



Do children with disability and their parents participate in planning, decision-making, and evaluation of support?

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Background

- UNCRC & UNCRPD – the same rights as others
- Opportunity to participate in the community and to live as others (SoL)
- Literatures:
 - Child participation -- a challenge
 - Insufficiently mature
 - Parents' participation
 - Positive outcome for students
 - Family Centered approach
 - Dunst, Trivette & Hamby (2007) –Meta-analysis
 - Satisfaction, self-efficacy in perception of control (support and life events), influence on child behaviour and well-being



Aim

Examine the current opportunities for children
and their parents to participate directly in
planning and evaluation of support



Research Questions

- To what degree do parents participate in the planning and evaluation of support?
- How do children with disability's opportunity to participate in the planning and evaluation of support currently look like?
- Do parents and professionals satisfied with the current opportunity that children have?



Participants – Parents and Professionals

144 Parents (109 families)

Gender

67% females

33% males

Background

79% born in Sweden

21% born in another country other than
Sweden

Employment

78% Employed/ maternity leave

16% student/ other

6% unemployed/ retired

157 Professionals

31% Social services

27% Health care/Psychiatry

22% Schools

11% Social insurance

9% Habilitering



Characteristic of the children

		n	%
Child's age group	0-6 years	13	12%
	7-12 years	43	39%
	13-19 years	54	49%
Child's gender	Boys	73	66%
	Girls	37	34%
Child's diagnosis*	Autism	71	
	ADHD	27	
	Chromosome	20	
	Physical disability	21	
	Intellectual disability	47	
	No diagnosis	3	



Sample of questions

Professionals

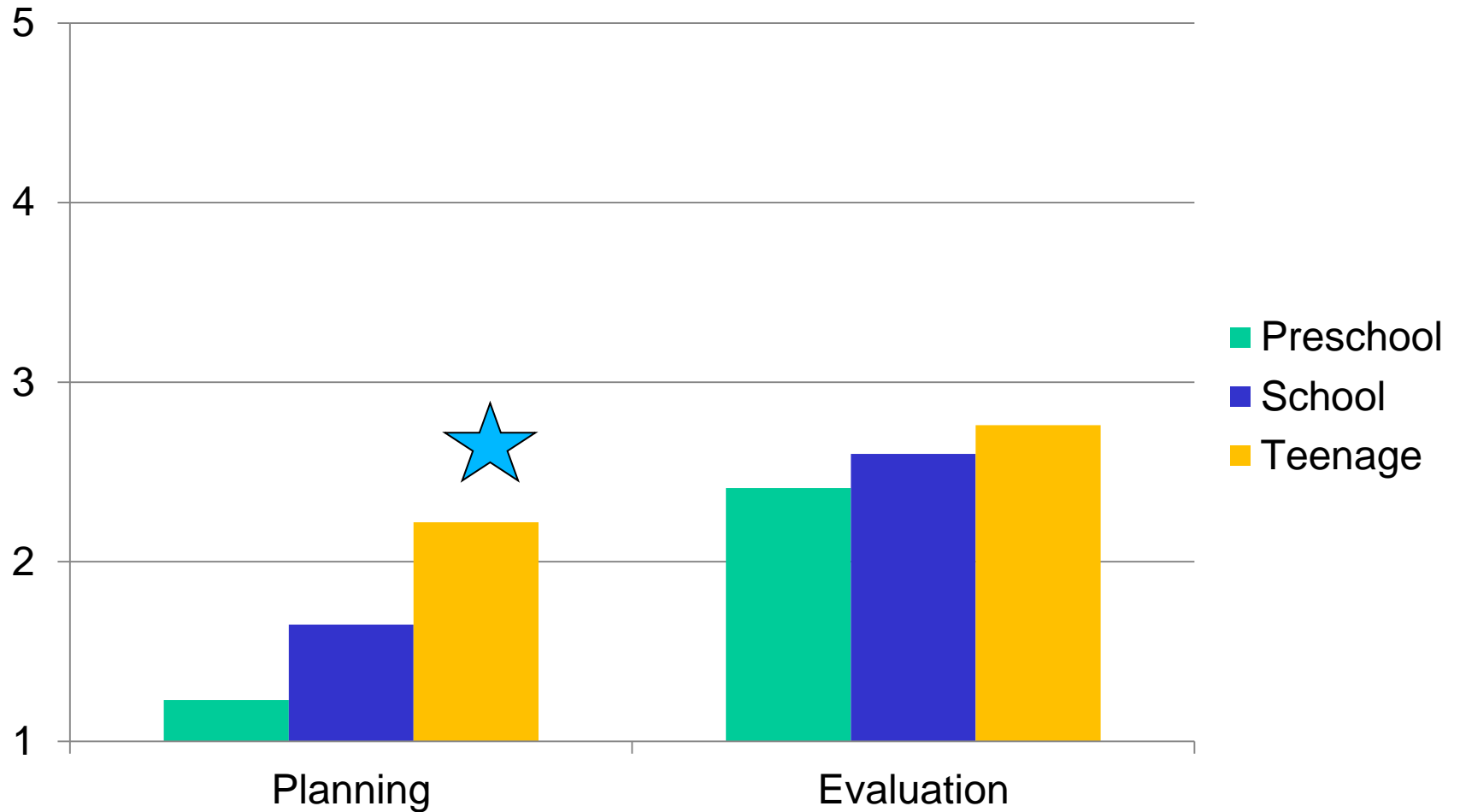
- How much do parents participate in the planning of support? (Scale 1-7, Not at all to Very much)
- Do you meet the child personally? (Scale 1-5, Never to Always)
- Are children allowed to express their opinion in the planning of support? (Scale 1-5, Never to Always)
- How do children express their opinion in the planning of support? (4 choices: 2 direct and 2 indirect)

Parents

- How much do you participate in the planning of support? (Scale 1-7, Not at all to Very much)
- How much do your child participate in planning their own support? (Scale 1-5)
- How often anyone ask about your child's opinion of support? (Scale 1-5)
- How do children express their opinion about support? (4 choices: 2 direct and 2 indirect)

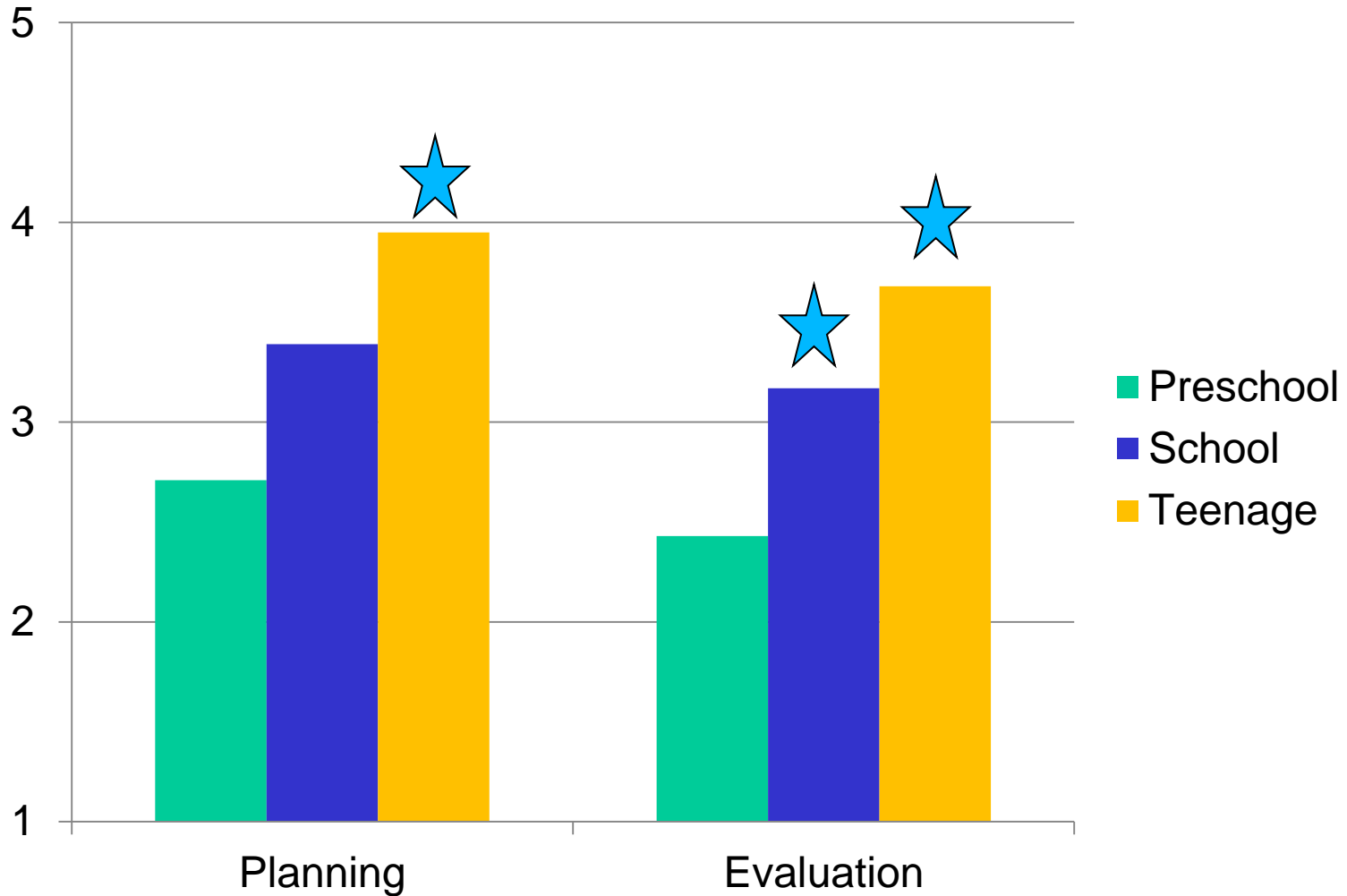


Results: Children's participation (Parents' report)





Results: Children's participation (Professionals' report)





Results: Children's participation

- ✓ Face to face meetings
- ✓ Limited children's participation
 - ✓ Professionals rely more on indirect than direct means of communication with the children -- especially younger children
 - ✓ Parents wish that their children are given more opportunity to directly participate in the meetings with professionals
 - ✓ Professionals reported higher opportunity for children to participate
 - ✓ Parents and professionals were neither satisfied nor dissatisfied



Results: Parents' participation

- Parents' participation
 - Limited
 - ✓ Mothers reported higher participation in the planning of support than fathers
 - ✓ Professionals reported higher parents' participation in the planning of support than parents
 - ✓ Parents and professionals were neither satisfied nor dissatisfied



Conclussion

- Parents' and children's participation are limited
- Mothers -more active in planning of support
- Children's participation -- Age matters!



Thank you!

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Discussion

- Can Family Centered Approach be implemented? What are the strength and weaknesses of FCA?
- Who is responsible to move the issue of children's participation forward?
 - Specific policy in the organizations?
 - Professionals? Parents?