Breaking down Barriers

Unmet needs:

Challenges faced by parents and caregivers of children with disabilities in Sierra Leone

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Executive Summary

The unique challenges faced by parents or caregivers of children with disabilities remain underexplored in Sierra Leone, thereby contributing to the limited support systems and services available to this group. In light of this issue, this study examines the challenges encountered by parents and caretakers of children with disabilities and the mechanisms required to provide sustainable care.

Interviews were conducted with parents and caregivers of children with disabilities across the five regions of Sierra Leone. The findings indicate that even though the prevalent challenge among parents across all regions was the emotional and financial toll of caring for their children with disabilities, regional variances do exist. Support is direly needed to overcome these varying challenges. The challenges include difficulties with access to education and healthcare services (Western Area), access to business opportunities and shelter (South), access to loans and microfinance (East), and access to social support services (North and North-West).

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Central to all of these varying challenges is the need to strengthen collaboration between government agencies, community organisations, and NGOs to enhance the delivery of support services.

In essence, this study highlights the profound impact of unmet needs on the well-being of both parents and children. It shows that inadequate support services and resources exacerbate parental stress, diminish quality of life, and hinder the holistic development of children with disabilities. This study also recommends that policymakers prioritise the enhancement of existing support systems and develop targeted interventions, such as access to financial, educational, and social services, to address the unique circumstances of families raising children with disabilities.

Introduction

Research has shown that families caring for children with disabilities experience higher levels of stress (MacDonald & Callery, 2008), face challenges with physical and mental ill health (While et al. 1996), curtailed employment opportunities (Anderson et al., 2007), rumour-mongering and poverty (Gona et al., 2010), and disrupted family and social relationships (Yatchmenoff et al., 1998).

In Sierra Leone, parents of children with disabilities face myriads of challenges to provide sustainable care for their children, and they experience feelings of discrimination, stigma, and exclusion in many domains of their lives. This is because the perception of disability in Sierra Leone is stereotyped and comes with negative implications for both the children with disabilities and their caregivers. While the country has made strides in advancing disability rights and inclusion, significant gaps remain in the

support systems available to families. Existing policies and programs, such as the 2011 Persons with Disability Act, seek to prohibit discrimination against persons with disabilities and achieve equalisation of opportunities. This Act provides a foundation for addressing the needs of children with disabilities but does not consider the needs of parents or caregivers of children with disabilities. As such, parents or caregivers of children with disabilities face a multitude of challenges in providing sustainable care for their children. As a nation striving for inclusivity and equitable access to services, it is crucial to understand the diverse needs of these parents and explore avenues for enhancing existing support systems.

Methodology

To capture the nuanced experiences and perspectives of parents and caregivers of children with disabilities across Sierra Leone, a qualitative approach was adopted through face-to-face interviews and focus group discussions. The interviews were recorded and copious notes were taken to document key themes, observations, and insights. Interview sessions were designed to be conversational and open-ended, allowing participants to share their experiences, concerns, and aspirations freely. This methodology facilitated an in-depth exploration of parental needs and challenges, allowing for rich data collection and analysis.

A purposive sampling technique was employed to select participants representing diverse demographics, including geographic location, socioeconomic status, and disability types. Potential participants were identified and invited to participate in the study in collaboration with the NGO OneFamilyPeople. The selection of the parents or caregivers was based on the different categories of children with disabilities, while drawing upon the expertise of OneFamilyPeople. In the East region, the study was conducted in Kono Town, and five (5) parents and caregivers were interviewed. In the Western region, interviews were conducted with sixteen (16) parents and caregivers in Freetown's urban and rural areas. In the Northern region of Makeni, a total of eight (8) parents and caregivers were interviewed, while in the Southern region of Bo, a total of five (5) parents and caregivers participated in the focus group discussion. The North-West region (Kambia) was represented by six (6) participants (parents/caregivers). A total of thirty-five (35) key informant interviews were conducted, and one (1) focus group discussion comprising five (5) participants. An interview guide directed each session and aimed to explore

Healthworker Costancia Samwel Mkome (48) is assisting the doctor with the consultations. PHOTO: JAN-JOSEPH STOK

Isatu, her husband and her son with P.C. in Kambia District. PHOTO: CBR WORKER – WELFARE SOCIETY FOR DISABILITY

various aspects of caregiving experiences, including challenges faced, support systems utilised, and recommendations for improvement. Ethical considerations were paramount throughout the research process, with informed consent obtained from all participants before conducting interviews.

Emotional Impact and Support Systems
Regardless of geographical location, a prevalent theme among parents was the emotional toll of caring for children with disabilities. Many parents reported feeling emotionally drained and overwhelmed by daily challenges. Across all regions, parents described the emotional toll of caring for children with disabilities as shared by a parent: "It is overwhelming at times, dealing with the stress and uncertainty. We need more emotional support services to cope with the challenges." Many parents expressed gratitude for the support systems provided by community organisations and NGOs but stressed the need for additional resources and assistance. "The support groups have been our lifeline, but they can only do so much. We need more help from the government and NGOs," a caregiver remarked. Respondents sometimes expressed dissatisfaction with the quality of support provisions, such as counselling and advocacy services, although they also recognised limitations such as limited funding and staffing affecting these services.

Financial Challenges
Most parents of children with disabilities fall under the low-income category. As such, transportation fares, school fees (especially for private schools), and other associated expenses pose a significant financial burden for many of these families, hindering their ability to provide quality education for their children. Only a few parents interviewed had full-time jobs or ran their own businesses. Many are living on handouts from relatives and welfare organisations.

Challenges in Accessing Education and Transportation
A notable challenge highlighted by parents across all regions (although most strongly in the Western region) was the difficulty in accessing education and related support services for their children with disabilities. A parent noted, "Our children deserve the same opportunities as others, but the lack of accessible schools and medical facilities makes it difficult." Schools are few and far between, and special needs schools are non-existent in most regions. The inclusive education policy encourages children with disabilities to attend regular schools. Still, such schools lack the infrastructure, resources and expertise, in terms of staff and learning materials, to better serve children with disabilities. Additionally, transportation emerged as a significant barrier and pressing concern, with parents struggling to transport their children to school and medical appointments due to limited transportation options and infrastructure. As shared by a parent, "We often have to rely on unreliable transportation options, which affects our children's access to essential services.

Calls for Improvement and Policy Interventions
Parents strongly desired improvement in existing support systems and called for targeted policy interventions to address their needs more effectively. Specifically, there was a plea for increased financial assistance to alleviate the economic challenges faced by families, particularly in covering school fees and transportation costs. "We need more funding for disability services and favourable policies for better coordination between agencies to address the gaps," they urged. Additionally, parents and caregivers stressed the need for greater accessibility to business opportunities and microcredit schemes to promote their economic empowerment and self-sufficiency.

Regional Variances in Support Needs
While the above findings highlight the main patterns in the data, the study came across some regional variances worth mentioning. In the Southern region, respondents especially emphasised the importance of access to business opportunities and shelter to sustain their families. Similarly, there was a strong demand for loans or microcredit to support entrepreneurial endeavours and economic empowerment in the East. In the words of a participant, "We struggle to make ends meet, especially with medical expenses. A little financial assistance or giving loans for businesses would go a long way in easing our burden."

Conversely, parents in the Western region of Freetown emphasised the importance of access to education and healthcare services, with one participant stating, "Getting my child to school and medical appointments is a daily challenge. We need better transportation options to access these essential services."

Parents in the North and North-West regions highlighted the lack of accessibility to support services and expressed frustration with the limited resources available. One interviewee remarked, "We feel forgotten by the government. There are no services for our children with disabilities, and we struggle to find help." Future research should further explore and clarify these regional variances.

Conclusion

This study has sought to illuminate the needs and challenges faced by parents of children with disabilities in Sierra Leone, with a focus on understanding existing support systems and avenues for improvement. The findings underscore parents' multifaceted challenges, including economic insecurity, emotional strain, and barriers to accessing essential services such as education and transportation. Even though support systems provided by various organisations and NGOs exist, significant gaps persist in meeting the practical needs of parents and children with disabilities. These findings, therefore, highlight the urgent need for comprehensive policy interventions and targeted support initiatives to address the needs of parents and caregivers of children with disabilities more effectively.

Mohamed and his daughter with albinism in East-end Freetown.
PHOTO: CBR WORKER - CHESHIRE SERVICE

There are no services for our children with disabilities, and we struggle to find help.

Recommendations

1. There is a need for targeted interventions that are cognisant of the unique circumstances of parents and caregivers of children with disabilities from a regional perspective.

2. Expand and strengthen emotional and psychological support for parents and caregivers of children with disabilities by providing counselling services and establishing peer support groups. These initiatives will address the emotional toll and provide a network of emotional and practical support for families.

3. Provide economic empowerment through loans, financial assistance, and business opportunities: Increased financial support mechanisms are needed to help alleviate families' economic burden, particularly in paying school fees and transportation costs. Access to microcredit can promote economic empowerment and self-sufficiency among parents. Village savings and loan associations and promoting income-generating activities may be a means to further economic empowerment.

4. Implement measures to improve access to education and related support services for children with disabilities, including providing scholarships and transportation assistance.

5. There is a need to strengthen collaboration between government agencies, community organisations, and NGOs to enhance support service delivery and bridge existing gaps in care provision. Organisations serving this community and other stakeholders must prioritise collaboration based on beneficiaries' diversity, priorities, and perspectives to maximise the benefits of cooperation while mitigating potential barriers.
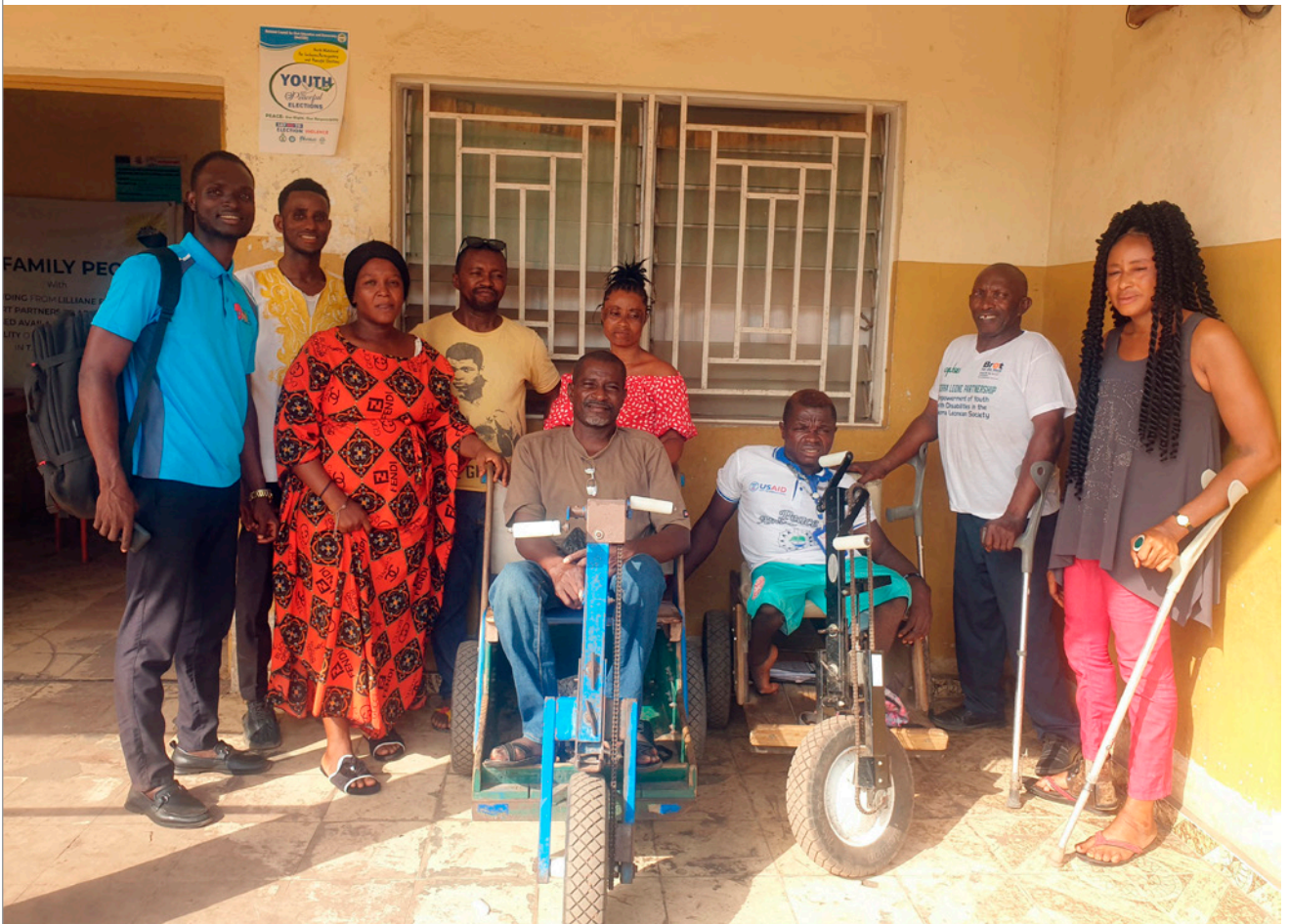
The director and CBR Team in Bombali District. PHOTO: CBR WORKER - POLIO PERSONS DEVELOPMENT ASSOCIATION

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Director CBR Team of Cheshire Service in East-end Freetown. PHOTO: CBR WORKER - CHESHIRE SERVICE