



CHALLENGES IN ACCESSING PRIMARY HEALTHCARE FOR CHILDREN WITH DISABILITIES IN ENUGU STATE: PERSPECTIVES FROM PARENTS

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Abstract

Background: Access to healthcare is an important determinant of health and wellbeing, but children with disabilities may encounter multiple and interrelated barriers when seeking healthcare. These barriers may involve communication, transportation, physical accessibility, availability of appropriate healthcare personnel and equipment, affordability, and negative attitudes towards disability.

Objective: To explore the challenges encountered by parents in accessing primary healthcare for children with disabilities in Enugu State, Nigeria.

Methods: A phenomenological qualitative research design was adopted. Five parents of children with disabilities were recruited through purposive and snowball sampling from selected special schools with boarding facilities in Enugu State. Data were collected using semi-structured in-depth interviews and analysed thematically. The broader study involved 56 participants, including special-school staff, parents, healthcare providers and healthcare-agency staff.

Results: Parents reported challenges related to communication, transportation and movement to and within healthcare facilities, inaccessible medical equipment, availability of healthcare personnel and services, payment for healthcare services and medications, inadequate health-insurance support, and discrimination and stigmatization. Communication difficulties were particularly important because parents often served as intermediaries between their children and healthcare professionals. Transportation was complicated by the need to accommodate wheelchairs and other mobility requirements. Within healthcare facilities, parents reported difficulties accessing examination rooms, toilets, diagnostic areas and examination equipment. Financial challenges resulted in substantial out-of-pocket expenditure, while negative attitudes were reported in public places, healthcare facilities and within families.

Conclusion: Parents of children with disabilities encounter multidimensional barriers to primary healthcare access in Enugu State. These barriers are interconnected and may prevent children from receiving timely, appropriate and equitable healthcare. Strengthening disability-inclusive primary healthcare requires improved communication support, accessible transportation and infrastructure, appropriate medical equipment, adequate healthcare personnel, financial protection and effective implementation of disability-related policies.

Keywords: Children with disabilities; primary healthcare; healthcare access; parents; disability; Enugu State; Nigeria; universal health coverage.

Introduction

Cataract surgery is the commonly performed ophthalmic procedure and is typically conducted under general anesthesia. Access to healthcare is a multidimensional process involving the ability of individuals to recognise a health need, seek care, reach healthcare facilities, interact with healthcare professionals and obtain appropriate services.¹ Children with disabilities may experience additional difficulties because of physical, communication, sensory, intellectual and social barriers. The World Health Organization has recognised that people with disabilities experience additional barriers to mainstream and specialist healthcare services despite having the same fundamental right to healthcare as everyone else.²

Healthcare access for children with disabilities is influenced by several interacting factors. These include awareness and communication, geographical and physical accessibility, availability of healthcare personnel and services, affordability, and attitudes towards disability.³⁻⁶ Such challenges can occur across the continuum of primary healthcare, including health promotion, disease prevention, treatment, rehabilitation and supportive care.⁷

Communication is particularly important for children with hearing, speech, intellectual or other communication impairments. Parents frequently become instrumental in communicating with healthcare professionals on behalf of their children. Communication barriers between children, parents, teachers and healthcare professionals may create gaps in care and may contribute to adverse health outcomes.⁸ The problem can be compounded when healthcare workers lack appropriate communication strategies or disability-specific training.

Transportation is another important determinant of healthcare access. Children with mobility impairments may require wheelchairs or other assistive devices, making conventional public transportation difficult to use. Evidence from Nigeria and other settings has identified problems involving transportation infrastructure, vehicle accessibility, driver attitudes and the additional burden placed on caregivers.⁹⁻¹¹

Physical accessibility within healthcare facilities is equally important. The presence of a healthcare facility does not necessarily guarantee access when patients cannot enter consulting rooms, laboratories, diagnostic units or restrooms, or when examination equipment is inaccessible.¹²⁻¹⁴ Inaccessible examination tables and weighing equipment may also raise concerns regarding safety and quality of care.¹⁵

Availability of appropriate healthcare personnel, medicines and equipment is another challenge. Children with disabilities may require healthcare professionals with disability-specific competencies and access to rehabilitation and other specialised services. Inadequate staffing, equipment and medicines can reduce the capacity of healthcare facilities to respond adequately to their needs.¹⁶⁻¹⁸

Financial barriers may further restrict healthcare utilisation. Families caring for children with disabilities may incur additional expenses related to medicines, specialised food, assistive devices, transportation and repeated healthcare visits.¹⁹⁻²¹ High out-of-pocket expenditure can therefore place considerable pressure on families and may result in difficult choices between the healthcare needs of the child and those of other household members.

Attitudinal barriers are also important. Children with disabilities and their caregivers may experience stigma, discrimination, mockery, segregation, neglect and inadequate empathy in public places, healthcare facilities and within families.²²⁻²⁵ Negative attitudes among healthcare professionals may discourage families from seeking care or may compromise the quality of the healthcare encounter.

Nigeria has established legislative and policy frameworks intended to protect persons with disabilities, including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the Discrimination Against Persons with Disabilities (Prohibition) Act and the National Health Insurance Authority framework.^{26–28} However, the existence of legislation does not necessarily guarantee implementation or effective access to healthcare.

In Enugu State, there is limited qualitative evidence specifically documenting how parents experience these barriers while seeking primary healthcare for children with disabilities. Understanding these experiences is essential for developing disability-inclusive health services and advancing universal health coverage (UHC). This study therefore explored the challenges encountered by parents in accessing primary healthcare for their children with disabilities in Enugu State.

2. Methods

2.1 Study design: The study employed a phenomenological qualitative research design to explore the experiences of stakeholders regarding access to primary healthcare for children with disabilities.

2.2 Study setting: The study was conducted in selected special schools with boarding facilities in Enugu State. The schools were registered under the Enugu State Ministry of Education and included public, private and faith-based special schools. The study focused on challenges encountered while obtaining primary healthcare for children with disabilities.

2.3 Study participants and sampling: The parent subgroup consisted of five parents of children with disabilities. The wider study involved 56 participants comprising special-school staff, parents, healthcare providers and healthcare-agency staff. Four of the five parents were self-employed. Participants were recruited using purposive and snowball sampling. The study report indicates that five parents, four healthcare providers and three healthcare-agency staff were among the stakeholder participants.

2.4 Data collection: Data were collected using semi-structured in-depth interviews and focus group discussions. Interview guides were developed by the researcher for the different participant categories and included questions concerning the challenges encountered in accessing primary healthcare for children with disabilities.

2.5 Data analysis: Data were manually analysed using thematic analysis. The broader study identified six major themes: extracting and understanding information; getting to the healthcare facility and using services when needed; access within the hospital; obtaining required healthcare services; funding healthcare for children with disabilities; and attitudinal influences.

2.6 Ethical considerations: Participants gave informed consent before participation. Confidentiality and anonymity were maintained during data collection and reporting.

3. Results

3.1 Parent characteristics

Five parents participated in the study. Four of the five parents were self-employed. The thesis interpreted this finding in relation to the substantial amount of time required to care for children with disabilities, noting that such caregiving responsibilities may be difficult to combine with conventional public- or private-sector employment.

3.2 Communication challenges

Communication emerged as an important challenge in accessing healthcare. Communication with children with disabilities in hospital was perceived as considerably more difficult than communication with children without disabilities. Parents were instrumental in communicating their children's health problems to healthcare professionals. The study found that communication difficulties could create gaps in care and potentially contribute to missed or delayed diagnosis.

One parent described an experience in which inadequate communication contributed to a missed diagnosis that almost resulted in a serious adverse outcome for her son. The finding illustrates the importance of effective communication between children with disabilities, their caregivers and healthcare providers. Communication difficulties have similarly been reported among children with disabilities and among patients with communication disorders.^{8, 29, 30}

3.3 Knowledge and awareness of disability rights

The study found limited knowledge among respondents concerning regulations and policies intended to protect the healthcare rights of children with disabilities. The thesis reported that many respondents, particularly parents, had limited awareness of relevant disability legislation and questioned its effectiveness.

Limited awareness of disability rights may prevent parents from demanding services and accommodations to which their children are legally entitled. The thesis further noted that effective dissemination of information concerning disability policies and rights is necessary, particularly through accessible communication channels and different languages.

3.4 Transportation and external accessibility

Accessibility challenges became particularly apparent when children needed healthcare outside the school environment. Although the special schools generally had school clinics and most had functioning school buses, problems involving vehicle maintenance, drivers, roads and transport availability were reported.

Public transportation posed additional challenges. Parents and other respondents reported inadequate space for wheelchairs and uncomfortable seating arrangements for children with disabilities in commercial buses, tricycles and motorcycles. Some healthcare facilities were also located considerable distances from the schools or homes of the children.

Transportation barriers may lead to delayed healthcare utilisation. Families may experience considerable physical, logistical and financial burdens when travelling with children requiring wheelchairs or other assistive equipment. These findings are consistent with previous evidence concerning transport barriers among persons with disabilities.⁹⁻¹¹

3.5 Internal accessibility within healthcare facilities

Parents and healthcare professionals reported difficulties accessing several areas within healthcare facilities. These included examination rooms, examination beds, restrooms, laboratory areas, X-ray rooms and ultrasound units. When children using wheelchairs could not enter some areas, parents, caregivers or school staff sometimes had to lift and carry them.

The findings also revealed concerns about inaccessible medical equipment. Height-inaccessible examination tables and non-wheelchair-accessible weighing scales may compromise safety and quality of care. Similar concerns have been documented concerning accessibility of medical diagnostic equipment for patients with disabilities.¹²⁻¹⁵

3.6 Availability of healthcare personnel, medicines and equipment

Although all the special schools had school clinics, the availability of healthcare personnel varied considerably. Nurses in private special schools were reported to be more consistently available, including outside normal working hours, whereas nurses in public special schools were less consistently available.

Participants reported the absence of specialist doctors able to manage children with disabilities and shortages of medicines in school clinics and health centres. Inadequate medical equipment was also reported. Some healthcare professionals improvised in order to provide services when appropriate equipment was unavailable.

These findings indicate that healthcare availability involves more than the physical existence of a healthcare facility. Appropriate personnel, medicines, equipment and disability-responsive services must also be available when required.

3.7 Financial and affordability challenges

Financial difficulty was a major challenge. Participants reported that many parents were considered poor and had difficulty paying for healthcare. Children with disabilities may require additional expenditure for special food, assistive devices, transportation and medical appointments.

Healthcare payments were often required before services were provided, resulting in substantial out-of-pocket expenditure. Some parents lived outside Enugu State and had difficulty settling healthcare bills after treatment. The financial consequences of caring for a child with a disability may also affect siblings and other members of the extended family.^{19–21}

Only a small number of philanthropists were reported to provide healthcare assistance. Charity organisations generally provided food, snacks, drinks, toiletries and other material support rather than sustained healthcare financing. The thesis also identified limited financial capacity among NGOs as a possible explanation.

3.8 Health-insurance and government financing challenges

The study found limited government financial support for healthcare among children with disabilities. According to the findings, there was no specific health-benefit package adequately addressing the healthcare needs of children with disabilities within the study setting.

Most children in the special schools were reportedly not enrolled under the National Health Insurance Authority, apart from a small number who may have been covered through their parents. Consequently, healthcare costs were primarily borne by parents. The thesis further reported difficulties involving health-maintenance organisations, delays, administrative bottlenecks and inadequate benefits.

These findings are consistent with evidence that inadequate insurance coverage and high out-of-pocket expenditure can create substantial barriers to healthcare for people with disabilities.^{20,21}

3.9 Attitudinal challenges in public places

Parents reported negative attitudes towards children with disabilities in public places, including mockery and name-calling during transportation to healthcare facilities. Some commercial vehicle drivers were also reported to discriminate against children with disabilities, particularly wheelchair users.

These findings are consistent with reports of discrimination and lack of empathy towards people with disabilities in transportation settings.^{9,31,32} Negative attitudes can discourage families from seeking healthcare and may increase the emotional burden associated with healthcare utilisation.

3.10 Attitudinal challenges within healthcare facilities

Parents reported negative attitudes among some healthcare workers, including lack of empathy, unfriendly behaviour, irritability and inadequate willingness to provide care. However, positive examples were also identified, including healthcare professionals who provided free or subsidised treatment and healthcare personnel who assisted with communication.

The findings suggest substantial variability in healthcare-provider attitudes. Knowledge and disability competence may influence these attitudes, and appropriate disability training may improve healthcare professionals' ability to provide respectful and responsive care.^{33,34}

3.11 Attitudinal challenges within families

The five parents participating in the study demonstrated positive attitudes towards their children; however, the broader findings revealed substantial negative attitudes towards children with disabilities within some families. Some parents reportedly prioritised the needs of children without disabilities before attending to children with disabilities. Others reportedly hid their children at home or considered sending them to school a waste of resources.

The study also identified considerable hardship among some mothers, including abandonment by husbands and inadequate family support. Such experiences demonstrate that healthcare access cannot be separated from the wider social and economic environment in which families care for children with disabilities.

3.12 Policy implementation and healthcare access

The study reviewed the UNCRPD, the Discrimination Against Persons with Disabilities (Prohibition) Act and the National Health Insurance framework. The findings suggested a substantial gap between policy provisions and implementation. Although the legislation provides for accessibility, non-discrimination and protection of persons with disabilities, participants reported limited practical implementation.

The study further found limited awareness among parents regarding disability rights. The thesis noted that even where parents were aware of relevant policies, their knowledge was often limited and they remained uncertain about how to obtain the rights and services provided for under the policies.

The absence of sign-language interpreters in major public hospitals used by the participants was identified as an important gap. Similarly, the reported absence of reserved parking spaces and limited enforcement of accessibility provisions further illustrated the implementation gap.

4. Discussion

4.1 Principal finding

The findings demonstrate that parents of children with disabilities encounter multiple and interconnected barriers when accessing primary healthcare. These barriers occur across the entire healthcare pathway, from communication and decision-making to transportation, entry into healthcare facilities, clinical assessment, payment for services, and interactions with healthcare personnel.

4.2 Communication and awareness

Communication difficulties were among the most important challenges identified. Parents frequently functioned as intermediaries between their children and healthcare providers. This creates an additional caregiving responsibility and may compromise the completeness and accuracy of clinical information when communication mechanisms are inadequate. The finding is consistent with evidence that parents and healthcare professionals experience multiple communication barriers when caring for children with complex healthcare needs.⁸

4.3 Accessibility

Physical accessibility was not restricted to reaching the healthcare facility. Parents encountered barriers within facilities, including inaccessible examination rooms, restrooms, and diagnostic units. The need to lift children from wheelchairs demonstrates how inaccessible infrastructure transfers the physical burden of healthcare access from the health system to families. Similar structural barriers have been documented in healthcare systems internationally.^{12–15}

4.4 Availability

The study revealed shortages of healthcare personnel, medicines, and appropriate equipment. In particular, the limited availability of specialist healthcare services for children with disabilities may result in delayed or incomplete care. Disability-responsive healthcare requires adequate human and material resources rather than simply the physical presence of a healthcare facility.

4.5 Affordability

Financial barriers were particularly significant because healthcare expenditure for children with disabilities may extend beyond routine consultation and medication costs. Families may also need to finance transportation, assistive devices, special food, and rehabilitation. High out-of-pocket payments can therefore create continuing financial vulnerability.^{19–21}

4.6 Attitudinal barriers

Negative attitudes towards children with disabilities were reported at public, healthcare-facility, and family levels. These included discrimination, mockery, stigma, lack of empathy, and neglect. Importantly, the findings also demonstrate that positive attitudes are possible, as some healthcare professionals and parents demonstrated empathy and advocacy.

4.7 Policy and implementation

The findings highlight an implementation gap between disability-related legislation and the actual healthcare experiences of families. The existence of policies does not automatically translate into accessible healthcare. Effective implementation requires enforcement, monitoring, disability awareness, adequate resources, and mechanisms through which violations can be reported.

4.8 Universal health coverage implications

The findings have important implications for universal health coverage (UHC). UHC requires people to obtain the healthcare services they need without financial hardship.³⁵ Children with disabilities cannot be considered effectively covered when they remain unable to communicate with healthcare providers, reach healthcare facilities, navigate the physical environment, obtain appropriate equipment, or afford required services. The thesis similarly concluded that inadequate healthcare access for children with disabilities may impede achievement of UHC in Enugu State and Nigeria.

5. Strengths and Limitations

Strengths

The study provides detailed first-hand accounts from parents caring for children with disabilities and examines healthcare access across multiple dimensions. The use of qualitative interviews allowed experiences that may not be captured by quantitative surveys to be explored in depth. The broader study also included other stakeholder groups, enabling comparison of perspectives.

Limitations

The parent subgroup consisted of only five participants; therefore, the findings should be interpreted as an in-depth qualitative account rather than a prevalence estimate. The study was conducted in Enugu State and may not be generalisable to other Nigerian states with different social, economic, and healthcare environments. The thesis also noted that all participants belonged to one religion, which may have influenced some findings concerning beliefs and cultural interpretations of disability. Interview interruptions and emotional distress experienced by some parents also affected aspects of the data-collection process.

6. Conclusion

Parents of children with disabilities in Enugu State encounter substantial challenges in accessing primary healthcare. These challenges encompass communication and awareness, transportation and physical accessibility, availability of healthcare personnel and equipment, affordability, health-insurance coverage, and negative attitudes. These barriers frequently occur simultaneously and may reinforce one another.

The findings indicate that the physical presence of healthcare services does not necessarily constitute effective access for children with disabilities. Achieving equitable access requires disability-responsive healthcare facilities, accessible transportation, appropriate medical equipment, trained healthcare personnel, effective communication mechanisms, and adequate financial protection.

Improving healthcare access for children with disabilities will contribute to a more inclusive healthcare system and support the principle of leaving no one behind. The thesis recommends stronger enforcement, implementation, and monitoring of disability-related policies, disability competence among healthcare providers, public awareness, and financial assistance for families caring for children with disabilities.

7. Recommendations

Based on the findings of the study, the following recommendations are proposed:

i. Healthcare-provider competence

Disability competence or “disability consciousness” should be incorporated into the training and continuing professional development of healthcare providers to enhance their knowledge, attitudes, communication skills, and capacity to respond appropriately to the healthcare needs of children with disabilities.

ii. Public awareness

The government should support sustained public-awareness programmes that provide accurate and accessible information on disability, the rights of children with disabilities, and available healthcare and support services. Such programmes should aim to reduce stigma, discrimination, and misconceptions surrounding disability.

iii. Policy implementation

Commitments under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the National Health Insurance framework, and the Discrimination Against Persons with Disabilities (Prohibition) Act (DAPDAN) should be effectively implemented, monitored, and enforced to ensure that existing policy provisions translate into meaningful improvements in healthcare access.

iv. Financial protection

Government should provide stronger financial assistance and subsidised health-insurance coverage for children with disabilities and their families to reduce the burden of out-of-pocket healthcare expenditure and improve access to needed healthcare services.

v. Accessible infrastructure

Healthcare facilities should be designed and modified to accommodate children with disabilities. This should include accessible entrances, toilets, examination rooms, diagnostic areas, parking spaces, and appropriate medical equipment to facilitate safe and equitable access to healthcare.

vi. Communication support

Disability-inclusive communication mechanisms should be available within healthcare facilities. Where required, this should include sign-language interpretation and other appropriate communication support to enable effective interaction between children with disabilities, their parents or caregivers, and healthcare providers.

vii. Transportation

Disability-inclusive transportation should be incorporated into healthcare-access planning, particularly for children who use wheelchairs or require other forms of mobility assistance. Transportation systems should accommodate their mobility needs and reduce the logistical barriers associated with accessing healthcare facilities.

viii. Monitoring and accountability

Relevant authorities should establish effective mechanisms for monitoring the implementation of disability legislation and policies and for responding appropriately to reported violations. Regular monitoring and accountability should be used to ensure that legislative provisions translate into practical improvements in healthcare access for children with disabilities.

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