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Co-development of the CMAP Book: A tool to enhance children's participation in pediatric rehabilitation

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Co-development of the CMAP Book: A tool to enhance children's participation in pediatric rehabilitation

Purpose: The purpose of the co-development project was to create a tool that enhances children's active participation and agency in rehabilitation and in everyday life.

Materials and methods: Action research was the methodological approach. Participants in the different phases of the process (2015-2017) were children with disabilities, parents and rehabilitation professionals. The co-development process included: 1) designing the tool's first version, 2) piloting the tool, 3) evaluating the tool by collecting feedback and reflection, 4) generating the tool's final version.

Results: Through the co-development process, an accommodating and digital tool called the CMAP Book – a description of the child's meaningful activities

and participation - was developed. The CMAP Book is used with an electronic app enabling the identification and description of what is meaningful in daily life from the child's perspective with videos, photos, pictures, recording and writing. The tool enables the child, family and professionals to prepare and build collaboration in rehabilitation with flexibility according to child and family needs.

Conclusions: Use of the CMAP Book promotes the active involvement of the child and parents in designing the rehabilitation process in daily life in partnership with professionals. The stakeholder involvement in the co-development facilitated meaningful results and a concrete tool for rehabilitation.

Keywords: co-development; participation; digital tool; children with disabilities; pediatric rehabilitation

Implications for rehabilitation

- The CMAP book is a new tool that enhances the child's active participation and agency in the rehabilitation process based on meaningful activities in everyday life expressed by the child.
- Identifying and utilising meaningful issues in the child's daily life through collaboration increases the child's commitment and motivation, and thus may enhance the benefits and effects of rehabilitation.
- Through co-development, the child and his/her family can be active and equal partners not only in development projects but also in the rehabilitation process.
- In the future, child-specific practices and policies should be developed to promote participatory coresearch between families and clinicians linked to the daily lives of families with children.

Introduction

The last two decades have witnessed important changes in the provision of pediatric rehabilitation. There has been a change from a biomedical towards a broader, more bio-psycho-social way of thinking [1–4]. The child´s participation has been identified as one of the most important factors for a successful pediatric rehabilitation [5–7]. However, the definition of participation is multidimensional. It has been defined to relate to the profound dimensions of belonging, attachment, and influence [8,9]. The International Classification of Functioning Disability and Health (ICF) was the first conceptual model to emphasise participation as a crucial part of functioning as well as the importance of environmental factors as a means of identifying facilitators and barriers for participation [1]. Participation in the ICF is defined as "involvement in life situations" [1]. Additionally, The United Nations Convention on the Rights of the Child highlights the child´s right to be heard and to be part of decisions concerning herself/himself [10]. Traditionally participation has been seen as the right to be involved in matters that concerns oneself, and for example Shier [11] has conceptualised this by the Pathway to Participation model based on Hart's [12] Ladder of Participation. In recent years, pediatric rehabilitation has emphasised the ecological approach, in which rehabilitation is understood as an interactive process between the child, his/her family and the environment [7,13]. Different participation-based concepts and theories have lately been developed [7,14,15,16]. Yet, many concepts and methods that are developed to enhance children's participation, are developed by adults [9].

In Finland, rehabilitation for children and youth with special needs is free of charge, but a rehabilitation plan is the prerequisite for starting and financing rehabilitation services. Laws and directives require that rehabilitation is planned by a multiprofessional team within the public sector, which in practice is mostly the hospital district in which the child lives [17,18]. The rehabilitation service (i.e. different therapies) are realised by

rehabilitation professionals (service producers) in the child´s home region. Children and their families visit the hospitals for follow-up and rehabilitation planning regularly every 1-2 years. The aim of the visit is to set rehabilitation goals and to decide on the content of interventions. During the visit, there is a general review of the child´s functioning by professionals at the hospital. The rehabilitation service producers, school and kindergarten teachers are invited to send a report prior to the meeting. In some cases, these professionals are invited to take part in the meeting. Meetings are led by the physician or someone else in the multiprofessional team. During the meeting the child and his/her parents are heard, but mostly professionals inform about results from the assessments conducted, the connection to the child´s participation in everyday life being somewhat lacking. [19,20]. A recent study showed that both children and their parents had a possibility to describe their experience of the child´s function in everyday life during the rehabilitation planning meeting [21]. Previous studies however, have showed that the child´s and parent´s voice in written reports is not well noted [22], and there is some uncertainty in how to involve the family in the rehabilitation planning process [20]. Thus, a tool to systematically enhance the child´s possibility to express his/her thoughts and wishes for meaningful participation in everyday life, helps the child to prepare and commit to her/his own rehabilitation process.

A child-specific culture in rehabilitation needs structures that empower the child to work in partnership with the involved adults. To maximise children’s active participation their individual agency should be recognised and enabled. The child's agency changes and adjusts in real-life situations and is thus built in context-based manner. Modalities of agency describe child's competencies, abilities, emotions, desires, compulsions and possibilities that interact with each other and are dependent on the context and environment where the participation takes place. [23]. In order to enable the

child's agency in rehabilitation, professionals need ways to build partnership with the child and his/her family in their daily life environment and through the rehabilitation process [24].

When aiming to strengthen the child's performance and participation in her/his daily life, it is important to identify such participation that is meaningful to the child [25]. To best enable child empowerment and identification of the child's perspectives, child-driven tools need to be developed. Thus, the aim of this co-development process was to design, pilot, evaluate and generate the final version of the new tool to enhance children's participation and agency together with children and their families. This co-development was part of a LOOK-project (Right of the Child to Participate in His/Her Rehabilitation – Assessing the Child's Best Interest) carried out by Metropolia University of Applied Sciences in collaboration with the Central Union of Child Welfare. The project was funded by the Social Insurance Institution of Finland (2015-2017).

Materials and methods

Action research [26] was selected as a methodology approach enabling evidence-based co-development. Results from a literature review [27] and a qualitative research [28] served as basis for the multiphase co-development process. The purpose of the descriptive literature review was to survey measures, tools or good practices that strengthen the child's participation. Only generic methods and tools that enable children's active participation in partnership with adults were chosen. The literature search was conducted (spring 2015) in Cinahl, Medline, Social Sciences and Cochrane databases and a Finnish database Theseus. Eleven instruments and 17 tools met the criteria set by the project workers. The review recognised four potential tools /practices /assessment methods that

could be useful in the co-development [27]. Results showed that enhancing the child's participation in rehabilitation and in daily life calls for a systematic and process-like approach based on a partnership between the child and the adults (Appendix 1). The qualitative research data was collected through individual functional interviews with children (n=6), focus group discussions with parents (n=4) and professionals (n=30) and a future workshop (n=8). The data was analysed by inductive content analysis [28]. The results were summarised (Appendix 2) to serve in the co-development process (Figure 1).

The action research based co-development process in the project included: 1) designing the tool's first version in collaborative workshops utilising results from the literature review and interviews, 2) piloting the new tool, 3) evaluating the tool by collecting feedback and reflection from a seminar and educational course, 4) generating the tool's final version and producing an e-publication (Figure 1). The collected data was analysed by using content analysis [29] in the different phases of the process.

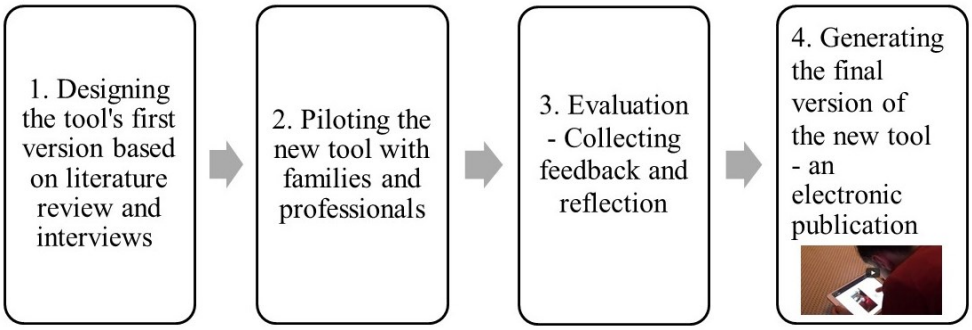


Figure 1. The Co-development process in the action research.

1) Designing the tool's first version

Specialists of rehabilitation (n=30; 14 physiotherapists, 2 speech therapists, 5 occupational therapists, 1 pediatric neurologist, 6 other experts and 2 parents) participated in addition to project workers (n=3) in a collaborative workshop. First, the

results of the literature search and the results of the focus group interviews were presented. Then, the participants discussed in groups and reflected on the needs and ideas for the tool. After collective idea-sharing of the description of the child's meaningful activities and participation, the participants were asked to deliberate what is the main task of the new tool and how it could be used in rehabilitation and to write answers to three topics: 1) what influence does the new tool have on the child's rehabilitation? 2) how should the new tool best be used in the child's rehabilitation? 3) what should be considered when developing the new tool? The group discussions were audio-recorded and the group's written memos were used as data in the development process. Additionally, 20 people (9 occupational therapists, 9 physiotherapists, 1 nurse and 1 parent) wrote written feedback after the collaborative workshop, answering the question "what kind of influence do you think the new tool can have on the child's rehabilitation?"

The first version of the new tool called Children's Meaningful Activities and Participation in Rehabilitation, the CMAP Book, was co-created by project workers. Co-creation was implemented by combining knowledge in an innovative way (Table 1).

Table 1. Designing the CMAP Book.

1) Designing the tool's first version	**Co-creation by combining data**			**Result**
	Baseline data	**Collaborative workshops**	**Technical implementation**	**CMAP Book version 1.0**
	Results of the literature review	Results of content analysis of the audiotaped and written material	Reviewing appropriate digital applications	
	Results of the focus group interviews	Results of the content analysis of the feedback		

	Reviewing theories of participation and agency			
2) Piloting, 3) evaluating and 4) generating the final version of the new tool	**Co-creation by combining the tool's first version and data**			**CMAP Book e-publication**
	Pilot testing	**Feedback and reflections at CMAP Book course (days 1 and 2)**	**Technical implementation**	
	Results of the piloting the CMAP Book	Results of the questionnaires	Co-designing the final version of the CMAP-tool	
	Results of the e-mail feedback from professionals	Results of the group discussions	Co-designing an accessible e-publication for families and professionals including word- and pdf- documents and video materials	

2) Piloting the new tool

Parents and children who participated in the interviews [28] and who volunteered to pilot test the CMAP Book were asked to create a description of the child's meaningful activities and participation with the Book creator application by following the drafted instructions. Two of the interviewed families volunteered. Additionally, two families were recruited through one of the therapists who participated in the co-development process. After trying the tool, the participants were asked about general thoughts about the tool and development needs, benefits and possible use for the tool in rehabilitation and what change it brings to the current rehabilitation. All in all, four pilots were conducted to develop the clarity of the instructions and usability of the tool and to assess the usefulness of the tool in rehabilitation. Two feedback discussions were held in the child's home and two discussions were conducted by phone. The project worker

wrote memos arising from the discussions. Additionally, feedback about the instructions were collected from professionals through email (Table 1).

3) Evaluation - Collecting feedback and reflection

The first version of the new tool was presented at a round-table seminar organised for active development partners, key actors from phases 1 and 2. Written feedback of the first version of the CMAP Book was collected from participants (occupational therapist n=9, physiotherapist n=9, nurse n=1, parent n=1). The feedback was utilised for finalising the CMAP Book and for planning of the educational course for professionals (Table 1).

The feedback and reflection of the first version of the CMAP Book was collected at the CMAP Book educational course organised by Metropolia UAS. The feedback was collected from two questionnaires to rehabilitation professionals during the course (Table 2). The questionnaires contained open ended questions and additionally the questionnaire on course day 1 included statements about the CMAP Book that were rated on a five-point Likert scale. Open ended questions on course day 1 were: "What influence can the CMAP Book have in the child's rehabilitation? and "Do you have some other comments or suggestions about the CMAP Book?" With the open ended questions on course day 2, the participants evaluated what they had learned in the training course and there was also a possibility to give open feedback about the CMAP Book.

Table 2. Participants in the CMAP Book educational course.

Course	**Occupation**	**Working sector**	**Feedback forms**
Day 1 **n=110**	Occupational therapist: 51 Physiotherapist: 20 Speech therapist: 18 Nurse: 3 Teacher, special education: 3	Private: 57 Public: 35 Other: 6	n=98

	Rehabilitation counsellor: 2		
Day 2 n=37	Occupational therapist: 25 Physiotherapist: 6 Speech therapist: 4	Private: 34	n=34

Reflection on the CMAP Book was collected from workshops on course days 1 and 2. On course day 1, the workshops were carried out as a group discussion (n=4). The first group discussed how the CMAP Book can be utilised in rehabilitation. The second group first listened to the conversation from three different perspectives - child, family and professionals - and then continued the discussion. One participant listened to the conversation and wrote down the reflection. By the second day of the course, the participants had used the CMAP Book in practice. The reflection of the user experience was also carried out as a group work. The small groups (n=7) of 4-5 professionals, discussed and wrote down the core issues of the benefits and difficulties of using the CMAP Book.

4) Generating the tool's final version

The three project workers and an expert in e-publications co-designed the final version of the CMAP Book (Table 1). The final version was designed for professionals and families and therefore the accessibility of the publication was important. Additionally, a summary of the knowledgebase and key elements of the CMAP Book were generated based on the collected data during the co-development process.

Results

The results are presented following the phases of the co-development process. The outcome of the process was the CMAP Book (http://metropolia.e-julkaisu.com/lapsen-metkut/metku-kirja/).

1) Results from designing the first version of the tool

Co-development of the tool in collaborative workshops resulted in criteria of the tool's main elements and use of the tool in the child's rehabilitation. The co-development resulted in a definition of the purpose of the tool. The CMAP Book describes what is important for the child in her daily life enabling his/her views to act as a starting point for planning and implementing rehabilitation in family and professional collaboration. The use of the CMAP Book helps the child to prepare for rehabilitation and follows the child's rehabilitation process. The CMAP Book enables an insight into the child's world that helps to adjust rehabilitation responding to the child's and family's needs and is suitable for child and family daily life and routines in a real-life context.

The results showed that it was important to explore and describe what is meaningful from the child's perspective and use this information to plan and integrate child-specific and meaningful rehabilitation into the child's daily life. It was highlighted that the description is shared with the professionals in the child's rehabilitative network to create shared understanding of the child's views and daily life. Possible digital applications were seen as motivating for the children. Also, the digital tool enabled constant updating and the use of for example videos, photos and written text in order to

produce the description of meaningful activities, participation and environment from the child's perspective.

The first version of the tool was drafted by the project team members based on the baseline data and results from the workshops. The main themes and example questions that can be used when describing the child's meaningful activities and participation in his/her daily life, were formulated (Table 3). The example questions and prompts aimed to guide the adults in facilitating discussion with the child in a sensitive way that enables the child's own perspectives to be at the centre of attention. The importance of modifying questions and discussion themes individually based on child's interests and understanding was highlighted.

Table 3. Examples of the discussion themes, questions and prompts in the CMAP Book.

Discussion themes describing meaningful activities and participation for the child in his/her everyday life	Questions and prompts for discussion with the child
What kind of tasks, activities or participation does the child find meaningful, would like to learn, or otherwise think are important? Take photographs/videos of these and describe things that are associated with them. You can use example questions and prompts to discuss with the child in order to explore and describe the child's perspective.	Let's take a photo or a video of an activity that's important to you. What would you like to take a photo or a video of? - What makes you happy? - What would you like to learn? Could you tell me what's happening in this video/photo? What do you want to do here? - What do you don't want to happen? - Are you doing (the activity being described) alone or together with someone? Who are you doing it with? - What in this activity can you do well? - What about this activity, do you want to do it on your own, and what do you want to have help with?
What kinds of activities, things and routines are associated with the child's normal everyday life? You can take photos or videos of these things and routines, or they can be drawn or written about in the child's CMAP Book.	Let's describe here how you (theme in question). What do you want to tell about your (theme in question)? Do you have an example of that situation? How do you want to describe (the theme in question) to the book?

Examples of themes to describe in the Book from the child's perspective: - How the child expresses his/her will and communicates - How the child copes with activities of daily living at home/ day-care/ school/ other everyday environments - How the child takes care of himself/herself - How the child moves in different everyday environments - What are the child's leisure activities and hobbies - The child's social relationships and interaction with the immediate family and peers - How the child learns new things and applies this information in practice -Which factors help the child's functioning in everyday life - What kinds of assistive technology does the child use - How adults close to the child can best support the child's functioning	Have you noticed something that helps you to … (theme in question)? Is there something that makes it harder for you to … (theme in question)? How do you want the adults or peers to help you to … (theme in question)?

For technical implementation, a project worker sought a free-to-use digital application enabling flexibility and creativity in the making of the description, and one that is available for everyone and works with different devices. After the exploration of different possible applications, the Book creator application was identified as a digital tool that fulfilled the criteria defined by the participants. With the application, the child could make an electronic book describing meaningful activities and participation with videos, photos, as well as drawings, writings, recordings and downloading pictures and inserting links from the internet. The Book creator application (bookcreator.com) was initially created and implemented in children's education and was therefore usable for children.

3) Results from piloting the new tool

Four children and their parents pilot tested the CMAP Book. Three parents, one child (10 years) and one therapist participated in the feedback discussion after piloting the tool. During three pilots, the child and parent collaboratively created the CMAP Book by using the child's own tablet and in one pilot the child's therapist also participated in the making of the book. In one pilot, Jason (8 years), who has a severe disability and communication limitations, participated in creating the book by choosing photos and videos. Example page of Jason's CMAP Book is presented here as an example of the pilots (Figure 2).

Jason and his parents found it important to describe their family and Jason's personality, his own interests and the family activities, Jason's communication, movement and self-care abilities, daily environment and routines. Jason's book also included descriptions of ways to support the child's smooth daily living from Jason's perspective in order to share and inform about practices that help him to participate.

Jason's mother described that the main benefit from the book was that the adults in Jason's daily environments saw the boy's personality, strengths and capabilities in a new light and not focusing solely on his restrictions and difficulties. According to his mother, understanding the child's view through the description in the book, helped Jason and adults who did not know him so well, to create a positive relationship and to overcome challenges in daily life situations. Jason's family decided to use the book in rehabilitation planning in order to present what is meaningful and what the support needs are in a daily environment from Jason's perspective. In daily life situations and especially with new staff, the book was used to share information and know-how on how to support Jason's functioning and to integrate rehabilitation in daily activities.

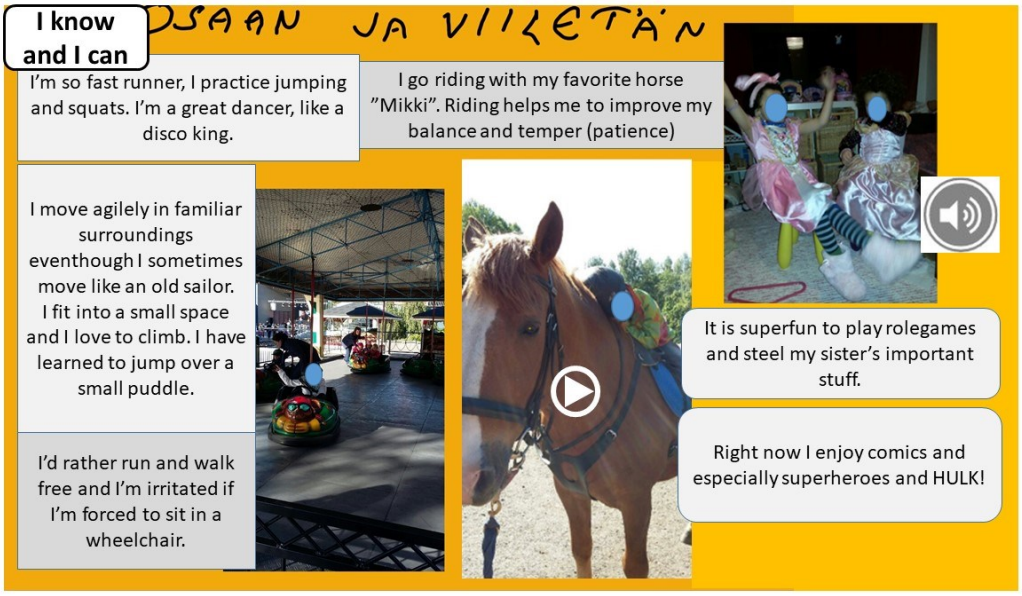


Figure 2. Example of Jason's CMAP Book; I know, and I can [30].

All the participants agreed that the CMAP Book enabled the child's participation in rehabilitation planning and brought the child's perspectives from daily life concretely to the centre of the rehabilitation discussion through videos and photos. Themes and example questions (Table 3) for the child and parents making the book were considered clear and important topics. Participants found it important that the book is strength-based, enables and saves the child's own expressions and is written in the first-person. The positive view of the child's capabilities, interests and learning potentials and environmental resources, helped to support the child's self-identity and affirmative mindset towards future possibilities.

In one feedback discussion, mother and child (Robert, 10 years) indicated that it would be useful to show with videos to the rehabilitation professionals, how the activity is done in real-life situations and also follow-up and present the achieved development in certain activities with videos in the book. Robert also commented in the feedback

discussion that the professionals could read his opinions from the book so he would not have to “explain the same things over and over again”.

Participants found it useful that the child and family could prepare themselves by creating the CMAP Book before rehabilitation planning. Thus, the CMAP Book could work as a starting point to a collaborative discussion about the child’s needs and preferences and continue with identification of concrete goals for rehabilitation and planning on how to reach the goals. Participants considered that the CMAP Book helps to create shared understanding on the child’s everyday circumstances and environmental factors influencing her/his participation and agency. Parents indicated that the CMAP Book needs to be showed and used in the child’s school or day-care to share information, practices and know-how on how to support their participation and respond to their needs.

Pilot testing revealed, however, the need for individuality and flexibility in making and use of the book according to child and family needs. Thus, the themes described in the book may vary. The possibility for creativity and personality of the book was appreciated. The use of the Book creator application was considered easy, but time was needed to get to know the application and make the description. Some parents wished for the therapist to inspire and guide them in the making and using of the book. The instructions were modified and shortened based on the feedback and some example questions were made with images to help to communicate with children using pictures.

4) Results of the evaluation

Participants’ reflective discussions and answers in questionnaires (round-table seminar, training days 1 and 2) about the tool and its use in rehabilitation, confirmed the results from the previous phases. Participants considered the tool inspiring and highly needed

in pediatric rehabilitation to enhance collaboration in rehabilitation networks and shift the focus into what is meaningful for the child in her daily life. A summary of the benefits of using the CMAP Book in rehabilitation that the participants indicated in the reflective discussions and open answers in questionnaires from training day 1 (n=98) and 2 (n=34), is presented in Figure 3. The results show benefits in the use of the tool not only for the child but also for parents, professionals and collaboration.

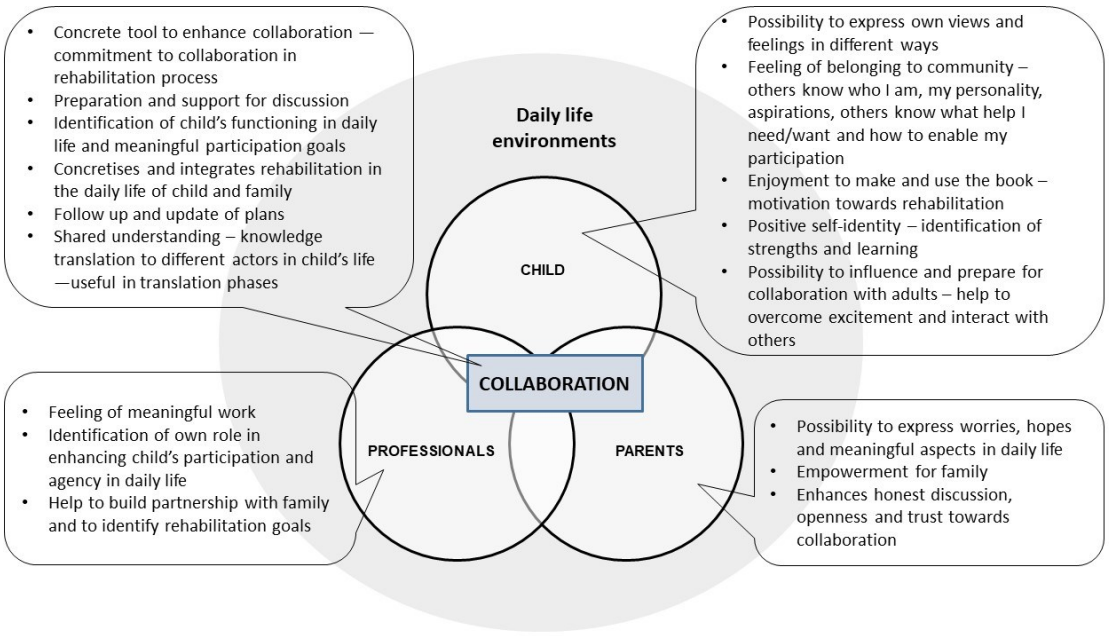


Figure 3. Benefits of using the CMAP Book.

Mean values of statements in the questionnaires in day 1 (n=98) are presented in Table 4. All participants 'agreed' or 'strongly agreed' with the statements evaluating the usefulness of the CMAP Book indicating that the tool is useful in enhancing the child's active participation and agency in rehabilitation and everyday life.

Table 4. Mean values from participants' responds to statements concerning the CMAP Book (n=98); 1= Strongly disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 =

Agree, 5 = Strongly agree. The results in the table have previously been published in Finnish [31].

Statement		Mean	Standard deviation
The CMAP Book	...strengthens taking into account the child's views in rehabilitation	4,3	0,5
	...strengthens integrating rehabilitation into the daily life routines and activities of the child and family	4,3	0.6
	...enhances the building of the child's rehabilitation based on the child's strengths	4,4	0,6
	...enables the child's participation in rehabilitation planning	4,2	0,7
Making the CMAP Book	...helps to identify what is meaningful activity and participation in the child's daily life	4,7	0,6
	...helps to identify factors in the child's environment influencing the child's participation	4,2	0,6
Using the CMAP Book	...in rehabilitation planning enhances building rehabilitation based on the child's needs.	4,3	0,7
	...in rehabilitation planning enhances building rehabilitation based on the family's needs in daily life.	4,1	0,7
	...enhances collaboration between child, parents and professionals.	4,4	0,6
	...enhances the child's active agency in daily life.	4,2	0,7
The CMAP Book is a useful tool for	...rehabilitation professionals	4,5	0,6
	...the child.	4,4	0,6
	...the parents.	4,4	0,6
	...professionals in the child's daily life (schools, day-care etc)	4,4	0,6
I will	...utilise the CMAP Book in my own work.	4,2	0,7
	...recommend and familiarise client families to use the CMAP Book	4,2	0,7

Participants in the second training day's reflective discussion indicated challenges in using the CMAP Book that were subsequently considered in finalising the CMAP Book instructions. The main challenge was the time-resources and knowhow needed to use the tool in collaboration with family. Participants stated that children with more severe impairments and lack of communication abilities need more support from adults in expressing their views and making choices on what is described in the book. Thus, guidance and tips on how to facilitate the child's own expression and explore

what is meaningful for the child were added to the instructions in order to ensure that the child's view is described, not the adults' view. Additionally, participants identified the need to verify that also children and families who don't have the opportunity to use their own tablets or computers, can make the CMAP Book by others means or mobile phone applications if they want to.

The findings emphasised that the children's and families' individual resources and preferences need to be taken into account in using the CMAP Book. The child and parents decide whether they want to create the book and with whom, when and how the book is used in rehabilitation. Making the instructions available, visually attractive and easy to put into use was important.

5) Generating the final version of the new tool and e-publication

Results of the co-development was summarised in the last step of the co-development process in order to generate the final version of the CMAP Book. The CMAP Book allows rehabilitation professionals to apply their existing knowledge-base and skills when using the tool. Table 5 presents the summary of the knowledge-base and key factors in the use of the CMAP Book that underline the importance of considering all the dimensions of the child's agency, acknowledging different forms of participation and considering the child's functioning in interaction with the environment. Also, knowledge related to the rehabilitation process, the child's daily life environment and building collaboration are needed.

Table 5. Summary of the knowledge-base and key factors of the CMAP Book- tool (the summary has previously been published in Finnish in the CMAP e-publication [30]).

Knowledge base	Key factors
Dimensions of agency	Enabling the child's agency in different situations Reinforcing the child's self-image and identity Appreciating the child's participation and views (expressing opinions, feelings, dreams, making a difference) Letting the child set the pace Strength-based approach Interaction and communication suitable for the child
Different forms of participation	Enabling the child's active participation Using play, experiences, games Enabling succeeding, learning and experiencing joy Participating in activities and situations that the child finds enjoyable Promoting feeling of security (emotional and physical) Believing in the child's abilities, encouraging and supporting the child Creativity
Functioning (ICF)	Interaction between the child and the environment in promoting functioning Individual functioning Environment: restricting and promoting factors
Rehabilitation process	Enabling and promoting exchange between the child and the environment Learning process Process management skills Setting goals and drafting an action plan together Negotiation skills Principles that direct the process: continuity, flexibility, predictability, agreeing on responsibilities
The child's daily environment	Considering family culture (e.g. resources, structures, preferences, everyday routines) and different environments (home, day-care centre, school, hobbies) Child-specific and family-centred approach The child's participation in the community, appreciation and support for friendship building
Collaboration	Interaction through dialogue, reciprocity Determining common practices and goals in collaboration Collaboration values: Partnership, honesty, trust, security Shared multidisciplinary frameworks and methods of action

Changes made for the final version of the CMAP book included layout and grammatical modifications, adding of videos, pictures and user experiences and examples to the text. Also, issues concerning data protection and ethical considerations

in using the CMAP Book with the Book creator application were added to the instructions.

To make the tool easily available and disseminated, an e-publication was created (metropolia.e-julkaisu.com/lapsen-metkut/metku-kirja/). Electronic publication also enabled the integration of word- and pdf-documents and video instructions on how to use the Book creator application and how to create the description of the child's meaningful activities and participation in dialogue with the child.

Discussion

According to this study's findings, the child-specific tools, such as the new CMAP Book, can help the child, family and professionals to build partnership that is based on shared understanding of the child's meaningful participation, individual needs, wishes and aspirations in her/his daily life. Costa et al. [32] emphasise that the child's possibilities for feelings of relatedness, competence, autonomy, and meaningful personal orientation need to be identified together with the child and family in order to establish meaningful goals for rehabilitation. The use of CMAP Book support family and professionals to create a joint understanding in multidisciplinary rehabilitation planning and goal setting resulting in a coherent and common rehabilitation plan with meaningful goals. Use of the photos [33], videos, writing and recordings helps the child's own expression and concretises their views enabling her/his participation in rehabilitation planning, identification of goals and discussion with adults.

The Convention on the Rights of the Child (1989) [10] as well as the Convention on the Rights of Persons with Disabilities (2007) contain an obligation to respect the evolving capacities of children and the right of children to preserve their identities [34]. Thus, describing an empowering picture of the child's functioning and agency is essential when creating and using the CMAP Book in rehabilitation and in the

child’s daily life situations. Adults should direct the discussion in such a way that the child's identity is protected and his/her positive self-image, feelings of competence and encouraging vision towards future possibilities, are strengthened.

Identifying environmental factors supporting or restricting participation emerge as important in order to provide opportunities for the child’s meaningful participation in everyday life [35,36]. These factors influencing participation can be identified and described in the CMAP Book from child’s perspective and take into account when designing rehabilitation.

Individual resources, support needs and preferences play a key role in using the CMAP Book in rehabilitation. The child and family determine the way and how they use the CMAP Book in rehabilitation and thus, ownership of the rehabilitation process and the tool is within the child and family enabling family empowerment. The findings of the co-development process show, however, that parents and children wished for guidance and support from professionals in the making of the book at their own pace and by their own means.

The CMAP Book combines and concretises in a new way the interaction between the child’s active participation, agency and daily life, building collaboration through the rehabilitation process (Figure 4). The CMAP Book turns the basis of rehabilitation participation upside down; adults participate in the child’s world instead of the child participating in rehabilitation defined and designed by adults.

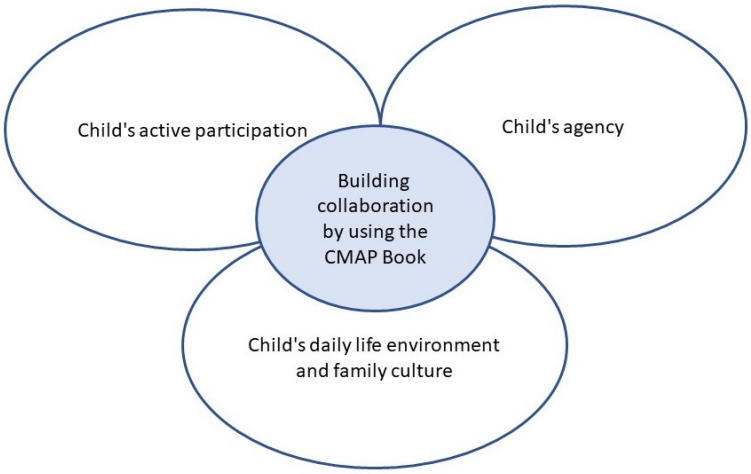


Figure 4. The CMAP Book in collaborative rehabilitation.

The CMAP Book is first and foremost a tool for the child and used in partnership with the child as an agent. The co-development of the CMAP Book used the ICF-framework [2] and theory of agency [23] and thus, it is usable in multidisciplinary rehabilitation and in partnership that is built in the child's daily life network, not limited by professional or organisational boundaries. Rehabilitation in the child's world is a process of learning and exchange between the child and the environment [7,13]. With the CMAP Book, the focus is on the interaction between the child and environment – not on the child or environment alone – as is in many other tools provided for children and developed by adults.

A clear limitation in the co-development process of the CMAP Book is the limited number of children involved. Six children participated in photo-elicitation interviews but only one child participated in the feedback discussion after piloting the tool. Three other children participated also in the pilots but due to communication limitations, they did not participate in the discussion with the researcher.

Current research has a strong focus on child participation in rehabilitation. Future studies need to focus on their participation as a developer of their own

rehabilitation and related services. The co-development practices used in the CMAP book's development enabled the collection of rich and multifaceted data, creation of shared understanding, learning and engagement of multiple stakeholders. Interesting viewpoint for future research is, whether the co-development practices used in research and development processes could be harnessed to shape individual rehabilitation in family- professional collaboration.

Recently family and child involvement have been promoted in research. Stakeholders can be involved in research in different roles varying, for example, from a listener to a co-thinker, advisor, partner or decision-maker, as defined by Ketelaar et al. [37] and Smits et al. [38]. Developing a true partnership and collaboration between researchers, clinicians and service users requires time, effort and ongoing dialogue from the beginning of the partnership and throughout the process [39]. Children with disabilities often need alternative ways of communicating in order to effectively collaborate with the researchers, and researchers need know-how on how to enable children's meaningful participation [40]. As in rehabilitation, various strategies and tools such as drawing, using pictures or photographs (photo-elicitation), are needed to engage children in research [40,41]. The CMAP Book could be a useful tool in building communication and collaboration with children thus enabling the child's participation in the development of health care and rehabilitation services and their participation in such research. The development partnership requires the building of informed co-agency and the CMAP Book could be an applicable tool in this collaboration.

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Declaration of interest

The authors report no conflicts of interest.

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References

1 World Health Organization. International Classification of Functioning, Disability and Health. Geneva; WHO, 2001.

2 World Health Organization. International classification of functioning, disability and health: Children and youth version: ICF-CY. Geneva; WHO, 2007.

3 Rosenbaum P, Gorter J. The 'F-words' on childhood disability: I swear this is how we should think! Child Care Health Dev. 2012;38(4):457–463.

4 Vargus-Adams JN, Majnemer A. International Classification of Functioning, disability and health (ICF) as a framework for change: revolutionizing rehabilitation. J Child Neurol 2014;29(8):1030–1035.

5 Vroland-Nordstrand K, Eliasson A, Jacobsson H, et al. Can children identify and achieve goals for intervention? A randomized trial comparing two goal-setting approaches. Dev Med Child Neurol 2016;58(6):589–596.

6 Goldstein D, Cohn E, Coster W. Enhancing participation for children with disabilities: application of the ICF enablement framework to pediatric physical therapist practice. Pediatr Phys Ther 2004;16(2):114–120.

7 Palisano R, Chiarello L, King G, et al. Participation-based therapy for children with physical disabilities. Disabil Rehabil 2012;34(12):1041–1052.

8 Anaby D, Law M, Majnemer A, et al. Opening doors to participation of youth with physical disabilities: An intervention study. Can J Occup Ther 2016;83(2):83–90.

9 Kangas J. Enhancing children's participation in early childhood education through the participatory pedagogy [dissertation]. Helsinki: University of Helsinki; 2016.

10 United Nations [Internet]. Convention on the rights of the child. General Assembly resolution 44/25 of 20 November 1989. Available from: https://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx

11 Shier H. Pathways to participation: openings, opportunities and obligations. Child Soc 2001;15(2):107–117.

12 Hart R. Children's participation. From tokenism to citizenship. UNICEF International Child Development Centre. Innocenti Essays 1992;4:1–44.

13 Järvikoski A. Monimuotoinen kuntoutus ja sen käsitteet. [Multifaceted rehabilitation and its concepts] Helsinki: Sosiaali- ja terveysministeriö, Sosiaali- ja terveysministeriön raportteja ja muistioita; 2013:43. Finnish.

14 Reedman S, Boyd R, Trost S, et al. Efficacy of participation-focused therapy on performance of physical activity participation goals and habitual physical activity in children with cerebral palsy: a randomized controlled trial. Arch Phys Med Rehabil 2019;100(4):676–686.

15 Anaby D, Law M, Majnemer A, et al. The effectiveness of the Pathways and Resources for Engagement and Participation (PREP) intervention: improving participation of adolescents with physical disabilities. Dev Med Child Neurol 2018;60(5):513–519.

16 Imms C, Granlund M, Wilson PH, et al. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. Dev Med Child Neurol 2017; 59(1):16–25.

17 The Social Insurance Institution [Internet]. Place: Publisher; 2020 [December 14]. Available from: http://www.kela.fi.

18 Rissanen P. Rehabilitation plan. In: Rissanen P, Kallaranta T, Suikkanen A, editors. Rehabilitation. Helsinki: Kustannus Oy Duodecim. 2008; p. 625–646.

19 Øien I, Fallang B, Østensjø S. Goal-setting in paediatric rehabilitation : perceptions of parents and professionals. Child Care Health Dev. 2010;36(4):558–65.

20 Jeglinsky I, Brogren Carlberg E, Autti-Rämö I. How are actual needs recognized in the content and goals of written rehabilitation plans? Disabil Rehabil 2014; 36(6):441–51.

21 Jeglinsky I, Kaakkuriniemi E, Veijola A, et al. Profiles of functioning of children with cerebral palsy in Finland: analysis of multi-professional family meetings. Disabil Rehabil 2019;Nov22:1–7.

22 Jeglinsky I, Salminen A-L, Brogren Carlberg E, Autti-Rämö I. Rehabilitation planning for children and adolescents with cerebral palsy. J Pediatr Rehabil Med: An Interdisciplinary Approach 2012 (5):203–215.

23 Jyrkämä J. Toimijuus, ikääntyminen ja arkielämä. Hahmottelua teoreettismetodologiseksi viitekehykseksi. [Agency, ageing and daily living. Outlining framework for theoretical methodology] Gerontologia 2008;(4):190–203. Finnish.

24 Järvikoski A, Martin M, Autti-Rämö I, et al. Shared agency and collaboration between the family and professionals in medical rehabilitation of children with severe disabilities. Int J Rehabil Res 2013;36(1):30–37.

25 Rezze BD, Law M, Eva K, et al. Therapy behaviours in paediatric rehabilitation: essential attributes for intervention with children with physical disabilities. Disabil Rehabil 2014;36(1):16−22.

26 Kemmis S, Wilkinson M. Participatory action research and the study of practice. In Bill Atweh, Stephen Kemmis, Patricia Weeks, editors. Action research in practice: partnerships for social justice in education. London: Routledge;1998:21–36.

27 Vänskä N, Pollari K, Sipari S. Lasten osallistumista ja toimijuutta vahvistavat kuntoutuksenhyvät käytännöt kirjallisuudessa. Kuvaileva kirjallisuuskatsaus. [Good rehabilitation practices to enhance children's participation and agency in the literature. Descriptive literature review.] Kelan työpapereita 94/2016. Finnish.

28 Sipari S, Vänskä N, Pollari K. Lapsen edun toteutuminen kuntoutuksessa. Osallistumista ja toimijuutta vahvistavat hyvät käytännöt. [Realization of the best interests of the child in rehabilitation. Good practices to strengthen participation and agency]. Helsinki: Kela, Sosiaali- ja terveysturvan raportteja 5/2017. Finnish.

29 Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008;62(1):107–115.

30 Sipari S, Vänskä N, Pollari K. Lapselle merkityksellinen toiminta kuntoutumisessa – Lapsen Metkut. [Children's Meaningful Activities and Participation in rehabilitation – Child's MAP.] Metropolia University of Applied Sciences, Right of the child to participate in his/her rehabilitation – Assessing the child's best interests (LOOK) – project, 2017. Available: metropolia.e-julkaisu.com/lapsen-metkut. Finnish.

31 Vänskä N, Sipari S, Pollari K, et al. Lapsen oikeus osallistua kuntoutukseensa. LOOK-hankkeen arviointiraportti. [The child's right to participate in his or her rehabilitation. LOOK project evaluation report.] Helsinki: Kuntoutuksen kehittäminen, Kela; 2018. Finnish.

32 Costa U, Brauchle G, Kennedy-Behr A. Collaborative goal setting with and for children as part of therapeutic intervention. Disabil Rehabil 2017;39(16):1589–1600.

33 Vänskä N. Sipari S, Haataja L. What makes participation meaningful? Using photo-elicitation to interview children with disabilities. Phys Occup Ther Pediatr 2020;40(6):595–609.

34 UN General Assembly, Convention on the Rights of Persons With Disabilities: Resolution/Adopted by the GeneralAssembly, January 24, 2007, A/RES/61/106. Available from: http://www.refworld.org/docid/45f973632.html

35 Shikako-Thomas K, Kolehmainen N, Ketelaar M, et al. Promoting leisure participation as part of health and well-being in children and youth with cerebral palsy. J Child Neurol [Internet] 2014;29(8):1125–33. Available from: https://www.narcis.nl/publication/RecordID/oai:dspace.library.uu.nl:1874%2F304608

36 Anaby D, Law M, Coster W, et al. The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. Arch Phys Med Rehabil [Internet] 2014;95(5):908–17. Available from: https://www.clinicalkey.es/playcontent/1-s2.0-S000399931400032X

37 Ketelaar M, Smits DW, Meeteren K, et al. Involvement of young people and families in all stages of research; what, why and how? In: Imms C, Green D, editors. Participation, optimizing outcomes in childhood-onset neurodisability. London: Mac Keith Press; 2020:105–118.

38 Smits DW, Meeteren K, Klem M, et al. Designing a tool to support patient and public involvement in research projects: the Involvement Matrix. Res Involv Engagem. 2020;6:30.

39 Bartlett D, Chiarello LA, Hjorngaard T, Taylor BS. Moving from parent "consultant" to parent "collaborator": one pediatric research team's experience. Disabil Rehabil 2016;39(21):2228–2235.

40 Bailey S, Boddy K, Briscoe S, et al. Involving disabled children and young people as partners in research: a systematic review. Child Care Health Dev. 2014;41(4):505–514.

41 Gonzales M, Phoenix M, Saxena S et al. Strategies used to engage hard-to-reach populations in childhood disability research: a scoping review. Disabil Rehabil 2020;30:1–13.

Appendix 1. Potential tools/ assessment methods/ good practices from the literature review.

Tool/ assessment method/ good practice	**Description of the tool/ assessment method/ good practice**
The ecological assessment of activities and participation (Palisano R, Chiarello L, King G, et al. Participation-based therapy for children with physical disabilities. Disabil Rehabil 2012;34(12):1041–1052.)	The purpose of the tool is to collaboratively assess and define what needs to happen in order to achieve the child's participation goal.
Describing a child's everyday life, a method that supports the agency of a disabled child. (Rancken L. Lapsen arjen kuvaaminen, vammaisen lapsen toimijuutta tukeva menetelmä. YAMK-opinnäytetyö. Helsinki: Metropolia Ammattikorkeakoulu 2014.) [Finnish]	Action research resulted in a description of a method that supports the child's agency by describing the child's views on a ppt-programme.
Collaborative care planning using the participation and environment measure for children and youth (PEM-CY) (Khetani MA, Cliff AB, Schelly C, Daunhauer L, Anaby D. Decisional support algorithm for col-laborative care planning using the participation and environment measure for children and youth (PEM-CY): a mixed methods study. Phys Occup Ther Pediatr 2015;35(3):231–252.)	The purpose of the study was to find out the usability of the PEM-CY in the collaborative planning of the rehabilitation of children with disabilities. The article describes a four-step model for making a rehabilitation plan in collaboration with the family. The article suggests that to enable the child's participation, an interview with the child can be conducted or the child can fill in PEM-CY, or identify what activities he /she wants to change.
Participation-based therapy for children with physical disabilities. (Palisano R, Chiarello L, King G, et al. Participation-based therapy for children with physical disabilities. Disabil Rehabil 2012;34(12):1041–1052.)	Article describes principles for collaborative rehabilitation process that is based on five stages. The presented model for participation-based therapy enables child's agency by emphasising the child's opportunity to share his or her own views throughout the process, involving the child in decision-making and respecting self-determination.

Appendix 2. Results from qualitative interviews.

Qualitative interviews/ participants	**Key results**	**Summary of the results**
Children's perspective with individual photo-elicitation interviews: Children with disabilities receiving multiprofessional rehabilitation (N=6), aged 5-11 years	Making choices based on feelings and interests; motivation from dreaming future possibilities; enjoying play together with peers and family; learning and feeling competent	**The tool should enable:** • **the child as an agent:** identification of child's emotions and dreams, support for child's identity, child's possibility to express views, influence and make choices, child's involvement and feeling of belonging in everyday life situations and communities. • **meaningful participation:** enjoyment and positive experiences, playfulness with digital application, attached to child's world, child-paced, individual support for learning and enable feelings of competence • **collaboration between child, parent and professionals:** possibility to prepare, flexibility, continuity, sharing of responsibilities, shared understanding of goals and practices to reach goals, learning and developing together, dialogue and reciprocal negotiation.
Parents' and professionals' perspective with four focus group interviews: Rehabilitation professionals (N=30) Parents (N=4)	Collaboration based on shared understanding of what, how and who; attention to child's daily life; child as a developer of own rehabilitation; collaborative negotiation of child's rehabilitation	
Future workshop with parent and professionals (N=8)	Future-oriented practices that respond to individual and changing needs of the child and family	