

Participation of children with disabilities in low- and middle-income countries: A scoping review

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DECLARATION OF ORIGINALITY

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The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, the applicable research ethics approval.

The author declares that she has observed the ethical standards required in terms of the University of Pretoria's code of ethics for researchers and the policy guidelines for responsible research.

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ABSTRACT

The available literature exploring the participation in children with disability is biased to high income countries and a paucity is noted for children with disability specifically those living in low- and middle-income countries (LMICs). Furthermore, the definition provides the World Health Organisation of participation and participation related construct but is limited and unclear with regards to the operationalisation and measurement of the construct. Therefore, the current study aims to identify the number of studies that explore participation in children with disabilities in LMICs and describe these studies according to the attendance setting, gender, type of disability of participants, and the settings and geographical distribution of the countries the studies were conducted in. Furthermore, to determine the participation measuring tool used by the included studies, to describe the respondents to participation measures used by included studies; and to describe participation in studies as related to fPRC.

Method: A scoping review methodology was used in this study. The six stages from the scoping review framework refined on the Joanna Briggs Institute's scoping review methodology guided this review.

Results: A total of 25 studies met the selection criteria and are included in this review. The results revealed that publications are biased to countries in the higher economic classification within the lower- and middle-income economic classification. The participants of the studies used for the purposes of this research were mostly children with cerebral palsy (CP) and intellectual disability within the school setting. The main focus was on the construct of attendance with the related concepts such as activity competence and sense of self being the constructs least focused on in the included reviews. Most of the studies included do not specify the measuring tool used to collect data but rather a specified method was used to gather data on the participation of children with disabilities living in LMICs.

Conclusion: There is growing literature which focuses on exploring participation in children with disabilities living in LMICs.

Key words: Participation, low-middle income countries, children, disabilities, participation measures

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List of Abbreviations

ARG	Argentina
BGD	Bangladesh
BRA	Brazil
CAPE	Children's Assessment of Participation and Enjoyment
CHN	China
CP	Cerebral Palsy
fPRC	Family of Participation-Related Concepts
GNI	Gross National Income
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual Disability
IND	India
IRN	Iran
KEN	Kenya
LKA	Sri Lanka
LMICs	Low- to Middle-Income Countries
MEX	Mexico
MWI	Malawi
NGA	Nigeria
TUR	Turkey
USD	United States Dollar
WHO	World Health Organisation
ZAF	South Africa

1. PROBLEM STATEMENT AND LITERATURE REVIEW

1.1 Participation

The International Classification of Functioning, Disability and Health (ICF) is an important health classification constructed by the World Health Organisation (WHO, 2001). The ICF aims to provide a common language and classification for both health and health-related areas (WHO, 2001). The framework provides a classification of health and disability at an individual and population level. The ICF describes three levels of human functioning, namely, body structure and functioning; activities and participation; and environmental factors (WHO, 2001). The activities and participation category has nine domains prescribed under it, namely: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life area and community; and social and civic life (WHO, 2001).

The participation constructs as defined by WHO (2001 p. 10) is “an involvement in a life situation”. However, the definition is critiqued and viewed as broad yet lacking the specification of the participation construct's operationalisation (Imms *et al.*, 2016). Furthermore, the definition does not provide insight on how a participation construct can be measured (Imms *et al.*, 2016).

The lack of a clear definition and operationalisation participation has resulted in authors conducting a review of the language to describe participation (Imms *et al.*, 2016). This inconsistency in operationalisation of participation and measuring of the construct is attributed to the limitation in the operationalisation of the participation construct and the lack of suggestions on how to measure the construct. The lack of a clearly operationalised definition of participation was described by Adair *et al.* (2018). In a cluster of papers, the authors further emphasise the rationale on the suggestion of a Family of participation and Participation-Related Constructs Framework (fPRC) (Adair *et al.*, 2018; Imms *et al.*, 2016) as a construct for understanding participation. This framework was constructed to capture the multidimensional aspect of the participation construct and was based on a systematic review of the literature (Adair *et al.*, 2018) and language use of participation discussed in section 1.1.

The research study conducted by Adair *et al.* (2018) suggested 51 standardised tools to measure participation and related constructs. These tools were deemed to be suitable for capturing the important factors which underlie the participation construct. However, Adair *et al.* (2018) caution researchers to note the aim (i.e., participation as an outcome or process) of their research when

selecting tools to use to measure participation. The 51 standardised measuring tools prescribed by Adair *et al.* (2018), adopted a quantitative method of data collection (i.e., questionnaire, interview) and children with disabilities were reported to experience challenges with the traditional data collection methods used in research studies. This essentially means that the prescribed participation measuring tools need to be adapted in order for children with disabilities to participate in the study. Ibrahim *et al.* (2021) suggest that these adaptations may include the use of graphic symbols or photo elicitation to augment understanding of the items in questionnaires or interview schedules or make use of observations as a method of data collection.

All 51 standardised participation measuring tools (Adair *et al.*, 2018) were developed in English and were intended for use in developed countries. A few of the participation measuring tools have recently been adapted and translated into Swedish, German, Chinese, Greek, Dutch, French and Spanish, which are languages predominantly used in developed countries (Adair *et al.*, 2018). The Picture my Participation (PMP) is the only standardised tool that has been developed in order to measure participation in children with disabilities living in developing countries. However, this echoes how most participation measures are mainly specified for measuring participation for children with disability living in developed countries. With the rapid increase in research exploring participation in children with disabilities living in developing countries, a change in the aforementioned is anticipated.

1.2 Defining the participation constructs using a family of participation and related constructs

The review conducted by Adair *et al.* (2018) reports on the importance of the operationalisation of participation construct and participation related constructs. This is linked to the impact that it has on the intervention outcome that is aimed at increasing participation for children with disabilities. The emphasis placed on the importance raised surrounding this construct provided reason for this scoping review adopting the fPRC (Imms *et al.*, 2016). The fPRC framework views participation as a multifaceted and complex construct which goes beyond just ‘being there’.

The review conducted by Imms *et al.* (2016) investigated the operationalisation of the participation construct and suggested strategies that can be employed to measure participation in a research study. The authors proposed the fPRC framework and suggested that participation has two

components, namely attendance and involvement (Imms *et al.*, 2016). The definition of participation by Imms *et al.* (2016), identified family of participation and related constructs, which are:

- Attendance - the actual undertaking of the activity; and
- Involvement - the experience of taking part in an activity.

The definition also included a family of participation-related construct concepts, which are:

- Preference for a particular activity - the opportunity to choose an activity that is meaningful or valuable.
- Sense of self - the intrapersonal outcome of participation and related to factors such as confidence, self-esteem, and satisfaction; and
- Activity competency – the ability to execute an activity in a manner that meets the standards of execution.

The inclusion of “participation related” concepts in the definition of participation allow for a clear picture to be drawn in the description of the relationship between intrinsic- (personal) or extrinsic human factors (environmental and cultural) (Adair *et al.*, 2018, p. 1102). The focus on involvement enables researchers to understand variables such as motivation, persistence, and social connection, which would positively impact intervention strategies aimed at increasing participation and allowing the inclusion of children with disabilities in their day-to-day activities (Imms *et al.*, 2016; Adair *et al.*, 2018).

1.3 Participation patterns and restrictions for children with disabilities

Disability is “an umbrella term for impairments, activity limitations and participation restrictions” (WHO, ICF-CY, 2007, p. 228). The WHO prescribes that disability is not being an individual with a condition but rather an interaction between an individual with a condition, environmental and personal factors (WHO, 2007). WHO (2007) report that disability has various forms (physical- or intellectual disability) and severity (mild to severe). Literature continuously shows that individuals with disability experience more participation restriction in everyday activities than their peers without disabilities (Chien *et al.*, 2017).

Similarly, Gilboa and Fuchs (2018) found that typically developing children and youth have higher participation levels and take part in a range of activities, as opposed to their peers with intellectual disabilities and autism. Participation restrictions experienced by youth with intellectual

disabilities extend to restricted participation in leisure activities, employment, and the building of social relations (Gilboa & Fuchs, 2018). Furthermore, the authors reported a higher participation for youth with intellectual disability in activities under the domains of self-care, general tasks, demands and domestic life, while lower participation was reported for activities in the domains of community, social- and civil life, interpersonal interaction, and relations (Gilboa & Fuchs, 2018). A systematic review conducted by Shields *et al.*, (2014), shows that there are more similarities than differences in the participation pattern of children with intellectual disability (ID) and their typically developing peers. The study identified differences such as, fewer social activities in the community; fewer family enrichment activities; as well as fewer formal activities for children with ID to participate in. The review further reports lower participation in physical activities and, recreational and social activities as compared to their typically developing peers.

Chien *et al.* (2017) identified a paucity of research regarding children's participation in various age groups concerning the type and the severity of the disabilities. This is observed when participation research into persons with ID is limited, as most studies focus on physical disabilities and rarely focus on moderate- to severe ID diagnosis (Chien *et al.*, 2017).

1.4 Importance of exploring participation in children with disability

Participation is an important variable which allows social inclusion and the enhancement of the child's wellbeing (Murphy, Carbone & The Council on Children with Disabilities, 2008). Additionally, participation contributes positively to everyday functioning, mental function and psychosocial state (Arvidsson *et al.*, 2012), making it an integral part of clinical practice and targeted outcome in rehabilitation and healthcare (Chien *et al.*, 2017). The participation level of children within their social contexts (school, home and community) shows their state of wellbeing and their quality of life (Piškur *et al.*, 2012). Furthermore, Piškur *et al.* (2012) state that when children participate within their social context, they acquire knowledge and develop the necessary skills needed to interact, play, work and live with other individuals.

Rehabilitation goals often aim to use assessment findings to provide intervention in order to enhance the individual's functioning in different contexts (Adolfsson *et al.*, 2010). Studying the participation level in children with disability will contribute to finding intervention strategies that will improve practice, focusing on enhancing participation in children with disability (Chien *et al.*, 2017).

Adolfsson *et al.* (2010) state that the strategies may be found by identifying participation barriers, participation enhancers, possible collaborations with relevant individuals and environmental modifications.

Exploring participation in children with disability is critical in policymaking and modification as the findings become recommendations guiding policymakers in drafting policies which encourage children with disability to participate in all activities (e.g., policy informing curriculum adaption for all children with disabilities). The importance of exploring the participation of children with disability is essential in order to raise awareness; develop assessment and intervention in clinical and rehabilitation settings, act as a mechanism in policy change and remodeling; and work as an indicator of the key areas that need to be further researched in order to bridge gaps in the literature. The actual methodology may differ for each research study, depending on the age group, the type of disability, and the study's geographical focal point.

Focusing on participation in various geographical areas is important as patterns of participation in children with Disability may differ in various regions (Schlebusch *et al.*, 2020). This is attributed to personal and environmental factors which act as a barrier or facilitator of participation. Furthermore, the statistics of individuals with a disability are not the same for all geographical areas. This is evident in low- and middle-income countries (LMICs), as most of the world's population with disability live in these regions (Mitra *et al.*, 2011).

When exploring participation in children with disabilities, it is critical that we also focus on who's "voice" is echoed by current literature. There are two methods used by studies to capture these voices, namely, self-rating and proxy rating. Both methods are reliable and valid data collection methods used to capture different aspects and details of life (Nilsson *et al.*, 2015). The use of these methods allows for a broader understanding in the participation of children with disabilities through both the child's perspective as well as the observer's. The study conducted by Nilsson *et al.*, (2015), reports that the self-reporting method allows for children to give a narrative to their personal experience of participation. The study continues to report that the proxy rating allows for an observer (i.e., caregiver, teacher etc.) to only validate the information provided by the child but to also provide information on the level of independence in participation and the child's competency in participation (Nilsson *et al.*, 2015).

1.5 Current literature exploring participation in low- and middle-income countries

This scoping review includes research studies from LMICs. The World Bank provides a scale that describes each country's Gross National Income (GNI). As per the 2020 fiscal year and calculated using the World Bank Atlas method, low-income countries are defined as those with a GNI per capita of US\$1,025 or less in 2018; lower-middle-income countries are those with a GNI per capita between US\$1,026 and US\$3,995; upper-middle-income countries are those with a GNI per capita between US\$3,996 and US\$12,375; and high-income countries are those with a GNI per capita of US\$12,376 or more (World Bank, 2019).

The present study focuses on investigating and establishing the extent and scope of the current literature on the participation of children with disability in LMICs. The list of countries classified as LMICs includes Benin, Tanzania, Bangladesh, South Africa, Argentina and Iran, to name but a few (World Bank, 2019). The scoping review conducted by Schlebusch *et al.* (2020) is the most recent review conducted which maps out the current literature of participation in children with disability in LMICs. The majority of literature on participation studies in children with disability is based on developed countries. In contrast, the majority of children with disability live in LMICs (Olusanya *et al.*, 2018, as cited in Schlebusch *et al.*, 2020). However, this paucity in research does not imply that no literature is available in the context of middle-to-lower income countries.

Schlebusch *et al.* (2020) conducted a scoping review which included 74 studies that explored participation in children with disabilities in LMICs over the period of 2010 to 2016. The research studies included in the scoping review were from 20 LMICs; however, most studies came from middle-income countries such as India, Turkey, South Africa and Kenya (Schlebusch *et al.*, 2020). The scoping review included 74% of studies that used the quantitative methodology (Schlebusch *et al.*, 2020).

Schlebusch *et al.* (2020) used the family of participation and participation related concepts to map out the research studies. The following participation and related concepts were used:

- Participation as an independent variable;
- Participation as a dependent variable;
- Children related outcome; and
- Measurement of participation or participation related outcome.

Firstly, participation was an independent variable, which focused on studies that explored participation as a process (Bhutia *et al.*, 2015; Braccialli *et al.*, 2016; Dursun *et al.*, 2015; Ghosh & Datta, 2012; Kosaner *et al.*, 2012; McConkey *et al.*, 2013; Movahedi *et al.*, 2011). These studies contributed 10% to the total number of studies included in this scoping review, and the studies were primarily found in sport activities, school participation and music programs (Schlebusch *et al.*, 2020).

Secondly, participation was a dependent variable, these studies looked at participation as an outcome, with the focus on both involvement and attendance as constructs. Schlebusch *et al.* (2020) report that 57 % of the included studies formed part of this theme (i.e., participation as outcome), half of these studies focused on attendance as a measured outcome (Do Amaral *et al.*, 2014; Badr & Mourad, 2009; Bunning *et al.*, 2014; Rodríguez & Fano, 2016). These studies were conducted in 11 geographical regions, using sampled children with both disabilities and chronic health conditions taking the caregiver's perspective to explore participation. A quarter of the studies focused on involvement as measured outcome (Akalin & Sucuoglu, 2015; Bastable *et al.*, 2016; Cuhadar & Diken, 2011). These studies were primarily based in Turkey and sampled children with developmental disabilities such as autism, attention deficit disorder and Down syndrome, and used professionals' perspective to explore participation. The last quarter of these studies focused on both the attendance and involvement construct (Avramović & Žegarac, 2016; Bantjes *et al.*, 2015; Conchar *et al.*, 2016; Du *et al.*, 2016). These studies were conducted in a range of countries, and the children sampled had physical disabilities, developmental disabilities and chronic health conditions. The data was collected from the child's perspective.

Thirdly, the focus was on the child-related outcome; these studies measured outcomes such as activity competence, sense of self and preference (Adeniyi & Omigbodun, 2016; Aykut, 2012; De Brito Brandão *et al.*, 2012;). The majority of the studies were conducted in Brazil and Turkey. The sample of children used had a range of disabilities and chronic health conditions, and data were collected based on the perspective of caregivers, children and professionals.

Lastly, the focus was on measurement of participation and participation related constructs; these studies looked at developing, validating or adapting a participation measuring tool (Tlaculio-Parra *et al.*, 2010; Shenai & Wadia, 2014; Nelson *et al.*, 2016; Jacob *et al.*, 2014). Most of the studies were also conducted in Brazil and Turkey, and data were collected based on the perspective of caregivers, children, and professionals.

The scoping review conducted by Schlebusch *et al.* (2020) landscaped the scope and extent of literature that explores the participation of children with disabilities or chronic health conditions from LMICs. However, the study had limitations which prevented results from being generalised to all children with disabilities or chronic health conditions within LMICs. Schlebusch *et al.* (2020) report that participants were recruited from the school context only, meaning that access to children with disabilities or chronic health conditions not enrolled in schools was impossible. This affected the number of participants the researchers could recruit for research and applicability of recommendation to the inaccessible children.

Furthermore, most of the studies included in the review focused on children with disabilities and very few of the studies sampled children with chronic health conditions. Additionally, the scoping review focused on children with disabilities or chronic health conditions but did not consider or discuss the co-occurrence between disability and chronic health conditions (Schlebusch *et al.*, 2020).

Lastly, the review displayed the difficulty in capturing the multi-dimensional participation construct to make it feasible and practical to measure. In essence, the review was unable to distinguish between participation as a process and participation as a measured outcome to find ways to positively influence participation in children with disability or chronic health condition.

1.6 The rationale for conducting the scoping review

After a comprehensive review of the research study by Schlebusch *et al.* (2020), it is evident that the study was conducted from 2006 through 2016; therefore, a more recent update of the review is necessary. This review will provide insight into literature published from 2016 to 2020 and will discuss how the data contributes to findings presented on the scoping review conducted by Schlebusch *et al.* (2020). Hence, this study aims to build on a previous review conducted by Schlebusch *et al.* (2020). The present review will provide an update to the review by Schlebusch *et al.* (2020), focusing specifically on literature from 2010 through 2020. Furthermore, the present review looks at mapping out current literature and identifying how the included studies operationalise the construct participation and, lastly, how this construct is measured.

2. METHODOLOGY

2.1 Research aims

2.1.1 *Main aim*

The main aim of the present study is to update the scope of literature which explores on participation in children with disabilities in LMICs. Therefore, the main research question is: What is the volume, nature, and characteristics of the research conducted on the participation of children with disabilities living in LMICs?

2.1.2 *Sub-aims*

The study's sub-aims established a research gap in the literature on participation in children with disabilities in LMICs. These are outlined as follows:

- To identify the number of studies that explore participation in children with disabilities in LMICs and describe these studies according to age, gender, type of disability of participants, and the attendance setting and geographical distribution of the countries the studies were conducted in.
- To determine the participation measuring tool used by the included studies.
- To describe the respondents to participation measures used by included studies; and
- To describe participation in studies as related to fPRC.

2.1.3 *context of sub-aims*

Each sub-aim presented in this study uses terminology that is intended to provide clarity on the measure variables of the study. A common occurrence is that certain terminology overlaps, as a result requires clear definition to be distinguished from other similar terms. This allows for proper conceptualization of terms in accordance with their utilization or measure in any one study. For the present study, two terms used in the sub-aims were identified as requiring clear definition and distinguishability to eliminate any confusion for a reader.

The term “attendance setting” refers to the different settings where study was conducted and to which participants were exposed to. Examples of these settings are school, home and/or hospital environments. The term was selected with the purpose of identifying and presenting data on where current research is being conducted. In contrast to attendance setting, the term “geographical

distribution” refers to countries and countries’ economic status description where each of the included studies research was conducted.

The selection of a research methodology is crucial towards reaching the aims of a study by utilizing appropriate objectives. A systematic review is a method which is regarded as the “golden standard” for conducting research (Grant & Booth, 2009). This methodology allows for in-depth search and appraisal of data, synthesis of data and generation of solution orientated recommendation which can improve current policies and treatment/practices. However, a systematic review is not a suitable methodology for this study since the aims target the extent and size of current literature on a broad research topic. As a result, a scoping review methodology was used in the present study. A scoping review allows for the assessment of the extent and scope of the literature base (Grant & Booth, 2009); furthermore, it allows for the identification of a research gap in the literature (Grant & Booth, 2009). For this study, a scoping review methodology allowed for identifying and synthesising articles on participation in children with disability in LMICs (Arksey & O’Malley, 2005). This study will adopt a six-step methodological framework developed by Arksey and O’Malley (2005) used for a scoping review and updated by Tricco *et al.* (2016). The prescribed steps are as follows: The prescribed steps are as follows: (i) identifying a research question; (ii) identifying relevant studies; (iii) study selection; (iv) charting the data; (v) collating, summarizing, and reporting results; and (vi) optional consultation. The sixth step, consultation with stakeholders, will not be followed in the present study due to time limitations. The sixth step, consultation with stakeholders, will not be followed in the present study due to time limitations.

The study conducted by Nyanchoka *et al.* (2019), further reports that the data should be presented in a user-friendly format which when synthesised aims to improve research planning and strategic research prioritisation. Furthermore, the present study allowed for a conclusion of whether a systematic review is needed on current literature discussing participation in children with disability in LMICs.

The advantages of using a scoping review methodology are; the review is able to answer a broad-spectrum research question; it yields findings that indicate whether systematic research is required to further research synthesising the literature and; the methodology is systematic, transparent and replicable therefore increasing the reliability of the review (Grant & Booth, 2009; Sucharew & Macaluso, 2019). However, the methodology has disadvantages such as; the review shows the

existence of literature as opposed to the quality of articles; therefore, the possibility of bias in findings are charted.

Arksey and O'Malley's (2005) scoping review framework outlines six stages which guide its review process; these steps further refine the Joanna Briggs Institute's scoping review methodology (Peters *et al.*, 2017). The first stage of the process is to identify the research question that will guide the review. The research question will follow the population, concept and context instead of the population, intervention, comparison and outcome context since scoping reviews investigate intervention outcomes. Therefore, the present study identified population (children with disability), context (participation) and concept (low- and middle-income countries).

2.3 Ethical considerations

A researcher is responsible for protecting a research participant's integrity, welfare, and rights (McMillan & Schumacher, 2014). Since a scoping review does not use human participants for the purposes of collecting data, no direct responsibility to human participants will be applicable for this study. However, it is the researcher's responsibility to ensure that all included studies cited were provided ethical approval and that none of ethical behaviors were infringed. In the present study, this was done by ensuring that all included participant's information was consented for and kept confidential.

Ethical consideration was granted by the ethical committee from the University of Pretoria (Attached as Appendix A). The researcher observed all ethical behavior when dealing with data in published papers included in the study, this ensured that each dataset was captured and represented in its original form and no alterations were made. Finally, all work which originated from others was accredited and acknowledged accordingly to avoid plagiarism.

2.4 Protocol

A protocol was developed before the systematic searches were performed as a directive of the scoping review procedures (Tricco *et al.*, 2016; Petticrew & Roberts, 2006). The protocol introduced the transparency of the procedures followed to collect, synthesise and present data, allowing the

scoping review study to be replicable. The protocol also included the inclusion- and exclusion criteria to reduce the bias selection of studies included in this research study (Moher *et al.*, 2009).

2.5 Search strategy

The prescribed search strategy by the Joanna Briggs Institute manual (Peters *et al.*, 2017) is a multi-faceted strategy, and it aims to avoid a biased yield of studies. The electronic database platform searches included the EBSCOhost platform (including databases Academic Search Complete), the Cumulative Index to Nursing and Allied Health Literature [CINAHL], E-Journals, Education Resources Information Centre [ERIC], Google scholar, MEDLINE, PsycARTICLES, and PsycINFO, Africa Wide Information.

The search terms were adopted from the research study conducted by Schlebusch *et al.* (2020) and are represented in Table 1 below. These search terms were entered into different databases to yield studies that form part of this scoping review data.

Table 1: *Search terms*

Criteria	Search Terms
Population (age)	Child* OR youth OR adolescent* OR teenager* OR toddler* OR infant* OR paediatric OR paediatrics
Population (disability)	Disabled* OR 'special needs' OR impairments OR 'developmental delay*'
Concept	Participation OR engagement OR attendance OR involvement OR 'everyday functioning' OR 'ADL' OR 'activities of daily living' OR 'everyday life situation'
Context	'Developing Country*' OR 'Low-income-country*' OR 'Middle-income-country*' OR 'Third-world' OR 'Underdeveloped country*' OR Afghanistan OR Benin OR Burkina Faso OR Burundi OR Cambodia OR Central African Republic OR Chad OR Comoros OR Congo OR Eritrea OR Ethiopia OR Gambia OR Guinea OR Guinea-Bissau OR Haiti OR Korea OR Liberia OR Madagascar OR Malawi OR Mali OR Mozambique OR Nepal OR Niger OR Rwanda OR Sierra Leone OR Somalia OR South Sudan OR Tanzania OR Togo OR Uganda OR Zimbabwe OR Armenia OR Bangladesh OR Bhutan OR Bolivia OR Cabo Verde OR Cameroon OR Congo OR Côte d'Ivoire OR Djibouti OR Egypt OR El Salvador OR Georgia OR Ghana OR Guatemala OR Guyana OR Honduras OR India OR Indonesia OR Kenya OR Kiribati OR Kosovo OR Kyrgyz Republic OR Lao PDR OR Lesotho OR Mauritania OR Micronesia OR Moldova OR Morocco OR Myanmar OR Nicaragua OR Nigeria OR Pakistan OR Papua New Guinea OR Philippines OR Samoa OR São Tomé and Príncipe OR Senegal OR Solomon Islands OR Sri Lanka OR Sudan OR Swaziland OR Syrian Arab Republic OR Tajikistan OR Timor-Leste OR Ukraine OR Uzbekistan OR Vanuatu OR Vietnam OR West Bank and Gaza OR Yemen OR Zambia OR Albania OR Algeria OR American Samoa OR Angola OR Azerbaijan OR Belarus OR Belize OR Bosnia and Herzegovina OR Botswana OR Brazil OR Bulgaria OR China OR Colombia OR Costa Rica OR Cuba OR Dominica

Criteria	Search Terms
	OR Dominican Republic OR Ecuador OR Fiji OR Gabon OR Grenada OR Iran OR Iraq OR Jamaica OR Jordan OR Kazakhstan OR Lebanon OR Libya OR Macedonia OR Malaysia OR Maldives OR Marshall Islands OR Mauritius OR Mexico OR Mongolia OR Montenegro OR Namibia OR Palau OR Panama OR Paraguay OR Peru OR Romania OR Serbia OR South Africa OR St Lucia OR St Vincent and the Grenadines OR Suriname OR Thailand OR Tonga OR Tunisia OR Turkey OR Turkmenistan OR Tuvalu.

The phased screening of the research studies was illustrated using a PRISMA diagram, see Figure 1 below (Moher *et al.*, 2009; Tricco *et al.*, 2016). Arksey and O'Malley (2005) report that using a PRISMA diagram allows for a clear illustration of the process of study selection narrated in text. Additionally, the PRISMA diagram consists of a checklist which guides the researcher through phased reviewing and ensures that all reviewing process proceedings are conducted (Moher *et al.*, 2009; Tricco *et al.*, 2016). The PRISMA diagram is a standardised prescribed manner of reporting in a systematic review and Meta-analysis, therefore, deemed suitable for a scoping review (Moher *et al.*, 2009; Tricco *et al.*, 2016). This standardised way of reporting allows for the caption of the number of studies included- and excluded in each level, and the rationale for excluding studies in each review level (Peters *et al.*, 2017).

An updated search was conducted (01/01/2020 to 31/12/2020), results of this search were combined with the initial search (01/01/2016 to 01/04/2020) and represented using the PRISMA diagram (refer to Figure 1 below).

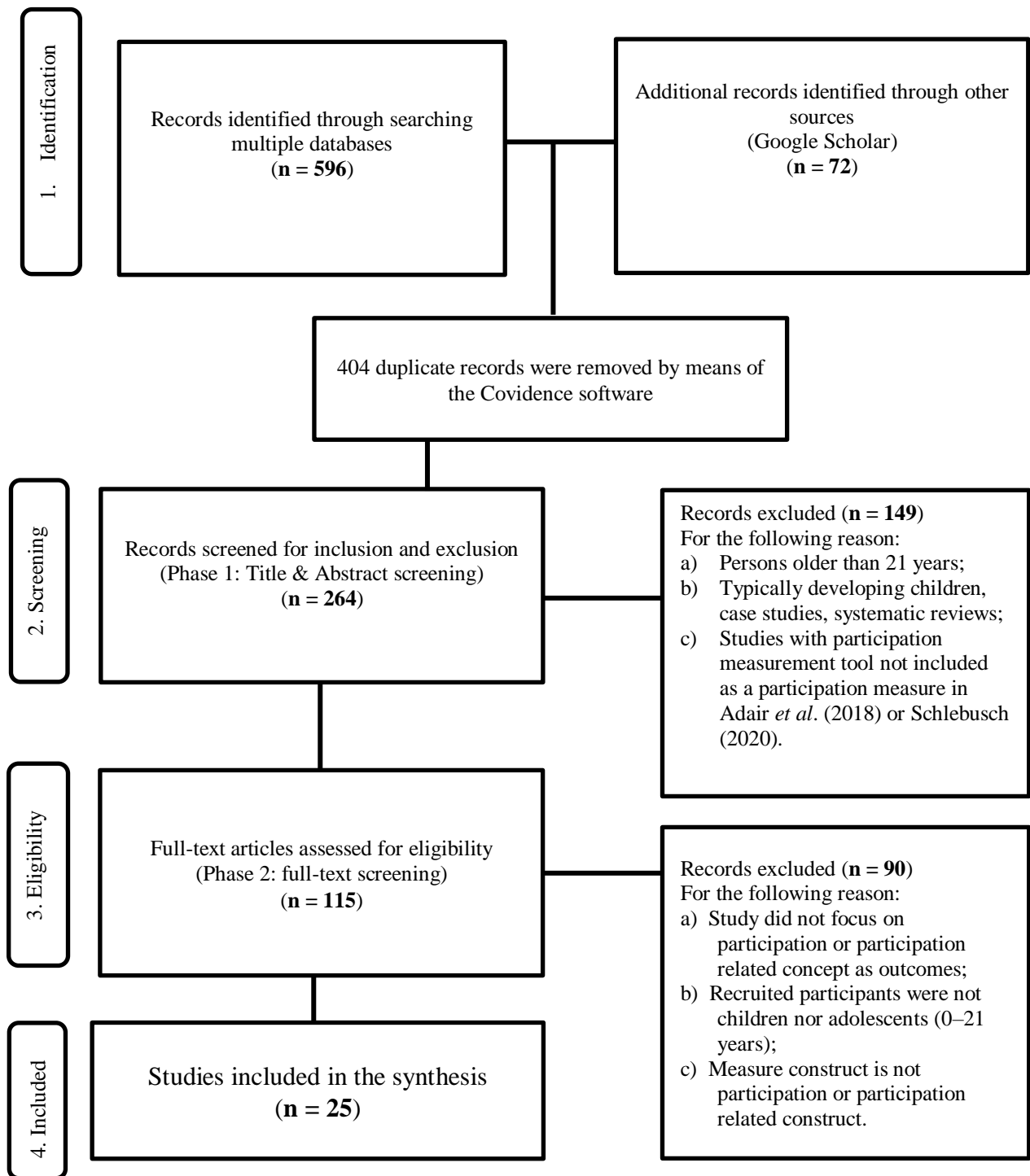


Figure 1: Scoping review flow diagram

Source: (Tricco *et al.*, 2016)

In using the search terms tabulated in Table 1, each database yielded a different number of research studies that may be considered for inclusion in this scoping review. The number of yielded research studies per database is represented in Table 2 below.

Table 2: *Search strategy and yielded studies*

Database	Total Minus Duplicates
CINAHL (EBSCOhost)	105
E-Journal (EBSCOhost)	03
ERIC (EBSCOhost)	29
MEDLINE (EBSCOhost)	32
PsycARTICLES (EBSCOhost)	25
PsychINFO (EBSCOhost)	36
Africa Wide Information (EBSCOhost)	32
Google scholar	2
TOTAL	264

2.6 Inclusion- and exclusion criteria

An inclusion- and exclusion criteria were adopted from the study conducted by Schlebusch *et al.* (2020); this was developed before the search process in order to eliminate bias in selected studies which were included in the scoping review. Table 3 below, illustrates the inclusion- and exclusion criteria used to select studies in this scoping review.

Table 3: *Inclusion- and exclusion criteria*

Criterion	Inclusion	Exclusion	Justification
Population (age)	Children and youth 0–21 years old.	Persons older than 21years	There is a paucity of research exploring participation in children with disabilities (Gilboa & Fuchs, 2018).
Population (diagnosis)	Children that have a disability (including special needs, impairments, developmental delay, development disability, ADHD).	Typically, developing children, children at risk, such as low birth weight, HIV, orphans, poverty-stricken, have challenging behaviour and those from dysfunctional families.	Children with disability are reported to have limited participation as compared to their peers (Chien <i>et al.</i> , 2017).
Context	LMICs countries, according to information from the World Bank.	High-income countries.	The majority of individuals with disabilities live in LMICs (Olusanya <i>et al.</i> , 2018 as cited in Dada <i>et al.</i> , 2020a).
Outcome	Concept of participation and family of participation related constructs (refer to Appendix B).	Body function (not within an activity). Quality of life of the children. Health-related quality of life wellbeing. Prevalence of disability studies. Disability or inclusion policies, inclusion -when there are no direct outcomes related to the child with a disability. Papers where there is no outcome on the child's level or any other caregiver (professional) outcomes.	Participation is a necessary construct to explore in children with disabilities; the data collected impacts intervention programme and measuring tools developed to increase participation and promote inclusion for children with disabilities (Adair <i>et al.</i> , 2018).
Design	Qualitative research Quantitative research Multi-or mixed method research.	Systematic reviews, literature reviews.	Adopted from the initial scoping review conducted by Schlebusch <i>et al.</i> (2020).

Criterion	Inclusion	Exclusion	Justification
Source Type	Primary/original research published as peer-reviewed journal articles.	Expert opinions, meta-analyses, systematic reviews, scoping reviews, books, conference proceedings, policy reviews.	Adopted from the initial scoping review conducted by Schlebusch <i>et al.</i> (2020).
Time and Language	Published in English, publication dated January 2016 – April 2020.	Publications not available in English or published before 2010.	This study forms an update of the study conducted by Schlebusch <i>et al.</i> (2020). Therefore, the time frame between the years 2010 and 2020 landscapes the updated literature on studies exploring participation in children with disabilities in LMICs. The inclusion of studies published in English benefit the researcher as the researcher is proficient in the English language.

2.7 Selection of studies

The scoping review used a software package named Covidence (Veritas Health Innovation, n.d.), which is helpful as a data management tool. The result of the research study will be imported in the Covidence program in the format of Comma-separated Values, Research Information Systems, or Extensible Markup Language. The software will remove all duplicate data imported to it; furthermore, one student researcher used the study selection tool to apply the inclusion criteria at title, abstract and full-text level (refer to Table 3). An inter-rater checked 40% of the screened articles which were screened at both title and abstract level and full-text level to ensure the reliability of studies included. A research article selection tool form (refer to Table 3) was adapted from Schlebusch *et al.* (2020).

- i. The selection tool form used the following questions to guide the studies selected for inclusion in the scoping review: Does the citation report on children (younger than 21) who have a disability or long-term health condition?
- ii. Does the citation describe an empirical research study using primary data published as a journal article in English (e.g., no reviews, opinion pieces, conference proceedings, policy reviews, etc.)?
- iii. Does the citation report that the research has been conducted in an LMIC (see Table 2 for a list of countries)?
- iv. Does the citation report the concept of participation OR any fPRCs of children with disability or long-term health conditions (the focus is on the level of the child, includes a broad focus such as described in Table 1 and Table 3)?

For the articles yielded from the databases, if the answer is **NO** for any of the questions, the reviewer will exclude the study, and if the answer is **YES** for all the questions, the study will be included in the full-text review.

The reviewing of the research studies was illustrated using a PRISMA diagram (Moher *et al.*, 2015; Tricco *et al.*, 2016) (Figure 1). Arksey & O'Malley (2005) reports that using a PRISMA diagram allows for a clear illustration of the process of study selection narrated in text. Additionally, the PRISMA consists of a checklist that guides the researcher through phased reviewing and ensures that all reviewing process proceedings are conducted (Moher *et al.*, 2015 ;Tricco *et al.*, 2016). The PRISMA is a standardized prescribed manner of reporting in systematic review and Meta-analysis, therefore, deemed suitable for a scoping review (Moher *et al.*, 2015 ;Tricco *et al.*, 2016). This standardized way of reporting allows for the caption of the number of included and excluded studies in each level, and the rationale for excluding studies is each review level (The Joanna Briggs Institute, 2015).

2.8 Data extraction

Charting is an iterative data extracting process whereby results are logically and descriptively summarised and presented. The results are aligned with the scoping review's aim and research question (Peters *et al.*, 2017). Additionally, charting is a technique that identifies, synthesises and summarises evidence (i.e., sorting studies into key themes) and identifies research gaps (Nyanchoak *et al.*, 2019; Peters *et al.*, 2017). This scoping review will use a narrative review approach when

charting results to allow for a broader review of the results presented, providing contextualised and understandable outcomes (Petticrew & Roberts, 2006).

A charting excel form (refer to Appendix B) was adopted from the study by Schlebusch *et al.* (2020). The forms allow data to be generally extracted (author, date of publication, title and country where the study was conducted); followed by method data extraction (design, sample size) and lastly, data extraction according to the research question and aim (age, gender and type of disability of the recruited participants, the attendance setting, country origin and economic status, participation measuring tools, respondents to the measuring tools, and participation and related constructs as per the fPRC). Appendix B on page 54, illustrates the summary of the characteristics of the studies.

The results are represented graphically below (distribution of studies geographically, the different disability groups, the age range, the gender of the participants, the research methods adopted, and the domains of participation). This part of the analysis sheds light on key areas that the current literature covers and determines the research interests and research gaps (Peters *et al.*, 2017).

An inter-rater (Ms Nokwanda Mbhele, currently enrolled for an honours degree in Psychology at the University of KwaZulu-Natal) conducted a reliability check of the data extraction excel sheet and articles included in the study (title and abstract level, full-text level and data extraction process). Title, abstract and full text level where level was correctly included as per the provided inclusion- and exclusion criteria. Discrepancies were discussed until consensus was reached.

2.8.1 Data extraction reliability

The screening was conducted by both this study's researcher (Miss N. Ndawonde) and the inter-rater (Ms. N. Mbhele). The inter-rater checked 40% of the articles at article and abstract level and at full text level. There was a 10% difference between the two parts (date of publication and measured outcome), both the sections verified the queried dates of publication and relooked at the measured construct (family of participation or participation related concepts).

Furthermore, the inter-rater checked 10% of the data included at extraction level, no discrepancy was recorded. The inter-rater used the data extraction excel sheet adopted from the study conducted by Schlebusch *et al.* (2020), in order to extract the target data that aligned with the aims of the study from the 10% of randomly selected articles.

3. RESULTS

A total of 25 articles (n = 25) were included in this review (refer to Appendix B), the results will be presented in accordance with the four sub-aims of this study : i) To identify the number of studies that explore participation in children with disabilities in LMICs and describe these studies according to age, gender, type of disability of participants, and the attendance setting and geographical distribution of the countries the studies were conducted in. ii) To determine the participation measuring tool used by the included studies. iii) To describe the respondents to participation measures used by included studies; and iv) To describe participation in studies as related to fPRC.

3.1 Sub-aim 1: Identify and discuss the studies

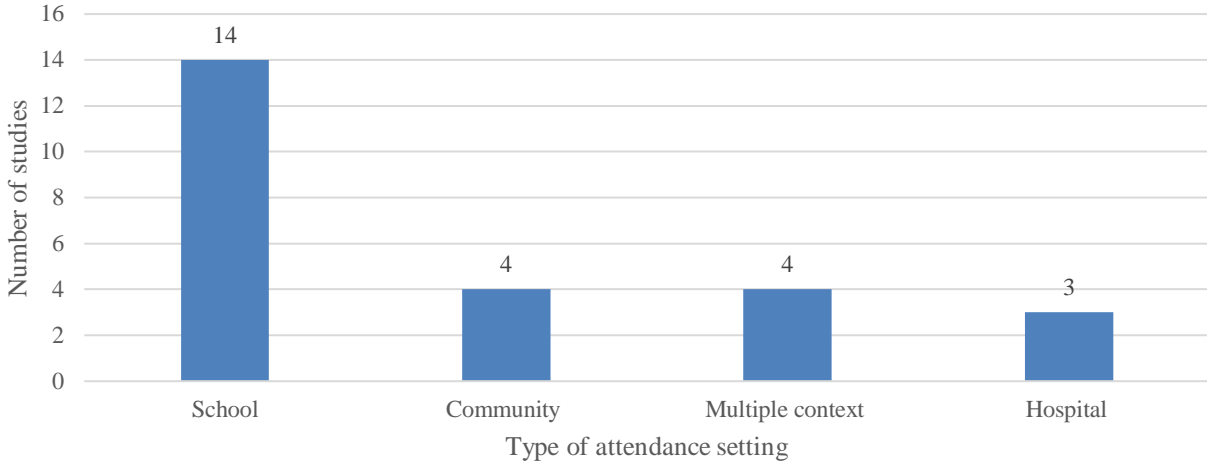
The research sub-aim one, aims to identify the number of studies that explore participation in children with disabilities in LMICs and describe these studies according to the age, gender, type of disability of participants, and the attendance setting and geographical distribution of the countries the studies were conducted in.

Table 4: Characteristics of participation of the included studies

Description	Results										
<p>Age of participants</p> <p>A total of 2740 children were recruited by the included studies; it is imperative to note that n=5 studies did not specify their sample size e (Hui <i>et al.</i>, 2018 ; Leege <i>et al.</i> , 2017; Martinez <i>et al.</i>, 2016 ; Mizunoya <i>et al.</i>, 2018).Most of the studies targeted to recruit participants within age range as opposed to specific age. Therefore, the scoping review adopted the current schooling age which used with the DOE as per detail in the CAPS and ECD policies. This means that recruited participants will be groups in the following categories: preschool (0-5 years), primary school (6-12 years), and high school (13-21 years). The majority of the included studies recruited children within age range of primary to high school (n=16), This is followed by four studies contributed which did not specify the age of the recruited participants, and three studies which recruited participants in preschool. Lastly, two studies specifically recruited children within the primary school age range.</p>	<div data-bbox="981 368 1906 866" data-label="Figure"> <p>The bar chart displays the distribution of studies based on the age range of participants. The y-axis represents the 'Number of studies' ranging from 0 to 18 in increments of 2. The x-axis represents the 'Age range' with four categories: Preschool, Primary School, Primary school to Highschool, and Not Specified. The bars are blue, and the exact number of studies is labeled above each bar.</p> <table border="1"> <thead> <tr> <th>Age range</th> <th>Number of studies</th> </tr> </thead> <tbody> <tr> <td>Preschool</td> <td>3</td> </tr> <tr> <td>Primary School</td> <td>2</td> </tr> <tr> <td>Primary school to Highschool</td> <td>16</td> </tr> <tr> <td>Not Specified</td> <td>4</td> </tr> </tbody> </table> </div> <p>Figure 2a: Age of the recruited participants</p>	Age range	Number of studies	Preschool	3	Primary School	2	Primary school to Highschool	16	Not Specified	4
Age range	Number of studies										
Preschool	3										
Primary School	2										
Primary school to Highschool	16										
Not Specified	4										

Description	Results															
<p>Gender of participants</p> <p>Collectively, the 25 included studies recruited both boys and girls as participants. The majority of the studies, 60% (n = 15) did not specify the gender of the recruited participants, 32% (n = 8) of the studies recruited both boys and girls and the studies that solely recruited both boys and girls and the studies that solely recruited girls and boys made up 4% respectively (n = 1) each of the contributed studies. Even though the results shows that studies respectively recruited only girls and boys contribute same number of studies , the raw data of gender recruitment by each study represented in data extraction excel sheet (Appendix) show that majority of the studies recruited mostly boy except for the study conducted by <i>Du et al.</i>, (2016).</p>	<div style="text-align: center;"> <p>GENDER OF PARTICIPANTS INCLUDED</p> <table border="1"> <caption>Data for Figure 2b: Gender of the participants</caption> <thead> <tr> <th>Gender</th> <th>Percentage</th> <th>Number of Studies (n)</th> </tr> </thead> <tbody> <tr> <td>Both</td> <td>32%</td> <td>8</td> </tr> <tr> <td>Boy</td> <td>4%</td> <td>1</td> </tr> <tr> <td>Girl</td> <td>4%</td> <td>1</td> </tr> <tr> <td>Not specified</td> <td>60%</td> <td>15</td> </tr> </tbody> </table> </div> <p>Figure 2b: Gender of the participants</p>	Gender	Percentage	Number of Studies (n)	Both	32%	8	Boy	4%	1	Girl	4%	1	Not specified	60%	15
Gender	Percentage	Number of Studies (n)														
Both	32%	8														
Boy	4%	1														
Girl	4%	1														
Not specified	60%	15														

Description	Results																								
<p>Type of disability</p> <p>The included studies recruited participants with a range of diagnoses, which are illustrated in Figure 2b. Most of the studies (n = 7) recruited children with Intellectual disability. Six studies recruited children with multiple diagnosis of disability, followed by Cerebral palsy which contributed three studies and two studies did not specify the diagnosis of the children recruited. one study was contributed by studies that recruited children with ADHD, Autism, Developmental coordination disorder, idiopathic scoliosis, Osteogenesis imperfecta and severe mobility limitation.</p>	<div data-bbox="824 427 1899 976" data-label="Figure"> <table border="1"> <caption>Type of Disability for included studies</caption> <thead> <tr> <th>Type of disability</th> <th>Number of studies</th> </tr> </thead> <tbody> <tr> <td>Intellectual disability</td> <td>7</td> </tr> <tr> <td>Multiple diagnosis</td> <td>6</td> </tr> <tr> <td>Cerebral palsy</td> <td>3</td> </tr> <tr> <td>Not specified</td> <td>2</td> </tr> <tr> <td>ADHD</td> <td>1</td> </tr> <tr> <td>Autism</td> <td>1</td> </tr> <tr> <td>Developmental...</td> <td>1</td> </tr> <tr> <td>Idiopathic Scoliosis</td> <td>1</td> </tr> <tr> <td>Physical disability</td> <td>1</td> </tr> <tr> <td>Osteogenesis imperfecta</td> <td>1</td> </tr> <tr> <td>Severe mobility...</td> <td>1</td> </tr> </tbody> </table> </div> <p>Figure 2c: Type of diagnosis of participants</p>	Type of disability	Number of studies	Intellectual disability	7	Multiple diagnosis	6	Cerebral palsy	3	Not specified	2	ADHD	1	Autism	1	Developmental...	1	Idiopathic Scoliosis	1	Physical disability	1	Osteogenesis imperfecta	1	Severe mobility...	1
Type of disability	Number of studies																								
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Description	Results										
<p>Attendance setting</p> <p>The studies included in this scoping review were conducted in various contexts such as schools, hospitals and communities; moreover, some of the included studies were conducted in more than one context. The results reflect that the majority of the studies (n = 14) were conducted in a school context followed by community setting (n = 4), with three studies being conducted in the hospital setting (n = 3). Some of the studies were conducted in more than one setting with the results reflecting under multiple context (n = 4) setting.</p>	<div data-bbox="775 244 2040 820" style="border: 1px solid black; padding: 10px;"> <p style="text-align: center;">Attendance setting</p>  <table border="1" style="margin-left: auto; margin-right: auto;"> <thead> <tr> <th>Type of attendance setting</th> <th>Number of studies</th> </tr> </thead> <tbody> <tr> <td>School</td> <td>14</td> </tr> <tr> <td>Community</td> <td>4</td> </tr> <tr> <td>Multiple context</td> <td>4</td> </tr> <tr> <td>Hospital</td> <td>3</td> </tr> </tbody> </table> </div> <p>Figure 2d: Attendance setting</p>	Type of attendance setting	Number of studies	School	14	Community	4	Multiple context	4	Hospital	3
Type of attendance setting	Number of studies										
School	14										
Community	4										
Multiple context	4										
Hospital	3										

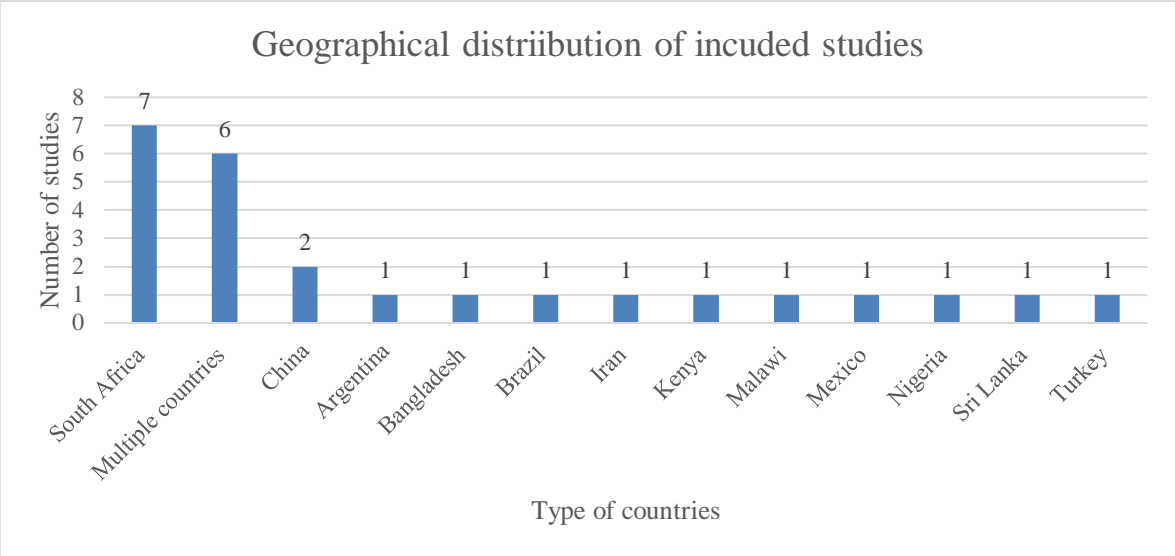
Description	Results																												
<p>Geographical distribution</p> <p>Most of the included studies were conducted in South Africa (n = 7), followed by China (n = 2). One study (n = 1) was conducted in Argentina, Bangladesh, Brazil, Iran, Kenya, Malawi, Mexico, Nigeria, Sri Lanka and Turkey respectively. Lastly, six studies were conducted across multiple countries (n = 6).</p>	 <p>Geographical distribution of included studies</p> <table border="1"> <thead> <tr> <th>Type of countries</th> <th>Number of studies</th> </tr> </thead> <tbody> <tr><td>South Africa</td><td>7</td></tr> <tr><td>Multiple countries</td><td>6</td></tr> <tr><td>China</td><td>2</td></tr> <tr><td>Argentina</td><td>1</td></tr> <tr><td>Bangladesh</td><td>1</td></tr> <tr><td>Brazil</td><td>1</td></tr> <tr><td>Iran</td><td>1</td></tr> <tr><td>Kenya</td><td>1</td></tr> <tr><td>Malawi</td><td>1</td></tr> <tr><td>Mexico</td><td>1</td></tr> <tr><td>Nigeria</td><td>1</td></tr> <tr><td>Sri Lanka</td><td>1</td></tr> <tr><td>Turkey</td><td>1</td></tr> </tbody> </table>	Type of countries	Number of studies	South Africa	7	Multiple countries	6	China	2	Argentina	1	Bangladesh	1	Brazil	1	Iran	1	Kenya	1	Malawi	1	Mexico	1	Nigeria	1	Sri Lanka	1	Turkey	1
Type of countries	Number of studies																												
South Africa	7																												
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Mexico	1																												
Nigeria	1																												
Sri Lanka	1																												
Turkey	1																												

Figure 2e: Geographical distribution

3.1.1 Economic status classification of the included research studies

The economic status classification of the studies included in this review was done in accordance with the World Bank (2020) classification. The GNI, which is calculated using the Atlas method, is used to classify and categorise the countries. These categories are namely; lower-income (GNI of < US\$1 025), lower- middle-income (GNI of US\$1 026 – US\$3 995), upper- middle-income (GNI of US\$3 996 – US\$12 375) and high income (GNI of < US\$12 376).

Table 5 below illustrates the economic status classification of the included studies. Most of the included studies (n = 14) were conducted in the upper- middle-income countries, followed by five studies (n = 5) being conducted in the lower- middle-income countries, two studies (n = 2) were conducted in low-income countries and a further four studies (n = 4) were conducted in countries with different socioeconomic classifications.

Table 5: *Economic status classification description of the included studies*

Economic Status Classification	Country	Studies Included in the Scoping Review
Low-income (n = 2)	Malawi (MWI; n = 1); multi-countries (n = 1) (Guinea, Sierra Leone, Togo, Niger)	Nelson <i>et al.</i> , 2017(MWI); Hui <i>et al.</i> , 2018
Lower- middle-income (n = 5)	Bangladesh (BGD; n = 1); Kenya (KEN; n = 1); multi-countries (Morocco, Philippines, India) (n = 1); Nigeria (NGA; n = 1); not specified countries (n = 1)	Adeniyi, 2016 (NGA); Leege, 2017; Mizunoya <i>et al.</i> , 2018; Moyi, 2017 (KEN); Power <i>et al.</i> , 2019 (BGD)
Upper- middle-income (n = 14)	Argentina (ARG; n = 1); Brazil (BRA; n = 1); China (CHN; n = 2); Iran (IRN; n = 1); Mexico (MEX; n = 1); South Africa (ZAF; n = 6); Turkey (TUR; n = 1); Sri Lanka (LKA; n = 1)	Bastable <i>et al.</i> , 2016 (ZAF); Batton <i>et al.</i> , 2020; Bonney <i>et al.</i> , 2017 (ZAF); Conchar <i>et al.</i> , 2016 (ZAF); Du <i>et al.</i> , 2016 (CHN); Higashida <i>et al.</i> , 2017 (LKA); Hu <i>et al.</i> , 2016 (CHN); Martinez <i>et al.</i> , 2016 (MEX); Mehraban <i>et al.</i> , 2016 (IRN); Nunes <i>et al.</i> , 2016 (BRA); Rodriguez <i>et al.</i> , 2016 (ARG); Sakiz, 2017 (TUR); Samuel <i>et al.</i> , 2020 (ZAF); Sondag <i>et al.</i> , 2016 (ZAF)
Multiple-countries (n = 4)	India (IND) and South Africa (ZAF) (n = 2); South Africa and Sweden (n = 2)	Dada <i>et al.</i> , 2020a; Dada <i>et al.</i> , 2020b (IND & ZAF); Dada <i>et al.</i> , 2020c (ZAF &SWD); Arvidsson <i>et al.</i> , 2020 (ZAF & SWD)

3.2 Sub-aim 2: Determine the participation measures used by the included studies

According to the fPRC, participation and related constructs are variables that can be measured using appropriate tools. These tools are available but limited in numbers and this can be attributed to linguistic, culture and financial factors to name but a few. Even though there is a limited number of measuring tools, there are more than 41 standardized participation measuring tools which aim to collect data correctly and reflect reliable and valid results. Therefore, the reporting on the measures used in the included studies, this scoping review highlights how participation is measured for children with disabilities and chronic health conditions in LMICs.

The majority of the studies used standardised measures of participation ($n = 14$). Seven of the studies were prescribed by Adair *et al.* (2018). The World Health Organisation Disability Assessment Schedule (Ustun *et al.*, 2010) was used in two studies ($n = 2$) (Higahsida *et al.*, 2017; Mizunoya *et al.*, 2018). The Individual Child Engagement Record (Kishida & Kemp, 2006) was used in two studies ($n = 2$) (Bastable *et al.*, 2016; Hu *et al.*, 2016) and Children's Assessment of Participation and Enjoyment (CAPE) (King *et al.*, 2004,) was used in three studies ($n = 4$) (Mehraban *et al.*, 2016; Dada *et al.*, 2020a; Dada *et al.*, 2020b, Samuel *et al.*, 2020). Standardised participation measures were identified in three studies ($n = 3$) by means of a scoping review conducted by Schlebusch *et al.*, (2020); CP quality of life-teens (Power *et al.*, 2019), the joy and fun assessment (Nunes *et al.*, 2016), the kid play profile (Sunday *et al.*, 2016). This was followed by three studies ($n = 3$) which used the PMP instrument which was constructed by Arvidsson *et al.* (2020).

Most of the studies which used the standardised tool conducted the measuring tool in the local language of the recruited participant. Cultural adaptations and/or translations were made to the measures of participation so that the tool can be relevant and relatable to the participants. An example of the aforementioned is the study conducted by Power *et al.* (2019) who report on the translation of the measuring tool to Bengali and to allow for the tool to be culturally and linguistically relevant and relatable for the participant.

Furthermore, some of the included studies ($n = 11$) did not specify a participation measuring tool (Adeniyi *et al.*, 2016; Bonney *et al.*, 2017; Conchar *et al.*, 2016; Du *et al.*, 2016; Nelson *et al.*, 2017; Rodriguez *et al.*, 2016; Leege, 2017; Hui *et al.*, 2018; Martinez *et al.*, 2016; Moyi, 2017; Sakiz *et al.*, 2017). These studies instead listed the adopted methods used for data collection, which included

in-depth questionnaires, observation, video recording and the review of logbooks in order to gather data on the participation of children with disabilities who are living in LMICs.

3.3 Sub-aim 3: Describe the respondents to participation measures

The included studies sampled a variety of respondents to the participation measuring tool. This is an important area to focus on as it provides insight on the voices that the current literature carries as seen in Figure 3 below.

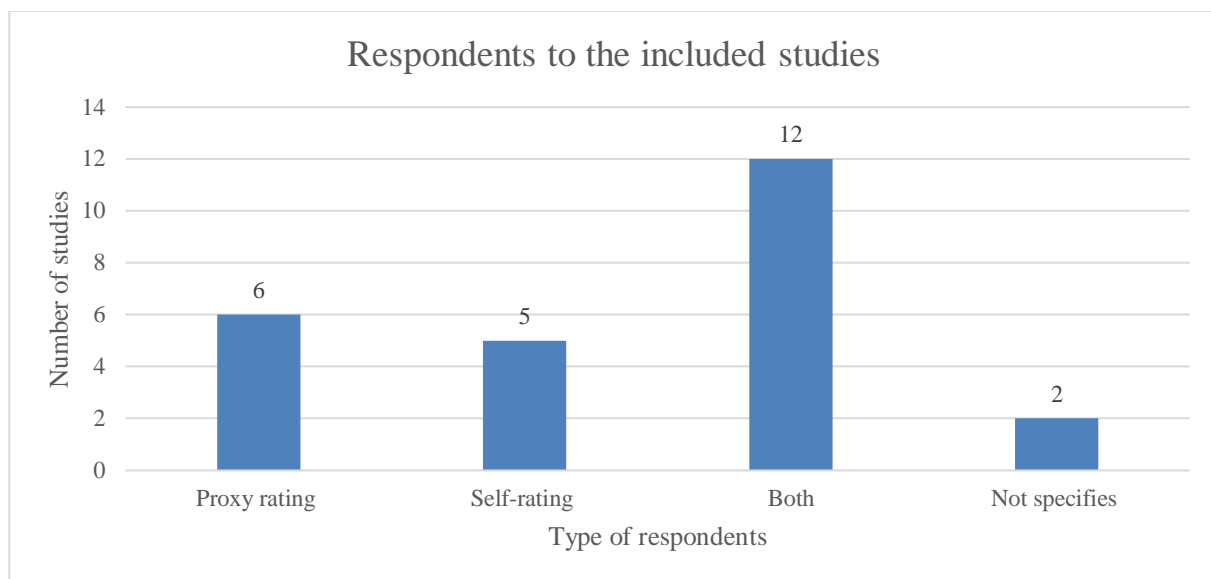


Figure 3: Respondents to the participation measuring tool

Most of the included studies ($n = 12$) used both proxy rating and self-rating (Conchar *et al.*, 2016; Dada *et al.*, 2020a; Dada *et al.*, 2020b; Hui *et al.*, 2018; Leege, 2017; Mizunoya *et al.*, 2018; Power *et al.*, 2019; Sondag *et al.*, 2016; Moyi, 2017). This was followed by studies that used the proxy rating ($n = 6$) described as participation in children with disability; the proxy rating included caregivers ($n = 2$) (Nelson *et al.*, 2017; Adeniyi, 2016) and professionals ($n = 4$) (Nunes, 2016; Hu *et al.*, 2016; Martinez *et al.*, 2016; Bastable *et al.*, 2016). None of the studies exclusively asked siblings to proxy rate the participation measuring tool. A total of five studies ($n = 5$) asked the children directly about their participation patterns (Bonney *et al.*, 2017; Du *et al.*, 2016; Higashida *et al.*, 2017; Mehraban *et al.*, 2016; Rodriguez *et al.*, 2016). Two studies ($n = 2$) did not specify the individuals who rated the participation (Moyi, 2017).

3.4 Sub-aim 4: To describe participation in studies as related to family participation and participation-related concepts

The fPRC framework (Imms *et al.*, 2016) was used to describe the participation and participation related by concepts focused on by the 25 studies included in this scoping review. The framework seeks to capture the multi-dimensional and evolving aspect of the participation concept, and the following was proposed:

- Participation has two elements to it which are attendance and involvement.
- Identification of child-related construct; and
- Measuring tools used to measure participation and participation related tool.

The framework is used to describe the measurable outcomes of the studies included in this scoping review (refer to Table 6 below). The results show that most of the studies (n = 18) had participation as their measure outcome, and amongst these studies, the attendance element (n = 7) was dominantly measured as the outcome. The child-related outcome that falls under the participation related construct had a total of two studies (n = 2), with one study (n = 1) focussing on activity competence as a measured outcome and the sense of self. Lastly, one study (n = 1) could not be described as fPRC; this study focused on the development and translation of participation measuring tools (Power *et al.*, 2019).

Table 6: Mapping the included studies according to the fPRC framework

Author Publication Year	Country Economic status	Title of the Study	Participant's characteristics (Age, gender, disability)	Findings of the Study	Participation Construct Measured	Measurement Tool (Respondent to the tool)
Adeniyi et al. 2016	Nigeria lower-middle income	Effect of a classroom-based intervention on the social skills of a pupil with ID in South West Nigeria	- 12 to 19 years - 16 boys and 14 girls - Intellectual disability	Children with ID exhibit improvement in their social skills following training.	Activity competence	- Not specified - Method used: Questionnaire <i>(Caregiver's perspective)</i>
Arvidsson et al. 2020	South Africa and Sweden Upper-middle income	Content validity and usefulness of Picture My Participation for measuring participation in children with and without intellectual disability in South Africa and Sweden	- 6 to 18 years - both genders - Intellectual disability	The 20 selected activities in the PmP are relevant to children in ZAF and Sweden. The instrument was useful for children with disability for both countries and passed as a tool to measure participation across all contexts. However, the psychometric and clinical properties of the instrument still require further research.	Attendance and involvement	Picture my Participation (Arvidsson et al., 2020) <i>(Child and caregiver's perspective)</i>
Bastable et al. 2016	South Africa Upper-middle income	The effect of a non-powered, self-initiated mobility programme on the engagement of young children with severe mobility limitations in the South African context	-2 to 6 years - not specified - Severe mobility limitations	The level of engagement improves in children with severe mobility impairment following participation in the programme.	Involvement	The individual child engagement record (Kishida & Kemp, 2006) <i>(Professional perspective)</i>
Batton et al. 2020	South Africa Upper-middle income	Test-retest reliability of Picture my Participation in children with intellectual disabilities in South Africa	- 7 to 17 years - not specified - Intellectual disability	The PmP can reliably be used at component level and as a screening tool for intervention planning to identify participation restriction in children with ID.	Participation measure	Picture my Participation (Arvidsson et al., 2020) <i>(Child's perspective)</i>

Author Publication Year	Country Economic status	Title of the Study	Participant's characteristics (Age, gender, disability)	Findings of the Study	Participation Construct Measured	Measurement Tool (Respondent to the tool)
Bonney et al. 2017	South Africa Upper- middle income	The efficacy of two activity-based interventions in adolescents with a developmental coordination disorder	- 13 to 16 years - Girls only - Developmental co-ordination disorder	Participants experienced improved motor proficiency, muscular strength, predilection for physical activities, running and agility and self-efficiency. However, findings showed no significant difference between the result of the two intervention groups.	Attendance and involvement	- Not specified - Method Used: Self-administered questionnaire <i>(Child's perspective)</i>
Conchar et al. 2016	South Africa Upper- middle income	Barriers and facilitators to participation in physical activity: The experience of a group of South Africa adolescents with cerebral palsy	- 12 to 18 years - 7 boys and 8 girls - Cerebral palsy	Inclusive programmes have created the impediment for increasing participation in physical activities for individuals with physical impairment.	Attendance and involvement	- Not specified - Method used: In-depth questionnaire <i>(Child's and professional's perspective)</i>
Dada et al. 2020c	South Africa and India Upper- middle income	The participation of children with intellectual disabilities: Including the voices of children and their caregivers in India and South Africa	- 5 to 18 years - 137 boys and 86 girls - Intellectual disability	There are interesting differences and similarities in participation patterns, both between countries, caregivers and children. The differences between countries were mostly related to the intensity of participation, with whom, and where participation occurred.	Participation	Children's Assessment of participation and Enjoyment (King <i>et al.</i> , 2004) <i>(Child and caregiver's perspective)</i>
Dada et al. 2020b	South Africa	The role of social support in participation perspectives of caregiver of children with intellectual disability in India and South Africa	- 7 to 18 years - not specified - Intellectual disability	Perceived social support of caregivers differs between countries and is associated with their child's participation.	Participation	The Children's Assessment of participation and enjoyment (King <i>et al.</i> , 2004)

Author Publication Year	Country Economic status	Title of the Study	Participant's characteristics (Age, gender, disability)	Findings of the Study	Participation Construct Measured	Measurement Tool (Respondent to the tool)
	Upper- middle income					(Not specified)
Dada et al. 2020a	South Africa and Sweden Upper- middle income	Agreement between participation ratings of children with intellectual disabilities and their caregivers.	- mean age of 12 years - 137 boys and 86 girls - Intellectual disability	While primary caregiver and children's rating were similar for both frequency and perceived importance, the caregivers' choices were uniformed and the children's were diverse.	Participation	Picture my Participation (Arvidsson et al., 2020) (Child's and caregiver's perspective)
Du et al. 2016	China Upper- middle income	Relevant areas of functioning in patients with adolescent idiopathic scoliosis (AIS) on the international classification functioning framework (ICF) – disability and health; the patient's perspective	- 12 to 18 years - 271 boys and 704 girls - idiopathic scoliosis	Patient's with AIS report activity limitation and participation restriction resulting from body structure and function impairment. Environmental factors may be seen as facilitators or enablers in participation.	Attendance and Involvement	Semi-structured interview adapted from the ICF (Child's perspective)
Higashida et al. 2017	Sri Lanka Upper- middle income	The relationship between community participation of disabled youth and socioeconomic factors: Mixed - methods approach in Sri Lanka	- 15 to 29 years - Gender not specified - Children with disability	Factors such as educational experience, household dynamic and household economic conditions are perceived as important factors to be included when exploring the relationship between the community participation and socioeconomic factors of the disabled youth.	Attendance	- Not specified - Method used: Questionnaire adapted from WHO community-based rehabilitation indicator (Child's perspective)
Hu et al. 2016	China	Adolescent group empowerment: Group-centred occupations to empower adolescents with	- 3 to 6 years - not specified	Children gained group empowerment through participating in community-based activities; furthermore,	Involvement	The individual child engagement record (Kishida & Kemp, 2006)

Author Publication Year	Country Economic status	Title of the Study	Participant's characteristics (Age, gender, disability)	Findings of the Study	Participation Construct Measured	Measurement Tool (Respondent to the tool)
Mehraban <i>et al.</i> 2016	Iran Upper-middle income	Design and validation of a new scale to assess the functional ability of children with juvenile idiopathic arthritis (JIA)	- 8 to 14 years - 15 boys and 15 girls - Cerebral palsy	The Children assessment of participation and functional ability (Capfun) is a new instrument that assesses functional ability in children with juvenile idiopathic arthritis. It also has good reliability and validity.	Attendance	The Children's Assessment of participation and enjoyment (King <i>et al.</i> , 2004) (Caregiver's perspective)
Mizunoya <i>et al.</i> 2017	15 developing countries	The effectiveness of responsive teaching parent-mediated developmental intervention programme in Turkey: A pilot study	- school aged children - not specified - Different types of disabilities	Post-intervention mother's responsiveness improved as well as their children's engagement.	Attendance	The World Health Organisation disability assessment schedule (Ustun <i>et al.</i> , 2010) (Not specified)
Moyi 2017	Kenya Lower-middle Income	Effectiveness of responsive teaching with children with down syndrome	-6 to 17 years -not specified - different types of disabilities	Responsive teaching yielded significant improvements in responsiveness effect, engagement and child development, which was noted amongst the intervention group.	Attendance	- Not specified - Method used: Focus group (Not specified)
Nelson <i>et al.</i> 2016	Malwai Low income	Developing a music programme for preschool children with cochlear implants	- 8 to 18 years - not specified - Different disabilities	Participation in- and enjoyment of musical activities was noted for both children and parents. Pre-lingual deafened cochlear implant users should be systematically involved in musical activities to help them acquire skills that are easily acquired by their hearing peers.	Attendance	- Not specified - Method used: Semi-structure interview, direct observation and focus groups (Caregiver's perspective)

Author Publication Year	Country Economic status	Title of the Study	Participant's characteristics (Age, gender, disability)	Findings of the Study	Participation Construct Measured	Measurement Tool (Respondent to the tool)
Nunes et al. 2016	Brazil Upper-middle income	The tremendous potential of technology to level the playing field in global education	- 3 years - 2 boys - Autism spectrum disorder	The impediment for participation in an inclusive education may be attributed to technology-based programmes.	Involvement	- Not specified - Method used: Video recordings <i>(Professional's perspective)</i>
Power et al. 2019	Bangladesh Lower-middle income	A quality-of-life questionnaire for adolescents with cerebral palsy: Psychometric properties of the Bengali Cerebral palsy quality of life questionnaire (CPQoL- teens)	- 10 to 18 years - not specified - Cerebral palsy	The CPQoL- teens self- and proxy report questionnaire successfully translated to Bengali and showed excellent feasibility and strong psychometric properties confirming suitability to assess indication of CPQoL.	Measuring tool	CPQoL-teens (non-standardised tool) <i>(Child's and caregiver perspective)</i>
Rodriguez et al. 2016	Argentina Upper-middle income	Disability and school attendance in 15 low- and middle-income countries	- 15 to 18 years - not specified - Osteogenesis imperfecta	Disability attributed to the reduced probability of school attendance, and this could not be attributed to other factors such as socioeconomic status, individuals' characteristics and household characteristics.	Attendance	- Not specified - Method used: Self-administered questionnaire adopted from functional independence measures <i>(Child's perspective)</i>
Sakiz 2017	Turkey Upper-middle income	School enrolment and attendance for children with disabilities in Kenya: An examination of household survey data	-8 to 15 years -31 boys and 19 girls - Intellectual disability, Learning disability , Orthopaedics	Children with disability are less likely to enrol or attend school; this is attributed to the challenges they face when attending school.	Attendance	- Not specified - Method used: Logbooks <i>(Professional's perspective)</i>

Author Publication Year	Country Economic status	Title of the Study	Participant's characteristics (Age, gender, disability)	Findings of the Study	Participation Construct Measured	Measurement Tool (Respondent to the tool)
			disability, ADHD, visual - hearing, speech and language disability.			
Samuel et al. 2020	South Africa Upper- middle income	Children in South Africa with and without intellectual disability "rating of their frequency of participation in everyday activities"	- 6 to 12 years - not specified - Intellectual disabilities	The importance of gaining a child's perspective of participation relative to their peers without ID.	Participation	Children Assessment of Participation and Enjoyment (King <i>et al.</i> , 2004) <i>(Child's and caregiver's perspective)</i>
Sunday et al. 2016	South Africa Upper- middle income	The meaning of participation for children in Malawi: Insights from children and caregivers	- 8 to 9 years - not specified - Physical disability	A difference was noted in the five levels of engagement and the interaction of children with disabilities across all activities and subjects.	Involvement	The kid play profile <i>(Caregiver's, professional and sibling's perspective)</i>

4. DISCUSSION

This discussion aims to align the results of volume, nature and characteristics of the included studies with the current literature. This will allow for better contextualisation of the results and thus better understanding of the extent of literature exploring participation in children with disabilities who live in LMICs.

4.1 Identification volume of literature through the description of participant's characteristics

The current literature, which focuses on exploring participation in children with disability, is limited to developed countries. Table 5 on page 27, shows that most of the scoping review studies were conducted in countries that fall under the upper-middle-income classification (i.e., South Africa), conforming to the general trend of publication of participation related research being based on countries on the high end of the economic classification. Several studies which aim to explore and describe participation of children with disabilities who live in LMICs share a uniformed observation on the available literature being biased to western countries or high-income countries (Schlebusch *et al.*, 2020; Dada *et al.*, 2020a, Samuels *et al.*, 2020; Olusanya *et al.*, 2020). The reported trend can be attributed to the financial affordability possessed by the countries of high-income classification to fund research projects to be conducted as compared to countries of lower- and middle-income classification who may have limited to no available funding to conduct research. The scoping review conducted by Schlebusch *et al.* (2020), report on the same finding in studies published between the years 2010 and 2016. This can be showcasing that upper-middle-income countries are able to afford resources to conduct research.

The present scoping review investigated the settings in which the studies were conducted and the results show that the school setting was the primary setting in which the studies were conducted (Figure 2d on page 23). Literature shows that schools provide easier access to a large sample size of school age participants, a good participant retaining rate and a cost-effective measure for both participants (i.e., no travelling fees; research is mostly conducted during school time) and researchers (i.e., no rental costs; availability of teachers to assist in conducting research) (Bartlett *et al.*, 2017). In contrast to the studies included in the research conducted by Schlebusch *et al.* (2020), the hospital setting was also used to conduct research. This finding illustrates how research is acknowledging

hospitals as a setting where children with disability participate in. Children with disabilities frequently visit hospitals for medical treatments depending on their needs related to the type of disability or limitations that they may have. In such instances, they are often subjected to intervention programmes in order to increase participation in family activities (i.e., an augmentative or alternative communication board used to increase communication during bath time routine). Therefore, studies conducted in the hospital setting allow understanding on the accessibility of hospitals to children with disabilities, intervention programmes they are involved in as well as health professionals who attend to them.

The review included studies that dominantly recruited children with multiple diagnoses as opposed to a specific diagnosis; this may be attributed by need to create data that aims to describe participation of children with disabilities living in LMICs as such data is lacking in current available literature. Whilst a sampling of a large number of participants can allow a plausible generalisation of results gathered from the research conducted, a broad-spectrum analysis for data generation doesn't necessarily produce the best recommendations for a specific diagnosis. Therefore, generating policy or treatment strategies aimed at increasing and improving participation in children with disabilities may be challenging without specific and targeted research outcomes. The diagnosis of CP contributed the second highest articles and this aligns with the current literature, which reveals that LMICs have 3.4–100 per 1000 birth cases where children are diagnosed with CP (Mahlaba *et al.*, 2020), which may be attributed to the high maternal infection, neonatal jaundice, neonatal convulsion and infection, birth asphyxia and premature birth reported in LMICs as compared to high-income countries. The results from the present study show that ID contributed the same number of publications as studies that recruit children with CP and this illustrates true evidence that ID is ranked as the most severe disability which are commonly occurring in children worldwide, despite the majority of literature available being limited to CP (Olusanya *et al.*, 2020 as cited by Dada *et al.*, 2020a). The low study contribution from developmental coordination disorder, osteogenesis imperfecta and idiopathic scoliosis diagnosis is based on the low ranking of prevalence scale for these diagnoses.

The children's age was also used to capture diverse characteristics of the 2740 children with disabilities included in this scoping review. The Curriculum Assessment Policy Statement (DoBE, 2019) was used to present the age ranges of children recruited in the studies included in this scoping review. For most of the children recruited in the studies used, their age was not specified but were instead identified as school-age children, which relates to any ages between 0 and 21 years of age. This finding shows and emphasises that researchers dominantly use schools to recruit child

participants for research, and children in primary school had higher recruitment levels than children in high school. Although this number comparison does not give a conclusive implication, literature has shown that children with disability in the adolescence stage of life (13 to 21 years) have lower levels of attendance and enrolment in schools. This results from limited schools which provided educational services to children with special needs which is specifically true in LMICs. Additionally, socio-economic status stands as a huge limitation in educational access especially for children with disabilities living in LMICs.

To further specify the characteristics of the recruited participants in the included studies, the gender of the participants was reported. Male participants were mostly recruited for the studies, and this aligns with the current literature, which reports that male children are mostly allowed by society to access school, whilst females face roles and responsibilities such as household chores and taking care of the family (Mizunoya *et al.*, 2017). The aforementioned clearly shows that even though children with disabilities face limitations when enrolling or attending schools, females not only face extrinsic factors which they experience with males (i.e., long-distance to schools, no transportation, inclusive curriculum, availability of teachers), in addition they face intrinsic factors such as parental decisions which are shaped by culture and society (Muzinoya *et al.*, 2017).

Even though the results of this review align with the study conducted by Schlebusch *et al.* (2020), it is imperative that the need for literature which illustrates an increase in enrolment and attendance of females in schools is noted. The study conducted by Du *et al.* (2016) predominantly recruited females and this bares evidence of the aforementioned.

4.2 Description participation in children with disabilities living in LMICs as per the fPRC framework and participation measures

The participation construct is reported as the most focused on outcome by current literature and the results from the present scoping review align with this finding. The results from the study conducted by Schlebusch *et al.* (2020) report participation as a primarily measured outcome and particularly the element of attendance. The study by Schlebusch *et al.* (2020) continues to specify the element of participation which was most measured, and the results that ‘attendance’ was the element of participation which was mainly focused on. This concluded that most of the study explored participation in children with disability in respect to the frequency of their participation in an activity,

the range of activities that children participate in and lastly the diversity of the activities that children with disabilities participate in.

The child-related concepts were the least measured in the review conducted by Schlebusch *et al.* (2020). Imms *et al.* (2016) reiterate these findings as this study shows that child-related concepts were the least measured outcome by the studies included in the scoping review. This finding drew attention following a report by Adair *et al.* (2018), which states that most studies measured child-related concepts as participation. This then raises concern on whether the limited number of studies measuring child-related concepts as the outcome is attributed to the incorrect measuring of child related concepts as participation, as previously discussed. Since the present scoping review did not investigate the correct conceptualisation of constructs measured by the included studies, the present study will not elaborate on the aforementioned rationale for limited studies measuring child-related concepts. However, this study confirms that the attendance construct is the most focused on participation construct and is followed by the involvement construct. This observation may be attributed to the focus of research on exploring participation in children with disabilities on their attendance and involvement with activities, but very limited on the competence or self-sense of children with disability and on the activity they participate in.

In line with the study conducted by Schlebusch *et al.* (2020), the present scoping review extracted data on measures for the participation constructs and participation related constructs. The majority of the studies not specifying the measuring tool used standardised participation measuring tools prescribed mostly by Adair *et al.* (2018). Additionally, few of the studies included in this review used measuring tools identified by the study conducted by Schlebusch *et al.* (2020). This indicates that the measuring tools used to measure participation or participation-related concepts for most of the studies succeeds the 51 standardised participation measuring tools prescribed by Adair *et al.* (2018) as well as an increase in the development of measuring tools that can be used in research to ensure relevance and applicability of the measure for children with disabilities living in LMICs.

The use of standardised participation measuring tools increases the validity and reliability of findings presented by the present study. To ensure reliability and the validity of the results, some of the studies which used a standardised measuring tool adapted the tools by using the participants' local language and removing items that are culturally inappropriate to the participant. This enabled understanding and the correct responses from the participants, ensuring the validity and reliability of the collected data.

Despite the majority of the studies included using standardised measuring tools, close to half of the studies did not use the standardised measuring tools which are prescribed by Adair *et al.* (2018) and Schlebusch *et al.* (2020). This is indicative that the available standardised participation measuring tools used to measure participation in children with disability are sometimes not linguistically and/or culturally relatable to children with disabilities in LMICs. This results in researchers using alternative methods to already existing measuring tools, to enable them to collect valid and reliable data on the participation of children with disabilities.

4.3 Respondents to the participation measures used in the included studies

The United Nations acknowledges the need to observe children's basic rights to voice their views and opinions (UNICEF, 1988 as cited in Huus *et al.*, 2015). However, research aimed at exploring participation in children with disabilities continues to limit the voiced opinions that predominantly rely on proxy responders. This indicates that caregivers, teachers, siblings, coaches and any other personnel related to the child with disability are mostly relied upon to respond to the child's participation within different activities and within the children's different contexts. The general trend is also seen in results for the present scoping review; the voice that was dominantly heard was that of the proxy responders, specifically professionals working with the child with disability (teachers, coach or health professionals); additionally, this trend was also reported by the findings from the study conducted by Schlebusch *et al.* (2020).

Self-rating and proxy rating are both reliable and valid data collection methods even though they capture different aspects and details of life. The use of these methods allows for a broader understanding in the participation of children with disabilities. The proxy rating can be used to collect data for children with disabilities who have difficulty rating their participation independently and correctly. Proxy rating is also used to validate some of the ratings given by children who may have underrated or overrated their participation. However, the proxy rating is not only used for validation and filling in for when children with disabilities cannot report on their participation, it is also used to collect data from the observer and from those who are involved in a child's life on a regular basis or who assist the children to participate in their daily activities. Additionally, a proxy (i.e., caregivers, teachers or health professionals) usually have normative expectations for participation and, therefore, result in negative ratings (Nilsson *et al.*, 2015). They are also reported to experience difficulty giving

sufficient activities that may often not be done by the proxy's children, or bias information may be collected on participation in the activity of low importance to the rating of the proxy (Huus *et al.*, 2015).

The narrative on the experiences of participation in children with disabilities can be collected from the children themselves, however, this requires research in order to rely on self-rated data. However, with the current limitation reported on the research, including children with disability, there is limited literature that echoes children's voices when analysing the participation amongst children with disabilities. This limitation can be attributed to the traditional data collection methods in research not being accommodative of challenges introduced by the disability and tailored to the needs of children with disabilities (Nilsson *et al.*, 2015). These findings call for the adaptation of the traditional methods of data collection, and this implies that the use of visual representation from the Talking Math to augment the understanding of questions asked. With the aforementioned limited studies which ask children to report on their findings, the present study shows that there is an increase in literature, especially in LMICs. This brings hope to the increase of the inclusion of children with disabilities in research which results in the recommendation and intervention plan deduced from the data collected in order to help echo the children's voice.

Even though the studies with proxy rating contributed more than self-rated studies, the present review also showed that studies which combined proxy rating and self-reporting contributed the most studies. This illustrates how research acknowledges the viable data which can be collected from the use of both methods and how this continuum including both proxy and self-rating allows for current literature to capture the complex multifaceted construct such as participation through using numerous voices.

5. CRITICAL EVALUATION, CLINICAL IMPLICATION, FUTURE RECOMMENDATION AND CONCLUSION

5.1 Critical evaluation of the study

Study limitations are important to acknowledge as they affect the description, interpretation, and summarising of the results presented by the research study. Moreover, limitations are disclosed with the aim to increase the credibility of the results presented.

Firstly, the scoping review methodology used in this study was able to identify the literature but did not include any iterative quality appraisals of the articles exploring participation in children with disabilities in LMICs.

Secondly, this study's participation construct had a limitation in the prescribed way of measuring the construct and the ambiguity between the participation construct and participation related construct (Adair *et al.*, 2018). Therefore, the selected fPRCs used in the included studies were not investigated as to whether they correctly measure the intended concept/construct of participation, but rather what the authors reported they measured.

Thirdly, the scoping review included peer-reviewed publications only. Thus, any other publication which has not been peer-reviewed was excluded even if it explored participation in children with disabilities in LMICs.

In the fourth instance, only articles published in English were included in the studies, based on the fact that the researcher is proficient in English, and this indicates that the exclusion of articles published in other language results in literature is bias.

Lastly, the time frame for the included studies is from 01/01/2016 up to and including 31/12/2020; which indicates that recent updating of literature has not to be done (01/01/2021 to 31/06/2021). However, there has recently been a flurry of research papers in this area of research found in a recent update of the literature in a special edition on participation in the *International*

Journal of Environmental Policy, the *African Journal of Disability* as well as the *Scandinavian Journal of Disability*.

While one reviewer (the researcher - Nombuso Ndawonde) was used for the selection and data extraction process, an inter-rater was used to review 40% of the articles in the title and abstract level as well as the full-text level. Additionally, the reviewer (the researcher - Nombuso Ndawonde) extracted data from all 25 studies included in the present review and an inter-rater reviewed 10% of the studies which is below the recommended percentage of 30–40% of studies that the inter-rater is required to check.

The strength of the study is that it is an update of the study conducted by Schlebusch *et al.* (2020); this has been interpreted as both the study's weakness and strength. The scoping review conducted by Schlebusch *et al.* (2020) was recently conducted, and this may result in a large amount of the data being shared in the recently published paper. This review offers an update to this rapidly developing area of research.

5.2 Clinical implications

Data collected from research studies that explore participation in children with disabilities play a vital role in shaping the assessment and intervention strategies used by clinical practitioners. Current literature shows that research studies exploring participation in children with disabilities are limited to high-income countries and the availability of standardised participation measuring tools. This does not imply that clinical proceedings should be 'cut and pasted' from high-income countries but rather encourage clinicians to use the literature and participation measuring tools available as a benchmark and thereafter adopt the measuring tools to relate and be relevant to children with disabilities in LMICs. This adaptation includes the cultural relevance of items used in the assessment tool and the use of native languages of the participants when administering the measuring tool.

In providing clinical services which aims to increase participation and promote inclusion in children with disability, clinicians are encouraged to utilise the 51 standardised participation measuring tools prescribed by Adair *et al.* (2018) as well as the measuring tools further listed by Schlebusch *et al.* (2020) to establish participation in children with disability. These participation measuring tools are valid and reliable in the data they collect and assist in identifying of areas where

intervention is needed. However, clinician's need to be wary that these measuring tools were constructed and formalised on the population in high income countries with English as the majority language used for these measuring tools. Therefore, adaptation to the measuring tool in order to make it culturally and linguistically relative to children in LMIC is important.

5.3 Future recommendation

Although there is a notable expansion of literature that explores participation in children with disabilities, the included studies' appraisal has not been done as it does not form part of scoping reviewing. The integrity of the participation outcome measure used for each of the included studies has not been confirmed. Taking this into consideration, a systematic review can be conducted on the available literature exploring participation in children with disabilities in LMICs. This will allow for quality appraisals of selected participation constructed or participation related concepts measured by researchers and data extracted from the review and recommend policies and intervention strategies that target to increase participation and improve inclusion for children with disabilities.

It will benefit the extent of future research which focuses on exploring participation in children with disability in LMICs, if the research prioritizes the voice of children. This will provide an opportunity for the data collected to bring understanding of participation specific to how the child experiences it within their different environment they interact in. Future research should prioritize girl participants, so as to gain an understanding of whether there is a difference in participation between girls and boys, and the contributing factors this difference. Lastly, the use of AAC is recommended to provide children with different ways to communicate or respond to a study besides being restricted to verbal output.

5.4 Conclusion

Participation is an area of interest in research in the LMICs with 25 research studies included in the present review. The review continues to report that the majority of the children were diagnosed with CP but also identified ID as a common disability, with males being the majority of participants recruited. However, emergent literature shows that the marginalisation of females participating in research studies may be equalised.

Furthermore, the review shows that the participation construct is mainly measured using standardised participation measures - measuring tools identified in the research study. However, the few studies that used standardised participation measuring tools were linguistically and culturally adapted; this was made to ensure relevance and acceptability to the countries and contexts.

Lastly, the use of the fPRC framework was used to describe the included studies and results show that Attendance was the majority measure participation construct.

In conclusion, there is indeed an emergence of literature in LMICs exploring participation in children with disabilities. However, more research needs to be conducted in order to understand the participation of children with disabilities and participation related constructs as described by Adair *et al.* (2018). Additionally, the methodology used in research studies should consider adaptation which aims to allow children with disabilities to independently rate their participation in daily activities.

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APPENDIX A
ETHICS COMMITTEE APPROVAL LETTER



Faculty of Humanities

Fakulteit Geesteswetenskappe
Lefapha la Bomotheo



4 June 2020

Dear Miss N Ndawonde

Project Title: Participation of children with disabilities in low- and middle-income countries:
A scoping review
Researcher: Miss N Ndawonde
Supervisor: Prof S Dada
Department: CAAC
Reference number: 19210133 (HUM018/0420)
Degree: Masters

Thank you for the application that was submitted for ethical consideration.

The Research Ethics Committee notes that this is a literature-based study and no human subjects are involved.

The application has been **approved** on 4 June 2020 with the assumption that the document(s) are in the public domain. Data collection may therefore commence, along these guidelines.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. However, should the actual research depart significantly from the proposed research, a new research proposal and application for ethical clearance will have to be submitted for approval.

We wish you success with the project.

Sincerely,

Prof Innocent Pikirayi
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotheo

Research Ethics Committee Members: Prof I Pikirayi (Deputy Dean); Prof KL Harris; Mr A Bizos; Dr A-M de Beer; Dr A dos Santos; Ms KT Govinder; Andrew; Dr P Gutura; Dr E Johnson; Prof D Maree; Mr A Mohamed; Dr I Noomé; Dr C Puttergill; Prof D Reyburn; Prof M Soer; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

APPENDIX B
DATA EXTRACTION SHEET

DISCLAIMER : THE FORMAT OF THE DATA EXTRACTION SHEET HAS BEEN ATTACHED IN WORD FORMAT DUE TO ACTUAL SHEET BEING UNATTACHABLE DUE TO SIZE . PLEASE FIND THE ORIGINAL DOCUMENT AS A SEPARATE DOCUMENT SUBMIT ALONG WITH MINI-DISSERTATION

APPENDIX B
Research conducted on the participation of children with disabilities
living in low- and middle-income countries: A scoping review
Description and References of included studies

Author Year of publication Country	Type of disability Study participants present with	Gender	Age range (years)	Study aim	Research design Type of study	Focus of the study and measured participation outcome	Measuring tool for participation	Findings
Adeniyi 2016 Nigeria (Lower-middle income)	Intellectual disability	16 boys and 14 girls	12-19 years	To investigate the effect of a social skills training for pupil with intellectual disability attending a special school in South west Nigeria	Quantitative	<i>Child related concepts</i> - Obtain of competence in social skills	caregiver's perspective , questionnaire-self administered	Children with intellectual disability exhibit improvement in their social skills following training

APPENDIX C
PLAGIARISM DECLARATION FORM

UNIVERSITY OF PRETORIA
PLAGIARISM POLICY AGREEMENT

The University of Pretoria places great emphasis on integrity and ethical conduct in the preparation of all written work submitted for academic evaluation.

While academic staff teaches you about referencing techniques and how to avoid plagiarism, you too have a responsibility in this regard. If you are at any stage uncertain as to what is required, you should speak to your lecturer before any written work is submitted.

You are guilty of plagiarism if you copy something from another author's work (e.g. a book, an article or a website) without acknowledging the source and pass it off as your own. In effect, you are stealing something that belongs to someone else. This is not only the case when you copy work word-for-word (verbatim), but also when you submit someone else's work in a slightly altered form (paraphrase) or use a line of argument without acknowledging it. You are not allowed to use work previously produced by another student. You are also not allowed to let anybody copy your work with the intention of passing it off as his/her work.

Students who commit plagiarism will not be given any credit for plagiarised work. The matter may also be referred to the Disciplinary Committee (Students) for a ruling. Plagiarism is regarded as a serious contravention of the University's rules and can lead to expulsion from the University.

The declaration which follows must accompany all written work submitted while you are a student of the University of Pretoria. No written work will be accepted unless the declaration has been completed and attached.

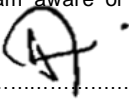
Full names of the candidate:.....Nombuso Ndawonde

Student number:.....u19210133.....

Date: ...30/06/2021.....

Declaration.

1. I understand what plagiarism is and am aware of the University's policy in this regard.

SIGNATURE OF CANDIDATE:

SIGNATURE OF SUPERVISOR:

This document must be signed and submitted to the Head: Student Administration within two months of registering for the research component of the programme.

UNIVERSITY OF PRETORIA
DECLARATION OF ORIGINALITY

This document must be signed and submitted with every essay, report, project, assignment, dissertation and/or thesis.

Full names of student: ...Nombuso Ndawonde.....

Student number: ...u19210133.....

Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.
2. I declare that this ...mini-dissertation .. (e.g. essay, report, project, assignment, dissertation, thesis, etc.) is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.
3. I have not used work previously produced by another student or any other person to hand in as my own.
4. I have not allowed, and will not allow anyone, to copy my work with the intention of passing it off as his or her own work.



SIGNATURE OF STUDENT:.....

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<i>Initial – Student</i>	N
<i>Initial – Supervisor</i>	

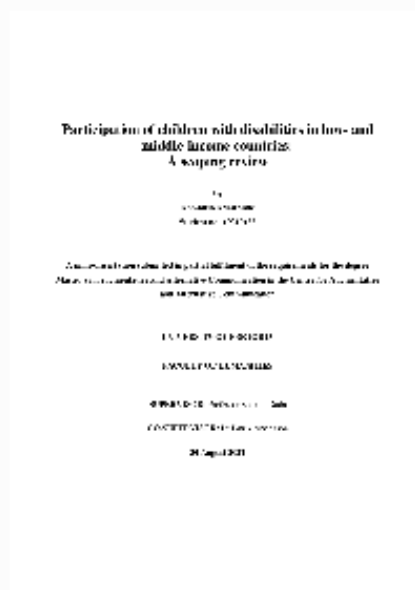


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APPENDIX D
LETTER FROM LANGUAGE EDITOR

JANINE ELLIS
LANGUAGE EDITING / TRANSCRIPTION / TYPING
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Client

Nombuso Ndawonde
Mini-Dissertation
University of Pretoria

P O Box 28164
Sunridge Park
6008

9 August 2021

DECLARATION

To whom it may concern,

I hereby declare that I fully language edited the mini-dissertation of Ms Nombuso Ndawonde titled: *Participation of children with disabilities in low- and middle-income countries: A scoping review*. All aspects of this mini-dissertation were carefully looked at, corrections made and suggestions given with regards to certain wording and sentence structure. The layout and presentation and referencing of this mini-dissertation was edited as per the referencing and technical/style template/guide provided by the client. Final acceptance of all proposed corrections/changes/ comments is the personal choice/discretion of the client be it correct or not.

This service was rendered from 09 July 2021 to 17 July 2021, with final checks having been made on 09 August 2021.

Kind regards



Janine Ellis

