A Call for Re-visioning Participation: Realist Review of Participation in Community-based Rehabilitation for the Inclusion of Children with Disabilities in Low-Income and Low-Middle-Income Countries

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ABSTRACT

Background and Objective. Community-based rehabilitation (CBR) represents a multifaceted social intervention designed to tackle issues related to access, equity, and service quality. Within the framework of CBR, participation stands as a pivotal principle, albeit one that frequently goes unnoticed, particularly concerning children with disabilities. Consequently, this realist synthesis embarks on an exploration of the present landscape, participation mechanisms, and resulting outcomes within CBR initiatives tailored for children with disabilities in low and low-middle-income countries.

Methods. The realist approach is utilized to explain the causal mechanisms and explore the context, mechanism, and outcome of participation in CBR programs. A systematic search was conducted across ten databases up to April 2021. Studies were included if they involved children with disabilities aged 17 years and below, were implemented in World Bank-classified low-income or low-middle-income countries, discussed implementation mechanisms and community participation, and described outcomes. No language restrictions or publication type limitations were applied. The search process employed double screening of title, abstract, and full-text levels, followed by a snowballing technique. Quality assessment followed the RAMESES standards for realist reviews. Data extraction and analysis yielded context-mechanism-outcome configurations.

Results. Thirteen articles were included in the synthesis, from which three context-mechanism-outcome configurations were identified: (1) family-facilitated intervention through training in the immediate environment of children with disabilities leads to knowledge translation of caregivers, (2) inaccessible healthcare services require establishing a referral system and augmenting human resource to ensure the system's capacity to accommodate the magnified need, and (3) established collaboration of researcher, professionals, and community with stakeholder involvement in the CBR management leads to program adoption and documented effectiveness. Both training and establishing referral systems as implementation mechanisms pose sustainability challenges due to dependency on funding. Overall, participation as a form of agency is more often an implied concept. Training is a common mechanism of implementation, where women play a critical role as proxies of children with disabilities, being their caregivers and advocates. Positive and negative outcomes focus on the condition of children with disabilities and the trainees' knowledge and awareness.

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Conclusion. A critical analysis of children's and community's participation in the context, mechanism, and outcome unravels the non-participation of children with disabilities and tokenism of the community stakeholders in the CBR programs. Maximizing the contribution of children with disabilities and community stakeholders is called for, aligned with the ladder of participation, toward their democratic participation. Study limitations include the paucity of published CBR programs reporting participation mechanisms in low and low-middle-income countries and the exclusion of studies from economically disadvantaged communities in high-income countries.

Keywords: community participation, developing countries, disabled children, community health services

INTRODUCTION

Community-based Rehabilitation

Around 650 million individuals live with a disability in the Asia-Pacific area alone,[1] while 93 million children worldwide[2] struggle with comparable issues. Unfortunately, discrimination against children with disabilities is pervasive, especially in low-income countries (LIC) and low-middle-income countries (LMIC), making them the society's most oppressed members of society. Their marginalized condition results from barriers to quality, equity, and accessibility to educational, medical, and humanitarian services.[1,3-5] Regrettably, the lack of available resources makes it even less likely that these kids will receive good care.[6]

Community-based rehabilitation (CBR) targets rehabilitation, equalizing opportunities, and social inclusion of all persons with disabilities. By fostering collaboration between community leaders, individuals with disabilities, and their families, CBR ensures that everyone has an equal chance to succeed.[7] It strives to eliminate the barriers that hinder the participation of individuals with disabilities in various aspects of life such as health, education, livelihood, and social activities.[8] CBR recognizes the complex nature of disability and works towards addressing the underlying causes and effects while promoting empowerment and participation among children with disabilities.[9,10] Overall, CBR programs foster opportunities to increase children with disabilities' empowerment and participation.[10] Through its rights-based approach, CBR acknowledges the medical, social, and political dimensions of disability, acknowledging the discrimination and exclusion faced by children with disabilities.[11]

Participation in Community-based rehabilitation

Participation is a fundamental principle of CBR, built upon cooperation, mutual respect, and embracing diversity to foster growth.[12] Participatory approaches are emphasized as CBR transitions from the medical model of disability to the human rights model, essential for promoting social mobilization and shaping disability policies.[11,13]

To elucidate what participation can be, Arnstein[14] introduced the eight levels of citizen participation, each representing the increasing levels of citizen control, authority, and agency. In this typology, the two bottom rungs, namely (1) Manipulation and (2) Therapy, highlight the "curing or educating" of participants through participation as a means for them to enter higher levels of control. A contingent ladder of participation for children was conceptualized by Hart, which focuses on children's participation in projects ranging from activities directed by an authority to activities done voluntarily. Similarly, it would also have eight rungs, with the three bottom rungs namely (1) Manipulation; (2) Decoration; and (3) Tokenism, categorized as non-participation, and the five upper rungs, (4) Assigned but Informed; (5) Consulted and Informed; (6) Adult-initiated, Shared Decisions with Children; (7) Child-initiated and Directed; and (8) Child-initiated, Share Decisions with Adults, depicting the degrees of children participation. Even though the model does not imply the necessity of children to function on the highest rungs of the ladder consistently, it still highlights the principle that programs available should be designed to allow children to participate at their highest level of capacity to exercise their rights of citizenship.[15]

Stakeholder involvement is essential for the success of CBR programs.[16] By actively engaging with the community, obstacles can be identified, and solutions can be suggested, leading to more effective and sustainable outcomes. Participation, particularly of persons with disabilities, plays a crucial role in improving their quality of life and paves the road for empowerment.[7,17,18] This active involvement not only helps to identify resources and increase awareness of skills but also contributes to the development of leadership within the community.[19] Additionally, active community involvement fosters a sense of accountability and empowerment through collective effort.[20] Ultimately, the full participation of the community is key to the effectiveness and long-term success of CBR programs. It is through this collaborative approach that CBR programs can truly make a meaningful and lasting impact on the lives of individuals with disabilities.[9]

Given the undeniable positive outcomes that arise from participation, it is a phenomenon that can either be successfully achieved or regrettably overlooked, or even incorrectly applied, within the realm of CBR.[9] This discrepancy can be attributed to divergent perspectives and motivations surrounding the program, which challenges meaningful discourse and shared understanding.[9,21,22]

Realist Review

A realist review is a research synthesis strategy based on an explanatory approach. It generates causative explanations of the context, mechanism, and outcome (CMO) in a program.[23] A complex social intervention, such as CBR, can yield different outcomes in different contexts due to contextual factors in the individual, interpersonal relationships, and the wider community.[24]

Without an exact theory that predicts outcomes of participatory mechanisms in every context, configurations that relate to the CMO may identify emerging patterns.[25] A rapid review of literature led to relevant definitions of CMO regarding CBR. Context includes aspects such as structure, dynamics, and relations.[26] The mechanism encompasses the actor, the action, the target(s) of the action, and agencies.[27] Outcomes encompass implementation, service, and client outcomes.[28] Implementation outcomes indicate changes at the population level within the providing system. Client outcomes refer to individual-level improvements in consumer well-being. Service outcomes pertain to the quality improvement of CBR programs in LIC and LMIC.

OBJECTIVES

Through the identification of recurring patterns with the relationship of the context, mechanism, and outcomes of the participatory approach in CBR for the inclusion of children with disabilities, this realist review aims to describe how the participatory approach of CBR program for children with disabilities is implemented and the conditions and caveats that influence its implementation, with the following objectives:

1. Understand the contextual factors that produce the outcomes of participatory approaches
2. Understand mechanisms underlying the participation of stakeholders in the conduct of CBR programs for children that cause their intended and unintended outcomes
3. Describe the intended and unintended outcomes of the participatory approach of CBR programs for children

METHODS

Realist Design

This is a realist review based on the RAMESES standards registered in UP Manila- Research Grants Administration Office with reference number RGAO-2021-0407.[29] The ethics approval for the broader research associated with this review was granted by the University of the Philippines Manila Review Ethics Board, with the assigned code UPMREB 2022-0461-01. In a realist review method, it is deduced that no theory can fully describe and foresee what the outcome would be in different contexts, but rather, it is assumed that people would make the same decisions about the utilization of resources.[23] It is not absolute that people would always choose the same options, but specific contexts affect people's choices. These semi-predictable human behaviors are called demi-regularities, and these are further elaborated through the underlying theories divulged in a realist review where the CMOC is analyzed. This approach enables the examination of how and why interventions work in different contexts, going beyond just identifying knowledge gaps or scoping a body of literature, which is the typical purpose of scoping reviews, or producing statements to guide decision-making, a common goal of systematic reviews.[30] Instead, this realist review aims to investigate the complex interplay of factors that influence the effectiveness of interventions in CBR programs.

Inclusion and Exclusion Criteria

Studies were included if the participants of the CBR program were children with disabilities, aged 17 years old and below, and their families. Articles were also included if the program was implemented in Low-Income or Low-Middle-Income Country (LIC and LMIC),[31] implementation mechanisms and community participation were discussed, and outcomes were described. No language restrictions were applied, publications of any type were included, and no limitation was set in the year of publication. Studies that focused on the general population were excluded.

Data Management, Analysis, and Synthesis

The search utilized a systematic approach and extensive snowballing. The researchers used ten research databases to search for primary studies to include. Keywords and search terminologies were listed and developed. The following search terms were used: "community based rehabilitation" OR "CBR" OR "community based inclusive development" AND "participatory" OR "community participation" OR "stakeholder engagement" AND "children" OR "children with disabilities" AND "LIC" OR "low income country" OR "LMIC" OR "low middle income country" OR "developing country" OR "global south". Search and screening were done until April 2021.

A double screening approach was used to screen titles and abstracts where pairs screened the same set of articles independently while working in pairs to ensure consistency and reduce bias. This double screening approach aimed to ensure consistency in the application of the selection criteria, reduce bias, and minimize random errors.[32] The full-text screening was performed by seven reviewers, again working independently before comparing results. Complete copies of articles were acquired for the studies that seemed to align best with the research question. In cases of disagreement, a mediator facilitated the discussion until a consensus was reached, ensuring that decisions were made collaboratively. To expand the search, snowballing technique[33] was done, reviewing the reference lists of articles that did not meet the inclusion criteria from the previous screenings. This approach allowed identification of potentially relevant studies that the initial search strategy might have missed. All articles identified through snowballing were subjected to a full-text review by the same team of seven reviewers, maintaining consistency in the evaluation process.

A data extraction table through an Excel spreadsheet was made to organize and gather information from the articles that met the inclusion criteria. The complete data extraction table for this realist synthesis is available as a supplementary material. The recurrent CMO of the CBR programs implemented in the articles became more evident

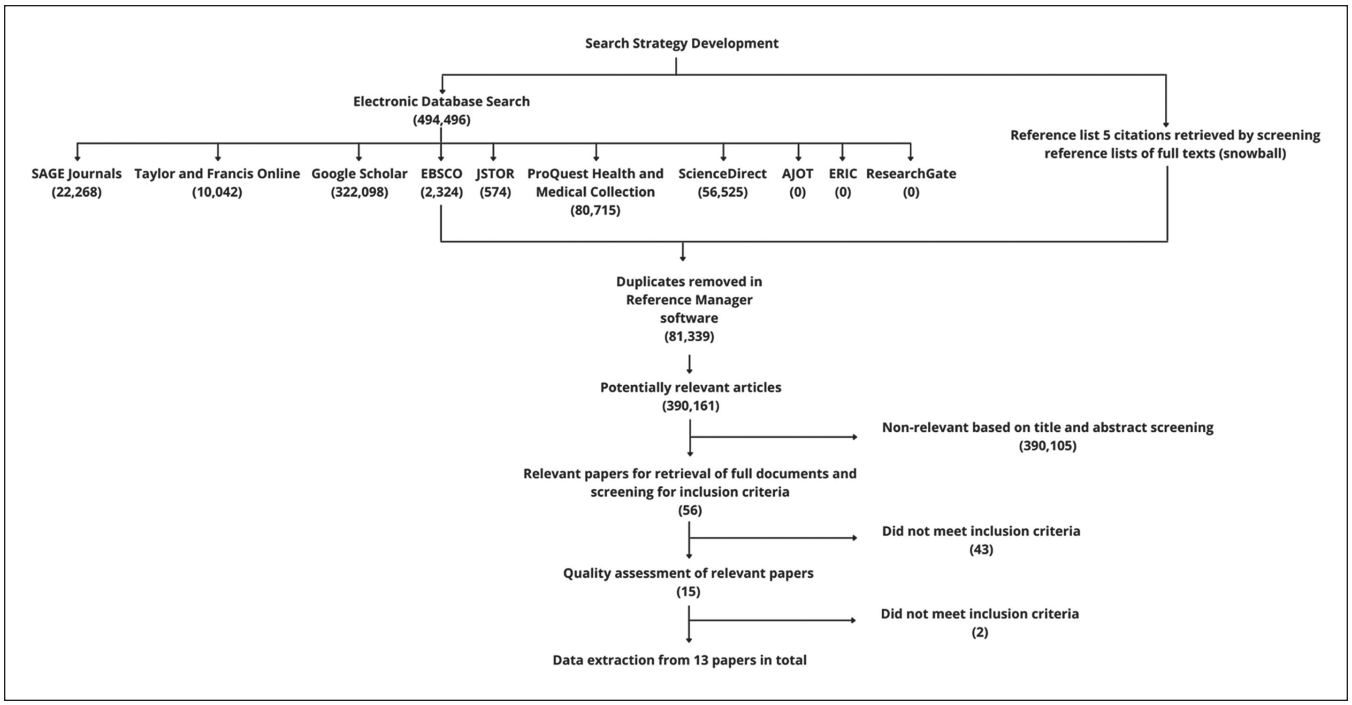

Figure 1. Flow chart of search results.

by utilizing the data extraction table. Using content analysis, the researchers generated recurring themes from the data extraction. Frequent and relevant entries in the CMO were analyzed, and patterns of relationships among them were explored, leading to the generation of the CMOC. Data analysis and synthesis results were regularly discussed to ensure the validity of the individual inferences regarding participation in CBR for children with disabilities.

RESULTS

The search from the ten electronic databases resulted in 494,496 articles (Figure 1). Mendeley was used as the reference manager to remove the duplicates yielding 390,161 potentially relevant articles. Among these articles, 390,105 were considered non-relevant based on title and abstract screening. Fifty-six articles underwent full-text screening, of which 43 did not meet the inclusion criteria. Overall, 13 articles were included for data charting. In charting the information from the studies, attention was given to each program's context, mechanism, and outcomes as categories of knowledge contribution.

General Characteristics of Included Articles

The 13 studies published between 1988 and 2021 met the inclusion criteria: seven (7) qualitative[34-40] five (5) mixed methods[41-45], and one (1) quantitative study.[46] The background of the authors' professions includes health, education, and social development (Table 1). While three (3) articles explicitly stated they were guided by the WHO CBR model, eight (8) articles used different approaches, and two (2) articles did not mention any conceptual framework guiding their CBR program. In terms of the children involved with the program, four articles were focused on a single diagnosis, visual impairment[41], motor impairments[37] intellectual disability[35,39], and cerebral palsy.[40] The rest of the nine (9) articles' CBR programs catered to several diagnoses or impairments. Notably, only one (1) article[45] accounted for children not diagnosed with a disability.

Context

The CBR context, as shown in Table 2, pertains to the community where the program was implemented. Out of 13 articles reviewed, nine (9) articles are from LMIC, while the other four (4) are from LIC, covering Africa, South Asia, and South America, with a notable predominance of articles from India. Most CBR programs were implemented in multiples sites, with a focus on household implementation such as home training for caregivers[45] and home visits for palliative care were done.[46] Pre-existing relationships between the researcher of the studies, the community, and volunteers were noted before the program was implemented.[44,45] An example is the article by Sen & Goldbart,[42] wherein the two authors took leadership roles in implementing this program representing the Indian Institute of Cerebral Palsy and Manchester Metropolitan University in the United Kingdom. O'Toole,[45] on the other hand, was able to conduct surveys and interviews before the actual implementation of the program.

Notably, articles from India and Africa have highlighted the significant role of women's groups in leading initiatives

Table 1. General Characteristics

Characteristics	Article reference number
Associated Profession of Researchers	
Health Professions	35, 36, 37, 39, 41, 42, 43, 44, 46
Education	34, 37, 38, 42, 45
Social Development	40
CBR Framework/Model Used	
International Classification of Functioning (ICF)	34
CBR Guidelines (WHO)	35, 37, 45
Family Involvement Model	42
Social Ecologic Model	44
Kerala Model (community-led approach)	46
Society for the Elimination of Rural Poverty (SERP) Model	39
Community-based Participatory Approach	36
Decolonizing Methodology Approach	38
Participatory Rural Appraisal	43
Disability Diagnosis/Type	
Visual impairment	41, 43
Motor impairment	34, 36, 37, 38, 42, 45
Cerebral palsy	36, 40, 42, 45
Cognitive disability	34, 42
Intellectual disability	35, 36, 38, 39, 42, 43, 45
Autism	38
Multiple disabilities	35, 36
Congenital anomalies	36
Deaf	38, 45
Epilepsy	45
Down's syndrome	45
Speech delay	45
Undiagnosed	45

Table 2. CBR Context

Common characteristics	Article reference number
Low-Income Countries (LIC) (n=4)	
The Democratic Republic of the Congo	41
Uganda	37
Kenya	38
Guyana	45
Low Middle-Income Countries (LMIC) (n=9)	
Zambia	34, 44
India	35, 36, 39, 40, 42, 43
Bangladesh	46
Site Implementation (n= 13)	
Households	34, 35, 40, 41, 42, 43, 44, 45, 46
Schools	36, 38, 45
Rehabilitation centers	36, 37
Health centers	43, 44
Church	44
Training institution	45
Neighborhood centers	39
Community Dynamics (n=3)	
Existing local groups	36, 39, 44
Stigma regarding disability in the community	36, 44

for children with disabilities. In the Government of Kerala, the "Kudumbashree"[36] has been actively involved in this sector, as mentioned in the articles. Additionally, the Mandal Disability Forum and Mandal Women's Forum[39] have also been recognized for their contributions in this area. Furthermore, the articles specifically mentioned the influential role of mothers of children with disabilities in Zambia.[34] These women have been instrumental in advocating for the rights and well-being of children with disabilities in their respective regions. Overall, the articles emphasize the important leadership and advocacy efforts of women's groups and mothers in addressing the needs of children with disabilities in India and Africa.

Out of all the articles, two highlighted the stigma faced by children and their families from community members, leading to significant discrimination that adversely impacts the community participation of these children.[36, 44]

Mechanism

Mechanisms refer to implementation strategies employed in the CBR programs (Table 3). Charting for this section adapted concepts from the framework of Proctor, Powell, & McMillen.[27] It starts with naming or labeling the implementing strategy used. The term "actor" refers to individuals or organizations responsible for implementing the designated intervention action. "Action" represents the particular series of steps needed to implement the program. Implementation strategies also depend on their objectives or the conceptual "action targets" they aim to influence. Lastly, since the realist review focuses on eliciting stakeholder participation, an additional category, "behavior target," is added, similar to Hickey, Odeny, Petersen, et al.[47] This encompasses any behavior exhibited by the system, organization, providers, children, caregivers, and community members, which may serve as a prerequisite or an actual pathway to participation in the CBR program.

The articles demonstrated a wide range of perspectives when it came to categorizing the implementation strategies for CBR. While some were highly specific, others lacked adequate details in their descriptions. However, in most of the articles, family-facilitated interventions may be implied. Although the concepts of actor, action, action target, and behavior target are interconnected, there is a noticeable concern about aligning the actions with the intended targets. This issue arises from objectives of the CBR program that are vaguely worded or not specific enough. Similarly, the articles mostly hinted at the actual pathways to participation.

In terms of the actors in program implementation, ten (10) articles included the researchers themselves in the CBR program at varying degrees. For instance, Chowdhury, Shopna, Lynch-Godrei, et al.[46] primarily engaged in interviewing primary caregivers to gather information on the child's health problems. Elder & Odoyo[38] led the implementation of the program by organizing weekly inclusion meetings. Sen & Goldbart[42], on the other hand, provided training to

Table 3. CBR Mechanism

Common characteristics	Article reference number
CBR Implementation Strategy (n=13)	
CBR approach (in general)	34, 37, 41
Family-facilitated intervention	36, 37, 40, 42, 44, 46
Inclusive education system *with Community-based Participatory Research and Decolonizing Methodologies*	38
Cannot determine or insufficient detail to determine	35, 38, 39, 43, 45
Actor (n=13)	
Project researchers	34, 35, 37, 38, 40, 41, 42, 43, 45, 46
Primary caregiver trainees	35, 36, 37, 39, 40, 42, 45
Community worker trainees	35, 36, 37, 39, 40, 41, 42, 43, 44, 45
Local government (district/state/ministry)	36, 39, 42, 44
External fieldworkers (rehabilitation workers, assistant rehabilitation workers)	36, 37, 40, 44
Community members (church volunteers, neighborhood groups)	36, 38, 41, 43, 44, 45
Local self-help groups	36, 39, 44
Health professionals	35, 41, 43, 44, 45
Members of NGO	35, 37, 40, 41, 44
Action (n=13)	
Screening	35, 37, 41, 43
Interviews	34, 36, 38, 46
Training	35, 36, 37, 39, 40, 42, 43, 44, 45
Therapeutic maneuvers and Orthotic workshop	37
Establish referral system	37, 39, 41, 43, 44
Creation of an adult committee (teachers)	38
Action Target (n=12)	
Increase awareness and develop competencies and skills	35, 36, 37, 39, 40, 42, 43, 44, 45
Address stigma	35, 36, 42, 44
Describe barriers	34
Create inclusive education practices	38
Increase detection of childhood blindness	41, 43
Address lack of services	36
Provide linkages	39
Behavior Target (n=11)	
Active support groups	36, 39, 44
Volunteerism	39, 41, 42, 45
Engagement in the CBR Management	34, 36, 37, 40, 42, 43, 44
Participation in training	35, 36, 37, 39, 40, 42, 43, 44, 45

fieldworkers and implemented intervention programs for proper positioning of children with cerebral palsy.

Training is a dominant concept in terms of action that has resulted in increasing awareness and competencies as action targets and attendance to this training as behavior targets. Nine (9) articles explicitly stated training of community-based workers, with seven (7) of these articles implementing training of the caregivers of the children. For example, competencies and skills were facilitated for community resource persons[39] and women community members[36,37,42] who in turn provided training to parents of the children. Specific training topics were noted to address the needs of children with cerebral palsy, such as proper positioning and customized furniture.[40,42] Additionally, three (3) articles provided the community locals with training on detection and intervention. Specifically, two articles stated the education of villagers and parishioners for detecting visual impairment.[41,43] Another article mentioned the community's education, while families of children with disabilities joined rehabilitation provided by community caregivers.[44] Only one study mentioned highly specialized intervention directed to the child with a disability through therapeutic maneuvers and orthosis workshops.[37]

In response to the multifaceted needs of the children, a referral system was developed across five (5) articles to improve access to health[37,41,43,44] and education services.[39] It is noteworthy that only three (3) articles explicitly mentioned the involvement of local self-help groups, predominantly women who were engaged in training initiatives. For instance, women with motor disabilities were actively engaged as community resource persons (CRPs)[39], while special neighborhood groups (NHGs)[36] along with a volunteer workforce of community caregivers (CCG) were established to regularly meet with the mothers and caregivers of the children with disabilities.[44]

Overall, seven (7) articles engaged community members in the process of CBR Management Cycle. In this aspect, multiple components were noted from needs assessment,[36,40,41,43] resource mobilization,[36] identification of sites, development of materials in collaboration with families, observation, and reflection.[40] However, some articles only made vague references to the involvement of families and the community in decision-making during the planning and implementation stages.[37,42] This indicates a disparity in the level of community engagement across the articles, with some demonstrating a more thorough integration of community participation throughout the research process.

Outcomes

The 13 articles were categorized according to client, service, and implementation outcomes based on the conceptual framework by Proctor, Silmere, Raghavan, et al.[48] and Proctor, Landsverk, Aarons[49] (Table 4). Client outcomes focus on assessing whether the intervention is achieving the intended improvements in the well-being, health, or functioning of the target population. On the other hand, service outcomes pertain to evaluating whether the program is effectively meeting its quality improvement objectives Finally, implementation outcomes center on the process of introducing and executing the program to the community.

Client outcomes were documented most, particularly improved condition of the children with disabilities either through direct health services, referral system, or as an effect of the trainees' application of knowledge to the children. For instance, articles highlighted improved eye health and

Table 4. CBR Outcomes

Common characteristics	Article reference number
Implementation (n=7)	
Limitation on services (penetration)	44*
Positive uptake towards the CBR program	
(adoption)	37, 39, 40, 43, 44, 45
(sustainability)	36, 45
Stigma	36, 44
Service (n=8)	
CBR program is effective (effectiveness)	35, 36, 37, 38, 40, 42, 43, 44
Client (n=9)	
Improved condition of children with disabilities	36, 40, 41, 43, 45, 46
Increased knowledge and awareness of participants	34, 35, 40, 42, 43, 45

**negative outcomes*

lifestyle of children after provision of free surgery if they were diagnosed with cataracts or other eye problems[41] and through the utilization of available healthcare system.[43] Moreover, one article noted there were notable improvements observed in children with motor disabilities compared to those with hearing and speech problems.[50] Furthermore, articles by Hamblin & Musa,[40] O'Toole,[45] and Hearst, Adelli, Hepperlen, et al.[44] emphasized the positive impact of applying learned knowledge through proper screening, referral, and home interventions on child outcomes. These documented outcomes collectively demonstrate the effectiveness of interventions in improving the well-being of children with disabilities, whether through direct healthcare services, referrals, or the application of knowledge by caregivers and fieldworkers.

In terms of implementation outcomes, several articles have documented the adoption of CBR programs. These articles note the initial uptake of the programs at both the family and community levels. For instance, articles by Penny, Zulianello, Dreise, et al.,[37] Narayan, Pratapkumar, & Reddy,[39] Hamblin & Musa[40] and Deka, Syiem, Saikia, & Surong[43] reported that community resource persons played a crucial role in identifying and mobilizing children for assessment, as well as providing them with necessary support through the available health care system. Hearst, Adelli, Hepperlen, et al.[44] documented that through the community caregivers, there was increased engagement of families. Furthermore, it was consistently highlighted that parents' involvement is the most critical factor in successfully implementing the CBR program, with the family being at the core of these efforts.

There were notable adverse outcomes mentioned in three (3) articles. It was documented that Augustine[36] and Hearst, Adelli, Hepperlen, et al.[44] that the program did not effectively reduce the stigma surrounding children with disabilities and their families in the community. Augustine[36] and O'Toole[45] also expressed concerns about the sustainability of the program, stating that while there were positive outcomes, it remained uncertain if the parents could achieve complete independence even with the support of community groups. This complexity is further exacerbated by the reliance on specific stakeholders. Similarly, there were children with disabilities who did not achieve the desired level of independence in their daily lives.[36] Particularly in the article of Chowdhury, Shopna, Lynch-Godrei, et al.,[46] only 2 out of the 46 children showed significant improvement. The article by Hearst, Adelli, Hepperlen, et al.[44] further discussed challenges in accessing services due to increased membership in the Zambian Association for Persons with Disabilities (ZAPD). This led to a doubling of clinic appointments for referrals to physiotherapy. However, the health system failed to expand its capacity to support these families, resulting in extended waiting times.

Context-Mechanism-Outcome Configurations

The analysis of the relationship between the CMO resulted in the identification of three CMOCs (Table 5) along with developed statements. The first CMOC underscores the significance of tailoring training to the specific needs and environment of the participants, particularly when it comes to family-facilitated mechanisms. Caregivers are able to quickly learn effective strategies when they are taught in the context of their immediate tasks and learning environment. Furthermore, individualized programs that are based on the participants' immediate environment make the translation of training much easier. As a result, children with disabilities have shown noticeable improvements. It is clear that customizing training to the unique needs and environment of the participants is essential for success in family-facilitated mechanisms.

The establishment of referral mechanisms is a key focus of the second CMOC. These mechanisms allow community stakeholders to provide the necessary healthcare services for children with disabilities. However, prior to the implementation of these mechanisms, it is crucial to enhance the knowledge of the key stakeholders within the community regarding the significance of health services. It is crucial to acknowledge that gaining access to these services intensifies the need for them and necessitates adjustments to be made within the healthcare system to manage the heightened demand. Without proper accommodation, these services may become inaccessible due to long waiting times. It is crucial for the healthcare system to adapt in order to meet the needs of the community and ensure timely access to necessary services.

Both the first and second CMOCs raise concerns about sustainability. In the first CMOC, while training community key stakeholders and primary caregivers may enhance their knowledge and skills, it does not guarantee self-reliance. The training itself may or may not promote independence from trainers, which is crucial for the sustainability of the CBR program even after the initiating agency has left the community. Similarly, in the second CMOC, relying on local resource mobilization to establish a healthcare referral

Table 5. Context-Mechanism-Outcome Configurations

Context	Mechanism	Outcome	CMOCs	Statement	Evidence (Reference Number)
Households of children with disabilities as training and implementation site	Health professionals lead caregiver and community training for family-facilitated interventions for children with disabilities.	Increased knowledge and skills of community key stakeholders and caregivers, leading to improved condition of children with disabilities.	Family-facilitated intervention through training in the immediate environment of children with disabilities leads to knowledge translation of caregivers.	The immediate task environment of the children with disabilities and their families must be considered to provide contextualized training programs, aiding caregivers' translation of learning to their children. Self-reliance of caregivers must be emphasized for program sustainability.	36, 40, 41, 42, 45
Strong stigma on disability in low-resource community	Enjoining community key stakeholders to establish referrals to health services and organization membership.	Increased membership in the organization and magnified need for health services without capacity augmentation, lead to penetration issue.	Inaccessible healthcare services require establishing a referral system and augmenting human resources to ensure the system's capacity to accommodate the magnified need.	Inaccessible healthcare services require establishing a referral system and augmenting human resources to ensure the system's capacity to accommodate the magnified need.	36, 39, 41, 42, 43, 44, 45
Established relationships between researchers, agencies, local organizations, and community	Researcher-led CBR program implementation inciting intersectoral involvement in the management cycle.	Participants have positive uptake of the program (adoption) and documented effectiveness of the program.	Established collaboration of researchers, professionals, and community with stakeholder involvement in the CBR management leads to program adoption and documented effectiveness.	Interagency cooperation of program facilitators, implementers, and stakeholders promotes the community's involvement in the program management process. A sense of community harmonizes the efforts of researchers and private and government organizations that lead to research that document the program's effectiveness.	42, 44, 45

Sustainability Issue

system may overwhelm the existing system. The increased community awareness may create a greater demand for services, putting the long-term viability of the CBR program at risk. For the community, it is imperative to possess the agency and capacity to adapt to evolving needs and effectively manage the demand for services.

The last CMOC emphasizes the importance of collaboration between professionals and the community to achieve the goals of the CBR program. The formulation of CBR programs requires the teamwork and communication of all participating agencies, rather than being the sole responsibility of one organization. This collaboration between universities and the community promotes the academic practice of evidence-building in CBR through research. Through partnerships, professionals and the community can ensure that the CBR program is effective and meets the needs of all stakeholders.

DISCUSSION

Summary of Findings

A closer examination of the implementation mechanisms and outcomes of participation reveals a scarcity of empirical articles pertaining to its application in CBR programs. One of the many reasons is that there is variation in how participation is defined, depending on the paradigm of disability one uses that influences one's worldview. The medical model of disability, for instance, focuses on the deficits of children with disabilities, whereas a rights-based approach emphasizes the dignity of individuals irrespective of their abilities. CBR programs have been in existence for more than three decades and have undergone significant developments, transitioning from a narrow focus on impairments to a broader emphasis on community development. However, these programs still tend to underestimate the capabilities of children, as they are predominantly designed, implemented, and evaluated by adults. Consequently, they adopt a more individualistic perspective on disability, prioritizing client outcomes over the service and implementation outcomes that may impact surrounding social structures like policies and the political motivation of stakeholders.

An analysis of the articles based on the level of children's participation depicted by Hart,[15] points to the children with disabilities' non-participation. At best, these programs view consultation and dialogue with the community and families of children with disabilities as stand-ins for their involvement. Along the same line, applying Arnstein's[14] Ladder of Participation points to the CBR programs' focus on outcomes of the children with disabilities as relevant to their medical condition. In the most favorable scenarios, these programs grant parents a platform for expression, but their influence in addressing concerns may be constrained, illustrating a form of tokenism. Children with disabilities,

their families, and communities rely heavily on initiating agencies involved in temporary projects, creating insecurity and doubts about their sustainability.

CBR programs commonly have the primary caregivers, often mothers, as the substitute participants for children with disabilities. Mothers of children with disabilities are typically the primary caregivers, particularly when their children are left out of early childhood development opportunities. In addition to their caregiving responsibilities, these mothers embrace expanded roles as protectors, champions, advocates, and defenders of their rights. Parents and caregivers play a critical role in consistently advocating for and securing essential services on behalf of their children with disabilities. Beyond the mere provision of accessible physical facilities, their role also involves being vocal advocates in effectively addressing issues related to stigma and exclusion. While it is important for parents to nurture their children's self-advocacy skills, they undeniably play a crucial role in fighting for the acceptance and acknowledgment of their children with disabilities, both during their formative years and beyond the age of 18.[51]

It is not uncommon for children with disabilities to be overlooked, lacking visibility and a voice, due to the perceived complexity of their participation in CBR, particularly for those facing difficulties in expressive or receptive communication. Although there have been changes in how we view children's agency, these changes have not fully included children with disabilities. As a result, they have been significantly excluded from participating in research and consultation efforts.[52] In studies of children with disabilities, researchers often rely on proxies, usually adults around them, instead of directly engaging the children to gather insights into their experiences and perspectives.[53] This approach can limit the accuracy and depth of the data collected. To ensure that the voices of children with disabilities are heard and understood, researchers need to prioritize engaging with them directly.

Children with disabilities are often portrayed as passive recipients of services in the CBR program with the assumption that they have to be the object of intervention until they acquire the competencies of independent adults. In a study conducted by Akyol,[54] children begin to take a more active role and gain awareness of their choices as active participants if they are included in decision-making processes and planning activities. Hence, children's presence must be magnified. Children must be seen for their possible contribution to society even as they grow up.[55] Children may play a crucial role in community development. They have a fundamental right to participation, particularly when the issue concerns them, is understood by them, and is deemed by them to be important.[15] For all the recent international development focus on the elimination of poverty and on 'leaving no one behind',[56] it is clear that persons with disability are often 'othered' so much that they become invisible in policies and strategies designed to improve the lives of the majority[57,58]. This exclusion and silencing are magnified among children with disabilities.[59]

Community participation is the backbone of effective CBR programs. It is both a means and an end. Child, family, and community participation in CBR is a component of the mechanism of implementing CBR. It revolves around accepting the people's potential, respecting community views and the reality of their experiences rather than imposing knowledge and ideas outside the community. It works from a mutually shared terrain towards a shared outcome.[60] Active involvement of the community in the CBR process is a vital component in developing a sense of ownership and sustainability of the program itself. CBR programs must ensure that persons with disabilities and their families have opportunities to make decisions throughout the process and express their needs that exemplify the community's inclination towards the importance of 'hearing from your people'.[61]

Participation is also the CBR program's end goal in itself. The target of CBR is for persons with disabilities to become empowered rights claimants of the community and for society to protect their human rights through changes within the community.[9] This way, those with disabilities will be valued members of their community through their joint efforts with the relevant community stakeholders, ultimately yielding a program for the persons with disabilities.

Strengths, Limitations, and Future Directions

The realist review methodology enabled researchers to elucidate configurations exploring the context, mechanisms, and outcomes of participation in CBR, thus contributing substantive knowledge to the participatory implementation of these programs. However, this review is constrained by the paucity of published CBR programs reporting implementation mechanisms in LIC and LMIC, indicating a pressing need for further research to uncover emerging configurations. Moreover, the exclusion of studies from economically disadvantaged communities in high-income countries, due to disparate global poverty thresholds, limits the generalizability of the findings. This realist review did not include a formal risk of bias assessment for the included studies. While evaluating methodological quality of included studies could provide valuable information, the focus of this realist review was to understand how and why CBR participation interventions achieve their intended outcomes in specific contexts, ultimately toward refining a theory, rather than to evaluate treatment efficacy. This focus required a practical approach in including all relevant literature, regardless of study design and methodological issues. Future systematic reviews could include a formal risk of bias assessment for included studies to build on the results of this realist review.

The study's outcomes highlight several areas necessitating further research and policy exploration to enhance CBR programs in the Philippines. To bolster a family-centered approach, future investigations could examine the feasibility of integrating culturally appropriate training modules and support systems for families of children with disabilities into existing social welfare frameworks. Additionally, research

could explore the potential benefits of explicitly incorporating these family support provisions into the Magna Carta for Disabled Persons.

Strengthening referral systems requires policy modifications at both national and local echelons. Future studies may investigate facilitators and barriers in the coordination between rural health units and specialized care facilities. Furthermore, research could assess the feasibility of local government units enhancing the capacity of barangay or city health workers in disability-related care.

Additional research may inform the development of policy frameworks to institutionalize community engagement in CBR initiatives. This could entail revising local governance codes to mandate the inclusion of persons with disabilities and their families in decision-making processes related to health and social services. To address the lack of child participation, studies could explore the utility of guidelines for child-friendly and disability-inclusive participatory methods in community programs, potentially informing the incorporation of such guidelines into national policies on children's rights and welfare.

The findings on stigma and service deficits underscore the necessity for more robust disability-inclusive policies. Further research may be conducted on effective localized programs for anti-stigma campaigns and disability awareness initiatives, involving various government departments and offices.

To address sustainability concerns, future research could examine potential measures to promote the long-term viability of CBR initiatives. Feasibility studies on tax incentives for private sector involvement in CBR funding or support, or allocating a percentage of annual budgets specifically to disability-inclusive community programs, as opposed to focusing on dole-out programs, could provide valuable insights.

Lastly, to foster collaborative research, a comprehensive scoping review could be conducted on the outcomes of partnerships between Filipino universities and international researchers in disability studies, potentially facilitated by research grants or academic exchange programs.

These research suggestions, which have significant policy implications, stem from the study's findings and provide a roadmap for enhancing the effectiveness, participatory nature, and sustainability of CBR programs in the Philippines. Future research should focus on policy analysis that may reveal additional configurations of context, mechanisms, and outcomes in CBR participation. By addressing these areas through evidence-informed policy development, the Philippines can progress towards creating a more inclusive society that embraces children with disabilities and their communities.

CONCLUSIONS AND RECOMMENDATIONS

To the authors' knowledge, there have only been a few realist reviews on the participatory approach in CBR for the inclusion of children with disabilities. In reference to the ladder of participation, the synthesis of the articles depicts the non-participation of children with disabilities and the tokenism of the primary caregivers and community stakeholders. CBR programs often undervalue the capacity of children with disabilities to participate as contributors. Hence, this paper advocates revisiting how participation is envisioned among the community, especially the children with disabilities. CBR programs need to be sensitive to the children's development and find methods that maximize their ability to participate in programs for them. The findings affirm that participation is both a means and an end for the inclusion of children with disabilities in low-resource communities.

Supplementary Material

Supplementary Table S1: Complete data extraction table containing Context-Mechanism-Outcome configurations from the realist synthesis of CBR programs for children with disabilities. Available at https://bit.ly/42ulAUg.

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