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# Participation of fathers and siblings in home rehabilitation programmes for children with neuro-developmental delay: a scoping review

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## Abstract

**Background** The role of, and impact on, mothers caring for children with neuro-developmental delay (NDD) is well documented. However, the role of fathers and siblings in families of children with NDD remains significantly understudied, particularly in low- and middle-income countries (LMICs). There has been an increased call for holistic rehabilitation of children with NDD at the family level. This study aimed to explore the involvement of fathers and siblings in the home rehabilitation programmes of children with NDD.

**Methods** A scoping review was conducted using the Joanna Briggs Institute (JBI) Peters et al.'s methodology and reported according to Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines. Articles were retrieved from PUBMED, ScienceDirect, PsycINFO, SCOPUS, PEDro, and Google Scholar. Reference lists of relevant studies were also manually searched.

**Results** Thirty research articles were identified. Father and sibling participation in home-based rehabilitation and caregiving is low in LMICs compared to high-income countries due to economic factors and cultural beliefs. Reduced participation stresses mothers and reduces developmental outcomes in children with NDD.

**Conclusions** This review highlights the need for rehabilitation professionals to encourage father and sibling participation in caregiving for children with NDD in home rehabilitation programmes.

**Keywords** Rehabilitation, Home-based programmes, Neuro-developmental delay, Fathers, Siblings, Participation, Facilitators and barriers

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## Introduction

Neuro-developmental delay (NDD) is slowness to meet or not reaching the expected stage of development in one or more of the five developmental domains (motor, cognition, communication, adaptive skills and social-emotional) compared to the expected development for a child's age group [1–4]. NDD involves an impaired development of the central nervous system and it affects numerous areas of the child's functioning including language, behaviour, sleep, physical abilities and mental health. Examples of conditions associated with NDD include autism spectrum disorder, intellectual impairments and cerebral palsy [5]. Developmental problems in children account for a greater global burden of disease; they accounted for 34% of disease burden in 2019 [6]. Almost 95% of children living with an impairment are in low- and middle-income countries (LMICs) [7, 8], with the Sub-Saharan Africa (SSA) region disproportionately affected. For example, SSA accounts for 73% of all developmental delay cases worldwide [8]. The most common cause of NDD, highly prevalent in low-income settings, is cerebral palsy [9].

The family is an important nucleus for providing and supporting the healthcare needs of children diagnosed with NDD. Being an active partner in the therapy of a child with NDD may be empowering to some parents, whilst others may perceive it as a burden or overwhelming [10, 11]. Yet, without adequate support to the family members, especially mothers, their health and wellbeing is compromised [12]. The role of fathers cannot be over-emphasized as it has been shown that they have a strong link to child behaviour and developmental outcomes [13, 14]. Rates of developmental delay were reported to be higher for a subgroup of fathers who were not involved in the caregiving of their child, at levels of 59%, 50%, 47% and 27% for cognitive, language, social-emotional and motor skills, respectively [15]. Interestingly, participation of male caregivers was associated with improved school performance, social and cognitive development in children [16, 17]. Fathers and siblings should play a key role to help and support mothers of children with NDD through acts of practical assistance and emotional support involving empathy, emotional reassurance and self-esteem support [18]. Important previous studies revealed that any increase in the father's participation in parenting children with NDD is associated with a decrease in stress experienced by mothers in parenting [19, 20].

Unfortunately, there is a gap in the collective family contribution to home-based healthcare where fathers in particular and siblings, appear to display minimal to reduced involvement and participation as compared to mothers or maternal guardians in early childhood development (ECD) [2, 9, 21–24]. A study by Dambi et al. (2015) pertinently showed that caregivers who were

mothers in low-income countries suffered from significant stress, physical strain and discomfort when left to undertake child caregiving roles on their own [25]. The role of a "partner or father figure" is significant for mothers who shoulder their responsibility for nursing their children suffering from a lifelong NDD.

Kauchali and Davidson (2006), Bakare et al. (2014) and Dambi et al. (2015) underscored the importance of prioritizing public health interventions and research focusing on the rehabilitation of children with NDD at the family and home-based level [25–27]. The limited attention given to this area may indicate existing challenges or barriers hindering the active involvement of fathers and siblings in the rehabilitation of children diagnosed with NDD. To support this, Towers (2007) and Ogourtsova et al. (2021) similarly reported fathers of children with NDD impairments claiming that healthcare professionals (HCPs) would marginalise and exclude them in treatment sessions [28, 29]. It is unclear whether this situation persists, however it is a research gap that must be investigated given that more research continues to focus on mothers as the primary caregiver in the home setting compared to their male counterparts [30]. This is all despite the shifting state of gender roles in families where more women are engaging in out of the home economic opportunities and more fathers become stay-at-home parents [31, 32].

Fjermestad et al. (2021) allude to the possibility that in low- to middle-income countries, siblings have increasing informal caregiving duties and can be under even more stress because of that [5]. This can set off a barrier to their participation in caregiving to their siblings diagnosed with NDD. Clinical facilities and healthcare professionals are more readily available and community support systems are better setup to support the needs of siblings to children with NDD [33]. Unfortunately, in low-income countries, clinical facilities and HCPs are unavailable or too expensive for most families [27, 34]. It is most likely that, in low-income countries where public health facilities are under-resourced, support for families living with children diagnosed with NDD will face significant challenges in their lifelong rehabilitation.

## Objectives of the scoping review

1. To determine the level of participation of fathers and siblings in the rehabilitation of children with neuro-developmental delay (NDD).
2. To identify the facilitators and barriers affecting the participation of fathers and siblings in the rehabilitation of children with neurodevelopmental delays (NDD).

## Methods

In this scoping review, we employed the Joanna Briggs Institute (JBI) 9-step methodology outlined by Peters et al. (2020), which offers a comprehensive and systematic framework for conducting scoping reviews (see Additional File 1) [35]. This method was chosen to ensure a thorough identification, mapping, and analysis of existing literature on the participation of fathers and siblings in home rehabilitation programs for children with NDD. The decision to conduct a scoping review was further justified by the need to rapidly map key concepts, identify primary sources, and explore the range and nature of research on this underexplored topic, particularly in low- and middle-income countries. This approach aligns with the objectives of investigating the extent, summarizing findings, and identifying gaps in the literature, as outlined by Arksey and O'Malley (2005) [36].

To maintain transparency, replicability, and adherence to high reporting standards, the review was reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines [37]. Additionally, the detailed review protocol was registered with the Open Science Framework (OSF) [38], under registration number: KB6ET (retrieved from <https://doi.org/10.17605/OSF.IO/KB6ET>), ensuring a structured

and transparent approach to the research process. This scoping review provides a comprehensive foundation for understanding existing research and guiding further studies in this critical area.

### Identifying relevant studies

Peer-reviewed studies were identified from the following electronic databases: PUBMED, ScienceDirect, PsycINFO, Africa Wide, SCOPUS and PEDro. Google Scholar search engine was used to access grey literature such as university repositories. Additional searches included checking lists of references from the most relevant studies and expert suggestions to identify missed research papers from the initial electronic database searches and manual search of reference lists.

Expert consultations were conducted with professionals from the University of the Witwatersrand and the United Bulawayo Hospitals, Department of Paediatrics. Research supervisors SM, LC, and JD, experts in the field, reviewed the preliminary findings and provided feedback on the comprehensiveness and relevance of the identified literature. This process, involving direct communication via email and virtual meetings, ensured the scoping review was thorough and aligned with current knowledge, while identifying any potential gaps [39]. The primary aim of our scoping review was to map the existing literature on a well-defined topic with a focus on synthesizing evidence rather than exploring broader practical implications. Given this focus, our review required in-depth technical knowledge, which was effectively addressed through expert consultation rather than broad stakeholder engagement.

The first author (PM), a paediatric physiotherapist, conducted the literature search and was guided by a university librarian (JM) and an archivist (DS) at the National University of Science and Technology. If additional information was required or if the full article was not available online, PM emailed or connected with the authors of the main research or reviews on social media. A reminder was issued to the author if there was no response after two weeks. If no response was received after four weeks of the initial contact, the information as found in the original literature was presented or the article was excluded if not available online and no responses were received from the author(s).

Table 1 is an example of how we searched PUBMED database articles, guided by the PCC framework for (Population/Concept/Context) presented in Table S1 (see Additional File 2). Boolean terms (and/or) and Medical Subject Heading (MeSH) terms were used [38], supplemented by truncation and wildcard operators (\*) for comprehensive information retrieval. As a demonstration, we entered the following to search papers in PUBMED database: “*Neurodevelop\**” and “*neuro-develop\**” was

**Table 1** General search strategy

Search #	Keyword	Alternative words (with * Truncation Notation)
1	Neuro-development	Neuro-develop* OR Neurodevelop* OR delay OR impairment OR disability AND
2	Father	Husband OR married spouse OR parent AND
3	Child	Child* OR Son* OR Daughter* OR Paediatric* AND
4	Sibling	Sibling*, Brother*, Sister* AND
5	Rehabilitation	Rehab* OR Therapy OR Intervention NOT “drug centre” AND
6	Home-based	Homecare OR Intervention OR Therapy OR Support AND
7	Participation	Participat* OR Involv* OR Engag* OR Contribut* AND
8	Programme	Program* OR Plan* OR Scheme* AND
9	Facilitators	Facilitator* OR Enabler* AND
10	Barriers	Barrier* OR Constraint*

used to find publications that had relevance in subject to this scoping review based on subjects related to *neu-rodevelopment, neurodevelopmental, neuro-development, neuro-developmental OR delay OR impairment OR disability*. The search query was refined as follows: (“Neurodevelopmental delay” OR NDD OR Neurodevelop\* OR Neuro-develop\* OR delay OR impairment OR disability) AND (father\* OR husband OR “married spouse” OR parent OR sibling\* OR brother\* OR sister\*) AND (participation OR involvement OR engagement OR facilitators OR barriers). This aimed to retrieve literature that addresses both the level of participation and factors influencing participation in the home rehabilitation programmes of children with NDD, aligning closely with our research objectives. This search strategy was replicable and we adapted it to the rest of electronic databases searched.

### Article selection

This review focused on studies that reported on the roles played in caregiving by fathers and siblings of children with NDD, barriers and facilitators they encounter in home rehabilitation programme participation; and the nature of programmes available for home-based rehabilitation for these children and their effectiveness. Pre-determined inclusion and exclusion selection criteria for the articles included in the scoping review is presented in Table 2.

This scoping review considered published literature and empirical studies which were peer reviewed in leading scientific databases and additional grey literature. Quantitative, qualitative and mixed-method studies were included in the scoping review.

Automated de-duplication was done using a reference management software, EndNote version 21. For duplicate studies, the final published version was retained, pre-published versions were discarded. In cases where studies

were reported in more than one publication, only articles reporting the most complete and detailed data set were considered. In exceptional circumstances where these articles were addressing different components that meet the inclusion criteria, both articles were considered. Two impartial reviewers (JD and LC) screened the titles and abstracts for each article included in the preliminary list to determine whether they met the inclusion criteria for the scoping review. Any differences between selected and non-selected sources were resolved by consensus. In circumstances where consensus was not reached, the final decision was made by the most senior principal author of this scoping review (SM), who carefully weighed and balanced the opinions of the reviewers to make a final determination on which articles should be included in the final scoping review.

### Charting the data

PM used a data extraction tool created by the first author (PM) and reviewed by SM, LC and JD to abstract data from the publications included in the scoping review. To minimize bias, extracted information was reviewed and verified by LC and JD; any discrepancies were rectified by SM. Specific information on the participants, concepts, context, research techniques and significant findings that are pertinent to the review question, as well as generic information about the research study such as citation details, were included in the data extraction form (see Additional File 3).

This extracted data form was piloted by PM on five articles from PUBMED to make it as generic as possible and easily usable for all studies and to look for agreement between data extractors. There was a high rate of agreement with the external reviewer (reaching approximately 90%). In areas where there were disagreements, adjustments were made. These adjustments increased specificity and sensitivity of the extracted data form.

**Table 2** Inclusion and exclusion criteria for articles accepted

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>→ Articles with explicit mention of:               <ul style="list-style-type: none"> <li>• Father and/or sibling(s) participation in home rehabilitation programmes.</li> <li>• Neurodevelopmental home rehabilitation programmes.</li> <li>• Barriers to participation of fathers and/or siblings in home rehabilitation programmes.</li> <li>• Efficacy of home rehabilitation programmes in neuro-developmental disability.</li> </ul> </li> <li>→ Articles that clearly stated the medical condition of children in the study.</li> <li>→ Care recipients in the study should be children aged 18 years and below.</li> <li>→ Peer-reviewed articles.</li> <li>→ Grey literature articles.</li> <li>→ Full article available.</li> <li>→ Articles published in English.</li> </ul>	<ul style="list-style-type: none"> <li>→ Studies where full research articles are not available.</li> <li>→ A non-research or review articles (publications that do not present original research findings e.g. editorials, opinion pieces, commentaries, letters to the editor, book reviews, news articles, magazine articles and essays).</li> <li>→ Articles reporting on secondary data (e.g. meta-analyses).</li> </ul>

### Collating, summarizing and reporting the results

A multi-methods approach was employed to analyse the data, addressing both the qualitative and quantitative aspects of the scoping review’s objectives. Frequencies of studies by country and by continent were presented. The extent of participation of fathers and siblings in the rehabilitation of children with NDD was quantitatively summarized by extracting and synthesizing numerical data from the included studies. This provided a clear measure of participation levels. Concurrently, a qualitative content analysis, based on methodologies by Vaismoradi et al. (2016) [40] and Bengtsson (2016) [41], was conducted to identify and categorize key themes related to factors influencing participation. These factors were classified into ‘facilitators’ and ‘barriers,’ offering a comprehensive understanding of the contextual influences

on participation. This combined approach ensured that the study thoroughly addressed both the extent of participation and the factors affecting it, providing valuable insights for future research.

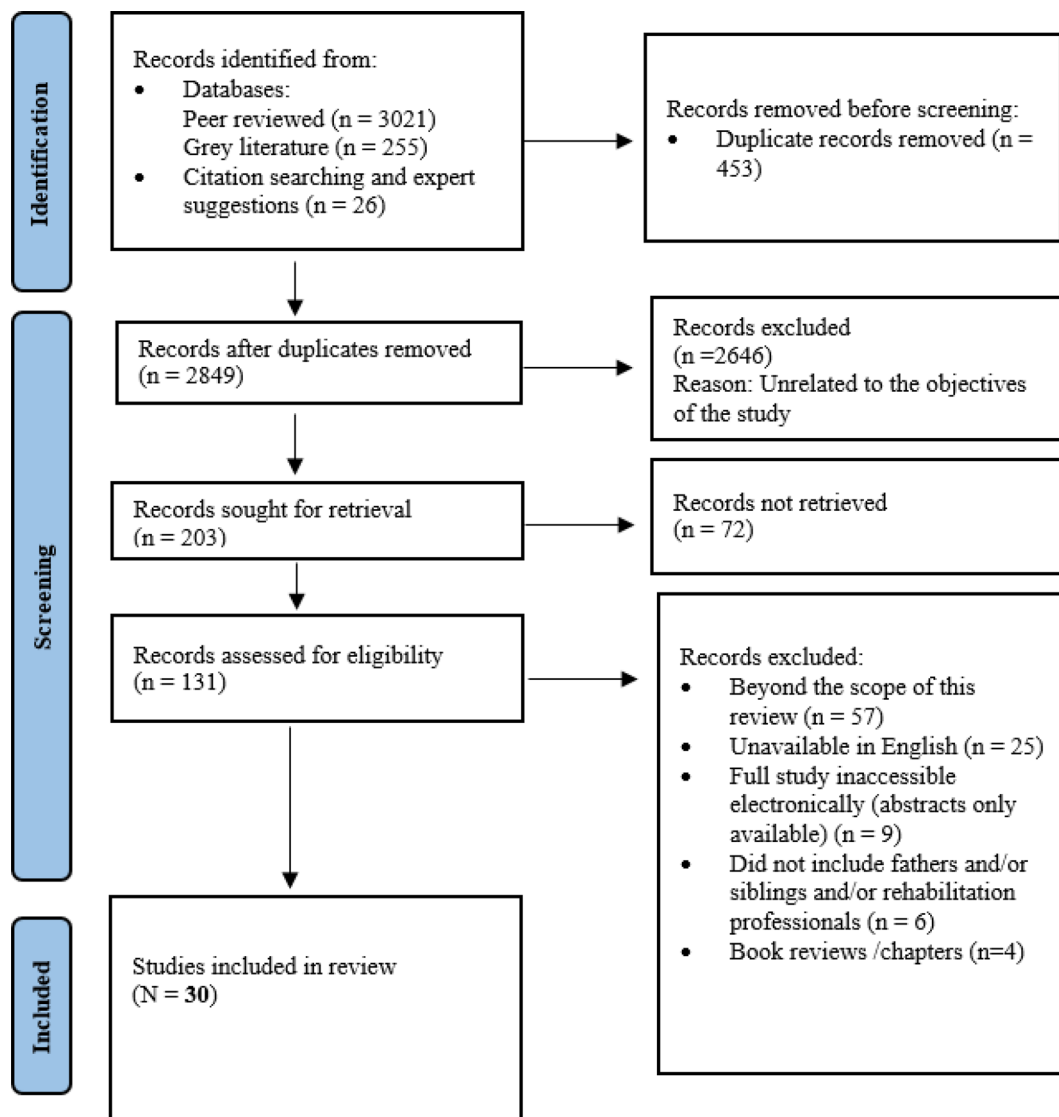
## Results

### Study selection and description of studies

Out of the 3302 studies imported for screening, 453 duplicate studies were removed, leaving 2849 papers for title and abstract screening. A total of 203 studies remained to be evaluated for eligibility after 2646 study titles and abstracts were found not meeting the inclusion criteria. Out of those 203 studies, 72 were not retrieved; 101 articles were disregarded due to failure to satisfy the inclusion criteria. Finally, 30 studies satisfied the inclusion criteria after all screening phases had been completed as shown in Fig. 1.

### Characteristics of the included studies

The date range for publications was from 2000 to 2024. Distribution by continents: North America [total  $n=9$ ; United States of America – USA ( $n=7$ ) and Canada ( $n=2$ )], which was at par with Africa [total  $n=9$ ; Ghana ( $n=2$ ), Zimbabwe ( $n=2$ ), Ethiopia ( $n=1$ ), South Africa ( $n=2$ ), Uganda ( $n=1$ ), Malawi ( $n=1$ )]. Oceania contributed [total of ( $n=3$ ); Australia ( $n=3$ )] and Asia [total  $n=4$ ; South Korea ( $n=1$ ); China ( $n=1$ ) and India ( $n=2$ )]. Finally, other continents were Europe [total  $n=1$ ; United Kingdom ( $n=1$ )] and South America [total  $n=1$ ; Brazil ( $n=1$ )]. Multiple country study in Europe ( $n=1$ ), multiple countries in Asia ( $n=1$ ), multiple countries unspecified ( $n=1$ ). Fourteen studies clearly originated from high-income countries (HICs) in Europe, North America, Asia and Oceania. Eight originated from Middle Income Countries (MIC) and another seven from



**Fig. 1** PRISMA-ScR flow diagram detailing the search process

low-income countries (LIC). One multiple country study is from unspecified economic classification zones. Articles included were summarised in Table S2 (see Additional File 4).

### Study outcomes

Out of the 30 studies included, 11 focused on the participation of fathers and the significance of their involvement, two focused on the participation of siblings, and two studies took an all-inclusive approach to participation of fathers and siblings in rehabilitation programs for children diagnosed with NDD. Other studies ( $n=4$ ) were largely maternally inclusive and highlighted the increased stress levels mothers as primary caregivers for children with NDD encounter due to the lack of support from fathers, immediate family members and the extended family members. These studies emphasized the importance of engaging other family members in caregiving roles to improve the quality of life of mothers. Studies that pointed to the role of home rehabilitation programmes to children with NDD ( $n=3$ ); studies highlighted deep rooted stigma associated with NDD in low-income settings, posing as a barrier to participation in rehabilitation programmes by fathers and other family members ( $n=2$ ). The rest ( $n=6$ ), discusses a wide spectrum of themes ranging from the call for health professionals to engage other family members in the care of children with NDD, financial burden of having a child with NDD in the family to involvement of fathers in research teams on conditions involving their children with NDD and advocated for the inclusion of fathers and siblings in home rehabilitation programmes highlighting its significance in reducing maternal stress and improving maternal developmental outcomes. The following themes resonated from the analysis of the findings of studies included in this scoping review in line with objectives of this study:

### Levels of participation of fathers and siblings in the rehabilitation of children with neuro-developmental delay

Levels of participation were categorised as participation of fathers and participation of siblings. Six studies reported on the participation of fathers and three of these studies quantified participation of fathers into percentages. Specifically, Song, Chun and Choi (2015) reported participation rates for fathers in South Korea (HIC) to be 70% ( $n=82$ ) which was associated with low stress levels in mothers; father participation was more than 50% in three items and was less than 50% in the remaining 11 items [20]. The lowest participation was 12% in men-only support groups [42]. Higher statistics were reported by da Cruz et al. (2019) for participation by fathers in Brazil (MIC) at 91% ( $n=23$ ) [43]. On the contrary, Olawale, Deih and Yadaar (2013) reported from Ghana (LIC) that

as much as half of parents (50%,  $n=52$ ) in their study of which 32.7% comprised fathers, believed in an alternative kind of care for their children as opposed to medical rehabilitation interventions [44]. The negative effects of caregiving on parents was reported in five studies. Three studies revealed the negative effect of non-participation of fathers in caregiving of children with neurological conditions to include high stressing levels in mothers and decreased developmental outcomes in children with NDD. Vadivelan et al. (2020), a qualitative study conducted in India (MIC country), specifically states major interpersonal stressors as lack of support and help from husbands and siblings of the child with disability [45]. Ten participants who were female caregivers participated in semi-structured in-depth interviews. Two studies [46, 47] reported on the participation of siblings in qualitative descriptions but none of these quantified the level of participation of siblings into specific percentages.

### Facilitators and barriers to the participation of fathers and siblings in the rehabilitation of children with neuro-developmental delay

Eight studies identified by the scoping review made poignant reference to facilitators for participation by fathers. However, no studies reported barriers to sibling participation in caregiving or administering home rehabilitation programmes and one study pointed to facilitators to participation of siblings. The facilitators and barriers to father and sibling participation overarched into personal (presence or lack of priorities, specialised supports) and environmental factors (supporting and none-supporting) themes as shown in Table 3.

### Discussion

The purpose of this scoping review was to explore the involvement of fathers and siblings in the home rehabilitation programmes of children with NDD. The major findings from this scoping review revealed the widely reported low level of participation by fathers compared to mothers of children with NDD [53]. Six studies examined father participation, with three quantifying it as percentages. For instance, Song, Chun, and Choi (2015) found a 70% participation rate for fathers in South Korea (HIC), associated with low maternal stress [20]. This was in support of Laxman et al. (2015) who reported that father participation in the caregiving of children with neuro-developmental conditions is associated with low stress levels on mothers [54]. Participation varied across activities, with rates exceeding 50% in some and dropping as low as 12% in men-only support groups [42]. Conversely, da Cruz et al. (2019) reported a higher father participation rate of 91% in Brazil (MIC) [43]. However, siblings were reported to be eager and helpful playmates to children with developmental disabilities [51], although

**Table 3** Facilitators and barriers to father and sibling participation

FATHERS:	Facilitators	Barriers
<b>Personal factors</b>	<ul style="list-style-type: none"> <li>• Collaboration between therapists and parents [10, 11].</li> <li>• Inclusion of fathers in research teams (i.e. family engagement in research) [29].</li> <li>• Condition of the child [48].</li> </ul>	<ul style="list-style-type: none"> <li>• Work commitments by fathers [43].</li> <li>• Lack of knowledge about the condition of the child [42, 49].</li> </ul>
<b>Environmental factors</b>	<ul style="list-style-type: none"> <li>• Family activities and collective planning [42].</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical personnel failing to engage parents [50].</li> <li>• Cultural, superstition and religious beliefs [51].</li> <li>• Financial challenges [52].</li> </ul>
<b>SIBLINGS:</b>		
<b>Personal factors</b>	<ul style="list-style-type: none"> <li>• Family harmony with greater sibling warmth [46].</li> </ul>	Not reported
<b>Environmental factors</b>	<ul style="list-style-type: none"> <li>• Low sibling conflict [46].</li> </ul>	Not reported

their participation was not quantified as percentages. The scoping review also confirmed in low-income countries the stigma, superstitions and social out-casting faced by families with children diagnosed with NDDs that live in communities that are deeply religious and hold strong cultural beliefs as contextual barriers to participation of fathers in the care of children with neuro-developmental conditions in some African contexts [51, 55]. Significantly, these studies provided insight into the participation of fathers with respect to mothers in the caregiving of their children diagnosed with NDD and the role siblings of such children can play also; and influential factors to participation.

#### Levels of participation of fathers and siblings in the rehabilitation of children with neuro-developmental delay

Participation of fathers and siblings is scantily reported. Quantified participation rates of fathers range from 45.5 to 91% showing variation from one setting to the other. One study included by the scoping review, Vadivelan et al. (2020) confirmed the outmoded behaviour of fathers from the past decades as men who would show limited interest, display physically punitive discipline methods and reduced participation in supporting their spouses in caregiving for their child with NDD [45]. Abusive and alcoholic husband were non-supportive and a source for stress to mothers due to the lack of participation by fathers.

This is in contrast to the 70-points score reported by Song, Chun, and Choi (2015), which assessed fathers' participation in parenting activities. In their study, a score of 70 points on the parenting participation scale indicated that, on average, fathers demonstrated a level of

involvement that was higher than moderate but not quite at the highest possible level of engagement. The scale, ranging from 0 to 100, was used to quantify the extent of fathers' involvement in daily parenting tasks, with higher scores reflecting more active participation [20]. This study examined mothers of disabled kindergarteners in Gwangju (in South Korea – High-income country), distributing 100 questionnaires randomly, 82 of which were fully completed and included in the study. Using a modified questionnaire, fathers' parenting participation was assessed with 30 Likert-scale questions. Parenting stress in mothers was measured with 35 questions. Results indicated fathers' greater-than-moderate participation in parenting, correlating with lower maternal stress levels. The study highlights the potential impact of fathers' involvement in reducing maternal stress among families with disabled children living with disability. It is also reported by Bagner (2013) that single mothers were more likely to drop out of rehabilitation programmes compared to two parent families [53]. This underscores the role of a father to the family with a child with NDD. In the high-income countries, at least seven studies from the USA ( $n=4$ ), Canada ( $n=1$ ), Australia ( $n=2$ ) showed fathers demonstrating greater participation in caregiving and support to their spouses. Among middle income countries, a study done in Brazil reported 65% participation of fathers in carrying babies on their lap and aiding locomotion and 74% participation in playing with children [43]. Joint mother and father participation was reported to be at 45.5% in the multicounty study [56]. This indicates a significant variation of participation of fathers from country to country, this potentially justifies that participation of fathers in child caring cannot be generalised.

Two studies [46, 47] reported on the participation of siblings in qualitative descriptions but none of the studies quantified the level of participation of siblings into specific percentages. Nonetheless, these two studies advocated for the inclusion of siblings in caregiving of children with neurological conditions as greater sibling warmth and lower sibling conflict were protective factors for children with Down syndrome, one of the causes of NDD [46]; and siblings can act as role models to their siblings diagnosed with CP and can assist in their intervention programmes [47]. While the participation of siblings has not been quantified in previous studies, it is essential to recognize their potential role in the caregiving process for children with cerebral palsy [57]. Dambi, Jelsma, and Mlambo (2015) acknowledge the presence of 3(6.5%) caregivers who were siblings of children with cerebral palsy [25]. This finding underscores the significance of siblings in providing care and support for their affected brothers or sisters. Despite the lack of quantification, the inclusion of sibling caregivers highlights the multifaceted nature of caregiving dynamics within families affected by

NDD. Understanding the extent of sibling involvement in caregiving is crucial for comprehensively assessing the familial support network and identifying potential facilitators and barriers to their participation. Therefore, future research should aim to quantify and explore the specific roles and contributions of siblings in the rehabilitation process, aligning with the objective of identifying facilitators and barriers to the participation of siblings in the care of children with NDD in specific contexts.

#### **Facilitators and barriers to the participation of fathers and siblings in the rehabilitation of children with neuro-developmental delay**

Two studies identified by our scoping review made poignant reference to facilitators for participation by fathers [29, 48] and one reported facilitators to participation of siblings [46], thus pointing to the areas that need further research. One study referred to the importance of sibling involvement in the care of children with NDD as they increase development of motor skills and encourage participation of their siblings with NDD during play [58]; and inclusion of siblings in the care of children with NDD is strongly being advocated for [46]. The study undertaken by Parkes et al. (2011) underscores the necessity for clinicians involved in physiotherapeutic rehabilitation of children to exercise caution in presuming parental stress levels solely on the basis of the severity of the child's motor impairment in NDD cases and consider the presence of other alternative factors in the family setup that can bring up counterintuitive outcomes [59]. Turbiville and Marquis (2001) is one early study which referred to family activities and collective planning as key facilitators for fathers' participation [42]. The article by Fisman et al. (2000) placed emphasis on the family harmony with greater sibling warmth and lower sibling conflict as key facilitators for their participation [46]. Also, the condition of the child can be a facilitator to better participation of fathers as fathers to children with Congenital Zika Syndrome (CZS) participates better than fathers of children with other similar conditions such as Cerebral palsy. This shows that CZS is less stigmatised compared to other conditions like CP. Hence, eliminating stigma facilitates participation of fathers in home rehabilitation programmes for the affected children [48].

Home-based therapy for children with NDD presents significant challenges in low-income countries. Factors such as low family support, limited resources, lack of knowledge and poor attitudes negatively impact participation and adherence to home-based therapy [50]. Studies from Africa and middle-income countries (Brazil, India) have highlighted the debilitating effects of poverty on families seeking rehabilitation services for children with NDD [44, 48]. Financial hardships, reported by health service providers in Uganda, hinder access to

adequate staffing and resources [60]. In contrast, fathers in Brazil have been observed to actively engage in the care of their children with the highest participation rates in providing practical and resource support to their children [48]. Similarly, studies from China demonstrate fathers' resilience in the face of financial challenges, with as high as 88.5% of respondents not giving up working for their children's well-being [52].

Other environmental barriers such as culture, superstition and religious beliefs to participation were significant for families in Africa compared to other continents. One specific study by Kyeremateng et al. (2019) revealed that in Ghana, children with NDD and medically diagnosed with hydrocephalus are described as 'nsuoba', meaning 'water children' [51]. Additionally, studies from Africa reveal the prevalence of superstitions and social stigma faced by families with children diagnosed with NDD, impacting their access to rehabilitation services [51, 55, 60]. This is well articulated by Olawale, Deih and Yadaar (2013) who stated that: 'Typically in the African society, conditions such as cerebral palsy are normally associated with witchcraft and sorcery. Most families perceive it as a punishment from "gods" for a wrong act committed by a family member, most especially the mother' [44]. These findings underscore the need to address socioeconomic factors and cultural beliefs to enhance the participation of fathers and siblings in the rehabilitation of children with NDD in low-income countries, especially in African contexts. Further, Tsomondo (2018) highlights the need for disability awareness programmes so as to mitigate the stigma associated with disability in low-income contexts [55].

Other barriers to participation identified by the scoping review were father's low level of education and low interest to gain knowledge on the NDD of their child [42, 49]. These are consistent with previous research findings on father participation in early childhood development programmes [61]. Fathers with limited education may encounter difficulties in comprehending and navigating the complexities associated with the condition of their child, potentially impeding their active engagement in rehabilitation programmes. Moreover, fathers lacking interest or awareness regarding their child's condition were likely to have limited participation. These findings emphasize the significance of targeted interventions aimed at educating and involving fathers in the rehabilitation process, thereby improving outcomes for children with NDD. Future research and clinical practice should prioritize addressing these barriers to promote increased father and sibling involvement and support in the care and rehabilitation of children with NDD.



### Implications for future research and clinical practice

The scarcity of quantitative data on the involvement of fathers and siblings in rehabilitation programmes for children with neuro-developmental conditions, particularly in low-income countries, highlights the need for more quantitative studies in these contexts. While our review identified significant barriers and facilitators to father participation, there is a paucity of research on sibling involvement. Further studies focusing on siblings are warranted to enhance our understanding of their role in rehabilitation programmes. The observed variations in father and sibling participation, as well as barriers and facilitators to their participation, may stem from economic and cultural disparities across different countries. Future research should explore geographical contextual differences to address specific barriers and facilitators that may be more pronounced in certain regions. By analysing these findings, we can propose targeted interventions, policy adjustments, or program enhancements that address identified challenges and promote more effective family engagement in the rehabilitation process. We recommend a novel approach by rehabilitation professionals that actively engages fathers and siblings in home rehabilitation programmes. This approach has the potential to reduce stress and physical burden on mothers while improving developmental outcomes for children with NDD.

### Strengths and limitations

This scoping review utilised studies from peer reviewed journals from different electronic databases and grey literature. Despite yielding few articles, the grey literature contributed to our findings by providing unique and context-specific insights that were not captured in the peer-reviewed sources. Qualitative, quantitative and mixed method studies from both high and low-income countries were included in the scoping review from six continents. The authors have experience with paediatric rehabilitation of neuro-developmental delay impairments from lower-middle-income country (PM and JM), upper-middle-income country (SM) and high-income country (LC). This potentially enhanced the authors' understanding of the aim of this scoping review. An experienced librarian guided the authors, enabling extensive literature search from different electronic databases. Despite the strength of our study of the inclusion of global literature, this scoping review had its limitation to publicly accessible articles and only those in English because of limited financial resources for translating studies published in other languages, we could have potentially missed other relevant articles in other languages; quality of the included studies was not assessed as per protocol of scoping reviews, unlike in systematic reviews where quality of articles is assessed [39, 62, 63]. Despite that, the authors

made an attempt to report on the included list of study research designs and sample sizes, to give the reader a general appreciation of the rigour of the studies included.

### Conclusion

This scoping review revealed a dearth of literature on the participation of fathers and siblings in home rehabilitation programmes for children with NDD. It highlighted the disparity in caregiving roles between genders, with fathers being less involved compared to mothers. Economic hardships in low-income countries and cultural beliefs exacerbate stigma and social exclusion of families with NDD children, further limiting father participation. Conversely, siblings exhibit early acceptance and willingness to engage in activities to support their siblings with NDD. Understanding the level of involvement, barriers and facilitators in low-income contexts is crucial for policy and practice. Future research should explore participation dynamics in diverse settings, particularly in Africa, to address the knowledge gap identified in predominantly high-income countries studies. This review contributes to a global understanding of rehabilitation programme participation, guiding further research and informing interventions worldwide. Rehabilitation professionals should adopt a novel approach that involves fathers and siblings in home rehabilitation programmes. This approach has the potential to reduce stress and physical strain on mothers while enhancing developmental outcomes for children with NDD.

### Abbreviations

CP	Cerebral Palsy
HCPs	Healthcare professionals
LIC	Low-income country
LMICs	Low-and Middle-Income Countries
MeSH	Medical Subject Headings
MIC	Middle-income country
NDD	Neuro-Developmental Delay
PCC	Population/Concept/Context
PRISMA-ScR	Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews
PsycINFO	Psychological Information Database
PUBMED	Public/Publisher MEDLINE
SCOPUS	Scientific Citation Indexing

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12887-024-05119-w>.

Supplementary Material 1  
Supplementary Material 2  
Supplementary Material 3  
Supplementary Material 4

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#### Author contributions

PM conceptualised the study with the guidance SM, LC and JD. PM searched the data bases and drafted the manuscript. SM, LC, JD reviewed the draft manuscripts and guided all the revisions. All authors have read and approved the manuscript.

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#### Data availability

The datasets generated and/or analysed during the current scoping review are available within this research paper and its additional material files. All relevant data sources used in this study are publicly accessible, and citations have been provided accordingly.

#### Declaration

##### Ethics approval and consent to participate

This scoping review involves secondary analysis of articles available in the public domain hence it does not require ethical approval [64]. However, for reassurance that there are no complications in this research and to meet requirements for certain publishers that foreseeably require ethical clearance number, this research was ethically reviewed and approved by the University of Cape Town Human Research Ethics Committee (Approval number: 482/2023) and by the Medical Research Council of Zimbabwe (Approval number: MRCZ/A/3100). Sources of data (both grey and published literature) were cited appropriately. Consent was not applicable as the study did not involve human subjects.

##### Consent for publication

Not applicable.

##### Competing interests

The authors declare no competing interests.

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