for the whole class'*, but also essentials for welfare such as food, with one parents witnessing portions such as '*half a cup of porridge'*. Moreover, parents were critical of the staffing resources, pointing to the lack of a therapist and again comparing the teachers to '*babysitters*'.

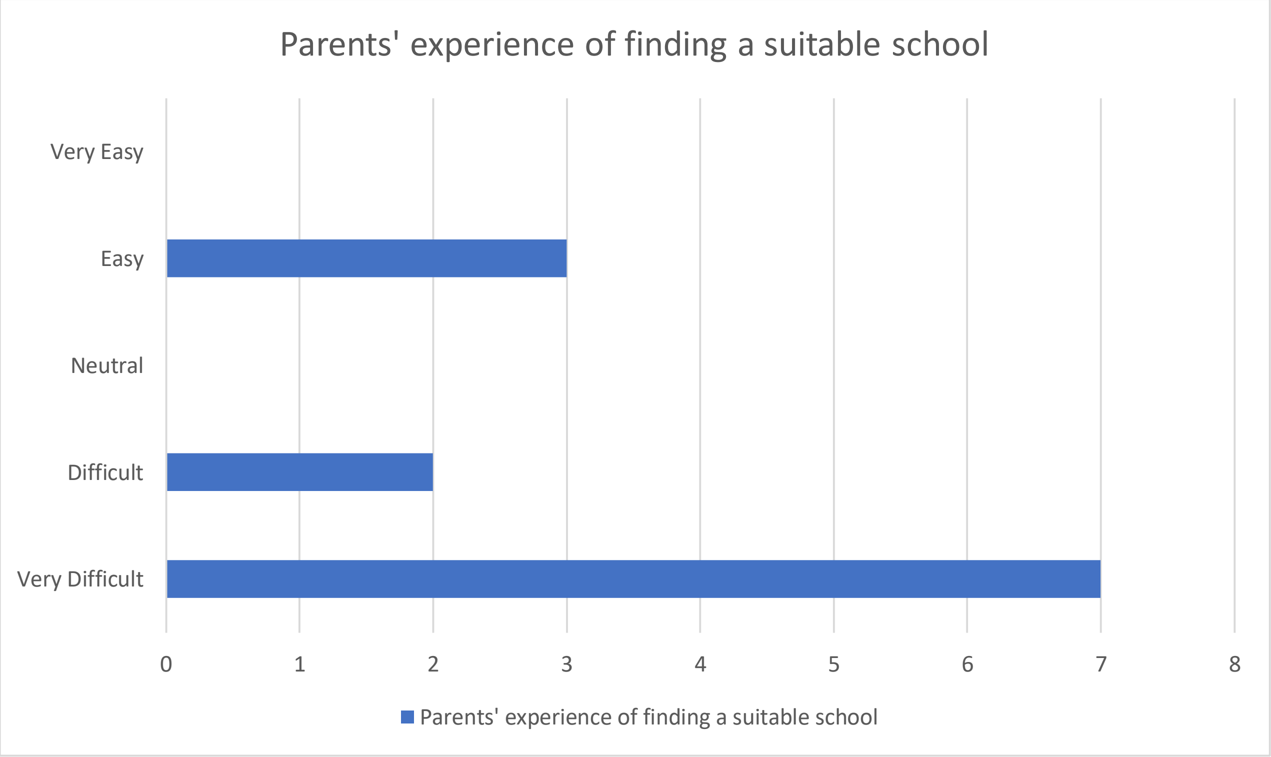
1 parent stated that the school was able to assist their child with inclusion and learning to some extent. She said the teachers seemed '*actively interested'* in fostering skills in activities of daily living, though lacked the expertise to employ more individualised techniques relating to autism.

2 parents / guardians answered yes to this question, stating that their schools were *'child-friendly'* and *'supportive*', employing teachers with '*good people skills'*.

10. Summary of experiences of finding a suitable primary school

Respondents were asked to summarise the ease or difficulty of finding a suitable school for their autistic child. Over half (9 of 12) assessed the process as very difficult or difficult with only 3 of 12 finding it easy.

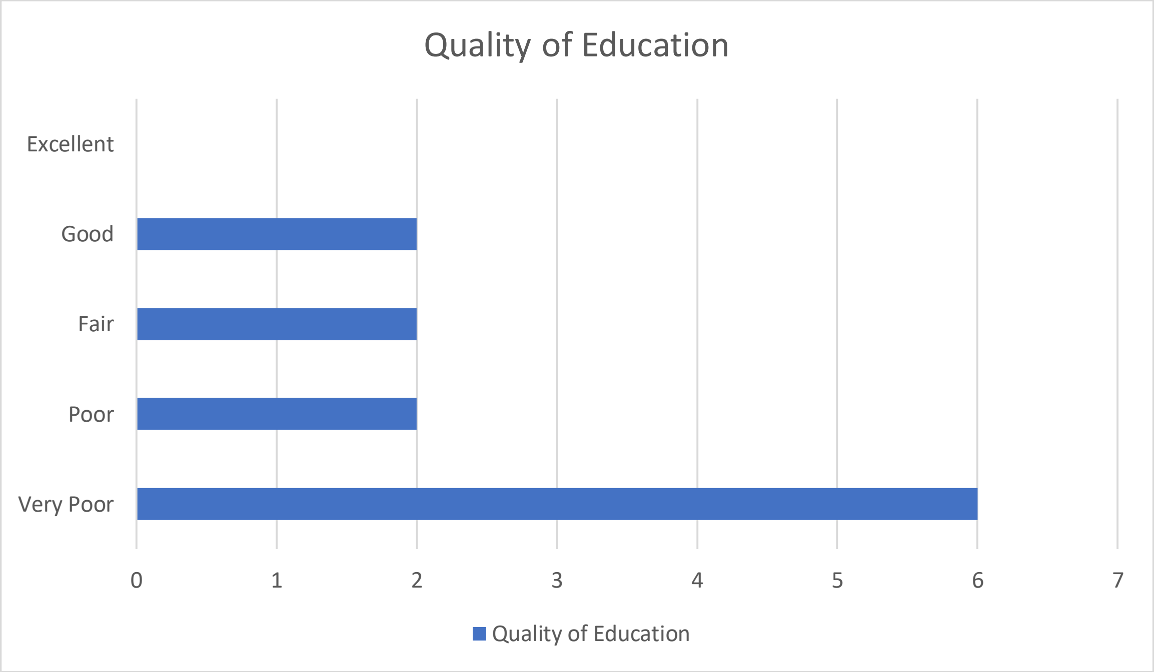
Figure 8. Ease of finding a suitable primary school.



11. Overall rating of quality of education

Respondents provided an overall rating of the quality of education their child received. Half (6 of 12) rated the education as very poor and a further 2 rated it as poor. The remaining 4 of 12 parents / guardians provided ratings of fair or good, none assessed their child seduction as excellent.

Figure 9. Rating of the quality of education received by children of the respondents.



12. Suggestions for educational improvements

Finally, parents were asked an open-ended question regarding the various ways in which their child's primary education could have been improved. Namely, what could have been done differently to help or improve your child's primary education? The suggestions were as follows:

- **Attitude of teachers** – teachers should '*get serious'* about what they are doing.
- **Quality and affordability of schools** – a greater number of public special schools that are cheaper, better equipped, with trained staff are needed.
- **Separate autism sections** – dedicated sections within schools for children with autism.
- **Resources** – adequate provision of key resources.

- **Government intervention** – active government assistance on a national and regional level that recognises and plans for the needs of autistic children and young adults with autism who are seeking employment.
- **Individualised teaching programmes** – tailored curricula that identify specific strengths of children, e.g. toy making and art, in order to aid the transition into adulthood. Expanded pre-vocational and placement options should replace activities such as ‘beadwork’.

Discussion of Findings

Early Years

Lack of awareness relating to autism:

The findings highlight a concerning lack of autism awareness among parents. For instance, 4 out of 12 parents or guardians took no action upon noticing differences in their child’s early development. This suggests 2 key awareness-related issues. Firstly, it indicates that even obvious traits of autism are not widely recognised, with parents sometimes perceiving them as temporary delays. Secondly, the results suggest that many parents or guardians did not know where to seek professional guidance or whom to contact for assessment and support.

Psychological distress and stigma exacerbated by lack of information, advice and support:

Parents experienced strong and sometimes overwhelming emotions as they became aware of the differences in their children’s development. These emotions included confusion, sadness, anxiety, isolation and depression. The depth of these feelings was extremely significant in the emotional welfare of the families concerned.

Disturbing emotions related to uncertainty were identified by half of the research respondents. They did not know who to turn to or what to do next. This lack of support often resulted in confusion and intense anxiety.

Parents also experienced criticism from others, evoking feeling of deep stigma and shame. This was particularly true amongst mothers who are often blamed by others for giving birth to a disabled child. In some instances, women internalise the burden of blame onto themselves, resulting in guilt and emotional isolation. Half of the research respondents reported experiencing stigma or isolation. 1 mother explained how her neighbours had told their children not to play with her autistic son, resulting in her wanting to withdraw from wider social interactions.

Moreover, the results demonstrated how the burden of psychological stress and strain contributed to family conflict. Nearly half of respondents reported family breakdowns as a result, for example husbands deserting their families leaving the mothers to care for the autistic children alone. These challenges are not unique to families affected by autism but they highlight the fact that people with disabilities of all kinds remain highly stigmatised in Kenyan society.

The need for information, advice and support, is critical during the child’s early years, however our findings show that access to such support often comes too late, when families have almost given up on understanding their child’s condition. Examples were given of the first guidance coming at around age 5 years or later, often when parents first start to seek out a school for their child. Additionally, the type and quality of advice and support was variable, some coming from family and friends including advice to seek assistance from traditional healers. Others were given guidance from more formal sources such as teachers or were signposted to educational assessment services and healthcare professionals.

Our findings therefore clearly show that children with autism and their parents and guardians are at very high risk of poor mental health due to the detrimental thoughts and emotions associated with autism. The gravity of this issue should not be underestimated and to tackle the problem a great deal of improvement is needed in the provision of information, advice and support services. It is therefore essential for service providers and professionals working in this field to not only acknowledge the emotional toll on families but to approach children with autism and their parents with empathy, sensitivity, and support, ensuring they feel seen, heard, and guided through an often-daunting journey.

Traditional beliefs about causes of autism:

The findings suggest that, in the absence of reliable, evidence-based information about their child’s condition, parents often turn to informal sources for explanations. Their strong desire for answers, combined with feelings of uncertainty and anxiety, can make them particularly vulnerable to unscientific and inaccurate beliefs about autism. A third of our respondents reported being told by family and friends that their child was ‘cursed’ and were encouraged to seek help from traditional healers or witch doctors. This is deeply concerning, as attributing autism to supernatural causes may lead families to pursue ineffective, or even harmful treatments, instead of seeking appropriate medical or therapeutic care. These findings reinforce the urgent need for accessible, accurate information from properly trained professionals.

Affordability of services:

A recurring theme in the findings was the significant financial burden associated with raising an autistic child. The cost of essential services—such as healthcare, therapy (speech, occupational, and physiotherapy), and education—was frequently cited as a major barrier, with many parents unable to afford them. While private-sector services were generally perceived as superior to government provisions, their high costs made them inaccessible to most families. Half of the parents expressed a strong desire to access private healthcare but were financially constrained.

Some parents who could afford private services reported a degree of satisfaction; however, service quality varied even within the private sector. For instance, 1 parent was pleased with their child’s private school whilst another grandparent recalled a distressing experience with an inaccurate diagnosis at a well-known private hospital, highlighting inconsistencies in service quality.

Overall, the findings suggest that while many parents aspire to access private services, financial limitations make this impossible for most. These constraints not only restrict families' choices but also contribute to financial anxiety and feelings of inadequacy, as parents worry about failing to provide the best possible care for their children. Furthermore, even for families with the financial means, access to specialized autism services remains highly limited in both the public and private sectors, underscoring the broader need for improved and affordable autism-related support.

Negative impact of medical services:

The data reveals that in some instances medical services can have a profoundly negative impact on both the physical and mental health of autistic children and their parents or guardians. Alarmingly, 5 out of 12 respondents reported instances of malpractice when recounting their experiences with medical professionals, suggesting that medical interventions may, in some cases, actually worsen the situation rather than improve it.

One particularly distressing example involved a doctor at a private hospital falsely informing a parent that autistic individuals only live to the age of 15 years, an assertion that undoubtedly heightened feelings of helplessness and distress. Additionally, anecdotal evidence revealed alarming instances of patient neglect, deliberate abuse by nurses, and even physical harm inflicted on mothers during labour. Reports also highlighted cases of misdiagnosis, including an unnecessary surgery that not only proved unnecessary but was also performed incorrectly, resulting in severe blood loss.

These findings underscore the inadequacy of medical services, which, in some cases, appear to be actively harmful. Many doctors lack the necessary knowledge to provide accurate information about autism, leaving parents without clear guidance or support. Meanwhile, some nurses demonstrate a troubling disregard for patient well-being. This highlights the urgent need for improved medical training, awareness, and accountability to ensure that families receive the compassionate and competent care they deserve.

Primary Years

Difficulties in accessing a suitable school:

One of the most fundamental findings from this research was the clear presence of significant barriers to accessing a suitable school for the autistic children. The majority of respondents (9 out of 12) reported experiencing significant barriers and **8 of the 12 parents / guardians stated that there was no school available that was suitable for their child's needs**. The reasons for the unavailability of schools were multiple and are discussed below.

Lack of support and guidance on accessing primary education:

When asked about the support or advice they received regarding access to primary education for their children, several parents and guardians reported receiving no meaningful guidance. This was primarily due to a lack of accessible information, uncertainty about where to seek help, and concerns about receiving misleading advice.

Those who did seek guidance identified a range of sources including hospitals, therapists, other parents, and schools. However, there was no evidence of a consistent or centralised source of reliable information. This fragmented support system exacerbates uncertainty, adding to the confusion and anxiety already experienced by both parents and children. As a result, families struggle to make informed decisions about the best educational path for their child.

Given the critical role of primary education in a child's development, there is an urgent need for clearer, more effective guidance. Establishing a trusted, well-structured support system would not only ease parental concerns but also ensure that children with autism have access to the right educational opportunities from the outset, laying the foundation for their future success.

Specific barriers

Affordability:

A significant barrier to accessing a suitable school was unaffordability. Most parents felt that there were private schools available, but the majority of respondents (8 out of 12) reported that they were unable to afford the private school fees. Given the cyclical relationship between poverty and disability, where poverty increases the risk of disability, and disability can cause poverty, families with an autistic child are more likely to face economic difficulties. As a result, the high cost of education becomes an even greater barrier for these families.

Conversely, a minority (4 out of 12) parents / guardians reported that they were in a position to afford a suitable school. Therefore, and perhaps unsurprisingly, the financial situation of a family appears to be a prominent factor in their ability to access a suitable school or not.

Parental knowledge and attitudes regarding access to schooling:

This research did not attempt to map out the full range of school provisions available to children with autism. Instead, it focused on parents' awareness of educational options for their children. Due to the lack of information and guidance (as discussed earlier), most parents had only a limited understanding of suitable schools. Understandably, their search efforts were often confined to schools in their immediate vicinity.

Many parents initially approached mainstream primary schools, often with apprehension about how the school administration would respond. In some cases, they were outright denied admission, with responses ranging from blunt and dismissive to more sympathetic but still exclusionary. While some parents were directed toward alternative options, such as special units or dedicated special schools, others were left without clear guidance.

One particularly distressing case involved a mother whose son was initially accepted into a mainstream school. However, at the end of his first day, the head teacher bluntly informed her that her son was not suitable for the school and told her never to bring him back. On top of the emotional distress and disappointment, the school refused to refund the advance payment of school fees. Reflecting on the experience, she said: *'I hated that man, absolutely hated him – that experience meant I kept my son at home. I didn't look for another school for a whole year.'*

This example illustrates a wider feeling amongst parents that they are left isolated without help to navigate the educational structures. They felt '*very angry with society*' and '*let down by the education system'*. These frustrations were so intense that one parent stated that it drove them to the point of '*wanting to commit suicide'*.

For many parents, unfamiliarity with disability meant they did not initially understand the distinction between mainstream and special schools. It was often only after learning about special education provisions that they began making further inquiries. Some parents expressed relief upon discovering special schools, where their children would be among peers with similar learning needs.

However, access to special schools remained a significant challenge. Many parents found that there were no suitable schools within a reasonable distance or that only a single special school or unit existed in their area. This created additional logistical difficulties, particularly regarding transportation. Some children had to travel long distances to school each day, and parents were often unwilling to let them travel alone due to safety concerns. As a result, they had to arrange for accompaniment, frequently at an additional cost, such as motorbike taxi fares.

To summarise, the findings outline severe difficulties in accessing a suitable school. Intervention is clearly needed to ensure that the children receive support at a crucial stage in their development and to reduce the emotional toll on families.

Experiences of quality of education:

When asked a series of questions about how the children got on during their time at school, the responses spanned both social and academic issues. Although a few respondents were generally positive about their child's education, the majority were much more critical and painted a picture of poor attitudes, teacher knowledge and school resourcing.

Attitudes of teachers and other staff:

It was reported that many teachers did not have a positive attitude towards the children they teach. 9 out of 12 parents or guardians experienced negative attitudes from the schools towards their children with autism, adding to the stigma they experience. They said teachers were not motivated to make an effort to understand or care about their autistic children. Some responses actively criticised the behaviour of some staff as 'impersonal' and not putting in any effort to support the children. Teachers were said to focus on poor behaviour and were too ready to categorise the children as disruptive. There were also reports of bullying from other adolescents within the school. They also had low expectations for the learners resulting in little effort to enhance educational progression.

Although the majority expressed this negative picture, 3 out of 12 parents offered a more positive outlook, saying their child's teachers were generally friendly, positive and had 'good people skills'. This strongly suggests that poor attitudes from teachers are by no means inevitable and given training, motivation and resources it is likely that a shift in attitudes could be achieved, leading to a more supportive and inclusive learning environment for autistic learners.

Teacher's Knowledge and teaching strategies:

Although parents were initially relieved that they had found a school that would enrol their child, their assessment of the levels of teachers' knowledge, techniques and strategies was not favourable. After their children had attended school for some years, 9 out of 12 respondents did not believe that the schools used effective teaching methods or that teachers were well trained in appropriate or specialist techniques or strategies specific to their autistic children. Parents commented on the teachings as 'guess work' and said that their children 'don't improve'. 1 respondent expressed exasperation with the teaching describing it as '*just babysitting'* and another said their school is *'just better than the children being at home'*. In many cases respondents stated that the special units do not progress learners through an achievement-based approach, so there is no progress and no thoughts of what the students will do when they finish school. They said there is '*stagnation'* and '*children are stuck in the same class for multiple years, remaining at the beginners' level of primary education'*. Furthermore, respondents identified a lack of academic progress and slow development of language skills. As for extra curricula activities, very few were identified. One mother recalled the time their child went to another school to compete in sports, but went on to say, ‘that never happened again’.

It should be noted that not all parents had negative experiences of schools: 3 parents explained how in their children’s schools, teachers generally had a positive attitude and learners showed improvement in areas such as skills of daily living. They felt the teacher’s knowledge and methods were reasonable, although no respondents had experienced high levels of expertise or teaching excellence.

Resources for Schools:

Inadequate staffing levels, teaching resources, and school infrastructure were identified as major constraints to autistic children’s learning. While conditions vary across schools, one mother described the special unit her son attended as a small, overcrowded room divided into 2 classes, with only 1 teacher and no teaching assistant. Toilet facilities were reportedly appalling, and meals were both nutritionally inadequate and insufficient in portion size. Another mother expressed a similar concern, stating, *‘My child is always extremely hungry after school; I wonder what they have fed her?’*

Classroom teaching resources were also found to be severely lacking. Respondents reported situations where an entire class had to share a single bag of blocks. Additionally, schools often lacked any type of pre-vocational and vocational training equipment, and specialist therapy resources were scarce. One mother recalled that her daughter’s school once had a therapy room with necessary equipment, but ‘*it had now all gone missing’.*

Given these challenges, the Teacher Service Commission (TSC) should review staffing in government schools to ensure adequate teacher allocation and that qualifications align with learners’ needs. Additionally, head teachers and school boards should receive support to manage budgets effectively and transparently while actively engaging parents and the wider community in resource mobilization. Addressing these resourcing gaps is critical to improving the quality of education and support for autistic children.

Summary of the educational experience:

Overall, the findings suggest that children with autism do not receive an adequate quality of education. 8 out of 12 parents or guardians categorised their child's overall experience of education as Poor (2) or 'very poor' (6).

Recommendations

To ensure autistic children in Kenya receive the education, care, and opportunities they deserve, significant improvements must be made in multiple areas. The following recommendations address key challenges identified in this research:

Access to Information, Advice, and Early Support

- Establish centralised, trusted sources of information for parents, ensuring early access to diagnostic services and guidance on autism.
- Increase awareness campaigns to dispel myths and stigma surrounding autism, particularly in rural communities.
- Strengthen the role of support organisations in providing emotional, practical, and educational assistance to families.

Improving Educational Access and Suitability

- Develop clear pathways for school placement, providing parents with reliable information on available mainstream and special education options.
- Increase the number of affordable, government-funded schools with appropriate autism-friendly programmes.
- Provide transportation support for families who struggle to access distant schools, reducing logistical and financial burdens.

Enhancing Teacher Training and Expertise

- Implement mandatory autism training for all teachers, ensuring they understand autism-specific learning needs and behavioural strategies.
- Promote the use of Individualised Education Plans (IEPs) to tailor learning experiences to each child's strengths and challenges.
- Shift the focus from purely academic progression to include life skills, pre-vocational training, and employment preparation for autistic students.

Strengthening School Resources and Infrastructure

- Increase funding to ensure adequate staffing levels, including teaching assistants in special units.
- Improve school infrastructure, ensuring safe, hygienic, and autism-friendly learning environments.
- Equip schools with teaching materials, therapy resources, and vocational training tools to enhance learning outcomes.
- Encourage community involvement and resource mobilisation to support schools with additional materials and infrastructure improvements.

Strengthening Government Oversight and Policy Implementation

- The Teacher Service Commission (TSC) should review staffing in government schools and ensure appropriate teacher-student ratios.
- Government agencies should conduct regular quality assessments of special education units to ensure standards are met.
- National and county governments should allocate increased budgets for autism education, prioritizing both accessibility and quality.

By implementing these recommendations, Kenya can work toward a more inclusive and effective education system, upholding its commitments as stated in the Kenyan Constitution and the UN Convention on the Rights of Persons with Disabilities.

Annotated Bibliography

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Appendices

1. Focus Group Questions for parents / guardians:

Early Years

1. What age was your child when you first noticed that they may be somehow different to other children of the same age?

a) Before they were 1 yr.

b) between 1 and 2 yrs

c) between 2 and 3 yrs

d) between 3 and 4 yrs

e) Over 4 years

2. What were the particular differences you first noticed?

3. How did it make you feel when you noticed these differences?

4. Did you have any knowledge about what might be causing the differences, or what was going on?

5. Did you take any particular action when you first noticed the differences?

6. Did you get any information, advice or support? If YES – from where / who?

7. Did you get any kind of assessment or diagnosis?

8. What were the responses of other people when the differences in your child became apparent? (family, friends, neighbours, community)

9. In those early years what were your thoughts about how your child's condition might affect their future life, and the future of the family? (including their education)

Primary Education Years

1. When your child reached primary school age, did they start attending school?

Yes – (if yes at what age and what kind of school – e.g. Standard Government, private, special?)

No – (if 'NO' why not?)

2. Did you receive any support or advice specifically about your child's education? (from whom- and what sort of advice /support?)

3. Was there a school available that was suitable for your child's needs.

Yes / No

4. Were there problems or barriers to accessing a suitable school? Please explain your experience of finding a suitable school for your child.

5. How did your experiences of getting a school for your child make you **feel?**

6. How many different schools did your child attend?

7. Generally, how did they get on?

8. Did the school staff have specific **knowledge** about your child's special needs?

9. What was the **attitude** of the school towards your child?

10. Did the school have **teaching strategies**, expertise or techniques to assist your child with inclusion and learning?

11. In summary, how easy or difficult was it to find and get enrolled a suitable primary school for your child?

a) Very easy

b) Easy

c) Neutral

d) Difficult

e) Very difficult

f) Almost Impossible

12. Overall - How would you rate the **quality** of the education your child received?

a) Excellent
b) Good
c) Fair
d) Poor
e) Very Poor

13. What could have been done differently to help or improve your child's primary education?

2. Timelines of Educational Experiences Research Tool with Examples: