

Exploring challenges in collecting self-reported data about facilitators and barriers for participation in everyday activities

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AIM

To identify the challenges of collecting self-reported data about contextual barriers and facilitators of participation in everyday activities?

PARTICIPATION






- Participation has two dimensions, attendance, and involvement.
- These are influenced by both
 - intrinsic characteristics of the person
 - factors extrinsic to the person, context, and environment

DESIGN AND METHODS

With the conversational tool Picture My Participation children in three countries Sweden, South Africa and China were asked about their attendance, and involvement in twenty activities







		Attendance				Involvement		
		Always 4	Sometimes 3	Not really 2	Never 1	Very involved 3	Somewhat involved 2	Minimally involved 1
Home and Community Activities								
1. Personal care Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)								
2. Family mealtime (with usual family members)								
3. My own health Looking after his/her own health (medication)								


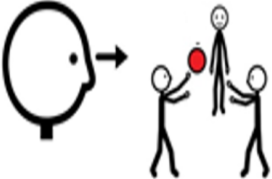

PICTURE SUPPORT

Pictures was used for all questions and answers

Attendance template

Always	Sometimes	Not really	Never
			

Involvement Template

Very	Somewhat	Not
		



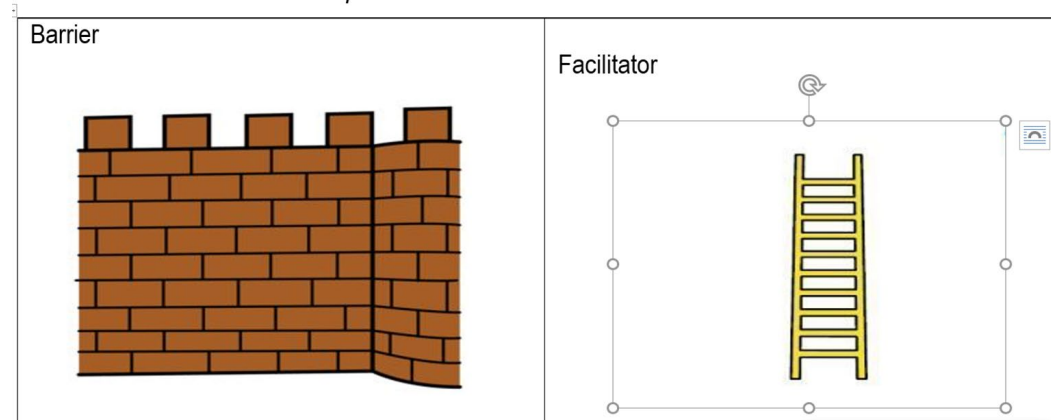
The children selected the three most important activities, out of the twenty activities that we asked about

BARRIERS AND FACILITATORS

For the three most important activities the child were asked about facilitators and barriers

Their responses were categorized as different types of facilitators or barriers

Barriers and Facilitators Template



BARRIERS AND FACILITATORS TEMPLATE

Products and technology



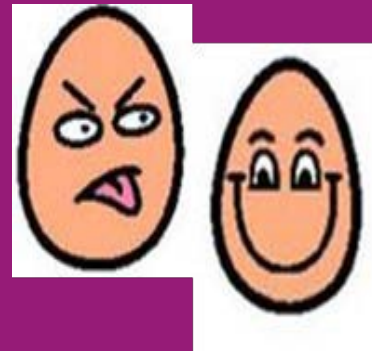
Natural environment and human-made changes to the environment



Support and relationship



Attitudes



Service, systems and policies



RESULT

Facilitators and Barriers for participation in China

Primary caregiver's voice

Facilitators

- The optimistic attitude of the primary caregiver
- Adequate family support
- Active environment in school and policy
- Attractive characteristics of children with IDs

Barriers

- Insufficient knowledge
- Attitudes and skills in primary caregivers
- ID-related characteristics of children
- Stigma and Chinese culture
- Lack of support from society

Facilitators and Barriers for participation in Sweden and South Africa

Self reported by the children

Facilitators

- Satisfaction
- Personal capability
- Being included
- Having access to resources

Barriers

- Personal functioning
- Social exclusion
- Lack of resources

Facilitators and Barriers for participation in Sweden:

Self reported by children

	Facilitator	Barrier
Products and technology	7	5
Natural environment and human-made changes to the environment	4	4
Support and relationships	23	7
Services, systems and policies	4	1

Examples of adaptations that the interviewer made during the interview with the child

- The primary caregivers were present and somewhat involved in the interview
 - For example, the child had speech difficulties, so the parent sat with them throughout the interview and explained what the child said
- Gave extra time to think
- The child was initially a bit shy; we had to sit in her room after playing for a while
- We drew signs above each scale and the child wanted to draw them herself, which made her a little more independent

CONCLUSION

- When asking children about barriers and facilitators both how the interviewer conversate about facilitators and barriers and the type of contextual factors mentioned seems to be important to facilitate the conversation
- It is important to adapt the questions and the way of asking based on the child's Individual needs



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QUESTION

How can we help children and primary caregivers in putting words on barriers and facilitators for participation?



The PMP instrument are described on a Webb page <https://ju.se/center/child-pmp.html>



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