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# Children’s involvement in the development and evaluation of parent-focused mental health interventions: A scoping review protocol

## Abstract

**Objective:** (i) describe methods used to involve children in the development and/or evaluation of parent-focused interventions to prevent or treat **child** mental health problems; (ii) summarize **perspectives of** children or adults about these methods; **(iii) highlight any reported enablers and barriers, and (iv) identify guidance and make** recommendations for further research .

**Introduction:** Parent-focused interventions (where children are not primarily involved or are excluded) have been implemented to address varied child mental health outcomes. However, it is unclear to what extent, and to what ends, children have been involved in developing and evaluating such interventions. **Engaging children** in formative research activities, with or without their parents, has the potential to improve quality and implementation.

**Inclusion criteria:** Eligible studies will involve children (5-12 years) in the development **and/or** evaluation of parent-focused interventions aimed at preventing or treating common child mental health problems (**e.g.** anxiety, depression, ADHD and disruptive behavior) delivered in any setting (e.g., school, community, home, health facility). Eligible parent-focused interventions may include one or more psychosocial practice elements targeting behavioral, cognitive, emotional, interpersonal, social, and/or environmental factors implicated in the onset and maintenance of child mental health problems.

**Methods:** Comprehensive searches will be conducted in five electronic databases (PsycINFO, Medline, CINAHL, Embase, and SCOPUS). Gray literature will also be sourced using Google searching, searching of key organization websites and via notifications on social media. Eligible studies will be English language primary studies. Findings across a range of methodologies will be charted and combined into a narrative synthesis.

**Keywords:** patient and public involvement; children; participation, mental health intervention; parent-led

- 29    **Abstract word count: 248**
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- 31

## Introduction

Increasing attention is being placed on children's involvement in mental health research. There are several drivers for this, including legislation and policy. The United Nations convention on the rights of the child sets out the importance of consulting with children about matters that concern them(1). Further, research funders (e.g., National Institute of Health Research) are committed to involving children as "partners" expecting children to act as research advisors and/or co-researchers(2). This is mirrored in service development where children's voices are meant to inform service improvement.

Involving children in the development and evaluation of interventions to address their mental health problems ensures they are tailored to address their unique needs, concerns, and preferences, contributing to the effectiveness of the interventions(3). In addition, this involvement results in 'learning in action' (p359(4)), creating new knowledge relating to how to engage with and make sense of everyday contexts(4).

Yet mental health interventions are still often developed *for* children rather than *with* children, and parental views typically hold sway if any 'user' involvement is undertaken(5). This is based on certain (erroneous) assumptions about children's developmental capacity to reflect reliably on their internal states and experiences(6), and resource-related/pragmatic considerations (e.g., (7)). The relative exclusion of children from intervention development and evaluation is particularly apparent in relation to parent-focused interventions. Such interventions involve working primarily or exclusively with individual parents or groups of parents, following from evidence linking child mental health problems with modifiable parenting behaviors(8). Parent-focussed interventions are characterized by parents implementing a structured, evidence-based treatment protocol (e.g Cognitive Behavioral therapy) or supporting a child with self-help resources (e.g. psychoeducation) independently at home while receiving training and/or limited assistance from a trained therapist(9). In these interventions, while the aim is to address children's mental health, parents are typically the only direct participant; children do not have any contact with a professional(10). Examples of programs of this type include Parent-led Cognitive Behavioural Therapy (11) and Timid to Tiger(12) for child anxiety problems, and Triple P – Positive Parenting (13) for disruptive behavior problems.

There is no existing evidence synthesis examining if, how and to what extent children have been involved in and influenced the design and evaluation of parent-focused interventions. Children's involvement in the development and evaluation of parent-focused interventions could range from providing responses to self-report measures (often only parent or teacher reporting is used,

particularly with younger children), providing data in feasibility studies (i.e. via questionnaires or interviews) including them as research advisers and/or involving them in co-design activities at the design stage. While there are two reviews on **the involvement of** children generally in health research (e.g.(14, 15)), there is a paucity of reviews specific to mental health. One such review examines co-design of digital interventions for mental health(16) and another reviews youth participatory action research to promote mental well-being and resilience(17). While there are reviews on the effectiveness of parent-focused interventions(18) there are none that have examined children's involvement in the development and evaluation of parent-focused interventions. This is an important gap in the literature, given the growing use of parent-focused interventions(18), including in the UK where parent-focused interventions are recommended among first-line interventions in national clinical guidelines for a variety of child mental health problems(19). There is potential for children's views about these interventions to inform more acceptable, feasible and effective approaches.

The aim of the scoping review is to address this knowledge gap and formulate priorities for future research by mapping children's involvement in the development and evaluation of parent-focused interventions in existing literature. **Scoping review methodology has been selected because the intention of the review is to capture all the available literature on the given topic and to map the extent, range and nature of the literature, providing a synthesis of current knowledge, highlighting gaps for future research(20).** In order to map the broad ways that children may have been involved in the development and evaluation of parent-focused interventions, any involvement at any level (i.e. as study participants, consultants, collaborators) and at any stage of the research process will be included. The objectives are to: (i) describe methods used to involve children in the development and/or evaluation of parent-focused interventions to prevent or treat mental health problems; (ii) **summarize perspectives of children or adults about these methods; (iii) highlight any reported enablers and barriers, and (iv) identify guidance on involving children and make recommendations for further research.** Preliminary searches of MEDLINE, the Cochrane Database of Systematic Reviews, PROSPERO, and *JBI Evidence Synthesis* were conducted, and no prior or ongoing systematic or scoping reviews on the topic were identified.

## Review question(s)

The main overarching research questions for the review is in what ways have children (5-12 years) been involved in the development and/or evaluation of parent-focused interventions to prevent or treat common child mental health problems (i.e., anxiety, depression, ADHD, disruptive behavior)?

Additional sub-questions are as follows:

- I. What methods have been used to involve children?
- II. What are children and/or adults perspectives on the methods used to involve children?
- III. What are the reported enablers and barriers of involving children?
- IV. What guidance is available on involving children?

## Inclusion criteria

### *Participants*

Studies involving any children from any country, aged 5-12 years (i.e., those in primary or elementary school). This age range has been chosen because parent-focused interventions are predominately targeted at the mental health of younger children(10).

### *Concept*

Any studies that involve children in the development and/or evaluation of parent-focused interventions will be included. Children's involvement in any aspect relating to the design or development of interventions (e.g. codesign studies) and/or in the evaluation of interventions (e.g. feasibility studies, qualitative studies) including in providing self-report measures in effectiveness studies will be included. This review will consider studies where children have been involved at any stage in the research process. In terms of evaluations, we will include studies that involve children as (assenting) research participants and/or gather their perspectives (e.g. viewpoints, opinions, etc.) or those of adults (i.e. researchers, parents) about the children's involvement, as well as studies where children take the role of co-researchers or advisors.

Parent-focused interventions (e.g. parent-led therapist assisted, parent-delivered, guided parent delivered) are defined as those where training and support is delivered to **a parent** by a healthcare professional in order for them to support their child's mental health independently(12,13). Eligible parent-focused interventions may include one or more psychosocial (e.g. psychological or social environment influences) practice elements targeting behavioral (e.g. problem-solving), cognitive (e.g. mindfulness), emotional (e.g. emotional regulation), interpersonal (e.g. communication skills), social and/or environmental factors implicated in the onset and maintenance of common child mental health problems(21). The primary objective should be preventing or treating common mental health problems, specifically anxiety, depression, ADHD, or disruptive behavior difficulties, i.e., the four most prevalent categories of childhood mental health problem in the UK(22). Studies of interventions that involve parallel sessions with children and parents, as well as family intervention studies, will be excluded. In this review "parent" is broadly defined to include any parental caregiver (including biological and non-biological caregivers, e.g. foster parent).

## *Context*

This review will include parent-focused interventions delivered to parents in any setting (e.g. healthcare service, school) with training and techniques utilized to support their children in their everyday life (e.g. in a home setting).

## *Types of sources*

Primary studies published in peer-reviewed journal articles and gray literature reports will be included. Opinion papers, editorials, dissertations, and conference abstracts will be excluded. Dissertation and conference abstracts were excluded because searching for these resource-intensive, they may not contain adequate information, and the information may not be reliable(23,24).

## **Methods**

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews(25) guidance and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)(26) reporting standards will be used.

## Search strategy

Initial limited searches of MEDLINE (via OVID), Cumulative Index to Nursing and Allied Health Literature (CINAHL via EBSCO information Services) and Google were undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles, were used to develop a full search strategy for APA PsycINFO (via EBSCO), MEDLINE (via OVID), CINAHL (via EBSCO), Excerpta Medica (EMBASE, via OVID), and SCOPUS (see Appendix 1), adapted for each database. Searches will be limited to English Language as the project has no funding for translation. To avoid bias relating to publication date and to capture the full spectrum of available literature on ways of involving children no date restriction will be applied. Applying a date restriction in this review would be arbitrary as the focus relates to how children are involved rather than the effectiveness or relevance of the intervention. Hand searching will be conducted to identify further gray literature and any missed peer reviewed articles including searches of Google of the first 200 hits for combinations of key search terms (typically used to search for gray literature) and relevant websites of key organizations (such as Youth Endowment Fund, The Children's Society, Mental Health Foundation), examination of reference lists of included articles, searches of publications of key authors, and notifications on social media.

## Study/Source of evidence selection

All identified citations will be collated and uploaded into *EndNote version 21 / 2023 (Clarivate Analytics, PA, USA)* and duplicates removed. Citations will then be imported to *Rayyan version 2022 (Rayyan Systems, Cambridge, USA,)* for title and abstract screening and further identified duplicates removed. Following a pilot test, titles and abstracts will be assessed against the inclusion criteria. Potentially relevant sources will be retrieved and their citation details exported to Excel for full text screening. The full text of selected citations will be assessed against the inclusion criteria, with reasons for exclusion at full text will be recorded and reported. To enhance reliability and accuracy at least 20% of the articles will be screened independently by two reviewers and inter-rater reliability reported at each of the screening stages(27). Any disagreements that arise between the reviewers during the selection process will be resolved through discussion, or with additional reviewer/s. The results of the search and the study inclusion process will be reported in full in the final report, presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram(26).

## *Data extraction*

Data will be extracted from eligible papers using a data extraction tool developed by the reviewers. As suggested by Daudt, van Mossel, and Scott (28, at least 20% of data extracted will be charted by two authors independently. Once sufficient agreement (> 80%) has been reached in the trial phase, the two authors will independently apply the tool to the remaining studies then compare their results to agree upon the charting of each article. The extracted data will include participant characteristics (children); information about the intervention; evaluative and development methods (indexed to a relevant typology of co-design processes e.g. (29) with degree of children's influence at each research stage noted using the participation lattice(30). Data that describes the methodologies used to involve the children, how and what stage they were involved in the study and any data relating the perspectives (viewpoints, options etc.) captured by qualitative **methodologies**, (e.g. interviews, focus groups) and/or ratings scales of children involved or relevant adults (e.g. teachers, parents, researchers etc.) will be extracted from studies. Critical appraisal of the studies has been considered, but as typical appraisal tools focus on the quality of the research and this review focusses on children's involvement in the research process, the studies will be categorized based on degree of children's participation and their influence.

A draft data extraction tool (see Appendix 2) will be modified and revised as necessary during the data extraction process with modifications detailed in the resulting report. Any disagreements that arise during data extraction will be resolved through discussion, or with an additional reviewer/s. Authors of papers will be contacted to request missing or additional data, where required.

## *Data analysis and presentation*

Extracted data will be presented in a chart(31) to provide an overview of the findings, describing ways children have been involved, and children's and adults perspectives on that involvement and any identified enablers and barriers of children's involvement and guidance. Stages of involvement and degrees of participation will be categorized for each study using relevant tools (29,30) and reported in the chart. Charted findings will be combined in a narrative synthesis(32) to show how and with what results children have been involved identifying key considerations relating to the involvement of children in the development and/or evaluation of parent-focused mental health interventions (using enablers and barriers and guidance). Key gaps in the literature will be identified with suggestions for future research and recommendations for involving children.

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## Appendix I: Search strategy

### MEDLINE (Ovid)

Search conducted on 23rd October 2023.

| Search                      | Query                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Records retrieved |
|-----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| #1                          | Child/ [Mesh] OR (child* OR kid* OR girl* OR boy*)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | 3,783,018         |
| #2                          | Attitude/ [Mesh] OR perception/ [Mesh] OR patient participation/ [Mesh] OR stakeholder participation/ [Mesh] OR (Experience OR Opinion* OR View* OR Attitude* OR Perception* OR Perspective* OR Involvement OR PPI OR Child report* OR Participation OR Child-reporting OR Child reporting OR Participatory research OR Participatory method* OR Participatory approach* OR Participatory design OR Participatory model* OR Co-produce* or Coproduce* OR Co-research or Coresearch OR Co-creation OR Cocreation OR Co-design* OR Codesign* OR Co-develop* OR Codevelop* OR Co-investigator* OR Coinvestigator* OR Advisory group* OR Advisory council OR Child-led OR Child led OR Research partner OR Consultation | 3,395,992         |
| #3                          | (Parent-led OR Parent led OR Parent directed OR Parent delivered OR Parent-delivered OR Parent focus* OR Parent-focus* OR (Parent* adj2 program*) OR (Parent* adj2 intervention*) OR (parent* adj2 class*) OR (parent* adj2 group*) OR (parent* adj2 course)).                                                                                                                                                                                                                                                                                                                                                                                                                                                      | 15,548            |
| #4                          | Mental health/ [Mesh] OR anxiety/ [Mesh] OR anxiety disorders/ [Mesh] OR depression/ [Mesh] OR depressive disorder/ [Mesh] OR cognitive behavioral therapy/ [Mesh] OR problem behavior/ [Mesh] OR motivational interviewing/ [Mesh] OR (Mental health OR Anxiety OR Depress* OR Trauma OR Cognitive behavioural therapy OR Cognitive behavioral therapy OR Cognitive behaviour therapy OR Cognitive behavior therapy OR CBT or Behavioural problems OR Behavioral problems OR motivational interviewing OR cognitive analytic therapy)                                                                                                                                                                              | 1,353,779         |
| 5#                          | 1 AND 2 AND 3 AND 4                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | 1,271             |
| Limited to English language |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | 1,248             |



**Appendix II: Data extraction instrument**

| Author | Year | Country | Participant characteristics (e.g. specific target group, ages of children) | Details about the mental health Intervention | How children have been involved | Strategies used to involve children | Findings related to children's views/involvement | Enablers of children's involvement | Barriers to children's involvement | Research stages involved | Degree of participation |
|--------|------|---------|----------------------------------------------------------------------------|----------------------------------------------|---------------------------------|-------------------------------------|--------------------------------------------------|------------------------------------|------------------------------------|--------------------------|-------------------------|
|        |      |         |                                                                            |                                              |                                 |                                     |                                                  |                                    |                                    |                          |                         |

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