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Full Length Research

Parental Involvement and Advocacy in Special Education: Voices of Parents of Children with Autism

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Autism Spectrum Disorder (ASD) is a complex neuro developmental condition that affects communication, social interaction, and behavior. Globally, there is growing recognition of the crucial role that parental involvement and advocacy play in supporting the educational experiences and outcomes of children with autism. In Nigeria, however, systemic, cultural, and institutional barriers continue to hinder the full inclusion of parents in special education processes. This study explores the voices, lived experiences, and advocacy efforts of Nigerian parents of children with autism within the education system. Guided by a qualitative design with a descriptive survey component, the study examines the nature of parental involvement, identifies barriers and enabling factors, and analyzes how socio-cultural, economic, and institutional contexts influence their participation. Data were collected through structured questionnaires and semi-structured interviews with a purposive sample of parents across selected states in Nigeria. Findings indicate that while some parents actively engage in Individualized Education Plans (IEPs), school visits, and advocacy at policy levels, many face significant challenges such as stigma, lack of awareness, limited resources, and unsupportive school environments. Cultural misconceptions about autism further complicate advocacy efforts. The study highlights the resilience of parents through the development of informal support networks and adaptive coping strategies. Recommendations include stronger institutional support, culturally sensitive awareness campaigns, and inclusive education policies that prioritize parent-school collaboration. This research underscores the urgent need to empower parents as key stakeholders in the education of children with autism in Nigeria, aligning with global goals for inclusive and equitable education for all.

Keywords: Autism Spectrum Disorder (ASD), parental involvement, Special Education

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neuro developmental condition marked by challenges in communication, social interaction, and the presence of repetitive behaviors and restricted interests [1]. While the global recognition of autism has grown considerably in the past two decades, disparities in awareness, diagnosis, and intervention remain stark between high-income and low- to middle-income countries (LMICs), including Nigeria [2], [3]. Current estimates indicate that approximately 1 in 100 children are affected globally, though these figures are believed to be underreported in sub-Saharan Africa due to limited diagnostic infrastructure and widespread stigma [3].

In Nigeria, autism is often misunderstood, frequently attributed to spiritual afflictions or supernatural causes, which in turn shape community responses and institutional neglect [4], [5]. Formal diagnostic services are limited and concentrated in urban areas, and the absence of national data hampers the formulation of evidence-based interventions [6]. As a result, the responsibility of navigating the complexities of autism and accessing education and care falls disproportionately on parents. For many Nigerian parents, securing educational support for their children with autism involves navigating stigma, underfunded schools, inadequately trained teachers, and rigid policies that do not account for neuro diversity [7].

Globally, parental involvement in the education of children with disabilities is widely acknowledged as critical to student outcomes. Research from the United States and Europe indicates that active parental participation is positively correlated with academic achievement, increased communication skills, and better social adjustment among children with ASD [8], [9]. Family-centered practices and Individualized Education Plans (IEPs), which are standard in many Western education systems, enable parents to collaborate with educators to tailor learning environments to their child's needs [10]. Furthermore, parental advocacy has been central to legislative milestones such as the Individuals with Disabilities Education Act (IDEA) in the United States, which guarantees free and appropriate public education for all students with disabilities [11].

In contrast, the educational landscape in LMICs often lacks both the infrastructure and legal frameworks to support such engagement. In many African contexts, education systems are still grappling with the concept of inclusive education, and parental involvement is frequently minimal, informal, or reactive rather than proactive [12]. The role of the parent as an advocate is further hindered by cultural norms that emphasize deference to authority figures like teachers and school administrators [13]. In Nigeria, advocacy by parents of children with autism is emerging as a crucial strategy to bridge systemic gaps in the provision of special education. However, parental engagement remains largely unstructured and unsupported by the state. According to Ajuwon [4], many Nigerian parents assume advocacy roles not by choice but out of necessity, in response to a lack of appropriate services or the outright denial of school enrollment to their children. Advocacy often takes the form of community awareness, school negotiations, or legal confrontations, but is frequently constrained by socioeconomic status, education level, and access to networks [14].

Olusanya [6] argues that Nigeria's policy environment is insufficiently responsive to the rights of children with disabilities, with implementation often lagging behind legislative provisions. For example, while the 2018 Discrimination Against Persons with Disabilities (Prohibition) Act is a landmark law that mandates inclusive education, its enforcement remains weak, particularly in rural and peri-urban areas. This policy gap places the burden of advocacy squarely on parents, many of whom are already stretched thin financially and emotionally [15]. Culturally, parental involvement is also shaped by deep-rooted beliefs about disability. In some communities, the birth of a child with autism is perceived as a curse or punishment, leading to social ostracization of the entire family [16]. Such stigmatization discourages open discussion and impedes the formation of parental support groups or alliances. Furthermore, religious interpretations of disability may prioritize spiritual interventions over medical or educational ones, delaying diagnosis and denying children timely access to learning opportunities [17].Educational institutions in Nigeria are generally ill-equipped to accommodate studentswith ASD. Many teachers lack formal training in special education or inclusive pedagogy [18]. As a result, teachers often feel overwhelmed, unprepared, or even resistant to accommodating children with autism in their classrooms. This lack of capacity contributes to the exclusion of students with ASD and increases the pressure on parents to "teach at home" or seek costly private alternatives [6]. Teacher-parent collaboration, a key feature of successful inclusion in other settings, is thus either superficial or adversarial in Nigeria.

Studies such as those by Alade and Akinlabi [19] reveal that most school administrators do not consider the voices of parents when designing or implementing school-based interventions. This neglect not only demoralizes families but also limits the educational potential of the child. Advocacy, when undertaken, is often an uphill battle involving bureaucracy, miscommunication, and marginalization. From a global health perspective, the disparities in access to autism services in Nigeria reflect broader issues of health inequity, policy failure, and resource allocation. Autism services are typically bundled within broader disability or mental health services, which are underfunded and poorly integrated into primary health and education systems [3]. Moreover, while international donor support has helped address other conditions like HIV/AIDS or maternal mortality, autism and disability rights remain peripheral in Nigeria's global health collaborations [2].

Addressing the needs of families of children with autism requires multisectoral responses that go beyond schools and include ministries of health, education, social services, and justice. Empowering parents as stakeholders in this ecosystem is essential for creating sustainable and inclusive educational frameworks. Globally, parent advocacy has been instrumental in shifting discourse and policy around disabilities, and there is potential for similar grassroots movements in Nigeria if given adequate support [20], [8].

STATEMENT OF THE STUDY

Given these complex and intersecting challenges, this study seeks to foreground the experiences and voices of Nigerian parents of children with autism. It aims to examine how they engage in advocacy, interact with schools, and navigate structural and cultural barriers in pursuit of their children’s educational rights. The central research questions ask: What forms of involvement and advocacy do Nigerian parents of children with autism undertake? What obstacles and facilitators shape their efforts? And how can policy and practice be reshaped to better include and support them?

PURPOSE OF THE STUDY

The study aims to fulfill the following objectives:

1. To explore the lived experiences of parents of children with autism in navigating special education systems in Nigeria.
2. To document the advocacy strategies parents employ to support their children's right to education and inclusion.
3. To identify cultural, religious, and community beliefs that shape societal attitudes toward autism and how these impact parental roles.
4. To assess the role of government policies, teacher preparedness, and school responsiveness in enabling or constraining parental involvement.
5. To provide practical recommendations for enhancing parent-school collaboration, advocacy frameworks, and inclusive educational practices.
6. To contribute to the broader discourse on inclusive education in sub-Saharan Africa by offering parent-centered, locally grounded perspectives.

RESEARCH QUESTIONS

1. What forms of involvement and advocacy do Nigerian parents of children with autism engage in within the education system?
2. What are the barriers and enablers to effective parental advocacy in the context of autism and special education in Nigeria?
3. How do socio-cultural, economic, and institutional factors influence parental involvement in special education?
4. In what ways do parents interact with educators, school administrators, and policymakers in supporting their children’s education?
5. What coping strategies and support networks do parents utilize in the face of challenges?

METHOD

Research Design

This study adopts a qualitative phenomenological research design, aimed at exploring the lived experiences and perceptions of Nigerian parents of children with Autism Spectrum Disorder (ASD) as they navigate the challenges of involvement and advocacy within the special education system. Phenomenology is particularly suitable for studies that seek to understand complex social and emotional realities from the perspective of those who experience them [21]. In this context, it enables the researcher to explore how parents make sense of their advocacy efforts, the systemic barriers they encounter, and the emotional and socio-cultural dynamics that inform their actions.

Research Setting

The research was conducted in three major cities in Nigeria, Lagos, Ibadan, and Abuja, chosen for their relatively higher concentration of special needs schools, availability of diagnostic services, and active parental support networks. These urban areas provide a varied representation of parental experiences within both public and private educational settings and reflect some level of regional diversity within the country.

Population and Sample

The target population comprises parents or primary caregivers of children diagnosed with autism who are currently enrolled in primary or secondary schools (public or private) in Nigeria. Given the focus on parental voices, only individuals who are actively involved in their child's educational journey and have engaged in advocacy-related activities (formal or informal) were eligible.

A purposive sampling technique was used to recruit participants, as this method is suitable for selecting individuals who can provide rich, detailed, and relevant information related to the research questions [22]. Snowball sampling was also utilized, wherein initial participants referred others within their networks, especially within parent advocacy groups and non-governmental organizations (NGOs) working in special education.

A total of 20 participants (15 mothers and 5 fathers) were selected to provide a balance of perspectives and diversity in socio-economic background, educational attainment, and types of advocacy experience.

Instruments for Data Collection

The interview guide was pre-tested with two parents who met the inclusion criteria but were not part of the main study. Their feedback was used to refine the wording of questions and ensure cultural sensitivity and clarity. Additional data were collected from field notes and observations, including non-verbal cues, interview context, and emotional tone, which enriched the interpretation of narratives. The primary instrument for data collection in this study was a semi-structured interview guide, designed to capture rich, qualitative data from parents of children diagnosed with Autism Spectrum Disorder (ASD) who are enrolled in Nigerian schools. The guide was developed based on an extensive review of the literature on parental involvement, advocacy, and special education [23, 24], as well as insights from previous qualitative research on autism in Africa [5; 25].

The guide contained a mix of open-ended questions, follow-up prompts, and probes to encourage depth and clarity. The flexibility of the semi-structured format allowed the interviewer to pursue emerging themes while maintaining alignment with the study objectives [26]. To ensure content validity, the interview guide was reviewed by: Two experts in special education in Nigeria, one parent advocate and a qualitative research methods specialist. Their feedback helped refine question clarity, cultural relevance, and ethical sensitivity. A pilot test was conducted with two parents (not included in the main sample) to confirm the appropriateness and flow of the questions. Adjustments were made accordingly.

Methods of Data Analysis

Data analysis was conducted using thematic analysis as outlined [27]. This six-phase approach included: familiarization, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Emerging themes were cross-checked with theoretical frameworks, to ensure interpretive depth and coherence [28; 29].

Procedure for Data Collection

The primary method of data collection was semi-structured, in-depth interviews, which allowed participants to freely narrate their experiences while ensuring consistency across core topics. The interviews were conducted both face-to-face and via Zoom, depending on participants' preferences and logistical feasibility, and lasted between 45 to 75 minutes each. An interview guide was developed based on the research objectives and relevant literature. The questions focused on themes such as: Initial experiences with diagnosis; interactions with schools and teachers; types of advocacy activities engaged in; barriers and enablers in the school system; emotional and social support networks, and policy awareness and expectations. All interviews were audio-recorded with consent, transcribed verbatim, and anonymized to protect the identity of participants.

RESULTS AND DISCUSSION

Research Question 1: What forms of involvement and advocacy do Nigerian parents of children with autism engage in within the education system?

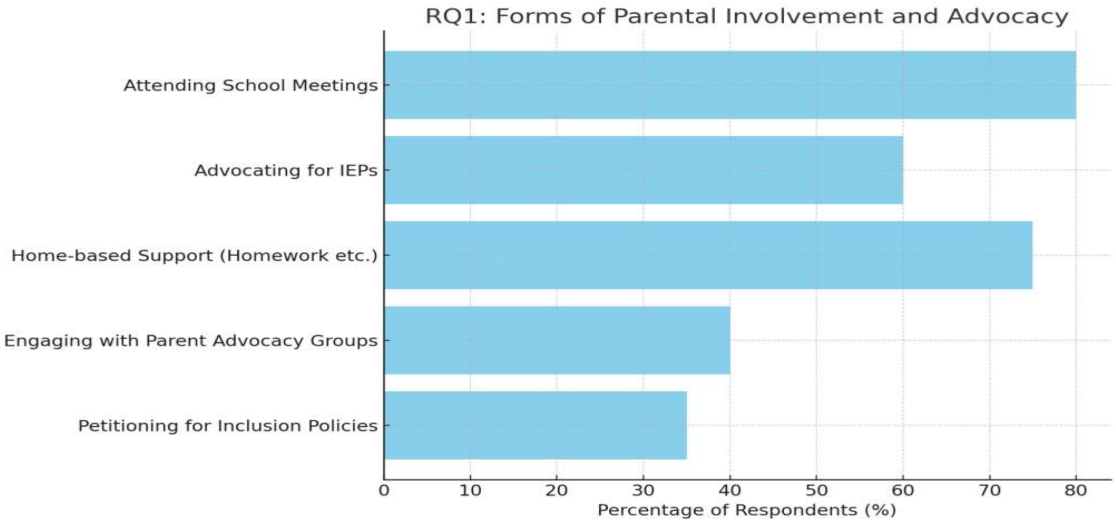

Figure 1: Forms of Parental Involvement and Advocacy

As shown in Figure 1, the result showed that the data reveals that attending school meetings (80%) and providing home-based academic support(75%) are the most common forms of parental involvement. Over 60%of parents report advocating for Individualized Education Programs (IEPs)**.** Engagement in parent advocacy groups and petitioning for inclusive policies were less frequent, though still significant, suggesting growing awareness and activism among parents.

Parents in the study actively engaged in various forms of involvement such as attending school meetings, advocating for individualized learning plans, and seeking out private therapy and intervention services. These findings align with [24], who emphasize the proactive roles parents often assume in sub-Saharan African contexts due to insufficient institutional support. In Nigeria, this form of "informal advocacy" often replaces the lack of structured institutional mechanisms for parent-teacher collaboration [30]. Internationally, [31] highlight the necessity of parent-school partnerships for optimal outcomes in special education, and the lack thereof often leads to parents taking on dual roles as caregivers and advocates. In the Nigerian context, this is further complicated by systemic inefficiencies in the education sector, such as untrained teachers and limited resources [32].

Research Question 2: What are the barriers and enablers to effective parental advocacy in the context of autism and special education in Nigeria?

Table 1: Parents rated financial constraints on Barriers and Enablers

Barrier/Enabler	N	Mean Score	Standard Deviation
Lack of Awareness about Autism	50	66.42	8.12
Cultural Stigma	50	59.51	8.88
Financial Constraints	50	73.90	6.87
Supportive School Staff	50	57.24	12.95
Access to Training	50	50.96	9.25
Negative Teacher Attitudes	50	55.99	7.92
Government Support Programs	50	40.55	11.01

As shown in table 1, the result showed that the data reveals Parents rated financial constraints as the most significant barrier to advocacy (M = 73.90), followed by lack of awareness(M = 66.42) and cultural stigma (M = 59.51). On the enabling side, while supportive school staff (M = 57.24) and access to training (M = 50.96) are moderately impactful, the low mean score for government support programs (M = 40.55) suggests underutilization or ineffectiveness of existing structures. These results underscore the need for systemic educational and policy reforms.

The study identified financial hardship, limited awareness, societal stigma, and bureaucratic rigidity as key barriers to effective parental advocacy. These challenges are not unique to Nigeria but are prevalent in many low- and middle-income countries (LMICs). For instance, [33] note that disability-related stigma significantly deters families from seeking educational services in African countries. The findings here affirm this, particularly with many parents citing fear of social exclusion or mislabeling as a reason for avoiding formal advocacy channels. On the enabling side, support from informed educators, exposure to advocacy workshops, and peer-to-peer mentoring emerged as positive factors. Similar observations are made by [34], who report that parental empowerment is strongly influenced by access to informational resources and emotional support networks.

Research Question 3: How do socio-cultural, economic, and institutional factors influence parental involvement in special education?

Table 2: Socio-cultural, economic, and institutional factors influence parental involvement

Factor	N	Mean Score	Standard Deviation
Socio-cultural Beliefs	50	57.75	9.24
Economic Hardship	50	75.21	10.39
Institutional Support	50	49.41	15.08

As shown in table 2, the result showed that the mean score for economic hardship **(**75.21) is notably the highest, highlighting financial strain as a significant inhibitor of parental involvement. Socio-cultural beliefs also show moderate influence (M = 57.75), indicating that perceptions and stigmas still affect engagement levels. Institutional support is the lowest (M = 49.41, SD = 15.08), suggesting inconsistency or lack of dependable school or government structures for parents. The influence of socio-economic status on parental involvement was evident in the data, with wealthier parents more likely to engage in higher levels of advocacy. This is consistent with findings by [35],who argue that socio-economic disparities significantly affect access to quality special education services in Nigeria. Parents from higher income brackets are often able to afford private diagnosis, therapy, and even international consultations, while those from lower-income backgrounds rely on overstretched public resources. Culturally, beliefs associating autism with spiritual punishment or witchcraft remain pervasive, particularly in rural areas [36]. These cultural perceptions create a climate of silence and shame, leading to under-reporting and reluctance to seek support. Institutional challenges, such as insufficient training of special education teachers and the absence of autism-specific curricula, exacerbate this issue [37].

Research Question 4: In what ways do parents interact with educators, school administrators, and policymakers in supporting their children's education?

Table 3: Stakeholder Interactions in supporting their children's education

Stakeholder Interaction	N	Mean Score	Standard Deviation
Interaction with Educators	50	63.88	10.43
Interaction with School Administrators	50	59.19	11.51
Interaction with Policymakers	50	40.38	15.90

As shown in table 3, the result showed that parents reported the highest engagement with educators(M = 63.88), reflecting regular teacher-parent communication. Interaction with school administrators was also substantial (M = 59.19), suggesting their involvement in educational planning and support. However, interactions with policy makers were significantly lower (M = 40.38), pointing to limited influence or participation in educational policy-making. This gap underscores the need for inclusive governance structures that value parental input in special education reforms. Data revealed robust engagement with educators and, to a lesser extent, with school administrators. However, interaction with policymakers was notably limited. This aligns with a broader critique of top-down policymaking in Nigeria's education sector, where parents are often excluded from policy discourse [38]. Parents' stronger engagement with educators reflects a dependence on classroom-level interactions rather than institutional advocacy, which is consistent with findings from [39], who advocate for structured platforms that enable direct dialogue between parents and policymakers. The gap identified in this study calls for the institutionalization of parent councils and representation in school governance structures.

Research Question 5: What coping strategies and support networks do parents utilize in the face of challenges?

Table 4: Reported Coping Strategies and Support Networks

Strategy/Support Network	Frequency	Percentage (%)
Personal Coping (e.g., prayer/meditation)	45	90.0%
Religious Groups	42	84.0%
Parent Support Groups	36	72.0%
Extended Family Support	31	62.0%
Online Communities	28	56.0%
Counseling Services	19	38.0%

As shown in table 4, the result showed the most prevalent coping mechanism reported by parents was personal coping strategies, including prayer or meditation (90%), followed closely by involvement in religious groups (84%). Parent support groups (72%) and extended family (62%) also played critical roles. Meanwhile, counseling services were the least utilized (38%), possibly due to accessibility issues or social stigma. These findings highlight the cultural reliance on faith-based and communal supports in Nigeria, with a relatively low uptake of professional mental health services. The data emphasized a heavy reliance on personal coping strategies such as prayer and meditation, as well as involvement in religious and peer support groups. This finding echoes the work of [40], who observed that Nigerian families often seek comfort and resilience in faith-based frameworks when faced with health and educational crises. These support networks offer emotional relief, practical advice, and a sense of community, especially in the absence of state support. Notably, the low uptake of professional counseling services may be attributed to both financial limitations and a lack of culturally sensitive services [41]. International studies, like that of [42], have shown that effective coping strategies in parents of children with autism significantly correlate with reduced stress and improved advocacy outcomes. Thus, integrating psychological support with existing religious and cultural frameworks could enhance coping effectiveness in the Nigerian context.

CONCLUSION

This study explored the forms, challenges, and determinants of parental involvement and advocacy in special education for children with autism in Nigeria. The findings reveal that while parents are deeply involved in their children's education—both informally and formally—they encounter numerous obstacles that hinder the full realization of their advocacy potential. These obstacles include financial burdens, limited awareness, cultural misconceptions, and a lack of institutional responsiveness. Despite these challenges, many parents have adopted creative strategies to support their children, drawing on religious faith, peer networks, and community-based resources. However, the effectiveness of these efforts is often moderated by broader socio-economic and institutional factors. Wealthier and more educated parents, for instance, were observed to be more effective in advocating for their children, highlighting the persistent inequalities within the system.

Interactions between parents and educators were relatively strong, but engagement with administrators and policymakers remained minimal. This indicates a disconnect between grassroots advocacy and policy-level influence, a gap that needs to be bridged for inclusive education policies to be fully effective. While supportive educators and community groups play an essential role, their efforts must be complemented by systemic reforms. Ultimately, the study underscores the need to empower Nigerian parents with the resources, knowledge, and institutional support necessary to become effective advocates. Addressing the identified barriers—especially cultural stigma, lack of awareness, and institutional inertia—is critical for building a truly inclusive educational environment for children with autism in Nigeria. The integration of parent voices into educational planning and policy formulation is not just desirable—it is essential.

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AUTHOR CONTRIBUTIONS STATEMENT

Name of Author	C	M	So	Va	Fo	I	R	D	O	E	Vi	Su	P	Fu
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CONFLICT OF INTEREST STATEMENT

Authors state no conflict of interest.

INFORMED CONSENT

All references used for the write-up of this paper have been adequately acknowledged under references.

ETHICAL APPROVAL

This study adhered strictly to ethical research protocols. Ethical approval was obtained from the University Research Ethics Committee, and informed consent was secured from all participants. Participants were informed of their right to withdraw at any stage without consequences, and assurances were given regarding confidentiality and data protection. Pseudonyms were assigned, and all digital files were stored on password-protected devices. Particular sensitivity was observed in handling emotionally charged topics, especially when discussing stigma or systemic failures, and appropriate referrals were provided for psychological support where necessary.

DATA AVAILABILITY

The data that support the findings of this study are available on request from the corresponding author, [Adebisi, R. O.]. The data, which contain information that could compromise the privacy of research participants, are not publicly available due to certain restrictions.

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