

## Systematic review

### 1. \* Review title.

Give the title of the review in English

Systematic review of interventions to increase involvement in the habilitation/rehabilitation process for children with disabilities and their families

### 2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

### 3. \* Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

23/06/2020

### 4. \* Anticipated completion date.

Give the date by which the review is expected to be completed.

31/05/2021

### 5. \* Stage of review at time of this submission.

Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.

**Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO.** If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.

This field uses answers to initial screening questions. It cannot be edited until after registration.

The review has not yet started: No

Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here.

We are in the phase of screening titles/abstracts/fulltext articles to include eligible studies

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## 6. \* Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Anna Karin Andersson

**Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:**

Anna Karin

## 7. \* Named contact email.

Give the electronic email address of the named contact.

annakarin.andersson@ju.se

## 8. Named contact address

Give the full institutional/organisational postal address for the named contact.

Jönköping University, Box 1026, 55111 Jönköping, Sweden

## 9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+46739101759

## 10. \* Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Jönköping University

**Organisation web address:**

ju.se

### 11. \* Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Dr Anna Karin Andersson. Jönköping University  
Professor Mats Granlund. Jönköping University  
Professor Henrik Danielsson. Linköping University  
Professor Gillian King. Bloorview Reseach Institute  
Professor Lars-Olov Lundqvist. Örebro Univeristy  
Dr Karina Huus. Jönköping University  
Dr Will Farr. Sussex Community NHS Foundation Trus  
Charlotte Karlsson. Jönköping University  
Professor Shakila Dada. University of Pretoria  
Linda Sjödin. Jönköping University  
Lisa Palmqvist. Linköping University  
Magnus Ivarsson. Linköping University  
Jennifer Gothilander. Mälardalen University

### 12. \* Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

Swedish Research Council

#### Grant number(s)

State the funder, grant or award number and the date of award  
2018-05824

### 13. \* Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

### 14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

### 15. \* Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

What are the content and outcomes of interventions focusing on increasing child and family involvement in the habilitation/rehabilitation process?

### 16. \* Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or

attachment below.)

Searches are conducted in the following electronic bibliographic databases: CINAHL, ERIC, MEDLINE, PsycINFO, Web of Science Core Collection, Scopus. In addition, corresponding authors of included articles will be contacted via e-mail to inquire about additional studies that have been published or are unpublished, in order to avoid publication bias. Search date 2020-06-23, publications after 2001 to present, peer-review journals, English

### 17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**.

<https://documentcloud.adobe.com/link/review?uri=urn:aaid:scds:US:2caf269a-6b0d-4d8f-8a5d-c1f79323432d>

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

### 18. \* Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Participation in habilitation/rehabilitation process

### 19. \* Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Children with disabilities, developmental delays, adolescents with disabilities, 3 - 18 years. Children with a diagnosed disability that is (primarily) associated with impairment (s) in the ICF-domains mental functions (b1), seeing and related functions (b210-b229), hearing functions (b230), and/or neuromusculoskeletal and movement-related functions (b7). Examples of diagnoses fulfilling criteria are intellectual disability (ID), autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), hearing impairment, seeing impairment, cerebral palsy (CP) and acquired brain injury (ABI). All psychiatric conditions (as stated in DSM-V) except neurodevelopmental disorders are however excluded.

### 20. \* Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

Interventions to increase children's and families involvement in the habilitation process are those that aims to increase participation including both attendance and involvement or engagement. Interventions include e.g. early interventions, rehabilitation, habilitation, therapy treatment, strategy, and program. Involvement is seen both as a means and an end. Involvement as a means, the outcome of the intervention can be e.g.

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knowledge, well-being, empowerment self-efficacy, skill. Examples of involvement as an end include collaboration, co-production, satisfaction with service, and shared decision making. Exclusion criteria are interventions aiming for effects on body and activity level or specific child outcomes e.g. mobility, communication, learning/achievement in school.

#### 21. \* Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

No comparison group needed

#### 22. \* Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

Quantitative-, longitudinal-, cohort- or follow-up-, over time-, prospective- and retrospective studies will be included. Studies without quantitative data, review articles, theoretical articles without data and qualitative design will be excluded.

#### 23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

Studies in habilitation centers, rehabilitation centers, pediatric centers, hospital, specialist school, NGO, religious settings, and home will be included.

#### 24. \* Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Studies with outcomes including change in involvement score or other scale score pre- and post intervention

##### \* Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Difference pre- and post intervention

#### 25. \* Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

In addition to main outcomes we will also record descriptions of the content of the intervention

##### \* Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable

## 26. \* Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Search results are downloaded with full bibliographic information from the databases. Then, they are combined to one data source and duplicates will be removed. All returned reports will have their titles and abstracts assessed against inclusion criteria. This is done by each rater who gets a worksheet with study ID and title/abstract for their share of reports to rate. Selection at title and abstract screening is made by one rater, with additional rater who rates 10% of the records to get an interrater reliability. Any report selected at one stage in the screening process by at least rater will be included in the next stage. The full text selection will be rated by two raters, blinded to each other's rating. Any disagreements between the two raters will be resolved by a third rater. A standardized form will be used to extract data from the included studies for assessment of study quality and synthesis of the evidence. Extracted information will include: study setting; demographics characteristics; study methodology; main and secondary outcomes; reported moderators and mediators, and information for risk of bias assessment. Two review authors will extract data independently, and discrepancies will be identified and resolved through discussion (with a third author where necessary). Missing data required for assessment of relevant studies or for data synthesis will be requested from study authors.

## 27. \* Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

Two reviewers will independently assess each of the relevant articles. The selection of full-text articles will be read by both reviewers and any disagreement between the authors will be solved by a discussion with the involvement of a third reviewer. CASP – The critical appraisal skills programme checklist for systematic reviews will be used. This tool answers the three broad questions Are the results of the study valid? (Section A); What are the results? (Section B); and Will the results help locally? (Section C)

## 28. \* Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

Given the nature of the research question and the likely heterogeneity of included studies' methods and data, a meta-analysis is not appropriate. The data from included studies will be summarised using text and tables to compare and contrast findings across studies. A narrative synthesis (guided by Popey et al, 2006) will be undertaken to address the primary foci of the review. This will include textual descriptions of studies,

groupings and clusters, and tabulation. These will include (i) a summary of the participation/involvement outcomes for those with disability, including populations studied, time course (ie. length of follow up) and identification of outcomes measured and results; and (ii) where there is evidence of contributing factors to participation/involvement outcomes those factors will be identified and described along with evidence of strength and direction of relationships with participation/involvement outcomes. In addition, we will summarise the volume (number of studies, participants and participant groups) and quality of the evidence (risk of bias). The robustness of the synthesis will be assessed by

### 29. \* Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach. Traditional quantitative analysis of subgroups is not planned. However, as stated in the strategy for data synthesis, tabulation of results will be used as a method of comparing and contrasting data across studies. Groups of studies with similar populations, and/or outcomes, and/or time-courses will be considered together in the narrative synthesis where there are data to support this approach.

### 30. \* Type and method of review.

Select the type of review, review method and health area from the lists below.

#### Type of review

Cost effectiveness

No

Diagnostic

No

Epidemiologic

No

Individual patient data (IPD) meta-analysis

No

Intervention

No

Meta-analysis

No

Methodology

No

Narrative synthesis

Yes

Network meta-analysis

No

Pre-clinical

No

Prevention

No

Prognostic

No

Prospective meta-analysis (PMA)

No

Review of reviews

No

Service delivery

No

Synthesis of qualitative studies

No

Systematic review

Yes

Other

No

### Health area of the review

Alcohol/substance misuse/abuse

No

Blood and immune system

No

Cancer

No

Cardiovascular

No

Care of the elderly

No

Child health

Yes

Complementary therapies

No

COVID-19

No

Crime and justice

No

Dental

No

Digestive system

No

Ear, nose and throat

No

Education

No

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Endocrine and metabolic disorders

No

Eye disorders

No

General interest

No

Genetics

No

Health inequalities/health equity

No

Infections and infestations

No

International development

No

Mental health and behavioural conditions

No

Musculoskeletal

No

Neurological

No

Nursing

No

Obstetrics and gynaecology

No

Oral health

No

Palliative care

No

Perioperative care

No

Physiotherapy

No

Pregnancy and childbirth

No

Public health (including social determinants of health)

No

Rehabilitation

No

Respiratory disorders

No

Service delivery

Yes

Skin disorders

No

Social care  
No

Surgery  
No

Tropical Medicine  
No

Urological  
No

Wounds, injuries and accidents  
No

Violence and abuse  
No

### 31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.  
English

There is not an English language summary

### 32. \* Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

Sweden

### 33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

### 34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

Add web link to the published protocol.

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

**No I do not make this file publicly available until the review is complete**

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

### 35. Dissemination plans.

Do you intend to publish the review on completion?

Yes

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Give brief details of plans for communicating review findings.?

In addition to producing a easy-to-read summary of the findings, which will be made available free of charge on our website, a paper will be submitted to a leading journal in the field.

#### 36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Involvement; Disability; Child; Family

#### 37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

This review has not been published before by the research group

#### 38. \* Current review status.

Update review status when the review is completed and when it is published. New registrations must be ongoing so this field is not editable for initial submission.

Please provide anticipated publication date

Review\_Ongoing

#### 39. Any additional information.

Provide any other information relevant to the registration of this review.

#### 40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Give the link to the published review or preprint.