

Participation – as a means and an end in intervention work

Mats Granlund

Key note presentation

CAPA conference

Beitostölen, Norway

September, 2022



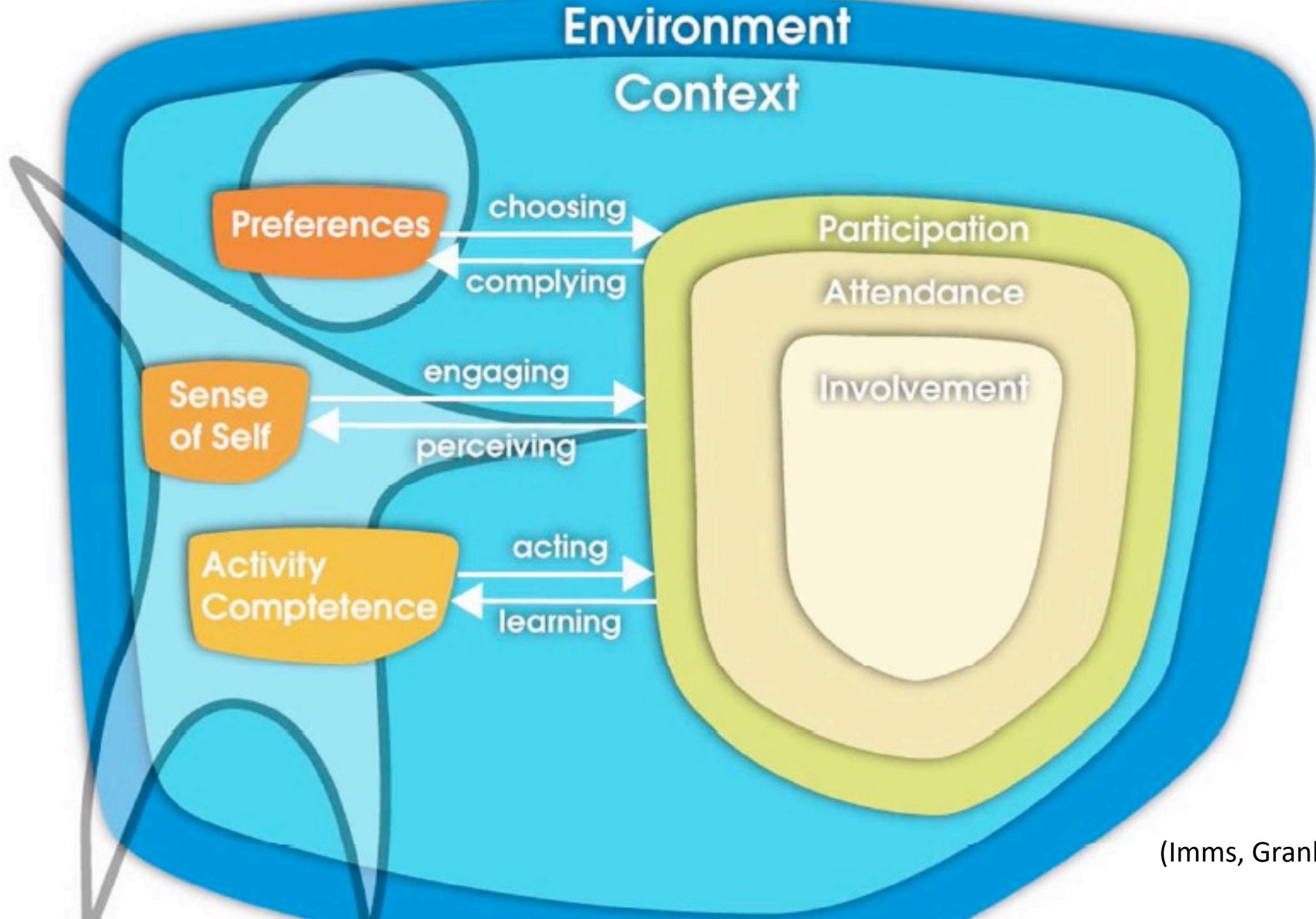
JÖNKÖPING UNIVERSITY
School of Health and Welfare



Bloorview
RESEARCH INSTITUTE



CAAC, University of Pretoria



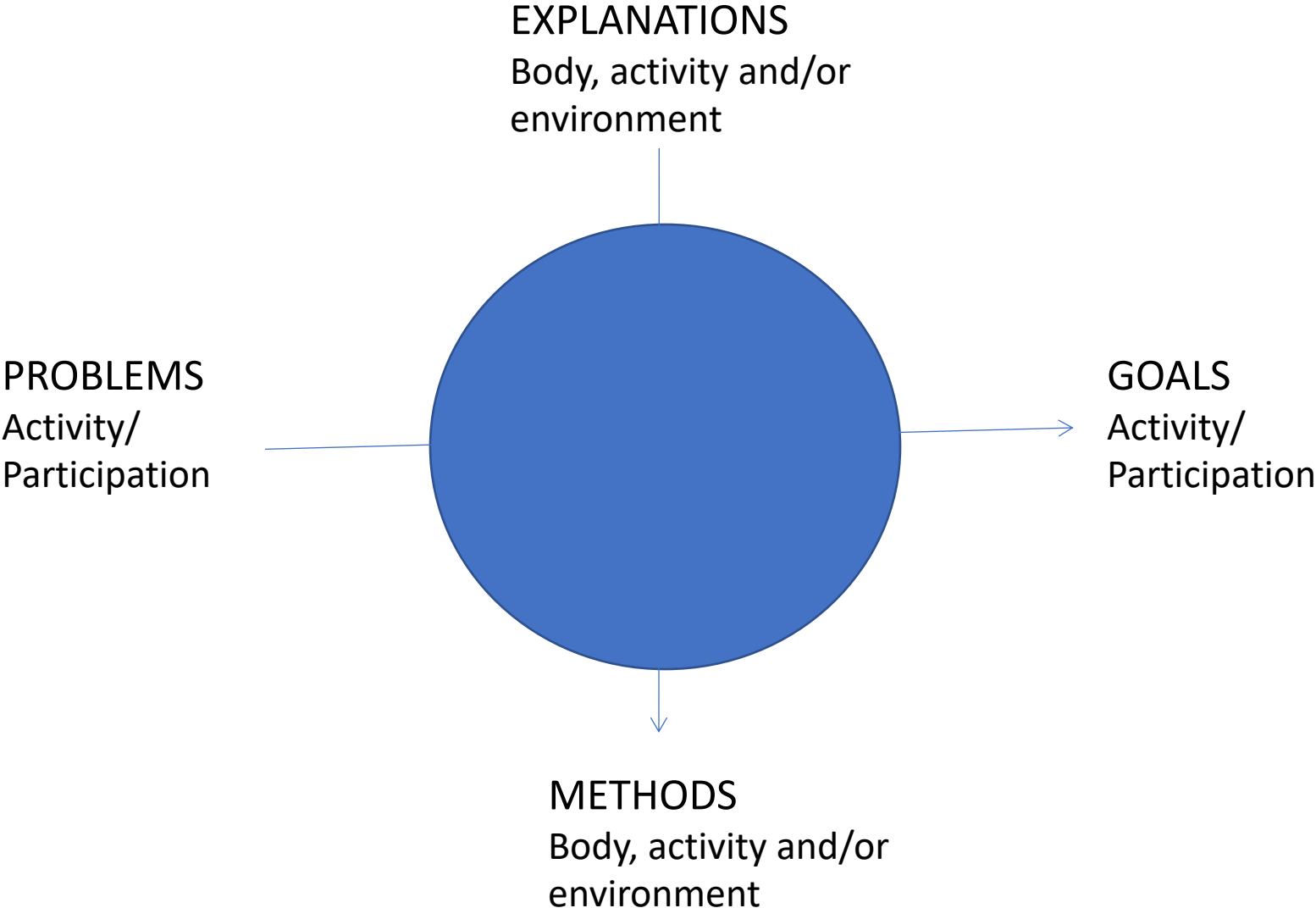
(Imms, Granlund et al, 2011)

What is an intervention?

The intentional steps taken to reach a desired outcome

- Measures (steps taken) must be intentional
- The outcome must be explicit and desired

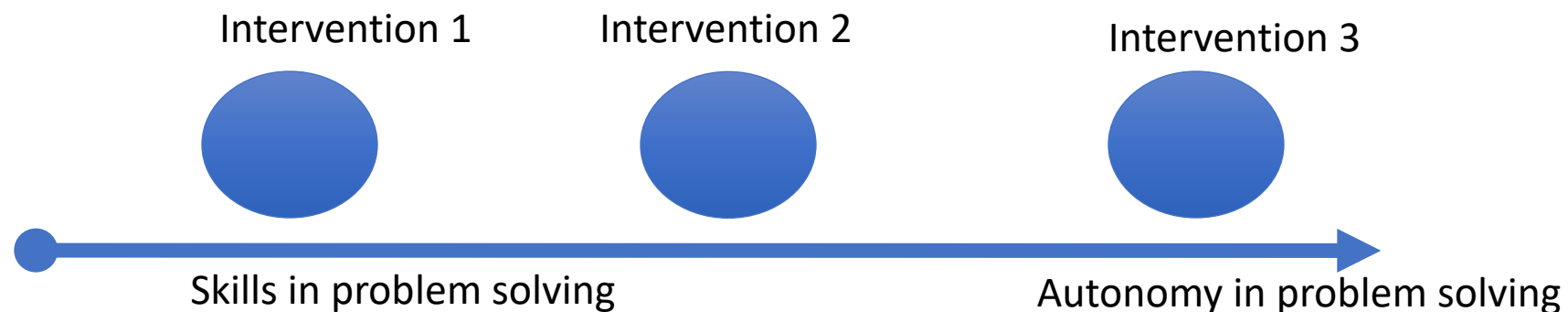
Planning, implementing and evaluating one intervention – participation as an outcome or a method



Characteristics in interventions

Interventions seldom consists of only one intervention or a specific series of interventions. A more correct description may be a set of possible interventions followed by factors that influence the interaction between a client/fanmily and these interventions (p.7, Knapp, 1995)

Participation intervention as a process over time



How the intervention process is performed can be an intervention in and by itself, participation as a means

What is an outcome??

- Another word for outcome is effect. Effects of an intervention can be defined as changes in behavior, attitudes, relationships, or environment during a specified time-period due to planned causes.
- Most effects have several causes where some are necessary (they are always there) while others are not.
- There are always several effects of an intervention, the evaluation of the outcome is done with the expected outcome as the criterion for success
- *Ideally the goal of an intervention is equal to the desired outcome →*
 - Who decides the goal?
 - Is the outcome equal to the goal?
 - Who specifies the desired outcome?
 - What other expected or unexpected outcomes than the desired ones are there?

Outcome dimensions

Intermediate - outcomes that facilitate further interventions to reach a long term goal

Instrumental – interventions expected to lead to other outcomes than those targeted

Ultimate – outcomes that are long lasting and important in and by themselves

(Schlosser & Braun, 1994)

Type of effects (outcomes??)

- Transient effects – outcomes that are specific in time, context and task, often motivating for participants
- Enduring effects - are broad and cover many contexts and tasks, less visible for participants
(Simeonsson, 1995)

Transient effect

Enduring effects



Participation in a certain context/activity

A person that autonomously choose where when and how to participate

An outcome matrix for participation effects

	Intermediate – facilitate further intervention	Instrumental – expected to lead to other outcomes than those specified	Ultimate – “long lasting” and important in and by themselves
Transient effect – specific in time, context and task	e.g skills in operating eye gaze technology to facilitate communication intervention aimed at increasing social interaction	e.g skills in walking and fine motor grip to “automatically” increase participation in outdoor play activities or enhancing attending and/or involvement in outdoor play activity to “automatically” increase skills	e.g enhancing attending and/or involvement in outdoor play activities. Involvement can be engagement or sense of belonging
Enduring effect – broad cover many contexts and tasks and lasts over time	e.g skills in identifying environmental facilitators and barriers for participation in natural environments	e.g skills in in self-advocacy as applied in natural settings or in planning a series of participation interventions in collaboration with professionals	Person that participates in a diversity of activities based on interest, personal obligations and societal demands in a life-long perspective

Participation as a means

- Participation as a means for the goal to learn , practice and/or use skills (important for future participation)
 - participation is an instrumental goal for reaching goals related to skills development (e.g Anaby with colleges, 2018, 2020, 2022)
 - persons with impairments are trained in analyzing environmental prerequisites and facilitators for participating as well as in self advocacy skills that facilitate adapting activities for enhancing participation (e.g Kramer et al, 2015, 2020) An intermediate or ultimate goal??
- Participation as a means for enhancing involvement in participation intervention planning and implementation

Participation as a means for enhancing involvement in participation intervention planning and implementation

Participation in defining the participation problem/problems

Participation in explaining the participation problems – person and environment

Participation in prioritizing what participation problems to solve

Participation in setting the goal/goals (is participation a means or an end?)

Participation in planning and implementing methods aimed at solving problem

Participation in evaluating outcomes regarding method implementation and goals

Intervention as a process – two dimensions

- being there

- being engaged while being there

	Aim for professional	Aim for child/parent
1. Defining the problem/assessment	collecting info. and ?	Decide/Learn??
2. Explaining the problem/assessment	collecting info. and?	Learn??
3. Setting the goal	target and evaluation ?	control over decision??
4. Designing and implementing the method	adherence/fidelity and?	utility of method?
5. Evaluating implementation and goal attainment	evaluation and ?	learn??

To define the problem

- A problem = The difference between how it is and how it ought to be. There is always more than one problem for a child/family
- A problem must be important to be prioritized
- A problem is usually only discussed if it is considered as solvable. What do the user know about solutions?
- If a problem is not considered solvable, how can it be redefined?

To explain a problem

- All problems have several explanations
 - Body functions -> adapt environment
 - Activity -> adapt environment
 - Environment
- Problems can be explanations to each other
 - Most problems focusing on things that happens too frequently can be matched to too seldom problems
 - Problems of participation can be explained by activity, body and environment factors
 - Problems tend to come in clusters
- The more explanations the more options for methods



Prioritizing among problems, selecting a goal for intervention

- The most important participation problem to intervene with according to the child
- A problem that can have effect on other problems if worked with
- The problem that seems easiest to intervene with



Desire to change activities as rated by children and parents (Liao et al, 2019)

Table 4. Comparison of the desire-to-change activities of children selected by the children ($n = 30$) and parents ($n = 28$)^a.

Number of Activities	Child	Parent
Total	91 (100%)	80 (100%)
Home domain	31 (34%)	37 (46%)
School domain	20 (22%)	19 (24%)
Community domain	40 (44%)	24 (30%)

^a Two of the parents each selected for their 2 children.

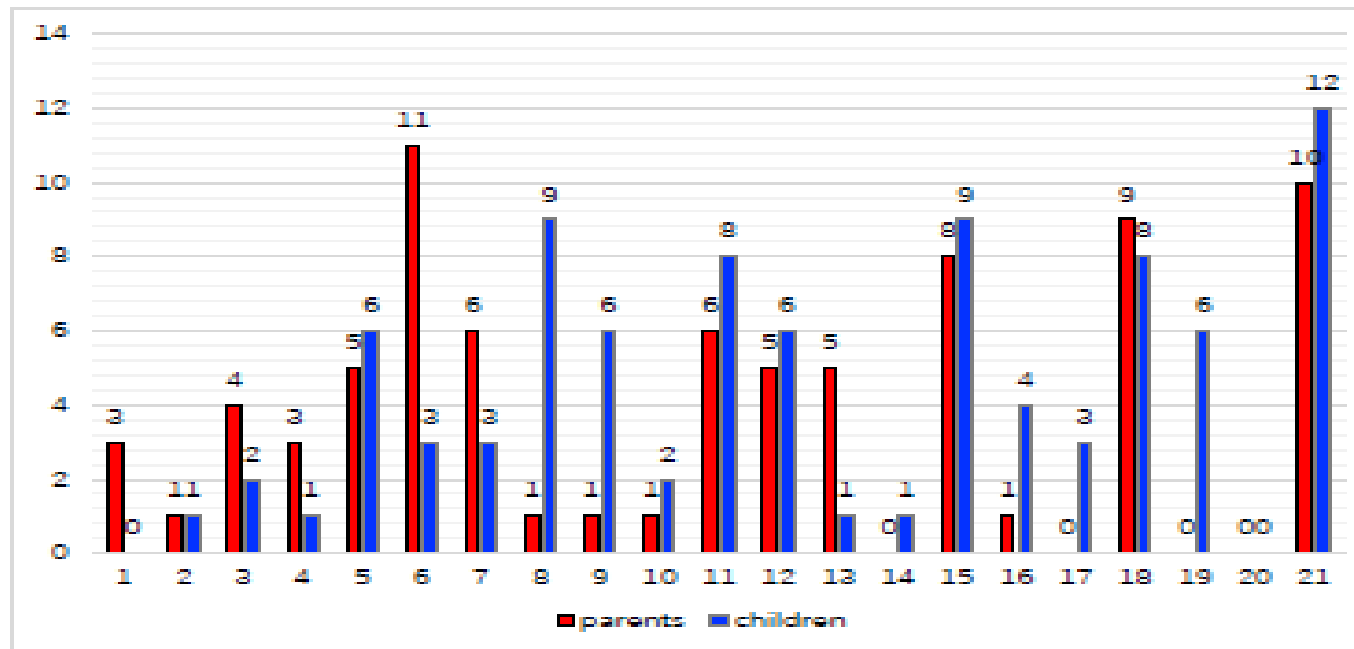


Figure 1. Frequency count of each item of the PMP-C being selected as desire-to-change activity by children and parents. Item names: 1st. Personal care; 2nd. Family mealtime; 3rd. Looking after one's own health; 4th. Gathering daily necessities for family; 5th. Meal preparation with or for the family; 6th. Cleaning up at home; 7th. Taking care of other family members; 8th. Taking care of animals; 9th. Interact with the family; 10th. Family/community celebrations; 11th. Getting together with other children in the community; 12th. Organized leisure; 13th. Quiet leisure; 14th. Religious and spiritual activities; 15th. Shopping and errands; 16th. Social activities in the community; 17th. Visit to health center; 18th. Formal learning at school; 19th. Overnight visits and trips; 20th. Paid and unpaid employment; 21th. Play and leisure at school. Note: PMP-C = Chinese version of Picture My Participation.

Children and parents rated the level of involvement for each selected desire-to-change activity. The mean scores for level of involvement of 91 activities selected by the children was 4.33 (in between somewhat involved to very involved, $SD = 0.78$), while the mean scores of 80 activities selected by the parents was 3.71 (in between minimally involved to somewhat involved, $SD = 0.69$), indicating that children generally rated themselves as more involved in their selected activities. The mean scores for level of involvement of the children's top five selected activities all fall in between somewhat involved to very involved; while the mean scores of the parents' top six selected activities all fall in between minimally involved to somewhat involved (Figure 2).

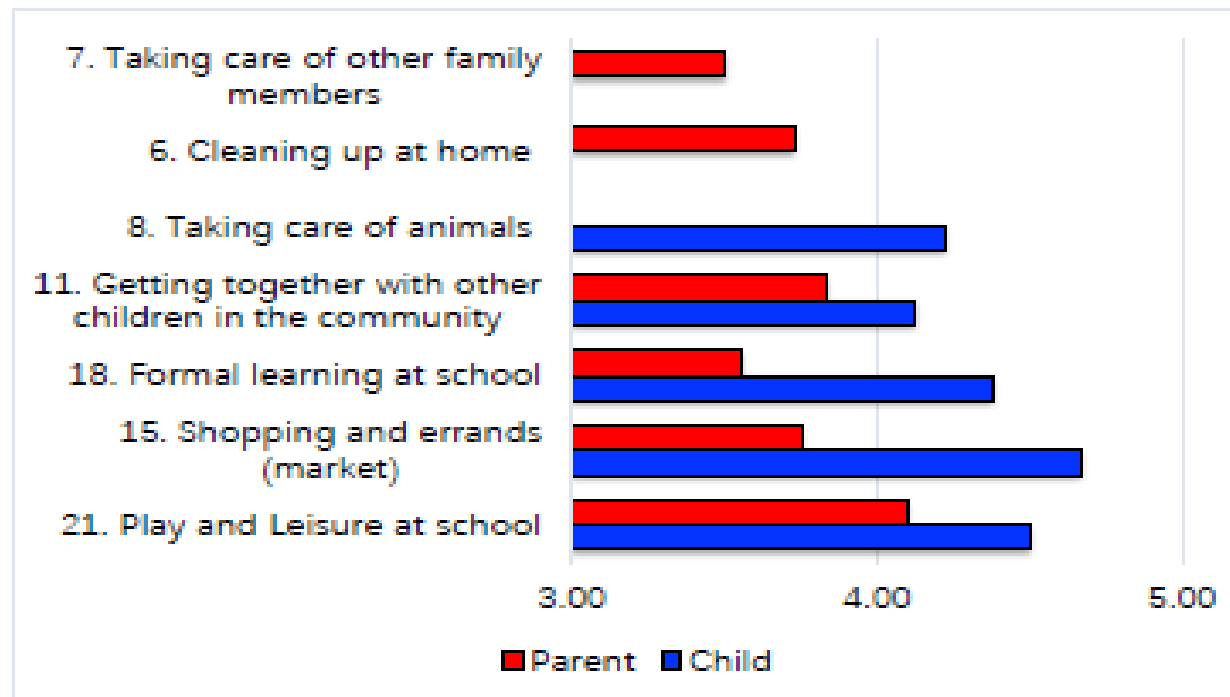


Figure 2. Mean scores for level of involvement of top 5 or 6 activities of the PMP-C selected and rated by children and parents. Level of involvement scoring: 5: Very involved, 4: Somewhat involved, 3: Minimally involved, 2: Not applicable, 1: Unsure or no answer. Note: PMP-C = Chinese version of Picture My Participation.

Setting the goal for intervention

- Goals related to diversity of participation, duration of participation or frequency of participation
 - Explanations are related to the availability or accessibility of an activity
- Goals related to the degree of involvement when being in the activity
 - Explanations are related to accomodation of activity or acceptability of activity



Using explanations to design intervention

- All interventions can be described as environmental variables added from outside the child
- Explanations that make it easier to understand problems but do not provide information useful for intervention
- Explanations that can be translated to interventions



Method

- Based on problem explanations
- Method is easy to perform by child/care providers
- Method should be easy enough to be automatized
- Changeable dependent on circumstances
- The method principle should have several possible expressions
- Can be used or supported by several persons

Family involvement in intervention process

From CHILD-PMH – ongoing study first wave

Involvement in assesemnt decision	Involvement in assessment	Involvement in team meeting decisions about goals	Involvement in planning and deciding on intervention methods	Involvement in planing Family goals and support
Professionals present an assessment plan and ask parents for feedback (3)	Professionals ask parents extensive questions about child's behavior and development (2)	Parents make suggestions about goals and services for their child (3)	Professionals suggest what methods should include and work together with parents on implem. (3)	A set of planned family services is offered from which parents can choose (3)
<u>Longitudinal</u> 28%	<u>Longitudinal</u> 43%	<u>Longitudinal</u> 42%	<u>Longitudinal</u> 49%	<u>Longitudinal</u> 60%

Percentage exhibited = proportion of responders 3 or lower

Professionals plan and decide

3 = mid scale

Parents plan and decide

Prime-Child : items with lower perceived engagement in one session

Descriptive Statistics						
		N	Min	Max	Mean	SD
1	Jag känner mig nöjd över hur insatsen/åtgärden går - Jag känner mig inte nöjd över hur insatsen/åtgärden går	32	4	6	5.41	0.615
2	I think the intervention is doable/I don't think the intervention is doable	32	3	6	5.09	1.027
3	I feel optimistic/not optimistic about the intervention plan	32	2	6	5.06	0.948
4	Jag tänker att målen för insatsen/åtgärden kommer att vara användbara - Jag tänker inte att målen för insatsen/åtgärden kommer att vara användbara	32	2	6	5.41	1.132
5	I can see how the plan for the intervention works/I can't see how the plan works	32	2	6	4.94	1.162
6	Habiliteringsplanen för insatsen /åtgärden har betydelse för mig - Habiliteringsplanen för insatsen /åtgärden har inte någon betydelse för mig	32	3	6	5.44	0.801
7	Jag är villig att arbeta för insatsen /åtgärden - Jag är inte villig att arbeta för insatsen / åtgärden	32	4	6	5.44	0.669
8	I think the different steps to reach the goal will work/I don't see how the different steps will work	32	3	6	5.00	0.916
9	After the visit I am optimistic about reaching the goal/I am not optimistic	32	3	6	5.03	1.031
10	Planen att uppnå målet möter mina behov - Planen att uppnå målet möter inte mina behov	32	2	6	5.22	1.070
11	Jag tror att insatsen /åtgärden kommer att hjälpa mig - Jag tror inte att insatsen / åtgärden kommer att hjälpa mig	32	2	6	5.41	0.911
12	I feel that I can manage to do the intervention/I don't feel I can manage to do the intervention	32	2	6	4.94	1.014
13	Jag var intresserad - Jag var inte intresserad	32	4	6	5.41	0.615
14	I perceive that I was involved in planning/I did not feel involved in planning	32	3	6	5.09	1.027
15	I was actively involved/I was not actively involved	32	2	6	5.06	0.948

Triangulation results from Involvement in process, PRIME and focus groups:

Regarding involvement in the process care providers and children are especially concerned about their involvement in decisions and planning related to the implementation of interventions.

Themes concern:

clarity and concreteness,

understanding why interventions are done and how to perform methods

individualization of information and goals.

Family outcomes survey (Bailey, Scarborough et al, 2004)

Instructions: Section B of the Family Outcomes Survey focuses on the helpfulness of early intervention. For each question below, please select how helpful early intervention has been to you and your family over the past year: Not at all helpful, a little helpful, somewhat helpful, very helpful, or extremely helpful.		Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful
Knowing your rights						
How helpful has early intervention been in...						
1.	giving you useful information about services and supports for you and your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	giving you useful information about your rights related to your child's special needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	giving you useful information about who to contact when you have questions or concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	giving you useful information about available options when your child leaves/continue in the program?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5.	explaining your rights in ways that are easy for you to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicating your child's needs						
How helpful has early intervention been in...						
6.	giving you useful information about your child's delays or needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7.	listening to you and respecting your choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8.	connecting you with other services or people who can help your child and family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.	talking with you about your child and family's strengths and needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10.	talking with you about what you think is important for your child and family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11.	developing a good relationship with you and your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping your child develop and learn						
How helpful has early intervention been in...						
12.	giving you useful information about how to help your child get along with others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13.	giving you useful information about how to help your child learn new skills?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.	giving you useful information about how to help your child take care of his/her needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15.	identifying things you do that help your child learn and grow?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16.	sharing ideas on how to include your child in daily activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17.	working with you to know when your child is making progress?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>