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CHALLENGES IN ACCESSING PRIMARY HEALTHCARE FOR CHILDREN WITH DISABILITIES IN ENUGU STATE: PERSPECTIVES FROM STAFF OF HEALTHCARE AGENCIES

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Abstract

Background: Children with disabilities (CWDs) frequently encounter multiple and interrelated barriers to accessing primary healthcare. These barriers may occur at individual, community, health-facility and health-system levels and may undermine equitable access to healthcare and the achievement of universal health coverage (UHC). The study aims to explore the perspectives of staff of healthcare agencies regarding challenges encountered in accessing primary healthcare for CWDs in Enugu State, Nigeria.

Methods: A phenomenological qualitative design was used as part of a broader study examining healthcare access for CWDs attending special schools in Enugu State. Three healthcare-agency staff representing relevant government health agencies, including the National Health Insurance Authority (NHIA), Universal Health Coverage (UHC) and National Primary Health Care Development Agency (NPHCDA), participated in in-depth interviews. The wider study included 56 participants comprising special-school staff, parents, healthcare providers and healthcare-agency staff. Data were collected using semi-structured interview guides and analysed thematically. Policy documents relating to disability rights and healthcare access were also reviewed.

Results: Healthcare-agency staff identified interconnected challenges involving awareness and communication, transportation and physical accessibility, availability of appropriate healthcare personnel and equipment, affordability and limitations of health-insurance coverage, and negative attitudes towards CWDs. Limited awareness of disability-related legislation was evident among some agency personnel. One agency participant reported knowledge of UHC but limited knowledge of other relevant international policies, while agency staff demonstrated differing levels of knowledge regarding the Discrimination Against Persons with Disabilities (Prohibition) Act (DAPDAN). Transportation was particularly problematic for children using wheelchairs, with difficulties involving vehicle access, transfer between wheelchairs and vehicles, and additional

transportation costs. Agency staff also identified the absence of disability-specific communication support, including sign-language interpreters, within healthcare facilities. Health-insurance limitations included inadequate coverage of disability-related needs and the absence of specific provisions for CWDs in the studied setting. Negative attitudes and stigma were also reported in public and family environments.

Conclusion: From the perspective of healthcare-agency staff, inadequate access to primary healthcare for CWDs in Enugu State reflects a system-wide problem extending beyond the physical availability of healthcare facilities. Strengthening disability-responsive financing, transportation, communication support, healthcare infrastructure, provider competence, public awareness and implementation of disability-related legislation is necessary to advance equitable healthcare access and UHC.

Key Words: children with disabilities; primary healthcare; healthcare access; healthcare agencies; disability; universal health coverage; Enugu State; Nigeria.

Introduction

Access to healthcare is a multidimensional concept encompassing the ability of individuals to identify healthcare needs, seek and reach appropriate services, obtain care and benefit from services that respond adequately to their health needs. For children with disabilities, access may be particularly challenging because disability can interact with communication barriers, transportation difficulties, inaccessible environments, inadequate healthcare resources, financial constraints and social discrimination.[1,2]

Children with disabilities require equitable access to preventive, promotive, curative, rehabilitative and supportive healthcare. However, the existence of a healthcare facility does not necessarily guarantee meaningful access. Structural, financial, informational and attitudinal barriers can prevent children with disabilities from obtaining appropriate care.[3]

Communication represents an important dimension of access. Healthcare professionals may experience difficulties obtaining accurate information directly from children with communication or sensory impairments, resulting in increased dependence on parents, caregivers, teachers or other intermediaries. Communication barriers between families, children and healthcare professionals may contribute to gaps in care and missed healthcare needs.[4,5]

Physical accessibility is similarly multidimensional. It includes transportation to healthcare facilities and accessibility within facilities, including consultation rooms, toilets, diagnostic units and medical equipment. Studies have demonstrated that inaccessible transport and healthcare infrastructure remain important barriers for persons with disabilities, including in low- and middle-income settings.[6–9]

Availability of appropriate healthcare personnel, specialist services, medicines and disability-accessible equipment is another important component of effective access. Resource limitations may result in delayed assessment, inappropriate care or the need for families and caregivers to compensate for deficiencies within the healthcare system.[10]

Financial barriers are also important because disability may generate additional healthcare-related expenditure, including transportation, rehabilitation, assistive devices, medicines and specialised services. High out-of-pocket expenditure may therefore disproportionately affect families caring for children with disabilities.[11,12]

Attitudinal barriers, including stigma and discrimination, may occur within families, communities, transport systems and healthcare facilities. Such attitudes can influence healthcare-seeking behaviour and may discourage families from seeking care.[13,14]

Nigeria has adopted disability-related legislation and international commitments intended to promote inclusion and protect the rights of persons with disabilities. The UN Convention on the Rights of Persons with Disabilities and Nigerian disability legislation establish important principles relating to accessibility, equality and participation.[15,16] Nevertheless, the existence of legislation does not automatically guarantee implementation.

Against this background, understanding the perspectives of healthcare-agency staff is important because these personnel occupy strategic positions within the health system and are involved in policy implementation, financing, programme development and health-system coordination. Their perspectives can therefore identify system-level barriers that may not be readily apparent from the experiences of families alone.

2. Methods

2.1 Study design

The study formed part of a broader phenomenological qualitative investigation of challenges encountered in accessing primary healthcare for CWDs attending special schools in Enugu State. The broader study used in-depth interviews, focus group discussions and review of relevant policy documents.

2.2 Study participants

The broader study included 56 participants. These comprised staff of four special schools, five parents of CWDs, four healthcare providers and three healthcare-agency staff. The healthcare-agency participants represented government health agencies, including the NHIA, UHC and NPHCDA.

The present manuscript focuses specifically on the perspectives of the three healthcare-agency staff. All three participated in in-depth interviews.

2.3 Data collection

Semi-structured interview guides were developed for the different participant groups. The questions addressed challenges related to awareness, accessibility, availability, affordability and attitudes towards CWDs. The guides were adapted to capture the specific experiences and responsibilities of healthcare-agency personnel.

2.4 Data analysis

Interview data were analysed thematically. The broader study generated six major themes and fourteen subthemes concerning access to healthcare. These included communication and knowledge of policies; transportation and access to healthcare facilities; accessibility within healthcare facilities; availability of healthcare personnel and resources; funding; and attitudinal influences.

2.5 Ethical considerations

Participants consented to participate in the study. Interviews were conducted at mutually agreed locations and in the participant's preferred language, either English or Pidgin English.

3. Results

3.1 Characteristics of healthcare-agency participants

Three healthcare-agency staff participated in the study, representing the government health-system agencies involved in health insurance, UHC and primary healthcare development. They constituted 5.4% of the 56 participants in the broader study.

3.2 Awareness, communication and knowledge of disability-related policies

The healthcare-agency staff identified limited awareness and inconsistent knowledge of disability-related policies as an important challenge. Although one agency participant demonstrated knowledge of UHC, awareness of other international disability-related policies was limited.

Knowledge of DAPDAN was similarly inconsistent. One agency participant indicated that the Act was known but not implemented, whereas another agency participant reported not knowing the regulation or whether it was operational.

These findings indicate a gap between the existence of disability-related policies and their dissemination and operationalisation among personnel responsible for health-system functions.

Communication was also identified as a practical barrier to healthcare access. The broader findings indicated that healthcare providers and caregivers often depended on parents, teachers or other caregivers to communicate children's health complaints.

An agency participant specifically advocated for the availability of sign-language interpreters and disability-specific communication support in healthcare facilities. The participant noted that such personnel could improve communication between healthcare providers and children with hearing or speech impairments.

3.3 Transportation and external accessibility

Transportation emerged as a major barrier, particularly for children who use wheelchairs. An agency participant described observing children being transferred from wheelchairs into vehicles and subsequently transferred back into wheelchairs after reaching the healthcare facility. Wheelchairs were sometimes placed in vehicle boots or secured on top of vehicles, illustrating the lack of disability-responsive transportation.

The agency perspective therefore suggests that transportation barriers extend beyond distance. They include vehicle design, wheelchair storage, physical transfer, availability of suitable transport and the financial burden associated with using more appropriate private transportation.

3.4 Accessibility within healthcare facilities

The broader findings indicated that physical access problems persisted after patients reached healthcare facilities. Examination areas, toilets, diagnostic units and other parts of hospitals could be difficult to access for wheelchair users. Children who could not independently access such spaces were sometimes physically lifted and carried by parents, caregivers or school staff.

The findings further indicated concerns about inaccessible examination equipment and other medical equipment. Such deficiencies can create safety concerns and may compromise the quality of clinical assessment.

3.5 Availability of healthcare personnel and disability-specific services

Healthcare-agency staff recognised the importance of disability-specific human resources within healthcare facilities. In particular, the availability of sign-language interpreters was considered important for improving access among children with hearing or speech impairments. However, such personnel were reported to be unavailable.

The broader findings also identified shortages of specialist personnel, medicines and appropriate medical equipment. School clinics in some settings relied on nurses with limited availability, while specialist services for CWDs were inadequate.

3.6 Financial barriers and health-insurance coverage

Healthcare-agency staff identified important limitations in existing health-insurance arrangements. Agency participants reported that some disability-related needs, including congenital conditions, hearing aids and some visual aids, were not covered by the existing insurance arrangements. They also reported that CWDs in special schools had not been adequately captured within the relevant scheme and that specific provisions for their healthcare needs were lacking.

The wider study showed that healthcare costs were largely borne by parents and that out-of-pocket payments constituted an important component of healthcare financing for CWDs. The thesis also identified limitations in the scope and effectiveness of health-insurance coverage.

3.7 Community and family attitudes

Healthcare-agency staff also described disability-related stigma at community and family levels. One agency participant described encountering a child with disability who was hidden within the home because of social stigma. The participant emphasised that acceptance and care for CWDs should begin within the family.

The broader findings demonstrated that stigma and discrimination could extend from public spaces to healthcare facilities and families. These included mockery, social avoidance, negative labelling and discriminatory treatment.

3.8 Policy implementation gap

A central finding from the healthcare-agency perspective was the gap between policy formulation and implementation. Agency staff expressed differing levels of knowledge of DAPDAN, with one reporting that the Act had been heard of but was not implemented and another indicating a lack of knowledge of the regulation.

The thesis's policy review similarly demonstrated that disability legislation contains provisions concerning accessibility, transportation, accommodation and protection from discrimination, while implementation remains inadequate.

4. Discussion

The perspectives of healthcare-agency staff demonstrate that barriers to primary healthcare for CWDs in Enugu State are systemic and interconnected. They extend from knowledge and communication to transportation, physical accessibility, availability of appropriate personnel and equipment, financing, health-insurance coverage and social attitudes. These findings are consistent with the broader thesis conclusion that inadequate healthcare access for CWDs reflects simultaneous challenges in awareness, accessibility, availability, affordability and attitudes.

Limited awareness of disability-related policies among some healthcare-agency personnel is particularly important because agencies responsible for health financing, planning and programme implementation are strategically positioned to translate legislation into services. Lack of policy awareness may weaken implementation and reduce the capacity of personnel to advocate for disability-inclusive services. Evidence from Nigeria similarly indicates that awareness of disability rights and the institutional mechanisms for accessing such rights remains limited.[15]

Communication barriers may also compromise clinical assessment and continuity of care. Previous evidence has shown that parents, healthcare professionals and teachers experience multiple communication challenges when caring for children with complex healthcare needs.[4] Communication difficulties can consequently result in incomplete histories, reliance on inference and missed opportunities for diagnosis or intervention.[5]

The agency participant's recommendation for sign-language interpreters and disability-specific communication support is therefore highly relevant. Such support should be regarded as a component of accessible healthcare rather than an optional additional service.

The transportation experiences described by healthcare-agency staff demonstrate that geographical proximity alone does not ensure accessibility. Wheelchair users may face multiple sequential barriers involving vehicle access, wheelchair storage, physical transfer and movement from the vehicle to the healthcare facility.

These findings are consistent with evidence from Nigeria demonstrating transportation difficulties among persons with physical disabilities.[6,7] Similar concerns have been identified elsewhere in Africa, where transportation systems and built environments may fail to accommodate people with mobility limitations.[8]

Importantly, the burden of inaccessible transportation is transferred to families and caregivers. The requirement to physically lift a child or dismantle and transport a wheelchair represents an additional burden that should be addressed through disability-inclusive transportation planning.

The study demonstrates that healthcare access does not end at the entrance of the hospital. Inaccessible consultation rooms, toilets, diagnostic areas and examination equipment can continue to prevent effective use of healthcare services.

This finding agrees with evidence that structural barriers may occur in healthcare offices, consultation rooms, laboratories, diagnostic areas and restrooms.[9,10] Inaccessible medical diagnostic equipment can also compromise safety and quality of care.[11]

For CWDs, therefore, accessibility should be incorporated throughout the patient pathway rather than treated solely as an architectural issue.

The absence of disability-specific personnel, including sign-language interpreters, represents an important health-system gap. The agency participant's recognition of the need for such personnel suggests that disability-inclusive services require both infrastructure and human-resource interventions.

The wider findings also identified shortages of specialist healthcare personnel, medicines and appropriate equipment. This is consistent with literature identifying inadequate healthcare resources as a barrier to effective healthcare for people with disabilities.[12]

Disability competence should therefore be incorporated into healthcare-worker education and continuing professional development. Training should include communication with children with different impairments, appropriate physical handling, disability rights, reasonable accommodation and respectful, person-centred care.

The findings indicate that health-insurance arrangements do not adequately protect families caring for CWDs from healthcare-related financial burden. Agency staff specifically identified exclusions involving some congenital conditions, hearing aids and certain visual aids and reported that CWDs in special schools were not adequately captured within the relevant scheme.

This is important because disability-related healthcare expenditure may involve recurrent costs for medicines, rehabilitation, assistive devices, transportation and specialist services.[13,14]

The continued reliance on out-of-pocket payment undermines financial protection, a central component of UHC. The findings therefore suggest the need for disability-responsive health-insurance benefit packages that explicitly cover essential services and assistive technologies required by CWDs.

Stigma and discrimination were identified across public, healthcare and family settings. The agency participant's account of a child being hidden within the home illustrates how social stigma can become an obstacle to healthcare itself.

Discrimination can also extend to caregivers. Evidence suggests that stigma associated with autism and intellectual disability may extend to family caregivers.[15] Within healthcare facilities, negative attitudes may manifest as impatience, avoidance, poor communication or reluctance to provide care.

However, the thesis also identified positive examples of empathy and advocacy. This is important because it indicates that negative attitudes are not inevitable. Healthcare-provider training, disability awareness and institutional leadership can contribute to more respectful and responsive care. Evidence from healthcare professionals in other settings similarly demonstrates that knowledge and disability competence can influence attitudes.[16]

The most important system-level finding is the implementation gap between disability-related legislation and actual service delivery. Nigeria has adopted disability-related legislation and is a party to international disability-rights instruments, but the findings indicate that policy provisions are not consistently translated into accessible services.

The policy review within the thesis identified provisions concerning accessibility, transportation, accommodation and protection from discrimination, yet implementation remains incomplete.

The implications are substantial. Policies without implementation mechanisms, monitoring, accountability and adequate financing may have limited practical effects. Effective implementation therefore requires defined responsibilities, resource allocation, monitoring indicators, enforcement mechanisms and accessible complaint and redress systems.

The findings have direct implications for UHC. UHC requires people to obtain needed health services without financial hardship.[17] For CWDs, effective coverage requires more than nominal eligibility for services. A child cannot be regarded as effectively covered when the child cannot reach the healthcare facility, enter the consultation room, communicate with providers, access appropriate equipment, obtain required specialist services or afford treatment.

The thesis similarly concluded that inadequate access to healthcare for CWDs may continue to impede the actualisation of UHC in Enugu State and Nigeria.

5. Strengths and Limitations

Strengths

This study provides an important health-system perspective by focusing specifically on healthcare-agency personnel who occupy strategic positions in health financing, UHC and primary healthcare development. The broader qualitative design also allowed triangulation across healthcare-agency staff, healthcare providers, parents and special-school staff. The use of in-depth interviews enabled participants to describe complex barriers that may not be adequately captured through quantitative approaches.

Limitations

The healthcare-agency subgroup comprised only three participants; consequently, the findings should be interpreted as an in-depth qualitative account rather than a representative assessment of all healthcare agencies in Enugu State. The study was conducted in Enugu State and the experiences may differ in other Nigerian states because of differences in health-system organisation, resources, disability services and socioeconomic conditions. The thesis also acknowledged limitations associated with the broader study, including interview-scheduling difficulties and the predominantly Christian composition of participants.

6. Conclusion

Staff of healthcare agencies identified substantial and interconnected barriers to primary healthcare access for children with disabilities in Enugu State. The barriers extend across awareness and communication, transportation, physical accessibility, availability of healthcare personnel and equipment, affordability, health-insurance coverage and social attitudes.

The findings demonstrate that healthcare access for CWDs cannot be achieved simply by increasing the physical availability of healthcare facilities. A genuinely disability-responsive health system must ensure accessible transportation and infrastructure, appropriate medical equipment, adequate healthcare personnel, disability-specific communication support, comprehensive financial protection and respectful treatment.

The policy implementation gap is particularly important. Although Nigeria has disability-related legislation and international commitments, effective implementation, monitoring and enforcement remain necessary to translate these provisions into meaningful healthcare access. The findings therefore have important implications for achieving equitable healthcare and UHC in Enugu State and Nigeria.

7. Recommendations

1. Disability competence: Disability competence should be incorporated into the education and continuing professional development of healthcare workers, including training in communication with children with sensory, intellectual and developmental disabilities.
2. Communication support: Healthcare facilities should provide disability-inclusive communication mechanisms, including sign-language interpretation and other appropriate communication aids.
3. Accessible infrastructure: Healthcare facilities should ensure accessible entrances, consultation rooms, toilets, diagnostic areas, parking spaces and examination equipment.
4. Disability-inclusive transportation: Transportation planning should incorporate the needs of wheelchair users and children requiring mobility assistance.
5. v.Health-insurance reform: The NHIA should develop and implement comprehensive disability-responsive benefit packages covering essential healthcare, rehabilitation, assistive devices and other disability-related needs.
6. Healthcare workforce: Adequate numbers of healthcare workers and relevant specialists should be made available to meet the healthcare needs of CWDs.
7. Public awareness: Sustained public education should address disability-related stigma, discrimination and misconceptions and promote the rights of CWDs.
8. Policy implementation: UNCRPD commitments and Nigerian disability legislation should be effectively implemented, monitored and enforced.
9. Monitoring and accountability: Health authorities should establish measurable indicators for disability-inclusive healthcare and mechanisms for reporting and addressing violations of disability rights.
10. x.UHC integration: CWDs should be explicitly incorporated into UHC planning, financing, monitoring and service-delivery frameworks so that disability does not become a determinant of exclusion from essential healthcare.

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