

**A participation-focused approach for children and adolescents with fetal alcohol spectrum disorders (FASD): A research practice and priority**



**10<sup>th</sup> International Conference on Adolescents and Adults with FASD**

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 Professor Laura Miller  
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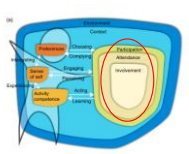
**Definitions of participation**

International Classification of Functioning, Disability and Health (ICF) Framework




[1., p.18]

Family of Participation Related Constructs (fPRC) Framework



[2., p.1]



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**Participation and FASD**







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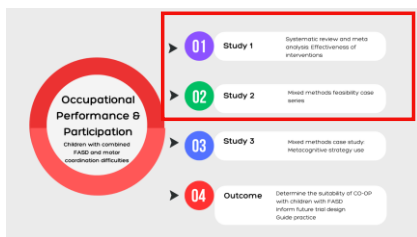
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## Research program



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## Study 1: Systematic review and meta-analysis



**Aims:** To describe allied health and educational interventions and their effectiveness for children and adolescents with FASD. To appraise the quality and strength of studies.

**Outcomes:** Any quantitative measures of child body function or structures (BFS), activity or participation that allowed comparisons to be made. Included measures of performance, skills, abilities and changes to BFS.

[3.]

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## Inclusion Criteria

Population	Intervention	Comparison	Outcomes	Study Design
<ul style="list-style-type: none"> <li>All FASD diagnosis</li> <li>Aged 5 ≤ 18 years</li> </ul>	<ul style="list-style-type: none"> <li>Any non-medical, dietary or neurophysiological interventions promoting functions, activity or participation</li> </ul>	<ul style="list-style-type: none"> <li>Any form other than medical</li> <li>Studies included without comparison</li> </ul>	<ul style="list-style-type: none"> <li>Any quantitative measure of child function, activity or participation</li> </ul>	<ul style="list-style-type: none"> <li>RCTs</li> <li>Non randomised control trials</li> <li>Pre-post</li> <li>Case studies</li> <li>Systematic reviews</li> </ul>

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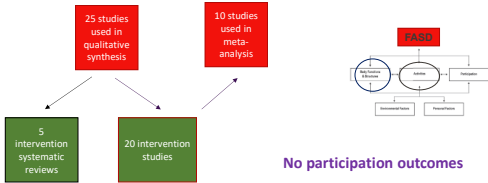
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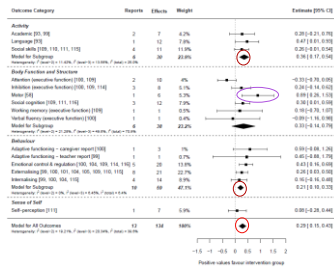
### Results



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### Results



10 studies used in meta-analysis

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### Take home messages



1. Ask children, caregivers and teachers about participation at home, school and in the community
2. Measure participation directly
3. Combine child/adolescent interventions that address their participation needs with those that build caregiver/teacher capacity (individual and context focused)
4. Embed interventions into children/adolescent's everyday environments



[4]



[5]

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### Study 2: Feasibility of CO-OP with children (aged 6-12 years) with FASD and motor coordination difficulties

1. Is CO-OP feasible and acceptable to implement with children (aged 6-12 years) with combined FASD and motor coordination difficulties to address occupational performance and participation goals?
2. What are the perceptions of children (aged 6-12 years) with FASD and caregivers about their participation in the CO-OP intervention?
3. Does participating in the CO-OP improve child and caregiver rated performance and satisfaction scores and performance quality on goals identified by children with FASD?

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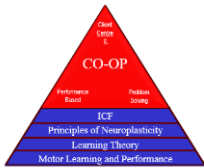
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### The CO-OP Approach



[6, p.18]



<https://www.youththerapy.com/blog/2015/11/18/occupational-orientation-to-daily-occupational-performance-approach/>

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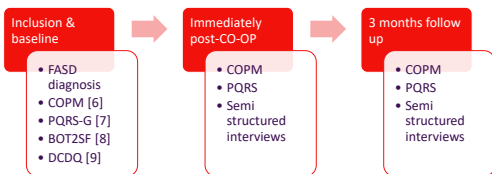
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### Methods



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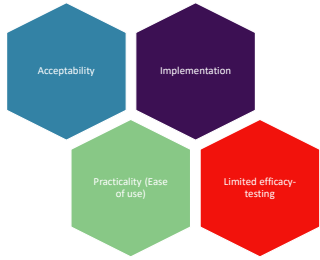
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**Evaluating feasibility [11]**

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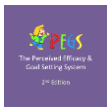
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**CO-OP Intervention**



[4]



[6]

- 3 goals set by child (PEGS & COPM)
- Weekly home visits to practice goals x 10 sessions
- After school sessions
- Reviewed home practice

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**Participants**

Characteristics	Josie*	Olivia*	Sarah*
Age	12 years	12 years	11 years
Gender	Female	Female	Female
Ethnicity	Caucasian	Caucasian	Vietnamese-Loatian
Other diagnoses	None	Autism Depression	Autism ADHD
Siblings	None	2	2
Home setting	Metro	Rural	Metro
Primary parent	Adopted mother	Biological father	Adopted mother
BOT2 SF	12 <sup>th</sup> percentile	4 <sup>th</sup> percentile	8 <sup>th</sup> percentile
DCD-Q Total Motor Score	38/75	30/75	46/75

\* Pseudonyms are used

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### Child-chosen goals

Participant	Goals practiced during CO-OP
Josie	1. Spread with a knife 2. Retrieve/replace items to/from the fridge 3. Tie shoelaces
Olivia	1. Writing neatly on lines 2. Remembering my turn in UNO 3. Keeping room tidy
Sarah	1. Crack an egg without eggshell for the dog's dinner 2. Ride bike without training wheels 3. Knitt a square

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### Acceptability - caregivers

*"I think its [choosing her own goals] good because, they're things that she finds frustrating. Her being able to choose things and then she is more likely to practice it and it's gonna have a bigger impact on her life because they are things that frustrate her"* (Josie's mother).

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### Acceptability - children

*"Stressful"* (Josie)

*"Help kids get into a routine"* (Olivia)

*"Helps them learn"* (Sarah)

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**Is CO-OP implemented as per protocol? (Implementation)**



*"Like everything else, it is dependent on a bunch of variables that neither you nor I really know [Olivia's response to participating in CO-OP]. I think it just came down to the mood on the day" (Olivia's father).*

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**Do participants find CO-OP easy to use in everyday life? (Practicality)**



*"I haven't really used it to be honest with you... It was more of a consequence of a bit of a hectic lifestyle we've been living at the moment. With me working away a lot and [partner] effectively being a single mum with three kids for a lot of the year. There is just not a lot of time to reinforce it and keep going over and over it again" (Olivia's father).*

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**Do participants continue to use CO-OP after therapy? (Practicality)**



*"I keep forgetting [to use GPDC]...I also, forgot about that as well [re: checking]" Josie*

*"I know that there's things that you do think about that you then go what's the goal here, what's the plan, how do we do it and all that, but, um, we don't remember to use the language" (Sarah's mother)*

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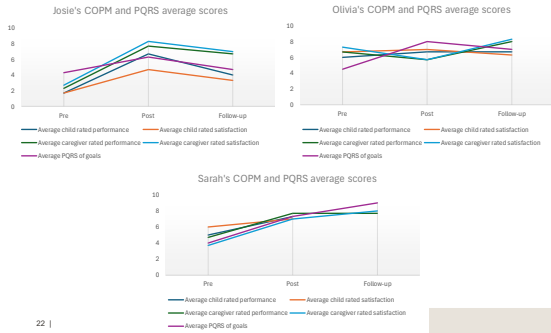
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**Can CO-OP improve goal performance? (Limited efficacy testing)**



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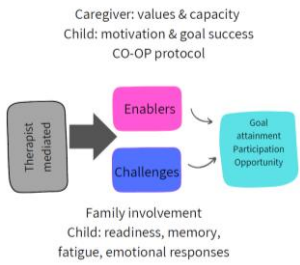
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**Discussion**



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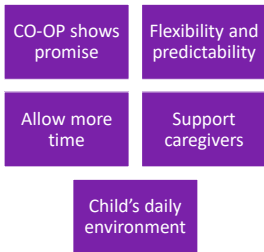
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**Take Away Messages**



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### Acknowledgements and contact details



Thank you to the carers and people with FASD from our advisory group who continue to provide feedback

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