

Participation of children and youth with disabilities and/or long-term health conditions living in low- and middle-income countries: a scoping review

Liezl Schlebusch^{1,*}, Karina Huus², Alecia Samuels¹, Mats Granlund², Shakila Dada¹

¹ Centre for Augmentative and Alternative Communication, University of Pretoria, Pretoria, South Africa

²Research Group, School of Health and Welfare, Swedish Institute for Disability Research, Jönköping University

* Correspondence to Shakila Dada, Centre for Augmentative and Alternative Communication, University of Pretoria, Pretoria 0028, South Africa. E-mail: shakila.dada@up.ac.za

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ABSTRACT

Aim: The purpose of this scoping review was to describe and map the literature available on the participation of young people (0–21y) with disabilities and/or chronic conditions living in low- and middle-income countries (LMICs).

Method: A systematic search and selection process identified 78 publications. Descriptive data were extracted using a data-charting form, and studies were mapped using the family of participation-related constructs framework.

Results: The findings demonstrated that, although the published evidence is steadily increasing, the participation research on this vulnerable population is still either absent or very scarce in the majority of LMICs, and very little is known about the participation of children with chronic health conditions. Most studies included in this review focused on attendance or ‘being there’.

Interpretation: Although attendance is an important aspect, more needs to be done to understand children’s experiences or involvement while attending, thus capturing both dimensions of participation.

Keywords: attendance, disabilities, health conditions, family of participation-related constructs (fPRC), International Classification of Functioning, Disability and Health (ICF), involvement, low- and middle-income countries, participation, scoping review

What this paper adds

- There is an increasing trend in research on participation patterns of children with disabilities in low- and middle-income countries.
- Most research focus on children's attendance, or 'being there'.
- We know very little about children's involvement, or experience, while attending daily activities.

Abbreviations

fPRC - Family of participation-related constructs

LMICs - Low- and middle-income countries

INTRODUCTION

Every child has the basic human right to participate in activities at home, at school, and in their community.¹ Meaningful participation in these daily activities is often associated with positive outcomes.^{2,3} However, young people with disabilities and/or chronic conditions are likely to face a wide range of participation restrictions and forms of exclusion, even more so for those living in resource-scarce environments. Given the human rights and human development perspectives, participation is arguably one of the most important outcomes for children with disabilities and chronic conditions and their families.

The World Health Organization's International Classification of Functioning, Disability and Health for Children and Youth describes participation as 'involvement in a life situation'.⁴ However, this broad definition does not capture the complexity of participation—a multi-dimensional and evolving phenomenon that interacts with personal and environmental factors over time. From a human rights perspective, participation may be mainly thought of as the right to 'be there', to be included. Yet, from a developmental perspective, participation should be more than that: a person should experience meaningful participation; be there and feel involved. Imms et al. capture this tension in their family of participation-related constructs (fPRC) framework.^{5,6} This model describes participation as comprising two essential elements: attendance ('being there') and involvement ('the experience of participation while attending'). The framework also identifies child-related factors (such as the competence or capacity to do an activity), which are often incorrectly equated as participation. Child-related competencies and capabilities are indeed important, but not always essential to a participation experience.

Furthermore, the authors propose that participation can be investigated as either an independent variable (i.e. participation as a process) or a dependent variable (i.e. participation as an outcome). An example of this distinction could be that (1) participation of a child in a sports activity (i.e. participation as a process) can potentially lead to improved social skills, or (2) improving a child's social skills can potentially lead to an increase in their participation in a sports activity (i.e. participation as the outcome). This interesting distinction might be particularly relevant for resource-scarce contexts.

Although participation-based research can have a direct, positive effect to help address the needs of children with disabilities and/or chronic health conditions, the current evidence is mainly limited to studies in high-income contexts.^{2, 3, 7, 8} Yet, most young people with disabilities and/or chronic health conditions in the world reside in low- and middle-income countries (LMICs).⁹ Exploring what research has been conducted on the participation of children living with disabilities and/or chronic conditions in LMICs is an essential step in providing insight into the experiences of this vulnerable population who are not yet well understood. Therefore, the purpose of this review is to describe the extent and scope of the research conducted on the participation of children and young people (0–21y) with disabilities and/or chronic health impairments living in LMICs.

METHODS

Scoping review

A scoping review (or scoping or mapping study) is one of the 14 types of review identified by Grant and Booth, and is the preferred methodology to map the literature on a particular research area.¹⁰ Scoping studies typically involve five steps: (1) identify the research question; (2) access all relevant studies; (3) determine which studies to keep for detailed analysis; (4) chart the data iteratively according to criteria established by the authors; and (5) organize and summarize the findings. First, we drafted a scoping review protocol plan (on the basis of guidelines and recommendations by Arksey and O'Malley^{11, 12}) to set the parameters for searching, screening, extraction, and analysis. This protocol plan was developed and refined in consultation with Swedish and South African expert panels who met at regular intervals throughout the study..

Eligibility criteria

To clearly articulate our scope of inquiry we defined the target population, the concept of interest, and the context. We considered the following inclusion guidelines (see Appendix S1, online supporting information, for a full description and definitions of eligibility criteria).

Population

The population of focus was children and young people (0–21y) with disabilities and/or chronic conditions living in LMICs. We used broad definitions of disability and chronic conditions, covering impairments, activity limitations, and participation restrictions. Disability was defined as 'long-term physical, mental, intellectual or sensory impairments that, in interaction with various attitudinal and environmental barriers, hinder full and effective participation in society on an equal basis with others'.¹ Chronic conditions were defined as a health problem lasting over 3 months, affecting children's normal activities and requiring hospitalization, and/or home health care and/or extensive medical care.¹³

Concept

The core concept examined in this scoping study is 'participation'; defined by the International Classification of Functioning, Disability and Health for Children and Youth⁴ as involvement in a life situation. We wanted to maintain a broad approach to generate a breadth of coverage. Therefore, we considered the concept of participation as well as participation-related constructs as conceptualized by Imms et al.⁶ We included the participation concepts of attendance and

involvement; as well as the participation-related concepts such as preferences, sense of self, activity competence, environment, and context. We also included studies about the conceptualization of participation, the measurement of participation, the factors influencing participation, studies comparing participation of children with disabilities and/or health conditions with other groups or countries, and participation intervention studies.

Context

We included studies conducted in LMICs (including lower middle-income and upper middle-income countries). We used the 2016 criteria for gross national income according to the Atlas method, which is an indicator of income that was developed by the World Bank. Low-income economies are countries with a gross national income per capita of US\$1025 or less; lower middle-income economies are countries with a gross national income per capita between US\$1026 and US\$4035; upper middle-income economies are countries with a gross national income per capita between US\$4036 and US\$12 475; and high-income economies are those with a gross national income per capita of US\$12 476 or more.

Types of information sources

We included all empirical quantitative, qualitative, and mixed-method studies, but did not include any grey literature, reviews, commentaries, or opinion pieces. Scoping reviews generally do not engage in grading or assessing the quality of evidence, and thus they provide comprehensive coverage of the existing evidence, regardless of quality. Although it is good to have an overview of all evidence, we wanted to have confidence in the quality of the evidence available, while still being broadly inclusive. After careful consideration, we decided to include only peer-reviewed studies; in other words, a board of scholarly reviewers in the subject area of the journal had reviewed the study for quality of research and adherence to editorial standards of the journal before articles were accepted for publication

Search concepts and strategy

Search terms were identified through ongoing discussion and feedback from the expert panels and in consultation with a health sciences information specialist to ensure the highest and most relevant yield of articles. The following search strategy of combined concepts of interest was applied, using Boolean logic queries: concept A (children and young people) 'AND' concept B (disability, long-term health conditions) 'AND' concept C (participation) 'AND' concept D (LMICs). We included only those studies published since June 2001 and before March 2018. The start date of June 2001 was chosen because that was when the International Classification of Functioning, Disability and Health was officially endorsed by all 191 member states of the World Health Organization as the international standard to describe and measure health and disability. Although no language restrictions were applied in the search strategy, we only included studies published in English. We searched six databases: PsycINFO; MEDLINE; CINAHL; PubMed; ERIC; and Africa Wide Information. An electronic search was conducted in December 2016 and again updated in April 2018 to identify articles meeting the inclusion criteria. See Appendix S1 for full search strings and limiters.

Study selection process

Search results were imported into Covidence, an online systematic review software program. To ensure reliability between reviewers, we developed a checklist based on the selection criteria. This checklist – the Study Selection Form (Appendix S2, online supporting information) – was reviewed and pilot-tested by the research team before it was used for the screening of citations (i.e. titles and abstracts) and the subsequent screening of full-text articles. The title and abstract of each citation were independently screened by two reviewers to determine which studies should be assessed further. All potentially relevant articles were investigated as full text. For fewer than 10 full-text articles that could not be obtained through institutional holdings available to the authors, attempts were made to contact the source author or journal for assistance in procuring the article. Full texts were retrieved and reviewed by two independent reviewers. Studies were excluded if they did not meet the eligibility criteria. When disagreement occurred between the two reviewers, a third reviewer was consulted to determine final inclusion.

Data Charting and Synthesis

We developed a data-charting form to determine which variables to extract to answer our research question. The data-charting form included a mixture of general information about the study and specific information relating to the research question. Data extraction was conducted by one reviewer for all included records; 10% of records were extracted by a second reviewer to ensure reliability. We conducted a basic numerical analysis of the extent, nature, and distribution of the studies included in the review. This part of the analysis highlighted the dominant areas of research in terms of geographical location and publication trends. We then organized the studies thematically according to the key concepts of the fPRC framework. A key issue was to describe the nature of the included studies. We used the fPRC framework to categorize the included studies into two groups: those that measured participation as (1) a process or (2) an outcome. We further subdivided the participation outcome studies into three groups (i.e. those that focused on attendance, those that focused on involvement, and those that combined both these constructs). Lastly, we identified studies that investigated child-related factors, and those that were concerned with instruments measuring participation.

RESULTS

Studies included

Figure S1 (online supporting information) outlines the number of records identified, studies included and excluded, and the reasons for their exclusion throughout the different phases of the review. The literature search resulted in a total of 3353 citations, of which 2050 were screened at title and abstract level. A further 1761 citations were excluded for not meeting the eligibility criteria. The remaining 289 full-text studies were assessed to decide whether they were eligible for inclusion in the review. We subsequently included 78 publications. Publications reporting on the same sample of participants were combined to result in a final 74 studies included in this review. Appendix S3 (online supporting information) provides a full description and contains citations of the studies.

As reported in Table 1, most of the studies (95%) were published after 2007. The studies were conducted in 20 LMICs, of which three studies (4%) were from low-income countries; 19 (24%)

were from lower middle-income countries; 53 (68%) were from upper middle-income countries; and three (4%) included multiple countries. Sixty-one per cent of the studies ($n=48$) were from four middle-income countries: Turkey, Brazil, South Africa, and India (Fig. S2, online supporting information). Studies focusing on children with disabilities were much more representative ($n=64$, 87%) than those on children with chronic health conditions. Although mental health was included in the search strategy, none of the studies reported on children with mental health problems. Almost three-quarters of included studies used a quantitative research design ($n=58$, 74%).

Table 1. Study characteristics

Characteristics of included articles ($n=78$)	<i>n</i>	%
Year of publication		
2001–2006	4	5
2007–2009	9	12
2010–2012	20	26
2013–2015	26	33
2016–2018 (January, February, March)	19	24
World Bank income categories		
Low-income countries	3	4
Malawi	1	
Nepal	1	
Zimbabwe	1	
Lower middle-income countries	19	24
Egypt	1	
Guatemala	2	
India	7	

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Kenya	5 ^a	
Nigeria	1	
Sri Lanka	1	
Vietnam	1	
Zambia	1	
Upper middle-income countries	53	68
Argentina	2	
Brazil	15 ^a	
China	3	
Iran	4	
Mexico	1	
Romania	1	
Serbia	1	
South Africa	8 ^a	
Turkey	18	
Multi-country studies	3	4
Child/youth study participants (<i>n</i> =74)		
Children with disabilities	64	87
Children with chronic health conditions	6	8
Children with disabilities and chronic health conditions	4	5

Males with disabilities and/or chronic health conditions	1298	25
Females with disabilities and/or chronic health conditions	1593	30
Sex not specified	2398	45
Study design		
Quantitative research design	58	74
Qualitative research design	9	12
Mixed/multi-methods research design	11	14

^a Includes publications that used the same study participants.

Next, as shown in Table S1, we discuss each of the research focus areas of the studies in relation to the fPAR framework.

Participation as a process or independent variable

This research area represented the smallest number of studies – only seven. These studies were published between 2011 and 2016, and they were conducted in Brazil, India, Iran and Turkey, while one was a multinational study. The study participants included boys and girls with cerebral palsy, intellectual disabilities, hearing impairments and/or visual impairments. Although the independent variable of participation is found mostly in sport or exercise programmes (n=5), one study investigated the effect of participation at school and another study looked at participation in music activities. The studies focused on diverse outcomes that ranged from gross motor function to self-concept and quality of life. All except one study used a quantitative research design.

Participation as an outcome or dependent variable

The intention of 42 studies (57%) was to investigate participation as an outcome, and half of these studies focused on *attendance*, a quarter on *involvement*, and another quarter on both constructs.

Attendance

There was a good representation of 11 countries and one multinational study. The study participants were boys and girls with a mixed range of disabilities, including developmental disabilities, cerebral palsy, and sensory impairments. This group also represented the most children with chronic health conditions. The evidence focused mostly on the caregivers' perspectives on the participation of their children, although some studies did solicit children's views, professionals' views, and three studies included the opinions of multiple groups.

Involvement

Evidence from Turkey represented seven out of the 11 studies. The study participants for this group were mostly children with developmental disabilities, including autism spectrum disorder, Down syndrome, and attention-deficit/hyperactivity disorder. All studies used a quantitative research design and all studies employed professionals to code time samples of video observations.

Attendance and involvement

Seven countries and one multinational study make up this group. Study participants were boys and girls with a range of disabilities, including cerebral palsy, developmental disabilities, physical disabilities and chronic health conditions. Interestingly, the majority of the studies were qualitative and sought the child's perspective through interviews and other data collection methods such as photo voice, focus groups, and participatory research methods.

Focus on child-related outcomes

A fifth of the studies (19%) investigated child-related outcomes such as activity competence, sense of self, or preferences. Brazil and Turkey collectively presented nine of the 14 studies. Most studies included children with cerebral palsy or developmental disabilities. All except one study used a quantitative research design, and most studies used questionnaires (either self-administered or in an interview format) to collect data from caregivers, children themselves, and professionals.

Measurement of participation or participation-related constructs

The purpose of eleven studies was the development, validation or translation of instruments that measure participation or participation-related constructs. Brazil and Turkey, and children with cerebral palsy made up half of the studies. The majority of studies employed a quantitative research design to elicit the perspectives of caregivers, children, or professionals, using mostly questionnaires. Three of the studies undertook translation of existing instruments; three studies were validation studies; and five focused on developing and validating new instruments.

DISCUSSION

This scoping review allowed us to provide an overview of the participation research conducted in LMICs on children with disabilities and/or chronic conditions. Although there was a steady increase in the number of studies (particularly since the launch of the International Classification of Functioning, Disability and Health for Children and Youth in 2007), it is still extremely small considering the 18-year timespan. The paucity of literature may be attributed to difficulties finding participants in LMICs as data collection needs to be supported by school systems providing access to children. If children do not attend school, data collection is difficult to conduct. When looking at the geographical nature of the evidence available in LMICs as obtained in this study, very little information is provided on all the LMICs and much more needs to be done to understand the situation of the majority of these young people. This is especially true for children with chronic medical conditions and those with mental health problems. There is very little evidence available on the participation of these children, yet comorbidities and interactions between disability and health in LMICs are very frequent.¹⁴

We anticipated that females might be underrepresented in the included studies and were pleasantly surprised to observe a roughly equal representation for those studies that reported on the participants' sex. There were also studies that compared the differences in participation between children with and without disabilities. Several reviews from high-income countries reported the differences in participation of children with disabilities compared with their typically developing peers.¹⁵ It will be beneficial to further investigate the reported participation of these two groups of children. A further investigation into the reported barriers to and facilitators of participation in LMICs is also warranted,¹⁶ given that previous studies showed that unsupportive physical, social, attitudinal, and institutional environments might limit the participation of young people with disabilities.^{4, 17}

We found the fPRC a useful guide to categorize studies, thus illustrating the multidimensional nature of participation. Using this framework, most studies set out to investigate participation as an outcome, and more specifically the 'being there' aspect of participation—gathering evidence on the diversity, frequency, duration, or range of participation activities. Although these are certainly worthwhile endeavours to report on and to promote the inclusion and attendance of children with disabilities, for researchers and practitioners more awareness and research is needed to understand the 'experience of participation while attending'. This includes elements of engagement, motivation, persistence, affect, and social connection—expectations that are highly variable within cultures¹⁸ and of which we currently know very little. It is a universal challenge to adequately capture the dimension of meaningful involvement.⁷ Current methodologies include the use of highly trained professionals to code time samples of video observations. The use of such methodologies warrants careful consideration in resource-scarce contexts, where there is often a need for measures to become briefer, simpler, and less expensive, to be feasible. When considering the way forward, the few studies that used an innovative mixed-method research design and included multiple perspectives is promising. Including quantitative and qualitative measures and perspectives is helpful in understanding the multidimensional nature of participation, and captures the cultural expectations of participation. The contributions to develop new measures and translate and validate existing instruments are noted.

Owing to a lack of clarity on participation and participation-related constructs, very often researchers inappropriately used measures of activity competence to evaluate participation.^{18, 19} This was also the case for some of the included studies. We want to encourage researchers in LMICs to be particularly careful to search and select (or develop) appropriate measures that are aligned with their research questions. Since participation may be investigated as either a process or an outcome, this places additional emphasis on the need for clarity. In this review, most of the studies used questionnaires developed in high-income countries to obtain quantitative data from caregivers, professionals, or children themselves. An important limitation is that the content of the measures developed in other countries may lack cultural relevance and equivalence.²⁰ Currently, there are limited participation measures designed for use specifically in LMICs. Since participation is a universal construct, this is not necessarily desirable. However, it is important to consider that although measurement items concerned with body functions and/or how activities are performed are more universal and may be applicable in different

cultures, measures of how frequently a child participates in daily activities or measures of the intensity of child engagement may be more specific to the cultural context. This would be pertinent in certain LMICs where stigma related to disability is prevalent, thereby limiting children's inclusion in various life situations. To further our understanding of the participation research conducted in LMICs, it will be important to consider how future studies measure participation. Using a multidimensional perspective means that the 'who', 'what', 'where', and 'how' of participation will have to be considered.

Furthermore, a focus on participation as a process (e.g. meaningful participation in home, school, or community activities) as a means of expanding children's functional capabilities can potentially increase the access to supportive environments for many children in resource-poor settings. In contrast, a focus on activity competence (i.e. cognitive, physical, and affective skills and abilities) can reinforce the need for specialized, individualized, and segregated clinical services that are often not available in such settings. Low-intensity interventions delivered by non-specialists are considered to be a viable solution to close the gap in access to care for most children with chronic conditions living in LMICs.^{21, 22} More research focused on participation as a process (e.g. participating in school, sport, community activities) can potentially provide feasible solutions for delivering sustainable and scalable services for this vulnerable group of children and young persons.

Limitations

There are notable limitations to our scoping review that must be considered when interpreting our description and summary of the results. First, the inclusion criterion of peer-reviewed articles created a potential publication bias. Significant results are more likely to be published than non-significant, negative, or inconclusive results. Our study aimed to present an overview of all material reviewed; consequently, issues of how best to represent this potentially large body of material are critical. Unlike in the case of a systematic review, we made no attempt to present a view about the 'weight' of the evidence in relation to particular interventions or policies. This is because the scoping methodology does not seek to assess the quality of evidence and consequently cannot determine whether studies provide robust or generalizable findings. Also, owing to the linguistic limitations of the authors, we only included English language publications, noting that many LMICs are non-English-speaking countries. We organized the studies thematically, according to fPRC. It fell beyond the scope of this study to clarify whether the authors selected the appropriate measures to assess the participation or participation-related constructs that they set out to investigate. A previous review reported that most studies presented as measuring participation, actually measured activity competence (capabilities) with scales anchored on a continuum from much support/dependent to no support/independent.¹⁸ Furthermore, this scoping review does not report on the overall findings of the included studies. Short summaries of the results are included in Appendix S3. Further investigations into specific outcomes are warranted, for example focusing on barriers and facilitators of participation, or comparing the participation of children with disabilities and those without.

Conclusion and implications

Our findings show that although several studies investigated the participation of young people with disabilities and/or chronic health conditions living in LMICs, much more needs to be done to understand the participation experience of this vulnerable group, particularly those with chronic health conditions and mental health problems. We found the fPRC framework to be a helpful model to illustrate the multidimensional nature of participation. This framework can assist participation-based researchers in LMICs to clarify their research focus and aid in the selection and/or development of appropriate measures. Using this framework, we found that most studies focus on the dimension of attendance: that is, reporting the incidence or prevalence of children with disabilities and/or health conditions taking part in daily life activities. Although this is an important aspect, the field needs to broaden its view to include an understanding of the children's experiences or involvement while attending, capturing both dimensions of participation. Finding feasible, practical, and pragmatic ways to capture this multidimensional construct is a universal challenge for researchers. Lastly, the idea of distinguishing between the investigation of participation as a process (e.g. participating in school, sport, or community activities), as opposed to participation as an outcome, holds promise in finding sustainable and scalable ways to positively influence the optimal development of children with disabilities and/or chronic health conditions living in low-resource contexts.

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Authors' contributions

LS conceived the study, designed the research protocol, conducted the literature search, conducted the data collection, analysis and interpretation, and prepared the first draft of the manuscript. SD and KH conceived the study, coordinated the review, assisted with the research protocol, performed relevance screening of studies, assisted with data collection, analysis and interpretation and assisted with drafting the manuscript. AS assisted with the research protocol, methodology and editing of the manuscript. MG assisted with the research protocol and final editing of the manuscript. All authors read the manuscript, provided substantial edits and/or comments on the content, and approved the final manuscript that is being submitted for publication.

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