

# Collaborative Goal Setting for Disabled Children Within Education: A Scoping Review

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## ABSTRACT

Successful collaborative goal setting for disabled children is an essential part of family-centred practice (FCP). There is a paucity of research that collates concepts or approaches to collaborative goal setting. This scoping review aimed to explore key features and the application of collaborative goal setting frameworks and approaches used in an educational context for disabled children and their families. Ten databases were systematically searched using the keywords and synonyms of collaboration, goal setting, children, and disability from 2000 to January 2023. Data were collated and analysed thematically. Twenty-four studies were included for review and four key elements were identified as supporting collaborative FCP: (a) adopting a child-centred approach to enhance the child's strengths and dreams; (b) using goal-setting tools to identify the child's current ability; (c) applying structured processes to achieve collaborative family-centred practice; and (d) accessing external support during collaborative goal setting. A new working model was developed from the findings, which describes collaborative constructs and practical strategies for child-centred goal setting. Exploration and use of this model may support professionals to enhance collaborative family-centred goal-setting practice.

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Key Words: Children, Collaboration, Disability, Education, Goal Setting

## INTRODUCTION

Collaborative goal setting in education is imperative for disabled children. Research has illustrated ways in which disabled students are missing out, including being unable to attend school or participate in education, with little change seen over the last 16 years (Clark & MacArthur, 2008). In the educational context, independent educational plans (IEPs) are one example of a formal approach to collaborative goal setting that is used for disabled children. In different countries IEPs are either a legislature requirement or considered good practice for disabled students (de Bruin, 2019). In New Zealand, it is mandatory to complete an IEP every six months for any student who receives Ministry of Education Ongoing Resource Scheme Funding (ORS) (Ministry of Education, 2017).

Family-centred practice (FCP), also referred to as family-centred care, is considered the gold standard philosophy and best-practice approach to rehabilitation service delivery for disabled children (King et al., 2004). The core principles of FCP include parental involvement in care and co-decision making (Carmen et al., 2008; Kuo, 2012), respectful family–professional partnership (Arango, 2011), and collaboration (Jolley & Shields, 2009; Kuo, 2012).

Co-decision making, self-determination, and autonomy for disabled persons and their families is supported by the United Nations Convention on the Rights of Persons with Disabilities (Andersen & Dolva, 2015; Curryer et al., 2015; Marshall &

Goodall, 2015; O'Connor et al., 2021; United Nations, 2006). In addition, national governing bodies advocate for independence, community inclusion, and supported decision making within health and education (Education Review Office, 2022; New Zealand Government, 2016, 2019; Zhang et al., 2019).

Within education, IEPs should emulate FCP and provide an opportunity to build family–professional relationships that support family empowerment and improved outcomes for the child (Casagrande & Ingersoll, 2017; Ministry of Education, 2011). Families should feel they are in a collaborative partnership with professionals and seen as the experts of their child (Edwards et al., 2018). Instead, families often feel stressed, disempowered, and not adequately prepared to engage in IEPs (Hodge & Runswick-Cole, 2008; Jessop, 2018). Families can feel overwhelmed and confused by the IEP process (Jessop, 2018) or perceive their role as passive, which reduces collaboration (Childre & Chambers, 2005b), especially when their concerns and priorities are not heard or reproduced into goals (Kurth et al., 2019). In particular, families from Indigenous cultures can disengage due to feeling fear, insecurity, frustration, and intimidation in the school setting (Sheehey, 2006).

The International Classification of Functioning Disability and Health (ICF) and the child adaptation version for children and youth (ICF-CY) are examples of biopsychosocial models used to guide collaboration in the rehabilitation setting (Martinuzzi et al., 2015), with more recent publications in education (CanChild, 2024b). CanChild (an organisation dedicated to

research for children and youth with disabilities and their families) developed a child- and family-friendly ICF-based tool called the F-words (Rosenbaum & Gorter, 2012), which consider the overall function and wellbeing of the child in every setting (Vargus-Adams & Majnemer, 2014). The F-words (i.e., fitness, function, friends, family, fun, future) replace the traditional ICF model terminology: health condition, body structure and function, activities, participation, environmental factors, and personal factors (CanChild, 2024a). They both provide a common language (Nguyen et al., 2021) to support holistic assessment, evaluation, and planning (Andrade et al., 2012; Mweshi, 2016) and focus on meaningful collaborative goal setting (Angeli et al., 2021).

Throughout this paper we have adopted disability-first language more recently recommended by disabled persons, including Autism New Zealand with their guide to language and terminology (Andrews et al., 2022; Botha et al., 2023; Monk, 2022). We acknowledge this is a shift from the traditional philosophy of seeing people first and then their disability (Gernsbacher, 2017), as advocated by the American Psychological Association (APA) referencing style (Pickren & Rutherford, 2018).

Working with disabled children in education and rehabilitation has exposed the primary author (LR) to a variety of ways in which therapists and educators assist children and families through goal setting. As such, LR has observed challenges with IEPs as the main form of collaborative goal setting, including confused families, families who do not come back to the next IEP, and professionals who struggle to find a process to support the families. There is limited research in the field of collaborative goal setting for disabled children and their families. A systematic review conducted by Goldman and Burke (2017) showed only five studies supporting parents of disabled students and their involvement at school. Families surveyed reported limited improvement in collaboration (Blietz, 1988; Brinckerhoff & Vincent, 1986; Hirsch, 2004; Mueller & Vick, 2019; Plunge, 1998). While a scoping review by Pritchard-Wiart and Phelan (2018) reviewed 62 papers and found family-centred care well represented with some descriptions of goal-setting theoretical frameworks, they concluded there were significant gaps in the literature around goal-setting theory and processes.

The purpose of this scoping review was to collate and summarise literature relating to collaborative goal setting to better understand the available framework(s) and/or approach(es) to enhance collaborative, family-centred goal setting for disabled children and to provide recommendations for education practice. The research questions were:

1. What are the key features of collaborative, family-centred goal setting frameworks/approaches?
2. What are the impacts of using these frameworks/approaches with disabled children and their family in an education context?

## METHODS

This scoping review was conducted using the five-stage methodological framework as described by Arksey and O'Malley (2005): (a) identify the research question; (b) identify relevant

studies; (c) study selection; (d) charting data; and (e) collating, summarising, and reporting the results by constructing themes to present a narrative account of the existing literature. The PRISMA extension checklist for scoping reviews (Tricco et al., 2018) was also applied.

### Identifying relevant studies

Following consultation with a University librarian, we searched the databases of Medline, CINAHL, Web of Science, Scopus, Cochrane, Education Research Complete, Education Database (ProQuest), ERIC (ProQuest), NZCER Journals Online, and Psych INFO in July 2020 and updated the search in January 2023. Searches used the key concepts and synonyms of collaboration, goal setting, children, and disability (see Appendix A) specifically tailored to each database. An example of the search strategy from one database (Medline) is included in Appendix B.

### Study selection

Following duplicate removal, articles were screened in three stages against the inclusion and exclusion criteria by LR (see Table 1): (a) title review; (b) abstract review (in the absence of an abstract, the full text was reviewed); and (c) full text review.

**Table 1**

*Inclusion, Exclusion Criteria and Associated Definitions*

Inclusion criteria	
Participant	Relates to children with disability aged up to 21 years Families, whānau, caregivers, and professionals working with disabled children
Concept	Frameworks or approaches for parent collaboration as the primary focus of the study or family-centred processes for goal setting or a framework for goal setting for disabled children
Context	Published between January 1 2000 and January 30 2023 Published in English Within education Within paediatric rehabilitation
Exclusion criteria	
	Full text not available Publications in a language other than English
Definitions	
Disability:	for the purposes of this study, disability will include only physical impairments and autism spectrum disorder lasting or expected to last six months or more and not eliminated by assistive devices
Family and caregivers –	for the purposes of this study, whoever the child lives with on a full-time basis

Two researchers (AC and LC) independently reviewed a selection of studies randomly chosen by LR to cross-check the eligibility process. In the case of eligibility uncertainty, studies were reviewed by AC and LC and continued to the next stage of screening if unanimous agreement was not reached. LR also reviewed and checked all cited references of the included

studies to determine eligibility, resulting in the addition of one reference. EndNote 20 software (Clarivate, 2021) was used to store, de-duplicate, and reference.

### Data charting, collation, and summarising

The data were charted in Microsoft Word (by LR), using the headings author, date, country, study design, participant, frameworks/approaches, and outcomes. Charted data were analysed narratively by constructing themes using a five-step process: (a) compiling: synthesising information from included papers into a table; (b) disassembling: mind mapping ideas from papers; (c) reassembling: grouping like ideas and concepts together; (d) interpreting: making sense of the links between concepts, and (e) concluding: summarising into a model (Castleberry & Nolen, 2018). The research team met regularly throughout the data charting, collation, and summary stages to discuss and refine the themes until consensus was reached.

## RESULTS

The initial search yielded 1026 studies, which were screened following the PRISMA process, resulting in 23 relevant studies for inclusion (see Figure 1).

### Characteristics of included studies

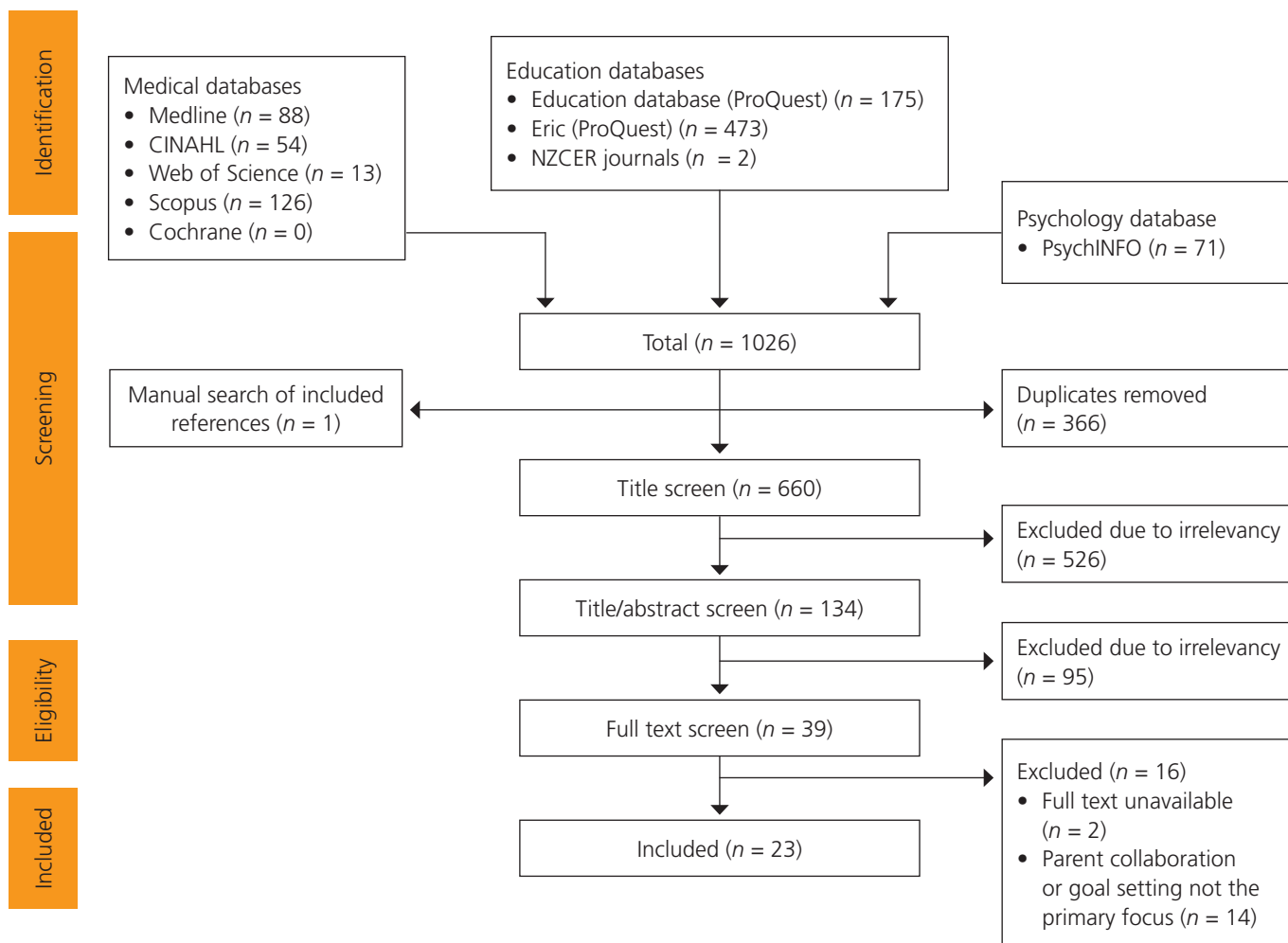
The study designs of the included studies were, expert opinion ( $n = 8$ ), qualitative studies ( $n = 8$ ), training programmes ( $n = 2$ ), theses ( $n = 2$ ), cohort studies ( $n = 2$ ), and a randomised control trial ( $n = 1$ ). The countries of study origin included the USA ( $n = 11$ ), Australia ( $n = 4$ ), Canada ( $n = 3$ ), South Korea ( $n = 2$ ), Israel ( $n = 1$ ), Norway ( $n = 1$ ), and Portugal ( $n = 1$ ). Studies were located in early childhood centres ( $n = 10$ ), schools ( $n = 8$ ), and rehabilitation centres ( $n = 6$ ) with the reported age ranges of participants varying between 0–5 years ( $n = 12$ ), 4–13 years ( $n = 4$ ), 5–21 years ( $n = 3$ ), 0–21 years ( $n = 1$ ), and 15–40 years ( $n = 1$ ). Two-thirds of the studies encompassed professionals from the wider education team including health professionals, teachers, school leaders, and service managers along with two studies that included solely physiotherapists. The remaining six studies included a multi-disciplinary healthcare team (Table 2).

### Key elements of collaborative goal setting for disabled children

Data synthesis of the included studies revealed four key elements for collaborative, family-centred goal setting for disabled children in educational settings: (a) adopting a child-

**Figure 1**

*PRISMA Flow Chart of Study Inclusion and Exclusion Process*



Note. CINAHL = Cumulated Index in Nursing and Allied Health Literature; NZCER = New Zealand Council for Educational Research.

**Table 2**  
*Characteristics of Included Studies*

Author(s), date, country, evidence level	Participants (N) children (age), disability type, families (n), professionals (n), context	Collaborative family-centred goal-setting frameworks or approaches <sup>a</sup>	Outcomes for disabled children and families
An et al. (2016) South Korea Expert opinion with case examples	1 male (10 years), 1 female (8 years) Physical disability Families (2) Physiotherapists (2) Outpatient rehabilitation	Four-step model of family professional collaboration: – Mutually agreed-upon goals using the client-centred interview process of the COPM. – Shared planning using visualising, scaling, routine, and activity matrix. – Shared implementation with shared reflection. – Shared evaluation using the COPM modified measure.	– The COPM was easy for families to answer questions. – Families found it more difficult to reflect on scaling questions about progress to goals and a preferred future. – Shows the feasibility of specific strategies to support collaboration.
An et al. (2019a) South Korea Randomised control trial	13 male, 5 female (4–12 years) Physical disability Families (18) Physiotherapists (16) Rehabilitation at hospital/clinic or family's homes	This 4-step model was evaluated by looking at how much professional and family collaboration occurred. Evaluation including referencing seeking, giving, positive behaviour, neutral behaviour, negative behaviour, giving direction, child-related behaviour, no interaction.	– Parents and therapists interact more frequently in goal setting. – Parents were more actively engaged during goal setting and planning.
Boavida et al. (2014) Portugal Training programme review	n unknown (0–21 years) Mixed disabilities Early childhood teachers (21), special education teachers (17), regular teachers (23), therapists (8) General disabilities Early intervention team (38), private non-profit (14), school groups (24), community service (1)	Training programme for professionals completing IEPs: five face-to-face sessions plus one email to learn a full process for IEP or IFSP interview: – Concept and philosophy. – Ecomap of the family and supports and routines-based interview. – Writing of a functional profile with increased knowledge on the use of International Classification of Function.	– Goals and objectives improved. – Use of routines-based interview developed a positive relationship with the family. – Improved information about routines at home.
Byington and Whitby (2011) USA Expert opinion with case examples	1 male (3 years) Physical disability Family (1) Professionals (n unknown) Early childhood centres	Family centred strategies as a framework for increased collaboration in IEPs: – Preparation prior to meeting, setting an agenda with families, bring advocate, start with a blank IEP, review current IEP prior. – IEP process – welcome, parking info, role expectations clear, neutral facilitator, name badges, agenda, guidelines for conduct. – Parent as the expert model. Personalising the meeting – child first, disability second. By doing a personalised presentation.	– Parents need to be empowered to be active members in early intervention. – Preparation pre meetings, increased family's confidence to be the advocate and the expert for their child. – Development of a visual portfolio so the focus is the child not the disability.

Author(s), date, country, evidence level	Participants (M) children (age), disability type, families (n), professionals (n), context	Collaborative family-centred goal-setting frameworks or approaches <sup>a</sup>	Outcomes for disabled children and families
Chambers and Childre (2005b) USA Expert opinion with case examples	1 male (6 years) Autism Family (1) Professionals (n unknown) Primary school	Person-centred planning model "true direction" to provide student centred IEP planning: – Family forms prior to meeting. – Student forms prior to meeting. – Team forms at the meeting.	– A process for collaborative decision making that allows families to feel like they are in true partnership with professionals.
Darrah et al. (2001) Canada Cohort study	5 male, 7 female (18 months–5 years) Cerebral palsy Families (12) Multidisciplinary therapists (n unknown) Outpatient therapy rehabilitation	Family-centred functional therapy as a framework. – Functional goals identified through the COPM by families in a 1:1 meeting. – Observation by the therapist. – Then together family and therapists identify constraints within the child, task, or environment preventing performance.	– Improved achievement of goals. – Families and professionals working on the same aspects.
Darrah et al. (2010) Canada Qualitative study	59 children (0–18 months) Cerebral palsy Parents: mothers (32), fathers (5) Managers (37), occupational therapists (23), physiotherapists (31) All services servicing children with cerebral palsy in rehabilitation and education	Therapists followed the concepts of family-centred service, functional therapy goal setting and coordination between programmes. This was reviewed to see if a standardised family-centred approach as a framework across services was required for collaboration.	– Standardised processes are required to achieve family-centred care and collaborative goal setting. – Checklists were recommended.
Debelak (2020) USA Thesis – mixed methods	n unknown (5–21 years) Mixed disabilities Parents (98) General teachers (88), special education teachers (35), psychologists (4), managers (14), service providers (13) All school systems: Home, day student, or special education	Looked at shared patterns and behaviours to obtain facilitators and barriers to shared decision making in IEP to guide school frameworks to include parents as shared decision makers.	– Mutual respect. – Parent advocates: to assist families through the process. – Communication: honest and open. – Stress and anxiety from parents. – Need for honesty: to move beyond participation to equal partners in decision making. Understand the daily schedule, progress, behaviour. – More informal, collegial relationships with IEP teammates – more frequent and information conversation will allow for a richer understanding of the child's needs.

Author(s), date, country, evidence level	Participants (N) children (age), disability type, families (n), professionals (n), context	Collaborative family-centred goal-setting frameworks or approaches <sup>a</sup>	Outcomes for disabled children and families
Gregg et al. (2011) USA Expert opinion with case example	1 female (5 years) Autism Extended family School professionals (n unknown) Transition from kindergarten to school	Strength-based family-created portfolio "Take a look at me". To be used for person-centred planning and goal setting in a family-centred framework.	<ul style="list-style-type: none"> <li>- Development of the portfolio gave the parent confidence at the IEP meeting to be a key participant.</li> <li>- Family empowerment.</li> <li>- The family filling out the portfolio engaged family and educators in a dialogue about the child that is about the holistic child, not just school activities.</li> </ul>
Hanscom (2015) USA Thesis – multiple single case design	3 male (2, 3, 5 years) Mixed disabilities Family members (1 or 2 per child) Teachers, speech and language therapists, occupational therapists, psychologists, principals (n varied) Early childhood	Development of themes and strategies to increase collaboration for IEPs. Provision of strategies and techniques as a framework to support collective and collaborative education planning.	<ul style="list-style-type: none"> <li>- Strategies for promoting effective collaboration.</li> <li>- Preparation: giving parents information about what to expect at an IEP. Giving info before they arrive at the IEP, not surprising them while there.</li> <li>- Communication: clear, less jargon so it is understood.</li> <li>- Clarity of roles in the meeting so everyone understands.</li> <li>- Collaboration: really depends on the perception of collaboration so this needs to be defined.</li> </ul>
Hebel and Persitz (2014) Israeli Qualitative research	20 children (3–21 months) Severe motor or cognitive disabilities Parents (1 or 2 per child) Teachers (9) Education non-profit organisations	Development of themes and patterns for barriers for parental involvement and collaboration for IEPs supporting a family-centred process.	<ul style="list-style-type: none"> <li>- Provide families with training to increase understanding of special education issues and clarify expectations.</li> <li>- Workshops to support parents to communication and collaborate with teachers: strategies for equal partnerships.</li> <li>- Written information about IEPs.</li> <li>- Leaders/teachers: increase opportunity to communicate with families.</li> <li>- IEP case manager: to support with the paperwork load.</li> <li>- IEP forms in language that is understandable to families.</li> </ul>
Jones et al. (2019) Australia Qualitative research	9 children (3–6 years) ASD Mothers (9) Teachers (5), speech and language therapists (3), occupational therapists (2), family support worker (1) Early childhood centres	Family goal setting tool: Autism Spectrum Disorder version as a framework for goal setting.	<ul style="list-style-type: none"> <li>- A comprehensive approach.</li> <li>- Supported family/professional collaboration.</li> <li>- Assisted with goal prioritisation.</li> <li>- Supported a reduction in stress associated with goal setting.</li> <li>- Practitioners described that the tool empowered families and enabled family-centred practice.</li> </ul>

Author(s), date, country, evidence level	Participants (N) children (age), disability type, families (n), professionals (n), context	Collaborative family-centred goal-setting frameworks or approaches <sup>a</sup>	Outcomes for disabled children and families
Kaczmarek et al. (2004) USA Qualitative research	44 children (unknown ages) Families (44) Early intervention teachers (38), related service providers (16), para professionals (8), early childhood teachers (6) Preschool centre "head start" classrooms	Family consultant model as a family-centred framework. Family consultants act as a liaison between families and professional staff and the broader community.	<ul style="list-style-type: none"> <li>- Model changed over time to be one of parent support for IEPs particularly to support them to fill in pre-IEP forms.</li> <li>- Issues with funding to continue the project.</li> </ul>
McDougall and Wright (2009) Canada Expert opinion	n unknown (unknown ages) Mixed disabilities Families (unknown) Professionals (unknown) Paediatric rehabilitation	International Classification of Function, Child, and Youth (CF-CY) and Goal Attainment Scale (GAS) to set collaborative goals with families.	<ul style="list-style-type: none"> <li>- Identifies the specific aspects of individual functioning and the environmental factors that a client's goals should target for change.</li> <li>- The ICF-CY formed the collaborative approach to determining needs.</li> <li>- The GAS provided the format for goal setting.</li> <li>- Both together allowed understanding how goals are meaningful and interrelated within the overall context of the client's life and long-term development.</li> <li>- Gave insight into family dynamics.</li> <li>- A better understanding of family expectations and where they were headed as a team.</li> <li>- Long-term vision gave them directions for appropriate and needed goals and objectives for the IEP.</li> <li>- Vision statement changes the overall tone of the meetings to be more positive and constructive.</li> <li>- Parents felt empowered because they believe their voices are heard and their values are reflected in the IEP.</li> <li>- "It allowed the parents to feel more a member of the team, feel respected by the team, and feel prepared."</li> </ul>
Meadan et al. (2010) USA Expert opinion with case examples	1 male (13 years), 1 female (6 years) Down Syndrome (1) Learning disabilities (1) Family Professionals Education	Person-centred planning for students and families. A team approach to problem solving by developing a holistic long-term vision. This is a destination for 3–5 years serving as a map for other goals. Described five approaches to person-centred planning and long-term goal setting: <ul style="list-style-type: none"> <li>- Circle of friends.</li> <li>- Choosing outcomes and accommodations for children.</li> <li>- Group action planning.</li> <li>- Making action plans.</li> <li>- Planning alternative tomorrow with hope.</li> </ul>	<ul style="list-style-type: none"> <li>- Beneficial for conflict prevention and resolution between families and educators; encouraged active parent participation through consensus building.</li> </ul>
Mueller and Vick (2019) USA Qualitative research	n unknown (15–40 years) Mixed disabilities Families (7) Administrators (8), facilitators (6), parent advocates (4), educators/facilitators (5), administrators/facilitators (2) Education and community homes	Facilitated IEP process as a framework for goal setting. Used a neutral facilitator and meaningful procedures intended to encourage family and professional IEP team members to collaboratively develop a meaningful educational program for students with disabilities.	<ul style="list-style-type: none"> <li>- Beneficial for conflict prevention and resolution between families and educators; encouraged active parent participation through consensus building.</li> </ul>

Author(s), date, country, evidence level	Participants (N) children (age), disability type, families (n), professionals (n), context	Collaborative family-centred goal-setting frameworks or approaches <sup>a</sup>	Outcomes for disabled children and families
Øien et al. (2009) Norway Qualitative research	9 male (23–50 months), 4 female Cerebral palsy Families (13) Service providers (13) Paediatric rehabilitation	COPM and GAS to structure a collaborative goal-setting process.	<ul style="list-style-type: none"> <li>– COPM supported the collaborative assessment.</li> <li>– GAS supported the joint process of goal writing and attainment.</li> <li>– Parents perceived themselves as drivers of the process and incorporated the child's perspectives in goal setting.</li> <li>– Parental perspectives were expressed and made into concrete goals.</li> <li>– Professionals' attitudes showed a commitment to the parents leading the process and partnerships.</li> <li>– Very few sound theoretical frameworks for goal setting in rehabilitation.</li> <li>– Principles of family-centred provides strong rationale for collaborative practice.</li> <li>– Self-determination theories show children are more engaged and focused if they are part of goal setting, but this is not well described.</li> <li>– Provided a clear yet flexible structure for both parental goal identification and prioritisation.</li> <li>– It still requires family-centred practices to be truly collaborative.</li> <li>– If parents are to be "true" partners with professionals in assisting their children's development, conscious effort on the part of professionals is required on top of this process.</li> <li>– Greater ease in goal setting.</li> <li>– Reduced parental anxiety.</li> <li>– Promoted more multi-disciplinary focus.</li> <li>– Allowed for a strength-based focus.</li> <li>– Increased the holistic approach to setting goals.</li> <li>– Empowered families, increasing their ownership of goals.</li> </ul>
Pritchard-Wiart and Phelan (2018) Canada Scoping review	n unknown (0–21 years) Physical disabilities Professionals (unknown) Paediatric rehabilitation	Reviewed papers that looked at family-centred care, goal-setting theory, social cognitive theory, mastery motivational, personal construct theory, self-determination theory.	
Rodger et al. (2004) Australia Cohort study	17 male, 5 female (27–49 months) Autism Families (22) Home facilitators: Doctoral students (22) Home-based early intervention	Modified COPM as a framework for goal setting.	
Rodger et al. (2012) Australia Qualitative research	8 children Mixed disabilities Parents (8) Occupational therapists (2), speech and language therapists (2), speech and language pathologists (2), psychologists (2), social workers (2), programme officers (2) Early childhood	Family goal-setting tool with four key themes: <ul style="list-style-type: none"> <li>– The facilitation of goal setting.</li> <li>– Strengths-based focus.</li> <li>– Family-centred processes.</li> <li>– Empowerment of families.</li> </ul>	



Author(s), date, country, evidence level	Participants (M) children (age), disability type, families (n), professionals (n), context	Collaborative family-centred goal-setting frameworks or approaches <sup>a</sup>	Outcomes for disabled children and families
Skouge et al. (2007) Hawaii Expert opinion with case examples	1 male (12 years) Development disabilities Family (1) Professionals (unknown) IEP transition to college	Use of a multimedia portfolio to give a voice to youth and their families – a self-determination model as part of family-centred practice.	<ul style="list-style-type: none"> <li>– Student-led presentation of their skills led to a more collaborative IEP process.</li> <li>– Child and parent were at the centre of planning.</li> <li>– Increased collaboration and consultation with families.</li> </ul>
Weatherill et al. (2012) Australia Qualitative research	7 children (5–16 years) Mixed disabilities Parents (7) Principals or teachers (7), physiotherapists (2), occupational therapists (3), speech and language therapists (3), service providers (2) School-aged therapy services	Reviewed four current models/frameworks of practice: <ul style="list-style-type: none"> <li>– Life Needs Model (LNM): A holistic design for transition points.</li> <li>– Relational goal-orientated model: A family-centred collaborative system to set goals.</li> <li>– Quality of life model: Setting of short-, medium-, and long-term goals for child participation.</li> <li>– Collaborative model of service delivery: based on family centred.</li> </ul> Produced a “bespoke” programme design for school-aged therapy service delivery including goal setting in a child-centred process.	Child or parent is at the centre as the experts. Increased collaboration.
Wells and Sheehy (2012) Hawaii Expert opinion	n unknown (5–21 years) Mixed disabilities Families (unknown) Professionals (unknown) School services for transition IEPs	MAPS – model/framework of person-centred planning used to engage parents in the planning process for IEPs.	Increase active participation by parents and students.
Whitbread et al. (2007) USA Training programme review	n unknown (5–21 years) Mixed disabilities Parents and educators (1328) Education	Description of training as a framework to foster collaborative partnerships with parent and professionals: Steps in the special education process. Laws and process affecting special education. The IEP. Person-centred planning. Family–school partnerships.	Addressed the training needs of parents and educators. Increased a positive outlook on future collaboration.

Note. COPM = Canadian Occupational Performance Measure; GAS = Goal Attainment Scale; IEP = independent education plan; IFSP = individualized family service plan; MAPS = making action plans.

<sup>a</sup> Conceptual/theoretical frameworks used for parent collaboration in goal setting; and, family-centred processes as a framework, utilised in goal setting.

centred approach to enhance the child's strengths and dreams; (b) using goal-setting tools to identify the child's current ability; (c) applying structured processes to achieve collaborative FCP; and (d) accessing external support during collaborative, family-centred goal setting. These key elements for collaborative goal setting are outlined below.

### *Adopting a child-centred approach to enhance the child's strengths and dreams*

A child-centred approach to FCP, such as focusing on the child's strengths and dreams, was described across six studies and was reported to be an important ingredient in the development of holistic and collaborative goals (Chambers & Childre, 2005a; Gregg et al., 2011; Meadan et al., 2010; Skouge et al., 2007; Weatherill et al., 2012; Wells & Sheehey, 2012). Weatherill et al. (2012) describe how a focus on the child's strengths and abilities improved relationship building and trust by highlighting to families that professionals understood their child and that their child was at the heart of the goal-setting process. While Chambers and Childre (2005a) showed that a child-centred strengths-based emphasis ensured that the child's interests and dreams were the focus for family-professional discussions, they also noted that using structured methods, such as a framework, helped to ensure a child-centred approach. Similarly, two studies reported that incorporating a structured portfolio that was family led and illustrated the needs and dreams of not only the child but the wider family, was holistic and supported child self-determination (Chambers & Childre, 2005a; Gregg et al., 2011; Skouge et al., 2007). In these studies reporting child-centred care, families felt empowered and more confident in the goal-setting process, which enhanced collaboration between families and professionals (Chambers & Childre, 2005a; Gregg et al., 2011; Meadan et al., 2010; Skouge et al., 2007; Weatherill et al., 2012; Wells & Sheehey, 2012).

### *Using goal-setting tools to identify the child's current ability*

Goal-setting assessment tools were frequently used ( $n = 9$  studies) to provide a structured and supportive approach for collaboration between families and professionals. The assessment tools reported across the included studies were the Canadian Occupational Performance Measure (COPM) (An et al., 2016; An et al., 2019a; Darrah et al., 2001; Jones et al., 2019; McDougall & Wright, 2009; Nguyen et al., 2021; Roger et al., 2004), the Goal Attainment Scale (GAS), the International Classification of Function, Child, and Youth (ICF-CY) (McDougall & Wright, 2009; Øien et al., 2009), the Functional Goal Setting Tool (FGST), and the Functional Goal Setting Tool: Autism Spectrum Disorder version (FGST: ASD) ( $n = 2$ ) (Jones et al., 2019; Roger et al., 2012).

All goal-setting tools were valid and reliable objective measures used to either investigate or evaluate specific goals. The COPM was shown to support families to identify their child's current ability alongside a therapist and to provide a direction for goal setting (An et al., 2016; An et al., 2019a; Darrah et al., 2001; Jones et al., 2019; McDougall & Wright, 2009; Nguyen et al., 2021; Roger et al., 2004), while the GAS and FGST, rather than reviewing current ability, supported families to set the goals (McDougall & Wright, 2009; Øien et al., 2009). The authors of these studies indicate that the use of these

objective measures added value to the goal-setting process. Families found the COPM easy to use, which supported active engagement during goal setting (An et al., 2016; An et al., 2019b). Darrah et al. (2001) indicated goals were more readily achieved as families and professionals were working together on the same success criteria for goal achievement. Studies that used the FGST and FGST: ASD Version found that the objective measures facilitated a holistic, family-orientated strength-based goal-setting approach (Jones et al., 2019; Roger et al., 2012). This, in turn, supported collaborative family-centred processes while prioritising goals (Jones et al., 2019). Two studies report improved holistic collaboration when the GAS was used in conjunction with other objective measures such as the COPM or ICF-CY, and parents felt the process enhanced their autonomy and partnership with the therapists and education team (McDougall & Wright, 2009; Øien et al., 2009). Furthermore, the goals were meaningful and interrelated to the child's life and long-term development.

### *Applying structured processes to achieve collaborative family-centred practice*

Seven studies highlighted structured processes that specifically focused on collaborative FCP (An et al., 2016; An et al., 2019b; Boavida et al., 2014; Byington & Whitby, 2011; Hanscom, 2015; Hebel & Persitz, 2014; Whitbread et al., 2007). Processes for promoting FCP included a four-step family-centred model (An et al., 2016, 2019b), using checklists to set up and run goal-setting meetings (Byington & Whitby, 2011; Darrah et al., 2010; Hanscom, 2015), and specific training for professionals and families (Boavida et al., 2014; Hebel & Persitz, 2014; Whitbread et al., 2007). Similar concepts were shared across the family-centred processes: the importance of knowledge and education regarding the individual's roles and processes, the need for clear communication, and the use of structured strategies for collaborative FCP.

Four papers illustrated that collaboration between families and professionals was dependent upon their knowledge of family-centred practices, their understanding of the purpose of the goal-setting process, and the individual's perception of collaboration (Boavida et al., 2014; Hanscom, 2015; Hebel & Persitz, 2014; Whitbread et al., 2007). Family-centred practices were reported to improve when there was clarity on roles during goal setting (Byington & Whitby, 2011; Hanscom, 2015; Whitbread et al., 2007). When families and professionals were educated about goal setting, they had a similar understanding of the processes, roles, and outcome expectations (Boavida et al., 2014; Whitbread et al., 2007). Other studies reported that comprehensive training for professionals improved their interviewing and communication skills (An et al., 2019b; Boavida et al., 2014). Furthermore, studies where families felt empowered as the expert of their child reported an increase in family participation in goal setting and school activities (Byington & Whitby, 2011; Hebel & Persitz, 2014).

Four papers reported family-centred practices were enhanced when communication was clear and transparent, such as when the meeting agenda for goal setting was set in advance by both the family and professionals (Byington & Whitby, 2011; Hanscom, 2015; Whitbread et al., 2007). In addition, An et al. (2016, 2019b) described structured strategies that were

also beneficial for collaborative FCP and parent participation, for example, agreeing on goals with the use of the COPM and shared planning for goal achievement. Further strategies included finding a mutually convenient time for all participants, ensuring the establishment of a relationship prior to the meeting, incorporating a wider view of long-term dreams, using set processes for meetings (An et al., 2016; Roger et al., 2004), and using checklists before, during, and after collaborative goal setting (Byington & Whitby, 2011).

### Accessing external support during collaborative family-centred goal setting

The use of an external facilitator was described by three papers to support the goal-setting process and was deemed beneficial for collaborative FCP (Byington & Whitby, 2011; Kaczmarek et al., 2004; Mueller et al., 2019). Facilitators were equipped with extra skills in communication, listening, and mediation, which improved communication between parents and professionals. In two papers, a neutral external facilitator empowered families and professionals to work collaboratively, especially if there was any form of conflict, and provided an atmosphere that was both fair and inclusive of all parties (Kaczmarek et al., 2004; Mueller & Vick, 2019). A novel example was illustrated in Kaczmarek et al. (2004), namely a family consultant model in which the facilitator was a family representative within the wider

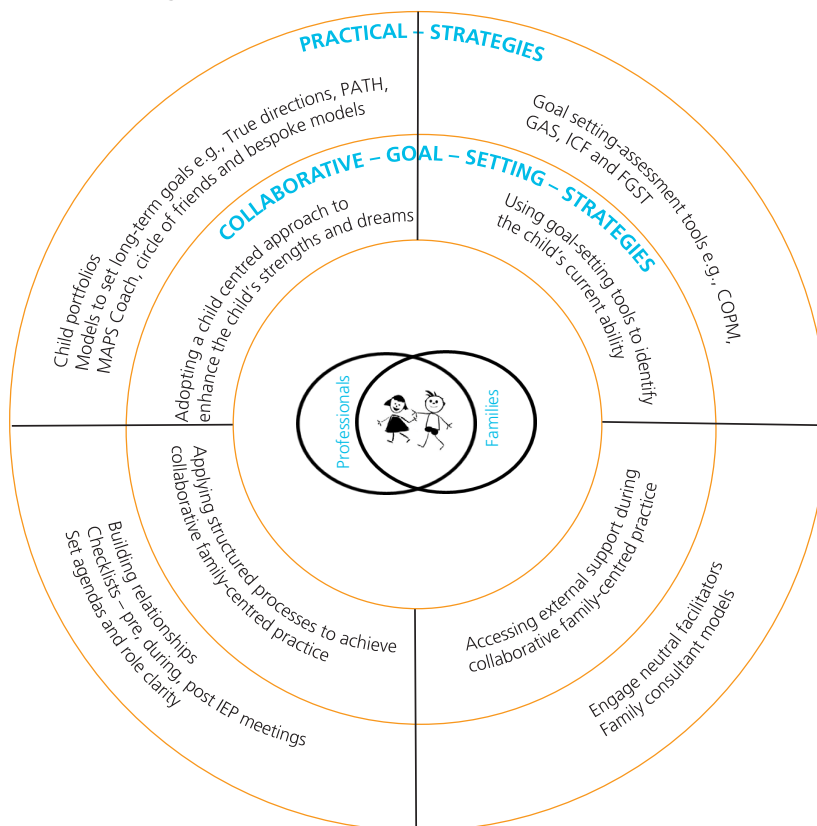
community who liaised with the professionals. The facilitator (family advocate) supported families to prepare, to actively participate in the goal-setting meetings, and ensured the family had an opportunity to voice their concerns and prioritise their child's needs (Byington & Whitby, 2011; Kaczmarek et al., 2004; Mueller & Vick, 2019).

### New collaborative family-centred goal-setting model

The results of this scoping review illustrate a complex picture of key elements for collaborative family-centred goal setting for disabled children in educational settings. We present a novel model of collaborative family-centred goal setting (Figure 2), which connects and expands the four key elements derived from the data to support the clinical practice of professionals (i.e., therapists and educators). The new model is built upon the founding principles of FCP, with the child at the centre of the model supported by the expertise of both family and professionals. Collaborative family-centred goal-setting constructs (represented by the four key elements as identified in this review) surround the child, family, and professionals. The outer layer of the model provides practical strategies for application derived from the included studies for use by professionals for collaborative family-centred goal setting for disabled children.

**Figure 2**

*Evidenced-based Collaborative Goal Setting Model*



Note. COPM = Canadian Occupational Performance Measure; FGST = Functional Goal Setting Tool; GAS = Goal Attainment Scale; ICF = International Classification of Functioning Disability and Health; MAPS = making action plans; PATH = plan alternative tomorrow with hope.

## DISCUSSION

The purpose of this scoping review was to collate, summarise, and synthesise collaborative goal-setting frameworks and/or approaches for disabled children and their families and provide recommendations for practice. A strength of this study was integrating the key collaborative elements into a model to support practice. The overarching global terminology of FCP was evident across many papers. FCP needs to be unpacked in any organisation to ensure there are effective processes in place. Processes may include checklists for meetings, orientation for staff, appropriate meeting spaces, role clarity, and processes for building trusted relationships. The findings from this review reflect Graham et al.'s work (2018, 2021) on occupational performance coaching (OPC), which did not feature with our search criteria. The fundamental process in OPC is "listening better". Graham et al. (2021) support the use of high-trust partnerships, collaboration, sustainable goals that are about families' dreams, and engagement that is autonomous, features that are also seen in our model of collaborative practice.

Many studies in this scoping review identified that to set short-term goals it is important to first understand the current skills of the child, to know their dreams for the future, and to focus on long-term planning. The use of standardised assessment tools provides a structure for effective communication between families and professionals that enables each party to understand their role in the collaboration (Bronstein, 2003). For example, goal-setting systems, such as the COPM, support families to see the child's current level of ability, which facilitates collaborative goal setting. Likewise, structured tools such as the GAS support professionals and families to navigate where their child is at and where they wish to go next. Maher (1983) recommends the GAS as a practical method to evaluate educational services for disabled children and was positive about the goal-setting flexibility. Carr (2016) notes that 33 years after its conception, the GAS remains an effective, accountable, and efficient process to use in an educational setting. However, the GAS has had a slow uptake in education. Tennant (2007) proposes this may be due to the rigorous training programme that is required for staff and families to be able to define and agree on the expected levels of achievement in order to use the GAS successfully.

The user-friendliness of complex structured goal-setting tools should be considered when in use. Tools such as the FGST and FGST: ASD Version require less training since they simply use pictures or visual supports to prompt families to consider a variety of ideas for goals and to prioritise needs. The pedagogy of visual tools is commonly recommended and widely used within special education (Knight et al., 2014; Schlosser et al., 2020). Visual tools provide an easy format for communication with families and may support them to feel like they are the experts about their child and allow their voice to be heard (Wiat et al., 2010).

As well as careful consideration of the chosen assessment tool, this scoping review has illustrated the merit of external facilitators for enhancing collaborative family-centred goal setting. External facilitators can support professionals and families in shared decision making and promote active parent participation (Mueller & Vick, 2017). When we are "in the moment", particularly if highly emotive, we often do not listen

to hear, but listen to speak (Dalton, 2010, 2011). Facilitators can support all participants to stop and listen to one another, facilitating dedicated space and time to collaborate (Schot et al., 2019). As shown in this review, family advocates are an alternative to an external facilitator and can assist with similar processes. Tucker and Schwartz (2013) report the families' desire for an advocate to support the understanding of their life outside of school. Advocates can support families through knowledge of collaborative goal-setting environments such as IEPs and special education (Burke & Goldman, 2018; Gershwin & Vick, 2019). Provision of support for navigating the goal-setting processes is crucial for culturally and linguistically diverse families who may have extra barriers to understanding (Burke & Goldman, 2018; Rossetti et al., 2018; Tucker & Schwartz, 2013). The importance of providing training for external facilitators and advocates has been highlighted in past literature (Burke & Goldman, 2018; Gershwin & Vick, 2019; Goldman & Burke, 2017; Goldman et al., 2020) and was apparent in this review. Finding a balance in which the family feels empowered, rather than disempowered by the "expert" advocate is critical, since feelings of disempowerment lead to less contribution (Burke & Goldman, 2018; Gershwin & Vick, 2019). Evidence of long-term sustainable funding for external facilitators of collaborative goal setting is lacking. However it has been noted that within schools, impartial and neutral professional staff may be able to take on the facilitation role (Mueller & Vick, 2017). A structured model to guide collaborative goal setting, such as presented in this review, may assist external facilitators and family advocates by providing a clear set of strategies to discuss with the family.

## LIMITATIONS

Scoping reviews, by their nature, are limited with the research not being appraised but assimilated; therefore, there is a component of author interpretation (Arksey & O'Malley, 2005). A third of the studies were expert opinions, which are valid but less scientifically robust – which adds to the limitations of the scoping review. Over half the studies were from the USA and Canada where the IEP system is legislated, and this may not translate to other countries with different IEP policy requirements or into the wider rehabilitation setting.

We were unable to register our scoping review because at the time of the protocol development there was no platform available to do so. Further robust scientific evidence such as randomised control trials, cohort studies, or qualitative research is required to validate the frameworks recommended in the expert opinion studies and our newly developed collaborative goal-setting model.

## CONCLUSION

This scoping review aimed to explore key features and application of collaborative family-centred goal-setting frameworks used in an educational context for disabled children and their families. We have illustrated the diversity of goal-setting frameworks and identified processes that may be used to increase overall FCP including checklists for meetings, orientation for staff, appropriate meeting spaces, role clarity, and processes for building trusted relationships. A model of collaborative goal setting for disabled children has been developed using the four interconnecting collaborative

constructs for supporting goal setting in an educational context identified in this scoping review. Practical recommendations for professionals working with disabled children and their families in education were provided. Future research should seek to explore these areas in greater detail to add to the small body of knowledge about collaborative goal setting, including IEP processes and FCP for disabled children and their families.

## KEY POINTS

This scoping review has illustrated key elements of collaborative goal setting including:

1. family-centred practice as a key component to collaborative goal setting
2. family-centred goal setting as a strength-based, short-term goal setting reflecting the child's long-term dreams
3. structured processes to achieve collaborative goal setting (i.e., using standardised outcome measures)
4. engagement of external facilitators that may support families during goal setting.

## DISCLOSURES

No funding source for this research. The first author (LR) works in a specialist school in a leadership capacity. There are no conflicts of interest that may be perceived to interfere with or bias this study.

## PERMISSIONS

None.

## CONTRIBUTIONS OF AUTHORS

Design conceptualisation, software use, data curation, project administration, LR; supervision, AC and LC; methodology, validation, analysis, writing – original, review and editing, visualisation, LR, AC and LC.

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## REFERENCES

- An, M., Palisano, R. J., Dunst, C. J., Chiarello, L. A., Yi, C.-H., & Gracely, E. J. (2016). Strategies to promote family-professional collaboration: Two case reports. *Disability and Rehabilitation, 38*(18), 1844–1858. <https://doi.org/10.3109/09638288.2015.1107763>
- An, M., Palisano, R. J., Yi, C. H., Chiarello, L. A., Dunst, C. J., & Gracely, E. J. (2019a). Effects of a collaborative intervention process on parent-therapist interaction: A randomized controlled trial. *Physical & Occupational Therapy In Pediatrics, 39*(3), 259–275. <https://doi.org/10.1080/01942638.2018.1496965>
- An, M., Palisano, R. J., Yi, C. H., Chiarello, L. A., Dunst, C. J., & Gracely, E. J. (2019b). Effects of a collaborative intervention process on parent empowerment and child performance: A randomized controlled trial. *Physical & Occupational Therapy In Pediatrics, 39*(1), 1–15. <https://doi.org/10.1080/01942638.2017.1365324>
- Andersen, C. S., & Dolva, A.-S. (2015). Children's perspective on their right to participate in decision-making according to the United Nations Convention on the Rights of the Child article 12. *Physical & Occupational Therapy in Pediatrics, 35*(3), 218–230. <https://doi.org/10.3109/01942638.2014.918075>
- Andrade, P. M. O., Haase, V. G., & Oliveira-Ferreira, F. (2012). An ICF-based approach for cerebral palsy from a biopsychosocial perspective. *Developmental Neurorehabilitation, 15*(6), 391–400. <https://doi.org/10.3109/17518423.2012.700650>
- Andrews, E. E., Powell, R. M., & Ayers, K. (2022). The evolution of disability language: Choosing terms to describe disability. *Disability and Health Journal, 15*(3), Article 101328. <https://doi.org/10.1016/j.dhjo.2022.101328>
- Angeli, J. M., Schwab, S. M., Huijs, L., Sheehan, A., & Harpster, K. (2021). ICF-inspired goal-setting in developmental rehabilitation: An innovative framework for pediatric therapists. *Physiotherapy Theory and Practice, 37*(11), 1167–1176. <https://doi.org/10.1080/09593985.2019.1692392>
- Arango, P. (2011). Family-centered care. *Academic Pediatrics, 11*(2), 97–99. <https://doi.org/10.1016/j.acap.2010.12.004>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Blietz, J. L. (1988). *The effect of parent training on increasing parent understanding of, participation in, and satisfaction with the individualized education program (IEP) conference* (Order No. 1988.8824915) [Doctoral dissertation, University of Nebraska]. ProQuest Dissertations & Theses Global. <https://www.proquest.com/dissertations-theses/effect-parent-training-on-increasing/docview/303568019/se-2>
- Boavida, T., Aguiar, C., & McWilliam, R. A. (2014). A training program to improve IFSP/IEP goals and objectives through the routines-based interview. *Topics in Early Childhood Special Education, 33*(4), 200–211. <https://doi.org/10.1177/0271121413494416>
- Botha, M., Hanlon, J., & Williams, G. L. (2023). Does language matter? Identity-first versus person-first language use in autism research: A response to Vivanti. *Journal of Autism and Developmental Disorders, 53*(2), 870–878. <https://doi.org/10.1007/s10803-020-04858-w>
- Brinckerhoff, J. L., & Vincent, L. J. (1986). Increasing parental decision-making at the individualized educational program meeting. *Journal of the Division for Early Childhood, 11*(1), 46–58. <https://doi.org/10.1177/105381518601100105>
- Bronstein, L. R. (2003). A model for interdisciplinary collaboration. *Social Work, 48*(3), 297–306. <https://doi.org/10.1093/sw/48.3.297>
- Burke, M. M., & Goldman, S. E. (2018). Special education advocacy among culturally and linguistically diverse families. *Journal of Research in Special Educational Needs, 18*(S1), 3–14. <https://doi.org/10.1111/1471-3802.12413>
- Byington, T. A., & Whitby, P. J. S. (2011). Empowering families during the early intervention planning process. *Young Exceptional Children, 14*(4), 44–56. <https://doi.org/10.1177/1096250611428878>
- CanChild. (2024a). *F-words in childhood disability*. McMaster University. <https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability>
- CanChild. (2024b). *ICF resources*. McMaster University. <https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability/icf-resources>
- Carmen, S., Teal, S., & Guzzetta, C. E. (2008). Development, testing, and national evaluation of a pediatric patient-family-centered care benchmarking survey. *Holistic Nursing Practice, 22*(2), 61–74. <https://doi.org/10.1097/01.HNP.0000312653.83394.57>
- Carr, R. A. (2016). Goal attainment scaling as a useful tool for evaluating progress in special education. *Exceptional Children, 46*(2), 88–95. <https://doi.org/10.1177/001440297904600202>
- Casagrande, K. A., & Ingersoll, B. R. (2017). Service delivery outcomes in ASD: Role of parent education, empowerment, and professional partnerships. *Journal of Child and Family Studies, 26*(9), 2386–2395. <https://doi.org/10.1007/s10826-017-0759-8>
- Castleberry, A., & Nolen, A. (2018). Thematic analysis of qualitative research data: Is it as easy as it sounds? *Currents in Pharmacy Teaching and Learning, 10*(6), 807–815. <https://doi.org/10.1016/j.cptl.2018.03.019>

- Chambers, C. R., & Childre, A. L. (2005a). Fostering family-professional collaboration through person-centered IEP meetings: The "true directions" model. *Young Exceptional Children*, 8(3), 20–28. <https://doi.org/10.1177/109625060500800304>
- Childre, A., & Chambers, C. R. (2005b). Family perceptions of student centered planning and IEP meetings. *Education & Training in Developmental Disabilities*, 40(3), 217–233.
- Clark, P., & MacArthur, J. (2008). Children with physical disability: Gaps in service provision, problems joining in. *Journal of Paediatrics and Child Health*, 44(7–8), 455–458. <https://doi.org/10.1111/j.1440-1754.2008.01327.x>
- Curryer, B., Stancliffe, R. J., & Dew, A. (2015). Self-determination: Adults with intellectual disability and their family. *Journal of Intellectual & Developmental Disability*, 40(4), 394–399. <https://doi.org/10.3109/13668250.2015.1029883>
- Dalton, J. (2010). *Learning talk 1: Build understandings*. Hands On Educational Consultancy Pty Ltd.
- Dalton, J. (2011). *Learning Talk 3: Build capabilities*. Hands On Educational Consultancy Pty Ltd.
- Darrah, J., Law, M., & Pollock, N. (2001). Family-centered functional therapy – A choice for children with motor dysfunction. *Infants & Young Children*, 13(4), 79–87. <https://doi.org/10.1097/00001163-200113040-00014>
- Darrah, J., Wiart, L., Magill-Evans, J., Ray, L., & Andersen, J. (2010). Are family-centred principles, functional goal setting and transition planning evident in therapy services for children with cerebral palsy? *Child: Care, Health and Development*, 38(1), 41–47. <https://doi.org/10.1111/j.1365-2214.2010.01160.x>
- Debelak, A. (2020). Facilitators and barriers to shared decision-making during IEP meetings [Doctoral dissertation, University of Cincinnati]. OhioLINK Electronic Theses and Dissertations Center. [http://rave.ohiolink.edu/etdc/view?acc\\_num=ucin1504781569291269](http://rave.ohiolink.edu/etdc/view?acc_num=ucin1504781569291269)
- de Bruin, K. (2019). The impact of inclusive education reforms on students with disability: An international comparison. *International Journal of Inclusive Education*, 23(7–8), 811–826. <https://doi.org/10.1080/13603116.2019.1623327>
- Education Review Office. (2022, September 28). *Thriving at school? Education for disabled learners in schools*. <https://ero.govt.nz/our-research/thriving-at-school-education-for-disabled-learners-in-schools>
- Edwards, A. G., Brebner, C. M., McCormack, P. F., & MacDougall, C. J. (2018). From 'parent' to 'expert': How parents of children with autism spectrum disorder make decisions about which intervention approaches to access. *Journal of Autism and Developmental Disorders*, 48(6), 2122–2138. <https://doi.org/10.1007/s10803-018-3473-5>
- Gernsbacher, M. A. (2017). Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58(7), 859–861. <https://doi.org/10.1111/jcpp.12706>
- Gershwin, T., & Vick, A. M. (2019). Ally versus adversary behaviors: The utility of a special education advocate during conflict between parents and professionals. *Journal of Disability Policy Studies*, 29(4), 195–205. <https://doi.org/10.1177/1044207319825497>
- Goldman, S. E., & Burke, M. M. (2017). The effectiveness of interventions to increase parent involvement in special education: A systematic literature review and meta-analysis. *Exceptionality*, 25(2), 97–115. <https://doi.org/10.1080/09362835.2016.1196444>
- Goldman, S. E., Goscicki, B. L., Burke, M. M., & Hodapp, R. M. (2020). Developing special education advocates: What changes during an advocacy training program? *Journal of Policy and Practice in Intellectual Disabilities*, 17(4), 308–317. <https://doi.org/10.1111/jppi.12345>
- Graham, F., Boland, P., Ziviani, J., & Rodger, S. (2018). Occupational therapists' and physiotherapists' perceptions of implementing occupational performance coaching. *Disability and Rehabilitation*, 40(12), 1386–1392. <https://doi.org/10.1080/09638288.2017.1295474>
- Graham, F., Kennedy-Behr, A., & Ziviani, J. (2021). *Occupational performance coaching: A manual for practitioners and researchers* (1st ed.). Routledge.
- Gregg, K., Rugg, M., & Souto-Manning, M. (2011). Fostering family-centered practices through a family-created portfolio. *School Community Journal*, 21(1), 53–70. <https://files.eric.ed.gov/fulltext/EJ932200.pdf>
- Hanscom, H. P. (2015). *Working together: The individual and collective experiences of a special education team* (Publication No. 3704438) [Doctoral dissertation, Northeastern University]. Digital Repository Service. <http://hdl.handle.net/2047/D20193821>
- Hebel, O., & Persitz, S. (2014). Parental involvement in the individual educational program for Israeli students with disabilities. *International Journal of Special Education*, 29(3), 58–68. <https://eric.ed.gov/?id=EJ1045957>
- Hirsch, S. A. (2004). *The impact of parent education on participation and satisfaction in multidisciplinary meetings for specific learning disabilities* [Doctoral dissertation, Oklahoma State University]. OSU Dissertations. <https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=9bd7365fd7ad367791d591c83c4e429aa6966985>
- Hodge, N., & Runswick-Cole, K. (2008). Problematising parent-professional partnerships in education. *Disability & Society*, 23(6), 637–647. <https://doi.org/10.1080/09687590802328543>
- Jessop, K. L. (2018). *Parental perceptions of preparation and readiness for meaningful engagement in the initial IEP meeting: The case of mid-town school district* (Publication No. 10817642) [Bachelor's dissertation, Doane University]. ProQuest Dissertations & Theses Global. <https://www.proquest.com/openview/f34d0bb68ea3c54f56f3950a18405738/1?pq-origsite=gscholar&cbl=18750>
- Jolley, J. & Shields, L. (2009). The evolution of family-centred care. *Journal of Pediatrics*, 24(2), 164–170. <https://doi.org/10.1016/j.pedn.2008.03.010>
- Jones, J., Rodger, S., Walpole, A., & Bobir, N. (2019). Holding the cards: Empowering families through an ASD family goal setting tool. *Topics in Early Childhood Special Education*, 39(2), 117–130. <https://doi.org/10.1177/0271121418766240>
- Kaczmarek, L. A., Goldstein, H., Florey, J. D., Carter, A., & Cannon, S. (2004). Supporting families: A preschool model. *Topics in Early Childhood Special Education*, 24(4), 213–226. <https://doi.org/10.1177/02711214040240040301>
- King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: A review of the literature. *Seminars in Pediatric Neurology*, 11(1), 78–86. <https://doi.org/10.1016/j.spen.2004.01.009>
- Knight, V., Sartini, E., & Spriggs, A. D. (2014). Evaluating visual activity schedules as evidence-based practice for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 45(1), 157–178. <https://doi.org/10.1007/s10803-014-2201-z>
- Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal Child Health Journal*, 16, 297–305. <https://doi.org/10.1007/s10995-011-0751-7>
- Kurth, J. A., McQueston, J. A., Ruppert, A. L., Toews, S. G., Johnston, R., & McCabe, K. M. (2019). A description of parent input in IEP development through analysis IEP documents. *Intellectual and Developmental Disabilities*, 57(6), 485–498. <https://doi.org/10.1352/1934-9556-57.6.485>
- Maher, C. A. (1983). Goal attainment scaling: A method for evaluating special education services. *Exceptional Children*, 49(6), 529–536. <https://doi.org/10.1177/001440298304900606>
- Marshall, D., & Goodall, C. (2015). The right to appropriate and meaningful education for children with ASD. *Journal of Autism & Developmental Disorders*, 45(10), 3159–3167. <https://doi.org/10.1007/s10803-015-2475-9>
- Martinuzzi, A., De Polo, G., Bortolot, S., & Pradal, M. (2015). Pediatric neurorehabilitation and the ICF. *NeuroRehabilitation*, 36(1), 31–36. <https://doi.org/10.3233/NRE-141188>
- McDougall, J., & Wright, V. (2009). The ICF-CY and goal attainment scaling: Benefits of their combined use for pediatric practice. *Disability and Rehabilitation*, 31(16), 1362–1372. <https://doi.org/10.1080/09638280802572973>

- Meadan, H., Shelden, D. L., Appel, K., & DeGrazia, R. L. (2010). Developing a long-term vision: A road map for students' futures. *Teaching Exceptional Children, 43*(2), 8–14. <https://doi.org/10.1177/004005991004300>
- Ministry of Education. (2011). *Collaboration for success: Individual education plans*. <https://seonline.tki.org.nz/Media/Files/A-K/IEP-Online/Collaboration-for-Success-Individual-Education-Plans>
- Ministry of Education. (2017). *Ongoing resourcing scheme (ORS)*. <https://www.education.govt.nz/school/student-support/special-education/ors/>
- Monk, R. (2022). *Autism terminology guidance from the autistic community of Aotearoa New Zealand: A living resource created by Autistic people with the support of Austism New Zealand*. Autism New Zealand. <https://autismnz.org.nz/resources/autism-terminology-resource-april-2022/>
- Mueller, T. G., Massafra, A., Robinson, J., & Peterson, L. (2019). Simulated individualized education program meetings: Valuable pedagogy within a preservice special educator program. *Teacher Education and Special Education, 42*(3), 209–226. <https://doi.org/10.1177/0888406418788920>
- Mueller, T. G., & Vick, A. M. (2017). An investigation of facilitated individualized education program meeting practice: Promising procedures that foster family–professional collaboration. *Teacher Education and Special Education, 42*(1), 67–81. <https://doi.org/10.1177/0888406417739677>
- Mueller, T. G., & Vick, A. M. (2019). Rebuilding the family–professional partnership through facilitated individualized education program meetings: A conflict prevention and resolution practice. *Journal of Educational and Psychological Consultation, 29*(2), 99–127. <https://doi.org/10.1080/10474412.2018.1470934>
- Mweshi, M. M. (2016). Use of the International Classification of Functioning, Disability and Health—Children and Youth (ICF-CY) in the management of children with disabilities. *International Journal of Neurologic Physical Therapy, 2*(1), 5–11.
- New Zealand Government. (2016). *New Zealand disability strategy 2016–2026*. <https://www.odi.govt.nz/nz-disability-strategy/>
- New Zealand Government. (2019, November). *The disability action plan 2019–2023*. <https://www.odi.govt.nz/disability-action-plan-2/>
- Nguyen, L., Cross, A., Rosenbaum, P., & Gorter, J. W. (2021). Use of the International Classification of Functioning, Disability and Health to support goal-setting practices in pediatric rehabilitation: A rapid review of the literature. *Disability and Rehabilitation, 43*(6), 884–894. <https://doi.org/10.1080/09638288.2019.1643419>
- O'Connor, D., Lynch, H., & Boyle, B. (2021). A qualitative study of child participation in decision-making: Exploring rights-based approaches in pediatric occupational therapy. *PLoS ONE, 16*(12), Article e0260975. <https://doi.org/10.1371/journal.pone.0260975>
- Øien, I., Fallang, B., & Østensjo, S. (2009). Goal-setting in paediatric rehabilitation: Perceptions of parents and professional. *Child: Care, Health and Development, 36*(4), 558–565. <https://doi.org/10.1111/j.1365-2214.2009.01038.x>
- Pickren, W. E., & Rutherford, A. (2018). *125 years of the American Psychological Association* (1st ed.). American Psychological Association. <https://doi.org/10.1037/0000050-000>
- Plunge, M. M. (1998). *The efficacy of self-administered videotapes for increasing parent participation during Individualized Educational Program meetings* (Publication No. 1998.9813744) [Doctoral dissertation, University of Wisconsin-Madison]. ProQuest Dissertations & Theses Global. <https://www.proquest.com/docview/304456928>
- Pritchard-Wiart, L., & Phelan, S. K. (2018). Goal setting in paediatric rehabilitation for children with motor disabilities: A scoping review. *Clinical Rehabilitation, 32*(7), 954–966. <https://doi.org/10.1177/0269215518758484>
- Roger, S., Braithwaite, M., & Keen, D. (2004). Early intervention for children with autism: Parental priorities. *Australian Journal of Early Childhood, 29*(3), 34–41. <https://doi.org/10.1177/1836939104029003>
- Roger, S., O'Keefe, A., Cook, M., & Jones, J. (2012). Parents' and service providers' perceptions of the family goal setting tool: A pilot study. *Journal of Applied Research in Intellectual Disabilities, 25*(4), 360–371. <https://doi.org/10.1111/j.1468-3148.2011.00674.x>
- Rosenbaum, P., & Gorter, J. W. (2012). The 'f-words' in childhood disability: I swear this is how we should think! *Child: Care, Health and Development, 38*(4), 457–463. <https://doi.org/10.1111/j.1365-2214.2011.01338.x>
- Rossetti, Z., Redash, A., Sauer, J. S., Bui, O., Wen, Y., & Regensburger, D. (2018). Access, accountability, and diverse families' participation in IEP meetings. *Exceptionality, 28*(4), 243–258. <https://doi.org/10.1080/09362835.2018.1480948>
- Schlosser, R. W., Shane, H. C., Allen, A. A., Benz, A., Cullen, J., O'Neill, L., Chiesa, L., Miori-Dinneen, L., Koul, R., & Pasupathy, R. (2020). Coaching a school team to implement the Visual Immersion System™ in a classroom for children with autism spectrum disorder: A mixed-methods proof-of-concept study. *Advances in Neurodevelopmental Disorders, 4*, 447–470. <https://doi.org/10.1007/s41252-020-00176-5>
- Schot, E., Tummers, L., & Noordegraaf, M. (2019). Working on working together. A systematic review on how healthcare professionals contribute to interprofessional collaboration. *Journal of Interprofessional Care, 34*(3), 332–342. <https://doi.org/10.1080/13561820.2019.1636007>
- Sheehey, P. H. (2006). Parent involvement in educational decision-making: A Hawaiian perspective. *Rural Special Education Quarterly, 25*(4), 3–15. <https://doi.org/10.1177/875687050602500402>
- Skouge, J. R., Kelly, M. L., Roberts, K. D., Leake, D. W., & Stodden, R. A. (2007). Technologies for self-determination for youth with developmental disabilities. *Education and Training in Developmental Disabilities, 42*(4), 475–482. <http://www.jstor.com/stable/23879853>
- Tennant, A. (2007). Goal attainment scaling: Current methodological challenges. *Disability & Rehabilitation, 29*(20–21), 1583–1588. <https://doi.org/10.1080/09638280701618828>
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine, 169*(7), 467–473. <https://doi.org/10.7326/M18-0850>
- Tucker, V., & Schwartz, I. (2013). Parents' perspectives of collaboration with school professionals: Barriers and facilitators to successful partnerships in planning for students with ASD. *School Mental Health, 5*(1), 3–14. <https://doi.org/10.1007/s12310-012-9102-0>
- United Nations. (2006, December 12). *Convention on the rights of persons with disabilities*. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>
- Vargus-Adams, J. N., & Majnemer, A. (2014). International Classification of Functioning, Disability and Health (ICF) as a framework for change: Revolutionizing rehabilitation. *Journal of Child Neurology, 29*(8), 1030–1035. <https://doi.org/10.1177/0883073814533595>
- Weatherill, P., Bahn, S., & Cooper, T. (2012). Bespoke program design for school-aged therapy disability service delivery. *Journal of Social Work in Disability & Rehabilitation, 11*(3), 166–183. <https://doi.org/10.1080/1536710X.2012.704204>
- Wells, J. C., & Sheehey, P. H. (2012). Person-centered planning: Strategies to encourage participation and facilitate communication. *Teaching Exceptional Children, 44*(3), 32–39. <https://journals.sagepub.com/doi/10.1177/004005991204400304>
- Whitbread, K. M., Bruder, M. B., Fleming, G., & Park, H. J. (2007). Collaboration in special education: Parent–professional training. *Teaching Exceptional Children, 39*(4), 6–14. <https://doi.org/10.1177/004005990703900401>
- Wiart, L., Ray, L., Darrah, J., & Magill-Evans, J. (2010). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. *Disability and Rehabilitation, 32*(3), 248–258. <https://doi.org/10.3109/09638280903095890>
- Zhang, D., Walker, J. M., Leal, D. R., Landmark, L. J., & Katsiyannis, A. (2019). A call to society for supported decision-making: Theoretical and legal reasoning. *Journal of Child and Family Studies, 28*(7), 1803–1814. <https://doi.org/10.1007/s10826-019-01381-0>

# Appendix A

## SEARCH TERMS

Concept 1	AND Concept 2	AND Concept 3	AND Concept 4
Collaboration OR	Goal setting OR	Children OR	Disability OR
shared decision-making family centered/centred family focused/focussed family-professional partnership	education goals therapy goals rehab* goals IEP independent education plans independent education program individual* education program individual* education plan	adolescen* young kid* youth child* young adult paediatrics pediatrics student* school students school age* elementary school high school middle-school middle school primary school	physical disab* disab* impair* moderate need* movement impair* long-term conditions special health care need developmental delay cerebral palsy autis* special ed* special need* mobility impair* developmental disab* autism spectrum

# Appendix B

## MEDLINE SEARCH

1. "Shared decision making" OR "family centered" OR "family centred" OR "family focused" OR "family focussed" OR "family professional partnership"
2. education OR therapy OR rehab\*
3. Goal\* OR "IEP" OR "Independent education plans" OR "Independent education program\*" OR "individual\* education program" OR "individual\* education plan"
4. adolescen\* OR young OR kid\* OR youth OR child\* OR paediatric\* OR pediatric\* OR student\* OR "school student\*" OR "school age\*" OR "elementary school" OR "high school" OR "middle school" OR "primary school" OR "young adult"
5. "physical disab\*" OR disab\* OR impair\* OR "moderate need\*" OR "movement impair\*" OR "long term condition\*" OR "special health care need\*" OR "developmental delay" OR "cerebral palsy" OR autis\* OR "special ed\*" OR "special need\*" OR "mobility impair\*" OR "developmental disab\*" OR "autism spectrum"
6. 1 AND 2 AND 3 AND 4 AND 5

Filters: English and > 1999 and school aged child.