

# Clinimetric properties of participation measures for 5- to 13-year-old children with cerebral palsy: a systematic review

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This study systematically reviewed the validity, reliability, sensitivity to change, and clinical utility of measurements of participation for children with cerebral palsy. Sixteen measures were identified and seven met the inclusion criteria of having 30% content measuring participation, for use with children aged 5 to 13 years with physical disability, and were condition specific. The Children's Assessment of Participation and Enjoyment (CAPE) assessed participation in leisure and recreation, while the School Function Assessment (SFA) and School Outcome Measure addressed participation in the school environment. The Assessment of Life Habits for Children (LIFE-H) measured participation in home, school, and community life, and the Children Helping Out: Responsibilities and Expectations assessed children's participation in household duties. The Canadian Occupational Performance Measure (COPM) and Goal Attainment Scaling (GAS) were individualized tools used to evaluate goal achievement. Results showed most instruments had adequate reliability and validity. The COPM and GAS were the only measures that reported adequate responsiveness to detect clinically significant change. Limited data are currently available to determine the responsiveness of the CAPE, LIFE-H, and SFA. A combination of assessments is required to capture participation of children in home, school, and community environments.

Effective assessment of outcomes in children with chronic health conditions is important to monitor their progress, evaluate interventions, and guide health policy.<sup>1,2</sup> The *International Classification of Functioning, Disability and Health (ICF)* provides a multidimensional perspective for measuring and documenting health outcomes.<sup>3</sup> It considers participation as involvement within a life situation and the ultimate outcome for individuals with disabling conditions. To achieve changes in participation, aspects of body structure and function, activity engagement, and environmental and personal factors are considered. According to this broad definition, children's participation needs to be considered across school, home, and community environments.

The emergence of new interventions for children with chronic disabling conditions, such as cerebral palsy (CP), necessitates comprehensive evaluation of outcomes across all domains of the ICF. This approach expands measurement outcomes from the traditional impairment level to include activity performance and societal participation.<sup>4</sup> The ICF model requires the consideration of a child's development within the context of the environment.<sup>4-6</sup> In a previous review of activity and participation measures for children with CP, there was a focus on child or family self-report tools.<sup>7</sup> A total of seven generic and condition-specific instruments were identified as objective measures of activity, functional performance, and participation for children aged 5 to 15 years that could be administered by postal questionnaire. All selected measures demonstrated sound psychometric properties; three, however, were measures of health status or generic measures of

See end of paper for list of abbreviations.

quality of life (QOL; i.e. the Child Health Questionnaire, Child Health and Illness Profile – Child Edition, and the Paediatric Quality of Life Inventory) and one that was a measure of health-related quality of life (HRQL). The content of selected measures was described using the ICF, although no distinction was made between ‘activity’ and ‘participation’.<sup>7</sup> Acceptance of the ICF as a classification system and framework to guide clinical practice and research requires each dimension be defined and measured.<sup>8</sup>

The aim of the current review was to identify systematically and evaluate assessments specifically targeting the area of participation for children with CP aged 5 to 13 years. Review of identified assessments would then guide the selection of participation measures for a clinical trial to evaluate upper limb rehabilitation in children with CP. Selection of appropriate measures would also have a broader application for clinicians and researchers wishing to measure participation of children with CP.

## Method

### SEARCH STRATEGY

Papers were initially identified by searches of computerized bibliographic databases: Medline (1966–July 2005), CINAHL (1982–July 2005), EMBASE (1988–July 2005), and PsycINFO (1985–July 2005). The search used the medical subject heading (MeSH) terms and text words for ‘cerebral palsy’ and ‘physical disability’. These were combined with search terms to limit the findings to the target age group. MeSH terms and text word for ‘outcome assessment’ and terms specific to aspects of ‘participation’ (school or home or community) were used to focus search results on assessment measures. Identified assessments were used as terms for a further search of electronic databases.

### INCLUSION/EXCLUSION CRITERIA

For the purposes of this review, definitions of activity and participation were adopted from the ICF.<sup>3</sup> Activity was defined as ‘a specific task or action undertaken by an individual’.<sup>3</sup> Participation was defined as ‘involvement within a life situation’.<sup>3</sup> Categories of participation outlined in the ICF included personal maintenance, mobility, information exchange, social relationships, home life, education, work and employment, economic life, and community, social, and civic life.<sup>3</sup>

The a priori inclusion criteria were: (1) any assessment that measures participation, including those which evaluate a combination of activity, participation, and environmental factors; (2) at least 30% of the assessment components should address participation. Current knowledge suggested that there would be a limited number of instruments that exclusively measured participation, therefore, this criterion was established; (3) suitable for use with children aged from 5 to 13 years with physical disability; and (4) condition-specific assessments for children with CP or generic assessments that could be used to compare children with CP with a reference population of children with typical development.

Assessments were excluded if they were: (1) not published in English, or (2) primarily assessed impairments, quality of life, HRQL, communication, or interpersonal relationships.

The titles and abstracts were screened by the first author. One key paper for each measure was selected on the basis that adequate detail was provided for determination of inclusion. Selected papers were reviewed for inclusion independently by the three authors. Assessments were included

following agreement by all raters and conflicting viewpoints were discussed until consensus was reached. Assessment manuals were sourced and a further electronic search was undertaken for included measures.

### DATA EXTRACTION AND QUALITY ASSESSMENT

A data extraction sheet adapted from the Outcome Measures Rating Form<sup>9</sup> allowed for the comparison of clinimetric properties of each assessment on the basis of clinical utility, validity, reliability, and responsiveness. Descriptive information was extracted for each assessment to identify the target population, purpose, domains/content of assessment, and number of scales/items.

Clinical utility was rated according to interpretability (meaningfulness of scores), feasibility (ease of administration, scoring, and interpretation), and how acceptable the measure was to assessors and respondents (utility vs burden). Time of administration, availability of a manual and clarity of instructions, format of assessment, and requirement for further assessor training were reviewed. The development of a test manual and normative sampling was also considered.

An assessment was considered valid if it measured what it purported to measure.<sup>10</sup> Content, construct, and criterion validity were considered. For the purposes of this review, ‘reliability’ measures the degree to which an item, scale, or assessment achieves the same score with variations in time of administration, location, populations, or different testers.<sup>9</sup> Internal consistency (degree to which items test the same characteristic), interrater reliability, intrarater reliability, and test–retest reliability were reviewed.<sup>10</sup> Measures of 0.80 or above were considered excellent, 0.60 to 0.79 as adequate, and less than 0.60 were considered poor for reported intraclass correlation coefficients.<sup>9</sup> Measures of 0.41 to 0.60 were considered moderate, 0.61 to 0.80 substantial, and 0.81 to 1.00 almost perfect for reported kappa statistics.<sup>11</sup>

## Results

Sixteen assessments were identified using the defined search strategies and papers for each measure were selected for review.<sup>12–27</sup> Three independent raters determined that seven assessments met the predefined inclusion criteria. Two raters were occupational therapists and one was a physical therapist, with considerable experience (18–33y) with outcome assessment and research with children with CP. The selected measures were the Children’s Assessment of Participation and Enjoyment (CAPE),<sup>18</sup> the School Function Assessment (SFA),<sup>21</sup> the School Outcome Measure (SOM),<sup>16</sup> Children Helping Out: Responsibilities, Expectations, and Supports (CHORES),<sup>20</sup> Assessment of Life Habits (LIFE-H),<sup>17</sup> the Canadian Occupational Performance Measure (COPM),<sup>22</sup> and Goal Attainment Scaling (GAS).<sup>25</sup> Discrepancy between raters occurred for the CHORES and SOM as to whether they met the inclusion criteria. Differences in the interpretation of content being activity or participation were resolved resulting in the inclusion of these two measures. Nine assessments were excluded. These are summarized in Table I with reasons for their exclusion outlined.

Descriptive data for each included assessment is summarized in Table II. Two assessments, the SFA and SOM, evaluated participation in the educational setting. The CAPE and LIFE-H evaluated participation in the community. The CHORES specifically dealt with participation in domestic tasks. Content of the

LIFE-H most comprehensively covered the areas of participation described by the ICF but did not include aspects of learning and applying knowledge. The COPM and GAS could potentially capture any aspect of participation outlined in the ICF, dependent on the goals identified by the client/team.

#### CLINICAL UTILITY

The majority of assessments used an interview format, most required proxy reporting, frequently by a parent or carer. The CAPE also had the option of the child completing the assessment while the COPM could involve a child (over 8y) in the goal setting process. School personnel completed the

**Table I: Assessments that did not meet inclusion criteria**

<i>Assessment</i>	<i>Reason for exclusion</i>	
1. Pediatric Motor Activity Log <sup>13</sup>	Primarily measures activity	
2. Pediatric Evaluation of Disability Inventory <sup>23</sup>		
3. Pediatric Outcomes Data Collection Instrument <sup>27</sup>		
4. Activities Scale for Kids <sup>12</sup>		
5. ABILHAND-Kids <sup>26</sup>		
6. Lifestyle Assessment Questionnaire <sup>15</sup>		Did not meet age criteria
7. Perceived Efficacy and Goal Setting System <sup>14</sup>		
8. Community Activities Questionnaire <sup>19</sup>		
9. Child and Adolescent Scale of Participation <sup>24</sup>		Designed specifically for children with acquired brain injuries

**Table II: Characteristics of selected participation measures**

<i>Assessment</i>	<i>Age range</i>	<i>Purpose</i>	<i>Content</i>	<i>Scales/Items</i>
CAPE <sup>18</sup> (children with/without disabilities)	6–21y	Participation	Activities outside mandated school tasks (h, i)	1. Two domains (a) Informal (40 items) (b) Formal (15 items) 2. Five dimensions assessed for each domain: diversity, intensity, with whom, where, enjoyment, preference 3. Five activity types: recreational, active physical, social, skill-based, self-improvement
SFA <sup>40</sup>	Elementary/primary school (5–12y) (PI and/or SI)	Activity/participation	School-related functional tasks (a, b, c, d, e, g, h, i)	Three parts: 1. Participation (six major school activity settings) 2. Task supports (adaptations and assistance for physical and cognitive/behavioural tasks) 3. Activity performance (physical and cognitive/behavioural tasks)
SOM <sup>16</sup>	School (3–18y)	Activity/participation	School-related functional tasks (a, b, c, d, e, g, h, i)	Minimal data set 1. Self-care and mobility (12 items) 2. Assuming student role (12 items for preschool and primary and 8 for high school) 3. Expressing learning (4 items for non-verbal students, 3 for verbal students)
CHORES <sup>20</sup> (children with/without disabilities)	6–11 years	Activity/participation	(e, f)	Two subscales 1. Self-care (12 items) 2. Family care (21 items) Two items parent rating: importance and satisfaction
LIFE-H (1.0) <sup>41</sup>	5–13 years with disabilities	Activity/participation	(b–i)	Long form: 248 items. Short form: 58 items 11 life habit categories. Each item rated on level of accomplishment, type of assistance, and level of satisfaction
COPM <sup>42</sup>	All ages and disabilities	Activity/participation	Dependent on goals set (a–i)	Client rating (1–10) of performance and satisfaction for identified occupations (self-care, productivity, and leisure)
GAS <sup>43</sup>	All ages and disabilities	Activity/participation	Dependent on goals set (a–i)	Individual goals expressed on 5-point scale. Each goal weighted according to importance

Domains of assessment related to International Classification of Functioning, Disability and Health:<sup>3</sup> (a) learning and applying knowledge; (b) general tasks and demands; (c) communication; (d) mobility; (e) self-care; (f) domestic life; (g) interpersonal interaction and relationships; (h) major life areas; and (i) community/social and civic life. CAPE, Children's Assessment of Participation and Enjoyment; SFA, School Function Assessment; SOM, School Outcome Measure; Life-H, Assessment of LIFE-Habits for Children; COPM, Canadian Occupational Performance Measure; GAS, Goal Attainment Scaling; PI, physical impairment; SI, sensory impairment.

SFA, school-based therapists the SOM, and parents/caregivers completed the remaining assessments.

Administration time varied considerably across assessments and was unclear for the CHORES, LIFE-H, and GAS. The greatest burden of administration time appeared to be for the SFA (approximately 1½ to 2 hours for initial assessment). Three assessments were available commercially, the CAPE, SFA, and COPM; however, access to the LIFE-H manual was unclear. Two assessments were research versions only, the CHORES and SOM. Details on the scoring and interpretability of each measure are detailed in Table III.

**VALIDITY**

Evidence for validity of each assessment is summarized in Table IV. Content validity was supported for all measures using expert panels. The SFA and CAPE used factor analysis and principal components analysis respectively to support validity. Children with CP were included as part of the sample for validation of both measures. A number of validity studies have been carried out with the COPM, predominantly with adult populations.<sup>22</sup> Initial validity testing for both the CHORES and

SOM were reported during test construction and involved children with CP in the respective samples. The GAS had variable results for validity reported.<sup>28</sup>

**RELIABILITY AND RESPONSIVENESS**

Details on assessment reliability and responsiveness are in Table V. Internal consistency was reported for three assessments, the LIFE-H, SFA, and the CAPE. There was no evidence for internal consistency for the SOM, CHORES, COPM, or GAS. High test–retest reliability was reported for the CHORES and SFA, and adequate to high reliability was reported for the CAPE, COPM, and LIFE-H. There was no evidence for test–retest reliability for the SOM or GAS. Adequate to excellent interrater reliability was reported for most assessments but intrarater reliability was reported for GAS and LIFE-H only. The COPM and GAS were the only measures that reported good responsiveness for detecting meaningful clinical change.

**Discussion**

Evaluation of outcomes for children with CP is a challenge for health professionals and researchers. The ICF provides a

**Table III: Clinical utility of selected participation measures**

<i>Assessment*</i>	<i>Format of administration</i>	<i>Administration time (min)</i>	<i>Assessor training</i>	<i>Scoring</i>	<i>Interpretability</i>
CAPE <sup>18</sup>	Self or interviewer Individual/group	30–45	NR	Ratings of each activity type: Diversity: 0 or 1; Intensity: 1–7; With whom: 1–5; Where: 1–6; Enjoyment: 1–5	Diversity 0–55 (55 highest) Overall scores and domain scores (formal/informal). Activity type scores
SFA <sup>40</sup>	Interview	90–120	Familiar with child in school setting	Part 1: 6-point scale Part 2: 4-point scale for assistance and adaptations Part 3: 4-point scale	CS generated for each of three parts and SEM and CIs for each criterion score
SOM <sup>16</sup>	Judgement-based therapist rating	10–15	NR	Self-care/mobility: 6-point scale for assistance required Expressing learning and assuming student role: 4-point scale related to performance	Not clear how results are summarized
CHORES <sup>20</sup>	Parent/caregiver questionnaire	NS	NR	Each task: yes/no Level of assistance: 7-point Likert scale Parent rating of importance/satisfaction: 6-point Likert scale	Performance score (max 33), self-care subscale (0–12), family care subscale (0–21). Weighted percentage: higher scores=greater independence
LIFE-H (1.0) <sup>41</sup>	Self or interviewer questionnaire	NS	NS	Accomplishment: Five levels Assistance: Four types Level of satisfaction: 5-point scale	Weighted score for each category and total (0–10) higher scores=greater accomplishment
COPM <sup>42</sup>	Semi-structured interview	30–45	NR	Identified problems rated on scale of 1–10 for importance Top five rated for performance and satisfaction from 1–10	Performance score (summed performance ratings/number of goals). Satisfaction score derived as above
GAS <sup>43</sup>	Semi-structured interview	NS	NR Recommend considerable clinician experience <sup>28,44</sup>	Individual goals written with 5-point scale 0=expected outcome +2=outcome exceeds expectations –2=less than expected outcome Each goal weighted <sup>45</sup>	T-score calculated=weighted average of scores Score of 50=goals on average attained; scores > 50=better than expected outcome <sup>45</sup>

\*See Table II for definitions. NS, not specified; NR, not required; CS, criterion scores; SEM, standard error of measurement; CI, confidence interval.

useful framework for both evaluation and intervention, considering aspects of body structure and function, activity, participation, and the influence of contextual factors on each domain. Enhanced participation can be viewed as the ultimate outcome for rehabilitation. Therefore, measurement of participation is necessary to evaluate the effectiveness of rehabilitation programmes. This review identified seven measures that captured aspects of participation for children with physical

disability. No one measure covered the full breadth of participation outlined in the ICF, necessitating the use of multiple assessments to measure this broad perspective.

Assessment burden is a consideration for both clinicians and researchers. Administration time was unclear for the LIFE-H, GAS, and CHORES. While detail of administration time was available for the remaining assessments, further time requirements for scoring and interpretation were not

**Table IV: Evidence for validity of selected participation measures**

Assessment*	Content	Construct (Convergent/Divergent)	Criterion
CAPE <sup>18</sup>	Comprehensive literature review; review by expert panel (research team members) Pilot work (children with and without disabilities)	Principal components analyses indicated five factors Small-to-moderate correlations between CAPE participation intensity and environmental, family, and child variables <sup>39</sup> CAPE activity types differentiate among different groups <sup>39</sup>	
SFA <sup>40</sup>	Panel of 30 experts, 40 service providers Factor analysis: physical and cognitive/behavioural function factors Two factors moderately correlated: 0.60 and 0.51 on two samples <sup>46</sup>	High correlation with VABS – classroom edn ( $r=0.56-0.72$ ) <sup>47</sup> KGM: Sign differences between children without disabilities, CP, and LD ( $p<0.005$ ) <sup>47</sup> KGM: High correct classification of students with autism and LD, but less accurate for TBI <sup>21</sup>	
SOM <sup>16</sup>	Panel of 42 therapists		
CHORES <sup>20</sup>	Parents confirmed tasks relevant to home life	Moderate-to-low correlation with CRI: $r=0.38$ ( $p<0.05$ )	
LIFE-H (1.0) <sup>41</sup>	Reviewed by expert panel; adapted from adult version Expert panel of parents, therapists, and researchers		Strong associations between domains of PEDI, WeeFIM, and LIFE-H. Self-care $r=0.83-0.94$ . Education/recreation: 0.79–0.91
COPM <sup>42</sup>	Identifies problems with occupational performance in self-care, productivity, and leisure <sup>48</sup>	Reported for adults with orthopaedic/stroke, schizophrenia, sub-acute nursing, haemophilia, pain, RA, neuro. rehab. <sup>22</sup> Compared with gross and fine motor function and disability <sup>49</sup> Significantly correlated to SPSQ, RNLI, and PPL <sup>50</sup> Significant correlation between performance score and physical domain SIP <sup>51</sup>	More successful in identifying problems vs open-ended questions <sup>52</sup> Moderate concurrence of problems identified on COPM vs spontaneously <sup>50</sup>
GAS <sup>43</sup>	10 paediatric therapists rated goals for infants: supported validity, did not differ significantly between therapists <sup>53</sup> Supported when goals are appropriate, reasonable, relevant, and complete <sup>28</sup> Reliant on clinical skills of goal setters; <sup>28,31,53,54,55</sup> Goals for children with CP supported by expert panel of experienced PTs. <sup>56</sup> Score biased by assessment and expected outcomes; <sup>28</sup> underestimation at baseline or level of expected improvement. <sup>53,54,57,58</sup> Floor effect, unable to record deterioration, <sup>28</sup> no procedure to assign weights; <sup>44</sup> difficulties weighting goals <sup>31,32</sup>		Low correlation between Peabody Gross Motor Scales and GAS T-scores <sup>53,58,59</sup> 12 studies correlate GAS with consumer satisfaction. Significance low to moderate positive correlations – non significant correlations <sup>28</sup>

\*See Table II for definitions. VABS, Vineland Adaptive Behaviour Scale; KGM, known groups method; CP, cerebral palsy; LD, learning disabilities (mental retardation); TBI, traumatic brain injury; CRI, Child Routine Inventory; PEDI, Pediatric Evaluation of Disability Inventory; WeeFIM, Functional Independence Measure for Children; RA, rheumatoid arthritis; neuro rehab, neurological rehabilitation; SPSQ, Satisfaction with Performance Scaled Questionnaire; RNLI, Reintegration to Normal Living Index; PPL, Perceived Problems List; SIP, Sickness Impact Profile; PTs, physiotherapists.

reported. The SFA presented with a significant burden for users, with an initial assessment time of 1½ to 2 hours. The three parts of this measure could be administered separately; however, no detail regarding the time requirements for each was available. The GAS presented with a different type of assessment burden. Inherent bias in the process of goal setting and evaluation has led to recommendations that the person setting and evaluating the goals should be independent from the intervention process.<sup>28</sup> This has implications for using the GAS in the clinical setting. A recent study comparing the GAS with COPM for paediatric rehabilitation research indicated that time required for scale development, retest, and scoring took, on average, 1 hour for the GAS compared with 24 minutes for the COPM.<sup>29</sup> The SOM contains a minimal dataset, specifically designed to collect data for population-based programmes over time. It has the minimum number of items possible necessary to capture the required information. While administration time is, therefore, minimal for the SOM, its primary purpose appears to be evaluation of school-based therapy at a programme level rather than at the individual level.

The CAPE was designed to measure directly children's participation in non-mandated school activities. It does not attempt to measure a child's competency or the degree of assistance they might need in activities, but provides a direct measure of what the child actually does. In contrast, the LIFE-H and CHORES both quantify the child's level of accomplishment in tasks and the amount of assistance required. The SFA participation section also directly measures participation, while the task supports and activity performance sections assess accomplishment and assistance. While the COPM was included as a potential measure of participation, it directs clients to identify areas of difficulty in the domains of productivity, leisure, and self-care. This may focus goal-setting more on activities rather than participation. In contrast, the GAS does not provide a similar framework, potentially allowing a greater variety of issues to be identified.

The psychometric properties of validity and reliability were reported for all assessments. The SFA and CAPE were both validated on large cohorts. The SFA Tryout Edition sampled 266 students with a variety of disabling conditions (physical, cognitive, emotional/behavioural, and communication). The CAPE

**Table V: Evidence for reliability of selected participation measures**

Assessment*	Internal consistency (Cronbach's coefficient alpha)	Test-retest	Intrarater (ICCs)	Interrater (ICCs)	Responsiveness
CAPE <sup>18</sup>	Formal domain: 0.35–0.42 Informal domain: 0.76–0.77 Activity types: 0.30–0.62	OP: 0.64–0.86 Diversity: 0.67–0.77 Intensity: 0.72–0.81 Enjoyment: 0.12–0.73	NA	Interviewer vs self-admin: Intensity: 0.82–0.99. Enjoyment: 0.47–0.78	NA
SFA <sup>40</sup>	Scales: 0.92–0.98	0.80–0.99	NA	Teachers vs OT: Participation: 0.70 Task supports: 0.68 Performance: 0.73 <sup>21</sup>	Change in participation/ resource requirement scores. Not in mobility task areas. <sup>54</sup> No change in mean CS for children receiving CE <sup>60</sup>
SOM <sup>16</sup>	NA	NA	NA	K: 0.73–0.96	NA
CHORES <sup>20</sup>	NA	0.88–0.92	NA	NA	NA
LIFE-H (1.0) <sup>41</sup>	DA: 0.97 SR: 0.90 Categories: 0.73–0.90 except IR (0.40)	TS for SF: 0.67 TS for LF: 0.73	DA: 0.82–0.96 SR: >0.90 except IR 0.64	0.70–0.91 (except IR: 0.62)	NA
COPM <sup>42</sup>	NA	0.76–0.89 <sup>61,62</sup>	NA	NA	Five studies supported responsiveness <sup>22</sup> 33 articles where COPM used as research outcome measure (12 paediatric studies) <sup>22</sup>
GAS <sup>43</sup>	NA	NA	0.96 <sup>56</sup>	0.51–0.95 <sup>28</sup> Investigator with: 1. Independent PT: 0.96 <sup>56</sup> 2. CCW: 0.79 <sup>56</sup> 3. TT: 0.6 <sup>54</sup> 0.98 <sup>56</sup>	Changes in goals for children with CP <sup>63</sup> and infants with motor delay <sup>53</sup> More responsive than behavioural objectives <sup>56</sup>

\*See Table II for definitions. ICCs, intraclass correlation coefficients; OP, overall participation; NA, not available; self-admin, self-administered; OT, occupational therapist; CS, criterion score; CE, conductive education; K, weighted kappa; DA, daily activities; TS, total score; SF, short form; SR, social roles; LF, long form; IR, interpersonal relationships; CP, cerebral palsy; PT, physiotherapist; CCW, childcare worker; TT, treating therapist.

was validated on 427 children and youths with physical disabilities (51% with CP), while the LIFE-H sampled 48 children with CP. The CHORES was validated on a small convenience sample size of 32 parents of school-aged children. Nineteen parents had children without disabilities and 13 had children with physical, learning, or behavioural disabilities. Due to the small sample size, generalization to other groups is limited. Similarly, the SOM was validated on a small sample of 42 therapists who worked in a school setting with children of wide ranging diagnoses. Both the CHORES and SOM remain in research form and further validation and reliability investigations are necessary. Issues of validity and reliability for the GAS have been reported widely with concerns raised regarding the appropriateness of goals set, potential bias in both the goal setting and evaluation process, subjectivity of weighting goals, and the generation of the *T*-score.<sup>30–32</sup> Nevertheless, the GAS and the COPM were the only two measures reviewed that had demonstrated ability to capture clinically important change and had been used as outcome measures.<sup>55,57–61</sup> The two studies reporting responsiveness of the SFA yielded conflicting evidence. However, sample sizes were very small and results should be viewed with caution.

Despite the recent emergence of a small number of measures of participation, formal evaluation of this construct in recent clinical trials for children with CP has not occurred.<sup>13,33–35</sup> There may be a number of reasons for this. First, the construct of participation itself is multidimensional and dependent on a range of child, family, and environmental factors.<sup>36</sup> Intervention targeting only one aspect, for example, physical functioning, may, therefore, have only limited impact on overall participation. Second, the measures themselves, apart from the COPM and GAS, have limited data available to suggest that they would be adequately sensitive to detect minimal clinically significant change. This is a vital consideration in the measurement of outcomes in clinical research.

There are several potential limitations with the current review. There may have been further measures of participation not published in English that were excluded. Five assessments were excluded on the basis of primarily measuring activity, which included not having at least 30% of the content assessing participation.<sup>12,13,23,26,27</sup> Three of these assessments, the Pediatric Evaluation of Disability Inventory, Activities Scale for Kids, and Pediatric Outcomes Data Collection Instrument contained some items that were regarded as measuring participation. Many assessments predate the ICF, and, therefore, do not reflect the conceptual framework classifying function and disability. An item-by-item analysis was, therefore, required to determine how items within an assessment could be described according to the ICF framework. The results of this analysis were influenced by the definitions of activity and participation adopted for the review. The World Health Organization has suggested that it is difficult to differentiate between activities and participation;<sup>3</sup> however, delineation of these constructs is considered essential for the ICF to be accepted as an international classification system.<sup>8</sup> Individual electronic searches for two assessments, the COPM and GAS, yielded in excess of 100 articles for each. It was beyond the scope of this review to appraise all articles. Key seminal works, reviews, and articles particularly addressing paediatric practice, were selected for appraisal. Therefore, some detail regarding these assessments may have been excluded.

As the focus of rehabilitation broadens to promote improved

function across all performance domains,<sup>37</sup> so does the need to measure outcomes more broadly. However, while trends in outcome measurement of children with CP over a 10-year period (1992–2002) indicate a shift to evaluate a broader perspective of functioning, capacity rather than performance in actual life situations continues to be emphasized.<sup>5</sup> The strong shift to adopt a ‘top down’ approach to assessment of children with disabling conditions suggests the focus of evaluation should determine how children participate in occupations in any given context.<sup>38</sup>

The importance of children’s participation in life situations is gaining greater attention in the area of childhood disability. However, little is known about how children with disabilities participate in everyday life.<sup>39</sup> The growing body of assessment measures identified in this review will provide the opportunity to develop a greater understanding of childhood participation. Researchers undertaking clinical trials in the area of CP now have a number of valid and reliable measures of participation to consider the broader impact of intervention on societal participation. As yet, there is little evidence to suggest how the more recent measures (CAPE, LIFE-H) may capture meaningful, clinically significant change over time.

## Conclusion

Results of this systematic review identified seven generic measures of participation suitable for children with CP. All assessments measured participation in a variety of environmental contexts, with no one measure covering all possible areas outlined by the ICF. The CAPE, SFA, and LIFE-H in combination cover participation in home, school, and community life. Reliability and validity is reported for all measures; however, the responsiveness remains unknown. Further use in clinical trials will be necessary to determine their responsiveness and research utility. Incorporation of participation measures in clinical trials will lead to a greater understanding of how interventions for children with CP have an impact on the broader context of societal participation.

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#### List of abbreviations

CAPE	Children's Assessment of Participation and Enjoyment
CHORES	Children Helping Out: Responsibilities and Expectations
COPM	Canadian Occupational Performance Measure
GAS	Goal Attainment Scaling
HRQL	Health-Related Quality of Life
ICF	International Classification of Functioning, Disability and Health
LIFE-H	Assessment of Life Habits for Children
SFA	School Function Assessment
SOM	School Outcome Measure



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