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Liliane Fonds

Breaking down Barriers



Pathways to Inclusion: Assessing Critical Success Factors in Community Based Rehabilitation Programs in Sierra Leone

Abstract

In Sierra Leone, Community-Based Rehabilitation (CBR) is a relatively new approach to promoting disability inclusion. This study explores the implementation of CBR strategies aimed at supporting children and youth with disabilities (CYwDs) in both rural (Kambia) and urban (Bombali) districts, in collaboration with two disability-led organiations. Through 34 interviews with various stakeholders and a survey, we have identified four key pathways to inclusion in CBR programming: family outreach, peer groups, community influencers, and stakeholder forums. Additionally, the study highlights four critical success factors: leading by example ("by us, for us"), promoting self-advancement and independence, embedding inclusivity within community structures, and addressing both immediate needs and root causes. However, structural challenges, such as limited services and funding, made certain aspects of the CBR approach more difficult to implement than others. The study concludes with recommendations for government and NGOs to enhance the effectiveness of CBR programs. ››

'Breaking down Barriers' was initiated by Liliane Foundation to contribute to more effective and evidence-based policies and programmes in the field of disability inclusive development. It does so by bringing together civil society organisations and researchers from the Netherlands, Cameroon, Sierra Leone and Zambia.

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Introduction

Community Based Rehabilitation (CBR) is a multi-sectoral approach aimed at improving the quality of life for people with disabilities by ensuring their inclusion and participation in society. This approach involves collaboration among various sectors such as health, education, livelihood, social services, and empowerment, the latter often considered as a cross-cutting issue. CBR is primarily used in low- and middle-income countries where services and funding are inherently limited. The goal is to develop basic services across a variety of sectors so the majority of people with disabilities (PWDs) have access close to their homes, rather than no access at all. When available, accessible, and affordable, PWDs are referred to secondary and tertiary facilities for specialised disability care, which is often only available in cities (if at all). In regions where state services and the workforce are underdeveloped, this poses a challenge for CBR programs. Therefore, CBR initiatives often focus on strengthening state services and those provided by religious institutions. This is achieved through lobbying for policy changes, collaborating with universities to improve the curricula for teachers and rehabilitation workers, and partnering with other organisations involved in bolstering state services.

In Sierra Leone, the first CBR program started in 2019 as a pilot, supported by the Liliane Fonds and implemented through the Sierra Leone Child Empowerment Programme (SLCEP) with three key partners: the Welfare Society for the Disabled (WESOFOD) in Kambia District, the Polio Persons Development Association (POPDA) in Bombali District, and OneFamilyPeople (OFP), a national NGO, which serves as the strategic partner providing capacity building, technical support, and oversight.

There have been a number of studies in Africa focused on assessing the impact of CBR programming on PWDs, families and communities *(Chappell, P., & Johannsmeier, C. 2009; Oliver M.2003)*, the role of DPOs *(Thomas M, Thomas M. J, 2002; Helander E, 1999)* and those of professionals and rehabilitation workers in the implementation of CBR programming *(Sharma, M., 2007; Kudzai, C. & Ganga, E., 2010)*. However, there have been few on understanding the pathways and success factors in CBR programming. This study addresses this gap in the literature.

CBR officer interview Kambia. PHOTO: AISHA IBRAHIM, SIERRA LEONE

It asks the following research questions:

- **Through what impact pathways do WESOFOD and POPDA achieve their outcomes?**
- **To what extent has WESOFOD and POPDA impacted the lives of Children and Youths with disabilities across the five dimensions of CBR?**
- **What design principles in WESOFOD and POPDA have been essential to the successes observed?**
- **What are the main challenges experienced by WESOFOD and POPDA?**

Methodology

In this study, the five main components of Community-Based Rehabilitation (CBR)—health, education, livelihood, social services, and empowerment—are examined through the programs of two organizstions in Northern Sierra Leone: WESOFOD, based in the rural Kambia District, and POPDA, located in the urban setting of Makeni in Bombali District. The focus is on evaluating the implementation of CBR strategies to support children and youth with disabilities (CYwDs) in Sierra Leone.

The study began with a desk review of project documents, such as reports and evaluations, to gain insights into previous CBR initiatives and to identify best practices, challenges, and areas for improvement. A total of 34 interviews were conducted, including staff from the three organisations (11), stakeholders (6), parents/ caretakers (8), and CYwDs (9). The interview with lead NGO OFP provided insights into the strategic direction and overall support offered to WESOFOD and POPDA. Interviews with WESOFOD and POPDA staff gave detailed information on the implementation, local adaptation, and challenges of CBR programs. Stakeholders, including community leaders, health workers, and educators, shared perspectives on community involvement and support for CYwDs. Interviews with parents and caregivers focused on the direct impact of CBR programs on families and their children, while those with children and youth, as direct beneficiaries, offered firsthand accounts of the programs' impact on their lives.

The interviews were supplemented by a survey distributed to CBR focal persons, stakeholders, and parents to gather quantitative data on the perceived effectiveness of the programs in addressing all five dimensions of the CBR matrix. This allowed us to identify patterns, which were further explored in the qualitative research. Data from the interviews and surveys were triangulated to gain a deeper understanding of how beneficiaries evaluated the services provided by both organisations, as well as the various pathways used in delivering them.

Ethical practices were strictly followed throughout the research process. Informed consent and assent for CYwDs were obtained from all participants before the interviews, and participants were assured of confidentiality and anonymity, with the option to withdraw from the study at any time.

The focus is on evaluating the implementation of CBR strategies to support children and youth with disabilities (CYwDs) in Sierra Leone

Pathways to Inclusion

The SCLEP program uses four change pathways to achieve its goals: family outreach, peer groups, community influencers and stakeholder forums.

1. FAMILY OUTREACH

In order to reach children and youths in communities, family outreach activities are conducted by CBR fieldworkers who engage directly with families of CYwDs. These activities include home visits, educational sessions, and counselling services. Through family outreach, the organisations raise awareness about disability issues, make referrals to appropriate services, identify CYwDs in need, build the capacities of caregivers, and provide counselling to support families in managing disability-related challenges.

As a result of family outreach activities, participants indicated increased access to services for CYwDs, improved skills among caregivers, enhanced independence for the children, and an overall better quality of life for the affected families. Respondents also noted that these activities helped to create a supportive environment where families feel empowered to care for their children with disabilities. As noted by a young woman "I was out of school and crawling from one place to another with no hope for the future till I was enrolled in this project, provided with a tricycle (locally made wheelchair) and enrolled in school."

2. PEER GROUPS

Peer group activities include organising school clubs, social clubs, parent support groups, and Mother-Led Protective Units, which focus on child safeguarding. These groups, which are facilitated by the implementing NGOs, provide a platform for CYwDs and their peers to interact, share experiences, and support each other, fostering a sense of belonging and community. Additionally, the parent support groups offer practical help, such as caring for each other's children to allow parents to generate income. They also exchange experiences on how to care for their children, learn from one another, and participate in Village Savings and Loan Associations to help break the cycle of poverty often associated with disability.

Respondents indicated that participating in peer group activities empowers CYwDs and has contributed to improved social interaction, emotional well-being, confidence, and relationship-building with peers. As reported by a young college student, "I stopped going out and hanging out with my friends after I became disabled. It was only after I was discovered by POPDA that I started socialising again through the peer group activities."

3. COMMUNITY INFLUENCERS

Community influencers are engaged through Chiefdom Rehabilitation Teams, composed of respected community leaders, religious figures, and other influential individuals. The nomination process is entirely community-led, with members identifying and selecting those they trust to represent their interests and promote inclusivity. These teams play a critical role in shaping perceptions and behaviours by conducting sensitisation and advocacy activities, encouraging positive attitudes towards disability, and fostering inclusive practices within their communities.

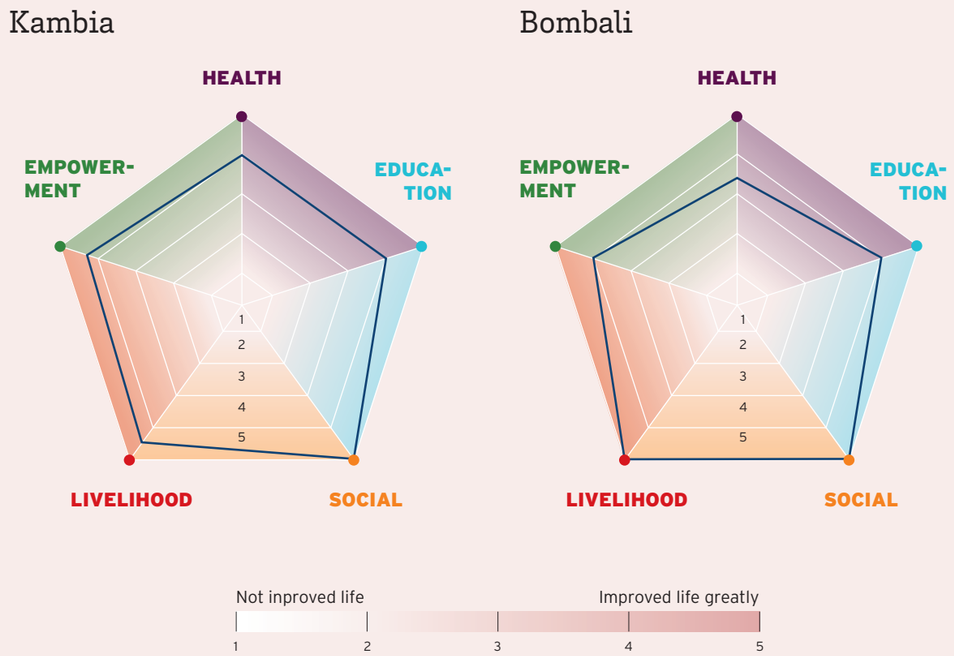
These efforts help create an environment where CYwDs are valued and included in many aspects of community life. As noted by a parent, "My religious leader often preaches about the importance of treating PWDs with utmost care and respect and including them in Masjid activities. Even though my child is disabled, he is an active member of the madrassa at the Masjid."

4. STAKEHOLDER FORUMS

Stakeholder forums involve organising meetings with Chiefdom District Rehabilitation Teams, service providers, and other relevant networks. These forums provide a platform for discussing challenges, sharing best practices, and coordinating efforts. Participants note that these forums facilitate information exchange and offer opportunities for organisations to engage stakeholders, lobby for policy improvements, and align efforts to support children and youth with disabilities (CYwDs) through collaborative activities.

As a result of these stakeholder forums, disability-friendly policies have been enacted, stemming from a better understanding of the challenges faced by CYwDs and other persons with disabilities (PWDs). This has led to a more cohesive and coordinated approach to addressing the needs of CYwDs. Stakeholders also work to raise awareness about these inclusive policies and the rights of CYwDs. As one respondent highlighted, "The successful lobby for a non-housing tax for PWDs in Kambia took place in one of these forums."

Figure 1: Perceived impact on improving lives



Perceived Impact

Figure 1 summarises the survey findings on the five dimensions of CBR in the Lusaka and Kafue areas. The overall results indicate a highly positive perception of ZECREP's impact. As illustrated in Figure 1, the CBR programs are viewed as being largely successful in improving the lives of both parents and children with disabilities, despite the presence of several challenges.

The results above reflect survey findings on the perceived impact and effectiveness of the programs, highlighting key strengths and areas for improvement. Respondents in each district rated the performance of various activities implemented under their respective CBR programs, covering the five dimensions of the CBR matrix. A scale of 1-5 was used, where 1 indicates no impact or improvement in the lives of children, youth, and parents, and 5 indicates significant improvement.

The aggregated data presented in Figure 1 offers a comprehensive overview of the current state of CBR programs in the districts.
Challenges related to education and health stand out in the diagram due to several interconnected factors. It is important to note that SECLEP itself provides few direct services and relies heavily on referrals. Given this, it becomes clear that the education and health sectors across Sierra Leone are severely underfunded, preventing councils from offering the specialised services required for the full inclusion of children and youth with disabilities. Even with adaptation projects undertaken by the CBR initiative in collaboration with local councils, schools remain largely inaccessible to children with disabilities. Additionally, there is a shortage of qualified healthcare personnel, and rehabilitation and health services are both expensive and inadequate, often leading to suboptimal outcomes.

Critical design principles/ success factors

Several factors contribute to the success of the SLCEP model shaped by the design principles that include:

1. **Leading by example (by us for us)**
2. **Promoting self-advancement and independence**
3. **Working with community structures to embed inclusivity**
4. **Addressing direct needs as well as root causes.**

LEADING BY EXAMPLE (BY US FOR US)
Both organisations were set up by persons with disability with WESOFOD having 90% and PODPA 60% of PWDs in leadership positions and programs led by individuals with diverse disabilities, ensuring authentic representation and leadership. With this principle, they are showing CYwDs and community members that it is possible to overcome one's disability and live as a productive member of society. By demonstrating that hard work and diligence can lead to positive outcomes over time, the organisations report that they have successfully convinced 70% of persons with disabilities (PWDs) in the communities where they operate to enrol in livelihood and skills development activities, encouraging them to leave street begging behind.

Moreover, they make it a point of duty to support PWDs through to tertiary education, and after graduation, these individuals become key members of the management team. They engage with government officials and nongovernmental organisations at both local and national levels in advocacy efforts. The principle of self-advocacy is central to their approach, enabling them to successfully advocate for the integration of disability issues into district development plans, ensuring long-term support.

The principle of leading by example also drives their income diversification efforts. Both organisations engage in social enterprises to generate additional income and reduce dependency on external funding. WESOFOD operates a carpentry workshop, a construction company, and an entertainment centre, while POPDA runs a utility workshop, a tailoring institute, and a bakery, all managed by PWDs.

Stakeholder interview Kambia. PHOTO: AISHA IBRAHIM, SIERRA LEONE.

Dr. Aisha Ibrahim with Wesofod team. PHOTO: AISHA IBRAHIM, SIERRA LEONE

PROMOTING SELF-ADVANCEMENT AND INDEPENDENCE

The activities enhance the independence and capabilities of CYwDs through the provision of educational opportunities, vocational training, and assistive devices that help CYwDs develop skills and confidence to lead independent lives. CYwDs are encouraged and provided with the resources to pursue higher education and vocational training, leading to greater self-reliance. These opportunities enable them to contribute to their communities and achieve economic independence. Additionally , the provision of tricycles that are constructed in their own workshops by PWDs enables independence of movement for many CYwDs, many of whom were homebound and out of school.

WORKING WITH COMMUNITY STRUCTURES TO EMBED INCLUSIVITY

The program's comprehensive approach involves various stakeholders and disciplines, including ministries and agencies, traditional and community leaders, medical and social service providers, enhancing its effectiveness and reach. Collaboration among different sectors ensures a holistic approach to supporting CYwDs, while breaking the barrier to inclusion and fostering community ownership to ensure the sustainability of initiatives. Through peer group activities and awareness raising by community influencers, stigma and discrimination is greatly reduced. Barriers are also broken by adaptive measures put in place in the schools these children attend. The setting up of support networks, community volunteers and referral pathways create the space for awareness and sensitisation campaigns aimed at changing community attitudes towards disability.

ADDRESSING DIRECT NEEDS AS WELL AS ROOT CAUSES

The program not only addresses the immediate needs of CYwDs, such as providing assistive devices, covering school fees, and adapting classrooms, but also tackles the underlying causes of exclusion and discrimination. For instance, it recognises that a key challenge lies in the absence or lack of implementation of inclusive policies. Therefore, the program works with councils and devolved ministries to develop or enforce policies that promote inclusivity.

Recognising that the root cause of many CYwDs being out of school is poverty, the program provides credit and grant schemes to bolster parents and caregivers economically and enable them to financially take care of their children's needs. Also, the provision of skills training for parents and caregivers better equips parents to support their children.

Challenges to the full implementation of the CBR model

Despite impressive achievements, SLCEP faces the following key challenges:

1. **Limited Quality of Health Services and high cost of rehabilitative services**

The health services available to CYwDs are often inadequate, impacting the effectiveness of CBR programs that rely on referrals. Many facilities lack the necessary equipment and trained personnel to provide high-quality care, leading to suboptimal outcomes for CYwDs. Moreover, the financial burden of accessing health and rehabilitation services is a major barrier for many families. High costs prevent many CYwDs from receiving the care and support they need, exacerbating their challenges. As such, the SLCEP program finds it difficult to provide a full CBR experience and WESOFOD and POPDA often improvise or provide out of pocket support to seek such services from private providers.

2. Lack of Comprehensive CBR Funding

Sustainable funding for the SLCEP program is limited, impacting the continuity and expansion of its services. The reliance on short-term funding is insufficient to provide consistent, long-term support for CYwDs. Without securing stable, multi-year funding, the program risks falling short of its potential to create lasting impact in the communities it serves.

3. **Staff Expertise: Lack of specialised training in CBR**

Many staff members at WESOFOD and POPDA, who are implementing the SLCEP program, lack specialised training in CBR, limiting their ability to effectively lobby and engage with the right stakeholders for quality service delivery. Since policymakers and service providers, as key rights holders, often lack expertise and awareness about disability and Community-Based Rehabilitation (CBR), it is essential that NGO staff possess the necessary knowledge to bridge this gap. Additionally, the implementing organisations are better equipped to support individuals with physical disabilities than those with visual or hearing impairments, as they lack staff proficient in sign language or braille.

4. **Local ownership**

Despite the presence of stakeholder forums, involving local councils and state officials in education, health, and livelihood sectors remains challenging. Local councils, overwhelmed by competing priorities, often allocate insufficient funds to make schools physically inclusive. This leads to disparities, with some communities lacking inclusive schools altogether and others having only a few. Consequently, these officials are not always invested in the program and sometimes fail to take ownership of critical processes.

Alhaji with his grandmother Reba. PHOTO: CHIARA BELTRAMINI

Conclusion

The SLCEP program demonstrates a robust approach to enhancing the lives of CYwDs in Sierra Leone, emphasising community-driven solutions and sustainable development. The program effectively employs family outreach, peer groups, community influencers, and stakeholder forums to support integration and empowerment. These strategies have significantly improved access to services, caregiver skills, and the social and emotional well-being of CYwDs. Community influencers and stakeholder forums have fostered positive attitudes and driven policy changes that benefit the broader community. The SLCEP's holistic approach is driven by authentic representation, promoting independence, integrating community structures, and addressing both immediate needs and the root causes of exclusion. Despite these successes, the program faces several key challenges, including inadequate and costly healthcare and rehabilitation services, lack of specialised training for diverse disabilities among service providers, and limited engagement from local councils and officials. Addressing these challenges and continued investment in CBR is crucial for sustaining and expanding existing initiatives. Such efforts will ensure lasting benefits for CYwDs across Sierra Leone, supporting the program's goal of fostering inclusive and empowered communities.

Annabel with her mother. PHOTO: CHIARA BELTRAMINI

Recommendations

FOR THE GOVERNMENT:

- Increase funding for health and rehabilitation services. Allocate additional resources to enhance the quality and accessibility of health and rehabilitation services for PWDs. Ensure that funding addresses the high costs and inadequacies currently impacting the effectiveness of these services.
- Expand training for health and education personnel. Provide specialised training in CBR techniques, including braille, sign language, and disability management, for healthcare and educational staff. This training should include both formal education and practical skills applicable to a wide range of disabilities. It is also important to employ sign language interpreters within these institutions, make information available in accessible formats and include a CBR module in the curricula of rehab professionals and teacher training colleges.
- Implement inclusive education policies. Enforce standards for disability-friendly infrastructure and inclusive practices in educational institutions. Ensure that schools are equipped to accommodate and support the diverse needs of CYwDs, including adaptations to physical spaces and teaching methods.
- Develop sustainable funding mechanisms for CBR programs. Collaborate with donors and stakeholders to create long-term financial solutions that ensure the continuity and effectiveness of CBR initiatives. This should include support for social enterprises and Village Savings and Loan Associations managed by persons with disabilities. Additionally, ensure that government subsidies are fully leveraged and accessible to all beneficiaries.
- Strengthen local ownership and accountability. Encourage local councils and state officials to actively engage with and take responsibility for disability-inclusive programs and initiatives. Provide education and resources to local authorities to ensure they understand the community-based nature of CBR and its interconnections across various sectors.

FOR NGOS:

- Address gaps in staff expertise. Invest in comprehensive training and development programs for staff to build expertise in all aspects of CBR, including less represented areas such as visual and hearing impairments.
- Leverage local resources for sustainability. Utilise local resources and develop social enterprises to generate additional income, reducing dependency on external funding. Promote and scale up sustainability initiatives, such as workshops, tailoring institutes, and other income-generating activities run by PWDs.
- Strengthen referral pathways and service integration. Develop and improve referral systems to ensure comprehensive support and service integration for CYwDs. Enhance coordination among various service providers and government ministries to create a seamless support network that addresses the multifaceted needs of CYwDs.
- Increase advocacy and awareness campaigns. Run targeted advocacy and awareness campaigns to influence policy and public attitudes towards disability and inclusion. Use these campaigns to highlight the benefits of CBR programs and the importance of inclusive practices in all areas of community life.
- Foster community ownership and engagement. Strengthen partnerships with local authorities, community influencers, and disability groups to promote local ownership of CBR initiatives. Engage in community education and involvement activities to build a supportive environment for disability inclusion and empowerment.

Dr. Aisha Ibrahim Interviews youth Bombali. PHOTO: AISHA IBRAHIM, SIERRA LEONE

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