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'Let's Grow Together': Understanding the *Current Provision of Early Childhood Development and Education for Children with Disabilities in Rural Malawi through Community-based Participatory Research*

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ABSTRACT

Focussing on the experiences and perceptions of parents and volunteer caregivers of children with disabilities, this paper reports on a study that explored the provision of early childhood development and inclusive education for children with disabilities in rural Malawi. Drawing on a community-based participatory research (CBPR) design, ten local community researchers and two Malawian researchers collaborated to interview forty caregivers and parents of children with disabilities attending ten Community Based Care Centres (CBCCS) in Southern Malawi. Findings are reported through four key themes: experiences of disability, inclusion, learning and developmental progress; factors influencing non-enrolment and absenteeism; barriers to learning and progress; and accountability and support channels. Five key components were highlighted: 1) relevance of peer interactions for learning outcomes and wellbeing; 2) the importance of the CBCC as (a model for) a safe space against discrimination; 3) relevance of quality education and pre-school teacher training; 4) necessity of material support to decrease absenteeism; 5) the need for greater community and state support for children with disabilities. The implications of the study's findings are discussed, including the importance and relevance of considering the perspectives of community based actors in program and policy design.

KEYWORDS

Disability; early childhood development; education; health; inclusion; Malawi; participatory research

Introduction

Early childhood development (ECD) is a significant phase of growth and development that influences outcomes across an individual's entire life and provides an important window of opportunity to prepare the foundation for lifelong learning and participation (World Health Organization [WHO], 2011). New government policy in Malawi sets out to increase the number of children with disabilities accessing ECD, particularly in community-based childcare centres (CBCCs). As such the UK Department for International

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Development, which has Malawi as one of its key target countries, funded the 'Let's Grow Together' project, a three year (2015 to 2018) multi-agency study that seeks to promote the inclusion of children with disabilities in Community Based Childcare Centres (CBCCs) in a rural district of Southern Malawi. To help explore this, 16 parents of children with disabilities who were attending ten CBCCs and 24 caregivers volunteering at the centres were asked to share their perceptions and experiences of inclusion of children with disabilities, within both the CBCCs and within their wider communities. This included their perceptions of the young children's experiences. This was undertaken through a community-based participatory research (CBPR) approach.

The paper describes the CBPR element in a multi-method study undertaken in ten CBCCs in 2016–17, outlines the context and methodology applied, shares the findings of the CBPR element and discusses the implications within the 'local' context. Overall, the findings have helped to build a picture of current provision of early childhood development and education (ECDE) services for pre-school children with disabilities in Malawi, and have contributed to the development of an *Inclusion Resource Pack*, now integrated into the basic two-week national training curricula for community-based Early Childhood Development (ECD) caregivers. The CBPR element of the wider mixed-methods study offers qualitative evidence to the Malawi Government and key stakeholders to understand more fully, the complex dynamics that enable or inhibit quality ECDE for children with disabilities in Southern Malawi.

Background

As part of the Sustainable Development Goal Agenda, the international community has committed to ensure inclusive and equitable quality early childhood development, care and pre-primary education for all by 2030 (SDG goal 4.2; UNGA, 2015). Access to quality ECDE for young children with disabilities is considered to be particularly important for stimulation and development of key functional skills (e.g. World Health Organization [WHO], 2018). ECDE services are required to raise awareness on childhood disability, reduce social stigma, build support networks and support carers who are often taking the greater caring responsibility at home (Ambikile & Outwater, 2012, Gladstone et al., 2016; Mirza, Davidson, & Rahman, 2009). It is also important to understand the impact caring for children with disabilities has on parents, to understand the extent to which current services meet primary carers' needs and find out how they are coping with caring for a child with a disability (Yousafzai, Lynch, & Gladstone, 2014).

The Malawian government has a multisector approach to ECDE, which is led by the Ministry of Gender, Children, Disability and Social Welfare (MoGCDSW) (World Bank, 2015). The Government of Malawi has revised the ECD policy (Government of Malawi, 2017a) and published a series of national guidelines and legal frameworks to support the implementation of 'integrated early childhood development' (IECD). In reality, however, over the past 15 years, much of the responsibility for the care and development of children aged three to five years has fallen upon individual parents and families, village heads and their communities. High levels of community investment have resulted in over 11,000 CBCCs being set up across Malawi (Government of Malawi, 2017b). Whilst CBCCs provide an early learning environment to children living nearby, it is reported that the quality of most of the CBCCs, measured in terms of infrastructure (buildings, sanitation facilities), staff numbers, capacity,

materials and equipment, has fallen short of the early childhood development Monitoring and Evaluation Framework set out by the MGCDSW (Munthali, Mvula, & Silo, 2008).

Methodology

The participatory element of the multi-method study drew heavily on the principles of community-based participatory research (CBPR). Using a participatory approach to understand childhood experiences is important (Kehily, 2004). CBPR involves respectful collaboration with the community: mutual dialogue, shared decision-making and low levels of hierarchy actively involve community-based actors in planning, data collection, analysis and dissemination (Greenwood, Fakih, Steff, Bechange, & Mwifadhi, 2016). It is an orientation for research that recognises the strengths of each participant and seeks to break down social injustice and the structural constraints that produce inequities of power (Levine-Rasky, 2015). It demands an awareness of positionality with vigilance towards one's own power (Pain, Kondon, & Kesby, 2007). CBPR increases knowledge and understanding of the situation being studied, constructs meaning together and integrates this into interventions and policy change to improve the quality of life for those of focus in the community (Greenwood et al., 2016).

Specific to disability, CBPR can enable community members, including people with disabilities, to identify key barriers to achieving the SDGs and inform how policy and programs can best meet the needs of people with disabilities (Greenwood, 2017). In the context of the wider study, this approach helped to build a picture of and the implications stemming from: experiences of disability, inclusion, learning and developmental progress; factors influencing non-enrolment and absenteeism; barriers to learning and progress; and accountability and support channels. The CBPR element drew on established ethical principles associated with the methodology: mutual respect, equality and inclusion, democratic participation, active learning, making a difference, collective action and personal integrity (Centre for Social Justice and Community Action (CSJCA) & National Coordinating Centre for Public Engagement (NCCPE), 2012 cited in Greenwood et al., 2016). Ethical permission was approved by the National Committee on Research in the Social Sciences and Humanities, the National Commission for Science and Technology in Malawi, and the Humanities & Social Sciences Ethical Review Committee, University of Birmingham. Ethical considerations were discussed in depth between the University of Birmingham and Chancellor College, Malawi, including CBPR ethical principles, informed consent and the nature of confidentiality.

Overview of Researchers

Recruitment of Peer-researchers

Two hired local researchers (from Chancellor College, Malawi) who were involved in the wider research, were requested to help identify and recruit community researchers. Ten community researchers were recruited including two researchers who had disabilities themselves. They were selected based on suggestions from local disability activists or brought forward as suitable candidates by parents of children with disabilities (See Table 1).

Table 1. Shows an overview of researchers involved and their roles.

Type of researcher	No. of researchers	Role
Local university (Chancellor College)	2	Recruited community researchers, supported each phase of research
Local community	10	Planning, data collection lead, analysis and write-up support
iNGO (Sightsavers)	1	Trained community researchers, supported each phase of research
UK University (Birmingham)	1	Principal Investigator oversaw phases of whole project.
UK Independent (Anthrologica)	1	Conducted data analysis and led on writing report

Training of Peer Researchers

The community researchers undertook training to lead semi-structured interviews and focus group discussions. They were also involved in data collection planning at the training workshop. The community researcher training provided by Sightsavers and Chancellor College, Malawi, in collaboration with the University of Birmingham focused on understanding, data and research collection skills and building confidence, and was designed to include those who are not literate or are vision impaired. A key part of the training was the approach to interviewing: gathering rich data with respect. Questions for participants were created during training and focused on key themes including experiences of disability, inclusion, learning and developmental progress, factors influencing non-enrolment and absenteeism, barriers to learning and progress, and accountability and support channels.

Recruitment of Participants and Data Collection

Participants were recruited through a purposive sample framework, and approached based on child disability reported by the CBCC head caregiver or a member of the management committee. Data were collected in ten CBCCs in rural localities of the Thyolo district in Malawi, using a mapping study of the district. Interviews and focus groups were undertaken across the ten research sites, in CBCCs and family homes, with a total of forty participants – 24 caregivers and 16 parents of children with disabilities. Interviews were recorded on voice recorders, transcribed and translated from Chichewa to English. Data were stored securely and anonymity ensured.

Additional data were gathered post analysis when community researchers reflected on the findings and the research process, and suggested ways of improving existing services at community and district level. This additional data fed into peer researchers making recommendations for the program rather than undergoing new analysis itself.

Data Analysis

The interview data were analysed by Anthrologica, an independent research-based organisation, using inductive, thematic analysis (Thomas, 2006) developed specifically for data generated through applied qualitative research. Dominant themes were drawn out, which involved systematically sorting through the material, and coding ideas and phenomena as they appeared and reappeared. The approach synthesised raw textual data into a brief summary format, and established links with the overall study objectives. It

developed an emerging structure of experiences in the raw data, which was critically analysed in line with the overall study objectives.

Community researchers then considered the analysis and its process and gave feedback. Many points of convergence were noted between the analysis of Anthropologica researchers and the community-based researchers. Points of divergence were discussed and resolved.

Findings

The findings present the experiences of parents of children with disabilities at CBCCs and CBCC caregiver experiences in four areas: disability, inclusion, learning and development progress; factors influencing non-enrolment and absenteeism at CBCCs for children with disabilities; reported barriers to effective learning and development progress for children with disabilities; and accountability and support channels.

Experiences of Disability, Inclusion, Learning and Developmental Progress

Caregivers and parents of children with disabilities reported a wide range of disabilities (physical, hearing, visual, speech, intellectual) although most did not know the corresponding medical term for the conditions they described. General descriptions were used, in these cases by female participants, such as: 'His eyes are not in their right place ... they look different. They are not as normal, as such he does not see very well'; 'He does not function very well in the head'; and 'He has floppy muscles whereby the legs are not strong enough for the child to be able to run and this makes him fall down each time.' Parents and caregivers described children with disabilities as being 'different' and compared their ability to function against activities of 'normal' children, stating that children with disabilities could not perform certain tasks that 'normal' children found easy. There were a large number of negative experiences shared by parents in trying to find a diagnosis for their child, and in seeking care. A few parents reported experiences that raised concerns about the treatment and protection of vulnerable minors. For example, one female participant, Christina,¹ recounted what happened to her son when she sought care for his disability:

'When the doctors ran their tests, they said that in order for the child to speak, we needed to beat him. They showed us how to beat him so he could talk. I felt sorry for him. I didn't want to treat my child that way.'

Several parents explained that their child and the wider family experienced discrimination from their community that focused around disability, and ways in which the discrimination impacted them. As Agness, a mother of a child with a physical disability mentioned: 'when they see us bring our children to the CBCC on our backs, they insult us ... it hurts, to say the least'. Some parents appeared resigned to this negative social norm, as Martha, a mother of four, including a child with a disability, reported: 'It hurts. Deep down in our hearts, we don't feel happy. But since there is a lot of discrimination these days we don't do anything.' There were also examples of other children expressing unease or unkindness towards children with disabilities. Another mother, Gloria, explained: 'When we reach the school, sometimes fellow

children point at him and talk about his disability in a way that is worrying for my child. It makes us sad to see this.'

Despite this, parents and caregivers felt that the greatest success of CBCCs was the disability-inclusive setting, in terms of social cohesion. Parents and caregivers noted the importance of the CBCC in teaching children both with and without disabilities key principles of respect, equality and non-discrimination. Parents sensed that caregivers developed a miniature model of society in the classroom where they taught the importance of non-discrimination and inclusion. Social cohesion and acceptance in the classroom seemed to create a safe learning environment for many of the children. One mother, Natasha, confirmed:

'When he is left at home it becomes very easy for the other children to tease him about his disability and it makes him sad. But when he comes here, he is happy because he is treated like everyone else.'

Parents and caregivers felt that attending a CBCC built positive social interactions and attitudes for those attending: children at CBCCs had access to their own social network and as a consequence were happier and more confident. Friendships were created regardless of disability, and children without disabilities learnt how to share, care for and communicate with children with disabilities. Linda, a female caregiver explained,

'At first they [other children] used to be staring at those with disabilities, but right now they are used to them and they are able to learn together as one family and they all know that there is no difference between them.'

Parents of children with disabilities, in turn, felt more hopeful for their child's future having seen improvements in their happiness and well-being. Martha, a mother of four including a child with a disability, explained:

'I get encouraged to send my child here because it makes him happy. Just to see that makes me happy also. I feel happy because my child doesn't find any problems here at the CBCC. Because of that, I feel encouraged to send my child to school because it's where he finds peace, more than just staying home with me.'

Caregivers shared experiences of children with disabilities learning through observing their peers, particularly peers without disabilities. They also expressed observing a growth in confidence when children with disabilities perceived themselves as being able to participate in activities alongside their peers. Eluby, a mother with a child with a physical disability that rendered him unable to walk well also perceived a similar confidence: 'It therefore increases his desire to play along and I just know he has hope that he himself will do that someday'. There was also acknowledgement that inclusion of children with disabilities was bringing change more generally, as Charmaine, a female caregiver at a CBCC confirmed: 'They were being isolated but things have changed now, after being enrolled in this school. They are able to observe what their friends are doing and able to do and copy others in the process.'

Most parents reported that their child's skill and overall development increased after enrolment at a CBCC and several observed that their child's ability to learn and interact at home increased after attendance at a CBCC. Some noted, for example, that their child had started to respond to questions when asked, and one parent indicated that their child had become toilet trained. Two parents shared that due to their attendance at a CBCC, their

older children with a disability had gone on to start primary school successfully. Caregivers named various curriculum-based skills that they had observed in children with disabilities including increased reading capacity, the ability to understand the calendar, and the English language. Despite articulating specific examples, caregivers felt that it was difficult to measure the learning outcomes of children with disabilities beyond the observation that they had become 'more knowledgeable'. In terms of physical improvement, one mother, Priscilla, suggested that engagement at a CBCC had a positive impact on her boy's on-going medical treatment: 'The doctors said that his movements might help the swelling go down because he plays a lot when he is here [at the CBCC]. He can stretch his legs now and has a chance to play with his friends.'

Factors Influencing Non-enrolment and Absenteeism from CBCCs

Across the study sites, caregivers believed that some parents did not enrol their children at CBCCs due to the type and severity of their disability. Absenteeism was particularly common in relation to intellectual, behavioural and learning disabilities as it was understood that parents and the wider community often perceived them as not 'fit' to learn. Parents indicated that they did not want 'to be a burden' on caregivers who were already taking care of 'so many' children. Naphiri, a stay-at-home mother of a boy with multiple disabilities explained, 'You ask yourself, if my child is behaving this way in the home, how then can it stay in school? If he picked up a stone, he would just throw it at anyone.'

Several caregivers acknowledged that caring for children with certain disabilities at the CBCC was challenging, especially those that had special requirements in relation to toilet issues. This was particularly the case for children with epilepsy. These children were perceived by caregivers to be at greater risk of non-enrolment because of community-based perceptions and a lack of understanding of the condition which caused discrimination. Nabanda, a female caregiver, reported: 'Some parents are afraid that their children have epilepsy, and as such they will pass on the disease to other children. That is why they do not send a child who has epilepsy to any of the CBCCs'. Children with severe medical conditions were at particular risk of absenteeism: they were sometimes absent from CBCCs for medical reasons: be it the severity of the condition, or for ongoing medical or rehabilitative treatment.

A parent's perception of their child's acceptance and ability was a key factor in child attendance at CBCCs. Some caregivers felt that parents feared their child with disabilities would be bullied at the CBCCs and further discriminated against by the wider community if attending. Others experienced some parents as having low expectations of their child and as such may not have considered enrolling them at a CBCC or trying to access services. Nabanda, a female caregiver, explained, 'You need to encourage them ... many think that children with disabilities cannot do anything or achieve anything in the future and that is why they do not have that passion and interest to send their children to the CBCC.'

Lack of food was the most frequently cited reason for absenteeism of all children, at the household and community level and in relation to services provided at the CBCC. This was more common during the dry season when food insecurity was more likely after poor harvests. Parents of children with disabilities indicated that they were likely to withdraw

their child when they could not afford to provide food or lunch money and there was no food provided at the centre. Some suggested they were 'ashamed' of their financial situation, and often wanted to make the situation easier on their child. One mother, Nangozo, explained the effect her financial situation could have on her child's education:

'My child feels excluded when the others are eating because he does not have any food of his own. Sometimes when I don't have any money I feel tempted to just tell the child to stay home that day so that he does not feel out of place when he is there without any food.'

Some caregivers confirmed the trend, as they stated that they had previously served fortified maize at the CBCCs, and had noted a rise in attendance numbers when a meal was served.

Other livelihood and economic factors also influenced attendance. The majority of parents engaged in the study were subsistence farmers whose livelihood depended on selling agricultural produce to markets. Children, with and without disabilities, were often absent from the CBCC on market days as their parents were unable to bring them to the centre, and the children were frequently required to work. Costs for uniforms, book bags and soap also prevented parents sending their children to school, sometimes temporarily, as Elizabeth, a female caregiver reported: 'When they [parents] do not have a tablet of soap, they do not send their child to school. But they always try their best to keep [attending] this CBCC, the only problem is their poverty.'

Value of the service was an important influencing factor. Caregivers felt that some parents did not see the benefits of enrolling their child with disabilities in ECDE activities, beyond concerns already raised here, which often linked to not attributing high value to mainstream education. Caregivers recounted experiences in which parents had withdrawn their child from a CBCC when they had not quickly seen material and educational gains, and many caregivers found it challenging to manage parental expectations adequately. Caregivers also felt that a lack of dedicated space for ECDE activities may compound attendance and enrolment issues. The majority of parents of children with disabilities, however, expressed that they continued to send their child to a CBCC, despite challenges in access, because it increased their ability to learn, improved well-being and offered a brighter future.

Some location specific reasons were also raised, particularly by parents. For example, there was confusion or misunderstanding about enrolment criteria in some CBCCs. Caregivers explained that some parents did not know their child was eligible to attend the local CBCC, especially if they did not live close by: 'they heard that they were not supposed to send their children here since they are from another village' (Nachisale, female caregiver). In other CBCCs, safe mobility and distance from home to CBCC, the bad condition of road infrastructure, and limited (appropriate) transport options further influenced enrolment and attendance. The rainy season made the situation harder, particularly for those who had to cross a river to reach the centre.

Barriers to Learning and Developmental Progress at CBCCs for Children with Disabilities

A lack of training emerged as a key issue, exacerbated by a high child-to-caregiver ratio. The caregivers who participated were volunteers at the CBCC in their community and

were often parents of children with disabilities themselves. Male and female caregivers expressed that they provided their time voluntarily because they had a 'passion for teaching' and assisting children with disabilities, but emphasised that they did not always have the requisite knowledge for teaching children with special needs who were 'different from normal children.' Such lack of training given to volunteer caregivers in the study is a reflection of the national situation (Özler et al., 2016).

All caregivers emphasised the importance of receiving additional competency training and skill development, particularly in sign language and other special education methods. Some caregivers had only received limited formal education themselves and prior to assuming their role at a CBCC had little training on 'caregiving' techniques to use in the classroom or ways to engage with children with different disabilities. Those who had received training would have participated in a two-week residential course that covers basic principles of child-care, physical and social-emotional development. It would have touched on some aspects of teaching pre-literacy and numeracy for children aged 3–5 years and provided some advice on how to handle children with disabilities at CBCCs (Government of Malawi, 2017b). Positively, caregivers reported a range of practices used to engage with children with disabilities, such as: 'we sit down with them and teach them slowly according to their pace so that they should be able to understand the whole concepts and content' (Victor, a male caregiver) and 'by isolating them after the lesson and repeating the same lesson again to them' (Olivia, a female caregiver). Caregivers also helped them to use the toilet and supported interpersonal engagement with specific support or instructions.

Caregivers feared they were not helping and expressed concerns that children with disabilities may not achieve their potential learning outcomes as they did not have the required skills to teach them appropriately. Male and female caregivers questioned whether they may 'teach the wrong behaviour' through lack of knowledge. Some reported feeling 'sad' about the lack of improvement children with disabilities made and their limited learning outcomes, and blamed themselves and their limited capacity for not succeeding in better educating these children at CBCCs. Although some parents recommended that teachers should 'speak louder' and write 'bigger words' for children with disabilities, they were not aware of specific educational engagement methods for teaching children with disabilities, and as such did not always question the quality of caregiving.

A high caregiver-to-child ratio had an impact on the quality of teaching. Classrooms were often full with very limited individual attention for those children in need, in particular those with complex disabilities. Also, as a result of the high number of children in the classroom, children with disabilities were separated from their peers at times (at least in centres that had more than two caregivers on staff at any one time). Teaching and play activities then took place in other community buildings such as a church or the house of a caregiver or local leader, as there was limited classroom space. Caregivers did not express any understanding of the detrimental effect of the separation of those with and those without disabilities on children's confidence, psychosocial wellbeing and learning outcomes.

Caregivers saw the lack of appropriate materials and educational resources for children with disabilities in CBCCs as an additional challenge to providing quality care. Many were dissatisfied with the current learning environment of CBCCs, which they characterised as

'unsafe', especially when classes were taught in different buildings in the community and not in a designated CBCC building. Lack of water, toilets and sanitation facilities made the situation very difficult as 'children with disabilities often soil themselves'. A lack of access to cleaning materials, first aid and medical kits and cooking utensils also made duty of care challenging. Parents stressed the importance of the CBCCs being equipped with appropriate indoor and outdoor resources for children with disabilities, emphasising that they were more vulnerable than children without disabilities and therefore needed particular or specialised materials.

Safe mobility and distance from home to the CBCC was a barrier to some children accessing the centre. Both parents and caregivers suggested there was a significant need for children with disabilities to have safe transport options and be given additional guidance on how to move around safely, particularly in relation to walking alone, and crossing a road or river.

Accountability and Support Channels

Parents and caregivers highlighted the important position of the village leader at the community level. With regards to CBCCs, the leader was seen to have a dual role: he or she acted as a dispute mediator (holding legislative power), and – if convinced of the value of the initiative – was a respected advocate and information provider about services the CBCC offered. Several parents emphasised the advocacy role held by a chief in relation to both inclusion and education. Phiri, a father of a child with multiple disabilities, for example, reported: 'We have a good chief who calls upon the parents to bring their children to the CBCC, but most parents neglect the call'; and explained that: 'We also approached the chief so that he should be able to speak about the CBCC during community meetings by telling or advising parents who have children with different disabilities to send them to the CBCC'.

School or CBCC committees also played a role in education and school-related matters at the community level. These usually comprised village leaders, parents and other community members. Some parents explained that such committees could help resolve disputes. Olivia, a female caregiver, explained that, 'Each time we have or face any challenge, we always call the school committee and the parents and then we sit down and discuss those challenges as a group and we always come up with a solution.' Although the committees acknowledged the lack of resources for CBCCs, they were not able to provide any additional materials or capacity.

Male and female caregivers and parents indicated that whilst they 'relied on the social welfare office' and other government bodies, such actors were not visible at the community level: 'We do write reports and send them to the social welfare office, and sometimes we ask [for] help from the members of parliament, and yet we do not get any support from them' (Steven, male caregiver). In the absence of effective government services, it was felt that NGOs should provide services and support for children with disabilities and their families, to access special education and necessary medical care.

Suggestions from Research Participants

The following recommendations were suggested to the research team by the caregivers and parents involved in the study. Resources: Parents and caregivers, alike, reported that CBCCs require more material resources designed to stimulate engagement and creative play for children with different disabilities. Barriers: Structural barriers should also be removed to improve access and dedicated space should be given to CBCCs to ensure the classroom environment is accessible, safe and conducive to learning and playing activities. The research participants, suggested removing or minimising financial and logistical barriers in order to encourage attendance. They suggested removing hidden costs and school fees, finding local solutions to distance and transport barriers, and local solutions to children being absent during market days. Nutrition: Parents and caregivers alike highlighted food access as an important factor in determining attendance at a CBCC. Since the inception of CBCCs, the Malawi Government has encouraged management staff to provide nutrition as part of the child's holistic development (Government of Malawi, 2017a), although frequent experiences of drought have led to periods where food supply to communities and CBCCs has been badly affected (Munthali, Mvula, & Silo, 2014). The provision of food for children at CBCCs would likely encourage attendance and raise nutritional status which would in turn support improved learning capacity.

Caregivers and parents also formulated some specific recommendations for their respective situations. Parents, for example, reported that measures should be put in place to stop bullying and discrimination at CBCCs. Caregivers reported that targeted outreach is needed to ensure that children with disabilities attend the centre and foster wider community support. They also emphasised the importance of receiving competency training and skill development, particularly in relation to ECDE and their capacity to adequately care for and teach children with a range of disabilities. Caregivers also suggested that they would benefit from psychosocial support as part of a CBCC package.

Discussion

Exploring the provision of inclusive early years education for children with disabilities through CBPR with a focus on parent and volunteer caregiver perceptions has created opportunities for much discussion and reflection. Community researcher suggestions have been prioritised for this paper.

Community Researcher Suggestions Based on Findings

Community researchers made various suggestions when reflecting on the findings. They suggested targeted outreach to parents of children with disabilities to promote enrolment and attendance, and to raise awareness amongst the community more broadly. They felt that by providing parents with more detailed information about what to expect from CBCCs, parental expectations may be better managed and therefore it would minimise the risk of a child being removed from a CBCC when their parents did not see noticeable improvement in their development. Community researchers agreed that it was essential to encourage parents to keep giving their children support at the household level. In a study testing the effectiveness of caregiver training and parenting support on

child development, Özler et al. (2016) suggest that an integrated approach of the two within CBCCs may be more effective in improving children's learning outcomes than programmes that focus only on improving CBCC quality. In addition, the activities at CBCCs could be reinforced to help improve and maintain learning and developmental outcomes. Targeted outreach around these activities has been planned within CBCCs as a result of such reflections. As future work is considered, it is also important to consider why services are not reaching children who are the most vulnerable, including those with intellectual and behavioural related disabilities.

Community researchers suggested that organisations involved in the implementation of services for children with disabilities should include developing and strengthening partnerships with existing support-providing agencies and establishing clear referral pathways. Practical recommendations included providing CBCCs with essential water and sanitation facilities, ensuring a dedicated space that is accessible, safe and conducive to learning, and providing more material resources designed to stimulate engagement and play for children with different disabilities. Meaningful child-adult interactions in stimulating and safe environments is widely seen as the most important (Walker et al., 2011) as well teachers having access to a variety of play and learning materials to effectively deliver high quality education (Dusabe, Pisani, Abimpaye, & Honeyman, 2019). In terms of learning, further inclusive education training to support the tracking of learning and development outcomes were recommended. To support the emotional needs of the children, the community-based researchers suggested ways of reducing discrimination and providing emotional support to parents and caregivers in CBCCs with the support of Child Protection Officers and the District Social Welfare Office. Engaging even very basic support from a variety of cadres to provide inter-agency ECDE collaboration to parents could have a positive impact on the developmental and educational prospects of children with disabilities (Lynch et al., 2018). The researchers acknowledged that barriers to attendance were complex and that removing hidden costs, finding local solutions to distance, transport barriers and market day absences were important and difficult to achieve.

Advocacy and policy suggestions made by community researchers were built on the above points at a local and national level. Beyond this, advocacy suggestions included developing enrolment criteria for CBCCs, enrolment at CBCCs to move beyond just recording the enrolment of disability type or severity of child's limitation to identifying simple ways to reaching out and supporting parents of children with disabilities. Community researchers also underlined that advocacy for inclusive early childhood development and education and CBCC attendance should work with local structures that are well respected and regarded as authoritative at the community level.

How the Findings Influenced the Study Intervention

The findings of the CBPR element of the wider study, along with reflections and suggestions from community researchers, fed into the development of an inclusive resource pack (IRP) that was integrated into an existing two-week national ECD training programme for caregivers. The IRP focused on how to include young children with disabilities in the daily activities of a CBCC. Caregivers required training in key areas of the curriculum to be able to ensure children with disabilities receive good quality care and teaching,

including understanding a child's disability in order to reduce discrimination and keeping records of development and learning. The final IRP contained a series of child case studies to help caregivers consider how to include and support children with a range of developmental difficulties and disabilities in their CBCC. There has been an increase in parental involvement as organisations are taking turns training community members, parents and caregivers on inclusion in their respective areas of influence. Some community-based organisations and international agencies (such as the World Bank), are engaging in the construction and renovation of ECD centres, and supporting school feeding programmes, have intensified via external organisations (such as the UN World Food Programme).

Methodological Success and Tensions

Some aspects of CBPR are more difficult to incorporate into education and social inclusion projects in the global South than others (Greenwood, 2017). This component of the wider study has had its own methodological successes and tensions. Community researchers and the two project researchers from Chancellor College made a considerable contribution to the research process. The research captured expressions of lived experiences of parents and caregivers in relation to young children with disabilities attending CBCCs, through the lens of their families and caregivers – an insight into the 'adult-view' on childhood (Punch, 2002). The perceptions of young children with disabilities were not included in the study because of budget restrictions. The experiences and perceptions of children enrolled in CBCCs is an important dimension to include in future research. In a later round of data collection for the wider study, however, a small number of community researchers were also able to assist in the collection of data for case studies of ECDE children, including making observations of learning sessions.

As expressed above, CBPR ideally involves members of the community in planning, carrying out data collection, analysis and dissemination. Theoretically, to shift nominal and instrumental participation to representative and transformational participation (White, 1996) community researchers would need to be involved in all decision-making and implementation processes. Yet, in practice this is not always practical or feasible. One value tension was balancing unavoidable data collection delays with being able to report findings in a timely way so as to influence the decision-making processes in the intervention. As a result, analysis was shared with community researchers and their feedback included, but community researchers were not able to undertake the analysis themselves. With less pressing deadlines, this would have been preferable, either throughout or at a deductive analysis stage. Another limitation with this approach was that community researchers were not included in initial planning because only once ethical clearance was granted could community researchers be included, as part of the ethical process to protect them. Community researchers need to set the agenda for change themselves, not simply react to an agenda that has been laid out for them by others (Samadi, McConkey, & Kelly, 2012). It is important to identify ways to ensure community researchers have ownership at the earliest stages of the process.

Conclusion

Exploring the perceptions of parents and caregivers of children with disabilities in rural Malawi, through a participatory methodology, highlighted a number of key opportunities, concerns and challenges. Findings demonstrated how various levels of discrimination of children with disabilities – in particular those with cognitive, behavioural and intellectual disabilities – and families of those children in both school and community-based settings have an impact on their attendance and development.

The CBPR element of the overall research emphasised the importance of including existing community structures (e.g. village elders, schools, CBCC committees) to promote education in general, and ECDE at CBCCs specifically. It showed the effect of limited monitoring and evaluation tools on the confidence and motivation of the caregiving volunteers, who often had not received much formal education, and on their ability to convince parents of the value of early learning and communication. It documented how experiences of childhood disability can affect a family unit, and how a CBCC can act as a bridge between the family and the community.

The CBPR element does not record the short and long-term learning outcomes that can be attributed to early learning over time, but a positive next step would be to engage children with disabilities to better understand their lived experiences of being part of an early learning activity. The process of this study provided key lessons and direction for developing the methods further, including in relation to community researchers setting the agenda for themselves.

This study has been able to make explicit the increasing momentum for changes in practice when supporting children with disabilities in rural communities in Malawi. New government policy expresses a greater commitment to increase the number of children with disabilities accessing ECDE service, particularly CBCCs. There is a strong desire to provide a stimulating and safe environment for quality inclusive learning for all young children to achieve their development potential. Yet, there remains much to do in terms of increasing the skill sets of caregivers and resourcing centres to enable them to be inclusive of children with disabilities.

Note

1. All names are pseudonyms assigned by the authors.

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