

Breaking down Barriers



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Blueprint for success in CBR/CBID?

Understanding the change pathways and critical design principles of the ZECREP project

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Abstract

Community-Based Rehabilitation (CBR)/Community-Based Inclusive Development (CBID) is a holistic approach to address the diverse needs of individuals with disabilities within their local communities. This paper explores the ZECREP project, a CBR/CBID project implemented in Zambia. Using a mixed methodology, this study provides insights into the change pathways and critical design principles of ZECREP. The findings highlight the impressive achievements of the project in promoting disability inclusion across the five CBR dimensions. ZECREP realises these achievements through four change pathways: 1. family outreach; 2. peer groups; 3. community influencers; and 4. stakeholder forums. These synergistic pathways involve a wide range of activities that transform the lives of children, youth with disabilities, and parents. The success of the ZECREP project relies on four core design principles:

1. holistically addressing both direct needs and root causes;
2. emphasising knowledge that changes attitudes and behaviours;
3. operating on a multi-level, multi-disciplinary and multi-stakeholder approach;
4. prioritising empowerment and self-reliance.

The previously mentioned change pathways, guided by these design principles, unlock ZECREP's greatest strength: two reinforcing dynamics that work in tandem. On the one hand, ZECREP educates parents and youth, empowering them to (self-) advocate for their needs and assert their rights vis-à-vis community influencers and power holders. On the other hand, it educates community influencers and power holders, making them susceptible to this advocacy, resulting in deeper attitudinal and behavioural change.



Home visits. PHOTO: CHESHIRE HOMES SOCIETY OF ZAMBIA

Introduction

Community-Based Rehabilitation (CBR) is a holistic and participatory approach to addressing the diverse needs of individuals with disabilities within their local communities (Blöse et al., 2024). While views on CBR have evolved, it is essential to understand that CBR originated as a response to the limitations of traditional medical models. It emphasises collaboration among community members, families, and individuals with disabilities (Rodríguez-Hernández, 2023). At the core of CBR lies the principle of inclusivity, acknowledging that individuals with disabilities should be active participants in their communities rather than passive recipients of care (Tanui & Makachia, 2023). CBR is built on the belief that rehabilitation is a collective responsibility that extends beyond medical professionals to include community members, educators, and social workers (Witter et al., 2018). This approach aligns with the World Health Organization's (WHO) definition of rehabilitation as a process that enables individuals to achieve and maintain optimal functioning and a sense of well-being in their physical, psychological, and social domains (Amara & Magnusson, 2022).

CBR typically incorporates five main components: health, education, livelihood, social services, and empowerment (Tanui & Makachia, 2023). Health services involve addressing medical needs, rehabilitation therapies, and ensuring access to essential healthcare (Witter et al., 2018). Educational components focus on inclusive education, ensuring that individuals with disabilities have equal opportunities for learning (Jere, 2020). Livelihood components aim to enhance economic empowerment by providing vocational training and supporting income-generating activities (Hunt, 2022). Social services encompass initiatives to promote social inclusion, community awareness, and the reduction of stigma and discrimination (Opoku et al., 2017). Empowerment refers to the process of fostering self-help groups, community-based organisations, networking, and collaboration to enhance the autonomy, participation, and influence of individuals with disabilities within their communities (Chubaya et al., 2021). Together, these five components make up the CBR-matrix as proposed by the WHO.

¹ The ZECREP program itself uses CBR. Hence, from now onwards, this paper uses this phrase. Given the similarities between CBR and CBID, the findings of this study are also of relevance to CBID.

While CBR programs share a common philosophy, their practical implementation varies widely across countries and contexts (Blanchet et al., 2015). This diversity is influenced by cultural factors, socio-economic conditions, varying national policies and the prevalence of different disabilities in a given region (Bongo et al., 2018). CBR is widely recognised for its potential to not only ameliorate the immediate needs of individuals with disabilities but also contribute to broader societal changes (Bennett, 2015). By actively involving communities, CBR can play a crucial role in helping to break down social barriers and reduce stigma, fostering a more inclusive and supportive environment (Opoku et al., 2017). Through CBR initiatives, access to education and vocational training empowers individuals with disabilities to lead more independent and fulfilling lives (Rahimah et al., 2021).

Research has shed light on the critical success factors of CBR in Sub-Saharan Africa, although to some extent, these factors remain poorly understood (Rahimah et al., 2021). Existing studies emphasise the importance of community sensitisation, teacher training, parent training, health worker training, media engagement, stakeholder collaboration and funding (Magnusson et al., 2022; Persson, 2014; Blanchet et al., 2015). While these findings are undoubtedly valuable, they do remain at an operational level. What is lacking is greater insight into the critical design principles of CBR, thus the values and fundamental ideas that underlie CBR programs that are essential for achieving impact. This is the gap this research seeks to address.

The study draws upon the Zambia Enhanced CBR Response Project (ZECREP) as a case study. ZECREP has been implemented in the 2020-2024 period by Archie Hinchcliffe Disability Intervention (Lusaka area), Twatasha Disabled and OVC Organization (Kafue area) and Holy Family Centre (Monze area). Broad support and coordination were provided by Cheshire Homes Society of Zambia with funding from Liliane Fonds. The study asks the following research questions:

- How, through what impact pathways, does ZECREP achieve its outcomes?
- To what extent has ZECREP impacted people's lives across the five dimensions of CBR?
- What design principles in ZECREP have been essential to the successes observed?

Methodology

The methodology employed in this study combined document analysis, interviews, and questionnaires to provide a holistic understanding of the ZECREP project. Fieldwork conducted in the Lusaka and Kafue areas in March 2024 facilitated first-hand observation and data collection within the project's operational areas, enabling an understanding of the local context and the implementation of ZECREP activities in these regions. Consent forms were utilised in the research to ensure that all participants were fully informed and voluntarily agreed to participate in the study. In-depth interviews were conducted with 25 key stakeholders, including staff members from Cheshire Homes Society Zambia (n=4), Archie Hinchcliffe Disability Intervention (n=3), and Twatasha Disabled and OVC Organization (n=4), providing valuable insights into their roles, experiences, and perspectives on the project. Additionally, interviews were held with parents/caretakers (n=9) and youth (n=4), capturing their unique experiences and perceptions.

Questionnaires were administered to CBR focal point persons at the implementing organisations and parents of children with disabilities who are ZECREP beneficiaries. These questionnaires aimed to gather quantitative data on the perceived impact of the project's critical activities on the lives of children and youth with a disability and their parents. The questionnaire focused on 17 core activities implemented within the ZECREP project, encompassing all five dimensions of the CBR matrix. Respondents were queried about their perceptions regarding the extent to which each ZECREP activity has improved the lives of parents and children. A 1-5 scale was used, where 1 signifies no improvement, and 5 indicates significant improvement. This study provides the aggregated findings of the survey.

At the end of the fieldwork, a follow-up interview was held with two Cheshire Homes Society Zambia staff members to validate the findings and tie up loose ends. Moreover, the preliminary research findings were presented and validated during a learning event in which 12 people participated, including the implementing organisations and a selection of key stakeholders, including parents and youth.



Making of Assistive Paper Technology by fieldworkers. PHOTO: CHESHIRE HOMES SOCIETY OF ZAMBIA



Participation in walk, commemorating the International Day of Persons with Disabilities (IDPD). PHOTO: CHESHIRE HOMES SOCIETY OF ZAMBIA

Change pathways

ZECREP realises its objectives by employing four distinct change pathways, each delineating the sequential steps through which activities are executed to attain desired outcomes. These pathways are complementary and synergistic and encompass:

1. Family Support
2. Peer Groups
3. Community Influencers
4. Stakeholder Forums

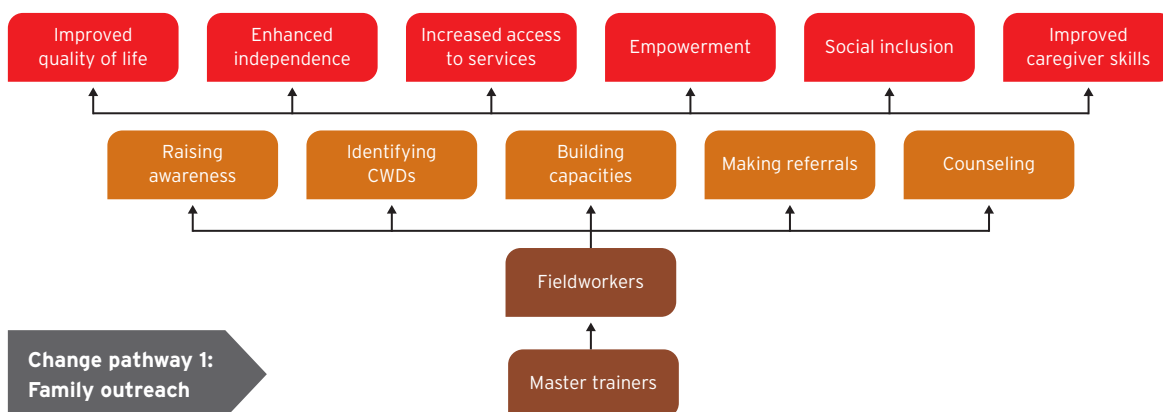
Pathway 1: family support

The first pathway focuses on reaching children with disabilities and their parents in the community (see Figure 1). It draws upon the work done by fieldworkers, who are community volunteers trained by master trainers employed by the ZECREP's implementing organisations. Through workshops led by these trainers, fieldworkers acquire essential skills, knowledge, and understanding to engage with parents and support children with

disabilities effectively. Core tasks include raising awareness, dispelling misconceptions, conducting assessments to identify children with disabilities, timely referral and basic intervention.

Figure 1: Family support change pathway

Fieldworkers further empower parents through education and guidance, enabling them to better understand and support their children with disabilities. They provide strategies for caregiving, such as feeding and nutrition, and encourage parental involvement in their child's development. Additionally, fieldworkers facilitate referrals to social services, clinics and schools, offering counselling and emotional support to families navigating the challenges associated with disability. These activities appeared to significantly enhance the quality of life for children and parents, promoting independence where needed and fostering greater inclusion within families and communities. Empowered with knowledge and support, parents educate their neighbours, contributing to reduced stigma and discrimination.

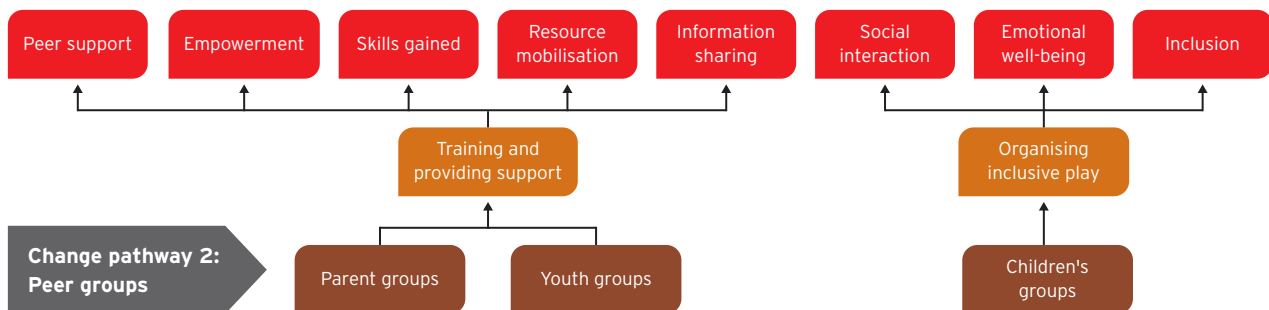


Pathway 2: Peer groups

The second change pathway in ZECREP focuses on forming and supporting peer groups: parent (including groups for fathers), youth, and inclusive play groups (see figure 2). Although parent and youth groups undergo distinct training and engage in varied activities, similar dynamics and outcomes can be discerned across both groups. These groups serve as platforms for collective action, support, and empowerment within communities. Through sharing experiences, challenges, and successes, members provide mutual support and encouragement to one another, fostering a sense of solidarity. By coming together and participating in group activities, members of parent and youth groups gain a sense of empowerment, developing confidence in their abilities to advocate for their rights, access services, and effect positive change. Moreover, the training provided to these groups equips members with practical skills and knowledge relevant to mobilising resources and undertaking entrepreneurial activities.

Figure 2: Peer group change pathway

The children's groups foster social interaction, emotional well-being, and inclusion among children with a disability. Through organised play sessions between these children and their able-bodied peers organised by the implementing organisations, these groups create opportunities for meaningful social engagement and interaction. Children with a disability develop friendships, build social skills, and experience a sense of belonging within their communities. These play sessions not only promote emotional well-being by providing avenues for joy but also contribute to breaking down barriers and stereotypes surrounding disability, fostering a culture of acceptance and inclusion among children of diverse abilities. As children with disabilities engage with their able-bodied peers, they gain confidence, develop a positive self-image, and experience a sense of belonging. Also, the peer groups strengthen relations between parents of children with and without disabilities.

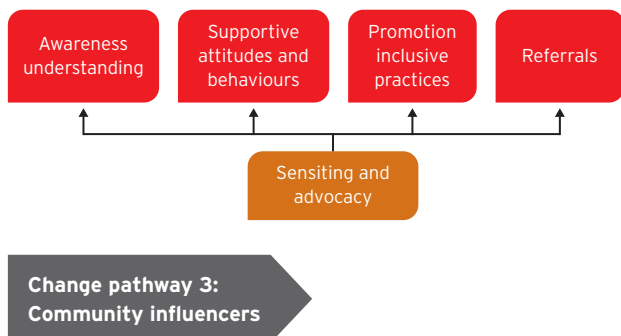


Pathway 3: Community influencers

The third change pathway focuses on sensitising church leaders, traditional healers, and traditional leaders (see Figure 3). Through educational workshops, these community influencers developed a deeper understanding of disability issues and increased awareness and empathy towards individuals with disabilities within their communities. This heightened awareness has led to adopting more supportive attitudes and behaviours, fostering a culture of inclusion and acceptance. Practical measures such as installing ramps in churches have been

implemented, improving accessibility for individuals with mobility impairments and promoting inclusive practices within religious settings. In Zambia, parents of children with disabilities often initially seek guidance from pastors or traditional healers, who frequently make unrealistic promises regarding curing these children. Due to the sensitising in ZECREP, these leaders now facilitate referrals to healthcare services, ensuring timely and appropriate medical attention and support for children with disabilities.

Figure 3: Community influencers change pathway

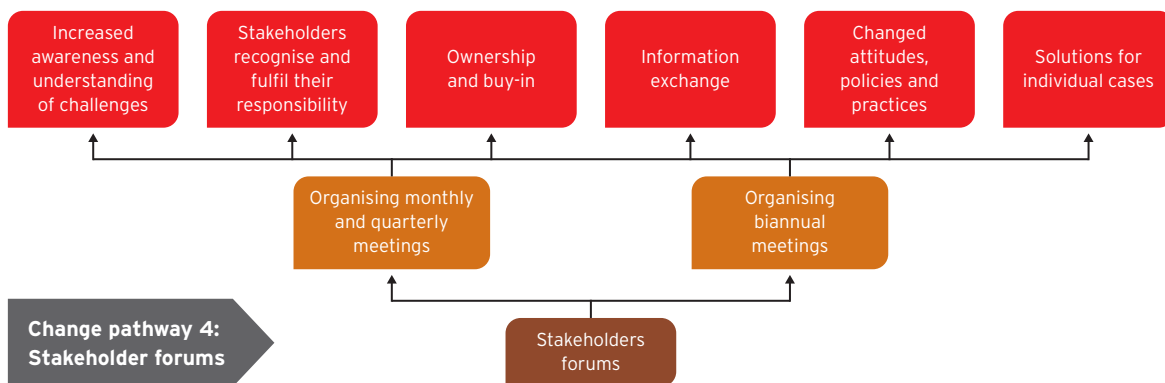


Pathway 4: Stakeholder forums

In each of the three catchment areas of ZECREP, stakeholder forums have been established. These forums target stakeholders such as various government ministries, the police, the district office, relevant NGOs and DPOs. These meetings serve as platforms for information exchange, discussing various disability challenges and possible solutions, and fostering changed attitudes and practices. The implementing organisations support the meetings, overseeing the organisation of monthly and quarterly meetings and ensuring follow-up on agreements reached. Through these engagements, stakeholders have gained heightened awareness of disability challenges and improved their understanding of disability-related issues. Consequently, stakeholders have begun to fulfil their responsibilities more effectively, demonstrating increased ownership and commitment.

Figure 4: Stakeholder forums change pathway

Moreover, bi-annual stakeholder forum meetings are convened, wherein parent and youth groups are invited to present their challenges directly to a specific stakeholder, each time with a specific thematic focus, such as healthcare access. This approach ensures that stakeholders better understand the challenges of parents, youth, and children with disabilities and contributes to them better addressing the needs advocated by these groups. As a result, parent and youth groups practice advocating for their needs while contributing to more responsive service provision.

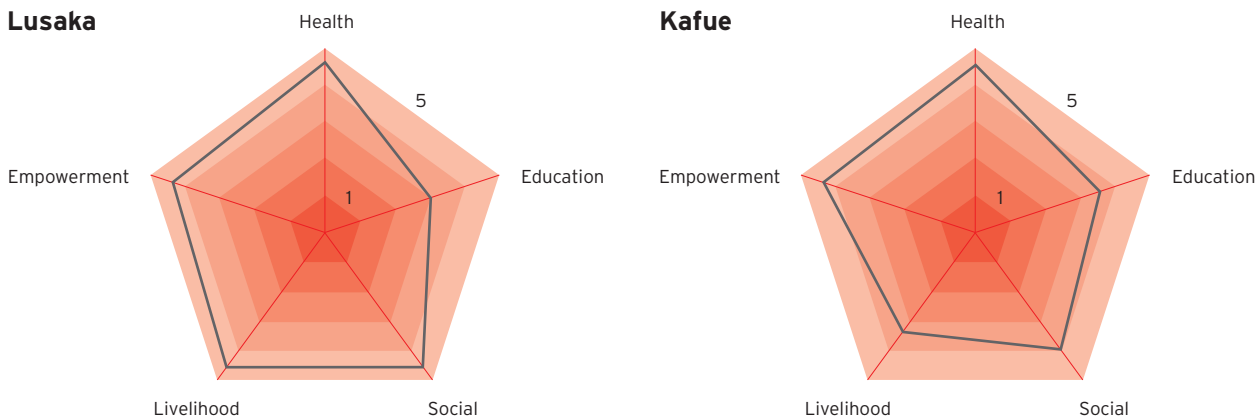


Perceived impact of ZECREP

There is little doubt that ZECREP has transformed the lives of many children with disabilities and their parents, as well as those of youth with disabilities. According to project statistics, ZECREP has reached 508 children, 640 youth, and 2662 indirect beneficiaries in the three project sites. As already apparent when discussing the project's change pathways, the range and depth of outcomes achieved are impressive. Many life-changing experiences and success stories were shared with the research team, with equally enthusiastic responses from the project's stakeholders.

In addition to interviews, this study also conducted a survey to understand the perceived impact of ZECREP. Figure 5 summarises the survey findings on the five dimensions of CBR in the Lusaka and Kafue areas. The overall picture emerging from the survey findings regarding ZECREP's perceived impact is very positive. This success positions ZECREP as a model worthy of upscaling and replication. The small sample size (n=13) does imply, however, that we must be careful in automatically assuming that the findings are representative of the broader population. Yet, the survey findings appear consistent with the qualitative findings, reinforcing, at the very least, the picture of ZECREP as a (very) successful project.

Figure 5: Perceive impact on improving lives



Challenges

Upon closer examination of the survey data, several observations emerge. Inclusive education, for instance, scores lower in both areas due to the prevailing gap between official government policy and practical implementation, resulting in limited acceptance of children with disabilities in schools. This is outside ZECREP's direct circle of influence, yet it does have a considerable impact, highlighting a limitation of the CBR approach, which relies on making existing government services accessible. A similar remark can be made about the lower score for livelihood in Kafue. Here, the parent and youth groups struggled to access government grants to start businesses and generate income.

ZECREP has three other challenges that are not immediately apparent from the survey results. First, the motivation of fieldworkers, who are volunteers, is a vulnerability. While the fieldworker model does function effectively, sustaining motivation among individuals without a personal connection to disability remains an issue. Volunteers who are parents of children with disabilities tend to be more motivated than other volunteers. Second, including fathers in the project remains a constant challenge, especially in father groups. Unlike mothers, fathers typically have difficulties committing themselves to project activities. In the face of poverty, they experience pressure to secure an income, while traditional norms emphasise the child caring role being for the mother. Thirdly, access to health and educational services in rural areas presents an ongoing challenge, with travel costs and time constraints acting as significant barriers for parents, impeding access to essential services.

Critical design-principles

The successes observed in the ZECREP project are anchored in four essential design principles:

1. **Holistically addressing both direct needs and root causes**
2. **Emphasising knowledge that changes attitudes and behaviours**
3. **Operating on a multi-level, multi-disciplinary and multi-stakeholder approach**
4. **Prioritising empowerment and self-reliance**

Holistically addressing direct needs and root causes

The ZECREP model is distinguished by its comprehensive approach, targeting all five domains of CBR while simultaneously addressing both direct needs and underlying root causes in each of the five CBR dimensions. The study found that this approach is essential for promoting disability inclusion effectively, as it acknowledges the multifaceted nature of disability and the interconnectedness of its various dimensions. By adopting a holistic approach, the model creates synergies between CBR dimensions, maximising their impact and sustainability. Moreover, it recognises the importance of realising immediate benefits for individuals with disabilities while also working towards securing long-lasting changes that address structural barriers. Direct needs are enormous and urgent and need to be addressed, but without addressing the root causes, the impact will be short-lived.

Emphasising knowledge that changes attitudes and behaviours

The ZECREP model, centred on capacity building, prioritises cultivating knowledge that fosters shifts in attitudes and behaviours towards inclusion. The study found that this emphasis on knowledge is critical for effectively promoting disability inclusion, as many disability-related challenges originate from a lack of understanding, negative attitudes, and unproductive behaviours. By equipping individuals with the necessary knowledge and understanding, the ZECREP model addresses these underlying issues, empowering children, youth, parents, community influencers and policy stakeholders to embrace inclusive practices and dismantle barriers to inclusion. Recognising that perceptions and beliefs often shape attitudes and behaviours, the model focuses on instilling accurate information, while fostering empathy and respect for persons with disabilities. The ZECREP model catalyses a transformative shift towards a more inclusive society through targeted capacity-building initiatives.

Operating on a multi-level, multi-disciplinary and multi-stakeholder

ZECREP employs an approach that is multi-level, multi-disciplinary and multi-stakeholder.

The research found that this approach is vital for effectively promoting disability inclusion. Immediate needs and root causes exist at the individual, family, community and policy levels, necessitating the need to address these diverse levels simultaneously. Furthermore, disability challenges span across disciplines (e.g. healthcare, education, legislation), underscoring the need for multi-disciplinary involvement to tackle the complexities of disability inclusion comprehensively. Finally, the multitude of challenges is too extensive for any single stakeholder to address, highlighting the importance of collaboration among multiple stakeholders.

Prioritising empowerment and self-reliance

Promoting empowerment and self-reliance among children, parents, and youth lies at the core of the ZECREP approach. The research findings illustrate that this emphasis is crucial for effectively advancing disability inclusion as it cultivates active engagement in driving positive changes that extend far beyond the confines of project timelines. By instilling a sense of agency and self-confidence, ZECREP equips many children, youth, and parents with the essential skills to navigate the complex landscape of challenges as independently as possible. Additionally, by providing a platform for parents and youth to interact with stakeholders, ZECREP amplifies their voices, enabling them to advocate for their needs and assert their rights within their communities. Overall, the emphasis on empowerment and self-reliance fosters resilience and allows individuals to harness their potential to overcome obstacles independently.

Conclusions

The findings highlight ZECREP's impressive outcomes achieved through four change pathways: 1) family support; 2) peer groups; 3) community influencers; and 4) stakeholder forums. These pathways are mutually supportive and involve a wide range of activities contributing to improved access to services, enhanced awareness and understanding, empowerment and (self-) advocacy, addressing discrimination and stigma, as well as changes in stakeholder attitudes and behaviours. Four mutually reinforcing core design principles underlie the positive changes observed: 1) holistically addressing direct needs and root causes; 2) emphasising knowledge that changes attitudes and behaviours; 3) operating on a multi-level, multi-disciplinary and multi-stakeholder approach, and 4) prioritising empowerment and self-reliance.

The original vision underlying CBR emphasised a holistic approach to promote disability inclusion, acknowledging that individuals with disabilities should be empowered to be active participants in their communities rather than passive recipients of care. First of all, this study's findings confirm the validity of these principles. However, they also highlight the importance of the political dimension of CBR in achieving lasting change, a perspective that has traditionally received less attention. ZECREP's approach, with its four complementary and synergistic change pathways, creates two mutually reinforcing dynamics. On the one hand, it educates parents and youth, empowering them to (self-) advocate for their needs and assert their rights vis-à-vis community influencers and power holders. On the other hand, it educates community influencers and power holders, making them susceptible to this advocacy, resulting in deeper attitudinal and behavioural change. It is in the interplay between these two dynamics where the main strength of ZECREP resides.



Traditional healers, medical personnel, and church collaboration. PHOTO: CHESHIRE HOMES SOCIETY OF ZAMBIA

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