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Measures used to quantify participation in childhood disability and their alignment with the family of Participation-Related Constructs: a systematic review

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ABBREVIATIONS

fPRC Family of Participation-Related Constructs

ICF International Classification of Functioning, Disability and Health

AIM We aimed to identify measures used to assess the participation of children with disabilities and to map the measures' content to the family of Participation-Related Constructs (fPRC) to inform future research and practice.

METHOD Six databases were searched to identify measures used to assess participation in health, psychology, and education research. Included studies involved children aged 0 to 18 years with a permanent impairment or developmental disability and reported use of a quantitative measure of participation. A second search sought relevant literature about each identified measure, including published manuals, to allow a comprehensive understanding of the measure. Measurement constructs of frequently reported measures were then mapped to the fPRC.

RESULTS From an initial yield of 32 767 articles, 578 reported one or more of 118 participation measures. Of these, 51 measures were reported in more than one article (our criterion) and were therefore eligible for mapping to the fPRC. Twenty-one measures quantified aspects of participation attendance, 10 quantified aspects of involvement as discrete scales, and four quantified attendance and involvement in a manner that could not be separated.

INTERPRETATION Improved understanding of participation and its related constructs is developing rapidly; thoughtful selection of measures in research is critical to further our knowledge base.

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[Boxed text to appear on page 2]

What this paper adds

- Our understanding of participation is evolving and expanding rapidly.
- Instruments selected to measure participation do not always align with emerging concepts.
- Matching research aims to a chosen measure's content will improve understanding of participation.
- Opportunities exist to develop validated participation measures, especially self-reported measures of involvement.

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Review

[Main text]

A systematic review of participation outcomes after health, education, or psychological interventions for children with impairments drew two main conclusions: first, that the available research was characterized by conceptual inconsistencies related to authors' ideas about 'participation' as an outcome; and second, that interventions aimed at enhancing participation, and the measures used to evaluate participation, typically targeted a broad range of participation-related constructs.¹

After a content analysis of research notions about participation, the family of Participation-Related Constructs (fPRC) was developed and published.^{2,3} This model provides a nuanced understanding of participation and can be used to describe the relationships among what we see as important intrinsic and extrinsic factors that can both be influenced by past participation and influence future participation.

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Within the fPRC, participation is defined by two constructs: attendance and involvement. Attendance is defined as ‘being there’ and is measured as frequency and/or the range or diversity of activities in which an individual takes part.¹⁻³ Involvement is defined as the experience of participation while attending, and includes elements of motivation, persistence, affect, and perhaps social connection.¹⁻³ This definition of participation is the construct of interest in this study. Within the fPRC, participation is operationally defined in a way that is conceptually separate from the life situations in which participation occurs, and the skills used within the activity; thus the concept can be applied to any activity or setting and with individuals of any level of competence. This conceptualization of participation is therefore distinct from those of prior authors who have proposed that the Activities and Participation chapters of the International Classification of Functioning, Disability and Health (ICF) can be divided such that some types of life situation constitute ‘activities’ (e.g. self-care tasks) and others ‘participation’ (e.g. interpersonal relationships).⁴

In the fPRC, concepts related to, but not synonymous with, participation include activity competence, sense of self, and preferences. Activity competence is defined as the ability to execute the activity being undertaken according to an expected standard and is often assessed in relation to the level of skill or independence an individual exhibits in performing the activity. Sense of self is defined as the intrapersonal factors related to self-efficacy, confidence, satisfaction, and self-determination. Preferences are defined as the interests or activities that are meaningful to, or valued by, that person.¹⁻³ In addition, the fPRC describes the context and broader environment in which participation occurs as being integral to the transactional processes that occur over time.^{2,3}

In the past, researchers reviewing participation measures have mapped measurement tools to the domains of the ICF⁵ or have used the definition of participation as described by the ICF to identify measures of participation. Although the ICF provides a helpful framework to understand the influence of various factors on an individual, the World Health Organization’s definition of participation provides little detail about the construct, making it difficult to use as a guide to select appropriate and specific measurement tools without a more refined parsing of the concepts behind it.

Our previous systematic reviews^{1,2} identified that sometimes measures of competence, preference, or aspects related to sense of self were used as if they were measures of participation. The fPRC highlights the two essential elements of participation as attendance and involvement.² Other related constructs in the framework, such as competence or preference, may be targets for intervention or for expected change after participation.

Measures chosen for research and practice must be chosen according to the purpose of measurement and the definition of the construct of interest. The definitions of the two key aspects of participation described in the fPRC, and the related concepts, may allow researchers, health professionals, and educators to distinguish the various factors and choose outcome measures that are targeted more precisely towards the chosen variable(s) and based upon clear and specific research questions.

Our current thinking about childhood disability has been strongly influenced by the World Health Organization's framework for health, as captured in the ICF.⁵ The concepts that underlie the element of participation in people's lives continue to evolve (as discussed in Imms et al.),³ and research is being undertaken both to assess interventions that promote participation and to understand how the best interventions work. It is therefore essential that the clinical and research fields have reliable and valid outcome measures to capture the important concepts that underpin participation, and are specific to the research questions being explored.

The overall aim of this systematic review was to provide a mechanism for informing measurement choice in participation-focused research and practice, guided by the fPRC. In this review, the focus was on participation and the intrinsic (that is, the within-person) rather than extrinsic (that is, context or environment) constructs within the framework. The specific objectives were (1) to identify measures that have been utilized to quantify participation for children with disability in previous literature; and (2) to map the content of the identified measures to the elements included in the fPRC framework. We chose to undertake this mapping exercise using the fPRC for three reasons: (1) there is evidence of early uptake of the conceptual framework in research (for example Albrecht and Khetani,⁶ Bonney et al.,⁷ and Chiarello),⁸ suggesting that others are finding the framework useful; (2) the process of mapping, if possible to do, may provide evidence in support of the way the constructs are presented in the framework; and (3) having clarity in how to think about measurement selection in relation to participation-based research may assist future research and practice endeavours.

METHOD

Search strategy and selection criteria

Search one

This review used a two-stage search approach. The first structured database search was undertaken in December 2015 using Medline, Web of Science, CINAHL, PsycINFO, ERIC

and Scopus. The primary purpose was to identify measures utilized to quantify participation in health, psychology, and education literature. The search included terms related to the population of children with disability, the concept of participation and assessment or measurement. The terms were developed on the basis of previous experience with systematic literature reviews on this topic^{1,2} and related literature. Where possible, Medical Subject Headings were chosen for inclusion (and, where appropriate, exploded) in the searches related to the population and participation. The publication of the ICF in 2001 (World Health Organization)⁵ resulted in a shift in the conceptualization of participation; therefore this search was limited to articles published during 2001 or later. Examples of the complete search strategies (including Boolean operators) for Medical Subject Headings (Medline) and non-Medical Subject Headings (Scopus) databases are provided in Appendix S1 (online supporting information).

The inclusion criteria for the first database search are shown in Table I. Studies were included if they presented data from participants aged 0 to 18 years with a permanent impairment or developmental disability according to the definition proposed by the UK's Equality and Human Rights Commission: '... a physical or mental impairment ... (that) has a substantial and long-term adverse effect on (the) ability to carry out normal day-to-day activities'⁹ (page 7).

Studies were included if they reported using a quantitative measure (that is, assigned a numeric score) to assess participation as described by the developers of the measurement tool. Measures were also included if the author described using a particular measurement tool to quantify participation even if it was not originally designed to quantify participation. We also included studies that used terms such as engagement or inclusion to ensure potentially relevant literature was not excluded.

Articles that were published in languages other than English were excluded, except where the details of the population and the participation measure were explicitly listed in an English abstract. Articles reporting the anticipated protocol for a study were included if they met the inclusion criteria for population and measurement. Studies that utilized measures of the environment (without a discrete measure of an individual's participation) were excluded because the focus of this review was on measures of the individual.

Although systematic reviews were excluded, the reference lists of relevant reviews were examined to identify pertinent articles that may have been missed during the database search. Similarly, generalized discussion papers that simply provided an author's opinion on

a topic and summarized other studies were excluded. Given the purpose of this study, qualitative studies were excluded, as were conference proceedings and theses.

Search two

A second search, undertaken in 2017, was conducted after the measures used to quantify participation were identified. At this time, the references cited in the studies identified in the first search, the names of the measures, and their original authors were searched using Google and relevant databases; e-mails were also sent to the authors of the measure when the information could not be accessed through the Internet. This search was not a structured database search and as such there were no associated inclusion and exclusion criteria.

During the second search, relevant literature (e.g. the primary introductory paper for the measures identified), a copy of the measure itself, and any available manuals were sourced to enable a thorough review of the developers' intention for the measure, the underlying construct, relevant definitions, items included, and the scale(s) of the measure. This information was sought to enable a detailed understanding of the measure, to support mapping it to the constructs of the fPRC.

Article screening and data extraction

One person from the research team (BA) performed the initial database search and screened the titles for potentially relevant articles. After screening of the titles, the articles were exported to Covidence Systematic Review Software (Veritas Health Innovation, Melbourne, Australia) to facilitate title/abstract and full text screening. The same researcher (BA), with one of two research assistants (KM, NA), independently screened the titles/abstracts and full texts deemed to meet the study selection criteria. Any discrepancies related to inclusion of studies were resolved through discussion, and if consensus could not be reached another independent researcher was available to review the study (CI).

Customized data extraction tools were designed to enable consistent independent data reporting for each of the searches. During the first search, sample details were extracted related to the sample size, age, diagnosis, sex, as well as the chosen participation measure. Data extraction was completed independently by BA, as well as one of two research assistants (KM, NA), and any discrepancies rectified by discussion and mutual agreement.

Two criteria were used to select measures for inclusion in the construct mapping process. First, the measure had to be available for use, and therefore needed to be named and have a supporting reference in the studies identified in this review to allow it to be located.

Second, because of the large number of identified published and referenced measures, the research team chose to map only those that were reported to have been used to assess participation in at least two articles, using any research design, identified in the first search. From our previous work on this topic it appeared that in the past researchers frequently chose 'popular' measures of participation when designing a study. Although this meant that the psychometric properties of the measure had often been investigated, it did not ensure that the measure would adequately capture or quantify the construct of interest.^{1,2} By choosing to review and map the more frequently reported measures, the results from this review pertain specifically to the measures that have often been used in the past.

Quality assessment

This systematic review did not aim to summarize the effectiveness of interventions or the risk of bias of studies. Given the focus on identification of measurement tools, no formal assessments of quality or risk of bias of the included studies were performed.

Data analysis

The primary analysis component of this review was performed by two members of the research team with different clinical backgrounds (BA is a physiotherapist; CI is an occupational therapist) and involved mapping the frequently identified measures to the fPRC. Owing to the complexity of this process, the mapping was completed by discussion and mutual agreement.

The fPRC framework and associated construct definitions³ were continually referenced when reviewing the materials related to each individual measure during each step of the process. The definitions for each construct in the fPRC are provided in Table II. The process of mapping each measure to the fPRC was based on the suggestions by Darzins et al.¹⁰ Assessment of the scale properties of each measure included reviewing (1) the purpose of the measure and definitions of constructs provided by the measure's authors in either the original article introducing the measure or as described on the measure document (e.g. survey form) or the associated manual; (2) each of the items/questions included in the measure and the phrasing used to describe the items; and (3) the scale(s) of the items (or response categories), the scoring system, and consideration of which construct was quantified by the final score.

Where possible, content from all three elements was used to inform decisions about how to map the measure to the fPRC, with a focus on the data encapsulated in the final score for the measure.

RESULTS

Of the 32 767 articles identified in the initial database search, 3673 underwent abstract screening and 578 were found to meet the inclusion criteria (Fig. 1). Of these, 61 articles utilized a measure that the authors had developed specifically for their study and 130 reported on counts of frequencies of attendance or engagement behaviour rather than reporting on a named/published tool. These measures did not meet the selection criteria for the mapping component of this review and are therefore not discussed further. Some articles reported using their own study-specific measure or counts of engagement as well as a previously published tool; in these instances, the article was included but only the published measure was extracted and considered for mapping to the fPRC. Of the measurement tools reported as being used to quantify participation, 118 were named and had previously been published, and therefore were considered for mapping against the fPRC. Table III shows the most frequently utilized participation measures, along with the number of articles that reported using the measure. The complete list of identified measures is provided in Appendix S2 (online supporting information). Not all measures in Appendix S2 were mapped to the fPRC because they did not meet our inclusion criteria for mapping: they are, however, provided for completeness of results. This means that the list may include measures that were never intended to assess participation by the original developer, and the reader is encouraged to carefully consider what participation-related construct is tapped by these measures using a mapping method similar to that used in this study.

Of the 118 identified measures, 51 were reported in at least two articles and were therefore included in the second search. Despite extensive searches and e-mails to the original authors, information required to map the measures (either the measures themselves and/or the scoring guidelines) was not available for nine of the identified measures: the Individual Child Engagement Record,¹¹ the Social Participation Questionnaire,¹² the Child/Adolescent Exercise Log,¹³ the questionnaire for the evaluation of limitations in activity and restrictions on participation (Attention-Deficit-Hyperactivity Disorder [ADHD] Parent and Teacher Version¹⁴ and TDAH [Spanish abbreviation for ADHD]),¹⁵ the Juvenile Arthritis Foot Disability Index,¹⁶ the Modified Student Participation Questionnaire,¹⁷ the Participation in Physical Activity and Sedentary Behavior Questionnaire,¹⁸ the Pediatric Community

Participation Questionnaire,¹⁹ and the Engagement Check.²⁰ Therefore, 42 measures were mapped to the fPRC.

The identified studies ($n=394$) that featured the published participation measures included samples of children of all ages, ranging from less than 12 months to 27 years, with sample sizes from 1 to 145 180. The most common diagnoses of included children were cerebral palsy (105 articles focused solely on children with this condition, plus other reports that combined children with cerebral palsy with other conditions), autism spectrum disorders (37 articles solely focused on this condition), and developmental coordination disorder (31 articles). Owing to the number of articles identified for data extraction, it is not possible to present the characteristics for each of these 394 studies; this information is available by e-mail from the research team.

The constructs addressed by the most frequently reported measures are shown in Table IV. According to the definitions associated with the fPRC, 29 of 42 mapped measures quantified participation attendance and/or involvement. Of these, 21 measures (or a subscale within a tool) quantified aspects of attendance and 10 measures quantified aspects of involvement. Four additional measures considered the constructs of attendance, involvement, and activity competence and resulted in composite scores, making it difficult to separate intertwined constructs for allocation to one particular construct of the fPRC. Two measures, the Canadian Occupational Performance Measure²¹ and the Goal Attainment Scale,²² were considered ‘empty’ scales, in that the item assessed is defined by the participant. Because of this individualization, the measurement constructs of these instruments can vary depending on the occupational performance problems (Canadian Occupational Performance Measure) or goals Goal Attainment Scale described by the user/participant. For example, depending on the client’s focus, a Canadian Occupational Performance Measure item might be mapped to activity competence (e.g. tying my shoe laces correctly), involvement (e.g. playing in the soccer team), or attendance (e.g. going to school each day of the week). Thus, the performance and satisfaction scales may or may not measure participation constructs.

For the participation-related constructs, 21 measures quantified aspects of activity competence; three measures were mapped to the construct of sense of self; two to preferences; and 11 were mapped to the context/environment component of the fPRC. One measure, the Child Behavior Checklist,²³ did not map to any of the constructs contained in the fPRC.

DISCUSSION

This systematic review identified 118 published measures used to quantify different aspects of participation for children with disabilities, 51 of which were used in at least two articles. The measures that were most frequently reported in the literature were the Children's Assessment of Participation and Enjoyment and its companion measure the Preferences for Activities of Children²⁴ ($n=87$ articles), the Assessment of Life Habits^{25,26} ($n=26$), the Child and Family Follow-Up Survey which included the Child and Adolescent Scale of Participation²⁷ ($n=22$), and School Function Assessment²⁸ ($n=22$). According to the definitions associated with the fPRC, most of the identified measures (or a subscale within the tool) quantified aspects of attendance. Activity competence was the most frequently quantified participation-related construct.

Since the introduction of the ICF⁵ in 2001, the understanding of participation has evolved, and now, according to the fPRC, participation has been defined as having two essential constructs: attendance and involvement.² The results from this review showed that nearly half of the identified measures that were mapped to the fPRC ($n=21$) focused on the measurement of attendance, and included observable aspects of the participation construct, such as diversity (the range of activities performed) or the frequency with which activities were performed. One explanation for the focus on attendance rather than involvement may be that it is easier to quantify objective outcomes related to 'being there' than to measure the more subjective 'in-the-moment' experience of participation (involvement). Attendance is a requirement for being able to experience involvement; however, attending an activity does not guarantee that someone will be involved in it. For this reason, the involvement construct is embedded within the attendance dimension.^{2,3} Although it may assist with how we understand participation, embedding the two constructs poses measurement challenges: should the measure of involvement always include an attendance element, or be distinct? Measurement principles would argue that separation of constructs is likely to result in more reliable measures with less chance that different raters will respond to different elements within a combined construct. With the evolution of our understanding of participation there is a need for the measures of participation to correspond to our conceptual thinking of the construct. Further, when choosing a measure from those that exist, researchers need to consider whether their interests lie in understanding or changing participation as an outcome (thus it is the dependent variable) or in using participation as an intervention to influence one or more of the participation-related constructs (therefore making it the independent variable). In addition, whether the focus is on participation attendance, participation involvement,

and/or the particular life situation or goals that are in focus, along with the quality of the instrument's psychometric properties, will all influence measurement choices.

Of the 42 measures available for mapping, only 10 had discrete subsections that quantified involvement, of which six quantified the enjoyment aspect of involvement (the Enjoyment score of the Children's Assessment of Participation and Enjoyment,²⁴ the Enjoyment score of the Children Participation Questionnaire,²⁹ the Enjoyment subsection of the Leisure Activity Questionnaire^{30,31} – adapted version,³² part one of the Child Engagement in Daily Life measure,³³ the Enjoyment score of the Participation in Childhood Occupations Questionnaire,³⁴ and the Children's Leisure Assessment Scale).³⁵ Although enjoyment of an activity may be important, it is a somewhat limited expression of involvement and assumes that participation always has to be an enjoyable experience. Other affective experiences, such as anger or sadness, may also be an important part of the involvement experience, for example in an argument or while attending a funeral, and these experiences need also to be considered in measurement. Four measures assessed involvement more holistically, for example through questions such as 'how involved was your child when completing this activity?' (the involvement score of the Participation and Environment Measures – Child and Youth version³⁶ and Young Children's version;³⁷ the Knox Preschool Play Scale;^{38,39} the child engagement level score of the Child Participation in Family Activities;⁴⁰ and the time spent involved in free play as measured by the Play Assessment for Group Settings).⁴¹ Although it might be considered more appropriate to choose these four measures when assessing this construct, the concept of involvement is complex, so it is possible that respondents (parents, observers, and teachers/professionals) may have difficulties answering the questions in a reliable or valid way when completing the tools.

The 10 involvement measures identified in this review are generally retrospectively rated, often by proxy respondents (parents, teachers, or therapists). Aspects of involvement such as enjoyment, sense of belonging, or deep focus on a task are personal subjective experiences and therefore may be difficult to capture when completed by someone other than the person who is involved in the task at hand. The lack of self-report or self-ratings is therefore a limitation in this suite of measures. Children from 4 to 5 years of age can make reliable self-ratings of perceptions if items and scales are adapted appropriately.^{42,43} One focus of future measurement development should be to identify methods that support the measures' validity and utility with children who have a wide range of abilities, including those with cognitive and communication impairments. Kramer et al. provide an exemplar in

this field in their development of measures in collaboration with young people with developmental disabilities.⁴⁴

Two observational tools were found that measure involvement in the 'here and now' within a relevant context (Knox Preschool Play Scale^{38,39} and the Play Assessment for Group Settings);⁴¹ however, neither of these are completed by the child. This may mean that these tools quantify aspects of involvement other than the personal experience of participation at the time of the activity. Further research is needed to better understand the relationship between self-rated and proxy-rated involvement as well as between rating involvement in the 'here and now' situation and retrospective ratings. When rating involvement retrospectively it may be that several aspects of involvement, such as sense of belonging and sense of the need to participate (i.e. importance or preference), may be captured because it is difficult to separate them in our thinking.

One alternative to self- and proxy ratings is to use counts of observed or self-reported behaviour as measures of involvement. Such counts may have limited value, however, as they are not completed by the person performing the activity and therefore may not capture some of the important personal and subjective aspects of the involvement construct. Nonetheless, when assessing very young children or those with limited functional communication, observation and proxy ratings are currently the only methods that we have to quantify and understand involvement. The involvement construct is complex and does require further investigation and characterization, both in relation to what constitutes involvement and the best methods of measurement. In this review, the 130 studies that utilized observational methods of behaviour (potentially including involvement) were identified but excluded from analysis and reporting; instead we plan to review and report on these measures separately.

Activity competence was the most commonly mapped participation-related construct in this review, being measured as a discrete or combined variable in 23 measures (or 25 if the Canadian Occupational Performance Measure and Goal Attainment Scale are included in this count). In part, this may be explained by the definition of participation and instructions provided within the ICF manual⁵ about how to measure participation; in particular, the description of 'level of difficulty' the individual has in doing a task. It could also be explained by the prevalence of measures available to assess activity competence, compared with participation, and the potential for researchers to select tools from what is available and easy to implement. It is also possible that researchers and practitioners have held the view that activity competence is a prerequisite for participation or that independence is synonymous with being able to participate. However, with the development of our

understanding of participation for people with impairments, this view is not supported by current thinking; it should be possible for all individuals to attend and be involved—how this is achieved may vary, but whether it is achieved should not.

The intent and methods of a systematic review directly influence the results. We aimed to compare the fPRC theoretical definition of participation with the operational definitions – or how people practically understand this construct – as evidenced by the measures chosen in previous research. By focusing on the measures previously utilized to quantify participation (regardless of whether they were originally designed for this purpose), our search strategy identified measures that mapped to constructs other than those described by the fPRC. For example, the Child Behavior Checklist²³ is intended to identify emotional and behavioural problems in children, so we do not recommend it to quantify participation. Presentation of the results of the mapping exercise may help to guide further discussion about (1) why particular measures were chosen in the past to quantify participation when not designed for this purpose; (2) which measures meet the definition of participation attendance/involvement as conceptualized by our research group; and (3) which participation (and related) constructs are without quantitative measures.

This review was designed to identify measures previously used to assess participation, and to determine which constructs of the fPRC framework were addressed by the identified measures. Only a few measures were mapped to the constructs ‘sense of self’ and ‘preferences’, which was due to the design of our review and its focus specifically on measures of participation rather than preference or aspects such as self-confidence. The measures identified in this article will, therefore, only represent a subset of those available. What this review does highlight, though, is that those constructs, along with activity competence, have in the past been used to quantify participation. The very common use of measures of activity competence in past participation research ($n=21$ instruments) perhaps highlights the lack of distinction between activity and participation as described by the ICF. However, these participation-related constructs are not synonymous with participation. Future research and practice can use the fPRC framework and methods described in this review to support searching for, and selecting, appropriate measures of the participation-related constructs, depending on the purpose of the research or practice question.

Preferences may be a way to operationalize a person’s history within the personal factors component of the ICF framework.⁵ Preferences are a function of earlier experiences, interests, and knowledge that can influence what people prioritize in their interaction with the environment.⁴⁵ Because preference measures primarily gather information about what types

of activity may lead to low or high participation for a certain individual, measuring preferences within participation-based research may be important.

Mapping for this review was based on the most frequently reported measures; therefore new or less frequently reported measures may exist that quantify different aspects of participation. A review of the results of the first search identified three measures that were published after 2014 but only reported once in the literature and therefore not formally mapped to the fPRC: the Children's Assessment of Participation with Hands,⁴⁶ the Functioning Scale of the Disability Evaluation System-Child Section II,⁴⁷ and the Matrix for the Assessment of Activities and Participation.⁴⁸

The measures mapped in this review were categorized according to the specific constructs of the fPRC framework; therefore this review provides information about what aspects of participation need to be represented when developing future measures of participation, if one is going to apply the fPRC concepts. The review cannot, however, provide information about the relationships between constructs. To obtain that information we would need representative measures and empirical data for all the constructs and tools to combine them. One such tool could be graphical modelling, as proposed by Kalisch et al.,⁴⁹ who have illustrated the utility of graphical modelling to understand how different components and chapters within the ICF can be conceptually linked and how empirical relations can be investigated.

Strengths and limitations

The comprehensive search undertaken in this review aimed to identify all measures of participation used in health, psychology, or educational research and used with children who have disabilities. There may be additional measures that have potential to be used to assess participation, such as the Student Engagement Instrument,⁵⁰ but because they have not been utilized with children with disabilities they were not identified in this search. Owing to the very large number of potential tools identified (118 named measures, 61 study-specific measures, 130 studies that included counts of observed behaviour), this review focused only on the named measures used more than once. Because the search focused on measures used to quantify participation, it was not an exhaustive search for measures of the participation-related constructs; therefore it is quite likely that there may be measures of these constructs that have not been identified.

The strength of the review in this respect lies in the methods used to 'map' measures according to a new way of considering 'participation' (the fPRC framework). This method

can be used by others when considering the measures reported in Appendix S2 that were not mapped (and which may or may not map to participation attendance and involvement) and when designing studies to help determine the most appropriate outcome measure to include.

Mapping the measures was particularly challenging when the measure included multiple constructs in the definition and scale properties. For example, part I of the School Function Assessment²⁸ included aspects of attendance, involvement, and activity competence in the instructions, item phrasing and the scale itself, but resulted in one composite score. Therefore, it was not possible to determine where in the fPRC part I of the School Function Assessment should best be mapped. It is also possible that having varying constructs within one scale may impact the consistency with which the measures are completed and scores are assigned to children's participation. Evidence about consistency can be found in reliability data of the measures reported, which was not examined in this review.

This review did not assess the reliability or validity of any included measures or subscales. While all measures identified in the review have previously been used with children with disability, any practitioner or researcher selecting measures must consider the validity of the tool for the specific population of interest and the reliability of the measure for its intended purpose. Our understanding of the participation construct has evolved and more recently developed measures, not identified by this review, may be more aligned to this new thinking.

CONCLUSIONS

The aim of using the fPRC to map the existing measures that have been used to assess participation was to identify which measures tapped the two primary dimensions – attendance and/or involvement – and which tapped related constructs. The clarity of these distinctions has been missing in the literature on participation, and therefore was the focus of this review. In any clinical or research endeavour, it is important to be specific and clear about the underlying (research) question. The question serves as the basis for choosing (or at times creating) the appropriate measure(s) for the concepts under consideration. Ensuring clarity around the research question is often a challenge and a source of frustration both to clinicians and to researchers; but the more precisely we can define (and then measure) the variables of interest, the more likely we are to move the field forward. As participation attendance and/or involvement may be investigated as either a process or an outcome, this places additional emphasis on the need for clarity.

One implication of the work our team has undertaken, through reviewing the literature related to participation,¹⁻³ is that there is evidence that ‘participation’ as a concept continues to evolve. This may be similar to the evolution of our understanding of ‘quality of life’ and the many ways to measure the variations of that concept. The best of the existing tools may have been valid for the original construct(s) they were created to measure. However, because participation is a ‘moving target’, measures need to be updated as our understanding changes. Consequently, as participation is ‘parsed’ and unravelled there must be a parallel development of tools to explore the concepts that are now seen to underlie it. There are currently tools that can capture this emerging set of details of participation, but there is also likely to be a need for the creation of further concept-specific measures in the future, in particular of the involvement construct.

Individuals wishing to communicate about participation outcomes or participation patterns in the childhood-onset disability field have a responsibility to ensure clarity of language. This means considering which participation-related constructs are in focus and selecting measures that are validly able to capture those constructs.

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SUPPORTING INFORMATION

The following additional material may be found online.

Appendix S1: Examples of search strategies.

Appendix S2: Complete list of measures used by prior authors to assess participation (as identified in search one) and their frequency of reporting.

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Table I: Selection criteria for search one

Include	Exclude
<p>Participants aged 0–18y of age (or mean/median within this age range); with a permanent impairment/developmental disability according to the definition proposed by the Equality and Human Rights Commission.</p> <p>Quantitative measures designed to assess participation or closely related constructs—whether expressed this way by the study researcher or as defined by the author(s) who designed the measure. To be considered for mapping to the family of Participation-Related Constructs the identified article needed to provide the name of the measurement tool and/or the original reference.</p> <p>As long as the measurement tool was clearly named, manuscript abstracts were considered even if the main body of the manuscript was written in a language other than English.</p> <p>Articles introducing a study protocol—as they are likely to describe and justify the outcome measures and variables.</p>	<p>Measures of the environment that do not include a distinct measure of participation for individuals, for example Craig Hospital Inventory of Environmental Factors.</p> <p>Classification systems designed to categorize children into groups rather than quantify change over time.</p> <p>Articles or abstracts not published in peer review journals; articles or abstracts published in languages other than English; conference proceedings; theses.</p> <p>Systematic reviews, although reference lists of pertinent articles were reviewed to ensure all relevant publications were located.</p> <p>Generalized discussion papers of participation measures that do not present new evidence from a scientific study.</p>

Qualitative studies—because our focus is on a quantitative outcome measures.

Studies focused on the participation of parents of children with disabilities (or their siblings) were excluded.

Table II: Definitions of the constructs as described by the family of Participation-Related Constructs^{2,3}

Concept	Definition
Attendance	‘Being there’ and measured as frequency of attending, and/or the range or diversity of activities in which an individual takes part.
Involvement	The experience of participation while attending that may include elements of engagement, motivation, persistence, social connection, and affect.
Activity competence	The ability to execute the activity being undertaken according to an expected standard; includes cognitive, physical, and affective skills and abilities. Activity competence can be measured as capacity, capability, or performed skill.
Sense of self	Intrapersonal factors related to confidence, satisfaction, self-esteem, and self-determination.
Preferences	The interests or activities that hold meaning or are valued.
Context	Setting for activity participation that includes people, place, activity, objects, and time. ^a
Environment	Broad, objective social and physical structures in which we live.
Other	Refers to other concepts that are discussed/considered as part of the measure aside from those listed here.

This table has been directly modified from the work of Imms et al.³ ^aFrom Batorowicz et al.⁵¹

Table III: Measures (utilized in two or more studies to quantify participation) and their frequency of reporting identified during search one

Participation measure and original reference	<i>n</i>	Reported versions
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Children's Assessment of Participation and Enjoyment (and Preferences for Activities of Children [PAC]) ²⁴	87	Adapted ×2; Greek ×1; Spanish ×4; Swedish ×2; Preschool version (adapted) ×1; included the PAC ×4
Assessment of Life Habits ^{25,26}	26	French ×1
Child and Family Follow-up Survey (CFFS), the Child and Adolescent Scale of Participation (CASP), and Child and Adolescent Scale of Environment (CASE) ²⁷	22	CASP used on own ×19 (Chinese ×2; Modified ×1); CFFS in entirety used ×2; CASE used ×1 (therefore not mapped)
School Function Assessment ²⁸	22	Chinese ×2; Swedish ×1
Canadian Occupational Performance Measure ²¹	15	
Test of Playfulness ⁵²	14	Original ×13; Version 3 ×1
Pediatric Evaluation of Disability Inventory ^{53,54}	13	Chinese ×1; Dutch ×1
Participation and Environment Measures for Children and Youth (PEM-CY) ³⁶ and Young Children's Participation and Environment Measure (YC-PEM) ³⁷	12	PEM-CY ×10; YC-PEM ×2
International Classification of Functioning Disability and Health checklist, using numeric qualifiers ⁵	9	
Lifestyle Assessment Questionnaire ⁵⁵	9	General ×6; cerebral palsy ×3
Goal Attainment Scale ²²	8	
Children helping out: responsibilities, expectations and supports ⁵⁶	7	
Children Participation Questionnaire ²⁹	7	
Assessment of Preschool Children's Participation ⁵⁷	6	Dutch ×1
Participation Questionnaire ⁵⁸	6	
Vineland Adaptive Behavior Scale ⁵⁹	6	Chinese ×1; Version II ×1
Physical activity monitors: duration and percentage of time spent performing dynamic activities ^a	5	Actigraph ×2; Actiwatch ×2; Activ8 ×1
Focus on the Outcomes of Communication Under Six ⁶⁰	5	
Frequency of Participation Questionnaire ⁶¹	5	Korean ×1
Knox Preschool Play Scale ^{38,39}	5	Revised ×4; (French ×1); Original ×1
Leisure Activity Questionnaire ^{30,31} – adapted version ³²	5	
National Survey of School Environments ^{62,63}	5	Original ×1; Adapted ×2; Swedish ×2
Pediatric Outcomes Data Collection Instrument ⁶⁴	5	
Seven-Day Leisure-Time Diary ⁶⁵ – adapted version ⁶⁶	5	
Activities Scale for Kids ⁶⁷	4	

Activity Card Sort ⁶⁸	4	Paediatric ×2; Preschool ×1; Child ×1
Child Behavior Checklist ²³	4	Only activities competence scale ×1 and parent form ×1
Individual Child Engagement Record ¹¹	4	Revised ×3; Original ×1
Participation and Activity Limitation Survey ⁶⁹	4	
Social Participation Questionnaire ¹²	4	
Child Engagement in Daily Life measure ³³	3	
Participation in Childhood Occupations Questionnaire ³⁴	3	
Physical Activity Questionnaire ⁷⁰	3	Adolescents ×2; Older children ×1
Play Observation Scale ⁷¹	3	
Activity Questionnaire for Adults and Adolescents ⁷²	2	
Child Behavior Rating Scale ⁷³	2	Korean ×1; Modified ×1
Child Participation in Family Activities ⁴⁰	2	
Children Leisure Activity Study Survey/Children's Leisure Assessment Scale ³⁵	2	
Child/Adolescent Exercise Log ¹³	2	
Questionnaire for the evaluation of limitations in activity and restrictions on participation (Attention-Deficit-Hyperactivity Disorder [ADHD] Parent and Teacher Version ¹⁴ and TDAH [Spanish abbreviation for ADHD]) ¹⁵	2	
Classroom Participation Questionnaire - Revised ^{74,75}	2	German ×1
Home and Community Activities Scale ⁷⁶	2	
Juvenile Arthritis Foot Disability Index ¹⁶	2	
Modified Student Participation Questionnaire ¹⁷	2	
Participation in Physical Activity and Sedentary Behavior Questionnaire ¹⁸	2	
Pediatric Community Participation Questionnaire ¹⁹	2	
Play Assessment for Group Settings ⁴¹	2	
Playground Observation of Peer Engagement ⁷⁷	2	
Questionnaire of Young People's Participation ⁷⁸	2	
The Engagement Check ²⁰	2	
World Health Organization Disability Assessment Schedule ⁷⁹	2	Arabic ×1, specifically last domain: participation in society

The complete version of this table is provided in Appendix S2. Some articles reported using more than one measure of participation. ^aReferences not provided for activity monitors; instead, the type of activity monitor is provided in the versions column. *n*, Number of articles that reported using the measure.

Table IV: Constructs quantified by identified measures ($n=42$) when mapped to the family of Participation-Related Constructs (fPRC)^{2,3}

Measure	Participation constructs		Participation-related constructs				Other
	Attendance	Involvement	Activity competence	Sense of self	Preferences	Context/environment	
Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children (PAC) ²⁴	Diversity score (number of activities completed); intensity score (relative frequency)	Enjoyment score (of the activities performed)			Preferences score (PAC)	With whom score; where score	
Assessment of Life Habits ^{25,26}			Items 1A (level of accomplishment) and 1B (type of assistance)	Item 2 (level of satisfaction)			
Child and Family Follow-up Survey including the Child and Adolescent Scale of Participation (CASP), Child and Adolescent Factors Inventory (CAFI), and Child and Adolescent Scale of Environment (CASE) ²⁷	Section 2 (CASP – 'being there and doing with others in a social context') ^a		Section 1; Section 3A (CAFI)			Section 3B (CASE)	
School Function Assessment (SFA) ²⁸	Part I: participation in same context as his/her peers; 'including physical and social-emotional aspects of participation'; and need for supervision ^b		Part III (functional performance of activities)			Part II adaptations raw score; Part II assistance raw score	
Canadian Occupational Performance Measure ²¹	?	?	?	?	?		

Measure	Participation constructs		Participation-related constructs				Other
	Attendance	Involvement	Activity competence	Sense of self	Preferences	Context/environment	
Test of playfulness ⁵²	Playfulness measure score is a combination of attendance (extent), involvement (intensity), and activity competence (skill)						
Pediatric Evaluation of Disability Inventory ^{53,54}			Part I functional skills scores ('capability to perform an item')			Part II caregiver assistance scores ('amount of assistance required to complete'); Part III modification scores	
Participation and Environment Measures for Children and Youth ³⁶	Frequency score ('how often')	Involvement score ('how involved')				Environmental helpfulness score ('help or make it harder'); environmental resources score ('available and/or adequate')	
Young Children's Participation and Environment Measure ³⁷							
Lifestyle Assessment Questionnaire ⁵⁵			Communication score; mobility score; self-care score				Domestic life score; inter-person community score
Goal Attainment Scale ²²	?	?	?				
Children helping out: responsibilities, expectations and supports ⁵⁶			Assistance score				
Children Participation Questionnaire ²⁹	Diversity score; Intensity score	Enjoyment score	Independence score				Parent satisfaction score ^c
Assessment of Preschool Children's Participation ⁵⁷	Diversity subscore; Intensity subscore; total score						

Measure	Participation constructs		Participation-related constructs				Other
	Attendance	Involvement	Activity competence	Sense of self	Preferences	Context/environment	
Participation Questionnaire ⁵⁸	Free active play score; frequency score of active organized sport						
Vineland Adaptive Behavior Scale ⁵⁹			All subscores ('frequency of independent performance')				
Activity monitor - duration and percentage of time spent performing dynamic activities ^d	Time spent active						Physiological measures of fitness and activity
Focus on the Outcomes of Communication Under Six ⁶⁰			Subtotal Part 1 (body function/capacity items); subtotal part 2 (performance items); total score				
Frequency of Participation Questionnaire ⁶¹	All activity item scores						
Knox Preschool Play Scale – Revised (Participation Dimension) ^{38,39}		Type, cooperation, humour, and language categories; total participation score					

Measure	Participation constructs		Participation-related constructs				Other
	Attendance	Involvement	Activity competence	Sense of self	Preferences	Context/environment	
Leisure Activity Questionnaire ^{30,31} Adapted Version ^{32,e}	Number of sessions per week (activities away from home and activities performed at home)	Enjoyment subsection (scale: low to high; activities away from home and activities performed at home)	Skill checklist subsection (scale: low to high; activities away from home)			Leisure companion checklist ('frequency spent with companions'; scale: never, hardly ever, sometimes, often, not applicable)	
National Survey of School Environments ^{62,63}	Actual participation score (scale: no participation to full participation) ^f					School environment checklist (broad objective [environment] and subjective [context] components); availability of activities score (scale: no participation to full participation)	
Pediatric Outcomes Data Collection Instrument ⁶⁴			Upper extremity and physical function core scale; transfers and basic mobility core scale; sports and physical functioning core scale	Happiness core scale			Pain/comfort core scale; global function core scale; expectations core scale
Seven-Day Leisure-Time Diary ⁶⁵ – adapted version ^{66e}	Activity type (minutes per day)					Who was there and where subsection	Activity intensity subsection (scale: rest, light, moderate, vigorous)

Measure	Participation constructs		Participation-related constructs				Other
	Attendance	Involvement	Activity competence	Sense of self	Preferences	Context/environment	
Activities Scale for Kids (ASK) ⁶⁷	ASK performance score		ASK capability score				
Activity Card Sort ⁶⁸	Current activity score; occupational profile of activities done		'Want to do' score				
International Classification of Functioning, Disability and Health (ICF) checklist using numeric qualifiers ⁵			ICF activity limitations (capacity using no assistive devices) and participation restrictions (performance: extent of participation restriction) subscale				
Participation and Activity Limitation Survey ⁶⁹	Filter questions: section A (e.g. 'Does a physical condition or mental condition or health problem reduce the amount or the kind of activity X can do at home?')		Section-based filter questions				Questions related to equipment
Child Engagement in Daily Life measure ³³	Part one (frequency of family and recreational activities)	Part one (enjoyment of family and recreational activities)	Part two (consistency of performance of self-care activities)				Questions related to cost

Measure	Participation constructs		Participation-related constructs				Other
	Attendance	Involvement	Activity competence	Sense of self	Preferences	Context/environment	
Participation in Childhood Occupations Questionnaire ³⁴	Frequency of performance score	Degree of enjoyment score	Degree of difficulty in performance score; Characteristics of performance score				
Physical Activity Questionnaire for adolescents (PAQ-A) ⁷⁰	PAQ-A score (scale reflective of frequency of attendance/ performance)						
Play Observation Scale ⁷¹			Social and cognitive play skills				
Activity Questionnaire for Adults and Adolescents ⁷²	Time spent in sedentary, light, moderate, and vigorous activities						Physiological score (based on metabolic equivalents)
Child Behavior Rating Scale ⁷³			Behavioural competence score				
Child Participation in Family Activities ⁴⁰	Average frequency score	Average child engagement level	Amount of assistance			Who else attended	
Children Leisure Activity Study Survey/Children's Leisure Assessment Scale ³⁵	Variety score; frequency score	Preference score (based on enjoyment levels)				Sociability score	

Measure	Participation constructs		Participation-related constructs			Other
	Attendance	Involvement	Activity competence	Sense of self	Preferences	
Classroom Participation Questionnaire - Revised ^{74,75}				Positive and negative affect subscales ('resulting from communication')		Understanding teacher and student subscales (understanding is 'knowing the meaning of what is said or asked')
Home and Community Activities Scale ⁷⁶	All activity scores					
Play Assessment for Group Settings ⁴¹		Time spent involved in free play (in the natural context) ^g				
Playground Observation of Peer Engagement ⁷⁷			Developmental appropriateness score			
Questionnaire of Young People's Participation ⁷⁸	All domain scores					
World Health Organization Disability Assessment Schedule (WHODAS 2.0) ⁷⁹			Domain scores and overall WHODAS 2.0 score (score based on the amount of difficulty to complete a task/activity)			

The constructs of environment and context were combined for this table because of the similarities between the two constructs and the limited number of measures mapped to the environment construct. The Child Behavior Checklist²³ was identified during the first search and mapped to the fPRC. During the mapping process the Child Behavior Checklist did not align to any of the constructs described in the fPRC and therefore has been removed from this table. A question mark refers to generic scales that are dependent on the goals described by the user; therefore it is not possible to map these measures. ^aThe CASP scale made it difficult to determine which participation construct it quantified. Scale: not applicable; unable; very limited; somewhat limited; age expected. ^bThe SFA had overlapping constructs in the scale for part I, making it difficult to assign to only one construct. ^cThis subscore refers to the parent's satisfaction of their child's participation not a proxy rating of a child's perceived satisfaction. ^dReferences not provided for activity monitors; instead, the type of activity monitor is provided in Table III (versions column). ^eThe adapted Leisure Activity Questionnaire and Seven-Day Leisure-Time Survey were essentially checklists: while they allow estimation of the time spent performing an activity, there was no calculated overall score. ^fThe description of the actual participation scale in this measure was ambiguous: it was difficult to determine whether scoring was based on attendance or the degree of involvement. ^gAlthough the scoring of this measure relates to the relative amount of time spent performing an activity, the items describe aspects of involvement; therefore it was mapped to the involvement construct rather than attendance. The grey shaded areas indicate measures that were mapped to participation-related constructs. Some measures included composite scores that included aspects of attendance and/or involvement as well as activity competence; these measures have also been highlighted in grey to ensure the reader understands that the composite scores may not necessarily solely describe aspects of attendance or involvement.

Figure 1: Article yield and number of included measures during mapping process (search one). ^aSome articles included a combination of published and study-specific measures as well as counts of attendance or engagement. fPRC, family of Participation-Related Constructs.

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Figure 1