

SCOPING REVIEW

Child-led goal setting and evaluation tools for children with a disability: A scoping review

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Abstract

Aim: To examine child-led goal setting and evaluation tools and approaches for children with a disability or developmental delay.

Method: Six databases were searched for studies that included population (children aged less than 18 years with disability or developmental delay); construct (child-led goal setting tool or approach); and context (developmental therapy or rehabilitation). The utility of tools and approaches across the goal setting and evaluation process was investigated using abductive content analysis.

Results: Fifty articles met the inclusion criteria. Three approaches and four tools for child-led goal setting and evaluation were identified. No studies reported the clinimetric properties of tools specifically for child self-respondents. Qualitative analysis revealed six distinct goal phases in which tools and approaches were used, which were synthesized into a new framework for child-led goal setting and evaluation titled DECIDE: Direct children to goal setting; Elicit goal topics and priorities; Construct a goal statement; Indicate baseline goal performance; Develop an action plan to address the goal; and Evaluate goal progress after the intervention.

Interpretation: Children actively participated in goal setting and evaluation across six DECIDE goal phases. Further clinimetric information is required to support use of goal setting and evaluation tools with child self-respondents. Future research should emphasize the development of multi-phase goal setting tools and approaches for diverse populations of children.

The paradigm shift towards person-centred care frameworks in allied health interventions has led to growing recognition that children should be actively involved in goal setting.¹⁻³ Children with disabilities and developmental delays experience substantial barriers to their participation and reduced autonomy in many life domains, which persist into adulthood.⁴ To address these barriers, children often access rehabilitation services, in which goal setting has a key role. Evidence-based clinical guidelines support goal setting to enhance collaborative practice and direct interventions towards meaningful areas for children and their families.⁵⁻⁷ Furthermore, children's engagement in goal setting

and their pursuit of goals is optimized when goals are self-generated and hold personal value.¹ Research findings indicate that child-led goal setting has the potential to positively influence the child-practitioner relationship,⁸ engagement in the intervention,^{2,9,10} development of self-determination skills,¹¹ and therapeutic outcomes.¹² However, children with disabilities and developmental delays currently have a marginal role in goal setting compared to their caregivers or health care professionals.^{3,13} It is essential to increase the agency and involvement of children with disabilities and delays in goal setting to improve self-efficacy, engagement, and outcomes.³

Abbreviations: COPM, Canadian Occupational Performance Measure; GAS, Goal Attainment Scale; ICF, International Classification of Functioning, Disability and Health; PEGS, Perceived Efficacy and Goal Setting System.

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Theories and frameworks adopted from adult literature may help inform goal setting in paediatric clinical practice; however, there are unique considerations when involving children.¹³ In this scoping review, the term 'children' encompasses individuals under the age of 18 years.¹⁴ When considering this age range, it is important to first acknowledge that children's ability to participate in goal setting evolves as they grow and develop.¹⁵ From early childhood through adolescence, children gradually develop autonomy, self-concept, problem-solving, and decision-making skills, thereby enhancing their capacity for self-determination. Thus, it is necessary to tailor goal setting approaches to support child-led involvement at different developmental stages.¹⁶ Second, goal setting with children who have disabilities and developmental delays may necessitate approaches that accommodate for their differing physical, cognitive, or communication needs.¹⁶ Finally, goal setting may need to capture multiple perspectives because of the interrelated roles of children and caregivers.¹⁷ Although family-centred practice is widely endorsed in paediatric health care, the recent literature underscores the risk of children's perspectives being overshadowed when caregivers are the primary focus.^{2,18} Additionally, child and caregiver perspectives on goals can differ considerably.^{12,19} Therefore, it is advisable not to place sole emphasis on caregiver goals; children's voices should also be amplified.²⁰

Structured approaches can aid engagement in goal setting.^{13,21,22} However, the tools and approaches that most effectively support the active involvement of children with disabilities and delays in goal setting have not yet been explored. Within the adult literature, structured goal setting approaches differ according to (1) their intended function, (2) the people involved, (3) the steps implemented, and (4) the content and characteristics of the goals set.²² Approaches may or may not include the use of goal setting tools, which provide a systematic method of capturing the client's perspective.²³ Identifying the characteristics of child-led goal setting tools and approaches is critical to determine their suitability for individual children.

Challenges in understanding and navigating the process of goal setting can contribute to a low uptake of goal setting approaches from paediatric health care professionals.²⁴ The ambiguous or inconsistent terminology for goal-related constructs contributes to this challenge.²⁵ Levack et al.²² defined goal setting as the 'establishment or negotiation of rehabilitation goals'. This definition emphasizes an initial step that occurs at the start of the intervention. However, in practice, goal setting for an intervention involves a continuum of actions.²³ Several steps may be required before a meaningful goal can be established with children, such as exploring possible goal areas. Furthermore, additional steps are required after goal setting to ensure that true collaboration has occurred, such as reviewing and evaluating goals with children to determine the effectiveness of an intervention.^{26,27} Without a shared language for the components of the goal setting and evaluation process, variation in implementation is likely.¹ Clarification is needed to distinguish between child-led goal setting and evaluation

What this paper adds

- Child-led approaches must respond flexibly to children's individual needs and strengths.
- Child-led tools and approaches have utility across six distinct goal phases (DECIDE framework).
- The DECIDE framework can guide clinicians and researchers in implementing child-led goal setting.
- Clinimetric studies are needed to validate goal evaluation tools for child self-respondents.

phases, and identify associated tools and approaches supporting these phases.

There is a scarcity of research examining child-led goal setting and evaluation tools or approaches. Existing systematic reviews related to goal setting that include children are limited in their scope, focusing on a single goal setting tool such as the Canadian Occupational Performance Measure (COPM)^{28,29} or the Goal Attainment Scale (GAS).³⁰ Other reviews have been conducted on goal setting in a specific paediatric population, such as children with motor impairments¹³ or autism spectrum disorder.²⁹ A more comprehensive review is necessary to gain conceptual clarity regarding the characteristics of, and processes for, child-led goal setting among a broad population of children with disabilities and developmental delays.

The aim of this scoping review was to examine the published literature to identify child-led goal setting and evaluation tools and approaches for children with a disability or developmental delay who are attending allied health therapy services for developmental therapy or rehabilitation. Specific objectives were to review published literature to: (1) identify the characteristics of child-led tools or approaches used during goal setting and evaluation; (2) examine the clinimetric properties and clinical utility of tools used for goal setting and evaluation with a child self-respondent; (3) examine the tools and approaches reported for use during child-led goal setting and determine the process steps that they represent for clinical practice; and (4) identify the characteristics of children with disabilities or developmental delays who are capable of self-responding during goal setting and evaluation.

METHOD

A scoping review was conducted, guided by the JBI (formerly the Joanna Briggs Institute) manual for evidence synthesis^{31,32} and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) extension for Scoping Reviews guidelines.³³ Scoping reviews are useful for exploring and synthesizing literature related to a complex concept.³⁴ A scoping review was deemed appropriate because this study aimed to examine child-led goal setting tools and approaches that are implemented before

and after any intervention type, rather than investigate the effectiveness of specific goal setting interventions. The protocol for this review was registered with PROSPERO on 4th May 2021 (no. CRD42021243318).

Search strategy

Primary searches were performed using six electronic databases (PubMed, Embase, CINAHL, Web of Science, Cochrane, PsychINFO) from the date of inception until March 2023. The search strategy included keywords and medical subject heading terms for the population ('child' and 'disability'), construct ('goal setting'), and context ('rehabilitation'). A complete list of search terms can be found in Appendix S1. Secondary searches were conducted using (1) reference lists of the included articles, (2) reference lists of relevant reviews, and (3) manuals of the included goal setting and evaluation tools (if available).

Article selection

Articles were exported to EndNote X9 (Clarivate Analytics, Philadelphia, PA, USA; www.clarivate.com), where duplicates were removed and then exported to the COVIDENCE systematic review software (Veritas Health Innovation, Melbourne, Australia; www.covidence.org) for screening. Two researchers reviewed each article independently to determine eligibility against the inclusion criteria. Articles were reviewed in two stages: (1) title and abstract and (2) full text. Discrepancies were resolved in consultation with all authors.

Inclusion and exclusion criteria

Articles were included if they: (1) involved children aged less than 18 years with a disability or delay in the context of developmental therapy or rehabilitation; (2) used a goal setting and evaluation tool or approach, reported in sufficient detail for replication; (3) involved children as self-respondents during at least one component of goal setting and evaluation; (4) reported original data for the tool or approach; and (5) were published in full text in a peer-reviewed journal. Articles were excluded if: (1) children were accessing services for reasons other than developmental therapy or rehabilitation, for example, medical conditions (e.g. asthma, cystic fibrosis), health conditions (e.g. obesity or weight management), or mental health conditions (e.g. anxiety or depression); (2) the study included a mixed cohort of children and adults and the data for children were not reported separately; (3) it could not be confirmed that children were involved as self-respondents during goal setting and evaluation, for example, goal setting and evaluation were completed with a proxy respondent only (such as a caregiver, therapist, or teacher), or the respondent during goal setting and evaluation was

unclear; or (4) children and caregivers responded jointly throughout all parts of goal setting and evaluation, and the independent contribution of children was not described. Studies were not excluded based on language.

Data extraction

Data extraction was guided by the CanChild Outcome Measures Rating Form criteria³⁵ and recorded in Excel. Extraction was completed by one author (AR) and checked by a second author for agreement. Data extracted included study characteristics (design, sample size, country), participant characteristics (age, diagnosis), and characteristics of the goal setting and evaluation tool or approach (setting, respondent, therapy discipline involved, purpose, clinical utility, clinimetric information).

Quality assessment

Quality assessment was not completed because the intention of this review was to identify and synthesize the characteristics of the goal setting tool or approach used, rather than examine the impact of the tool or approach on child outcomes. Furthermore, the implementation of the CONsensus-based Standards for the selection of health Measurement Instruments (COSMIN)³⁶ to assess risk of bias was not possible because no clinimetric data for tools used with child self-respondents were found.

Data synthesis

An abductive qualitative content analysis approach was applied to data synthesis, which included an inductive phase followed by a deductive phase.³⁷ The inductive phase provided a mechanism to identify and classify tools and approaches reported in the published literature. The deductive phase provided a mechanism to categorize these data using existing goal setting theory and author clinical experience, to develop a framework that could be applied in clinical practice.³⁷

The approach involved five steps, consistent with framework methodology,³⁸ as applied to systematic reviews.³⁹ First, one study author (AR) became immersed in the data to gain a broad view of the range and function of tools and approaches used with children (step 1: data familiarization). An inductive approach was used to code and cluster tools and approaches used for similar purposes (step 2: coding). The authors then used a deductive approach to propose draft groupings based on their analysis of the goal setting literature and their clinical knowledge and expertise. Together, the draft groupings comprised a working framework representing the phases of child-led goal setting and evaluation (step 3: developing a working analytical framework). A deductive approach was then used to group tools and

approaches into the phases of the framework and consider whether any additional phases were needed to accommodate all the data (step 4: applying the analytical framework). To maintain rigour, the lead author held regular meetings with all study authors to discuss and confirm data interpretation and management across each of the coding, grouping, and framework integration steps.

To summarize the results of the analysis, data were tabulated into a framework matrix to display how the tools and approaches were grouped into the final framework phases (step 5: charting data into a framework matrix). Additional strategies supporting children's involvement in goal phases were also identified and recorded in this table. While all studies reported children as self-respondents during at least one component of goal setting as per the inclusion criteria, the role of caregivers in goal setting was also identified. Data were extracted to capture when, within goal phases, (1) children self-responded, (2) children and caregivers responded together, (3) children and caregivers both responded, but separately. Descriptions of the goal phases within the framework were derived directly from the analysis to reflect the tools and approaches identified for each phase.

RESULTS

Primary and secondary searches retrieved 11 166 unique articles, of which 276 involved goal setting and evaluation for children (see the PRISMA flow chart in Appendix S2). Of these, 50 articles involved children as self-respondents during at least one phase of goal setting and evaluation. These articles were included in the final data extraction and synthesis. Articles involving children were excluded if: goal setting and evaluation was completed with a proxy respondent only ($n = 141$); goal setting and evaluation was only completed by children and caregivers as joint respondents ($n = 32$); or the respondent was not stated or unclear ($n = 53$) (see Appendix S3 for the references of these excluded studies).

Study characteristics

The characteristics of published studies involving child-led goal setting and evaluation are detailed in Appendix S4. Studies reporting the same data set of child-led goal setting are grouped together in the results. Children who self-responded were aged from 4 to 17 years, with sample sizes varying from 1 to 117 children. Children who were included in goal setting and evaluation had diverse diagnoses or developmental delays, the most common being developmental coordination disorder ($n = 12$),^{40–51} followed by general disability ($n = 10$)^{12,19,52–60} and cerebral palsy (CP) ($n = 7$).^{9,61–66}

Study inclusion criteria for children related to other developmental areas varied. The most common criterion was adequate cognition ($n = 24$ studies), including: children having average or higher cognition as measured on standardized testing;^{40–42,46–48,63,65–77} no intellectual delay as

per clinical or caregiver report;^{78,79} cognition above the level of a 5-year-old;^{19,52} cognition above the level of an 8-year-old;^{58,59} the ability to make choices between two options;^{19,52–54} or the ability to formulate goals.^{66,78} The second most common criterion was communication ($n = 19$ studies), with studies including: children having sufficient expressive and receptive language skills;^{63,67–69} able to communicate verbally;^{19,60,64,66} able to communicate or understand information at or above the level of a 5-year old;^{12,53–56,80} demonstrate age-appropriate language skills on standardized testing;^{73,76} have receptive language at a two-word level;⁸¹ or have intentional communication.⁸²

Child-led goal setting and evaluation tools

Four tools were identified in the literature to be used with child self-respondents during goal setting and evaluation.

Canadian Occupation Performance Measure

The COPM⁸³ was designed by occupational therapists as a self-report tool to evaluate perception of occupational performance with clients of all ages.^{83,84} Administration of the COPM is a multi-step process, beginning with a semi-structured interview covering the life domains of self-care, productivity, and leisure. The client is supported to prioritize problem areas and self-evaluate their performance and satisfaction of these areas at baseline using 10-point Likert scales. The COPM scales are designed to be re-administered after the intervention to measure change in occupational performance.⁸³

The COPM was the most frequently reported goal setting and evaluation tool used in research involving children as self-respondents. Thirty-one studies reported that children between the ages of 4 and 17 years self-responded using the COPM. The COPM was most commonly administered in its full form ($n = 23$).^{9,43,45,46,48,49,51,58,59,62–66,68–70,72,73,75,76,78,85} In six studies, an alternative tool or approach was used to capture children's goals, followed by the COPM rating scales to measure children's self-evaluation.^{40,41,44,47,50,79} Five studies used a modified COPM, in which only one component of the semi-structured interview was completed^{71,82,86,87} or an alternative rating scale was used with reduced response options.⁵⁷ Four studies reported that some children in their sample could not complete the COPM rating scales.^{48,62,65,72} Difficulties responding were attributed to children being unable to attend to or comprehend task instructions,^{48,65,72} or the reasons were unclear.⁶² A visual rating scale was used in three studies, all of which included children under 8 years of age, as an alternative to the numerical rating scale.^{48,62,85}

Good clinical utility of the COPM with child self-respondents was reported in one study.⁵⁸ In this study, 23 children aged between 8 and 12 years participated in semi-structured interviews to share their experiences of completing the COPM. All children completed the COPM.

Qualitative results revealed several key insights from children, including: (1) the COPM enabled them to express their wishes; (2) their preferences were integrated into goals and supports; and (3) the process of the COPM was suitable for them.⁵⁸ Children made suggestions to improve the accessibility of the COPM for other children, such as simplifying the rating scales.⁵⁸ Children's suggestions were triangulated with information from caregivers and occupational therapists in a subsequent study.⁵⁹ Findings were synthesized through a Delphi consensus process, resulting in 40 specific instructions for administering the COPM to children.⁵⁹

In terms of clinimetrics, no studies were identified that reported on validity, reliability, or responsiveness of the COPM, specifically when used with child self-respondents.

Goal Attainment Scale

The GAS is a goal setting and evaluation tool initially introduced in adult mental health care settings and which is now used extensively with other populations.^{30,88} The GAS is considered a 'content empty scale', meaning that the content used in the scale needs to be identified by the therapist or the client. Although a five-level table is commonly used to record the goal details, there is no standardized administration procedure.⁸⁹ Common principles of GAS administration are to use the 5-level table to: (1) document a client's current performance of a target goal activity before intervention; (2) construct a scale that represents their anticipated and preferred outcomes; and (3) evaluate goal attainment after the intervention.⁸⁹ While client involvement is encouraged, goal documentation is frequently therapist-driven.⁸⁹

Six published intervention studies were identified that involved children as self-respondents for the GAS.^{51,67,68,77,86,90} Three studies showed that children aged between 11 and 17 years could be successfully involved in constructing the GAS five-level scale, with assistance from a researcher, where 0 was the expected goal performance and -2 was the current goal performance. Children then self-evaluated their goal competence after the intervention, independently from their caregivers.^{67,77,86} While the GAS was feasible for these adolescent self-respondents, one study noted that the process was 'time-consuming' as some young people needed significant support to describe their goals and criteria for change. Therefore, it was recommended that the procedure should be carried out by trained therapists.⁷⁷

Two single case studies reported the use of alternative forms of the GAS with a child self-respondent. One study outlined use of a modified 'child-friendly' GAS, which retained the five-level scale but used numbers 0 to 4 to avoid negative scale points.⁹⁰ In a second study, a child rated their goal attainment after the intervention using a '7-point Likert GAS scale', in which 4 represented the expected goal achievement.⁵¹ Use of the GAS was discontinued in a study involving children aged 6 to 17 years with a hyperkinetic movement disorder. The reason reported for discontinuation was that children and therapists had difficulty scaling

the goals.⁶⁸ No studies were identified in this review that reported on the validity, reliability, or responsiveness of the GAS when used with child self-respondents.

KID'EM

KID'EM was designed as a communication tool to support children's motivation to take part in rehabilitation and facilitate the construction of therapy goals based on child preferences.⁶⁰ The tool prompts therapists to ask children questions about their interests, daily activities, and needs. The therapist supports children to operationalize goals using specific, measurable, achievable, realistic, relevant, timed goal principles.⁹¹ Finally, the therapist is prompted to identify with children the facilitators and barriers to their goal achievement. KID'EM was developed and evaluated in France.⁶⁰

KID'EM was piloted in one study with 50 children aged between 1 and 17 years with various disabilities who were attending physiotherapy.⁶⁰ The tool was useful for children over the age of 6 years who could communicate verbally. Physiotherapists using the tool reported that it assisted them to improve their therapeutic relationship and identify meaningful goals with children.⁶⁰

Perceived Efficacy and Goal Setting System

The Perceived Efficacy and Goal Setting System (PEGS) was developed to assist children aged 5 to 8 years to identify goal areas for occupational therapy.⁵³ Children use pictorial cards to indicate their self-perceived competence in everyday self-care, school, and leisure activities. Children then select priority goal areas from the cards representing areas in which they do not feel competent.⁵³

The PEGS was used in 14 studies, with children aged between 5 and 12 years.^{9,12,19,40-42,47,49,52-56,80} The PEGS is not intended to be used to rate or evaluate goal outcomes; thus, it was paired with the COPM in six studies.^{9,40-42,47,49} Three studies reported good utility of the PEGS in supporting children to express their views and priorities about goals.^{46,52,56}

Goals prioritized by children using the PEGS were relatively stable over time.^{54,55} Disparities in agreement were identified between items prioritized as goals by children and caregivers when completing the PEGS,^{19,54,55} although children's goals were achieved to the same extent as caregiver goals.¹² The PEGS has been adapted to an Austrian-German⁵² and Swedish⁵⁶ context. As the PEGS is not a goal evaluation measure, further clinimetric information, such as responsiveness, was not reported.

Child-led goal setting and evaluation approaches

Three child-led approaches were identified from the literature.



FIGURE 1 Summary of the six phases of the DECIDE framework for child-led goal setting and evaluation.

TABLE 1 Description of the child-led goal setting phases and components of the DECIDE framework.

Goal phase	Description
D	Direct children to goal setting Actions taken to direct children's attention to and engagement in goal setting, that is, building rapport.
E	Elicit goal topics and priorities Actions taken to support children to: (1) self-identify goal areas across the ICF as relevant and (2) prioritize the most important goal areas to be addressed through intervention from the children's perspective.
C	Construct a goal statement Actions taken to support children to construct a statement that represents the topic and desired outcome for each of their chosen goals.
I	Indicate baseline goal performance Actions taken to support children to self-evaluate each goal for (1) their current competence in that goal, (2) satisfaction with their competence, or (3) confidence or readiness to address the goal (goal self-efficacy).
D	Develop an action plan to address the goal Actions taken to identify with children (1) an action plan to address the goal, (2) facilitators and barriers to achieving the goal, and (3) strategies and people to help to address barriers.
E	Evaluate goal progress after the intervention Actions taken to support children to self-evaluate progress or goals after an intervention, including re-administration of outcome measures applied at the 'indicate' stage.

Abbreviation: ICF, International Classification of Functioning, Disability and Health.

ENGAGE approach for child-led goal setting

ENGAGE is a theory-driven approach that optimizes children's active participation in goal setting and evaluation.⁹ ENGAGE is underpinned by four principles: (1) goals are based on children's preferences; (2) goal setting occurs collaboratively; (3) goals drive intervention; and (4) goals and goal progress are used as motivation for therapy.

In one study,⁹ ENGAGE was delivered within a multidisciplinary inpatient and outpatient context with nine children with CP and their caregivers. Clinicians used customized goal setting tools and strategies to support children's active engagement and to identify goal content. A study-specific sentence completion tool was used to structure and record goals with children, which enabled children to identify the context and rationale for their goals. Qualitative results revealed that children could identify meaningful and motivating goals valued by both children and caregivers.⁹

International Classification of Functioning, Disability and Health-inspired goal setting in developmental rehabilitation

International Classification of Functioning, Disability and Health (ICF)-inspired goal setting⁶¹ was developed as a collaborative goal setting approach for children with disabilities that embedded the ICF.⁹² ICF activity and participation areas relevant to children were identified from the literature and translated into goal cards and an activity

checklist. A case study illustrated how the approach was implemented with a 17-year-old with CP.⁶¹ The context was an outpatient medical centre providing multidisciplinary developmental therapy. The adolescent used the ICF goal cards to self-identify and prioritize goals for intervention. Goals were operationalized collaboratively by the clinician and adolescent using specific, measurable, achievable, realistic, relevant, timed goal principles.⁹¹ Goal setting led to intervention planning and delivery, which directly addressed the adolescent's priorities.⁶¹

Personalized goals for positive behaviour support

An augmented communication approach was developed to support children with intellectual and developmental disabilities to articulate their preferences and priorities.⁸¹ The approach was implemented in one study⁸¹ with 14 children aged between 5 and 15 years who had diverse communication abilities. Goal setting and evaluation was completed by a single professional for the purpose of developing individualized positive behaviour support plans.

During the goal setting session, children were asked semi-open-ended questions about their views in topic areas relevant to a positive behaviour support framework.⁸¹ Children were presented with Talking Mats (Talking Mats Ltd, Stirling, UK) visual stimulus cards and asked to place them in the mat area corresponding to their preferred response. After the interview, children were encouraged to select one or two visuals that represented areas for which

they would like support, which were recorded as goals. Nine children engaged in the approach and identified goals. Five children with complex communication needs did not complete all steps of the approach, although some indicated their preferences for the activities depicted on stimulus cards non-verbally.⁸¹

Synthesis of tools and approaches

The data analysis of tools and approaches reported for use with children as self-respondents revealed six overarching phases of child-led goal setting and evaluation. We synthesized the six phases into a new 'DECIDE' framework to support decision-making in child-led goal setting and evaluation in both clinical and research contexts (Figure 1). The DECIDE goal phases are: Direct children to goal setting; Elicit goal topics and priorities; Construct a goal statement; Indicate baseline goal performance; Develop an action plan to address the goal; and Evaluate goal progress after the intervention. Descriptions of the goal phases derived from the analysis are presented in Table 1.

Phases were characterized by unique child-led actions related to goals completed by the therapist and child. Phases were considered distinct from each other because the actions involved had differing underlying purposes. In some instances, multiple actions were identified as important to child-led completion of that phase. For example, to 'elicit' goals, children needed to both identify goal areas and prioritize their preferred areas to be addressed in the intervention. Inclusion of both actions differentiated a child-led tool used to elicit goals from measures of other constructs, such as those identifying participation preferences. Furthermore, multiple dimensions of goal performance were evaluated with children in the 'indicate' and 'evaluate' phases, and tools identified had utility in supporting one or multiple of these actions.

The child-led approaches, tools, and additional strategies used in each study are displayed within the DECIDE framework matrix in Appendix S5. The tool or approach was grouped in the goal phase according to how it was used in the study. Additional strategies used to support children's involvement in goal phases included measures of preferences, activity, or participation (not specifically designed for goal setting), specific, measurable, achievable, realistic, relevant, timed goal principles, visual resources such as photos, and predetermined goal options and statements. Twenty-seven studies reported that caregivers were also involved in at least one DECIDE goal phase. A summary of tools and strategies used with child self-respondents in each DECIDE goal phase is provided in Appendix S6.

Data synthesis revealed that no single comprehensive tool or approach supporting all DECIDE goal phases is currently available. Thus, multiple goal setting tools and strategies were used to support children's involvement across goal phases in many studies ($n=19$). Moreover, the implementation of tools or approaches in goal phases with children varied. The

highest frequency of child involvement was noted for phase 2 of 'eliciting goals' ($n=45$) and the lowest frequency in phase 1 of 'directing children to goal setting' ($n=3$). Notably, no study described child-led involvement across all goal phases.

DISCUSSION

This scoping review provides a comprehensive overview of tools and approaches reported in the research for child-led goal setting and evaluation in developmental and rehabilitation settings. Analysis revealed that goal setting and evaluation with children who have disabilities or developmental delays should be considered as a multi-phase process. We identified and defined six distinct phases, which were synthesized into a new DECIDE framework for child-led goal setting and evaluation. We propose that children with disabilities and development delays can be supported to take an active role across the six DECIDE goal phases. Four tools and three approaches were identified that can support and enhance child involvement. However, there was an absence of clinimetric information supporting the use of child-led tools to evaluate goal outcomes with child self-respondents.

Clear recommendations regarding child-led tools or approaches appropriate for children in different age groups were lacking in the studies examined. However, findings indicated that children of diverse ages could be involved in self-responding during goal setting, with some studies including children as young as 4 years.^{62,81} Often, younger children were provided with additional support for choice-making. Support took the form of visual resources for eliciting or evaluating goals or the use of a tool, such as the PEGS, to provide concrete goal content. There is no specific lower age limit for children's participation in goal phases, rather the chosen tool or approach must consider children's developmental stage and provide the necessary support to promote involvement in goal setting and evaluation.

In addition to age, the data highlighted other developmental areas important to consider in child-led goal setting and evaluation. However, there was little agreement regarding the specific factors that indicate that children with disabilities or delays can be successfully involved. Cognitive abilities impacted the inclusion of children in studies that involved child-led goal setting, although the measure of sufficient cognition for participation varied. Children with communication impairments were also frequently excluded from goal setting. It is possible that their exclusion was associated with the frequent use of 'interview' format tools, such as the COPM or KID'EM, which rely on verbal expression to elicit goals. In contrast to the criteria frequently used, two studies in this review provided preliminary evidence that children with cognition and communication impairments can be supported to participate in goal setting using tailored, augmentative communication approaches.^{81,82} These findings are consistent with research by Mitchell and Sloper,⁹³ who found that children with learning disabilities or who communicate non-verbally value involvement in

decision-making; however, they require adapted approaches to support their participation. Further clarity regarding factors indicating child readiness to participate in goal setting is necessary. In addition, the identification of a broader range of tools and strategies for children with diverse communication and cognition abilities is needed to facilitate their meaningful inclusion.

There is a need to enhance the quantity and quality of research into child-led goal setting practices. Examination of child-led tools and approaches used in the DECIDE goal phases revealed that no study has described child-led involvement in all goal phases. Furthermore, the frequency of child involvement within goal phases varied between studies. For example, despite the theoretical importance of person-centred care,⁹⁴ tools and approaches used to 'direct' children to goal setting were described infrequently. Actions that may assist to direct children to goal setting, such as building rapport and providing education about goal setting, are essential for promoting relatedness and engagement during therapeutic interactions.^{1,95} These actions are particularly important for children new to child-led goal setting or who may have been provided with less contextual information than their caregivers before a goal setting session. Previous research suggested that children in these circumstances would be more likely to assume a passive role in interactions between their caregiver and a health care professional.^{2,96} Future research should ensure that goal setting tools and approaches used across all goal phases are considered, comprehensively described, and evaluated.

Results emphasized key factors that should be considered when selecting a goal setting and evaluation tool for children. First, the characteristics of the tool must align with the abilities of individual children. Results from this review suggest that tools adapted from adult research such as the GAS, which requires multilevel criteria development, may have poor utility for all child self-respondents, particularly younger children. Second, child-led tools had varied utility across the DECIDE goal phases. So, the choice of a tool must align with the construct of the target goal phase. For example, the PEGS and KID'EM can be used with children to elicit goal topics and priorities and construct a goal statement; however, they cannot be used to evaluate goal progress. The COPM, when used in its full form, can support children to elicit and evaluate goals; however, the tool does not include a manualized process to construct a goal statement. Eliciting a problem or priority area with a child does not guarantee that a meaningful goal has been constructed based on the child's preferences.⁹⁷ Finally, clinicians and researchers must use a combination of tools to support children in all goal phases. Future research should prioritize the identification of multi-phase tools to streamline the goal setting and evaluation process.

Approaches were identified that can optimize child involvement in goal setting and evaluation. The common purpose of approaches was to direct intervention towards child priorities. However, approaches differed in the underlying frameworks used, the service delivery context, and the

processes implemented. Child-led goal setting and evaluation that occurred in a multidisciplinary context often used an 'open' approach, which enabled children to elicit goals in any relevant life area.⁹ Goal setting completed by a single discipline typically used a 'closed' approach, in which the possible goal areas discussed were limited to topics relevant to that discipline and intervention.⁸¹ Where possible, health care professionals should use multidisciplinary and collaborative approaches to intervention planning and delivery when supporting children and families in rehabilitation settings.^{7,98} Goal setting procedures should be established that optimize time to enable meaningful goals to be established open approaches.^{24,99} Previous research suggested that allocating sufficient time for shared decision-making can enhance the efficiency of services delivered, therefore potentially decreasing overall service delivery time and cost.^{24,99,100} It is crucial to develop policies and procedures that optimize child involvement and support collaborative implementation of goal setting and evaluation approaches in practice.

Use of the DECIDE framework can benefit both researchers and clinicians involving children who have disabilities and delays in goal setting and evaluation. DECIDE provides common terminology that can be shared by clinicians, children, and families. Use of consistent terms enhances clarity regarding the purpose and process of goal setting and evaluation for intervention, thus supporting child involvement.⁹⁹ Furthermore, goal setting and evaluation procedures within organizations can be standardized using the DECIDE goal phases. Standardized procedures can support clinicians to consistently adopt and embed child-led goal setting practices into their service delivery.²⁴ The DECIDE framework goal planning form included in Appendix S7 can support the implementation of goal phases in clinical practice and research contexts. Implementation of the DECIDE framework, which considers the perspectives of children and caregivers, will inform the practical application of the framework in different practice contexts.

An unexpected finding of this review was the absence of studies reporting the clinimetric properties of the tools used to evaluate child-reported goal outcomes. Notably, commonly used tools such as the COPM and GAS were not developed for children; therefore, their robustness when used with child self-respondents is unclear. Previous research focused on the clinimetric properties of goal setting tools with caregiver proxy respondents, including the validity and interrater reliability of the COPM.^{101,102} However, the agreement between child self-ratings and caregiver proxy ratings when using the COPM is unknown. Poor interrater agreement between child self-ratings and caregiver proxy ratings has been found in other measures, such as those related to health,¹⁰³ quality of life,¹⁰⁴ child functioning,¹⁰⁵ and mastery of motivation.¹⁰⁶ Using caregiver proxy ratings is at times necessary and developmentally appropriate,¹⁰³ however, involving children as self-respondents has the potential to foster autonomy, self-awareness, and self-efficacy.¹⁰⁷ Further research into the validity, reliability, and responsiveness

of tools used to evaluate goal outcomes with child self-respondents would increase the confidence of clinicians and researchers using these tools with children in goal setting.

Limitations

This study has a few limitations. First, although a substantial amount of data was identified, the level of evidence of the included studies varied, and an assessment of methodological quality was not completed. Second, although a range of child-led tools and approaches are available, further research is needed to confirm the role that each of these tools and approaches have in treatment effectiveness, and whether they contribute to improved child and family outcomes. For both reasons, future research should focus on examining child-led goal setting within rigorous intervention study designs. Finally, it is possible that new tools and approaches used to support children's involvement in goal setting in clinical practice are not captured in the published literature. Further research exploring child-led goal setting in practices used by clinicians in current clinical practice will assist in enhancing knowledge in this area.

Conclusion

This review identified four goal setting and evaluation tools that exhibit promise in supporting children to self-respond: the COPM, the GAS, KID'EM, and the PEGS. However, further clinimetric testing is required to demonstrate the validity, reliability, responsiveness, and clinical utility of tools used to evaluate goal outcomes with child self-respondents. Three approaches that can support allied health professionals in multidisciplinary or unidisciplinary contexts to implement child-led goal setting were identified. The new DECIDE framework for child-led goal setting derived from this scoping review can guide clinicians and researchers in considering the tools and approaches needed for comprehensive goal setting and evaluation led by children. Careful consideration is needed to determine how the tool or approach aligns with the specific DECIDE goal phase being implemented and the child's unique abilities. Research gaps underscore the need for more comprehensive goal setting and evaluation tools and approaches that can optimally capture the perspectives of children with a diverse range of abilities across the DECIDE goal phases.

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CONFLICT OF INTEREST STATEMENT

The authors had no interests that might be perceived as posing a conflict or bias.

DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

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SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Systematic review database searches

Appendix S2: PRISMA flow chart

Appendix S3: Goal setting in the studies excluded from this scoping review

Appendix S4: Characteristics of published studies involving child-led goal setting and evaluation

Appendix S5: DECIDE goal phase synthesis

Appendix S6: DECIDE Child-Led Goal Setting and Evaluation Framework

Appendix S7: DECIDE Goal Setting and Evaluation Planning Form

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