

Doctoral Programme in Clinical Research
Department of Pediatric Neurology
Faculty of Medicine
University of Helsinki

Dissertationes Universitatis Helsingiensis 245/2025

Enhancing participation of children with disabilities in pediatric rehabilitation

Nea Vänskä

ACADEMIC DISSERTATION

To be presented, with the permission of the Faculty of Medicine
of the University of Helsinki, for public examination in Hattivatti Lecture Room,
New Children's Hospital, Stenbäckinkatu 9, Helsinki
on the 22nd of August 2025, at 12 noon.

HELSINKI 2025

Supervisors

Professor Leena Haataja, MD, PhD, University of Helsinki

Principal Lecturer Salla Sipari, PhD, Metropolia University of Applied Sciences

Reviewers

Professor Mats Granlund, PhD, Jönköping University

Docent Anna Ullenhag, PhD, Mälardalen University

Custos

Professor Leena Haataja, MD, PhD, University of Helsinki

Opponent

Docent Ilona Autti-Rämö, MD, PhD, University of Helsinki

Publisher: University of Helsinki

Series: Dissertationes Universitatis Helsingiensis 245/2025

ISBN 978-952-84-1089-8 (print)

ISBN 978-952-84-1088-1 (online)

ISSN 2954-2898 (print)

ISSN 2954-2952 (online)

PunaMusta, Joensuu 2025

To my family

ABSTRACT

This doctoral thesis aimed to describe elements that enhance participation of children with disabilities in pediatric rehabilitation practice. The thesis contains three original studies that were conducted utilizing a qualitative research design and inductive content analysis. Study I described meaningful participation in everyday life from the perspective of children with disabilities (n=9, 5–10 years) through individual photo-elicitation interviews. Study II explored how professionals and parents perceive practices for promoting a child's best interests in pediatric rehabilitation that aims to secure children's right to participation. The study data comprised of 11 interviews, with a total of 39 participants: five focus groups with professionals (n=27), three focus groups with parents (n=9), and three individual interviews with pediatric neurologists (n=3). Study III involved a co-development process with family members and professionals (n=334), which was set out to design, pilot, evaluate, and generate the final version of the new tool to enhance children's participation in rehabilitation that is embedded in everyday life.

Study I showed that meaningful participation for children constituted leisure activities that enabled children to experience enjoyment, autonomy, social involvement with peers and family members, and capability. In Study II, it was found that practices for promoting a child's best interests in rehabilitation included collective framing of child-specific rehabilitation, fostering a fulfilling daily life for the child, and ensuring appropriate and comprehensive rehabilitation to secure children's right to participation. The results demonstrated notable difficulties in family–professional collaboration with the child as an active participant as well as in addressing the child's and family's needs, especially as a cross-sectoral effort. A new tool, CMAP (Children's Meaningful Activities and Participation in rehabilitation) Book, was co-developed in Study III to enhance children's participation. The CMAP Book guides the identification of factors that either hinder or promote the child's participation and of what is important from the child's perspective in everyday life. Based on the three sub-studies, the key elements enhancing children's participation in rehabilitation were identified as follows: 1) Identification and embracing a child's meaningful participation; 2) Creating and applying child-specific practices in collaboration; 3) Collaborative building of a child's opportunities for participation and an inclusive daily life environment; and 4) Co-construction of a comprehensive view of a child's rehabilitation in accordance with the child's best interests.

This dissertation demonstrated that the elements enhancing a child's participation in pediatric rehabilitation practice are interactive, dynamic, and interwoven within the collaborative rehabilitation process enabling the

child's agency. The findings display a substantial tension between the current system-controlled and professional-led practices and the child-specific and collaboration-based practices created and embedded in the child's everyday situations. Shifting the emphasis to a collaboratively constructed and jointly integrated comprehensive view of the child's rehabilitation in daily life in accordance with the child's best interests appears to be decisively important. The results provide new evidence for how adopting a systemic and ecological approach could steer the rehabilitation process in line with a child's best interests and safeguard the child's right to participate. According to the findings, the elements enhancing children's participation are created and realized through child-specific partnership, focusing on what is important to the child in their daily life.

TIIVISTELMÄ

Tässä väitöskirjassa tavoitteena oli kuvata lasten osallistumista edistävän kuntoutuksen elementit. Väitöskirja koostuu kolmesta osatutkimuksesta, jotka perustuvat laadullisen tutkimuksen asetelmaan ja joissa analysointimenetelmänä on käytetty induktiivista sisällönanalyysiä. Osatutkimuksessa I kuvattiin, mitä on lapselle merkityksellinen osallistuminen arjessa erityistä tukea tarvitsevien lasten (n=9, 5–10 v.) toiminnallisilla yksilöhaastatteluilla. Osatutkimuksessa II kuvattiin, mitä ovat lapsen edun mukaiset käytännöt lapsen osallistumista edistävässä kuntoutuksessa ammattilaisten ja lasten vanhempien näkökulmasta. Tutkimusaineisto koostui 11 haastattelusta, joihin osallistui yhteensä 39 henkilöä: viidestä ammattilaisten ryhmästä (n=27), kolmesta vanhempien ryhmästä (n=9) sekä kolmesta lasten neurologin yksilöhaastattelusta (n=3). Osatutkimus III oli yhteiskehittämisprosessi perheiden ja ammattilaisten kanssa (n=334), jonka tarkoituksena oli suunnitella, pilotoida, arvioida ja tuottaa uusi lasten osallistumista edistävä väline lapsen arkeen nivotun kuntoutumisen yhteistoimintaan.

Ensimmäisen osatyön tulosten perusteella lapselle merkityksellinen osallistuminen koostui vapaa-ajan toiminnasta, jossa lapselle mahdollistui ilo ja nauttiminen, kokemus autonomiasta, pystyvyydestä sekä osallisuudesta yhteisössä ja yhdessä tekemisessä erityisesti kavereiden ja perheen jäsenten kanssa. Toisessa osatyössä osoitettiin, että lapsen edun mukaisia käytänteitä olivat: lapsikohtaisen kuntoutumisen yhteinen määrittely, lapsen hyvän arjen edistäminen sekä tarkoituksenmukaisen kuntoutuksen kokonaisuuden varmistaminen. Tulokset ilmensivät huomattavia haasteita perheen ja ammattilaisten yhteistoiminnassa, jossa lapsi toimii aktiivisena osallistujana. Erityisesti lapsen ja perheen tarpeiden huomioiminen lapsen edun mukaisesti oli haastavaa yli sektorirajojen toteutettavassa yhteistyössä. Kolmannessa osatyössä yhteiskehittämisen tuloksena oli lapsen osallistumista edistävä uusi väline, Metku-kirja (lapselle merkityksellisen toiminnan kuvaus). Sen käyttö ohjaa tunnistamaan lapsen osallistumista rajoittavia ja edistäviä tekijöitä sekä kuvaamaan lapsen näkökulmasta tärkeitä asioita arjessa. Kolmen osatyön tulosten perusteella lapsen osallistumista edistävät elementit kuntoutuksessa ovat 1) Lapselle merkityksellisen osallistumisen tunnistaminen ja hyödyntäminen, 2) Lapsikohtaisten käytänteiden luominen ja soveltaminen yhteistoiminnassa, 3) Lapsen osallistumismahdollisuuksien ja inklusiivisen arjen toimintaympäristön yhteiskehittäminen, ja 4) Lapsen kuntoutuksen kokonaisuuden rakentaminen yhdessä lapsen edun mukaisesti.

Väitöskirjatutkimuksen mukaan lapsen osallistumista edistävän kuntoutuksen elementit ovat vuorovaikutteisia ja sidoksissa lapsen toimijuutta

mahdollistavaan yhteistoiminnalliseen kuntoutumisprosessiin. Tulokset osoittavat, että nykyisten organisaatiolähtöisten käytänteiden ja lapsikohtaisesti soveltuvien ja yhteistoimintaan perustuvien käytänteiden välillä on jännitteitä, jotka horjuttavat lapsen edun mukaisen kuntoutumisen suunnittelua ja toteuttamista. Lasten kuntoutuksessa painopisteen tulisi siirtyä lapsen kuntoutumisen kokonaisuuden kehittämiseen ja yksilölliseen sovittamiseen lapsen arkeen sektori- ja organisaatorajoja ylittävässä yhteistoiminnassa. Tulokset tarjoavat uutta näkökulmaa siihen, kuinka systeeminen ja ekologinen lähestymistapa voisi ohjata kuntoutumista lapsen edun mukaisesti ja turvaten hänen oikeutensa osallistua. Väitöskirjan tulosten mukaan lapsen osallistumista edistävät elementit kuntoutuksessa kehitetään ja toteutetaan lapsikohtaisessa yhteistoiminnassa keskittyen siihen, mikä on lapselle tärkeää arjessa.

ACKNOWLEDGEMENTS

It's a bit hard to believe I've reached this point in my PhD journey. One of my friends likes to say that it's not a real adventure unless it gets tough in the middle; by that definition, I've had quite the adventure. I have so many people to thank, without whom I would not be standing here, happily, at the finish line.

My warmest thanks to my dissertation supervisors, Professor Leena Haataja and Principal Lecturer Salla Sipari. Leena, your warm and wise guidance at every step of this academic journey has been invaluable. Through every challenge and breakthrough, your support, patience, and insights have shaped both my dissertation and my growth as a researcher. I am thankful and honored to have had you as my supervisor. Salla, I am truly grateful that you asked me to onboard project planning that eventually turned into the child's right to participate (LOOK) project, and a starting point of my academic journey. You also asked me if I was curious to embark on a dissertation. That question opened a whole new landscape of meaningful learning and impactful collaboration for me. Thank you for all the support, co-creation, and inspiration along the way. It is such a privilege to work alongside you, and I deeply appreciate your leadership and foresight in developing pediatric rehabilitation and a good future for all.

I want to sincerely thank Docent, MD Ilona Autti-Rämö for agreeing to take on the role of the opponent. I truly appreciate your willingness to contribute your time and expertise to this task. My warmest thanks to the pre-examiners, Professor Mats Grandlund and Docent Anna Ullenhag, for your insightful comments and constructive feedback. Your careful review has been genuinely helpful for the finalization of this dissertation. Thank you, Professor Eeva Aronen, for agreeing to represent the Faculty of Medicine in the public defense of my doctoral thesis. I want to express my gratitude to my dissertation follow-up team, Emeritus Professor Kristiina Härkäpää and PhD Kirsi Pollari. Thank you for all of your support. Kirsi, your expertise and guidance in diving into the world of children's rights has been incredibly helpful.

My PhD journey has progressed alongside my work at Metropolia University of Applied Sciences. I've been fortunate to be able to apply the expertise gained through my research in my job and, in turn, my work has strengthened the skills essential for completing the dissertation. I am thankful for Metropolia and the Future Proof Health and Wellbeing Innovation Hub for providing a work environment that encourages continuous learning and development. I'd also like to thank Arvo and Lea Ylppö Foundation for providing financial support for my dissertation.

Research is first and foremost teamwork, and I could not have managed without my dear colleagues and friends. Krista Lehtonen, Ira Jeglinsky-

Kankainen, Anu Kinnunen: Thank you for co-curiosity and collaboration—your support during my thesis has been vital. Krista special thanks to you for our writing weekend in Tammissaari, which helped me take time and push at a critical moment. I'd also like to express my gratitude to my wonderful colleagues Sari Helenius, Pekka Paalasmaa, Kaisa Hartikainen, Mira Lönnqvist, Anna Kaipainen, Toini Palo, Minna Elomaa-Krapu, Anita Ahlstrand, and so many others that I have had the pleasure to learn, work, and collaborate with. I want to thank the National Association for Pediatric Rehabilitation (VLK) and the VLK Helsinki area team for sharing your passion to promote good lives for children with disabilities.

I have been fortunate to meet and collaborate with inspiring researchers in the field of pediatric rehabilitation during my PhD journey. Associate Professors Barbara Piškur and Dana Anaby, I am impressed by your expertise and the remarkable way in which you are advancing the development of pediatric rehabilitation. Thank you for your encouraging words and support along the way.

This dissertation would not have been possible without the children, parents, and professionals who were willing to invest their time and effort into this research. My heartfelt thanks to all of you. I also want to send my warm regards to my former colleagues and client families at ResiinaFysio. As a newly graduated physiotherapist, I was lucky to learn from you and to discover my professional passion for pediatric rehabilitation and enhancing children's wellbeing. I'd like to express my appreciation and respect to all professionals in multidisciplinary pediatric rehabilitation, such as Sanna Kujanpää and Tarja Ranta, whose remarkable work continues to improve the lives of children in family–professional collaboration.

Belonging to a community that uplifts and brings joy is both precious and essential in work as well as in daily life. I want to thank my family and friends who have shared the ups and downs with me over the years of completing this dissertation. First, I'd like to express my gratitude to my dearest mother Helena—thank you for your boundless love, which has always been there, quietly holding everything together. I dedicate this work in part to you and to the memory of Keijo Karttunen, whose support and belief in me helped carry this journey forward. To my sister Anu, who I can always count on, and my brothers Petri and Juha: thanks to you and your families for keeping me grounded and celebrating the achievements along the way. Minna and Simon, our close-knit community and friendship are so dear to me, thank you for all the joy, compassion, and shared experiences and adventures. Many thanks to my lovely friends, Anne, Nina, and Kati—I'm so lucky to have you in my life. Thank you also “Sorjat”, for keeping me energized through joint laughter and training. A collective big thanks and hugs to all my other dear friends, relatives and family members.

I dedicate this dissertation to my husband Henri and our daughters Linnea and Vilja—I love you more than anything. The love, support, and everyday life

with you have been the perfect counterbalance to this journey, and the most important thing of all. Now, it's time to celebrate!

To all the readers:

Enhancing children's participation is a collaborative effort; Welcome on board.

May 2nd, 2025,

Nea Vänskä

LIST OF ABBREVIATIONS

CMAP Book	A description of Children’s Meaningful Activities and Participation in rehabilitation (tool)
CRC	The Convention on the Rights of the Child
CRPD	The Convention on the Rights of Persons with Disabilities
ICF	The International Classification of Functioning, disability and health
Kela	The Social Insurance Institution of Finland
LOOK	Right of the Child to Participate in Rehabilitation, Assessing the Child’s Best Interest (project)
SDGs	Sustainable Development Goals

TABLE OF CONTENTS

Abstract.....	5
Tiivistelmä.....	7
Acknowledgements	9
List of abbreviations	12
List of original publications	15
1 Introduction.....	17
2 Review of the literature.....	22
2.1 Participation of children with disabilities in pediatric rehabilitation.....	22
2.1.1 Children’s right to participate as the foundation	22
2.1.2 Dimensions of participation	26
2.1.3 Child’s participation in a collaborative rehabilitation process.....	31
2.2 Factors influencing children’s participation in pediatric rehabilitation.....	35
2.2.1 Barriers and facilitators for children’s participation in encounters with professionals.....	35
2.2.2 Barriers and facilitators for children’s participation in daily life.....	37
2.3 Enhancing children’s participation as a core focus in pediatric rehabilitation.....	39
2.3.1 Participation-focused tools and practices.....	39
2.3.2 Participatory practices with children in goal setting and action planning.....	41
2.3.3 Knowledge needs in enhancing children’s participation	43
3 Aims of the study	44
4 Methods.....	45
4.1 Qualitative research approach.....	45
4.2 Study design and participants	48
4.2.1 Study I.....	48
4.2.2 Study II.....	49

4.2.3 Study III	50
4.3 Data collection	52
4.3.1 Study I	52
4.3.2 Study II.....	52
4.3.3 Study III	53
4.4 Data analysis	56
4.5 Ethical considerations	58
5 Results.....	59
5.1 Meaningful participation for children with disabilities (Study I)	59
5.2 Practices for promoting a child’s best interests in pediatric rehabilitation (Study II)	62
5.3 Tool for enhancing children’s participation in rehabilitation and daily life (Study III)	65
5.4 Summary of the study results: enhancing children’s participation	67
6 Discussion	70
6.1 Theoretical and practical implications.....	70
6.1.1 Interactive and interwoven elements enhancing children’s participation	70
6.1.2 Identifying and embracing a child’s meaningful participation	70
6.1.3 Creating and applying child-specific practices in collaboration.....	74
6.1.4 Collaborative building of a child’s opportunities for participation and an inclusive daily life environment	78
6.1.5 Co-construction of a comprehensive view of a child’s rehabilitation in accordance with the child’s best interests	80
6.2 Methodological considerations.....	84
6.2.1 Strengths and limitations	84
6.2.2 Ethical considerations.....	93
6.3 Recommendations for future research	95
7 Conclusions.....	99
References	101
Appendix.....	124
Original publications	127

LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following publications:

- I Vänskä N, Sipari S, Haataja L. What Makes Participation Meaningful? Using Photo-Elicitation to Interview Children with Disabilities. *Physical and Occupational Therapy in Pediatrics* 2020;40(6),595–609. doi: 10.1080/01942638.2020.1736234
- II Vänskä N, Sipari S, Haataja L. Practices for Promoting a Child’s Best Interests in Paediatric Rehabilitation – Perspectives of Professionals and Parents. *Journal of Child Health Care* 2024;0(0). doi: 10.1177/13674935241287880
- III Vänskä N, Sipari S, Jeglinsky I, Lehtonen K, Kinnunen A. Co-development of the CMAP Book: A tool to enhance children’s participation in pediatric rehabilitation. *Disability and rehabilitation* 2022;44(9):1709–1719. (ePub 25.5.2021). doi: 10.1080/09638288.2021.1921061

The publications are referred to in the text by their roman numerals.

1 INTRODUCTION

It has been estimated that 240 million children worldwide live with disabilities (UNICEF 2021). Disability is an “umbrella term”—including impairments, activity limitations and participation restrictions (WHO 2001)—which, in interaction with the child’s social, attitudinal, and physical living environment, may restrict their participation in society on an equal basis with others (UNCRC 2006).

This doctoral research focuses on children with disabilities and, especially, on their active participation in the context of pediatric rehabilitation. The term “children” refers to individuals who are younger than 18 years old (UNCRC 1989). In this study, children are primarily understood as children, rather than being defined by their disabilities or limitations in functioning. Therefore, they are mostly referred to simply as children in this study.

Children who receive rehabilitation may have varying disabilities, impairments, and functional statuses (Kerbl et al. 2016). Thus, it is not a group of children with certain challenges but heterogeneous needs that are individual, contextual, situational, and related to the factors in a person’s living environment (UNICEF 2021; WHO 2001). WHO (2017: 1) defines rehabilitation as “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.” In pediatric rehabilitation, the concept of habilitation is also used (Kerbl et al. 2016; UNCRC 2006) to underline that, for children with childhood-onset disabilities, the core of rehabilitation lies in learning and developing abilities, not in regaining lost abilities (Hayton & Dimitriou 2019). In this study, the concept of pediatric rehabilitation is employed, but it encompasses habilitation for children. For children with childhood-onset disabilities, rehabilitation is usually a long-term process with family–professional collaboration aiming to promote the child’s functioning and well-being in daily life and optimize their future opportunities (Järvikoski 2013; Rosenbaum & Gorter 2012; Trapacca et al. 2016). In addition to the children and their family members and rehabilitation professionals, collaboration in rehabilitation involves important contributions from actors in the immediate environment, such as schools and daycare facilities, as the child’s rehabilitation is implemented in their everyday lives and situations (Autti-Rämö et al. 2022; Sipari et al. 2022).

The adoption of UN’s Convention on the Rights of the Child (CRC) in 1989 sparked a movement advocating for children’s rights and provided a framework and justification for developing policies and practices to promote children’s wellbeing and participation (Streuli et al. 2011). Participation is underlined as a core human right for children and is highlighted in both the CRC (UNCRC 1989) as well as in the Convention for Persons with Disabilities (UNCRC 2006).

Moreover, the values of equity and participation are underlined by the UN's Sustainable Development Goals (SDGs), which state the needed focus to develop equitable and inclusive societies for all people without discrimination based on age, abilities, religion, or cultural background (United Nations n.d.). Focusing on children with disabilities, UNICEF's Disability Inclusion Policy and Strategy 2022–2030 set a vision for a barrier-free and inclusive communities that realize and secure children's rights and promote their achievement of full and effective participation (UNICEF 2022).

A significant step forward in Finland is the National Child Strategy, formulated in 2021, aiming to create a society that respects the rights of every child, strengthen children's inclusion in the society as equal members with valuable perspectives, and provide tools and opportunities for inclusion of children with disabilities (Finnish Government 2022). Overall, children's participation has a strong value base in democracy and in meeting social justice principles (Ullenhag et al. 2024), and it is seen as beneficial for developing sustainable societies and strengthening social capital (Simovska & Jensen 2009). The goal of equitable participation in society clearly states that an important challenge is to examine, advocate, and improve the participation opportunities of children with disabilities in different contexts (Long & Guo 2023), such as in pediatric rehabilitation (Ullenhag et al. 2024).

Participation has been increasingly recognized as a crucial element of every individual's functioning, health, and wellbeing (WHO 2001). Moreover, participation is linked with quality of life for every child, irrespective of if the child is typically developing or has a disability (Dahan-Oliel et al. 2012). One major factor pushing forward the interest in participation, in the field of rehabilitation and disability studies in the last twenty years, was the publication of the International Classification of Functioning (ICF), Disability and Health framework by WHO (2001). It was followed by a dedicated classification for Children and Youth in 2007 (Leonardi et al. 2022). The ICF classification provides a framework for multidisciplinary and interdisciplinary collaboration in pediatric rehabilitation (Björck-Åkesson et al. 2010), integrates the medical and social model of disability into the biopsychosocial model, and conceptualizes functioning, disability, and health with neutral terms without unnecessary negative connotations (WHO 2001: 3–9). According to the ICF framework, activities and participation together form one key component in a person's functioning, alongside the component of the person's body functions and structures. These components interact with contextual factors, including environmental and personal factors. This dissertation focuses on one interactive and multifaceted aspect of functioning—participation as being involved in life situations. (WHO 2001: 10–11.)

Tisdall (2012) presents that, in the same way that disability studies have sought to reconsider concepts pertaining to disabled people and disability,

studies focused on children and adolescents have aimed to rethink concepts regarding children and childhood. The traditional view of seeing children as vulnerable, passive, and incomplete is being replaced by a new paradigm of childhood years; that is, understanding childhood as a social construction and children as active social actors who construct their lives and influence the life of others and society around them (Karlsson 2020; Prout & James 2015). These redefinitions of disability and childhood are not just theoretical but closely tied to the movements supporting disability rights and children's rights and have pushed a change in policies and practices, especially with an emphasis on viewing children as agents and active participants in their social communities (Tisdall 2012).

This same paradigm shift can be seen in pediatric rehabilitation, wherein increasing interest is being placed on children's participation (Anaby et al. 2022). For example, the UN (2019) underlines that rehabilitation serves to promote the inclusion and participation of individuals with disabilities, enabling them to achieve, sustain, and maximize their independence, full physical, mental, social, and vocational ability, and participation in various facets of life including full and equal members of society. Accordingly, novel understanding in pediatric rehabilitation emphasizes participation in daily life as a main outcome, but participation is also a means in the pediatric rehabilitation process to thrive for children's opportunities to actively participate in their daily lives (Imms et al. 2017) and as equal members within their communities and society (Long & Guo 2023).

Even though children's and youth's participation have received growing interest, the actualization of children's participation rights continues to face both conceptual and practical challenges (Davies et al. 2024a; Hultman et al. 2019; Koller et al. 2024; McMellon & Tisdal 2020). Further, studies show that participation of children with disabilities is especially restricted in social and healthcare encounters with professionals (Hultman et al. 2019; Teleman et al. 2021) as well as in activities across different settings at home, school, and community (Allonsius et al. 2021; Axelson et al. 2013; Bedel et al. 2013)—which are the typical contexts in which children's rehabilitation is implemented. There is strong evidence that children with disabilities lack opportunities for equal participation because of restrictions caused by impairment and the attitudinal, social, and physical barriers in children's living environments, for example (Fauconnier et al. 2009; Steinhardt et al. 2019). Also, professional practices fail to realize children's participation rights (Teleman et al. 2021). Participation barriers lead to a risk of children and adolescents with disabilities being excluded from the benefits of participation, restrict their possibilities to realize their agency, and develop their capabilities (Gorter & Gibson 2015).

In pediatric rehabilitation, professionals and guardians of children with disabilities have the responsibility to collaboratively secure the realization of

the child's rights and enable their agency (März 2022). Although children's active participation in family–professional collaboration has been increasingly underlined in rehabilitation, there is a clear lack of research evidence on how to engage and what tools and strategies are needed to facilitate participation of children, especially for young children and children with difficulties expressing their views (Curtis et al. 2022). Moreover, pediatric rehabilitation comprises cross-sectoral efforts with a multidisciplinary and interdisciplinary approach, involving collaboration between healthcare professionals and specialists in education, employment, social welfare, and various other fields depending on needs of the child and family (Autti-Rämö et al. 2022; Kerbl et al. 2016; Sipari et al. 2022; Sipari et al. 2017a). Current literature has, however, remained scarce on collaborative promotion of children's participation rights in pediatric settings with interprofessional practice and cross-sectoral efforts (Koller et al. 2024).

The aim of this dissertation study is to describe the elements that enhance children's participation in pediatric rehabilitation—a challenge that arises from both practical needs and the knowledge gap in research and one that has significant implications at the societal, community, and individual levels. This study is based in Finland, where children with disabilities are entitled to receive rehabilitation funded by the Social Insurance Institution (Kela) if the child experiences considerable difficulties in everyday activities and participation (Kela 2023). Kela funded intensive medical rehabilitation for over 24,000 children, amounting to nearly 136,000 million euros in 2021 (Kela 2021). Considering the challenges in current pediatric rehabilitation practice and the significant investments at the individual, community, and societal levels, it is crucial to explore what is needed to promote the realization of children's participation rights in line with the child's best interests in rehabilitation and examine whether we are focusing on the right things within rehabilitation to strengthen the child's participation. Today, there is a substantial lack of understanding of the elements that enhance the child's participation in rehabilitation and enable the child to be an active participant and a subject influencing their own life.

This thesis was conducted as part of the LOOK (Right of the Child to Participate in his/her Rehabilitation, Assessing the Child's Best Interest) project (2015–2017). The LOOK project aimed to strengthen the participation of children with disabilities and was funded by the Social Insurance Institution of Finland (Kela). The project was managed by Metropolia University of Applied Sciences, in co-operation with the Central Union for Child Welfare.

This doctoral thesis includes three sub-studies. The first sub-study describes what children with disabilities perceive as meaningful participation. The second sub-study explores what the current and required rehabilitation practices are for promoting a child's best interest, which is intertwined with the child's right to be heard and the realization of a child's opportunities for active participation in rehabilitation. The third sub-study describes how a child's active participation in

rehabilitation can be enhanced with a concrete tool, co-developed in collaboration with family members and professionals. Finally, this thesis intends to advance knowledge and invite a multifaceted discussion on the elements that need to be assessed, determined, and balanced when enhancing participation of children in pediatric rehabilitation.

In this thesis, the pediatric rehabilitation process is underlined as a collaborative learning journey that is actualized through family–professional partnership, with the child as an active participant. A child’s right to participate creates a value base upon which child-specific rehabilitation is built upon through collaboration.

2 REVIEW OF THE LITERATURE

2.1 Participation of children with disabilities in pediatric rehabilitation

2.1.1 Children's right to participate as the foundation

2.1.1.1 Children's right to participation embedded in international conventions and national laws

The right to participation is a cornerstone of children's rights outlined in the United Nations Convention on the Rights of the Child (UNCRC 1989). The CRC, adopted in 1989 and ratified in 1991 in Finland, is a legally binding international agreement encompassing the principles of protection, promotion, and participation for all children and youth under 18 years. With a total of 54 Articles, the CRC covers a range of rights relating to education, healthcare, parental responsibility, children's freedom of religion and expression, and social security. (UNCRC 1989.) The best interests of the child (Article 3) and the child's right to be heard (Article 12) are at the core of the CRC as two of the four main principles that steer the application, utilization, and interpretation of other rights in the Convention, alongside with the child's right to life, survival, and development (Article 6) and non-discrimination of children (Article 2). The CRC emphasizes the importance of respecting and valuing children as active participants in society and acknowledging children's agency and respecting them as right-holders and actors who can influence their own lives, the lives of others, and society (Donnelly & Kilkelly 2011). For children with disabilities, the rights stated in the CRC are amplified by the convention on the rights of the persons with disabilities (UNCRPD 2006) that was ratified in 2016 in Finland.

In Finland, children's right to participation is embedded and reflected in several national laws through provisions that specifically mention the child's best interests and children's participation right in matters affecting them (Pajulammi 2014: 4–6). The Constitution of Finland (731/1999) entails that children must be treated equally as individuals and should be allowed to have a say in matters that concern them in accordance with their age and abilities. Further, other laws, such as the Child Welfare Act [Lastensuojelulaki] 13.4.2007/417, Perusopetuslaki [Basic Education Act] 1.8.1998/628, Social Welfare Act [Sosiaalihuoltolaki] 30.12.2014/1301, and Act on Early Childhood Education and Care [Varhaiskasvatuslaki] 13.7.2018/540, concretize children's participation rights and subjectivity in matters regarding themselves. The Act on the Status and Rights of Patients 17.8.1992/785 and Laki sosiaalihuollon asiakkaan asemasta ja oikeuksista [Act on the Status and Rights of Social Welfare

Clients] 22.9.2000/812 include a specific provision regarding the status of minors and requires that children's opinion be sought and that their care be planned in accordance with their age and developmental level, in mutual agreement.

Although children's participation rights have been integrated into different laws, in 2020, Finland's Ministry of Justice concluded that children's participation rights have been inadequately realized. As Streuli et al. (2011) point out, the laws present abstract rules and regulations but do not provide specific guidance on how to realize children's rights in everyday practice and encounters with individual children. Thus, further research-based knowledge is needed on how to enhance children's participation opportunities in practice.

2.1.1.2 Children's participation rights in the context of pediatric rehabilitation

Professionals working in pediatric rehabilitation engage with children daily, thereby encountering children's rights in their practice (Streuli et al. 2011). Children's participation rights have a strong value base in human rights (UNCRC 1989) as well as in the moral and ethical grounds of healthcare (Streuli et al. 2011). One core right of children and a central ethical principle guiding professionals' work is the child's best interests (Bester 2019; März 2022). The CRC obliges all professionals working with children to consider a child's best interests as primary in all decisions relating to children (Committee on the Rights of the Children 2013; UNCRC 1989). Thus, the assessment and determination of the child's best interests precede all decisions that affect the child (März 2022). The ultimate purpose of a child's best interests is to:

- safeguard the full and effective enjoyment of all the rights acknowledged in the Convention, and
- uphold the development of the child to their full potential (Pajulammi 2014: 250).

To safeguard children's best interests, it is critical that the views of the child are explored and considered in decision-making in accordance with the child's age and maturity as stated in Article 12 (UNCRC 1989). Children's right to participate in decision-making process together with adults recognize child as an agent, owner of rights and a subject in their world (Pollari 2019). Pollari (2019) outlines that the assessment of a child's maturity and capacity for decision-making is based on the interaction process between the professional and the child, including the child's guardian who has responsibility for the child's upbringing. In addition, children with disabilities are entitled to be provided with age-appropriate and suitable assistance based on the child's needs to engage in decision-making (UNCRPD 2006: Article 7.3).

In practice, acting in a child's best interests involves careful weighing of what is best for the child (Birchley 2014; März 2022; Streuli et al. 2021) through conducting a comprehensive evaluation and balancing the relevant factors in a certain circumstance (General Medical Council 2018; Lansdown 2000; Paul 2007; Streuli et al. 2011). Thus, the concept of the best interests of the child is described as situational, context-dependent, and adaptable (Quaye et al. 2021; Ruggiero 2022). Accordingly, the determination of a child's best interests includes exploring the child's own perspectives, the combination of up-to-date research on the child's growth and development (Pajulammi 2014: 250–251), identification of the child's individual characteristics and needs, and considering the short- and long-term consequences as well as the different perspectives of related stakeholders (Committee on the Rights of the Children 2013; Quaye et al. 2021; Ruggiero 2022).

The rights of children with disabilities are entangled in pediatric rehabilitation as guiding principles but also steer the focus of rehabilitation towards enhancing children's opportunities for active participation in their everyday communities and in society (Ullenhag et al. 2024). Accordingly, children's rights become concrete in children's access to such physical, social, and attitudinal environments that meet the child's needs for provision, protection, and participation (Campbell-Barr 2021; UNCRC 1989). Besides the right to be heard (UNCRC 1989: Article 12) and the freedom of thought (UNCRC 1989: Article 14), children with disabilities are entitled to living in conditions guaranteeing the child's dignity, self-reliance, and active participation in the community (UNCRC 1989: Article 23). Children's participation in everyday life is underlined as children's right to rest and leisure, to engage in age-appropriate play and recreational activities, and to take part in cultural life and the arts (UNCRC 1989: Article 31). Further, children with disabilities must be guaranteed the opportunity to participate equally with others in family and public life, health maintenance, education, and activities in daily life, including sports and leisure (UNCRPD 2006). Additionally, the CRPD underlines that persons with disability should have the possibility to express themselves using their own communication methods and to access public information on an equal basis with others (UNCRPD 2006: Article 21).

Rehabilitation, from the perspective of providing services, is linked to several articles in the CRC and CRPD. Article 23 acknowledges a child's right to special care based on the child's needs and access to services that enable them to attain the "fullest possible social integration and individual development" (UNCRC 1989). Article 24 in the CRC states the child's right to health and services such as rehabilitation. A separate article (UNCRPD 2006: Article 26) concerning re/habilitation states that it should:

- begin as early as possible,
- be grounded in a multidisciplinary assessment of individual needs and strengths,

- aim to enhance full participation and inclusion across all areas of life,
- not be compulsory, and
- be accessible close to a person's own community.

The CRPD directs that effective and appropriate actions must be taken to achieve and preserve a person's maximum independence, best possible physical, mental, social, and vocational ability as well as to secure their inclusion and participation in every aspect of life (UNCRPD 2006: Article 26). Although highlighted in both the CRC and CRPD, studies on current pediatric rehabilitation practices indicate a limited focus on fulfilling the aims of children's inclusion and participation in all areas of life (Anaby et al. 2016; Kronsell et al. 2021; Nisius et al. 2024; Nowak et al. 2020).

2.1.1.3 Critical views on research regarding children's right to participation in rehabilitation

The focus on children as social actors and rights-holders has led to research that critically reflects on the roles and positions that children are offered and acknowledges the unique viewpoints of the children (Karlsson 2020; Tisdall 2012). In research, examining adult perspectives alone is not sufficient for addressing issues related to children; it is also essential to explore the children's own perceptions (Karlsson 2020).

The participation rights of children with disabilities in the context of pediatric rehabilitation are multifaceted. It is, however, worth noting that the CRC represents the perspective of adults and that children themselves have not been involved in defining or developing the content of the Convention (Campbell-Barr 2021; UNCRC 1989). Thus, there is a limitation of knowledge pertaining to how participation rights are perceived by the children themselves. Another critique of current knowledge on children's participation rights is the prevailing perspective of seeing children with disabilities as vulnerable or incapable (Martin & Franklin 2009). This perspective tends to emphasize their limitations and downplay their abilities, thereby focusing more on the negative aspects of their impairment and how it may restrict their participation, especially in settings where adults hold power (Martin & Franklin 2009). Moreover, current research on children's right to participation focuses overly on children's and adults' encounters and interactions in official institutions, such as in hospitals or public healthcare settings (Foster et al. 2022; Olli et al. 2012; Ortju et al. 2022; Quayle et al. 2021). Consequently, Harcourt and Hägglund (2013) claim that research on children's rights lacks understanding from children's perspectives of their everyday life.

In the context of pediatric rehabilitation—which is often conducted in the everyday environment of the child, such as at child's home, school, or daycare, and in interdisciplinary collaboration including the family, rehabilitation, and education professionals (Härkäpää et al. 2020: 50–57)—focusing on merely

institutional contexts and interactions with a single professional is not enough. In line, Koller et al. (2024) underline the need to explore the collaborative promotion of children's participation rights with interprofessional practice.

2.1.2 Dimensions of participation

2.1.2.1 ICF classification: a biopsychosocial approach

The concept of participation is widely used, but it is defined and discussed differently, in relation to the contexts and fields of study (Lansdown 2009; Malone & Harting 2009, Pajulammi 2014: 6). In the context of pediatric rehabilitation, participation is often defined based on the ICF classification that is recommended to plan and evaluate interventions and outcomes and to develop services and policies (Maxwell et al. 2018; Paltamaa et al. 2011: 225–235; WHO 2001), with multidisciplinary and interdisciplinary collaboration (Björck-Åkesson et al. 2010).

The ICF classification conceptualizes disability and functioning as a biopsychosocial model by integrating the medical and social model of disability (WHO 2001). While disability is described by the medical model as consequence of an individual's medical condition or diagnosis, the social model frames disability as stemming from inadequacies in society, such as in policy, cultural norms, and physical environments, which leads to a failure in accommodating people's impairments (Haegele & Hodge 2016). The biopsychosocial model of ICF provides a comprehensive framework, wherein a child's functioning, health, and disability are understood as interwoven and interactive with factors in the child's environment, also considering a child's personal factors such as age, gender, and habits.

According to the ICF classification, participation is "involvement in life situations" (WHO 2001), thus covering a wide range of actions and encounters in a child's everyday life. Moreover, restrictions in participation refer to challenges that a child may experience in involvement (WHO 2001). Involvement remains unspecified in the ICF classification (Maxwell et al. 2018), with only a footnote (WHO 2001: 13) stating that involvement can be viewed as taking part, being included, engaged or accepted or as having access to needed resources. The ICF classification states that the subjective experience of sense of belonging should be distinguished from involvement. Thus, the ICF contains only qualifiers for capacity and performance for activities and participation, and there is no qualifier for involvement nor subjective satisfaction in the ICF for participation (WHO 2001). Because the current qualifiers can only be used to describe participation frequency or attendance, Grandlund et al. (2012) suggest that a person's subjective experiences should be added to the definition with a third qualifier.

The definition of participation in the ICF classification has received criticism because of its broad and nonspecific nature and interwovenness with activities, leading to different interpretations of its content and meaning in practice (Bernard et al. 2024; Maxwell et al. 2018; Steinhardt et al. 2022). Consequently, researchers argue that the construct of participation requires broader elaboration in the ICF classification, as it overlooks the individual's personal experiences (Bernard et al. 2024; Granlund et al. 2012; Maxwell et al. 2018). In pediatric rehabilitation, the differences and limitations in understanding the participation concept pose challenges for measuring participation and choosing appropriate strategies to enhance participation in practice (Coster & Khetani 2008; van de Velde et al. 2018). Additionally, the diverse definitions and utilizations of the concept hinder communication across different fields and the interdisciplinary formation of knowledge in pediatric rehabilitation (Kinnunen et al. 2021).

2.1.2.2 Participation as attendance and involvement

In recent years, Imms et al. (2016; 2017) have significantly advanced understanding of the concept of participation. Imms et al. (2017) presented the Family of Participation Related Constructs (fPRC) framework that is grounded in the ICF classification and focuses on the construct of participation. According to Imms et al. (2017), there are two main elements in participation: attendance and involvement in activities. Attending describes a child's physical presence, i.e., being where the activity takes place, and involvement describes the child's experience while attending. Imms et al. (2017) present that attendance is thus a prerequisite but not sufficient for the child's full participation. Involvement may include elements of engagement, motivation, persistence, social connection, and affect (Imms et al. 2017). Steinhardt et al. (2021) present that, as opposed to attendance, involvement is an internal state and interest towards a specific activity that is not necessarily visible outside. Accordingly, involvement can be described only by the child itself.

The participation-related constructs in the fPRC framework can be intrinsic factors (person-related) or extrinsic factors (context and environment related). Intrinsic factors include activity competence, sense of self, and preferences that are influenced by past and present participation and impact future participation. Extrinsic factors describe the participation context (see 2.1.2.4) and the environment that is the broader, external social, and physical structures where children live (Imms et al. 2017). Granlund and Imms (2024) state that participation as attendance and involvement applies similarly to the child's daily life situations on an individual level as well as withing the child's interactions with professionals and adults providing support and services.

2.1.2.3 Participation as having agency and opportunity to influence

Participation in literature refers to having agency (Karlsson 2020; Montreuil & Carnevale 2016) or as a child's sense of agency (Sairanen & Kumpulainen 2014). Agency is closely linked to taking part in decision making on issues concerning their own life and power to act and contribute to choices that influence a child's future (Kellet 2009). When a child is acknowledged as a social actor and agent, they own their rights and are enabled to have an impact on their own life course (Donnelly & Kilkelly 2011) and in social interactions (Mayall, 2002: 21).

Karlsson (2020) describes that the realization of a child's agency necessitates that the child is encountered as an actor with meaningful views. Especially adults, who are often in a position of power and control over a child, can either enable or restrict the child's opportunities for agency (Kellet 2009). Similarly, other factors in the environment, such as other children, social atmosphere, and physical spaces, as well as the child's personal factors, such as experiences and expectations and relationship between these factors, influence the child's opportunities to become an active participant in the community (Karlsson 2020). On the other hand, Montreuil and Carnevale (2016) define agency as "children's capacity to act deliberately, speak for oneself, and actively reflect on their social worlds, shaping their lives and the lives of others," which is not dependent on adults enabling their active agency but dynamic and changing in nature.

Jyrkämä (2007) presented a theory containing six modalities for human agency that relate to situations and environments. The modalities constructing a person's agency in each sociocultural context are their 1) abilities, 2) competences in relation to the activity and environment, 3) feelings and experiences about the activity and situation, 4) what the person wants and aims for, 5) possibilities, and 6) musts in the situation and environment. Although, Jyrkämä's theory was originally developed in the context of the elderly, the theory has been also utilized in studies with children (Hilppö 2016; Sairanen & Kumpulainen 2014) and applied in the development of pediatric rehabilitation practices (Sipari & Launiainen 2011).

As with the definition of children's agency, childhood studies often describe participation in terms of opportunity to express views, being listened to, and influencing and engaging in decision making in matters concerning themselves (Coyne & Harder 2011; Foster et al. 2022; Lansdown 2009). Many participation models focusing on children's participation in terms of opportunities for influencing and engaging in decision-making have been developed. For example, the ladder of participation theory (Hart 1992) categorized the various forms of adult-child interactions present in participatory practice. Further, Shier (2001) developed a model referring to a child's right to participate in the decision-making process (Appendix 1). Lansdown (2009) divided children's participation into three categories: a) consultative participation, where adults seek a child's

perspectives to understand their views and utilize this in knowledge building; b) collaborative participation, which enables children's engagement more fully in decision making in partnership with adults; and c) child-led participation, which is described as children taking initiatives and actions more freely with adults as facilitators.

Another model representing participation as being heard and influencing decisions is the model presented by Lundy (2007), which was originally developed in the education context and further applied in healthcare (Davies et al. 2024a). Lundy's model conceptualizes the right according to CRC's Article 12 (UNCRC, 1989) and has four key elements: space, voice, audience, and influence. Providing a space for children gives them the opportunity to express their views. The element of voice means that children are facilitated to express their views. The audience element ensures that children's views are listened to, and the element of influence secures that their views are taken seriously and appropriately acted upon. (Lundy 2007.) This model underlines the necessity of adults acknowledging their responsibility to provide opportunities and accommodations to children's needs to enhance their participation (Davies et al. 2024a).

2.1.2.4 Contextual and situational participation

Children's participation in everyday life, communities, and wider society is diverse and has many dimensions that are attached to the structures of the participation context and specific situation (Maxwell et al. 2018). Thomas (2007) describes participation related to children's different contexts as including daily-life interactions within relationships, participation in daily-life institutions, such as school or daycare, encounters in public services, participation in communities and public spaces, participation in commercial places such as shopping malls, participation within societal structures, and children's political participation.

The interconnectedness of participation and the environment and, more specifically, the participation context/life situation where the activity takes place has been well established in literature (Anaby et al. 2013; Steinhard et al. 2021; WHO 2001). Imms et al. (2017) define the "context" as the setting for participation, comprising the place, activity, people, time, and objects. These participation contexts have certain elements that influence a child's possibilities and capabilities to participate as well as feelings towards participation (Imms et al. 2017). These contextual factors influence a child's engagement through the child's motivation, feelings, and experiences during participation (Steinhard et al. 2021). Because children also have an impact on their surroundings, Imms et al. (2017) underlined the transactional relationship between the child and participation context, which promotes change over time in both the child and the environment. Imms et al. (2017) also presented that participation can thus be understood as an "entry-point" for a child's learning, development, and

promotion of functioning in everyday life in addition to participation being an outcome of learning and change.

Bronfenbrenner's (1979) bioecological model of human development has strongly influenced the understanding of how children's development progresses in interaction with the environment. The model has been applied to different study contexts, including pediatric healthcare and rehabilitation research (Foster et al. 2022; Kinnunen 2021). The model posits that environment can be divided into various interconnected systems: microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner 1979). Since its publication, Bronfenbrenner's model has expanded, and concepts regarding the person in context, interaction, and change over time have been emphasized, and chronosystem was included to the model (e.g. Bronfenbrenner 2018; Bronfenbrenner & Evans 2000). In this interconnected and multisystem environment, the child's development is a process in which the child learns abilities that enable them to cope with the complexity of the demands, forms, and content of these systems. The microsystem constitutes the child's immediate growth and development environment, such as their family, home, and daycare settings, which include people, activities, roles, and interpersonal relations. Mesosystems are shaped by the interrelations among different settings as the child grows and participates in a new environment, such as school. Exosystems refer to the wider environment in which the child does not actively participate in but which influence the child's immediate growth environment indirectly, such as the parent's workplace. The macrosystem is formed by the cultural, economic, and ideological atmosphere and actions in the society or community, which influence the forms and contents in the lower order systems. (Bronfenbrenner 1979: 16–27; Bronfenbrenner 2018.)

The bioecological model underlines the child's placement at the center and perceives the child's participation as an interaction with the environment's different systems (Bronfenbrenner 1979). Correspondingly, to enhance children's participation in pediatric rehabilitation, a child's immediate environment and activity context can be adapted to the child's needs and the practices promoting child's engagement between systems level can be utilized (Anaby et al. 2022; Imms et al. 2017). The characteristics of the environment at different system levels may also require the child to learn new skills in order to participate.

Figure 1 illustrates the dimensions of participation in this study's context of focusing on enhancing a child's participation in their daily life environments and rehabilitation in accordance with children's participation rights. Participation in this study is understood to constitute attendance and involvement (Imms et al. 2017). At best, participation provides children opportunities to engage in a meaningful way in everyday life situations (Palisano et al. 2012) that enable children to practice their agency (Kellet 2009). In this study, a child's participation is understood to be contextual and situational. Accordingly, the child's participation is changed and molded by interaction between the child

and the environment over time. In line with Bronfenbrenner (1979; 2018), the environment includes the different system levels with the child at the center and family being the child's key developmental environment.

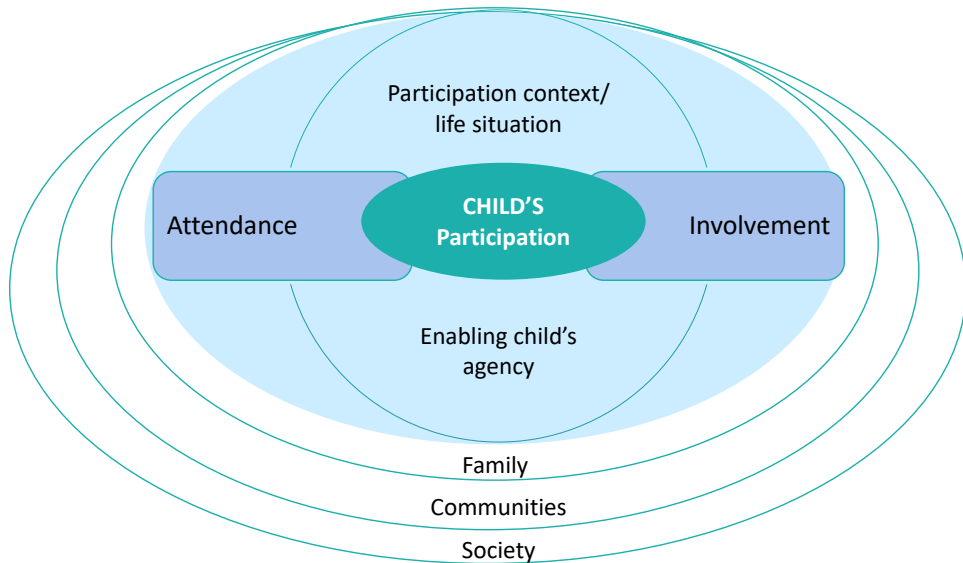


Figure 1 Interactive dimensions of participation in the child's interconnected and multisystem developmental environment

2.1.3 Child's participation in a collaborative rehabilitation process

2.1.3.1 Key elements in child–family–professional collaboration

Children's rehabilitation is based on individual needs and multidisciplinary collaboration between family and professionals (King & Chiarello 2014; Sipari et al. 2022). Due to the complex health needs of the children, pediatric rehabilitation is a long-term, goal-oriented and interactive process of learning and change for the child, family, and environment (Järvikoski 2013; Rosenbaum & Gorter 2012; Trapacca et al. 2016). In Finland, pediatric rehabilitation is based on an individual plan (Autti-Rämö et al. 2022), with a multiprofessional team within the public sector responsible for planning a child's rehabilitation. The rehabilitation plan, however, is usually implemented with rehabilitation professionals working in the private sector in the family's home area. The rehabilitation plan should be implemented as part of the child's and family's everyday life according to jointly agreed goals and relevant activities (Committee of Rehabilitation Reform in Finland 2017).

Depending on a child's needs and severity of the disability, the child's rehabilitation network may include several professionals from different occupations, such as pediatric neurologist, physical therapist, occupational therapist, speech therapist, nurse, rehabilitation counsellor, and social counsellor (Kerbl et al. 2016), and experts from the child's daily life network, such as teachers in kindergarten or school (Autti-Rämö et al. 2022). In Finland, the obligation for collaboration between the social and health sectors and early childhood education is mandated in both the Health Care Act [Terveydenhuoltolaki] (30.12.2010/1326) and in the Act on Early Childhood Education and Care [Varhaiskasvatuslaki] (13.7.2018/540). Also, the Social Insurance Institution of Finland (Kela), which provides access to rehabilitation services for people who experience severe functional restrictions in their everyday lives due to sickness or disability, requires that rehabilitation is conducted in collaboration with the child, family, and professionals working with the child in daily life (Kela 2022). From the perspective of a child or young person and their family, rehabilitation, education, and healthcare services form a comprehensive whole, promoting the child's functioning, learning, and wellbeing (Sipari et al. 2022).

Rehabilitation based on family–professional collaboration acknowledges the expertise of family members in their own situation, needs, and preferences; thus, the family is considered an equal partner in rehabilitation (An & Palisano 2014; Blue-Banning et al. 2004; King & Chiarello 2014). A collaborative rehabilitation process for the child means that every step of the process is planned while respecting the child's and family's preferences, utilizing shared goal setting and decision making, joint implementation, and evaluation of outcomes (An & Palisano 2014). Accordingly, the rehabilitation process should contain family–professional discussions and multiprofessional assessment that combines the child's and the parents' experiences of functioning in everyday life with the professionals' evidence- and experience-based knowledge (Jeglinsky et al. 2021; Novak et al. 2021). The general rehabilitation process, starting from the needs of the child, is illustrated in Figure 2.

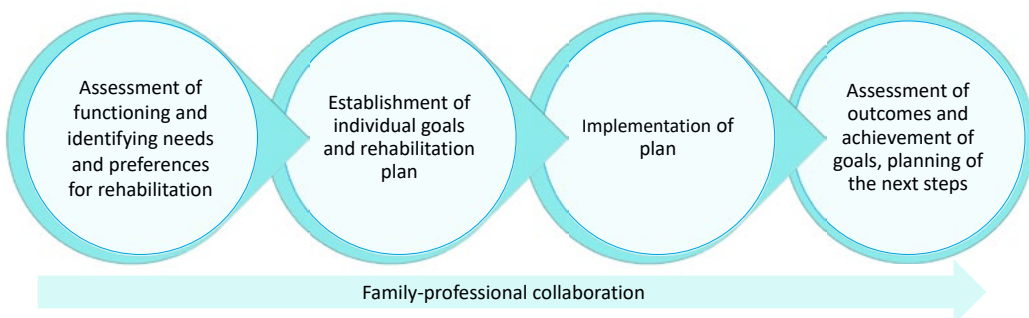


Figure 2 Example of a general rehabilitation process (modified from: An & Palisano 2014; Autti-Rämö 2021)

Family–professional collaboration with children as active participants facilitates the promotion of children’s best interests (Foster et al. 2022; März et al. 2022). Family–professional collaboration is strongly value-based, but it is also fundamental to successful rehabilitation (An & Palisano 2014; An et al. 2017; McCoy et al. 2019). Family–professional collaboration is associated with family empowerment and better outcomes in rehabilitation (Järvikoski et al. 2015). Järvikoski et al. (2013) found the following key factors that were connected to parents’ satisfaction with the planning and the correspondence between the rehabilitation plan and the needs:

- professionals’ sharing of information,
- a multidisciplinary team of rehabilitation and education professionals actively taking part in planning and implementing rehabilitation,
- parents’ experience that the child’s and parents’ preferences are heard, and
- the child’s motivation towards rehabilitation.

Further, the means of rehabilitation that were based on children’s needs were linked to increased participation in family and recreation activities (McCoy et al. 2019). Also, Novak (2011) found that parents experienced partnership-based home programs that responded to their family’s individual needs and situation beneficial.

Family–professional collaboration fosters child and parent engagement, which has been underlined as an essential component of a successful rehabilitation process (Antoniadou et al. 2024; King et al. 2020). In the fPRC framework, Imms et al. (2017) refer to engagement as a person’s active involvement in decision making and influence in matters on a personal and between-systems level. They argue that engagement is a unifying construct across ecological levels and that the content is determined by the direction of the focus or effort (Imms et al. 2017). Steinherd et al. (2021) presented that engagement constitutes a child’s behavioral, cognitive, and affective investment during participation in a certain context. Rehabilitation research on engagement has focused specifically on examining engagement from the perspective of rehabilitation services, such as the child’s and/or their parents’ engagement in therapy sessions (King et al. 2020; King et al. 2019; Melvin et al. 2021), and exploring professional strategies to promote child engagement in intervention process (Antoniadou et al. 2024). Accordingly, King et al. (2020) and Melvin et al. (2019) depicted engagement as a complex and multifaceted state and a dynamic process that professionals and family members construct together over time.

In a child’s collaborative rehabilitation, engagement is characterized by a child’s and parents’ involvement, investment, motivation, and commitment towards the rehabilitation or intervention process (Antoniadou et al. 2020; King et al. 2020). Based on the literature, it is important to direct more attention

to the child's and parents' engagement and collaboratively tailor rehabilitation that is meaningfully attached to their everyday situations (An & Palisano 2014; King et al. 2020) and to engage families in the development of collaborative practices (Chow et al. 2024).

2.1.3.2 Critical perspectives on children's participation in collaboration

In practice, the implementation of family–professional collaboration in pediatric rehabilitation varies greatly (Jeglinsky et al. 2012), and many researchers have posited that more weight should be given to collaboration with the family throughout the rehabilitation process (Järvikoski et al. 2015). From a family perspective, collaboration with many professionals and service providers is challenging and burdensome (Särkikangas 2020). With several stakeholders in the child's rehabilitation network, family–professional collaboration according to the child's best interest may involve multiple and possibly competing interests and pressures (Birchley et al. 2022). Thus, research indicates that the determination and promotion of the child's best interest within collaborative family–professional dynamics in healthcare practice are both complex and insufficiently studied (Birchley et al. 2022; Coyne & Harder 2011; März 2022; Woo et al. 2015).

According to several studies, children want to be active participants in family–professional collaboration, to be listened to and influence matters important for them (Bekken 2014; Coyne & Gallagher 2011; Davies et al. 2024b; Davison et al. 2021; Garth et al. 2009; Pritchard Kennedy 2012; Pritchard et al. 2022; Vinblad et al. 2019). For example, in a study by Pritchard Kennedy (2012), school-age children with chronic illness stated the importance of being actively supported in identifying and upholding their best interests in collaboration with parents and professionals. Studies show, however, that the child's role as an active partner in collaboration has been neglected, and children's active participation in planning their rehabilitation and care has been implemented inadequately or not at all (Curtis et al. 2022; Järvikoski et al. 2015; Kronsell et al. 2021; Nisius et al. 2024; Nowak et al. 2020; O'Connor et al. 2021; Teleman et al. 2021).

Söderbäck et al. (2011) argues that, in order to safeguard child's participation rights and the best interests of the child in healthcare situations, a distinction must be made between the adults' perspective and the child's own perspective. Traditionally, parents have acted as proxies for children, and children's perspectives have been interpreted through the lens of adults. Parents' and children's views may, however, differ as shown in studies regarding children with disabilities (Costa et al. 2017; Liao et al. 2019), chronic conditions (Napvan der Vlist et al. 2021), and children and youth with acquired brain injuries (Allonsius et al. 2021). For example, Costa et al. (2017) compared priorities for goals among children, parents, and teachers. They found that children prioritized goals focusing on specific activities and participation meaningful

for them, whereas parents focused on productivity, school, body functions, and task performance, and teachers on body functions and school activities. Thus, exploring the perspectives of both parents and children is considered as good practice (Allonsius et al. 2021; Liao et al. 2019; Söderbäck et al. 2011), and a more child-centered approach would include both the adults' child perspective and the child's own perspective (Coyne et al. 2016; Söderbäck et al. 2011; Sommer & Pramling-Samuelsson 2010).

Ehrich et al. (2015) pointed out that enhancing children's participation in family-professional collaboration needs the acknowledgement of children not only as rights-holders but also as collaborative "duty- and responsibility-bearers." However, at the same time, as researchers call for a more child-centered approach, some critique has been presented that services are directed only for children and do not consider what services could be offered to meet parent and family needs (King et al. 2017).

2.2 Factors influencing children's participation in pediatric rehabilitation

2.2.1 Barriers and facilitators for children's participation in encounters with professionals

There are several barriers and facilitators for a child's active participation in the rehabilitation process and encounters with professionals in healthcare. Children's opportunities to influence healthcare decisions vary, depending on, for example:

- professional practices (Coyne & Gallagher 2011; Davies et al. 2024c; Ehrich et al. 2015; Franklin & Sloper 2005; Garth et al. 2009; Jeglinsky et al. 2012; Quaye et al. 2019),
- the weight of the decision (Andersen & Dolva 2014; Coyne et al. 2014; Coyne & Gallagher 2011),
- the information available to the child (Coyne & Gallagher 2011; Davies et al. 2024c; Davison et al. 2021; Teleman et al. 2021),
- the interaction and level of trust between the child and the adults (Coyne & Gallagher 2011; Davies et al. 2024c; Davison et al. 2021; Teleman et al. 2021),
- children's own preferences on how they wish to participate (Coyne & Gallagher 2011; Garth et al. 2009; Quaye et al. 2019), and
- a child's age and abilities, as participation increases with age and development of the child's abilities (Garth et al. 2009; O'Connor et al. 2021).

Teleman et al. (2021) studied children's barriers to participation in pediatric rehabilitation services. They found that adult-centered services and lack of trust and power-imbalance in adult-child relationships form obstacles for children's participation. Similarly, Davison et al. (2021) described children's experiences when adults did not allow the child to participate or when the child's views were ignored. Ignorance triggered children's distrust towards staff and uncertainty about what was happening, which further caused fear, irritation, disengagement, and resistance in children (Davison et al. 2021). Karlsson (2020) stated that children's perspectives are easily overshadowed by adults' perspectives, who often control the time and space for knowledge construction with specialist knowledge, power, and experience. Coyne et al. (2016) stated that adult-centered practices in healthcare form asymmetric relationships between adults and the child, weakening the child's opportunities for agency. Accordingly, studies show that adults' attitudes and the belief that children need to be protected from their perceived inability to make good decisions prevail when determining what is in their best interest in healthcare (Davies et al. 2024a).

In a study of children's experiences of taking part in consultations at a pediatric rehabilitation unit, Bekken (2014) stated that children have negative experiences, such as not being listened to, the feeling of not being enough or adequate, and anxiety about what will be decided for them. Children's experiences in encounters with professionals are relevant because positive experiences are associated with favorable health outcomes (Doyle et al. 2013) and, thus, children's negative experiences may have an opposite influence. In a study by O'Connor et al. (2021), children experienced not engaging in decision making as a common practice, with the adult leading the discussion and child taking part when direct questions or alternatives to choose from were presented. In rehabilitation, the various professionals working in multidisciplinary teams and unclear role of children as part of the team also pose a challenge in children taking an active role in family-professional meetings (Koller et al. 2024).

Adults' know-how and skills to be attentive, sensitive, supportive, and encouraging enable children to express their own perspectives and experiences and facilitate children's participation (Davies et al. 2024c; Davies et al. 2024b; Söderbäck et al. 2011). Children value trusting relationships with the professional, being involved in discussions and decision-making, adults' treating them with respect, and their views being given due weight (Coyne & Gallagher 2011; Davies et al. 2024b; Davison et al. 2021; Garth et al. 2009). Trusting relationships/bonds are created through repeated contact and dialogue (Davison et al. 2021). Sharing accurate information in a manner that the child is able to understand, giving time to think and to ask questions (Davies et al. 2024b; Davies et al. 2024c; Davison et al. 2021), and talking to the child as much as they talked to the parents was appreciated by children and promoted positive emotions (Davison et al. 2021). On the other hand, unclear or no information given to the

children restricted their involvement or taking part in the decisions (Bekken 2014; Coyne & Gallagher 2011; Davison et al. 2021; Garth et al. 2009; Vinblad et al. 2019). Additionally, speaking too fast, busy schedules, and unfamiliarity between the child, professionals, and practices acted as barriers for building a trusting relationship with professionals (Coyne & Gallagher 2011; Davison et al. 2021). Bekken (2014) underlines the importance of implementing children's everyday experiences and knowledge of living with impairment into rehabilitation planning.

It is worth noting that parents may also act as barriers or facilitators for the child's participation in healthcare situations (Bekken 2014; Coyne & Gallagher 2011; Davies et al. 2024b; Davison et al. 2021; Garth et al. 2009; Quaye et al. 2019; Teleman et al. 2021; Vinblad et al. 2019). Teleman et al. (2021) underlined the need for discussions about what a child's participation should comprise of in pediatric rehabilitation as well as focus on managerial support and guidelines for practice to achieve the participation rights of children in encounters with professionals (Quaye et al. 2021).

2.2.2 Barriers and facilitators for children's participation in daily life

Children with disabilities experience participation restrictions in both younger (Di Marino et al. 2018) and older age groups (Bult et al. 2011; Steinhardt et al. 2019) and in different settings, such as in school (Asbjørnslett & Hemmingsson 2008; Eriksson et al. 2007) and in community and leisure activities (Bedell et al. 2013; Shikako-Thomas et al. 2014; Steinhardt et al. 2019; Ullenhag et al. 2014). Studies show that children face more difficulty engaging in community activities than in home-based activities (Di Marino et al. 2018). Although the forms of participation for children with and without disabilities in communities were alike in a UK-based study by Arakelyan et al. (2020), children with disabilities participated less for example in unstructured and organized physical activities (Arakelyan et al. 2020; Bedell et al. 2013; Bentzen & Malmqvist 2022) and had a more limited range of activities than typically developing peers (Engel-Yeger et al. 2009). Further, children with disabilities have more limited participation with friends (Arakelyan et al. 2020; Bedell et al. 2013), participate more actively with family-members or adults than with peers (Nyquist et al. 2016; Solish et al. 2010), and have fewer peer friendships (Eriksson et al. 2007; Solish et al. 2010). Children with disabilities experience lower autonomy than children without disability (Eriksson et al. 2007). It is worth underlining that children with disabilities experience as much enjoyment in participation as other children when given an opportunity to participate (Engel-Yeger et al. 2009) and wish to engage more with peers (Nyquist et al. 2016). Moreover, studies demonstrate that social participation is highly valued by children, especially adolescents (Bernard et al. 2024).

Studies show that barriers and facilitators for children's participation may exist in any domain in the ICF classification. Fauconnier et al. (2009) evaluated the participation variation for children with cerebral palsy (CP) in a cross-sectional European study. They showed that pain and impairments in walking, fine motor skills, communication, and intellectual abilities restricted participation (Fauconnier et al. 2009). In a study by McManus et al. (2008), where parents rated their children's participation, the results showed that the level of impairment of 8–12-year-old children with cerebral palsy was significantly associated with participation in everyday activities. Because of a significant variation in children's participation between regions, the researchers argue that the accessibility of services and environments varies in different regions, which explains differing participation, and also policies and regulations at the national level influence participation (Fauconnier et al. 2009). Research shows that a child's personal factors, such as gender (Law et al. 2004), age (Bult et al. 2011; Law et al. 2004; Orlin et al. 2010; Steinhardt et al. 2019), and preferences (King et al. 2006a; Souto et al. 2024; Steinhardt et al. 2019), also influence participation.

A substantial body of research exists on the impact of environmental factors on children's participation (Anaby et al. 2014; Bedell et al. 2013; Di Marino et al. 2018; Imms 2008; Law et al. 2004; Steinhardt et al. 2019). Colver et al. (2012) showed that physical, social, and attitudinal environments have a significant influence on participation in everyday activities and in social roles for children with CP, accounting for 14–52% of the variation in children's participation. Environmental factors—such as availability and adequacy of resources, i.e. information and suitable programs for the child (Souto et al. 2024)—and, further, physical, social, and cognitive demands of the activity as well as weather influence children's participation opportunities (Bedell et al. 2013). Maxwell et al. (2018) describes that availability, accessibility, affordability, accommodability/adaptability, and acceptability, “the 5 A's,” are central environmental dimensions for participation; their realization and features determines whether the activity environment will hinder or promote a child's participation. For example, Souto et al. (2024) found that insufficient support from staff and service providers, such as the unavailability of personal assistance, specialists, and information, restrict children's participation. Likewise, significant environmental facilitators or barriers to children's participation are their possibilities for interaction with other people and the ways that children are supported in their communication efforts (Fylkelnes & Ytterhus 2021).

Family function has a strong effect on children's participation (Di Marino et al. 2018). Further, family type, parental ethnicity, parental education and socio-economic status impact 5–12-year-old children's participation, as shown in a study by Arakelyan et al. (2019). The researchers also presented that parents with adequate resources, time, and support, along with mental and physical health and functioning, are in a good position to support children's participation

outcomes. Whereas lesser parental self-efficacy beliefs, parental support, parental time, family preferences, and negative activity orientation towards social and recreational activities negatively impacted children's participation (Arakelyan et al. 2019). Studies show that parents play a central role in enhancing a child's participation, utilizing a range of applicable strategies that aim to break down participation barriers and help the child with activity-related difficulties (Axelsson et al. 2014; Piskur et al. 2017). On the other hand, parents can also over-protect their children and hinder their attempts to participate (Heah et al. 2007).

Shields and Synnot (2016) explored the barriers and facilitators to participation in physical activity from the perspectives of children with disabilities (10–18 years), parents, and sport and recreation staff. The results show that the possibility to influence decisions about issues around the activity and participation, a pathway for mastering skills, and having a sense of competence and family support were important facilitators for children's participation. According to the findings, a lack of collaboration between stakeholders was a key barrier alongside negative attitudes among parents, staff, and peers (Shields & Synnot 2016). Participation restrictions create risks of being excluded from the benefits of participation. For example, limitations to participation in physical activity create a risk for health problems associated with inactivity (MacEachern et al. 2021; Woodmansee et al. 2016).

2.3 Enhancing children's participation as a core focus in pediatric rehabilitation

2.3.1 Participation-focused tools and practices

To enhance children's participation and address participation barriers, participation is seen as the main outcome of rehabilitation and also serves as a method to achieve the outcome (Granlund & Imms 2024). This emphasis on participation as a means and an end (Imms. et al. 2017) is described by the term "participation-focused" in this study.

In novel pediatric rehabilitation literature, the concepts of participation-based and participation-focused rehabilitation are both used. Both concepts underline a child's participation as the main outcome of rehabilitation and the importance of active involvement of the child and family in the process of achieving the desired outcome (Anaby et al. 2022; Palisano et al. 2012). In a study by Kolehmainen et al. (2020), participation-focused practice was determined as clinicians' behavior that targets participation outcomes, involves the child and/or parent in setting participation outcomes, and measures progress towards the established participation outcomes. Similarly, in participation-

based rehabilitation, the goals are aimed at enhancing children's possibilities to engage in their preferred activities in everyday life in a meaningful way (Palisano et al. 2012). Participation-focused rehabilitation includes participatory practices that promote a child's opportunities for active participation in the collaborative rehabilitation process, aiming to enhance participation in everyday life (Granlund & Imms 2024). Thus, participation-focused practices in pediatric rehabilitation contain tools and methods that a) are based on family–professional collaboration, b) consider children as active participants, and c) aim to enhance children's participation in their everyday life situations (Anaby et al. 2022).

In participation-focused rehabilitation, children's and families' active involvement in the assessment of everyday life participation by identifying preferred participation types and life situations of interests is important (Fauconnier et al. 2009). There are several participation assessments and measures available for children with disabilities (0–17 years), including self-report, proxy-report, and interview administrations (Chien et al. 2014; Quartermaine et al. 2024; Vänskä et al. 2016). The limitations of these tools include that most of these measures focus on parents' and professionals' perspectives and rely on proxy reports with parents completing standardized assessments or interviews (Schiariti 2014; Vänskä et al. 2016). Another shortcoming is that only a small number of self-reporting tools provide accessible design features to meet the needs of people with communication support needs (Quartermaine et al. 2024). In addition, another limitation of the existing participation measures is that they cover a different range of the activities and participation domains in the ICF classification, focusing on certain life areas such as recreation and play or child's activities and participation in home environment or school (Chien et al. 2014). Further, the focus of participation assessment is usually on quantifying the frequency, intensity, amount, or number of times a certain activity is taken part in. Thus, the focus is on the objective attendance dimension of participation and not on subjective involvement (Bernard et al. 2024; Granlund et al. 2021; Quartermaine et al. 2024).

In recent years, evidence on participation-focused intervention's effects and various benefits has accumulated (Adair et al. 2015). The findings from the systematic review by Adair et al. (2015) support the use of personalized programs that combine both individualized and group-based strategies to improve participation outcomes for children with disabilities; however, it only included a few high-quality studies. Several studies exploring interventions that aim to enhance children's participation in daily life situations underline the importance of identifying modifiable environmental factors that promote or restrict participation (Anaby et al. 2020; Dimakopoulos et al. 2024; Guichard & Grande 2017; Maciver et al. 2019; van der Kemp 2021) and creating solutions in collaboration to overcome obstacles in the participation context or promoting change in the way that a child and the setting interact (Ullenhag et al. 2024).

2.3.2 Participatory practices with children in goal setting and action planning

Individualized goal setting in family–professional collaboration has been underlined as a best practice in pediatric rehabilitation (Brewer et al. 2014; Øien et al. 2010). Although children’s active participation and self-identified goals have traditionally received little attention (Pritchard-Wiart & Phelan 2018), increasing consideration is placed on a child’s active involvement by regarding the child as a subject in rehabilitation planning and, especially, in establishing meaningful goals and, to some degree, also in the different phases of the goal-oriented rehabilitation process to achieve the set goal (Costa et al. 2017; Pritchard et al. 2022; Ryan et al. 2024; Vroland-Norstrand et al. 2016).

Studies show that children with disabilities can identify achievable goals (Vroland-Norstrand et al. 2016), and children’s participation in setting priorities for therapy goals has shown to improve their motivation and commitment to work towards the goal (Pritchard et al. 2022). In a scoping review, Curtis et al. (2022) reported, however, that there is limited knowledge regarding the ways in which and extent of how children take part in goal setting and implementing in occupational and physical therapies, despite its recognized importance in the literature. Similar findings have been reported with regard to multidisciplinary rehabilitation in Finland (Sipari et al. 2019); however, there are also studies showing children actively participating in rehabilitation planning within family–professional collaboration (Jeglinsky et al. 2021).

Studies indicate that the reasons behind children’s varying and, to some extent, neglected role in goal setting are (1) divergent views among the child, parent, and professionals regarding suitable goals (Costa et al. 2017; Pritchard-Wiart et al. 2022), (2) adults’ lack of confidence in children’s ability to set meaningful goals (Pritchard et al. 2022), and (3) organizational barriers, such as lack of time and professional know-how on practices to support child’s active role (O’Connor et al. 2021; Sipari et al. 2019). Also, Ryan et al. (2024) identified that children with communication difficulties were often excluded from goal setting, and the possible reason for this could be that many of the goal setting tools rely on interview-format and child’s verbal expression. Overall, literature shows the need to improve the theoretical basis for a child’s participation in collaborative goal setting in pediatric rehabilitation (Pritchard-Wiart & Phelan 2018).

Some goal-setting strategies and tools that are based on collaborative goal setting have been developed (Table 1), but their implementation with the child as an active contributor in practice varies (Anaby et al. 2016; Coussens et al. 2022; Curtis et al. 2022). It is also worth noting that some goal-setting tools, such as COPM and GAS, were not originally designed for children, making their reliability when applied to child self-respondents uncertain (Ryan et al. 2024). In Finland, many of the tools supporting children’s participation in goal setting

and participation-focused rehabilitation process have not been translated and/or evaluated in practice (Vänskä et al. 2016). Studies on the usability of the GAS method in Finland have shown that it requires adequate time to reflect upon the needs to achieve goals in family–professional collaboration as well as a special consideration for children’s possibility to actively participate in setting their own goals and plans to achieve the goals (Sipari et al. 2019).

Table 1 Goal-setting strategies and tools in pediatric rehabilitation based on family-professional collaboration with the child as an active participant

Goal-setting tools/ approaches	Short description of the tool/approach	Author
COPM: Canadian Occupational Performance Measure (adapted for children)	An interview-based method originally developed for occupational therapy, which is used to assess changes in functionality over time as perceived by the child/parent. COPM is used widely and adapted to several cultural contexts, including Finland (COPM 2024).	Law et al. 2005; Cusick et al. 2007
Enhancing Child Engagement in Goal Setting (ENGAGE) approach	ENGAGE aims to promote children’s participation in goal setting and to support clinicians to adapt the use of tools and strategies to meet the specific needs of children and their families. Ongoing study on the effects of the approach.	Pritchard-Wiart et al. 2022
Goal Attainment Scaling (GAS)	In the GAS method, developed in the 1960s in the mental health context, goal setting progresses step by step from identifying and naming the goal to choosing an indicator and modifying a scale to measure goal attainment, to finally assessing the achievement of the goal. The use of the GAS method is recommended by Kela, the funder of children’s pediatric rehabilitation in Finland (Kela n.d.).	Kiresuk & Sherman 1968; Kiresuk et al. 1994
Perceived Efficacy and Goal Setting Tool (PEGS)	Children (ages 5–9 years) self-assess their perceived competence in everyday activities by using a set of cards to set intervention goals.	Missiuna et al. 2006

Although participation has been underlined as the main outcome in rehabilitation, literature shows that this focus on participation is not yet seen in children’s rehabilitation goals (Anaby et al. 2016; Graham et al. 2020). Most goals set in pediatric rehabilitation are focused on body functions or, for example, on skill development and not on participation in everyday activities (Kolehmainen et al. 2020; Ryan et al. 2025). Contrary to what professionals might assume, enhanced skills or body functions do not automatically lead to improved participation (Adair et al. 2015).

In recent years, novel participation-focused tools have been developed that underline a child’s meaningful participation in daily life as a goal and support the utilization of participatory practices for development of an action plan to achieve the participation goal (Table 2). The approaches behind the tools are based on identification and removal of participation barriers, focusing on possibilities and strengths and co-developing solutions (Anaby et al. 2018; Palisano et al. 2022).

Participatory practices and co-development embraces children's, parents', and professionals' co-construction of knowledge and building a joint understanding of the ways to achieve rehabilitation goals (Palisano et al. 2022).

Table 2 Collaboration-based tools that support achieving child's participation goals

Tool	Short description	Author
Collaborative process for participation goals	A tool that guides a collaborative process in which family and rehabilitation professionals assess child, family, and environment strengths and areas for improvement to identify strategies and develop an action plan for participation goals.	Palisano et al. 2012; Palisano et al. 2022
PREP: Pathways and Resources for Engagement and Participation	Intervention that aims to minimize and/or remove barriers and identify and utilize supporters for participation within the environment to enable children/ youth to engage in preferred activity of their choice.	Anaby et al. 2018

2.3.3 Knowledge needs in enhancing children's participation

Despite the evidence on the benefits of participation-focused rehabilitation and importance of family–professional collaboration with the child as an active participant, pediatric rehabilitation practices have remained professional-led (Coussens et al. 2022; O'Connor et al. 2021) with a lack of focus on enhancing children's participation in their everyday lives (Anaby et al. 2016; Kolehmainen et al. 2020). A change in clinical practices towards participation-focused practices is needed but challenging and slow (Coussens et al. 2022), and the gap between research and practice has been well-identified (Anaby et al. 2022; Granlund & Imms 2024; Novak et al. 2021).

Given that participation is acknowledged to be a fundamental value (Streuli et al. 2011), understood as the means and principal outcome of rehabilitation (Imms et al. 2017; Palisano et al. 2012) as well as a key prerequisite for the development and well-being of the child (WHO 2001), there is a substantial lack in knowledge on how to address the challenges in realizing child's participation rights in multidisciplinary rehabilitation (Curtis et al. 2022; Koller et al. 2024). To shed light on this knowledge gap, this study describes the elements that enhance participation of children with disabilities in pediatric rehabilitation practice.

3 AIMS OF THE STUDY

The overall aim of this doctoral thesis was to describe elements that enhance participation of children with disabilities in pediatric rehabilitation practice. This thesis contains three original studies.

- Study I The aim was to describe meaningful participation in everyday life from the perspectives of children with disabilities.

- Study II The aim was to explore how professionals and parents of children with disabilities perceive the practices for promoting a child’s best interests in pediatric rehabilitation.

- Study III The aim was to design, pilot, evaluate, and generate the final version of a new tool to enhance children’s participation.

The three studies were designed to describe the elements enhancing children’s participation from three perspectives to cover the multifaceted whole of pediatric rehabilitation practice. The relationship between the aim of the dissertation and the aims of the original studies is presented in Figure 3.

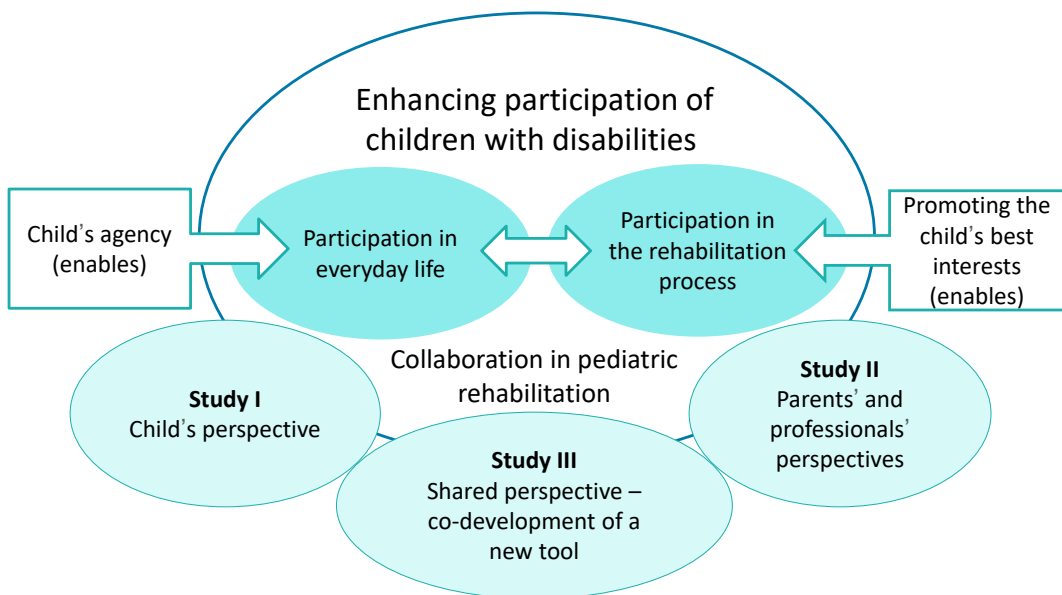


Figure 3 The three sub-studies of the dissertation research in the theoretical framework

4 METHODS

4.1 Qualitative research approach

Children's participation is a multidimensional and interactive phenomenon behind the study's methodological choices. In this research, the interest of knowledge is practical (Habermas 1978: 195–204), aiming to understand the elements enhancing children's participation in the daily practice of pediatric rehabilitation from different stakeholder perspectives. Unlike purely theoretical research, this study's findings aim to be of use to inform improvements and guide development in practice (Habermas 1978: 195–204) in accordance with children's best interests and to secure children's participation rights in rehabilitation.

Studying children's participation benefits from methodological choices that allow rich description and understanding of the multifaceted phenomenon in pediatric rehabilitation practice. Exploring the phenomenon from different perspectives is particularly important in the multidisciplinary pediatric rehabilitation process, in which the knowledge of the person's needs and situation is collected, shared, and applied individually in the person's daily life (Autti-Rämö et al. 2021; Jeglinsky et al. 2021). Thus, it makes sense 1) to choose research methods that enable participation of multiple stakeholders and accommodate their views to enrich the understanding of the study phenomenon (Lincoln et al. 2024) and 2) to allow both the exploration of a child's individual perspectives (Kvale 1996: 10–11) and the construction of common knowledge (Barbour 2007: 29–40) to shed light on the elements enhancing children's participation in pediatric rehabilitation.

This dissertation utilizes qualitative research methodology. Qualitative research traditionally stems from the need to understand the study phenomenon, meanings related to it, and build knowledge about the social world and human experience (Kyngäs 2020a; Lincoln et al. 2024). Typical qualitative research seeks to understand the study phenomena from an insider perspective and explore how people construct the world around them (Barbour 2007: xi-xy; Creswell & Creswell 2023: 5). Accordingly, in this study, enhancing children's participation in rehabilitation is explored from the perspectives of stakeholders with experience and expertise in pediatric rehabilitation—children with disabilities, their parents, and professionals.

A qualitative approach was selected in this study because it is especially suited for exploring a person's individual life experiences and the complex and multifaceted phenomena in their natural contexts (Kyngäs 2020a), such as participation. Another grounds for selecting the qualitative approach was that it allows for utilization of multi-perspective knowledge construction (Lincoln

et al. 2024). The constructivism paradigm means that knowledge is actively constructed, not just passively obtained (Schwandt 2000), and individuals form meanings of their experiences through interaction (Creswell & Creswell 2023: 9–10). This interactive meaning-making results in more informed and sophisticated reconstructions of knowledge (Guba & Lincoln 1994; Lincoln et al. 2024). In other words, knowledge is created through social interaction (Kvale 1996: 10–11). Koro-Ljungberg (2008) described social interaction as a space where researchers and participants engage in activities and collectively co-construct knowledge that is negotiated and interactive as well as situational and changing. Both the researcher and participant are knowing subjects who actively and intentionally engage in knowledge creation during interaction with others (Koro-Ljungberg 2008). In this study, a new understanding of the study phenomenon is produced through interaction, which enables participants to express and share views to form new knowledge (Creswell & Creswell 2023: 9–10; Kvale 1996: 10–11; Lincoln & Guba 2000).

This study focuses on the participants' perceptions: what and how participants describe the meanings of the study phenomenon (Kvale 1996: 3–7; Creswell & Creswell 2023: 9–10). The researcher supports participants' engagement by asking questions and facilitating discussion about the study phenomenon; this interaction between investigator and participants refines and elicits the creation of new knowledge (Creswell & Creswell 2023: 9–10; Guba & Lincoln 1994). The nature of knowledge in constructivism refers to individual or collective reconstructions that sometimes form consensus (Lincoln et al. 2024). In this study, instead of aiming to reach consensus, the goal was to produce rich and multifaceted understanding of the study phenomenon.

A special interest of this dissertation was to attain children's perspectives of meaningful participation. Accordingly, the methodological choices in this study acknowledge the child as an active participant in collaboration with parents and professionals. By enabling children's participation in the research, the aim was to align with the fundamental value of the right to participate in the study (Karlsson 2020). As McMellon & Tisdal (2020) state, the active involvement of children and young people in knowledge co-production and discussions about participation are essential to create practices and tools that are meaningful from the children's perspective and to enhance the realization of participation rights in their daily lives. Accordingly, the participation phenomenon was intertwined with the theoretical background, value base, and methodological choices of this dissertation.

In Study I, meaningful participation was described from the perspectives of children with disabilities and with experience in rehabilitation who took part in individual interviews. Study II explored the practices for promoting a child's best interest in pediatric rehabilitation from parents' and professionals' perspectives through interviews. In Study III, family members and professionals took part in

co-developing a new tool to promote child's participation. The study's qualitative data collection was conducted in multiple phases of the co-developmental process. An overview of the three sub-studies' design, questions, participants, and qualitative research methods are presented in Table 3.

Table 3 Overall description of the three sub-studies

Study	Study aims	Study question(s)	Participants	Data collection methods	Data analysis
I	To describe meaningful participation in everyday life from the perspectives of children with disabilities	What are the types of participation that are meaningful for children with disabilities? What do children consider meaningful in participation? What factors support or limit children's participation?	N=9 Children with disabilities receiving rehabilitation (5-10 years)	Individual photo-elicitation interviews	Inductive content analysis
II	To explore how professionals and parents of children with disabilities perceive the practices for promoting the child's best interests in pediatric rehabilitation	What are the current and required practices for promoting a child's best interests in pediatric rehabilitation from the perspectives of professionals and parents of children with disabilities?	N=39 Rehabilitation professionals (n=30), parents of children with disabilities (n=9)	Focus group and individual interviews	Inductive content analysis
III	To design, pilot, evaluate, and generate the final version of the new tool to enhance children's participation	What kind of tool promotes children's participation in collaborative rehabilitation?	N=334 Child with a disability (n=1), parents (n=6), rehabilitation professionals (n=328)	Literature, workshop discussions, oral and written feedback, questionnaires	Inductive content analysis Content analysis

4.2 Study design and participants

4.2.1 Study I

To describe meaningful participation for children with disabilities in their daily lives, three study questions were formulated:

1. What are the types of participation that are meaningful for children with disabilities?
2. What do children consider meaningful in participation?
3. What factors support or limit children's participation?

Children with disabilities aged 5–10 years and with experience of pediatric rehabilitation were selected as participants in the study through purposive sampling (Holloway & Galvin 2024: 141–144). Inclusion criteria for enrolling in the study was twofold. First, the child had taken part in rehabilitation funded by the Social Insurance Institution of Finland (Kela), who provide intensive medical rehabilitation to children who have an illness or impairment causing substantial challenges with daily activities (Kela 2023). Second, the child was able to express themselves through speech or other means of communication. The study design is described in Figure 4.

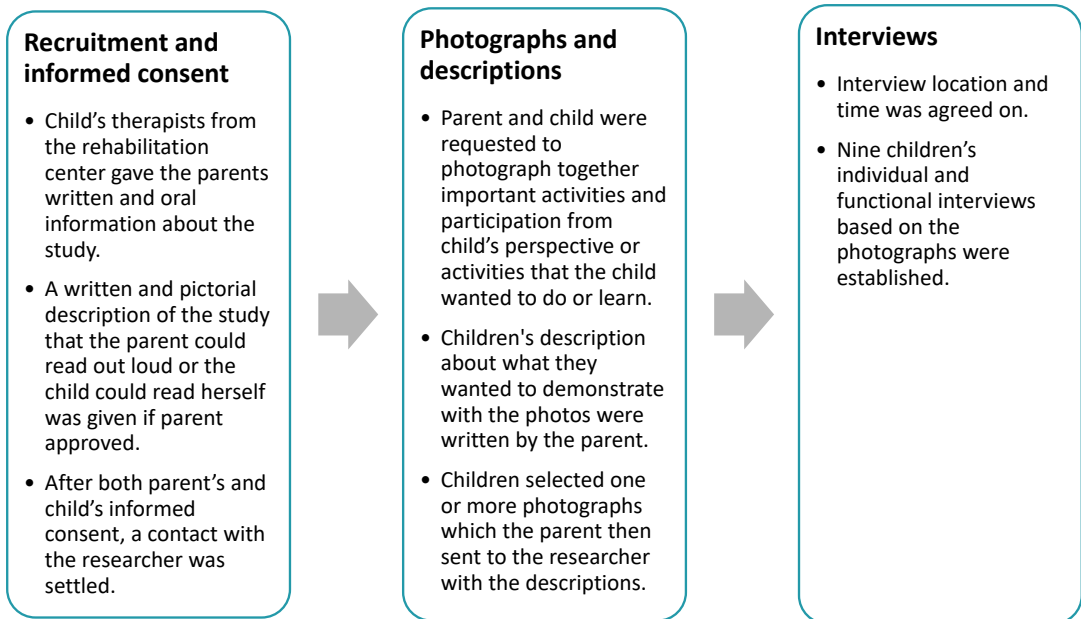


Figure 4 Study I design

Participants in the study included nine children with disabilities, aged between 5–10 years (mean age: 7.2 years). Four of the children were girls and five boys. The main type of disability for six of the children was physical/motor impairment resulting from cerebral palsy (n=4), hemiplegia and visual impairment (n=1), and specific developmental disorder of motor function (n=1). Two children had autism disorder and one had a developmental disorder. Seven children expressed themselves through speech and two also used pictures/sign language.

4.2.2 Study II

Study II set out to explore the practices promoting children’s best interests in rehabilitation from the perspectives of professionals and parents of children with disabilities. The participants were selected through purposive sampling (Holloway & Galvin 2024: 141–144). Participants were professionals with at least one year of experience in pediatric rehabilitation and parents who had experience of their child receiving rehabilitation by Kela. Kela delivers access to intensive rehabilitation services in Finland for people whose functional capacity is severely restricted in their everyday lives (Kela 2023). To enroll in the study, voluntary participants contacted the researcher directly or parents gave approval to the therapist to give their contact information to the researcher. The study’s design is presented in Figure 5. The study’s participants are listed in Table 4 and participant distribution in interviews are given in Table 5.

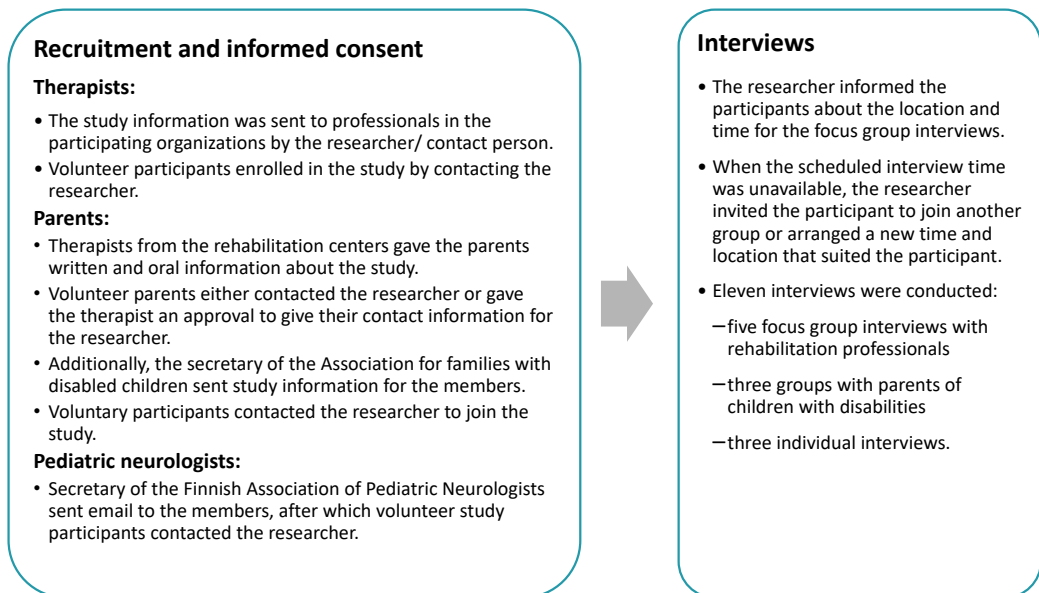


Figure 5 Study II design

Table 4 Study II participants

Participants	N (39)	Experience in rehab.	Work sector	Children's disabilities (N)	Children's ages
Physiotherapists	11	2-35 years, mean 18.9 years	Rehabilitation center (8), University hospital (3)		
Occupational therapists	9	6-16 years, mean 12.9 years	Rehabilitation center (6), University hospital (3)		
Speech therapists	3	3-25 years, mean 17.7 years	University hospital (3)		
Pediatric neurologists	7	2-28 years, mean 19.6 years	Hospital/University hospital (2), Provider of access to rehabilitation (1), Disability outpatient clinic (3), Centre for learning and consulting (1)		
Mother	8			Visual impairment and hemiplegia (1)	5-14 years,
Father	1			Cerebral palsy (5) Autism (2) Progressive neurological disorder (1)	mean 9.3 years

Table 5 Study II participants' distribution in interviews

Interviews (N= 11) / Participants (N=39)	PT	OT	ST	Mother	Father	PN
Group 1 (N=8)	4	3	1			
Group 2 (N=8)	4	3	1			
Group 3 (N=7)	3	3	1			
Group 4 (N=3)				2	1	
Group 5 (N=2)				2		
Group 6 (N=4)				4		
Group 7 (N=2)						2
Group 8 (N=2)						2
Individual interviews (N=3)						3

PT = physiotherapist, OT = occupational therapist, ST = speech therapist, PN= pediatric neurologist

4.2.3 Study III

The aim of Study III was to 1) design, 2) pilot, 3) evaluate, and 4) generate the final version of the new tool together with families and professionals through a co-development process. The aim of the tool was to enhance children's participation.

The study's design, with four phases of the co-development process, is described in Figure 6.

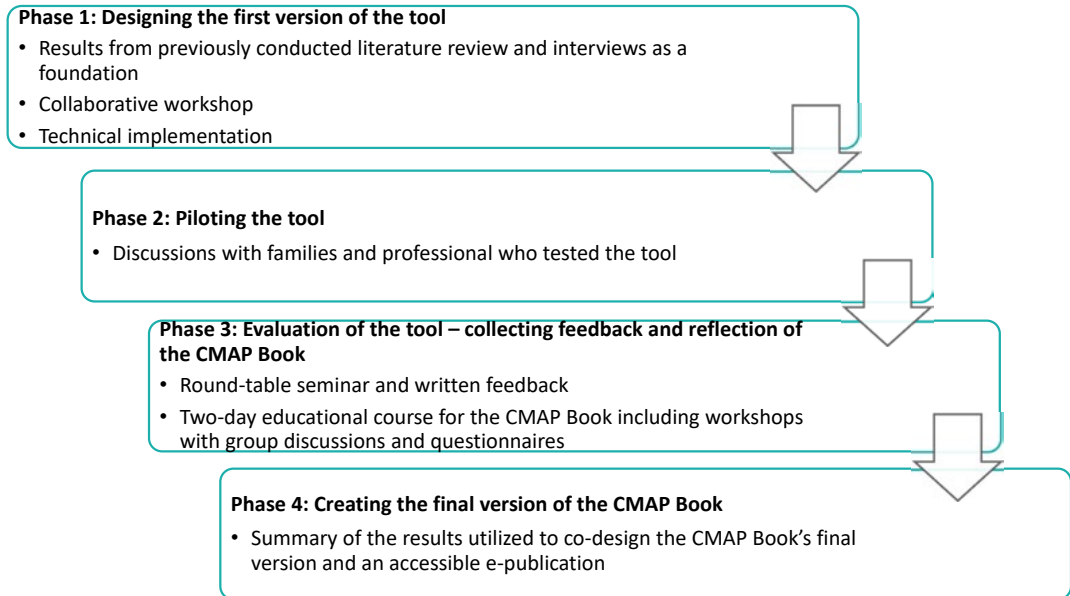


Figure 6 Study III design

This study was part of the LOOK project, and the study's participants were invited through the project's development network. The project's development network included university hospitals and three private, multi-professional rehabilitation centers that provided pediatric rehabilitation services financed by Kela. The developmental network expanded as the project progressed and as more participants expressed interest in joining the co-development process. The participants in the different phases of the co-development process reported in this dissertation study were a child with disability (n=1), parents of children with a disability and receiving rehabilitation (n=6), and rehabilitation professionals (n=328). The parents included five mothers and one father. Rehabilitation professionals were physiotherapists, occupational therapists, speech therapists, teachers/special educators, rehabilitation counsellors, nurses, pediatric neurologists, and other professionals working in pediatric rehabilitation. In total, during the multi-phased and iterative co-development process, there were 334 instances of participation in various forms, some of which involved the same participants (See Table 8, page 55). In other words, the lists of participants were not compared at different stages of the process to ensure that the count reflects unique individuals; rather, the total count indicates instances of participation through the different types of involvement in the co-development process.

4.3 Data collection

4.3.1 Study I

In Study I, the data was collected through functional interviews with children based on photographs (See Table 6). Photo-elicitation interviews (Einarsdottir 2005; McCloy et al. 2016) with children were held individually. Photography combined with individual interviews was chosen because it has been proven to be useful when identifying and analyzing children’s perspectives (Schiller & Einarsdottir 2009); this method enabled the active participation of children with functional limitations. The individual interviews with children included activities of their choice, such as play and drawing, to help the children feel comfortable and express their thoughts freely (Cameron 2006).

Table 6 Overall description of data in Study I

Study	Data collection	Number of participants	Description of material
Study I	Photo-elicitation interviews with children	N=9	Interview duration: 22–53 minutes (mean 38.4 min)
			Transcribed interview data in total: 89 pages (Times New Roman, font size 12, line spacing 1)

The location for the interview and whether the child wanted to be alone with the researcher or have their parent present was decided by the children along with their parents. Interviews were conducted mostly in the children’s homes (8/9), and one interview was conducted in a gymnasium at Metropolia University of Applied Sciences. In two interviews, the child’s parent was present and supported the child in expressing their views through pictures or sign language.

A semi-structured interview was guided by themes formulated based on the literature. The interview questions focused on the children’s photographed participation and what was meaningful for them in the participation type in question. The researcher aimed to support the child’s self-expression through sensitive and child-centered interactions, deepening the conversation with questions about topics the child raised.

4.3.2 Study II

To describe the practices for promoting a child’s best interests in pediatric rehabilitation, focus group interviews were designed to generate multifaceted discussion and knowledge construction among participants (Barbour 2007, 30–31; Krueger & Casey 2009: 1–6; Kvale 2007: 72). Previously, focus groups

have been successfully used in rehabilitation research to facilitate the creation of multifaceted understanding of multidisciplinary rehabilitation (for example, Jeglinsky et al. 2012; Øien et al. 2010; Sipari 2008).

In this study, the researcher facilitated the discussion and interaction between the group members, encouraged everyone to take part, and moderated conversations in line with the interview's themes (Barbour 2007: 32–33; Wilkinson 2004). The interview's themes were constructed based on the literature to obtain deeper insights into participants' perceptions on the practices for promoting children's best interests in rehabilitation. The themes were 1) child's agency and participation, 2) child, family and professional collaboration, and 3) realization of the child's best interests in practice. The conversations did not proceed in a predetermined order but were shaped by the views expressed by the participants. The interviews did not aim to reach consensus between the participants nor to compare the differences between groups but to gain multifaceted perspectives into the study phenomenon (Barbour 2007: 30–31; Kvale 2007: 72).

In total, eleven interviews were conducted in Study II (see Table 7). All the interviews were held in a private environment with no disturbances, enabling confidential discussion.

Table 7 Overall description of data in Study II

Study	Data collection	Number of participants	Description of material
Study II	Eleven interviews with parents and professionals	N=39	Interview duration: 79–129 minutes (mean time 106.7 min) Transcribed interview data in total: 379 pages (font Calibri, font size 12, line spacing 1.5).

4.3.3 Study III

The data collection in Study III followed the multiphase process of co-developing the tool enhancing children's participation (Table 8). In the study's first phase, a first version of the new tool was designed. As a foundation for the design, we utilized results from a literature review (Vänskä et al. 2016), interviews with children with disabilities (n=6), three focus group interviews with multidisciplinary rehabilitation professionals (n=23), one focus group interview with parents (n=3), and one future workshop with a parent (n=1) and professionals (n=7) (Sipari et al. 2017a).

The summarized results from the first co-development phase were presented in a collaborative workshop with rehabilitation professionals and parents of children with disabilities. The workshop utilized collective idea-sharing and

small group discussions, where participants were encouraged to engage in conversation on what the main task of the new tool would be, what the necessary features of the tool are, and how it could be used in rehabilitation. The audio-recorded discussions and small groups' written memos served as data.

In the second phase of the co-development process, four families piloted the new tool by following the draft of instructions for using the tool and describing the child's meaningful activities and participation in everyday life using the tool. Then, participants were asked to provide verbal feedback on the use of the tool, its benefits, the clarity of the instructions, and areas for improvement.

In the third phase of development, data was collected through written feedback from participants at the roundtable seminar with the project's development partners, where the new tool was introduced. The results were utilized for creating the final version of the tool and planning an educational course for rehabilitation professionals. Next, we evaluated the tool by collecting feedback and reflections from professionals taking part in the educational course. We used two questionnaires consisting of statements with five-point Likert scale, open-ended questions, and open feedback opportunities. During the educational course, we also collected data through group discussions with written memos. The questionnaires and discussions focused on exploring the participants' views on the use of the tool and the benefits and challenges of using it in rehabilitation. The second educational day's questionnaire also addressed participants' feedback regarding the usefulness and learning experiences of the training as well as open-ended feedback about the tool.

Table 8 Overall description of data in Study III

Phase of the study	Data collection	Number of participants	Description of participants
1. Designing the first version of the tool	Foundation for the design based on prior research: Literature review's results (reported in Vänskä et al. 2016)		
	Study results based on interviews with children with disabilities, parents, and professionals and a future workshop with parents and professionals (reported in Sipari et al. 2017a). Overall participants (n=40) in Sipari et al. (2017a) not included in this dissertation.		
	Collaborative workshop	N=30	5 OT, 14 PT, 2 ST, 1 PN, 6 other experts and 2 parents (1 mother/ 1 father)
2. Piloting the tool	Feedback discussion after four pilots with families	N=5	3 parents (3 mothers), 1 child with disability (10 years, boy) and 1 PT
3. Evaluation of the tool	Roundtable seminar, written feedback	N=20	9 OT, 9 PT, 1 nurse, 1 parent (father)
	Educational course day 1: four group discussions	N=110	51 OT, 20 PT, 18 ST, 3 nurses, 3 teachers/ special educators, 2 rehabilitation counsellors, 13 did not notify their occupation
	Educational course day 1: questionnaire	N=98	
	Educational course day 2: seven group discussions	N=37	25 OT, 6 PT, 4 ST, 2 did not notify their occupation
	Educational course day 2: questionnaire	N=34	

PT = physiotherapist, OT = occupational therapist,
ST = speech therapist, PN= pediatric neurologist

4.4 Data analysis

In Study I and II, the transcribed interview data was analyzed through inductive content analysis (Elo & Kyngäs 2008; Graneheim & Lundman 2004; Miles et al. 2020: 61–99). Inductive refers to the data-driven nature of research and means that the logic of reasoning in the analysis progresses from the individual to the more general. Thus, through inductive content analysis, we moved from empirical data towards a more conceptual interpretation of the phenomenon under study. (Miles et al. 2020: 61–99.) Since this dissertation’s central study phenomenon, “enhancing participation for children with disabilities,” had remained unaddressed in previous studies, especially from children’s perspective and existing understanding was fragmented (Kyngäs 2020b), inductive content analysis was especially suited for this study’s aim.

During the analysis process, we used a table to compile, organize, and display the data related to the research question. The analysis table helped structure the progress of the analysis step by step. The steps of the analysis are illustrated in Figure 7.

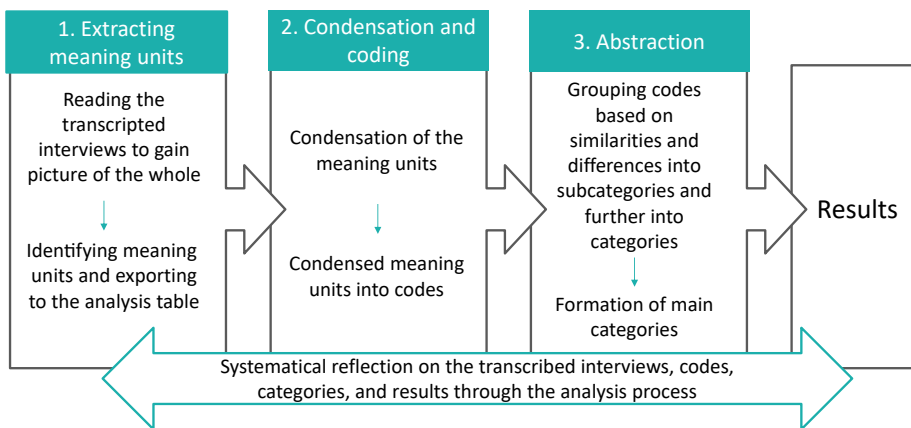


Figure 7 The inductive content analysis process (Elo & Kyngäs 2008; Graneheim & Lundman 2004)

In the first step of the analysis, the transcribed interviews were read through to gain a picture of the whole. The sections corresponding to the research question were marked in the material with a pen. Meaning units, consisting of words, phrases, or sentences that answered the study question, were identified. These meaning units were copied to the analysis tables’ left column. We were careful to consider the content and discussion in which the meaning unit was produced to ensure a correct interpretation. The analysis then proceeded by using the analysis table.

Second, the meaning units were condensed in the second column in the analysis table. The condensed meaning units were written close to the original text and then labelled with a code in the third column. “Codes” in this study refer to labels or “simplified expressions” that briefly describe the core content of the condensed meaning units related to the research question. The codes were then used to help with the identification and grouping of meaning units with similar content. (Miles et al. 2020: 62–64.) Since the amount of transcribed data was large, especially in Study II, we found it useful to mark the initial codes in different colors. The colors helped identify, compare, and group meaning units with the same core content.

Third, the next step of the analysis was the creation of categories through abstraction. This was done by grouping the codes based on similarities and differences into subcategories. Thus, subcategories included codes (with condensed meaning units and original meaning units from the transcribed interview text) that shared a commonality. An effort was made to keep the wording in the subcategories as close as possible to the transcribed text, condensed meaning units, and codes in order to preserve their concreteness and original meaning without adding the researcher’s interpretation. After the creation of subcategories, the analysis proceeded into creation of categories again, comparing the differences and similarities between the subcategories. Some subcategories did not merge with other subcategories but remained at the subcategory level. After the construction of categories, the main categories were formed, which described the research phenomenon at a more abstract level but were still faithful to the original data. Appendix 2 contains an example of the inductive content analysis process, progressing from left to right, in Study I.

The data in Study III was analyzed using content analysis (Elo & Kyngäs 2008) in the different phases of the study process (see Table 8). The data was collected in a multiphase process and was versatile in nature. Thus, not all data was analyzed using a table in a step-by-step process; instead, and an agile and iterative approach was used to guide the process of developing the tool forward. The results of the data analysis were often taken to the next meeting with the co-developer partners, as a basis for the discussion and the co-planning of the next steps. Data in Study III also included questionnaires with statements with five-point Likert scale and open-ended questions and feedback. During the analysis phase, the averages of the statements were calculated and the written responses were analyzed using content analysis.

4.5 Ethical considerations

Ethical issues were considered in all aspects and throughout the conducting of the research. The research followed the guidelines for responsible conduct of research (RCR guidelines 2012; TENK, 2019) at every step in the research process. This thesis was conducted as part of the LOOK (Right of the Child to Participate in Rehabilitation, Assessing the Child's Best Interest) project (2015–2017). Three rehabilitation centers and university hospitals took part in the LOOK project and provided the required permissions for the study.

The Ethics Committee of Universities of Applied Sciences in Helsinki metropolitan area approved Study I and Study II. Study III used results from interviews conducted as part of data collection during Study I and Study II. After this baseline data, the co-development process proceeded with collaborative workshops and piloting of the tool. Study III did not require an approval from the Ethics Committee because no sensitive data were collected and participants were volunteer partners in developing the new tool, not subjects in the study. All participation in this study was based on informed consent. Voluntary consent was obtained from both the guardian and then the child after providing written and oral information (TENK 2019).

5 RESULTS

5.1 Meaningful participation for children with disabilities (Study I)

The participation types that children perceived meaningful in everyday life included recreational activities and play, which enabled them freedom and engagement with family members or friends. Meaningful participation types were also tasks and responsibilities that the children wanted to take care of independently. The participation types and activities that children described are depicted in Figure 8.

Doing sports and physical activities	Creative play and activities	Tasks and responsibilities	Other informal leisure activities
<ul style="list-style-type: none">– Climbing and swinging (4)– Swimming and playing in the water (3)– Cycling (2)– Horseback riding (2)– Running, playing tag (2)– Football (1)– Parkour (1)– Skateboarding (1)– Trampoline (1)– Wheelchair basketball (1)– Sliding down a slope (1)– Ice hockey (1)	<ul style="list-style-type: none">– Imaginative activities with different kinds of toys or games (9)– Drawing and coloring (3)– Building robots, Lego objects, and castles (2)– Singing and acting (1)– Playing a musical instrument (1)– Playing/using an electronic device (2)	<ul style="list-style-type: none">– Going to school independently (1)– Learning to walk without falling at the family's cabin (1)– Doing stretches (1)– Doing homework (1)– Climbing stairs (1)– Watering own plant (1)	<ul style="list-style-type: none">– Eating (3)– Baking/cooking with parents or friends (2)– Visiting interesting/memorable places with family members or friends (2)– Hanging out and fooling around with family members or friends (2)– Watching TV / videos (1)– Reading (1)

Figure 8 Participation types and the number of children that named the activity as meaningful (Study I, Vänskä et al. 2020; reproduced with permission from the publisher)

The results encompassed four main elements that described meaningful participation for children: enjoyment, social involvement, autonomy, and capability. The results and the interactive elements of meaningful participation are depicted in Figure 9.

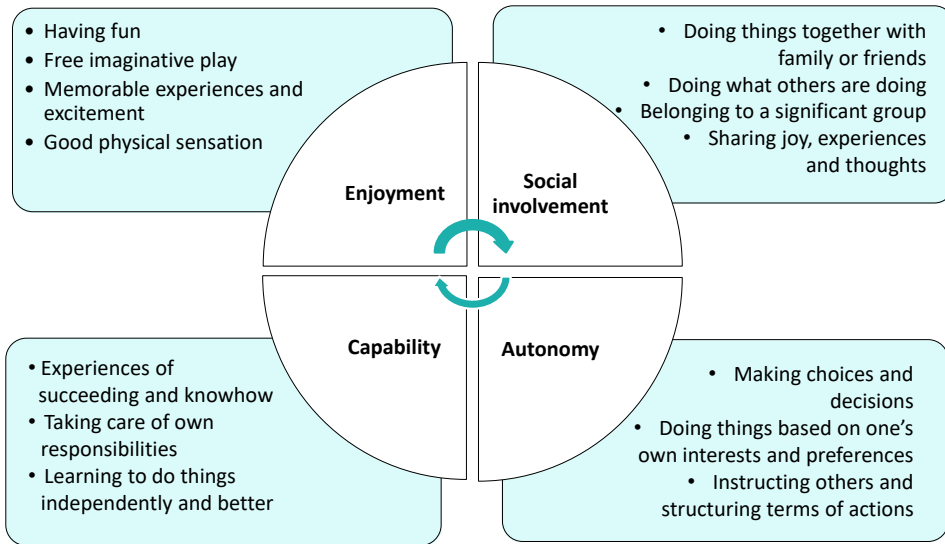


Figure 9 Elements in meaningful participation for children with disabilities (Study I, Vänskä et al. 2020; reproduced with permission from the publisher)

Children value enjoyable participation that enables them to have fun, use their imagination in play, have memorable experiences, and dare to do something exciting. Enjoyment also stemmed from good physical sensations within the environment, such as swimming in warm water, eating a treat, or being able to sit if tired. Meaningful participation included social involvement, which enabled children to do things with their family and/or friends and promoted children to feel included in a significant group, such as football team. For children, it was important to be able to join activities that the others were doing. Sharing joy and experiences with friends and having someone who wanted to listen to what they had to say were valued elements for children within meaningful participation.

Autonomy represented an element in participation that allowed children to have an influence on the activity and way of participating in the activity. Being able to choose, make decisions about, and determine the forms and ways of doing things based on their own interests and preferences was important for the children. Some children also wanted to be able to command what others did in the activity and they wanted to create and impact the terms of actions and participation situations.

Meaningful participation involved children's feeling of capability. Capability was reinforced by the experience of winning or succeeding in the activity and through having the skills and/or know-how to manage oneself in the activity context, such as knowing the rules of the game or what is appropriate and expected behavior in certain situations. Children felt it was important to develop their skills and know-how. Some children said that they were not interested in

learning or developing skills but enjoyed concentrating on interesting activities and relaxing by watching TV, for example. The factors that limited and supported children's participation were often opposite each other in the results (Figure 10).

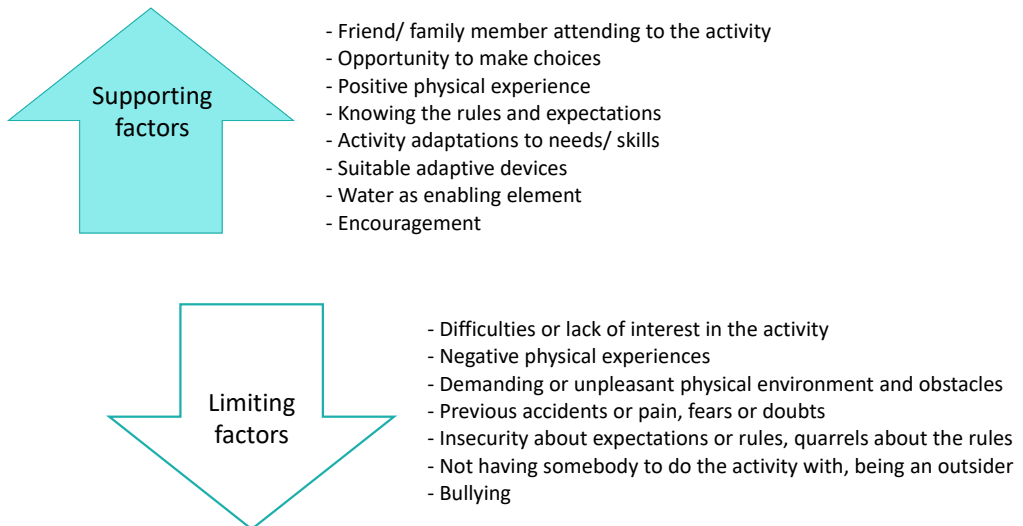


Figure 10 Supporting and limiting factors for participation from the children's perspective (Study I, Vänskä et al. 2020; reproduced with permission from the publisher)

Enjoyable emotional and physical sensations, such as feeling confident about taking part in the activity and warmth, promoted participation. Children's opportunities to make choices supported their participation. Water, and especially warm water, was described as an element that enabled children to do movements that they were not able to do on dry land.

Limiting factors for participation were difficulties the children experienced in the activity or not being interested in the activity. Environments with unpleasant features, such as cold, smell, or loud noises, were off-putting for children. Previous negative experiences, feelings of insecurity and fear towards the activity, activity setting, or other participants in the activity limited children's desire to take part. Not having someone to do the activity with, the feeling of being an outsider or being bullied were also limiting factors for participation.

5.2 Practices for promoting a child’s best interests in pediatric rehabilitation (Study II)

Three main themes described the practices for promoting a child’s best interests in pediatric rehabilitation from the perspectives of professionals and parents. Figure 11 presents the study’s core findings.

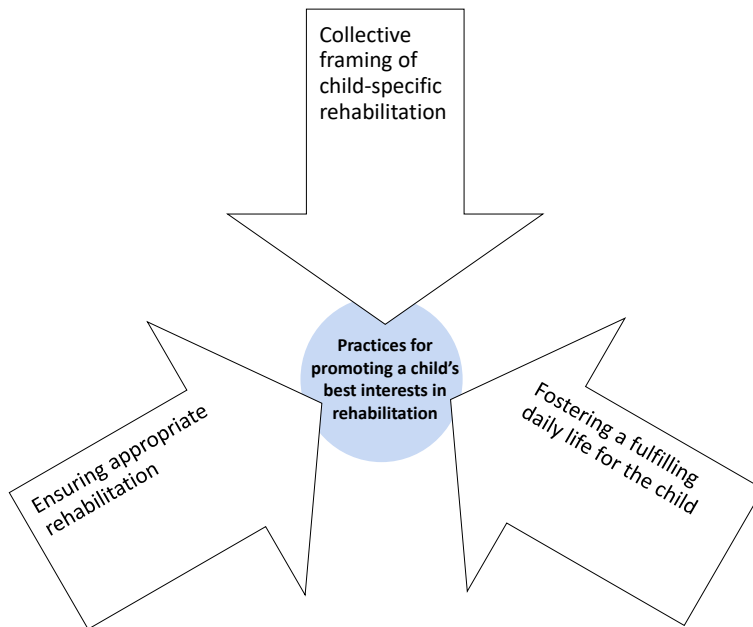


Figure 11 The core practices for promoting a child’s best interests in rehabilitation (Study II, Vänskä et al. 2024; reproduced with permission from the publisher)

The study’s results highlight the importance of family–professional partnership for promoting a child’s best interests. *Collective framing of child-specific rehabilitation* included four core practices: I) Defining an overall picture of rehabilitation needs and preferences, II) reaching a shared understanding of the child’s overall rehabilitation, III) building an empowering partnership, and IV) creating a safe space for the child’s involvement in rehabilitation planning.

The collective framing of children’s rehabilitation is based on an individual assessment. To identify the needs and preferences of the child and family, a multiprofessional assessment of a child’s functioning, wellbeing, and development was carried out. The assessment included identifying risk factors and problems in daily life, combining experience- and evidence-based knowledge, and exploring and including a child’s individual perspectives. To create a shared understanding of a child’s rehabilitation, it was necessary to negotiate and balance different perspectives and deliberate over what was in the best interests of the child.

The negotiation of a shared understanding was challenged by the number of people involved, the differing priorities and perspectives of professionals and family members, the various needs of the child and the family, as well as cultural differences. The results underline the need for unifying goals between different stakeholders in a child's developmental environment and making a comprehensive rehabilitation plan for the child. This was, however, described as challenging and uncommon in practice due to barriers in collaboration between education and social and healthcare professionals (e.g., lack of time resources and varying professional guidelines and practices). A comprehensive rehabilitation plan could secure a child's best interests, as it would better consider the child's and family's everyday needs, resources, and strengths and avoid multiple simultaneous and overlapping goals and plans for the child.

Collective framing of child-specific rehabilitation encompassed building an empowering partnership between child, family members, and professionals. Empowering partnership was built through practices that supported parents' active role and acknowledged their needs but also supported empowerment of the whole family. Trust and continuance in family-professional relationships were found to be important. Empowering partnership included practices that helped families in practical matters, such as arranging the required help and support network, providing everyday guidance with reliable and need-specific information, and learning to help the child together; however, it also included supporting the child and family members in dealing with and accepting disability and envisioning an empowering future. Promoting a child's positive and realistic self-perception and focusing on learning, strengths, and solutions was a desired approach to build empowering partnerships.

The practices for promoting a child's best interests, with a focus on the child's participation, establish an emphasis on creating a safe place for child's participation in rehabilitation planning. This includes respect for a child's personality and individuality, sensitive interaction, understandable information, enough time, and individual adaptations that enable the child to attend and influence encounters with professionals. Children's participation was described as resulting from learning when adults utilize practices that enable a child to learn how to take part in rehabilitation planning. At the same time, protecting a child from negative encounters and problem-based discussions were needed because of the usual negative focus on the child's restrictions and problems prevalent in discussions between families and professionals as well as in the child's daily life. The results highlight that the child's involvement in rehabilitation planning varied greatly, depending on professionals' practices, adults' know-how, and the child's age and functioning/abilities. The need to develop practices from a child's point of view was emphasized.

The determination of children's best interests in rehabilitation included *fostering a fulfilling daily life for the child*, which constituted two core practices: 1)

Building a participatory learning environment in everyday life and II) enhancing a child's functioning and meaningful daily life through the course of life. To build a participatory learning environment in a child's everyday life, focusing on participation outcomes in real-life contexts was needed. The participants emphasized the need to protect and advocate for child's participation rights and to ensure that the child's special needs were acted upon in daily life. Building a participatory learning environment included integrating rehabilitation into daily-life actions and building a rehabilitative network that collaboratively created solutions to support the child's possibilities for learning and participation, for example, in the child's school or daycare environment.

Targeting to modify environmental supporters and barriers for participation as well as supporting a child's social involvement and friendship-building was deemed important yet challenging. Collaboration across organizational and sectoral boundaries was described as particularly challenging; for example, rehabilitation efforts in schools. Although the importance of focusing on a child's participation opportunities in everyday life was acknowledged, the results show a lack of tools, joint practices, and clear responsibility for collaborative promotion of the child's participation in daily-life situations.

Promoting a child's best interests included practices that enhanced child's functioning and meaningful daily life through the course of life. The life-course perspective in discussion means balancing the needs in childhood and anticipating adulthood. Special attention is required for securing the child's abilities and future possibilities for happiness, independence, meaningful social relationships, support network, and involvement in the community. To attain this goal, the importance of a child's communication and interaction skills were underlined. The period of adolescence and transition into adulthood needed attention, with options to deal with the special issues concerning, for example, self-care, independence, disability, and identity.

The third theme for promoting child's best interests was *ensuring appropriate rehabilitation*, which included three core practices: I) Managing beneficial rehabilitation process, II) safeguarding equity and quality in rehabilitation, and III) objectively assessing the child's best interests.

It was in the child's best interests that the rehabilitation process is beneficial for the child. To this end, it was important to ensure a goal-directed rehabilitation process, arrange effective therapy sessions, and motivating rehabilitation. Realistic and meaningful rehabilitation goals should be identified and established together with the child and family. There was a strong need to tailor need-based rehabilitation with more flexibility. To determine rehabilitation according to the child's best interests, assessing benefits and possible disadvantages of rehabilitation also needed special attention. The results indicate that rehabilitation may exhaust the child or hinder participation in other activities,

such as hobbies or learning situations, if the overall approach and the scheduling of therapies are not carefully considered.

Ensuring impartial access to rehabilitation was important to safeguard equity and quality in rehabilitation. Many parents established the need to fight for their child's best interests in rehabilitation. The participants identified the risk for inequity resulting from varying professional practices, professional and parent resources, and structures in different settings that influenced the provision of rehabilitation. The practices for determination a child's best interests were unclear and confusing, with no common understanding or guidelines. Consequently, the need for know-how and equal practices for promoting the child's best interests and participation-focused practices was emphasized. Participants stated that the quality of rehabilitation based on the child's best interests could be enhanced through better possibilities for multiprofessional collaboration and knowledge exchange. Some professionals established the need for an objective assessment of a child's best interests to make decisions about the child's rehabilitation that were not emotionally influenced and biased.

5.3 Tool for enhancing children's participation in rehabilitation and daily life (Study III)

In Study III, we 1) designed, 2) piloted, 3) evaluated, and 4) generated the final version of the new tool to enhance a child's participation together with families and professionals. The results answer a study question: What kind of tool promotes children's participation in collaborative rehabilitation?

In the first phase of the co-developmental process, the collaborative workshop resulted in the definition of the purpose of the tool, criteria of the tool's main elements, and description of the tool's use in rehabilitation. The findings highlighted the importance of the tool to enable identification of children's perspectives as the starting point for rehabilitation planning, enabling children to prepare in meetings with professionals, and attaching the plans and collaborative implementation of rehabilitation more concretely to the child's and family's daily life. Also, the key themes and sample questions were developed to support the description of children's meaningful activities and participation in everyday life. Based on the results, the first version of the tool was drafted to be used with a digital application.

In the second phase, the children, parents, and professionals piloted the tool. They described the tool's benefits and usefulness and what aspects were especially important in using the tool in rehabilitation. The results in the pilot testing phase highlighted the importance of the strength-based and individual approach and of using the tool in collaboration. Based on the results, the tool's instructions for use were refined and shortened. Also, pictorial questions for

children were added to the instructions to make usability better for children that used pictures to communicate.

The evaluation results from the third phase of the co-development process, similar to those from the previous phases, highlighted that the use of the tool enhances the consideration of matters that are important to the child in rehabilitation. The use of the tool also reinforced the identification of the child's individual needs for meaningful participation in everyday life. All the mean values of the statements in the questionnaires from day 1 of the educational course (n=98) showed that the participants "agreed" or "strongly agreed" that the tool is useful in pediatric rehabilitation to enhance children's participation. The results indicated that the benefits of using the new tool extend beyond the child; both parents and professionals reported that the co-developed tool fosters collaboration among various stakeholders and concretizes and integrates rehabilitation into the daily lives of the child and their family. The challenges mentioned by participants, such as the need for sufficient know-how to use the tool, were considered when finalizing the tool's instructions.

In the fourth and final phase of the co-developmental process, an openly available e-publication of the new tool was created. To enhance the applicability and accessibility of the e-publication, videos, pictures, and user experiences were added to the text. Also, grammatical modifications and developments to the layout were made and instructions concerning data protection and ethical considerations were included.

As an outcome of the co-developmental process, a tool called the CMAP Book (Children's Meaningful Activities and Participation in rehabilitation) was produced. The CMAP Book is a digital and accommodating tool that can be used in children's rehabilitation, based on a child's and family's needs and preferences. The CMAP Book enables the identification and description of meaningful activities, participation, and environmental factors in daily life for the child with videos, photos, pictures, recording, and writing. The description includes the identification of supporters and barriers for participation from a child's perspective.

Creating a description with a CMAP Book is based on child-driven dialogue, which is supported by questions about activities and participation in everyday life that are meaningful for the child. The questions and prompts are constructed to cover the component of activities and participation, the supporters and barriers in the environment in the ICF classification (WHO 2001), and the modalities of human agency (Jyrkämä 2007). The CMAP Book utilizes the Book Creator application, but it can be used by any other means suitable for the child and family. An electronic publication of the CMAP Book contains the idea, theoretical background, and instructions with videos and examples on how to use the CMAP Book in rehabilitation (Sipari et al. 2017). An example section in the CMAP

Book, describing what is important from a child's perspective in everyday life, is illustrated in Figure 12.



Figure 12 Example of a page in the CMAP Book described by 6-year-old child (permission to publish from the child and parent, child not included in the research)

Based on the results, the description of a child's perspective with the CMAP Book helps the child, family, and professionals build a partnership that is based on a shared understanding of the child's meaningful participation in everyday life, individual needs, hopes and aspirations as well as factors promoting or hindering the child's participation. The CMAP Book can be used in identification of needs and strengths, collaborative goal setting and action planning for rehabilitation goals. The use of the CMAP Book can follow the child's rehabilitation process in terms of monitoring the child's learning and development and reaching their rehabilitation goals. The CMAP Book is used in family–professional partnership with the child as an agent.

5.4 Summary of the study results: enhancing children's participation

The results of the three sub-studies describe elements that enhance the participation of children with disabilities in pediatric rehabilitation from the perspectives of the child, parents, and professionals. A concrete tool, the CMAP Book (description of a Child's Meaningful Activities and Participation), is provided that can be used in family–professional collaboration with the child as an active participant. The main findings of the three sub-studies are summarized in Figure 13.

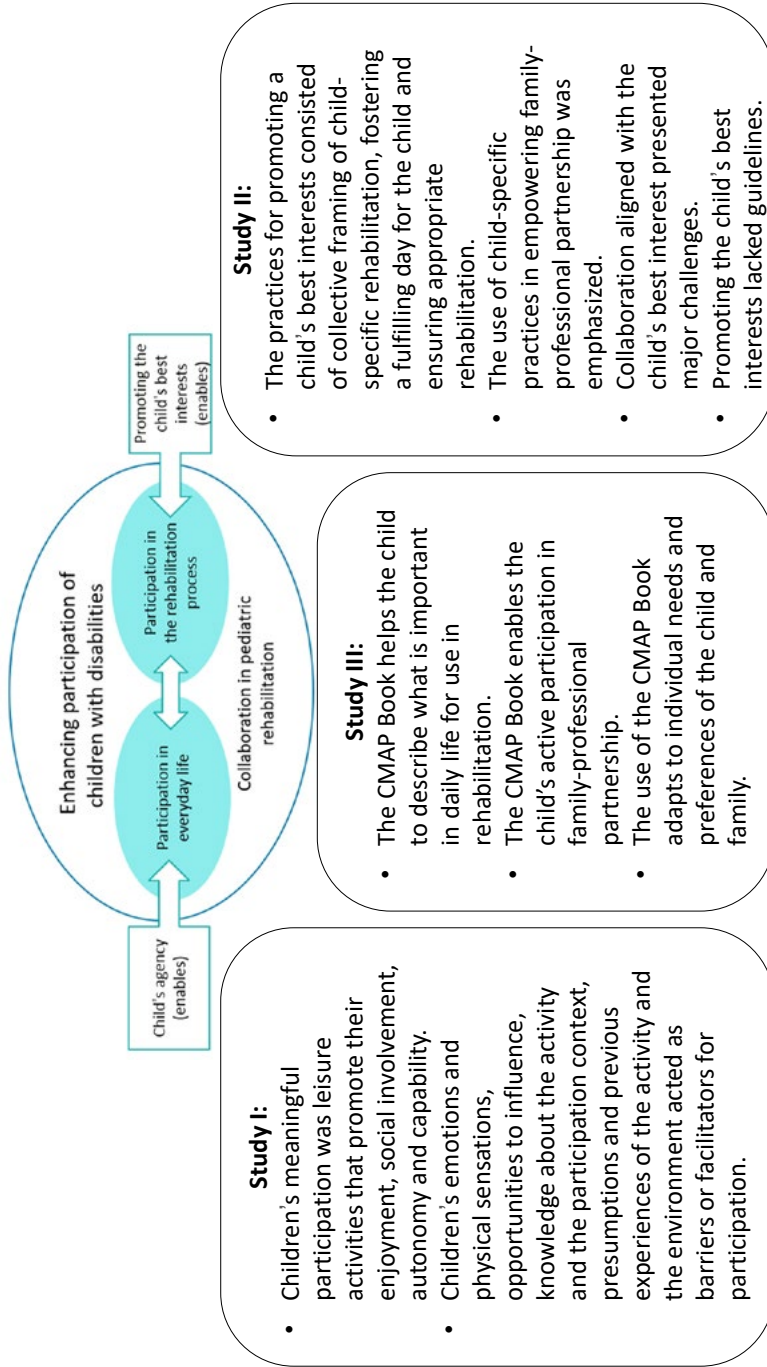


Figure 13 The main results of the three sub-studies: enhancing children's participation in pediatric rehabilitation

Based on Study I, identifying the factors contributing to meaningful participation from a child's perspective is central to enhancing children's participation in rehabilitation. The findings showed that children's emotions and physical sensations, opportunities to have influence, knowledge about the activity and the participation context, assumptions, and previous experiences all influence their decisions and motivation to participate. Meaningful participation enabled children to be active in making choices and influencing how, when, and with whom they participate in the preferred activity. Besides autonomy, meaningful participation facilitated enjoyment, social involvement with family or friends, and experiences of capability for the children. The results of Study I indicate that children's unique perspectives of barriers and facilitators for participation are important to identify and utilize in rehabilitation to enhance children's participation.

Study II's findings showed that enhancing children's participation in rehabilitation, in line with the child's best interests, is based on collective framing of rehabilitation, responding to a child's individual needs and preferences, construction of a participatory environment, and negotiating a comprehensive view of rehabilitation integrated in the child's and family's daily life. According to the results, a shared framework and practice guidelines for promoting a child's best interests in family-professional collaboration and know-how of child-specific practices are needed to ensure the realization of a child's right to participation.

The results from Study III demonstrate that enhancing a child's participation benefits from the use of strength-based and child-specific practices and tools, such as the CMAP Book. The CMAP Book enables active participation in family-professional partnership in rehabilitation, which is based on identification of the child's meaningful participation, individual needs, wishes, and aspirations in daily life as well as barriers and facilitators for participation from the child's perspective.

6 DISCUSSION

6.1 Theoretical and practical implications

6.1.1 Interactive and interwoven elements enhancing children's participation

This dissertation study aimed to describe the elements enhancing participation of children with disabilities in pediatric rehabilitation with three sub-studies. The results of the sub-studies underline the importance of child-specific practices and empowering family-professional partnership for enhancing children's participation in rehabilitation. According to the results, it was central that enhancing children's participation was related and adapted to the needs and resources of the individual child and family in their daily life. The starting point for enhancing children's participation was acknowledging and embracing children as a subject with unique views and turning attention to what constitutes meaningful participation from the child's perspective in their daily life.

This dissertation found that elements enhancing children's participation are realized in the interaction between the child and the environment and interwoven in the collaborative rehabilitation process. Four key elements are underlined from the dissertation's findings and are discussed in more detail in the next chapters:

1. Identifying and embracing a child's meaningful participation
2. Creating and applying child-specific practices in collaboration
3. Collaborative building of a child's opportunities for participation and an inclusive daily life environment
4. Co-construction of a comprehensive view of a child's rehabilitation in accordance with the child's best interests

6.1.2 Identifying and embracing a child's meaningful participation

The findings in this thesis from all sub-studies underlined that enhancing a child's participation needed acknowledgement of a child's unique views towards meaningful participation and exploring what is important for the child in their everyday life. According to the results (Study I, II, III), identification of a child's unique views requires avoiding assumptions about the typical needs of children led by, for example, presumptions based on the child's diagnosis. From the perspective of attaining children's rights and planning rehabilitation in accordance with a child's best interests, this emphasis on individuality is crucial (Krutzinna 2022) and underlined in the framework of ICF (WHO, 2007) and in the recommended evidence-based practices in pediatric rehabilitation (Novak

et al. 2021). The results of this thesis point out, however, that several factors challenge the consideration of a child's individual perspectives in rehabilitation and limit the implementation of participation-focused rehabilitation in practice. Nevertheless, the results also highlight practices that, when utilized, enhance children's participation and the best interests of the child and support the acknowledgement of the child's individuality.

The findings of this thesis contribute to existing research that identification of a child's views alongside with parents and professionals is essential to certify that participation-focused activities are meaningful, motivating, and contextually relevant (Simpson et al. 2022). This argument was strongly supported by this thesis's results in Study I, II, and III. In Study I, the children stated their desire to determine the ways and means of participating, when and how to participate, and with whom themselves. Further, in Study I and in line with Kanagasabai et al. (2018a), the child's preferences, physical and emotional experiences, and previous understandings influence their motivation towards participation. Notably, Study I found that a child's participation could be hindered by factors such as uncertainty about the rules of a game or in a swimming hall. Identifying these barriers from the child's perspective is crucial, as they could be relatively easy to resolve by providing clear and understandable information to children and translating instructions that may seem obvious to adults into a format that is accessible and comprehensible to the child.

Meaningful participation for children in Study I consisted of enjoyable leisure activities that enabled them to experience autonomy, social involvement, and capability. As in the results of Study I, the freedom to make and influence decisions (Kanagasabai et al. 2018a; Powrie et al. 2015; Willis et al. 2017), the opportunity to feel capable, learn, and develop (Kanagasabai et al. 2018a), having fun and enjoying activities (Heah et al. 2007; Kanagasabai et al. 2018a; Powrie et al. 2015; Willis et al. 2017), and feeling valued as a member of the group or community (Powrie et al. 2015; Willis et al. 2017) were important elements for children in their preferred activities. In Vinblad et al.'s (2019) study, similar elements (children's experience of feeling involved, feeling independent, and working in partnership) enabled children's empowerment in rehabilitation. In the work by Ryan and Deci (2000), similar elements—autonomy, relatedness, and competence—formed the basics of the self-determination theory. The connection between the self-determination theory and satisfactory participation from children's perspective was also noted by Coussens et al. (2020). Thus, the findings from Study I and previous studies indicate that meaningful participation fosters self-determination and enjoyment and that emphasizing these aspects when enhancing children's participation within the activity setting could enhance the appeal of the activity and boost the child's motivation to take part. Moreover, experiencing self-determination in life has been linked to increased quality of

life (Lachapelle et al. 2005), more favorable outcomes in school and adulthood, and greater satisfaction (Wehmeyer 2020).

In a study by Kallinen et al. (2021) on Finnish children's perceptions of factors promoting well-being in daily life, children embraced having the opportunity to actively engage and influence their own living environment. The key factors promoting well-being in daily life—the establishment of safety, feeling heard and understood, having opportunities for knowledge and decision-making, and active participation and agency (Kallinen et al. 2021)—resemble the elements found to enhance meaningful participation in Study I. Thus, the key elements of meaningful participation found in Study I have been confirmed as being critical from children's perspectives in many different studies and may be valid regardless of context.

It is worth noting that meaningful participation in this dissertation refers to participation that holds a special and positive value to the child. Thus, it makes sense that the results in Study I highlighted the importance of enjoyment. It can be argued, however, that participation may not always require positive emotions. Further, the results in Study I highlighted the social dimension of meaningful participation; that is, the feeling of belonging to a community was important to the children. However, meaningful participation also included activities that children could do by themselves, such as drawing or tasks they felt responsible for. Thus, meaningful participation does not always require the presence of other people. According to the results in Study I, all four elements related to meaningful participation did not need to be present all the time and in every activity. Instead, their significance varied depending on the child's preferences in the moment, activity, situation, and context.

An interesting finding from Study I is that none of the children described rehabilitation situations or encounters with professionals as meaningful participation but focused on leisure and participation with peers and family members. Accordingly, an important question revolves around what participation in children's everyday lives is valued and from whose perspective. According to Study II, rehabilitation may not always be planned and implemented in a way and in surroundings that supports the child's engagement. Adults also tend to focus their attention on participation in institutional contexts, such as school, and on skill development. They establish goals for more formal daily life activities and capabilities, whereas children focus their goals on enjoyable activities, independence, and social participation (Costa et al. 2017). If a child's perspectives are not identified and acknowledged, these differences in priorities result in the risk of the children's preferences being overshadowed by the adults' priorities for rehabilitation (O'Connor et al. 2021).

Disregarding the child's perspective may also lead to the disappearance of the overall picture—what ultimately matters in a child's everyday life and holistic wellbeing and development. For example, goals related to children's participation

in leisure and community-based activities are rarely set in rehabilitation (Anaby et al. 2016; Graham et al. 2020), in spite of the fact that children with disabilities experience loneliness, bullying, exclusion, and limited social contact with peers, especially outside of school (Woodgate et al. 2020). Correspondingly, the results in Study I demonstrated that children experience bullying, being an outsider, and not having someone to participate with, restricting their participation. According to Kwan et al.'s (2020) scoping review on the effects of social isolation and loneliness in children with neurodevelopmental disabilities, social exclusion and loneliness may have consequences on children's mental health, learning, and socio-emotional and behavioral development. Further, Kiuru et al. (2024) found that loneliness and being excluded by others (ostracism) exposes a child to a range of developmental risks. Thus, loneliness and social exclusion represent a significant risk for a child's overall development and wellbeing, underlining the need to focus on the matter in pediatric rehabilitation.

The importance of a child's opportunities for social involvement in everyday life was underlined from children's perspective in Study I, and its significance was further emphasized by parents and professionals in Study II. Study II's results showed that rehabilitation in the best interests of the child aims to build participatory daily life that promotes a child's opportunities for meaningful social interaction, friendship building, and sense of belonging. These findings are amplified by previous research. In a study by Melbøe and Ytterhus (2016), youth with intellectual disabilities highlighted the importance of belonging to a group and engaging in activities like their peers and family members. Similarly, the feeling of belonging in social interaction (Bernard et al. 2024) and being there where things happen with peers was stressed as being important by adolescents (Asbjørnslett & Hemmingsson 2008). Even though the importance of the issue has been outlined from various viewpoints, the results from Study II indicate that this emphasis on social involvement is not yet sufficiently recognized in rehabilitation. Considering the research findings in this thesis and in previous research, there is a need to focus rehabilitation interventions on children's participation in their everyday life to enable building friendships and enhance a child's opportunities for experiencing a sense of belonging in social communities (Kwan et al. 2020; Woodgate et al. 2020). To this end, it is essential to identify the relationships and communities in everyday life that are meaningful to the child and where and with whom a child wishes to experience the involvement.

According to the findings in this dissertation study, children's meaningful participation should permeate all aspects of rehabilitation. Based on the results (Study II and III), enhancing a child's participation is not a one-time event but a cross-cutting principle in the systemic and comprehensive rehabilitation process enabling child's agency. Thus, children's meaningful participation must not only be identified but also continuously upheld and embraced in all phases and interactions of their rehabilitation.

6.1.3 Creating and applying child-specific practices in collaboration

According to the results from Study II, a child's active role in family–professional partnership faced many barriers, as also noted in previous studies on rehabilitation (O'Connor et al. 2021; Teleman et al. 2021). In light of the findings (Study I, II, and III), child-specific practices are needed for creating opportunities for children to meaningfully engage in family–professional partnership through the rehabilitation process. As indicated by the results (Study I, II and III), child-specific practices are characterized by solutions and situations that are:

- collaboratively created and applied in a real-life context to meet the needs and preferences of the specific child,
- based on sensitive, accessible, and supportive interaction with child's own communication methods,
- accommodating to the child's pace, abilities, and interests in a safe environment for participation, and
- focused on meaningful participation of the child in their everyday life.

In line with this dissertation study's results, many prior studies have emphasized that children's opportunities for participation and influencing their own matters in healthcare situations are either enabled or hindered by the interaction between children and adults, depending on the quality and characteristics of the participation situation and context (Coyne & Gallagher 2011; Davies et al. 2024c; Davison et al. 2021; Teleman et al. 2021). This finding highlights the responsibility of adults to co-create participation opportunities in interaction with children and apply practices individually in an environment that is jointly accommodated to meet the child's needs.

According to the results in Study II and previous research (Franklin & Sloper 2009; Teleman et al. 2021), many factors related to the organization's operational practices and constraints of the rehabilitation professionals—such as limited time to address the needs of individual children—hindered the implementation of practices that align with the child's best interests and facilitate their participation. Based on the findings of this thesis and prior research (Anaby et al. 2022; Quaye et al. 2021, Särkikangas 2020), enhancing child participation also requires changes in organizational-level structures that guide professional practices.

The results in Study II showed the need to build a safe participatory environment to protect children from negative and problem-oriented discussion in rehabilitation meetings. Karlsson (2020) critiques that adult-centeredness is visible in how discussions revolve around problems, children's shortcomings, impairments, and needs. In practice, prior studies have demonstrated the need to consider the child's age and developmental level and create a balance between children's protection and participation rights and parents' needs (Paul 2007)

when determining which topics are discussed only between family caregivers and professionals. This approach aims to protect the child from unnecessary stress (Garth et al. 2009) and to ensure that some matters are addressed efficiently (Teleman et al. 2021). Also in Study II, parents and professionals called for honest and open discussion about diagnoses, needs, and difficulties in daily life. Accordingly, it is important to agree upon the best ways to approach and handle delicate matters in rehabilitation and respect the individual preferences of the child and family within the family–professional partnership.

Recent studies have called for a more empowering and strength-based approach in planning children’s rehabilitation (Kronsell et al. 2021) and focusing more on identifying solutions and future possibilities than on the child’s problems and impairments (Rosenbaum & Gorter 2012). This was also underlined in Study II. It is noteworthy that the children in Study I focused on their capabilities and possibilities for participation and rarely mentioned their functional limitations. To have successful rehabilitation for a child, rehabilitation shouldn’t feel like an obligation or an attempt to “fix” something about them (Rosenbaum & Gorter 2012). Instead, as the study’s results (Study I, II, III) underline, rehabilitation should be integrated into meaningful everyday activities, approached as fun, beneficial and useful, and a part of the child’s and family’s daily life, learning, and routines (as in Sipari et al. 2017a; Sipari 2008).

Based on the study’s findings and previous research, a child-specific approach in rehabilitation would identify and enable the child’s individual preferences and ways to participate (Study I, II, III), take into account their age, abilities, and developmental maturity (Study II; Pollari 2019), view the child’s participation and engagement in decision-making as an evolving learning process (Study II), support the child to engage and take responsibility in collaboration (Ehrich et al. 2015), and enable them to practice their agency (Coyne et al. 2016; Gorter & Gibson 2015). In creating and applying child-specific practices, along with the child’s and family members’ expertise and experiences, integrating diverse expertise in collaboration can promote a more multifaceted understanding and practical solutions (Styczen et al. 2024). For example, in pediatric rehabilitation, a developmental psychologist could provide important expertise to ensure that the practices and approaches align with the child’s cognitive and emotional abilities and processing of information that develops with the child’s maturity.

The findings of Study II support the need to focus on strengthening knowledge of practices for promoting a child’s best interests, which in this study was focused on the child’s right to participate. Also, prior research has found challenges and lack of expertise relating to realizing children’s rights to participate in healthcare encounters to promote their best interests (Davies et al., 2024a; Franklin & Sloper 2009; Sahlberg et al. 2020). Georgousopoulou et al. (2023) investigated pediatric healthcare providers’ degree of knowledge and practices regarding children’s rights; they found that 54% of the participants were

unaware of the contents in UNCRC (1989). For children’s rights to be secured in pediatric rehabilitation, professionals must be aware of the rights that belong to children, understand their significance, and know-how to implement them in practice (Georgousopoulou et al. 2023; Picton-Howell 2023). Accordingly, in the future, information on the responsibilities of professionals to secure a child’s best interests in family–professional collaboration should be implemented on different levels of studies regarding professionals and training of staff working with children. This need has also been underlined in the National Child Strategy (Finnish Government 2022).

Study III provides a concrete tool that is based on child-specific use in dialogue with children. The CMAP Book can be utilized in family–professional collaboration with the child as an active participant. According to the results from Study III, the CMAP Book provides children a feasible tool to express what is important in their daily life and to engage in rehabilitation planning. The CMAP Book could be described as a dialogue-based tool that helps structure, visualize, and utilize information generated by the child in family–professional collaboration. The results suggest that the CMAP Book may be applicable throughout the rehabilitation process, starting from identifying a child’s meaningful participation to steering the focus of rehabilitation towards the participation outcomes (Figure 14).

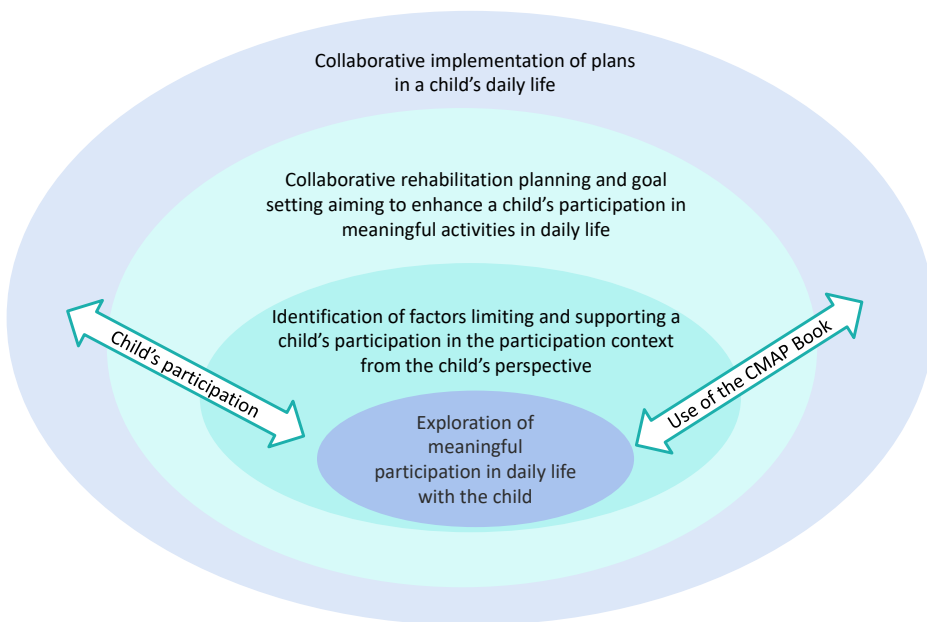


Figure 14 Enhancing meaningful participation with the child as an active participant throughout the rehabilitation process

Based on the findings in Study III, it appears that a strength-based use of the tool together with parents and professionals empowers the child and supports the co-designing of rehabilitation. Also, the results from Study I and III add to the knowledge that provision of various ways to express and concretize what is important to children, such as in the CMAP Book with photos, recordings, drawings, and videos, helps children's involvement in rehabilitation planning, identification of goals, and discussion with adults. These findings are supported by previous studies that suggest the use of accessible methods, alternative communication means, and strategies—such as pictorial support and easy-to-read texts to enable children's views to be heard—to gain information and influence matters relating to themselves (Thunber et al. 2022). Also, more creative and playful approaches to fully actualize children's participation opportunities are required in rehabilitation (Malone & Hartung 2009).

The guidelines of using the CMAP Book contain ethical considerations that need to be considered when using the tool in rehabilitation (Sipari et al. 2017b). It appears that the usability and feasibility of the tool is ultimately dependent on how the tool is used in a way that suits the situation, resources, and preferences of the family and the child and on their terms in rehabilitation. Thus, enhancing children's participation with the use of the CMAP Book is not just about the tool and its features but how the use of the tool is individually enabled, adapted, and applied within reciprocal, accessible, and supportive interactions with the child.

Based on the findings of Study III, families wish support from professionals in initiating the use of the CMAP Book. Some families, however, were proactive and introduced the tool to their child's rehabilitation professionals themselves. Thus, families are unique in this respect too. It is worth noting that most professionals that took part in developing the CMAP Book were physiotherapists and occupational therapists. Thus, the tool may be more easily applicable in their professional role in multidisciplinary pediatric rehabilitation than to other professional roles that were not as involved in the co-development of the tool. Moreover, in practice, the same challenges (such as busy work schedules and adult-centered practices) that limit the professionals' opportunities to build a shared understanding with the child and family (Study II; Davison et al. 2021; Teleman et al. 2021) may limit the child-specific use of the CMAP Book in family-professional collaboration. Study III shows that the use of the CMAP Book could guide professionals to prioritize the use of time resources and develop a revised orientation towards the planning and implementation of rehabilitation. However, this change toward a more child-specific rehabilitation may necessitate a meso-level transformation in the professionals' organizational culture, fostering more child- and family-oriented ways of working.

It is noteworthy that the CMAP Book tool belongs first and foremost to the child, not to the adults. This approach reverses the conventional adult-driven practices in rehabilitation, shifting the focus towards promoting the ownership

of the rehabilitation process to the child. Instead of merely asking how a child can be better engaged in rehabilitation or therapy interventions, the tool encourages collaboratively considering how rehabilitation can be better integrated into meaningful participation in the child's everyday life.

6.1.4 Collaborative building of a child's opportunities for participation and an inclusive daily life environment

The study's results (Study II and III) reinforced the idea that enhancing a child's participation in rehabilitation is a collaborative process of reciprocal learning, joint knowledge-building, and creating solutions for participation in a child's daily life. In Study II, enhancing children's participation in rehabilitation in line with the child's best interests included building a participatory learning environment in the child's everyday life. This was initiated by assessing a child's participation in real-life situations and through establishing participation goals.

Although there was awareness of the importance of participation, participation goals were not necessarily prioritized, as has also been shown by other studies in Finland (Sipari et al. 2019) and elsewhere (Anaby et al. 2016; Graham et al. 2020; Ryan et al. 2025). Setting goals related to participation cannot be established based on professionals' knowledge because participation goals build upon the child's and parents' knowledge of the child's involvement in daily life. Accordingly, when establishing participation goals, key knowledge and power shifts to the family. Research shows that rehabilitation professionals are often knowledgeable about the need for participation-focused practices, but the change in practice is slow and resources and know-how on practicalities may be lacking (Anaby et al. 2016). Coussens et al.'s (2022) study of professionals' views demonstrated that the resources and know-how available do not match with the needs for enhancing children's participation in daily life in practice. Similarly, in a study by Kolehmainen et al. (2020) in the United Kingdom, the researchers found that only in 37/122 children's cases, participation outcomes were a target of the intervention; in 16/122 cases, the child and/or parent were involved in setting participation outcomes; and in 24/122 cases, the progress towards participation outcomes was measured.

These findings from previous research and results of Study II reveal a contradiction between the still-prevalent professional-led practices and organizational structures that continue to steer the focus of rehabilitation towards a child's impairments. The novel approach places emphasis on participation-focused practices (Anaby et al. 2022), viewing the children as owners of their own rights (Streuli et al. 2011), and the understanding of the biopsychosocial model of disability that underlines the need to modify environmental factors to meet the child's needs (WHO 2007). In practice, this contradiction between the previous and more novel approach is challenging (Study II). To promote

change in pediatric rehabilitation towards focus on participation, Anaby et al. (2022) produced a participation-focused knowledge translation (P-KT) roadmap that describes an evidence-based, collaborative, and multi-level framework with guiding principles and strategies to support the uptake of participation-focused innovations.

According to the results from Study I, II, and III, enhancing children's participation requires the identification of barriers and supporters for participation and modifying the participatory context to meet the child's needs. Study I showed that the participation barriers in the participation context from the child's perspective may be somewhat surprising from the adults' perspective. For example, children described that a weird smell or not knowing the rules guiding actions in the new setting, such as in a swimming hall, acted as barriers for participation. Therefore, participation-assessment methods should be enhanced by considering factors that are relevant to the child within the context of participation.

Along with this study, previous studies have also stressed the importance of building an inclusive environment (Anaby et al. 2014; Anaby et al. 2022; Piškur et al. 2017) and stated that environmental factors should be assessed more systematically concerning children's current or future participation restrictions (van der Kemp et al. 2022). Study II showed that parents and professionals were aware of the influence of environmental factors promoting and hindering the child's participation in everyday life, but the systematic assessment and influence of those factors were missing or there were challenges in their practical implementation. Further, Study II demonstrates that efforts to enhance children's participation in daily life were significantly limited by unclear responsibilities, a lack of resources, and inadequate collaboration, which is consistent with earlier findings (Coussens et al. 2022; Phoenix et al. 2020; Piškur et al. 2017; Salminen et al. 2024). Especially in Study II, collaboration to enhance children's participation in educational setting was described as puzzling by parents and rehabilitation professionals, as the diverging priorities and practices between the systems became more pronounced.

Although collaborative goal setting is considered a key practice in successful rehabilitation (Costa et al. 2017; Pritchard-Wiart & Phelan, 2018; Pritchard-Wiart et al. 2022), and previous studies have emphasized the importance of collaboration across organizational boundaries to integrate rehabilitation in a child's daily life based on individual needs and goals (Kinnunen 2021; Sipari 2008), little attention has been paid in research to the way in which a goal-oriented network that might include several professionals and service providers across different organizations can be coordinated and facilitated. Study II shows that children may have many simultaneous rehabilitation goals and plans as well as education goals and plans. For example, according to Study II's results, one child may have over 10 simultaneous rehabilitation goals for different ongoing

therapies. Without collaboration within the child's rehabilitation network, these goals and their achievement may lack a sustainable foundation. Additionally, uncoordinated goal setting and planning practices in rehabilitation can place a burden on families, consume time, and lead to inefficient use of resources.

Study II suggests a need for placing greater emphasis on building a collaborative process for achieving and prioritizing a child's rehabilitation goals for participation, with active engagement of stakeholders in the participation context (Ullenhag et al. 2024). Tools, such as The Ecological Assessment of Activity and Participation (Palisano et al. 2012) and Pathways and Resources for Engagement and Participation (PREP) (Anaby et al., 2018), have been developed in recent years to support the uptake of a collaborative rehabilitation process to attain children's participation outcomes.

This study's findings (II, III) support the shift from a multidisciplinary approach and detached interventions by different disciplines into a transdisciplinary model of partnership (Boyer & Thompson 2014; Sipari et al. 2022). In a transdisciplinary model for rehabilitation, collaboration is based on joint assessment and practices in context, capacity-building of stakeholders in the child's daily life, a holistic view of the child's and family's needs, and shared understanding instead of organizing rehabilitation based on organizational and professional boundaries and expertise (Castro-Kemp & Samuels 2022; Coussens et al. 2022). One example of a novel transdisciplinary model in rehabilitation is the partnering for change (P4C) model developed by Missiuna et al. (2015). The aim of the P4C model is to establish a school environment that supports all children's participation through capacity building, collaboration, and coaching in context with the school as the client. In the model, occupational therapists focus on relationship building and knowledge translation in partnership with families and educators. (Missiuna et al. 2012; Missiuna et al. 2015.) Campbell et al.'s (2016) study in the Canadian context demonstrated a positive impact of the P4C model on school participation among all children, with and without special needs. Also, the implementation of the model has been shown to be feasible in the European context, such as in Sweden (Yngve et al. 2024) and the Netherlands (Meuser et al. 2022).

6.1.5 Co-construction of a comprehensive view of a child's rehabilitation in accordance with the child's best interests

According to the results in this thesis (Study I, II, III), co-construction of a comprehensive view of a child's rehabilitation according to a child's best interests is needed. Based on Study II, creating a comprehensive view requires expertise and experiences to be combined from multifaceted perspectives—children, parents, professionals in rehabilitation, education, and leisure—and in interaction with the specific circumstances of a child's developmental

environment. New knowledge was learned and constructed together during the child's rehabilitation. This result unveils an intriguing perspective and a new research focus on collaborative learning and joint capacity building among stakeholders through the child's rehabilitation process integrated in everyday life situations and contexts.

Study II's findings underlined the importance of collaboration at every step of a child's rehabilitation process. However, partially opposing viewpoints also emerged in the results, for example, about decision-making authority and a need for objectivity of professionals in assessing a child's best interests. Consequently, these findings reveal somewhat contradictory perspectives and priorities among the different stakeholders. The findings in Study II reinforce the previous understanding that ensuring a child's best interests is challenging and involves multiple competing interests and pressures that may be difficult to negotiate (Birchley et al. 2022). Notably, professionals in Study II were uncertain about how to address conflicts and differing perspectives or how to engage children in family-professional discussions.

The results in this study demonstrate that building rehabilitation in line with the best interests of the child through partnership requires special collaboration competences in building empowering child-family-professional partnerships. The importance of empowering partnerships (Kronsell et al. 2021; Phoenix et al. 2020; Reeder & Morris 2021), supportive relationships between child and professional (Antoniadou et al. 2024; Foster et al. 2022; Quaye et al. 2021), and the need for dialogue to negotiate the possibly differing preferences of children and parents (Nap-van der Vlist et al. 2021) have been demonstrated in previous research. Accordingly, Salminen et al. (2024) suggest that professionals need collaborative competencies and skills to create shared understanding and dialogic interactions. In Study II, collaborative and reciprocal exploring, learning, and negotiation together supported family-professional partnership building. Further, based on Study II's findings, an empowering relationship between children, parents, and professionals requires a conscious commitment to negotiating a shared understanding of the child's best interests and promoting children's and parents' possibilities to engage through the rehabilitation process.

To the best of our knowledge, Study II was the first study to explore the practices for promoting a child's best interests in pediatric rehabilitation. The study's findings enhanced the understanding of how children's best interests are promoted in the multidisciplinary rehabilitation process, which includes collaboration between system-levels. Alarming, the results from Study II indicate that limited time and collaboration, varying practices of different stakeholders, and the lack of a shared framework led to the dismissal of the child's best interests and a disregard of the child's perspective when determining and implementing children's rehabilitation. The lack of focus on children's participation in rehabilitation is problematic both from the children's

rights perspective as well as owing to aspects concerning the quality, ethics, and outcomes of rehabilitation and of education. Endorsing the principles of protection, promotion, and participation rights for children and young people is the responsibility of all healthcare professionals and guardians of children (Coyne et al. 2016; Shikako-Thomas & Shevell 2018; United Nations Human Rights Office of the High Commissioner 1989). Based on the results of study II, it can be stated that a shared framework and practice guidelines for joint determination of a child's best interests are necessary to ensure the realization of a child's right to participation.

The challenges of collaboration presented in Study II were evident on multiple levels: between children, parents, and professionals; between rehabilitation experts from different organizations and sectors, such as private and public; and between different professions, such as rehabilitation, healthcare, and education, following different guidelines and structures for practice. According to the results in Study II, the rigidity of the system and professional practices and lack of resources, know-how, and guidelines for collaboration hampered the realization of rehabilitation that would best serve a child's best interests and family's needs in daily life. Accordingly, the service provision and funding of rehabilitation in Finland have been described as fragmented and the collaboration and integration of services strenuous (Kinnunen et al. 2023; Miettinen et al. 2013; Särkikangas 2020: 196–204). Results obtained by Piškur et al. (2016), Phoenix et al. (2020), and Särkikangas (2020: 196–204) are consistent with our findings in Study II that parents indicate navigating and dealing with the complex and rigid rehabilitation system as laborious and challenging. Study II's findings reinforce prior studies presenting the need for cross-sectoral and transdisciplinary collaboration in a holistic manner, rather than addressing the child's and family's needs in a fragmented and isolated way.

Participation in rehabilitation is often discussed in literature from the perspective of individual interventions, such as a child's involvement in physiotherapy or occupational therapy. However, in a child's life, multiple activities occur simultaneously, all aimed at promoting the child's learning and functional abilities—at school, in extracurricular activities, during therapy sessions, and in daily life. Based on Study II, continuously requiring involvement and underlining efficiency with goal-oriented activities from the child as well as from their parents can become overwhelming for them and leave little room, for example, for relaxing family-time. According to Study II and prior research, the variety of therapies held in separate therapy spaces, along with the scheduling and transportation of the child, can be burdensome for families (Phoenix et al. 2020) and may even hinder the child's participation in other activities, such as hobbies. To promote effective rehabilitation, it is essential to examine the child's daily life as a whole rather than focusing solely on individual interventions to prevent it from becoming too burdensome or unmanageable, which could hinder

the well-being of both the child and their family instead of supporting it. Thus, a shift in perspective towards the child's and family's view is needed instead of a system-oriented view.

Overall, the results of Study II show a tension between the current practices, knowledge, and resources in rehabilitation and what the study results describe as elements in rehabilitation that enhance children's participation according to their best interests. In accordance with Anaby et al. (2022), the findings from this thesis emphasize the need to shift from professional-led practices towards a child-specific approach, focusing on meaningful participation from a child's perspective. In line with Granlund and Imms (2024), attention needs to be turned to viewing participation in the rehabilitation process as a means of empowering children to develop the skills and expertise necessary to define, shape, and enhance their own participation. Further, following Ullenhag et al. (2024), this study's results highlight the importance of a collaborative approach in facilitating the interactive processes of learning and change with the child, the family, and their everyday environment in a way that supports capacity building in context.

This dissertation study's results (Study I, II, III) indicate that enhancing children's participation in daily life should be actualized through a joint process that is responsive to the available resources and changing needs of the child and that anticipates the child's future. Joint determination of a child's best interests integrates the participation rights of the child within a comprehensive view of rehabilitation integrated in daily life and guides the collaborative process in accordance with the child's best interests. The synthesis of the accumulated knowledge of the multifaceted and interactive elements enhancing children's participation in pediatric rehabilitation is depicted in Figure 15.

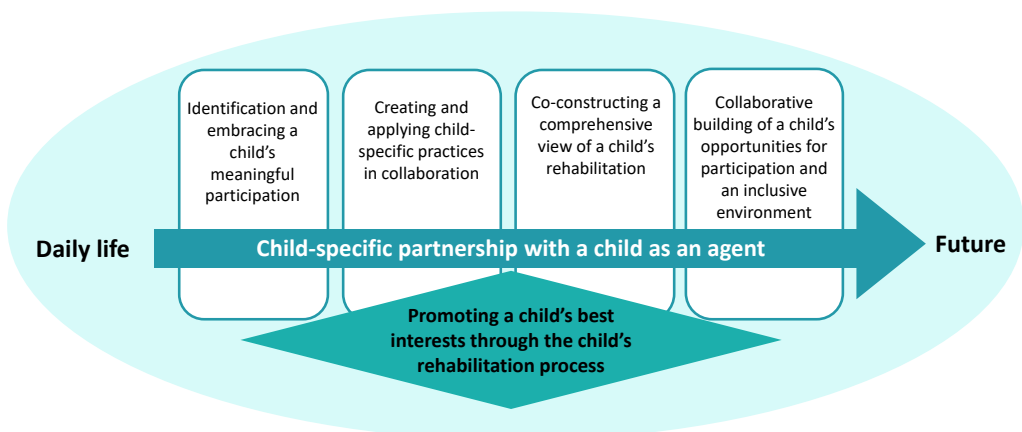


Figure 15 Elements enhancing participation of children with disabilities in pediatric rehabilitation practice in accordance with a child's best interests

The findings call for realizing children's right to participate as agents and to develop participation-focused rehabilitation in collaboration with children, families, and professionals. The findings from this dissertation crystallize into the insight that elements enhancing children's participation in pediatric rehabilitation practice are created and realized through child-specific partnership, focusing on what is important to the child in their daily life.

6.2 Methodological considerations

6.2.1 Strengths and limitations

This qualitative study shed light on the elements enhancing participation of children with disabilities in pediatric rehabilitation. First, this study's strength is that it described a multidimensional research phenomenon not just from one but from several perspectives: children, parents, and professionals. Second, the study was strengthened by the fact that the research phenomenon was not only structured theoretically but the results can also be used concretely in practice to enhance children's participation in family-professional collaboration aligned with the child's best interests. The study's findings promoted tangible benefits and changes in rehabilitation practices with a concrete co-developed tool for children, reinforcing the usefulness of the study and highlighting its relevance, thus making it worthwhile for participants to take part in this research.

The methodological approach in this qualitative study was social constructionism, wherein reality and meanings are jointly created in the interactions between persons (Guba & Lincoln 1994; Lincoln & Guba 2000). Accordingly, it is understood that research phenomenon related to human life, such as children's participation in this study, take shape and are realized through social interaction and individual experiences (Denzin & Lincoln 2000; Kyngäs 2020a). Therefore, objective truth about the study phenomenon cannot truly ever be established, and the understanding of the research phenomenon is thus always incomplete, changing, and taking shape through changes in society and participants' perspectives and meaning making over time (Lincoln et al. 2024). Accordingly, the results in this study, as with qualitative research overall, are context-specific, situational, and cannot be generalized. Although the focus in this study was not on generalizability or quantity, every observation obtained from a research phenomenon is valuable in a qualitative approach (Denzin & Lincoln 2000), and this dissertation provides new knowledge on elements enhancing children's participation that support the realization of children's participation rights and child-specific rehabilitation in practice.

This study's strength is that it unveiled the understudied perspectives of children with disabilities. Traditionally, in aiming to protect children, their

competence to engage in research has been questioned (Preston et al. 2024), especially in the case of children with disabilities (Fargas-Malet et al. 2010). The neglect of their perspectives has caused a lack of diversity in experiences and understanding of what is meaningful for the children (Njelesani et al. 2022). In this dissertation, Study I and Study III demonstrated that children are competent participants in the research process, especially if their participation is enabled through ethically sound choices and appropriate ways of participation that consider the unique needs of children (Kirk 2007). Adopting the child perspective in this dissertation research was about understanding children as active constructors of knowledge in a constantly changing relationship with the community and broader context of the phenomenon under study (Karlsson 2020). The child perspective was provided not only by the children themselves but adults in Study II and III were also encouraged to view the activities and questions in hand from the child's point of view (Sommer & Pramling-Samuelsson 2010).

In this study, the qualitative rigor of the research is assessed by utilizing the concept of trustworthiness, which is recommended as a vital concept in qualitative studies, instead of the concepts of reliability and validity (Krefting 1991; Kyngäs et al. 2020). Following the constructionism paradigm, trustworthiness entails credibility, dependability, confirmability, transferability, and authenticity (Lincoln et al. 2018). To establish credibility, the accurate description of participants and the selection of an appropriate method of data collection in line with the study's aim and phenomenon was considered carefully (Graneheim & Lundman 2004). Dependability was assured by warranting quality and consistency through the research and reporting in detail the study's processes and research methods in each sub-study, promoting the transparency of the choices made in this study, with their strengths and limitations (Kyngäs et al. 2020). To improve quality and consistency in the data-analysis phase, we used dialogue and reflection among co-researchers at every step of the process (Kyngäs et al. 2020). Confirmability of the study results was supported by careful inductive analysis and reporting findings that solely represented participants' insights into the study's questions. In this dissertation, a rich and detailed description of the study context, participants, and methods was utilized to promote transferability of the results. We fostered authenticity by presenting various citations in the reports that clearly illustrate the link between the findings and the data (Kyngäs et al. 2020). In the following sections, the choices made during the research process, along with their justifications, strengths, and weaknesses, are described in more detail.

The applicability of the research methods to the study of the phenomenon was carefully considered to fit the study questions. In line with this dissertation's philosophical perspective on research, methodological approach, and study aims, data was collected mainly through interviews. This enabled the co-construction

of knowledge via interaction and exploration of the perspectives of children, parents, and professionals. Study III also utilized workshops and questionnaires as data collection methods that produced multifaceted perspectives on the CMAP Book tool and its use in rehabilitation. In collecting this type of qualitative data using interviews and workshops, the researcher plays a particularly active role and is entangled in the quality of the research project (Kvale 1996: 147–153). The way that the researcher interacts and forms relationships with the participants, creates opportunities for expression of different views, and facilitates discussion about the phenomenon under study have an impact on the form and content of the data (Barbour 2007: 49–51; Krueger & Casey 2009: 85–88).

In this study, the researcher's previous experience in multidisciplinary rehabilitation and working as a physiotherapist with children with disabilities and their families worked as an advantage and supported the use and purposiveness of the selected study methods. For example, prior experience in conducting interviews and working within pediatric rehabilitation helped build sensitive and open interaction with the participants (Kvale 1996: 147–151), detect important topics and guide discussion deeper to enrich understanding of the phenomenon (Krueger & Casey 2009: 85–86) as well as identify many of the participants' underlying assumptions (Barbour 2007: 50). Additionally, establishing rapport and credibility with the participants (Barbour 2007: 50) and being able to ask relevant follow-up questions was enabled by experience in pediatric rehabilitation (Krueger & Casey 2009: 85–86). The researcher did not have prior relationships with the children or families involved in the study. However, she had encountered some of the professionals from previous work who voluntarily participated in the research. This may have influenced their responses or sharing of perspectives (Tong et al. 2007), but because professionals' data collection was based on focus groups, and not on individual interviews, the familiarity with few professionals in different groups is probable to only have a limited effect. The researcher strived to avoid making hasty conclusions or establishing preconceived limitations based on previous experiences without solid justification. Researcher triangulation and careful inductive analysis of the data that helped prevent biased data collection and analysis.

Kvale (1996: 105–108) states that interviewing is a craft that is learned by practicing it, which was also true in this study. Through the process, it was important to critically assess and reflect on one's actions as the researcher and facilitate participants' own thoughts without any personal presumptions (Tong et al. 2007). Although the researcher had previous experience in data collection through interviews, the practical expertise, for example, of structuring focus group discussions, moderating interactions, facilitating participants to elaborate on their perceptions about the study phenomenon, and establishing clear questions, developed through the process of the study.

In this dissertation, we took careful steps to minimize the disparity of power between the adult interviewer and the child (Einarsdóttir 2007) and between participants and the researcher (Kvale 2007: 10–22) as well as to promote participants' meaningful involvement in research. In the first sub-study, we deliberately designed the enrolment and research process to give the child as much decision-making power as possible at every stage, while remaining flexible and ensuring that we gathered the information essential for the research aim. In Study II, data collection was done through focus group interviews that were semi-structured to steer the discussion to provide knowledge in line with the research question in the time-frame available for the interview but also allow participants to elaborate freely (Barbour 2007: 74–91). In the third sub-study, the co-development process progressed collaboratively, with qualitative data collection at each stage of the process. The results of each phase were presented to the development group for review, allowing participants to influence the next steps of the process. Study III's findings support the use of a partnership-based approach not only in rehabilitation practice but also in developing rehabilitation (Sipari et al. 2023), as the children's, parents', and professionals' involvement in the co-development of the CMAP Book facilitated meaningful research findings and led to a concrete tool for enhancing children's participation.

In line with previous studies, in Study I and Study III, the use of child-centered methods, flexibility, and sensibility towards individual needs, feelings, and choices proved to be crucial in enabling children's meaningful participation in research (Clark 2006). Another strength of this study was that the research environment and operational methods supported children's free expression without any expectations or limitations on the part of the researchers. Following Karlsson (2020), who stated that the researcher needs to provide a participatory space in which the researcher enables the children to take part in research in ways that come naturally for them, the researcher in this dissertation aimed to listen and give physical space and time for the children to express themselves verbally and through actions, such as play and drawing (Cameron 2006). The photo-elicitation interviews in Study I proved to be a child-friendly means of exploring children's perspectives, concretizing the real-life participation context through photos, as presented in prior research (Einarsdóttir 2005; McCloy et al. 2016; Schiller & Einarsdóttir 2009). The data-collection method was also piloted by interviewing one child before the actual study was initiated.

To facilitate children's meaningful engagement in research, the researcher provided children the space and opportunity to guide the activities of their choice during the interview. Activities during the interviews included drawing, showing their favorite activities and skills, such as singing and swinging, showing toys, games, or other personal items, and imaginative play. In line with studies by Kanagasabai et al. (2018b) and Cameron (2006), the children's freedom to choose activities, draw, and physically demonstrate their meaningful participation

helped them communicate their thoughts, feel comfortable, and engage in the interview.

Besides flexibility and sensitivity to children's expressions, it was beneficial that the interviews mostly took place in the child's own daily environment, as the research context can impact what children discuss (Fargas-Malet et al. 2010). To gain perspectives on participation in a child's daily life, photos from daily life and interviews conducted in the child's homes were used to support what child shared about those matters. One child and their parent chose to hold the interview in the gymnasium room of the university, as the gymnasium was arranged in a way that was interesting and suitable for the child. Also, it was helpful that the children had the opportunity to prepare themselves for the interview through the photographs. The photos helped them focus on matters important to them without the researcher to steer the children's answers too much to obtain inductive data. Thus, the photos enhanced the credibility and consistency of the interpretation of children's opinions. The interviews were voice recorded and not videotaped, so some things that a child expressed only through action may have been discarded in the interview and data analysis if the researcher did not ask child to articulate the meaning of the action. Depending on the child's ability to function and communicate, it was easier for some children to express their points of view more richly than others. During the interviews, the smaller children were especially curious and played and explored the surroundings as they spoke. From time to time, their interest changed rather quickly and was focused more on playing than on discussion. Some questions were therefore repeated to make sure that the child had concentrated on the response and had brought up substantive views.

To guarantee that all the relevant perspectives were explored in the data and to ensure that the participants were appropriate for addressing the research question (Kyngäs et al. 2020), we selected the participants through purposive sampling (Holloway & Galvin 2024: 141–144). In this study, the collection of participants' background information was limited to information relevant to the study. We did not, however, collect more detailed demographic information of the participants, such as socio-economic status of the families, because this was not essential to the study phenomenon.

All participants were experts in pediatric rehabilitation either by experience or profession. The participants characterized a typical set of members of rehabilitation network of children with disabilities receiving Kela-funded rehabilitation in Finland. Diversity within the professionals taking part in the study was achieved through involving participants from different organizations representing both public and private sectors in rehabilitation and inviting two participants from each therapy discipline to take part in the group discussions (occupational, physical, and speech therapist). Some professionals also had a degree in music therapy or some other profession. Although the

participants represented different occupations, sectors, and experiences from the multidisciplinary rehabilitation, more participants from, for example, the education and social services could have made the data even more diverse. Also, it is noteworthy that the context of this study is the Finnish rehabilitation system, which limits the applicability of the results to other countries, cultures, and service systems.

The participants in this dissertation are limited in number, gender, and age, which may affect the generalizability of the results. The children in this dissertation were 5–10 years old, had different developmental, behavioral, physical, and/or motor disabilities and received rehabilitation funded by Kela. No adolescents or young people with disabilities participated in the study; therefore, the results lack their perspectives as well as the perspectives of children under 5 years old. Also, all the children were able to make themselves understood using their own means of communication. As a result, participants with greater communication-support needs are underrepresented.

Another clear limitation of this study is that, despite the effort, the number of children in this dissertation study is small (total $n=10$). Therefore, it is important to acknowledge that the results primarily reflect the adults' child perspective and children's own perspectives are limited in this study (Karlsson 2020; Sommer & Pramling-Samuelsson 2010). In Study III, only one child participated directly in the co-development of the CMAP Book, while the rest of the data was gathered with the children's parents and professionals. However, the foundation of the tool was based on interviews with six children receiving rehabilitation, as reported in Sipari et al. (2017a), which was not included in this dissertation study. Additionally, three other children voluntarily participated in the piloting phase of Study III, but owing to communication limitations, data was not collected directly with them but through the perspectives of their parents.

In this dissertation, the number of parents is also small, especially in comparison to professionals. Additionally, most of the participants representing parents in Study II and III were mothers. Hence, it may be possible that fathers of the children have different views of the study phenomenon. However, it can be argued that what is more important than gender is to recognize everyone's unique thoughts, which are not necessarily dependent on gender. Nevertheless, a limitation of this research is that very little is known from the fathers' perspective. This thesis focused to gain a multifaceted understanding of the study phenomenon and, thus, instead of the number of participants and optimal group size, the variety of different perspectives, the expertise of the participants, and the richness of the data are important factors concerning the trustworthiness of the study (Kyngäs et al. 2020). Overall, the quantity and quality of data in this dissertation study were substantial and robust.

There are many lessons to learn from how this study was conducted and what can be improved in future research endeavors. The recruitment process

for participants in this study proved to be time-consuming. The challenges of recruiting people in vulnerable positions and children with disabilities in studies has been well acknowledged (Banas et al. 2019; MacNeil et al. 2014). Enhancing recruitment channels in closer collaboration with organizations and families and allocating additional resources at this juncture of the research and during the co-development process of the CMAP Book could have been beneficial (MacNeil et al. 2024). Studies show that parents of children with disabilities experience significant burdens in daily life and struggle with time management (Särkikangas 2020) and, consequently, participating in additional activities, such as in this study, may have been too burdensome (MacNeil et al. 2024). The formulation of participation opportunities and designing the study in partnership with children, parents, and professionals from the start of the study could have mitigated barriers to participation that may not have been identified from the researchers' perspective (Sipari et al. 2023). Another issue that is noteworthy to consider is that it is possible that individuals inherently more inclined towards studying phenomena and those who prioritize the significance of children's participation may have exhibited greater enthusiasm for engagement in the study. Consequently, the research may not have captured participants with completely opposed viewpoints and experiences.

During data collection for Study I and II, flexibility in choosing interview locations was adopted to maximize participation, with the researcher traveling to locations suggested by participants for one-on-one interviews. Since the time of conducting interviews, data collection through Microsoft Teams or other forms of remote connection have been established successfully (for example, Sipari et al. 2022). In this study, remote interviews could have facilitated adults' participation and, in the future, organizing remote interviews makes sense in terms of time and resources. However, conducting children's functional interviews remotely might have been challenging, especially considering that some children needed support for communication.

In Study I, it is possible that the emphasis on leisure activities in the results reflected the context and timeframe in which the study was conducted and the photographs were taken—i.e., at home rather than in school or daycare settings and during spring, summer, and early fall, rather than in wintertime. Asking children to take photographs over a longer period and in more diverse situations and times, with support from their parents and with the required permissions, for example, from children's schools, might have resulted in a broader range of activities being represented. This approach, however, would have created more work for the families and could have increased the participation threshold.

In Study II, the size of the groups varied from two to eight due to last minute withdrawals from participation. Barbour (2007) suggests that researchers should over-recruit participants in the focus groups to avoid last-minute cancellations and a small number of participants in the groups, but we did not

do so in this study. One-on-one interviews and focus group interviews have been shown to be combined successfully (Barbour 2007: 44–45), as was the case in Study II. The interview methods were combined due to practicalities, and three individual interviews were conducted to obtain further data on the perspectives of pediatric neurologists. This proved to work to this study's advantage by enhancing the richness and value of the data. The pediatric neurologists in one-on-one interviews were highly experienced in pediatric rehabilitation, and the interviews provided in-depth insights into the study phenomenon. The role of the pediatric neurologist in a child's rehabilitation is often to be responsible for the management and planning of the whole, which is why individual interviews were a significant addition to the study material.

In focus groups, five to eight participants are often considered an optimal group size (Krueger & Casey 2009: 67–68). However, as the complexity of the topic under discussion increases, the participants' experience and passion for the subject intensifies, or the number of themes being addressed grows, it is advisable to reduce the number of participants (Krueger & Casey 2009: 67–68). Due to the broad and diverse study topic in Study II, and the aim to understand participants' perceptions, smaller groups allowed each participant the opportunity to express their views on the topic more deeply and comprehensively. Also, in Study II participants in groups of eight had less space to express their perspectives and some participants had a more active role than others. In smaller groups, the participation in discussion was more balanced and interactive between participants. Participants were given note-taking equipment, so that they could write down memos during the discussion to keep in mind issues they wanted to express, if they did not have the chance to say them right away. This promoted the richness of the discussion and ensured that, even in larger groups, no points were left unsaid, despite the potential need to wait for a turn. It should be noted that, in focus group interviews, however, group dynamics can influence the discussion (Barbour 2007: 30–32), and some participants may have refrained from expressing certain viewpoints because of the group setting.

According to Barbour (2007: 30–31), the value of focus groups lies in the richness of perspectives and interaction between participants. The researcher encouraged discussion with prompts and follow-up questions on the issues that arose from the conversation. For example, "Did I understand correctly that ...," "It emerged from the debate that ... Could you present a concrete example of how this works in practice." The researcher took notes to enable asking questions using the same concepts and wording that were originally used in the debate. After the first focus group discussions, we learned that it was useful to go through the notes with the participants to summarize the discussion and provide a comprehensive overview at the end of the discussion. At the same time, the participants could clarify or add if something important was missing. The notes were not used as data in the study, but all the discussions were recorded.

We decided to conduct focus groups in peer groups, such that parents were in one group, therapists in one, and neurologists in one group. We anticipated that peer groups would create a comfortable environment and allow participants to share their thoughts openly without power differentials (Krueger & Casey 2009: 21–23). Mixing parents and professionals might have caused some participants to feel intimidated with regard to voicing their own views. We also wanted to avoid situations in which the group would happen to have a professional and a parent with an ongoing therapy relationship that could have prevented them from openly sharing their experiences, especially negative ones. On the other hand, mixing participants could have broadened the discussion but could have caused ethical dilemmas in the sense that the relationship between parents and professionals would suffer from differences in perspectives and experiences. Barbour (2007: 30–32) underlines that participants' expressions in the focus groups are dependent upon context, interaction, and dynamics in the group. In Study II and III, the participants' feedback showed that they had found the conversation to be rich, perspective-expanding, empowering, and communal. The merit and value of the focus group discussions (Study I) and co-developmental process (Study III) for the participants was visible in the way they appreciated the opportunity to participate and hoped for similar discussions and co-development opportunities for the future as well.

In Study III, the data was versatile in nature, and we utilized data triangulation in one phase of the process to promote the study's credibility (Kyngäs et al. 2020). Different data collection means were used to evaluate the usability of the tool through conducting workshops with group discussions and collecting data with questionnaires. To reinforce trustworthiness, the logic of the data analysis through inductive content analysis was checked with researcher triangulation in the beginning of the data-analysis process. Through constant crosschecking of the original interviews, analysis, and results we ensured that the interpretations accurately represented the information that the participants provided. (Elo & Kyngäs 2008; Graneheim & Lundman 2004.) At the end of the analysis process in Study I, II, and at the final phase of data collection, Study III, we did not identify new categories and, thus, concluded that saturation of data had been reached, supporting the credibility of the research (Kyngäs et al. 2020). The analysis and main results of Study I and II were discussed with external researchers. Also, in Study I, to validate the interpretation of the data, the results were reflected upon with three children of the same age as the study participants but who did not belong to the study group. However, member checking was not completed with the original participants, which could have supported the study's credibility (Kyngäs et al. 2020).

Inductive content analysis was chosen as the analysis method in the sub-studies of this dissertation. As the topics in the sub-studies are relatively unexplored and the key was to describe the study phenomenon from the

participants' perspective without the constraints of a predefined theoretical framework during the analysis phase, a data-driven analysis was considered a suitable approach (Kyngäs 2020b). In Study II, applying deductive content analysis (Kyngäs & Kaakinen 2020) by utilizing a rehabilitation process (see Figure 2) as the theoretical framework for data collection and analysis could have yielded interesting results and described the elements of promoting a child's best interests through the different phases of a child's rehabilitation process. Choosing such a theoretical starting point for data collection and analysis would have, however, emphasized the expertise of professionals over the expertise and perspectives of the family.

The detailed description of the study's process and authentic citations from the participants were reported in the original articles to increase the transparency and trustworthiness of the analysis and results (Kyngäs 2020b). Also, to promote transparency of the analysis logic, the analysis process was described with examples of the analysis. Study II also provided a supplementary table describing the main categories, categories, and subcategories of the analysis. Miles et al. (2020: 6) argue that no qualitative research can slavishly follow a particular methodology but must apply and adapt the research methods to the particular subject and purpose. To make the application of research methods and choices in this research process evaluable by the reader, they have been described as transparently as possible. The challenge in writing qualitative research reports is to represent the results in a small number of words as faithfully as possible to the rich and multi-faceted results. For example, due to the word limit in the research articles, there were not as many quotations as we would have hoped to give the readers an opportunity to interpret the results' credibility. This challenge also applied to the description of the multi-phased Study III. The study's process with its methodological choices and justifications is, however, presented to the readers as transparently as possible to enable reasoning for how the results can be utilized and applied in other contexts.

6.2.2 Ethical considerations

As Kvale (1996: 110) indicates, even the choice of research topic constitutes an ethical decision, which in this study is well justified from the perspectives of society, communities, and individuals as well as academic and practical interests and benefits for children. The need to enhance children's participation in rehabilitation and everyday life is at the heart of this study, and the choice of topic underlines the commitment to promoting children's rights and acknowledges the equity of the child in family–professional collaboration as a foundation for good rehabilitation practice. Thus, a strength of this study was an ethically sound, justified, and “worthy topic,” which refers to the study topic's relevancy,

timeliness, significance, and interest; according to Tracy (2010), this is one marker for the quality of qualitative research.

All participation in this dissertation study was based on informed consent. Every participant was informed orally and using written material regarding the study and their rights. The researcher made sure that the participants understood their rights and what they were participating in before signing the approval. The participants had time to ask questions and consider their participation. The participants signed approval to take part in the study before the data-collection process. Two consent forms were signed, of which one remained with the study participant and the other with the researcher. Participants had the right to suspend their participation without giving a reason at any stage of the study. The study's rights, including withdrawing from the study, had no influence on the treatment of individuals or the rehabilitation services or benefits for the participants. Participation did not incur any costs for the participants, and they were not paid for it (TENK 2019). There were no interruptions in this study.

A key issue in this dissertation was exploring children's views and, thus, an important ethical issue was safeguarding their meaningful and voluntary participation in the research process (Karlsson 2020; Kirk 2007). Kirk (2007) presents that, although there are similarities in research conducted with children and adults, there are also differences that need to be considered. Therefore, children's participation in this study is presented here in more detail.

To secure a child's voluntary and meaningful participation, we paid special attention to appropriately tailored and visual, written and oral information that considers the children's ages, individual functioning, and needs. Before giving information to children and asking for their consent, approval from the child's parents was attained. Parents who agreed to their child taking part in the study were asked to pass on the study information to the child to read or the parent could read the information to the child. Study material for children used pictures and language easy enough for the children to understand. If the child was also willing to take part in the study, the parent contacted the researcher or gave a contact person in participating organization permission to give the parents' contact information to the researcher. Gaining consent both from the child's parent and from the child not only acknowledges the child's need for protection but also the child's own agency to make informed decisions. (ERIC 2024a; Harcourt & Sargeant 2012: 23–30.)

Attention to negotiating children's ongoing consent was carefully considered throughout the research process (ERIC 2024b). In Study I, children took photos with help of their parents of meaningful activities and participation in their everyday lives. Parents then sent the photos to the researcher with an explanation of what the child had meant by the photo. This step helped ensure that the photo was interpreted in a way that the child meant. Also, this step ensured that the photos were such that the parent knew what they were about and, thus,

tackled the potential challenges of the photos concerning issues of confidentiality (Fargas-Malet et al. 2010). Children had the opportunity to withdraw any photos from the study if they changed their minds about them. Before beginning data collection through interviews, the researcher explained what participation in the study entailed and asked if the child was still willing to participate. This was elaborated clearly with all participants and, especially, with the children. The child and researcher also agreed that, if the child changed their minds or wanted to stop the interview, they could just say “Ok, Nea, this is enough” or “Stop now.” One child used this option after 30 minutes of the data collection in Study I, stating “Enough with the questions, I just want to play with you now.” The ongoing negotiation of consent also included a commitment to checking the children’s willingness to participate throughout the interview and being sensitive and responsive to any negative reactions a child might have to being interviewed. Children’s participation in the interviews (Study I) was rewarded with tickets to an amusement park but, to avoid persuasion to participate in the study (ERIC 2022), the ticket was a surprise for the family and child and was sent after the interview by mail.

An important ethical issue in engaging children in research is children’s unequal power relationships with adults, stemming from adult-centeredness in society (Kirk 2007), practiced writing and verbal skills, experiences, and physical differences in size (Karlsson 2020). Thus, an effort was made throughout the research process to enable the child’s agency and to diminish the power inequity between the researcher and child. The child’s agency was enabled by supporting the child to make decisions about what to present through the photos and concentrating on research phenomena that the child was the best expert of (meaningful participation in daily life). The children decided where the interview took place along with their parents and what was done during the interview, and the child could freely discuss and decide what photos they wanted to talk more about. One child wanted to ignore a few photos as he had changed his mind about the importance of the activity presented in the photo. Responsiveness to children’s initiatives was shown in the many of the activities the children wanted to do and important things they wanted to present during the interviews.

6.3 Recommendations for future research

This thesis has extended the understanding of elements enhancing children’s participation in pediatric rehabilitation. It has also provided insights into the areas that need further investigation and development from the perspectives of the individual, community and organizations, and society.

This dissertation study’s findings indicate the need for promoting research in this area, especially from the viewpoints of children and young people. This

dissertation study involved perspectives from a small number of children, aged 5–10 years old, who were able to express themselves verbally and/or with alternative communication methods. Thus, there is a need to study meaningful participation from the perspective of young people with disabilities and of children experiencing more complex communication restrictions. Future research should also acknowledge the expertise and experiences of children and adolescents in defining, exploring, and developing meaningful participation opportunities.

In this study, enhancing children's participation was explored through a multidimensional lens: participation as a means and an end (Granlund & Imms 2024; Imms. et al. 2017) as well as a child's right (UNCRC 1989). The findings underline the importance of a child's involvement, agency, and influence over the rehabilitation process in family–professional collaboration. The findings further underscore the need to study children's participation as an outcome of the process (Granlund & Imms 2024), to identify meaningful everyday participation from children's perspective, and to identify promoting and restricting factors for participation in a child's everyday environments and in the participation context. In Finland, however, many participation-focused tools or participation measures have not been translated or implemented (Vänskä et al. 2016), and the research and adoption of validated tools should be promoted, especially within cross-sectoral and transdisciplinary collaboration.

In addition to children, participants in this study included parents and professionals. However, most of the participants representing family caregivers were mothers and only a few were fathers. Research on parental perspectives in rehabilitation has predominantly focused on the mothers' viewpoint, because they have been more active with regard to participating in these studies. Thus, more research is particularly needed from fathers' perspectives. In this study, there was also a lack of perspectives of professionals working in collaboration with rehabilitation experts and families, such as early childhood education and school staff as well as leisure program coaches and personnel, which should be addressed in future research.

Based on Study III, one strength of the CMAP Book was found to be its applicability to different situations in a child-specific way, directing attention in rehabilitation towards what constitutes meaningful participation for an individual child in their everyday life. A future step is to evaluate the usefulness of the CMAP Book for children of different age groups and with different backgrounds and needs. Another area of future research is to evaluate the use of the tool in family–professional partnership through the child's rehabilitation process and identify its potential benefits and challenges. To explore the child's individual perspective, it would be interesting to examine whether a tool similar to the CMAP Book could also serve as a data collection method in research, enabling children to participate actively and through enjoyable means. In addition, the

research findings offer insights into the co-development of new innovative tools that are owned by the child and family and whose use is grounded in an empowering partnership.

According to the results, the elements that enhance children's participation are realized in the interaction between the child and the environment. The results in this study imply that focusing on the child and the family alone is not enough to enhance the child's participation; instead, rehabilitation needs a more systemic approach to enhance participation and understand the transaction and interaction between different elements at various levels. Thus, the results of the dissertation advance the understanding of enhancing children's participation in rehabilitation toward a more systemic way of thinking. For example, the results in this dissertation described substantial challenges in child–family–professional collaboration in accordance with the child's best interests and with the individual needs of the family. These findings revealed a significant tension in current practices and silo-like implementation of rehabilitation and what was described as needed practices for promoting a child's best interests in rehabilitation. The contradiction arises from the fact that organizational structures and practices of professionals are based on a system approach that attempts to answer child-specific issues and needs through separate systems and silos. However, because the complex phenomenon of enhancing participation is systemic (Anaby et al. 2022), it calls for a more comprehensive approach that goes beyond discipline and organizational boundaries. In the future, it is important to explore what kinds of structures and practices enable a comprehensive response to the needs of the child and family as a collaborative effort across organizational silos. Another interesting study question would be to explore what the collective impacts of the participation-focused collaboration process integrated into a child's and family's everyday lives are.

Interestingly, the study's findings imply that the nature of the interaction and characteristics of collaboration have an impact on how children and family members experience and are motivated to participate in family–professional collaboration opportunities. In the future, attention should be given to the quality of collaboration and interaction between stakeholders that facilitate partnership building and promote effective participation-focused collaboration. Further, drawing on the findings in this dissertation, guidelines for participation-focused collaboration with practices to promote a child's best interests in rehabilitation are needed and should be developed in partnership with children, family members, and professionals.

Addressing the participation challenges and inequities that children with disabilities experience in their daily life is of major importance for future research and is the responsibility of the adults in children's daily life, professionals working with children as well as researchers and policy makers (Shikako-Thomas & Shevell 2018). Promoting meaningful change in practice and

exploring the complex challenges attached to the everyday lives of children call for partnership-based approaches in research (Sipari et al. 2023). Combining different perspectives, multidisciplinary expertise and experiences helps enrich the understanding of the phenomenon being studied and identify opportunities for improvement in practice and positive influences in daily lives (Morris et al. 2011). Also, from the perspective of children and their family members, they have the right to influence matters affecting them, including research (Karlsson 2020; Ketelaar et al. 2020).

Accordingly, novel research approaches underline the ethical responsibility and benefits of involving different stakeholders as equal partners at every step of the research process (Ketelaar et al. 2020; Morris et al. 2011; Preston et al. 2024; Sipari et al. 2023). Engaging children, their family members, and professionals working with children in different disciplines in rehabilitation research is enabled by participatory research partnerships (Sipari et al. 2023). The partnership-based research process has the potential to bridge the gap between research knowledge production and practice, thereby enhancing the overall impact of research within society (Sipari et al. 2023). Building partnerships based on equitable and reciprocal participation, however, demands investments and know-how in creating meaningful interaction and collaboration among different stakeholders (Nguyen et al. 2022). More knowledge on how to engage children as equal partners from the beginning to the end of the research process is needed (Morris et al. 2011; Njelesani et al. 2022).

Overall, research on the elements of enhancing children's participation in pediatric rehabilitation in accordance with a child's best interests is highly advisable in the future. A combination of children's unique perspectives, family members' experiences, and diverse professionals' expertise as well as constructing new knowledge and innovations in collaboration is needed to tackle the barriers and promote the possibilities to enhance all children's participation. The future steps in research should be taken together, in partnership with children, parents, professionals, and other stakeholders in pediatric rehabilitation.

7 CONCLUSIONS

The findings of this dissertation study present that the elements that enhance children's participation in pediatric rehabilitation practice are interactive, dynamic, and interwoven in the collaborative rehabilitation process. Based on the study's findings, the key elements enhancing children's participation in rehabilitation include 1) identifying and embracing a child's meaningful participation, 2) creating and applying child-specific practices in collaboration, 3) collaborative building of a child's opportunities for participation and an inclusive daily-life environment, and 4) co-construction of a comprehensive view of a child's rehabilitation in accordance with the child's best interests.

The findings present that a child's participation in family–professional collaboration in pediatric rehabilitation is enhanced by creating and applying child-specific practices, starting from identifying and embracing the child's unique perceptions of elements contributing to meaningful participation in daily life (Study I, II and III). From children's perspectives, the importance of identifying participation barriers and facilitators in the participation context as well as creating opportunities for leisure participation that enable children to experience enjoyment, social involvement, autonomy, and capability was underlined (Study I).

This dissertation's findings demonstrate that, at best, enhancing children's participation in rehabilitation is a collaborative process of joint knowledge-building, learning, and creating participation opportunities through constructing an inclusive everyday environment (Study I, II, III). The findings show substantial tension between the current system-controlled and professional-led practices and the child-specific practices collaboratively created and embedded in the child's everyday situations. The results reinforce the need to shift from the silo-like implementation of rehabilitation with separate interventions, plans, and goals to a co-constructed and comprehensive view of rehabilitation integrated into the child's and family's everyday life (Study II, Study III). The need for a systemic and partnership-based framework for rehabilitation with the child as an agent to enhance their participation according to the child's best interests was highlighted (Study II).

The study's results indicate that the CMAP Book is a useful tool for enhancing children's participation, enabling their agency in the collaborative rehabilitation process and shifting the focus of rehabilitation planning towards what is meaningful participation in daily life from the child's perception (Study III). The findings yielded a deeper understanding and signaled a necessary development in rehabilitation from adult-owned tools to child-owned tools. The study's findings support the use of a partnership-based approach not only in pediatric

rehabilitation but also in rehabilitation research and in developing rehabilitation practices, as the children's, parents', and professionals' involvement in this dissertation produced meaningful research findings and co-created a concrete tool for enhancing children's participation. Enhancing children's participation in pediatric rehabilitation involves having a comprehensive view of a child's rehabilitation that is created and embedded in the rehabilitation process through child-specific partnership, focusing on what is important to the child in their daily life.

REFERENCES

- Act on Early Childhood Education and Care (540/2018). Finlex, 2018. Available at: <https://finlex.fi/en/legislation/translations/2018/eng/540>
- Act on the Status and Rights of Patients (785/1992). Finlex, 1992. Available at: <https://finlex.fi/en/legislation/translations/1992/eng/785>
- Adair, B., Ullenhag, A., Keen, D., Granlund, M., & Imms, C. The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Dev Med Child Neurol*, 2015; Dec;57(12): 1093–1104.
- Allonsius, F., de Kloet, A., Bedell, G., van Markus-Doornbosch, F., Rosema, S., Meesters, J., Vliet Vlieland, T., & van der Holst, M. Participation Restrictions among Children and Young Adults with Acquired Brain Injury in a Pediatric Outpatient Rehabilitation Cohort: The Patients' and Parents' Perspective. *Int J Environ Res Public Health*, 2021; 18(4): 1625.
- An, M., & Palisano, R. J. Family-professional collaboration in pediatric rehabilitation: a practice model. *Disabil Rehabil*. 2014; 36(5): 434–440.
- An, M., Palisano, R. J., Yi, C. H., Chiarello, L. A., Dunst, C. J., & Gracely, E. J. (2017). Effects of a Collaborative Intervention Process on Parent Empowerment and Child Performance: A Randomized Controlled Trial. *Phys Occup Ther Pediatr*, 39(1): 1–15.
- Anaby, D., Avery, L., Gorter, J.W., Levin, M.F., Teplicky, R., Turner, L., Cormier, I., & Hanes, J. Improving body functions through participation in community activities among young people with physical disabilities. *Dev Med Child Neurol*, 2020; 62: 640–646.
- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disabil Rehabil*, 2013; 35(19): 1589–1598.
- Anaby, D., Khetani, M., Piskur, B., van der Holst, M., Bedell, G., Schakel, F., de Kloet, A., Simeonsson, R., & Imms, C. Towards a paradigm shift in pediatric rehabilitation: accelerating the uptake of evidence on participation into routine clinical practice. *Disabil Rehabil*, 2022; 44(9): 1746–1757.
- Anaby, D., Korner-Bitensky, N., Steven, E., Tremblay, S., Snider, L., Avery, L., & Law, M. Current Rehabilitation Practices for Children with Cerebral Palsy: Focus and Gaps. *Phys Occup Ther Pediatr*, 2016; 37(1): 1–15.
- Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M., Avery, L. & Teplicky, R. 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*, 2014; 95(5): 908–917.
- Anaby, D., Law, M., Feldman, D., Majnemer, A. and Avery, L. 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: 513–519.
- Andersen, C. S., & Dolva, A. S. Children's perspective on their right to participate in decision-making according to the United Nations Convention on the Rights of the Child article 12. *Phys Occup Ther Pediatr*, 2014; 35(3): 218–230.
- Antoniadou, M., Granlund, M., & Andersson, A. K. Strategies Used by Professionals in Pediatric Rehabilitation to Engage the Child in the Intervention Process: A Scoping Review. *Phys Occup Ther Pediatr*, 2024; 44(4): 461–488.
- Arakelyan, S., Maciver, D., Rush, R., O'Hare, A., & Forsyth, K. Community-based participation of children with and without disabilities. *Dev Med Child Neurol*, 2020; 62(4): 445–453.
- Arakelyan, S., Maciver, D., Rush, R., O'hare, A., & Forsyth, K. Family factors associated with participation of children with disabilities: a systematic review. *Dev Med Child Neurol*, 2019; 61(5): 514–522.
- Asbjørnslett, M., & Hemmingsson, H. Participation at school as experienced by teenagers with physical disabilities. *Scand J Occup Ther* 2008; 15(3): 153–161.
- Autti-Rämö, I. Kuntoutuksen vaikuttavuuden arviointi. [Assessment of the Effectiveness of Rehabilitation.] *Duodecim*, 2021; 137(13): 1369–1374. (Finnish)
- Autti-Rämö, I., Säilä, H., & Vuori, M. Lapsen kuntoutustarpeen tunnistaminen terveydenhuollossa [Identification of child's rehabilitation needs in health care.] In: Autti-Rämö, I., Salminen, A. L., Rajavaara, M., & Melkas S. (Eds.) *Kuntoutuminen*. Helsinki: Duodecim, 2022. (Finnish)
- Axelsson, A. K., Granlund, M., & Wilder, J. Engagement in family activities: A quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development. *Child Care Health Dev*, 2013; 39(4): 523–534.
- Axelsson, A. K., Imms, C., & Wilder, J. Strategies that facilitate participation in family activities of children and adolescents with profound intellectual and multiple disabilities: parents' and personal assistants' experiences. *Disabil Rehabil*, 2014; 36(25): 2169–2177.
- Banas, J. R., Magasi, S., The, K., & Victorson, D. E. Recruiting and retaining people with disabilities for qualitative health research: challenges and solutions. *Qual Health Res*, 2019; 29(7): 1056–1064.
- Barbour, R. Doing focus groups. In Flick, U. (Eds.) *The Sage Qualitative Research Kit*. London: Sage publications, 2007.
- Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y-C., Teplicky, R., Anaby, D., & Khetani, M. A. Community participation, supports, and barriers of school-age children with and without disabilities. *Arch Phys Med Rehabil*, 2013; 94(2): 315–323.
- Bekken, W. 'I want them to see that I feel normal': three children's experiences from attending consultations in paediatric rehabilitation. *Disabil Soc*, 2014; 29(5): 778–791.

- Bentzen, M., & Malmquist, L. K. Differences in participation across physical activity contexts between adolescents with and without disability over three years: a self-determination theory perspective. *Disabil Rehabil*, 2022; 44(9): 1660–1668.
- Bernard, M., Hoffmann, L., Richter, M., Völlm, C., Fink, A., & Dawal, B. Participation of adolescents with and without physical disabilities and chronic diseases: A comprehensive conceptualization. *Child Care Health Dev*, 2024; 50(2), e13240.
- Birchley, G. Deciding Together? Best Interests and Shared Decision-Making in Paediatric Intensive Care. *Health Care Anal*, 2014; 22(3): 203–222.
- Birchley, G., Thomas-Unsworth, S., Mellor, C., Baquedano, M., Ingle, S., & Fraser, J. Factors affecting decision-making in children with complex care needs: a consensus approach to develop best practice in a UK children's hospital. *BMJ paediatr open*, 2022; 6(1): e001589.
- Björck-Åkesson, E., Wilder, J., Granlund, M., Pless, M., Simeonsson, R., Adolfsson, M., Almqvist, L., Augustine, L., Klang, N., & Lillvist, A. The International Classification of Functioning, Disability and Health and the version for children and youth as a tool in child habilitation/early childhood intervention--feasibility and usefulness as a common language and frame of reference for practice. *Disabil Rehabil* 2010; 32 Suppl (1): S125–S138.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. Dimensions of Family and Professional Partnerships: Constructive Guidelines for Collaboration. *Except Child*, 2004; 70(2): 167–184.
- Bester, J. C. The best interest standard and children: clarifying a concept and responding to its critics. *J Med Ethics*, 2019; Feb45(2): 117–124.
- Brewer, K., Pollock, N., & Wright, F. V. Addressing the challenges of collaborative goal setting with children and their families. *Phys Occup Ther Pediatr*, 2014; 34(2): 138–152.
- Boyer, V. E., & Thompson, S. D. Transdisciplinary Model and Early Intervention: Building Collaborative Relationships. *Young Except Child*, 2014; 17(3): 19–32.
- Bronfenbrenner, U. *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press, 1979.
- Bronfenbrenner, U. Ekologisten järjestelmien teoria. [Ecological systems theory]. In: Vasta R. (Ed.) *Kuusi teoriaa lapsen kehityksestä [Six theories of child development.]* 4. print, originally published 1992. Tallinna: United press, 2018: 221–288. (Finnish)
- Bronfenbrenner, U., & Evans, G. W. Developmental science in the 21st century: emerging questions, theoretical models, research designs and empirical findings. *Social development*, 2000; 9(1).
- Bult, M. K., Verschuren, O., Jongmans, M. J., Lindeman, E., & Ketelaar, M. What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Res Dev Disabil*, 2011; 32(5): 1521–1529.
- Cameron, H. Asking the tough questions: a guide to ethical practices in interviewing young children. *Early child Dev Care*, 2006; 175(6): 597–610.

- Campbell-Barr, V. The Provision, Protection and Participation of Children's Rights in Professional Practice. In: Višnjić-Jevtić, A., Sadownik, A. R., & Engdahl, I. (Eds.) *Young Children in the World and Their Rights Thirty Years with the United Nations Convention on the Rights of the Child*. Cham: Springer, 2021: 221–233.
- Campbell, W., Kennedy, J., Pollock, N., & Missiuna, C. Screening children through response to intervention and dynamic performance analysis: The example of partnering for change. *Cur Dev Disord Rep*, 2016; 3(3), 200–205.
- Castro-Kemp, S., & Samuels, A. Working together: A review of cross-sector collaborative practices in provision for children with special educational needs and disabilities. *Res Dev Disabil*, 2022; 120: 104127.
- Chien, C. W., Rodger, S., Copley, J., & Skorka, K. Comparative content review of children's participation measures using the International Classification of Functioning, Disability and Health-Children and Youth. *Arch Phys Med Rehabil*, 2014; 95(1): 141–152.
- Child Welfare Act (417/2007). Finlex, 2007. Available at: <https://finlex.fi/fi/lainsaadanto/saadaskaannokset/2007/eng/417>
- Chow, A. J., Saad, A., Al-Baldawi, Z., Iverson, R., Skidmore, B., Jordan, I., Pallone, N., Smith, M., Chakraborty, P., Brehaut, J., Cohen, E., Dyack, S., Gillis, J., Goobie, S., Greenberg, C. R., Hayeems, R., Hutton, B., Inbar-Feigenberg, M., Jain-Ghai, S., Khangura, S., MacKenzie, J. J., Mitchell, J. J., Moazin, Z., Nicholls, S. G., Pender, A., Prasad, C., Schulze, A., Siriwardena, K., Sparker, R. N., Speechley, K. N., Stockler, S., Taljaard, M., Teitelbaum, M., Tradakis, Y., Van Karnebeek, C., Walia, J. S., Wilson, K., & Potter, B. K. Family-centred care interventions for children with chronic conditions: A scoping review. *Health expect*, 2024; 27(1): e13897.
- Colver, A., Thyen, U., Arnaud, C., Beckung, E., Fauconnier, J., Marcelli, M., McManus, V., Michelsen, S. I., Parkes, J., Parkinson, K., & Dickinson, H. O. Association between participation in life situations of children with cerebral palsy and their physical, social, and attitudinal environment: a cross-sectional multicenter European study. *Arch Phys Med Rehabil*, 2012; 93(12): 2154–2164.
- The Constitution of Finland (731/1999). Finlex, 1999. Available at: <https://finlex.fi/en/legislation/translations/1999/eng/731>
- Committee on the Rights of the Children. CRC/C/GC/14. General comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1). Geneva: United Nations, Convention on the Rights of the Child, 2013. Available at: https://www2.ohchr.org/English/bodies/crc/docs/GC/CRC_C_GC_14_ENG.pdf
- Committee of Rehabilitation Reform in Finland. Kuntoutuksen uudistamiskomitean ehdotukset kuntoutusjärjestelmän uudistamiseksi. [The Rehabilitation Reform Committee's Proposals for Reforming the Rehabilitation System.] Sosiaali- ja terveysministeriö. Sosiaali- ja terveysministeriön raportteja ja muistioita 2017:41. Available at: <https://julkaisut.valtioneuvosto.fi/handle/10024/160273> (Finnish)
- COPM. The Canadian Occupational Performance Measure, 2024. Available at: <https://www.thecopm.ca/> (accessed 10 November 2024).

- Costa, U. M., Brauchle, G., & Kennedy-Behr, A. Collaborative goal setting with and for children as part of therapeutic intervention. *Disabil Rehabil*, 2017; 39(16): 1589–1600.
- Coster, W., & Khetani, M. A. Measuring participation of children with disabilities: Issues and challenges. *Disabil Rehabil*, 20018; 30(8): 639–648.
- Coussens, M., Destoop, B., De Baets, S., Desoete, A., Oostra, A., Vanderstraeten, G., Van Waelvelde, H., & Van de Velde, D. A Qualitative Photo Elicitation Research Study to elicit the perception of young children with Developmental Disabilities such as ADHD and/or DCD and/or ASD on their participation. *PloS one*, 2020; 15(3): e0229538.
- Coussens, M., Maes, J., Desoete, A., Vanderstraeten, G., Van Waelvelde, H., & Van de Velde, D. Participation According to Clinicians Working with Young Children with Developmental Disabilities: A Long Way to Go. *J Autism Dev Disord*, 2022; 52(11): 4883–4896.
- Coyne, I., Amory, A., Kiernan, G., & Gibson, F. Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences. *Eur J Oncol Nurs*, 2014; 18(3): 273–280.
- Coyne, I., & Gallagher, P. Participation in communication and decision-making: children and young people's experiences in a hospital setting. *J Clin Nurs*, 2011; 20(15–16), 2334–2343.
- Coyne, I., Hallström, I., & Söderbäck, M. Reframing the focus from a family-centred to a child-centred care approach for children's healthcare. *J Child Health Care*, 2016; 20(4): 494–502.
- Coyne, I., & Harder, M. Children's participation in decision-making: balancing protection with shared decision-making using a situational perspective. *J Child Health Care*, 2011; 15(4): 312–319.
- Creswell, J. W., & Creswell, J. D. *Research design. Qualitative, quantitative and mixed method approaches*. 6th edition. Thousand Oaks: Sage publications, 2023.
- Curtis, D. J., Weber, L., Smidt, K. B., & Nørgaard, B. Do We Listen to Children's Voices in Physical and Occupational Therapy? A Scoping Review. *Phys Occup Ther Pediatr*, 2022; 42(3): 275–296.
- Cusick, A., Lannin, N. A., & Lowe, K. Adapting the Canadian Occupational Performance Measure for use in a paediatric clinical trial. *Disabil Rehabil*, 2007; 29(10): 761–766.
- Dahan-Oliel, N., Shikako-Thomas, K., & Majnemer, A. Quality of life and leisure participation in children with neurodevelopmental disabilities: A thematic analysis of the literature. *Qual Life Res*, 2012; 21(3): 427–439.
- Davies, C., Waters, D., & Fraser, J. A. Children's and young people's experiences of expressing their views and having them heard in health care: A deductive qualitative content analysis. *J Clin Nurs*, 2024c; Apr 33(4): 1506–1519.
- Davies, C., Waters, D., & Fraser, J. A. Factors that support children and young people to express their views and to have them heard in healthcare: An inductive qualitative content analysis. *J Child Health Care*, 2024b; Jun 4: 13674935241258515.

- Davies, C., Waters, D., & Fraser, J. A. Implementing Article 12 of the United Nations Convention on the Rights of the Child in health care: A scoping review. *Int J Hum Rights Healthc*, 2024a; 17(4): 378–391.
- Davison, G., Kelly, M. A., Conn, R., Thompson, A., & Dornan, T. How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis. *BMJ open*, 2021; 11(7): e054368.
- Denzin, N. K., & Lincoln, Y. S. The discipline and practice of qualitative research. In: Denzin, N. K., & Lincoln, Y. S. (Eds.) *Handbook of qualitative research*. 2nd edition. Thousand Oaks: Sage Publications inc, 2000: 1–28.
- Dimakopoulos, R., Vakalaki, T., Spinou, A., Michopoulos, I., & Papadopoulou, M. Effectiveness of therapeutic interventions on participation in children with cerebral palsy: A systematic review and meta-analysis. *Child Care Health Dev*, 2024; 50(4): e13301.
- Di Marino, E., Tremblay, S., Khetani, M., & Anaby, D. The effect of child, family and environmental factors on the participation of young children with disabilities. *Disabil Health J*, 2018; 11(1): 36–42.
- Donnelly, M., & Kilkelly, U. Child-friendly healthcare: delivering on the right to be heard. *Med L Rev*, 2011; 19(1): 27–54.
- Doyle, C., Lennox, L., & Bell, D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ open*, 2013; 3(1): e001570.
- Ehrich, J., Pettoello-Mantovani, M., Lenton, S., Damm, L., & Goldhagen, J. Participation of Children and Young People in Their Health Care: Understanding the Potential and Limitations. *J Pediatr*, 2015; 167(3): 783–784.
- Einarsdottir, J. Playschool in pictures: children's photographs as a research method. *Early Child Dev Care*, 2005; 175(6): 523–541.
- Elo, S., & Kyngäs, H. The qualitative content analysis process. *J Adv Nurs*, 2008; 62(1): 107–115.
- Engel-Yeger, B., Jarus, T., Anaby, D., & Law, M. Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *Am J Occup Ther*, 2009; 63(1): 96–104.
- ERIC, Ethical research involving children. 2024a. Informed Consent. Available at: <https://childethics.com/informed-consent/> (accessed 10 August 2024).
- ERIC, Ethical research involving children. 2024b. Process consent. Available at: <https://childethics.com/glossary/process-consent/> (accessed 10 August 2024).
- ERIC 2022. Ethical research involving children. Available at: <https://childethics.com/wp-content/uploads/2022/05/ERIC-Payment-Section-English.pdf> (accessed 10 August 2024).
- Eriksson, L., Welander, J. & Granlund, M. Participation in everyday school activities for children with and without disabilities. *J Dev Phys Disabil*, 2007; 19: 485–502.

- Fargas-Malet, M., McSherry, D., Larkin, E., & Robinson, C. Research with children: methodological issues and innovative techniques. *J Early Child Res*, 2010; 8(2): 175–192.
- Fauconnier, J., Dickinson, H. O., Beckung, E., Marcelli, M., McManus, V., Michelsen, S. I., Parkes, J., Parkinson, K. N., Thyen, U., Arnaud, C., & Colver, A. Participation in life situations of 8-12 year old children with cerebral palsy: cross sectional European study. *BMJ (Clin Res)*, 2009; 338: b1458.
- Finland's Ministry of Justice. "Kuullaan, mutta ei kuunnella" Lasten osallistumisoikeudet Suomessa. Arviointiraportti. ["Consulted but not Heard". Children's Participation Rights in Finland. Assessment Report.] Publications of the Ministry of Justice, Reports and guidelines, 10: 2020. Available at: https://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/162085/OM_2020_10.pdf?sequence=1&isAllowed=y (Finnish)
- Finnish Government. National Child Strategy, Committee report. (2022). The parliamentary National Child Strategy Committee, Helsinki. Available at: https://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/163977/VN_2022_16.pdf?sequence=1&isAllowed=y
- Foster, M., Quaye, A.A., Whitehead, L. & Hallström, I. K. Children's voices on their participation and best interests during a hospital stay in Australia. *J Pediatr Nurs*, 2022; 63: 64–71.
- Franklin, A., & Sloper, P. Listening and responding? Children's participation in health care within England. *Int J Child Rights*, 2005; 13(1/2): 11–29.
- Franklin, A. & Sloper, P. Supporting the Participation of Disabled Children and Young People in Decision-making. *Child Soc*, 2009; 23: 3–15.
- Fylkesnes, I., & Ytterhus, B. Whose voices matter? Use, misuse and non-use of Augmentative and Alternative Communication (AAC) among severely disabled children living in small group homes. *Scand J Disabil Res*, 2021; 32(1): 94–103.
- Garth, B., Murphy, G. C., & Reddihough, D. S. Perceptions of participation: child patients with a disability in the doctor-parent-child partnership. *Patient Educ Couns*, 2009; 74(1): 45–52.
- General Medical Council. Assessing best interests: 0–18 years: guidance for all doctors. 2018. Available at: <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/assessing-best-interests> (accessed 10 December 2023).
- Georgousopoulou, V., Voutetakis, A., Galanis, P., Kourti, F. E., Zartaloudi, A., Koutelekos, I., Dousis, E., Kosmidis, D., Koutsouki, S., Pappa, D., Igoumenidis, M., & Dafogianni, C. Assessing the Respect of Children's Rights in Pediatric Hospitals. *Medicina*, 2023; 59(5): 955.
- Graham, F., Timothy, E., Williman, J., & Levack, W. Participation-focused practices in paediatric rehabilitation for children with neurodisability in New Zealand: An observational study using MAPi audit tool. *Child Care Health Dev*, 2020; 46(5): 552–562.

- Graneheim, U. H., & Lundman, B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*, 2004; 24(2): 105–112.
- Granlund, M., Arvidsson, P., Niia, A., Björck-Åkesson, E., Simeonsson, R., Maxwell, G., Adolfsson, M., Eriksson-Augustine, L., & Pless, M. Differentiating activity and participation of children and youth with disability in Sweden: a third qualifier in the International Classification of Functioning, Disability, and Health for Children and Youth? *Am J Phys Med Rehabil*, 2012; 91(13 Suppl 1): S84–S96.
- Granlund, M., & Imms, C. Participation as a means-implications for intervention reasoning. *Front Rehabil Sci*, 2024; 5: 1399818.
- Granlund, M., Imms, C., King, G., Andersson, A. K., Augustine, L., Brooks, R., Danielsson, H., Gothilander, J., Ivarsson, M., Lundqvist, L. O., Lyngegård, F., & Almqvist, L. Definitions and Operationalization of Mental Health Problems, Wellbeing and Participation Constructs in Children with NDD: Distinctions and Clarifications. *Int J Environ Res Public Health*, 2021; 18(4): 1656.
- Gorter, J. W., & Gibson, B. E. Independence in adulthood: ethical challenges in providing transitional care for young people with neurodevelopmental impairments. In: Rosenbaum, P. L., Ronen, G. M., & Dan, B. (Eds.) *Ethics in Child Health: Principles and Cases in Neurodisability*. London: Mac Keith Press, 2015: 335–348.
- Guba, E. G., & Lincoln, Y. S. Competing paradigms of qualitative research. In Denzin, N. K., & Lincoln, Y. S. (Eds.) *Handbook of qualitative research*. Thousand Oaks: Sage, 1994: 105–117.
- Guichard, S., & Grande, C. The role of environment in explaining frequency of participation of pre-school children in home and community activities. *Int J DevDisabil*, 2017; 65(2): 108–115.
- Habermas, J. *Knowledge and human interests*. 2nd edition. London: Heinemann, 1978.
- Haeghele, J. A., & Hodge, S. Disability Discourse: Overview and Critiques of the Medical and Social Models. *Quest*, 2016; 68(2): 193–206.
- Harcourt, D., & Häggglund, S. Turning the UNCRC upside down: a bottom-up perspective on children's rights. *Int J Early Years Educ*, 2013; 21:4: 286–299.
- Harcourt D, Sargeant J. *Doing Ethical Research with Children*. Maidenhead, UK: Open University Press - McGraw-Hill Education, 2012.
- Hart, R. Children's participation. From tokenism to citizenship. UNICEF International Child Development Centre. *Innocenti Essays*, 1992; 4: 1–44.
- Hayton, J., & Dimitriou, D. What's in a word? Distinguishing between Habilitation and Re-habilitation. *Vision Rehabil Int*, 2019; 1(10): 1–4.
- Heah, T., Case, T., McGuire, B., & Law, M. Successful participation: the lived experience among children with disabilities. *Can J Occup Ther*, 2007; 74(1): 38–47.
- Health Care Act (1326/2010). Finlex, 2010. Available at: <https://www.finlex.fi/fi/lainsaadanto/saadaskaannokset/2010/eng/1326>

- Hilppö J. Children's Sense of Agency: A Co-Participatory Investigation. University of Helsinki, Faculty of Behavioural Sciences, Department of Teacher of Education, Research Report 382, 2016.
- Holloway, I., & Galvin, K. *Qualitative research in nursing and healthcare*. 5th edition. West Sussex, UK: Wiley-Blackwell, 2024.
- Hultman, L., Forinder, U., Öhrvall, A. M., Pergert, P., & Fugl-Meyer, K. Elusive Participation: Social Workers' Experience of the Participation of Children with Disabilities in LSS Assessments. *Scand J Disabil Res*, 2019; 21(1): 38–48.
- Härkäpää, K., Kippola-Pääkkönen, A., Buchert, U., Järvikoski, A., & Kallinen, M. Asiakkaiden ja terapeuttien äänellä. Kokemuksia ja arvioita Kelan vaativasta lääkinnällisestä kuntoutuksesta. [In the words of rehabilitation clients and therapists. Experiences and assessments of intensive medical rehabilitation.] Kela: Sosiaali- ja terveysturvan raportteja 21, 2020. (Finnish)
- Imms, C. Children with cerebral palsy participate: A review of the literature. *Disabil Rehabil*, 2008; 30(24): 1867–1884.
- Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. Participation: A systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Dev Med Child Neurol*, 2016; 58(1): 29–38.
- Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. 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.
- Jeglinsky, I., Kaakkuriniemi, E., Veijola, A., & Kiviranta, T. Profiles of functioning of children with cerebral palsy in Finland: analysis of multi-professional family meetings. *Disabil Rehabil*, 2021; 43(14): 2024–2030.
- Jeglinsky, I., Salminen, A. L., Carlberg, E. B., & Autti-Rämö, I. Rehabilitation planning for children and adolescents with cerebral palsy. *J Pediatr Rehabil Med*, 2012; 5(3): 203–215.
- Jyrkämä, J. Toimijuus ja toimintatilanteet – aineksia ikääntymisen arjen tutkimiseen [Agency and activities – ingredients for researching the daily life of the elderly.] In: Seppänen, M., Karisto, A., & Kröger, T. (Eds.) *Vanhuus ja sosiaalityö. Sosiaalityö avuttomuuden ja toimijuuden välissä* Jyväskylä: PS-kustannus, 2007: 195–217. (Finnish)
- Järvikoski, A., Härkäpää, K., Martin, M., Vasari, P., & Autti-Rämö, I. Service characteristics as predictors of parents' perceptions of child rehabilitation outcomes. *J Child Health Care*, 2015; 19(1): 106–117.
- Järvikoski, A., Martin, M., Autti-Rämö, I., & Härkäpää, K. 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.
- Järvikoski, A. Monimuotoinen kuntoutus ja sen käsitteet. [Multifaceted rehabilitation and its concepts.] Helsinki: Sosiaali- ja terveystieteiden tutkimuskeskus, Sosiaali- ja terveystieteiden tutkimuskeskus raportteja ja muistioita: 43, 2013. (Finnish)

- Kallinen, K., Nikupeteri, A., Laitinen, M., Lantela, L., Turunen, T., Nurmi, H., & Leinonen, J. Lasten arjen hyvinvoinnin tekijät. [Factors influencing children's everyday well-being.] *Kasvatus Aika*, 2021; 15(2): 4–21. (Finnish)
- Kanagasabai, P. S., Mirfin-Veitch, B., Hale, L. A., & Mulligan, H. A child-centered method of interviewing children with movement impairments. *Phys Occup Ther Pediatr*, 2018b; 38(3): 255–268.
- Kanagasabai, P. S., Mulligan, H., Hale, L. A., & Mirfin-Veitch, B. "I do like the activities which I can do..." Leisure participation experiences of children with movement impairments. *Disabil Rehabil*, 2018a; 40(14): 1630–1638.
- Karlsson, L. Chapter 13 Studies of Child Perspectives in Methodology and Practice with 'Osallisuus' as a Finnish Approach to Children's Reciprocal Cultural Participation. In: Ødegaard EE, Borgen JS. (Eds.) *Childhood Cultures in Transformation*. Leiden: Brill, 2020: 246–273.
- Kela n.d. [internet] Malli kuntoutuksen hyödyn arviointiin. [A model for assessing the benefits of rehabilitation.] Available at: <https://www.kela.fi/yhteistyokumppanit-kuntoutuspalvelut-palveluntuottajille-kuntoutuksen-mittaaminen-ja-arviointi-kuntoutuksen-hyodyn-arvioiminen> (accessed 18 May, 2024). (Finnish)
- Kela [Internet]. Rehabilitation for all ages. Last modified 27/2/2023. Available at: <https://www.kela.fi/rehabilitation-for-all-ages> (accessed 11 November 2023).
- Kela, statistics. Statistical registers (total material) produced from the rehabilitation benefits system. Kela – The Social Insurance Institution of Finland, 2021. Available at: http://raportit.kela.fi/ibi_apps/WFServlet
- Kela. Yksilöterapiat, Kelan vaativan lääkinällisen kuntoutuksen palvelukuvaus. [Individual Therapies, Service Description for Kela's Demanding Medical Rehabilitation.] Last modified 13.5.2022. Helsinki: Kela, 2022. Available at: <https://www.kela.fi/documents/20124/940710/palvelukuvaus-vaativan-laakinnallisen-kuntoutuksen-yksiloterapiat.pdf/200e3fed-12b2-a4c1-df3a-72feee7877ed?t=1661947698523> (accessed 29.7.2024). (Finnish)
- Kellet, M. Children and young people's participation. In: Montgomery, H., & Kellet, M. (Eds.) *Children and young people's worlds: Developing frameworks for integrated practice*. Bristol: Policy press, 2009: 43–60.
- van der Kemp, J., Ketelaar, M., & Gorter, J. W. Environmental factors associated with participation and its related concepts among children and youth with cerebral palsy: a rapid review. *Disabil Rehabil*, 2022; 44(9): 1571–1582.
- Kerbl, R., Sperl, W., Strassburg, H. M., Pettoello-Mantovani, M., & Ehrich, J. Overview of Habilitation and Rehabilitation for Children and Adolescents in Europe. *J Pediatr*, 2016; 172: 233–235.e2.
- Ketelaar, M., Smits, D. W., Meeteren, K., Klem, M., & Alsem, M. Involvement of young people and families in all stages of research; what, why and how? In: Imms, C., & Green, D. (eds.) *Participation, optimizing outcomes in childhood-onset neurodisability*. London: Mac Keith press, 2020: 105–118.

- King, G., & Chiarello, L. Family-centered care for children with cerebral palsy: conceptual and practical considerations to advance care and practice. *J Child Neurol*, 2014; 29(8): 1046–1054.
- King, G., Williams, L., & Hahn Goldberg, S. Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. *Child Care Health Dev*, 2017; 43(3): 334–347.
- King, G., Chiarello, L. A., Thompson, L., McLarnon, M. J. W., Smart, E., Ziviani, J., & Pinto, M. Development of an observational measure of therapy engagement for pediatric rehabilitation. *Disabil Rehabil*, 2019; 41(1), 86–97.
- King, G., Chiarello, L. A., Ideishi, R., D'Arrigo, R., Smart, E., Ziviani, J., & Pinto, M. The Nature, Value, and Experience of Engagement in Pediatric Rehabilitation: Perspectives of Youth, Caregivers, and Service Providers. *Dev Neurorehabil*, 2020; 23(1): 18–30.
- King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., Kertoy, M., & Petrenchik, T. Predictors of the Leisure and Recreation Participation of Children With Physical Disabilities: A Structural Equation Modeling Analysis. *Child Health Care*, 2006; 35(3): 209–234.
- Kinnunen, A. Löytöretkellä lapsen osallisuuteen, Substantiivinen teoria kouluikäisen erityistä tukea tarvitsevan lapsen osallisuuden mahdollistavasta yhteistoiminnasta. [On a discovery journey to a child's participation: Substantive theory of co-operation enabling the participation of a child with special needs at school age.] Doctoral dissertation. Kuopio: University of Eastern Finland, 2021. (Finnish)
- Kinnunen, A., Jeglinsky, I., Vänskä, N., Lehtonen, K., & Sipari, S. The importance of collaboration in pediatric rehabilitation for the construction of participation: the views of parents and professionals. *Disabilities*, 2021; 1(4): 459–470.
- Kinnunen, A., Vesterinen, A., Kippola-Pääkkönen, A., & Karhula, M. Partnership Working among Families, Therapists and Educationalists to Enhance Collaboration Enabling Participation of Children with Intellectual Disabilities. *Disabilities*, 2023; 3(3): 396–409.
- Kiresuk, T. J., & Sherman, R. E. Goal attainment scaling. A general method for evaluating comprehensive community mental health programs. *Community Ment Health J*, 1968; 4(6): 443–453.
- Kiresuk, T. J., Smith, A., & Cardillo, J. E. Goal attainment scaling. Applications, theory and measurement. Hillsdale, NJ: Erlbaum Associates, 1994.
- Kirk, S. Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *Int J Nurs Stud*, 2007; Sep1;44(7): 1250–1260.
- Kiuru, N., Salmela-Aro, K., Laursen, B., Vasalampi, K., Beattie, M., Tunkkari, M., & Junntila, N. (2024). Profiles of Loneliness and Ostracism During Adolescence: Consequences, Antecedents, and Protective Factors. *Child Psychiatry Hum Dev*, 2024: 10.1007/s10578-024-01664-8.
- Kolehmainen, N., Marshall, J., Hislop, J., Fayed, N., Kay, D., Ternent, L., & Pennington, L. Implementing participation-focused services: A study to develop the Method

- for using Audit and Feedback in Participation Implementation (MAPI). *Child Care Health Dev*, 2020; 46(1): 37–45.
- Koller, D., Espin, S., Indar, A., Oulton, A., & LeGrow, K. Children's participation rights and the role of pediatric healthcare teams: A critical review. *J Pediatr Nurs*, 2024; 77: 1–12.
- Koro-Ljungberg, M. A social constructionist framing of the research interview. In: Holstein, J. A., & Gubrium, J. F. (Eds.) *Handbook of constructionist research*. New York: A division of Guilford publications Inc, 2008: 429–444.
- Krefting, L. Rigor in qualitative research: The assessment of trustworthiness. *Am J Occup Ther*, 1991; Mar;45(3): 214–222.
- Kronsell, L., Svedberg, P., Nygren, J., & Larsson, I. Parents' perceptions of the value of children's participation in pediatric rehabilitation services: a phenomenographic study. *Int J Environ Res Public Health*, 2021; 18(20): 10948.
- Krueger, R. A, Casey, M. A. *Focus groups, A practical guide for applied research*. 4th edition. Thousand Oaks: Sage publications inc, 2009.
- Krutzinna, J. Who is "The Child"? Best Interests and Individuality of Children in Discretionary Decision-Making. *Int J Child Rights*, 2022; 30(1): 120–145.
- Kvale, S. *Interviews, An introduction to qualitative research interviewing*. Thousand Oaks: Sage publications inc, 1996.
- Kvale, S. *Doing interviews*. Flick U. (Eds.) *The Sage qualitative research kit*. Thousand Oaks: Sage publications inc, 2007.
- Kyngäs, H. Qualitative Research and Content Analysis. In: Kyngäs, H., Mikkonen, K., & Kääriäinen, M. (Eds.) *The Application of Content Analysis in Nursing Science Research*. Cham: Springer, 2020a: 3–12.
- Kyngäs, H. Inductive Content Analysis. In: Kyngäs, H., Mikkonen, K., & Kääriäinen, M. (Eds.) *The Application of Content Analysis in Nursing Science Research*. Cham: Springer, 2020b: 13–21.
- Kyngäs, H., Kaakinen, P. Deductive Content Analysis. In: Kyngäs, H., Mikkonen, K., & Kääriäinen, M. (Eds.) *The Application of Content Analysis in Nursing Science Research*. Cham: Springer, 2020.
- Kyngäs, H., Kääriäinen, M., & Elo, S. The Trustworthiness of Content Analysis. In: Kyngäs, H., Mikkonen, K., & Kääriäinen, M. (Eds.) *The Application of Content Analysis in Nursing Science Research*. Cham: Springer, 2020: 41–48.
- Kwan, C., Gitimoghaddam, M., & Collet, J. P. Effects of Social Isolation and Loneliness in Children with Neurodevelopmental Disabilities: A Scoping Review. *Brain Sci*, 2020; 10(11): 786–817.
- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., Verdugo, M. A., & Walsh, P. N. The relationship between quality of life and self-determination: an international study. *J Intell Disabil Res*, 2005; 49(10): 740–744.

- Laki sosiaalihuollon asiakkaan asemasta ja oikeuksista (812/2000). [Act on the Status and Rights of Social Welfare Clients.] Finlex, 2000. Available at: <https://www.finlex.fi/fi/lainsaadanto/2000/812> (Finnish)
- Lansdown, G. Implementing children's rights and health. *Arch Dis Child* 2000; 83(4): 286–288.
- Lansdown, G. The realisation of children's participation rights: critical reflections. In: Percy-Smith, B., & Thomas, N. (Eds.) *A Handbook of Children and Young People's Participation*. London & New York: Routledge, 2009: 11–23.
- Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., King, G., & Hanna, S. Participation of children with physical disabilities: Relationship with diagnosis, physical function, and demographic variables. *Scand J Occup Ther*, 2004; 11: 156–162.
- Law, M., Baptiste, S., Carswell, A., McColl, M. A., Polatajko, H., & Pollock, N. *The Canadian Occupational Performance Measure*. Ottawa, ON: Canadian Association of Occupational Therapists, 2005.
- Leonardi, M., Lee, H., Kostanjsek, N., Fornari, A., Raggi, A., Martinuzzi, A., Yáñez, M., Almborg, A. H., Fresk, M., Besstrashnova, Y., Shoshmin, A., Castro, S. S., Cordeiro, E. S., Cuenot, M., Haas, C., Maart, S., Maribo, T., Miller, J., Mukaino, M., Snyman, S., Trinks, U., Anttila, H., Paltamaa, J., Saleeby, P., Frattura, L., Madden, R., Sykes, C., van Gool, C. H., Hrkal, J., Zvolský, M., Sládková, P., Vikdal, M., Harðardóttir, G. A., Foubert, J., Jakob, R., Coenen, M., & Kraus de Camargo, O. 20 Years of ICF-International Classification of Functioning, Disability and Health: Uses and Applications around the World. *Int J Environ Res Public Health*, 2022; 19(18): 11321.
- Liao, Y. T., Hwang, A. W., Liao, H. F., Granlund, M., & Kang, L. J. Understanding the Participation in Home, School, and Community Activities Reported by Children with Disabilities and Their Parents: A Pilot Study. *Int J Environ Res Public Health*, 2019; 16(12): 2217.
- Lincoln, Y. S., & Guba, E. G. Paradigmatic controversies, contradictions, and emerging confluences. In: Denzin, N. K., & Lincoln, Y. S. (Eds.) 2nd Ed. *Handbook of qualitative research*. Thousand Oaks: Sage, 2000: 163–188.
- Lincoln, Y. S., Lynham, S. A., & Guba, E. G. Paradigmatic controversies, contradictions and emerging confluences, revisited. In: Denzin, N. K., Lincoln, Y. S., Giardina, M. D., & Cannella, G. S. (Eds.) 6th Ed. *Handbook of qualitative research*. Thousand Oaks: Sage, 2024: 75–112.
- Long, T., & Guo, J. Moving beyond Inclusion to Belonging. *Int J Environ Res Public Health*, 2023; Oct 10;20(20): 6907.
- Lundy, L. 'Voice' is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *Br Educ Res J*, 2007; 33: 927–942.
- MacEachern, S., Forkert, N. D., Lemay, J. F., & Dewey, D. Physical Activity Participation and Barriers for Children and Adolescents with Disabilities. *Int J Disabil Dev Educ*, 2021; 69(1): 204–216.

- Maciver, D., Rutherford, M., Arakelyan, S., Kramer, J. M., Richmond, J., Todorova, L., Romero-Ayuso, D., Nakamura-Thomas, H., Ten Velden, M., Finlayson, I., O'Hare, A., & Forsyth, K. Participation of children with disabilities in school: A realist systematic review of psychosocial and environmental factors. *PloS one*, 2019; 14(1): e0210511.
- MacNeil, M., Benoit, B., Disher, T., Newman, A. J., & Campbell-Yeo, M. Challenges and best practices for recruiting families of children with intellectual disabilities for health research. *J Intell Disabil*, 2024; 0(0).
- Malone, K., & Hartung, C. Challenges of participatory practice with children. In: Percy-Smith, B., & Thomas, N. (Eds.) *A Handbook of Children and Young People's Participation*. London & New York: Routledge, 2009: 24–38.
- Martin, K., & Franklin, A. Disabled children and participation in the UK. Reality or rhetoric? In: Percy-Smith, B., & Thomas, N. (Eds.) *A Handbook of Children and Young People's Participation*. London & New York: Routledge, 2009: 97–104.
- Mayall, B. *Towards a sociology for childhood. Thinking from children's lives*. Buckingham: Open University Press, 2002.
- Maxwell, G. R., Granlund, M., & Augustine, L. Inclusion Through Participation: Understanding Participation in the International Classification of Functioning, Disability, and Health as a Methodological Research Tool for Investigating Inclusion. *Front Educ*, 2018; (3): 41.
- McCloy, L., White, S., Lee Bunting, K., & Forwell, S. Photo-elicitation interviewing to capture children's perspectives on family routines. *J Occup Sci*, 2016; 23(1): 82–95.
- McCoy, S. W., Palisano, R., Avery, L., Jeffries, L., Laforme Fiss, A., Chiarello, L., & Hanna, S. Physical, occupational, and speech therapy for children with cerebral palsy. *Dev Med Child Neurol*, 2020; 62(1): 140–146.
- Mc Manus, V., Corcoran, P., & Perry, I. J. Participation in everyday activities and quality of life in pre-teenage children living with cerebral palsy in South West Ireland. *BMC pediatr*, 2008; 8: 50.
- McMellon, C., & Tisdall, E. K. M. Children and young people's participation rights: looking backwards and moving forwards. *The Int J Child Rights*, 2020; 28(1): 157–182.
- Melbøe, L., & Ytterhus, B. Disability leisure: in what kind of activities, and when and how do youths with intellectual disabilities participate? *Scand J Disabil Res*, 2016; 19(3): 245–255.
- Melvin, K., Meyer, C., & Scarinci, N. Exploring the complexity of how families are engaged in early speech-language pathology intervention using video-reflexive ethnography. *Int J Lang Commun Disord*, 2021; 56(2): 360–373.
- Meuser, S., Borgestig, M., Lidström, H., Hennissen, P., Dolmans, D., & Piskur, B. Experiences of Dutch and Swedish Occupational Therapists and Teachers of Their Context-Based Collaboration in Elementary Education. *J Occup Ther Sch Early Interv*, 2022; 17(1): 37–53.

- Miettinen, S., Ashorn, U., & Lehto, J. Talking about the institutional complexity of the integrated rehabilitation system-the importance of coordination. *Int J Integr Care*, 2013; 13: e007.
- Miles, M. B., Huberman, A. M., & Saldaña, J. *Qualitative data analysis. A methods sourcebook*. 4th edition. London: Sage Publications, 2020.
- Missiuna, C., Hecimovich, C., Dix, L., Campbell, W., Pollock, N., Bennett, S., Camden, C., DeCola, C., McCauley, D., Gaines, R., Cairney, J., & Stewart, D. *Partnering for change: Implementation and evaluation final report, 2013–2015: Final Report for the Ontario Ministry of Health and Long-Term Care and the Ontario Ministry of Education*. CanChild, McMaster University, 2015. Available at: <https://www.partneringforchange.ca/img/P4C-2015.pdf>
- Missiuna, C., Pollock, N., Law, M., Walter, S., & Cavey, N. Examination of the Perceived Efficacy and Goal Setting System (PEGS) with children with disabilities, their parents, and teachers. *Am J Occup Ther*, 2006; 60: 204–214.
- Missiuna, C. A., Pollock, N. A., Levac, D. E., Campbell, W. N., Whalen, S. D., Bennett, S. M., Hecimovich, C. A., Gaines, B. R., Cairney, J., & Russell, D. J. (2012). Partnering for change: an innovative school-based occupational therapy service delivery model for children with developmental coordination disorder. *Can J Occup Ther*, 2012; 79(1): 41–50.
- Montreuil, M., & Carnevale, F. A. A concept analysis of children's agency within the health literature. *J Child Health Care* 2016; 20(4): 503–511.
- Morris, C., Shilling, V., McHugh, C. & Wyatt, K. Why it is crucial to involve families in all stages of childhood disability research. *Dev Med Child Neurol*, 2011; 53: 769–771.
- März, J. W. What does the best interests principle of the convention on the rights of the child mean for paediatric healthcare? *Eur J Pediatr*, 2022; 181(11): 3805–3816.
- Nap-van der Vlist, M. M., Berkelbach van der Sprenkel, E. E., Nijhof, L. N., Grootenhuis, M. A., van der Ent, C. K., Swart, J. F., van Royen-Kerkhof, A., van Grotel, M., van de Putte, E. M., Nijhof, S. L., & Kars, M. C. Daily life participation in childhood chronic disease: a qualitative study on the child's and parent's perspective. *BMJ Paediatr Open*, 2021; 5(1): e001057.
- Nguyen, L., van Oort, B., Davis, H., van der Meulen, E., Dawe-McCord, C., Franklin, A., Gorter, J. W., Morris, C., & Ketelaar, M. Exploring the “how” in research partnerships with young partners by experience: lessons learned in six projects from Canada, the Netherlands, and the United Kingdom. *Res Involvem Engagem*, 2022; 8(1): 62.
- Nisius, K., Hoffmann, D., Görig, T., Georg, S., Krug, K., De Bock, F., & Eichinger, M. Perceived shared decision making and satisfaction with care among children and adolescents with special healthcare needs and their parents: Cross-sectional evidence from the PART-CHILD Study. *Patient Educ Couns*, 2024; 123: 108175.
- Njelesani, J., Mlambo, V., Deneke, T., & Hunleth, J. Inclusion of children with disabilities in qualitative health research: A scoping review. *PloS one*, 2022; 17(9): e0273784.
- Novak, I. Parent experience of implementing effective home programs. *Phys Occup Ther Pediatr*, 2011; May;31(2): 198–213.

- Novak, I., Te Velde, A., Hines, A., Stanton, E., Mc Namara, M., Paton, M. C. B., Finch-Edmondson, M., & Morgan, C. Rehabilitation Evidence-Based Decision-Making: The READ Model. *Front Rehabil Sci*, 2021; 2: 726410.
- Nowak, H. I., Broberg, M., & Starke, M. Opportunity to participate in planning and evaluation of support for children with disabilities: Parents' and professionals' perspectives. *J Intellect Disabil*, 2020; 24(1): 5–20.
- Nyquist, A., Moser, T., & Jahnsen, R. Fitness, Fun and Friends through Participation in Preferred Physical Activities: Achievable for Children with Disabilities? *Int J Disabil Dev Ed*, 2016; 63(3), 334–356.
- O'Connor, D., Lynch, H., & Boyle, B. A qualitative study of child participation in decision-making: Exploring rights-based approaches in pediatric occupational therapy. *PLoS one*, 2021; 16(12): e0260975.
- Olli, J., Vehkakoski, T., & Salanterä, S. Facilitating and hindering factors in the realization of disabled children's agency in institutional contexts: literature review. *Disabil Soc*, 2012; 27(6): 793–807.
- Orlin, M. N., Palisano, R. J., Chiarello, L. A., Kang, L., Polansky, M., Almasri, N., & Maggs, J. Participation in home, extracurricular, and community activities among children and young people with cerebral palsy. *Dev Med Child Neurol*, 2010; 52(2): 160–166.
- Ortju, L., Kankkunen, P., & Haaranen, A. Pikkulapsen osallisuus perusterveydenhuollon hoitotilanteessa – scoping-katsaus. [A toddler's participation in primary healthcare encounters - a scoping review.] *Sosiaalilääketieteellinen aikakauslehti*, 2022; 59: 313–326. (Finnish)
- Øien, I., Fallang, B. & Østensjø, S. Goal-setting in paediatric rehabilitation: perceptions of parents and professional. *Child Care Health Dev*, 2010; 36: 558–565.
- Pajulammi, H. Lapsi, oikeus ja osallisuus. [Children, rights and participation.] Doctoral dissertation, University of Lapland. Helsinki: Talentum, 2014. (Finnish)
- Palisano, R. J., Chiarello, L. A., King, G. A., Novak, I., Stoner, T., & Fiss, A. Participation-based therapy for children with physical disabilities. *Disabil Rehabil*, 2012; 34(12): 1041–1052.
- Palisano, R. J., Chiarello, L. A., Vänskä, N., Sipari, S. Content Validity and Utility of the Collaborative Process for Action Plans to Achieve Children's Participation Goals. *Disabilities*, 2022; 2(4): 626–640.
- Paltamaa, J., Karhula, M., Suomela-Markkanen, T., Autti-Rämö, I. (Eds.) Hyvän kuntoutuskäytännön perusta. Käytännön ja tutkimustiedon analyysistä suosituksiin vaikeavammaisten kuntoutuksen kehittämishankkeessa. [Basis of a good rehabilitation practice. From analysis of current practice and evidence to recommendations. A rehabilitation development project for severely disabled persons.] Helsinki: Kela, 2011. (Finnish)
- Paul, M. Rights. *Arch Dis Child*, 2007; 92(8): 720–725.
- Perusopetuslaki (628/1998). [Basic Education Act.] Finlex, 1998. Available at: <https://finlex.fi/en/legislation/1998/628>

- Phoenix, M., Jack, S. M., Rosenbaum, P. L., & Missiuna, C. Parents' attendance, participation and engagement in children's developmental rehabilitation services: Part 1. Contextualizing the journey to child health and happiness. *Disabil Rehabil*, 2020; 42(15): 2141–2150.
- Picton-Howell, Z. The human rights of children with disabilities: How can medical professionals better fulfil rather than breach them? *Dev Med Child Neurol*, 2023; 65: 1429–1435.
- Piškur, B., Beurskens, A. J., Ketelaar, M., Jongmans, M. J., Casparie, B. M., & Smeets, R. J. Daily actions, challenges, and needs among Dutch parents while supporting the participation of their child with a physical disability at home, at school, and in the community: a qualitative diary study. *BMC pediatr*, 2017; 17(1): 12.
- Piškur, B., Meuser, S., Jongmans, M. J., Ketelaar, M., Smeets, R. J. E. M., Casparie, B. M., Haarsma, F. A., & Beurskens, A. J. H. M. The lived experience of parents enabling participation of their child with a physical disability at home, at school and in the community. *Disabil Rehabil*, 2016; 38(8), 803–812.
- Pollari, K. Lapsipotilaan päätöksentekokyky ja sen arviointi. [The Decision-making capacity of Child Patients and Its Assessment.] Doctoral dissertation. Rovaniemi: University of Lapland, 2019.
- Powrie, B., Kolehmainen, N., Turpin, M., Ziviani, J., & Copley, J. The meaning of leisure for children and young people with physical disabilities: A systematic evidence synthesis. *Dev Med Child Neurol*, 2015; 57(11), 993–1010.
- Preston, J., Lappin, E., Ainsworth, J., Wood, C. L., & Dimitri, P. Involving children and young people as active partners in paediatric health research. *Paediatr Child Health*, 2024; 34(1): 11–16.
- Pritchard Kennedy, A. Systematic ethnography of school-age children with bleeding disorders and other chronic illnesses: exploring children's perceptions of partnership roles in family-centred care of their chronic illness. *Child Care Health Dev*, 2012; 38(6): 863–869.
- Pritchard, L., Phelan, S., McKillop, A., & Andersen, J. Child, parent, and clinician experiences with a child-driven goal setting approach in paediatric rehabilitation. *Disabil Rehabil*, 2022; 44(7): 1042–1049.
- Pritchard-Wiart, L., & Phelan, S. K. Goal setting in paediatric rehabilitation for children with motor disabilities: a scoping review. *Clin Rehabil*, 2018; 32(7): 954–966.
- Pritchard-Wiart, L., Thompson-Hodgetts, S., McKillop, A. B., Rosychuk, R., Mrklas, K., Zwaigenbaum, L., Zwicker, J., Andersen, J., King, G., & Firouzeh, P. A multi-center, pragmatic, effectiveness-implementation (hybrid I) cluster randomized controlled trial to evaluate a child-oriented goal-setting approach in paediatric rehabilitation (the ENGAGE approach): a study protocol. *BMC pediatr*, 2022; 22(1), 375.
- Prout, A., & James, A. A new paradigm for the sociology of childhood? Provenance, promise and problems. In: Prout A, James A. (Eds.) *Constructing and Reconstructing Childhood*. 3rd edition. London: Routledge, 2015: 6–28.

- Quaye, A. A., Castor, C., Coyne, I., Söderbäck, M., & Hallström, I. K. How are children's best interests expressed during their hospital visit? – An observational study. *J Clin Nurs*, 2021; 30: 3644–3656.
- Quaye, A. A., Coyne, I., Söderbäck, M., & Hallström, I. K. Children's active participation in decision-making processes during hospitalisation: An observational study. *J Clin Nurs*, 2019; 28(23–24): 4525–4537.
- Quartermaine, J. R., Rose, T. A., Auld, M. L., & Johnston, L. M. Participation measures that evaluate attendance and involvement for young people aged 15 to 25 years with cerebral palsy: a systematic review. *Disabil Rehabil*, 2024; 46(9): 1734–1750.
- The RCR guidelines. Responsible conduct of research and procedures for handling allegations of misconduct in Finland. Guidelines of the Finnish Advisory Board on Research Integrity, 2012. Available at: https://tenk.fi/sites/tenk.fi/files/HTK_ohje_2012.pdf
- Reeder, J. & Morris, J. Becoming an empowered parent. How do parents successfully take up their role as a collaborative partner in their child's specialist care? *J Child Health Care*, 2021; 25(1): 110–125.
- Rosenbaum, P., & Gorter, J. W. The 'F-words' in childhood disability: I swear this is how we should think!. *Child Care Health Dev*, 2012; 38(4): 457–463.
- Ruggiero, R. Article 3: The Best Interest of the Child. In: Vaghri, Z., Zermatten, J., Lansdown, G., & Ruggiero, R. (eds.) *Monitoring State Compliance with the UN Convention on the Rights of the Child. Children's Well-Being: Indicators and Research*, vol 25. Cham: Springer, 2022: 21–29.
- Ryan, R. M., & Deci, E. L. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *Am Psychol*, 2000; 55(1): 68–78.
- Ryan, A. K., Miller, L., Rose, T. A., & Johnston, L. M. Child-led goal setting and evaluation tools for children with a disability: A scoping review. *Dev Med Child Neurol*, 2024; 66(12): 1558–1569.
- Ryan, A. K., Miller, L., MacDonald, M., & Johnston, L. M. How do we capture child and family goals? Examining the goal setting practices used by community-based allied health professionals. *Disabil Rehabil*, 2025; Jan 21: 1–10.
- Sahlberg, S., Karlsson, K., & Darcy, L. Children's rights as law in Sweden-every health-care encounter needs to meet the child's needs. *Health expect*, 2020; 23(4): 860–869.
- Sairanen, H. & Kumpulainen, K. A visual narrative inquiry into children's sense of agency in preschool and first grade. *Int J Educ Psychol*, 2014; 3(2): 141–174.
- Salminen, J., Laasanen, M., Leinonen, L., Karukivi, M., Vornanen, R., Alin, M., & Kyttälä, M. Professional collaboration for children and adolescents with neurodevelopmental disorders: a scoping review. *Eur J Spec Needs Educ*, 2024; 40(1): 16–34.
- Schiariti, V., Klassen, A. F., Cieza, A., Sauve, K., O'Donnell, M., Armstrong, R., & Mâsse, L. C. Comparing contents of outcome measures in cerebral palsy using the International Classification of Functioning (ICF-CY): a systematic review. *Eur J Paediatr Neurol*, 2014; 18(1): 1–12.

- Schiller, W., & Einarsdottir, J. Special Issue: Listening to young children's voices in research – changing perspectives/changing relationships. *Early Child Dev Care*, 2009; 179(2): 125–130.
- Schwandt, T. A. Three epistemological stances for qualitative inquiry. In: Denzin, N. K., & Lincoln, Y. S. (Eds.) 2nd Ed. *Handbook of qualitative research*. Thousand Oaks: Sage, 2000: 189–214.
- Shikako-Thomas, K., Kolehmainen, N., Ketelaar, M., Bult, M., & Law, M. Promoting leisure participation as part of health and well-being in children and youth with cerebral palsy. *J Child Neurol* 2014; 29(8): 1125–1133.
- Simovska, V., & Jensen, B. B. Conceptualizing participation – the health of children and young people. World Health Organization Regional Office for Europe, 2009. Available at: https://pure.au.dk/ws/portalfiles/portal/399/Conceptualizing_Participation.pdf
- Shields, N., & Synnot, A. Perceived barriers and facilitators to participation in physical activity for children with disability: a qualitative study. *BMC Pediatr*, 2016; 16: 9.
- Shier, H. Pathways to participation: openings, opportunities and obligations. *Child Soc*, 2001; 15: 107–117.
- Shikako-Thomas, K., & Shevell, M. Promoting the human rights of children with neurologic conditions. *Semin Pediatr Neurol*, 2018; 27: 53–61.
- Simpson, K., Imms, C., & Keen, D. The experience of participation: eliciting the views of children on the autism spectrum. *Disabil Rehabil*, 2022; 44(9): 1700–1708.
- Sipari, S. Kuntouttava arki lapsen tueksi: kasvatuksen ja kuntoutuksen yhteistoiminnan rakentuminen asiantuntijoiden keskusteluissa. [Habilitative everyday life to support the child. Construction of collaboration in the discussions of rehabilitation and education experts.] Doctoral dissertation. Jyväskylä: University of Jyväskylä, 2008. (Finnish)
- Sipari, S., Kauppila, J., & Suhonen-Polvi, H. Kuntoutuksen kokonaisuuden rakentuminen [Building comprehensive habilitation.] In: Autti-Rämö I, Salminen AL, Rajavaara M, Melkas S (Eds.) *Kuntoutuminen*. Helsinki: Duodecim, 2022. (Finnish)
- Sipari, S., & Launiainen, H. Lapsen hyvä kuntoutus käytännössä. Lapsen ja nuoren hyvän kuntoutuksen toteutuminen palveluverkostossa – projekti 2007–2011. [Good Rehabilitation Practices for Children. Implementation of Effective Rehabilitation for Children and Adolescents in the Service Network – Project 2007–2011.] Helsinki: Vajaaliikkeisten Kunto ry, 2011. (Finnish)
- Sipari, S., Tammelin, M., Helenius, S., Janhunen, E., Rantakokko, M., Vänskä, N., & Harra, T. Knowledge Needs in Rehabilitation: Perspectives of Service Users and Professionals. *Front Rehabil Sci*, 2022; 3: 858081.
- Sipari, S., Vänskä, N. & Pollari, K. Lapsen edun toteutuminen kuntoutuksessa. Osallistumista ja toimijuutta vahvistavat hyvät käytännöt. [Realisation of the child's interest in rehabilitation. Good practices that enhance participation and agency.] Helsinki: Kela, Sosiaali- ja terveysturvan raportteja 5, 2017a. Available at: <http://hdl.handle.net/10138/220550> (Finnish)

- 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, 2017b. Available at: <https://metropolia.e-julkaisu.com/lapsen-metkut/> (Finnish)
- Sipari, S., Vänskä, N., Lehtonen, K., & Pihlava, J. Kuntoutuksen omat tavoitteet- tutkimus. GAS-menetelmän käyttö Kelan sopeutumisvalmennuskursseilla. [Using the GAS method in Kela-provided adaptation training courses. A study on the individual goals of rehabilitees.] Helsinki: Kela, Sosiaali- ja terveysturvan raportteja 20, 2019. Available at: <https://helda.helsinki.fi/handle/10138/306805> (Finnish)
- Sipari, S., Vänskä, N., Lehtonen, K., Helenius, S., Harra, T., Kinnunen, A., Väisänen, S., Jeglinsky-Kankainen, I. Participatory Research Partnership in Rehabilitation – Co-development of a Model for Collaboration Process. *Disabilities*, 2023; 3(3): 410–425.
- Solish, A., Perry, A. & Minnes, P. Participation of Children with and without Disabilities in Social, Recreational and Leisure Activities. *J Appl Res Intellect Disabil*, 2010; 23: 226–236.
- Sommer, I., & Pramling-Samuelsson, I. Introduction: A child perspectives and children's perspectives – a Scandinavian context. In: Sommer, D., Pramling-Samuelsson, I., & Hundeide, K. (Eds.) *Child Perspectives and Children's Perspectives in Theory and Practice*. London: Springer, 2010: 1–24.
- Sosiaalihuoltolaki (1301/2014). [Social Welfare Act.] Available at: <https://finlex.fi/fi/laki/ajantasa/2014/20141301> (Finnish)
- Souto, D. O., de Sousa, M. O., Ferreira, R. G., Brandão, A. C., Carrera, P. B., & Leite, H. R. What are the barriers and facilitators to participation of people with Down syndrome? A scoping review. *Dev Med Child Neurol*, 2024; Aug;66(8): 1013–1030.
- Steinhardt, F., Dolva, A. S., Jahnsen, R., & Ullenhag, A. Exploring two subdimensions of participation, involvement and engagement: A scoping review. *Scand J Occup Therap*, 2022; 29(6): 441–463.
- Steinhardt, F., Ullenhag, A., Jahnsen, R., & Dolva, A. S. Perceived facilitators and barriers for participation in leisure activities in children with disabilities: Perspectives of children, parents and professionals. *Scand J Occup Therap*, 2019; 28(2): 121–135.
- Streuli, J. C., Anderson, J., Alef-Defoe, S., Bergsträsser, E., Jucker, J., Meyer, S., Chaksad-Weiland, S., & Vayena, E. Combining the best interest standard with shared decision-making in paediatrics-introducing the shared optimum approach based on a qualitative study. *Eur J Pediatr*, 2021; 180(3): 759–766.
- Streuli, J. C., Michel, M., & Vayena, E. Children's rights in pediatrics. *Eur J Pediatr*, 2011; 170(1): 9–14.
- Styczen, L. M., Helseth, S., Groven, K. S., Hauge, M. I., & Dahl-Michelsen, T. Interprofessional collaboration for children with physical disabilities: a scoping review. *J Interprof Care*, 2024: 1–17.

- Särkikangas, U. Sosiaali- ja terveystalveluiden käyttö erityisperheiden arjessa: toiminnan ja ajankäytön näkökulma. [Everyday use of social welfare and healthcare services among special needs families - a perspective of activity and time use.] Doctoral dissertation. Helsinki: University of Helsinki, 2020. (Finnish)
- Söderbäck, M., Coyne, I., & Harder, M. The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. *J Child Health Care*, 2011; 15(2): 99–106.
- Teleman, B., Vinblad, E., Svedberg, P., Nygren, J. M., & Larsson, I. Exploring Barriers to Participation in Pediatric Rehabilitation: Voices of Children and Young People with Disabilities, Parents, and Professionals. *Int J Environ Res Public Health*, 2021; 18(19): 10119.
- TENK. Ihmiseen kohdistuvan tutkimuksen eettiset periaatteet ja ihmistieteiden eettinen ennakoarvointi Suomessa. Tutkimuseettisen neuvottelukunnan ohje, 2019. [Ethical Principles of Research Involving Human Subjects and Ethical Review in the Humanities in Finland. Guidelines of the Finnish National Board on Research Integrity, 2019.] Available at: https://tenk.fi/sites/default/files/2021-01/Ihmistieteiden_eettisen_ennakoarvioinnin_ohje_2020.pdf (Finnish)
- Thomas, N. P. Towards a Theory of Children's Participation. *Int J Child Rights*, 2007; 15(2): 199–218.
- Thunberg, G., Johnson, E., Bornman, J., Öhlén, J. & Nilsson, S. Being heard – Supporting person-centred communication in paediatric care using augmentative and alternative communication as universal design: A position paper. *Nurs Inq*, 2022; 29: e12426.
- Tisdall, E.K.M. The Challenge and Challenging of Childhood Studies? Learning from Disability Studies and Research with Disabled Children. *Child Soc*, 2012, 26: 181–191.
- Tong, A., Sainsbury, P., & Craig, J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health C*, 2007; 19(6): 349–357.
- Trabacca, A., Vespino, T., Di Liddo, A., & Russo, L. Multidisciplinary rehabilitation for patients with cerebral palsy: improving long-term care. *J Multidiscip Healthc*, 2016; 9: 455–462.
- Tracy, S. J. Qualitative Quality: Eight “Big-tent” criteria for excellent qualitative research. *Qual Inq*, 2010; 16(10): 837–851.
- Tuomi, J., & Sarajärvi, A. Laadullinen tutkimus ja sisällönanalyysi. [Qualitative research and content analysis.] 6th revised edition. Helsinki: Tammi, 2009. (Finnish)
- Ullenhag, A., Imms, C., Anaby, D., Kramer, J. M., Girdler, S., Gorter, J. W., Ketelaar, M., Jahnsen, R. B., Elliott, C., & Granlund, M. How can we reach long-lasting inclusive participation for all? A vision for the future. *Child Care Health Dev*, 2024; 50(2): e13249.
- Ullenhag, A., Krumlinde-Sundholm, L., Granlund, M., & Almqvist, L. Differences in patterns of participation in leisure activities in Swedish children with and without disabilities. *Disabil Rehabil*, 2014; 36(6): 464–471.

- UN. Habilitation and rehabilitation under article 26 of the Convention on the Rights of Persons with Disabilities. Report of the Office of the United Nations High Commissioner for Human Rights. Geneva: United Nations Human Rights Council, General Assembly, 2019. Available at: <https://documents.un.org/doc/undoc/gen/g19/012/52/pdf/g1901252.pdf?token=48FuqtBBkIyDmXTyTh&fe=true>
- UNCRC. United Nations Convention on the Rights of the Child. Geneva: United Nations Human Rights Office of the High Commissioner, General Assembly resolution 44/25 of 20 November, 1989. Available at: <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>
- UNCRPD. United Nations Convention on the Rights of Persons with Disabilities. Treaty Series, 2515, 3. Geneva: United Nations Human Rights Office, 2006. Available at: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Unicef. Seen, counted, included. Using data to shed light on the well-being of children with disabilities. New York: Unicef, United Nations Children's Fund, 2021.
- Unicef. United Nations Children's Fund, disability inclusion policy and strategy (DIPAS) 2022–2030. New York: Unicef, 2022. Available at: <https://www.unicef.org/media/134511/file/An%20inclusive%20world,%20starts%20with%20me,%20with%20you,%20with%20all%20of%20us.pdf>
- United Nations n.d. Department of Economic and Social Affairs, Sustainable Development. Available at: <https://sdgs.un.org/>
- van de Velde, D., Coussens, M., De Baets, S., Sabbe, L., Vanderstraeten, G., Vlerick, P., Van Malderen, L., Gorus, E., & De Vriendt, P. Application of participation in clinical practice: Key issues. *J Rehabil Med*, 2018; 50(8): 679–695.
- Vinblad, E., Larsson, I., Lönn, M., Olsson, E., Nygren, J. M., & Svedberg, P. Development of a digital decision support tool to aid participation of children with disabilities in pediatric rehabilitation services: Explorative qualitative study. *JMIR Form Res*, 2019; 3(4), e14493.
- Vroland-Nordstrand, K., Eliasson, A. C., Jacobsson, H., Johansson, U., & Krumlinde-Sundholm, L. 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.
- Vänskä, N., Pollari, K., & Sipari, S. Lapsen toimijuutta ja osallistumista vahvistavat kuntoutuksen hyvät käytännöt kirjallisuudessa. Kuvaileva kirjallisuuskatsaus. [Good Rehabilitation Practices in Literature that Strengthen Children's Participation and Agency: A Descriptive Literature Review.] Helsinki: Kela, Kelan työpapereita 94, 2016. Available at: <https://helda.helsinki.fi/bitstream/handle/10138/161355/Tyopapereita94.pdf?sequence=1> (Finnish)
- Vänskä, N., Sipari, S., & Haataja, L. Practices for promoting a child's best interests in paediatric rehabilitation - Perspectives of professionals and parents. *J Child Health Care*, 2024; 13674935241287880. Advance online publication.
- 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.

- Vänskä, N., Sipari, S., Jeglinsky, I., Lehtonen, K., & Kinnunen, A. Co-development of the CMAP Book: a tool to enhance children's participation in pediatric rehabilitation. *Disabil Rehabil*, 2022; 44(9): 1709–1719.
- Wehmeyer, M. L. Self-determination in adolescents and adults with intellectual and developmental disabilities. *Curr Opin Psychiatry*, 2020; 33(2): 81–85.
- Wilkinson, S. Focus group research. In: Silverman, D. (Eds.). *Qualitative research. Theory, method and practice*. 2nd edition. London: Sage publications, 2004: 177–199.
- Willis, C., Girdler, S., Thompson, M., Rosenberg, M., Reid, S., & Elliott, C. Elements contributing to meaningful participation for children and youth with disabilities: A scoping review. *Disabil Rehabil*, 2017; 39(17): 1771–1784.
- Woo, L., Shen, E., & Russel, E. Tensions regarding the processes associated with decision-making about interventions. In: Rosenbaum, P. L., Ronen, G. M. & Dan, B. (Eds.) *Ethics in Child Health: Principles and Cases in Neurodisability*. London: Mac Keith Press, 2015: 233–248.
- Woodgate, R. L., Gonzalez, M., Demczuk, L., Snow, W. M., Barriage, S., & Kirk, S. How do peers promote social inclusion of children with disabilities? A mixed-methods systematic review. *Disabil Rehabil*, 2020; 42(18): 2553–2579.
- Woodmansee, C., Hahne, A., Imms, C., & Shields, N. Comparing participation in physical recreation activities between children with disability and children with typical development: A secondary analysis of matched data. *Res Dev Disabil*, 2016; 49–50: 268–276.
- WHO. *International classification of functioning, disability and health: children and youth version: ICF-CY*. Geneva: World Health Organization, 2007.
- WHO. *ICF, International Classification of Functioning, Disability and Health*. Geneva: World Health Organization, 2001.
- WHO. *Rehabilitation in health systems*. Geneva: World Health Organization, 2017.
- Yngve, M., Baric, V., Lidström, H., & Borgestig, M. Feasibility of Partnering for Change (P4C) to create inclusive learning environments in Swedish compulsory schools. *Eur J Spec Needs Educ*, 2024; 40(1): 161–175.

APPENDIX

Appendix 1. Shier's (2001) pathways to participation-model

Table 9 Shier's (2001) pathways to participation-model

Levels of participation	Openings	Opportunities	Obligations
1. Children are listened to	Are you ready to listen to children?	Do you work in a way that enables you to listen to children?	Is it a policy requirement that children must be listened to?
2. Children are supported in expressing their views	Are you ready to support children in expressing their views?	Do you have a range of ideas and activities to help children express their views?	Is it a policy requirement that children must be supported in expressing their views?
3. Children's views are taken into account	Are you ready to take children's views into account?	Does your decision-making process enable you to take children's views into account?	Is it a policy requirement that children's views must be given due weight in decision making?
	<i>Minimum to achieve the UN Convention's children's right to participate</i>		
4. Children are involved in decision-making processes	Are you ready to let children join in your decision-making processes?	Is there a procedure that enables children to join in decision-making processes?	Is it a policy requirement that children must be involved in decision-making processes?
5. Children share power and responsibility for decision making	Are you ready to share some of your adult power with children?	Is there a procedure that enables children and adults to share power and responsibility for decisions?	Is it a policy requirement that children and adults share power and responsibility for decisions?

Appendix 2. Example of inductive content analysis

Table 10 Example of the data analysis from study I, answering the following analysis question: what do children consider meaningful in participation? (R=researcher, C=child)

Original meaning unit from the transcribed interview text related to the research question	Condensed meaning units (description close to the text)	Code (labels that describe the essential content in the meaning units)	Subcategory	Category	Main category
R: What do you like most about swimming? C: That I can decide what I want to do. I can play and do tricks and go down the waterslide.	Deciding what to do based on own wants	Deciding what to do	Making decisions and choices		Autonomy
C: Sometimes and sometimes not, but I rarely use them (floats in swimming). Depending on if I want to or not.	Using floats in swimming based on own wants	Making own choices about using aids in swimming			
R: What do you like about that drawing? C: Well, for example, it has a coloring picture, and you can choose and color it with any color.	Coloring pictures with the colors you choose	Choosing colors			
R: What is the best thing about drawing? C: Well, that you can draw in your own peace. R: Ok, you can then concentrate C: Yes R: What's a good drawing moment like when you have your own peace? C: Well, being alone at home, in my own room and having peace when there is no noise. N: Does the noise bother you? B: Well, yeah.	Drawing peacefully in own room at home and being able to concentrate when there is no noise	Concentrating on drawing without distractions	Concentrating on interesting activities	Doing things based on own interests and preferences	
I've missed the (stretching exercises) in the summer. I haven't done them terribly. I don't know, I can't do them when I'm not interested.	Not interested in doing the stretching exercises	Avoiding the uninteresting stretching exercises			
C: I have something to say. R: Yes? C: Guess what R: Well, what? C: I was skating with my shoes. R: With your shoes? C: Yes. Child's mom: Yes, we have agreed that when others go skating, you can join them with shoes. C: Yes. C: I want to go skating. I skate with my shoes.	Choosing to participate in skating in shoes	Preferring to join skating with shoes	Joining activity in preferred way		

Original meaning unit from the transcribed interview text related to the research question	Condensed meaning units (description close to the text)	Code (labels that describe the essential content in the meaning units)	Subcategory	Category	Main category
<p>R: How does practicing feel like? C: It is nice because I can command and tell what (name) needs to do</p>	<p>Practicing is nice because can command and tell what others need to do</p>	<p>Commanding and instructing others</p>	<p>Giving instructions</p>	<p>Instructing others and structuring terms of actions</p>	
<p>I would want to play games more, but I cannot. It's just boring when my little brother always goes to play on the computer, and I have to go and watch. So, I'll never get to play it terribly.</p>	<p>Boring because cannot play on the computer as much as would want to</p>	<p>Boring when not able to influence play time and amount</p>	<p>Influencing play time and amount</p>		

ORIGINAL PUBLICATIONS

- I Vänskä N, Sipari S, Haataja L. What Makes Participation Meaningful? Using Photo-Elicitation to Interview Children with Disabilities. *Physical and Occupational Therapy in Pediatrics* 2020;40(6): 595–609. doi: 10.1080/01942638.2020.1736234

© **copyright # 2024**, reprinted by permission of Informa UK Limited, trading as Taylor & Taylor & Francis Group, <http://www.tandfonline.com>

- II Vänskä N, Sipari S, Haataja L. Practices for Promoting a Child’s Best Interests in Paediatric Rehabilitation – Perspectives of Professionals and Parents. *Journal of Child Health Care* 2024;0(0). doi: 10.1177/13674935241287880

Sage Ltd. published the Contribution under this Creative Commons license: **Creative Commons Attribution license (CC BY4.0)**. This license allows others to re-use the Contribution without permission as long as the Contribution is properly referenced.

- III Vänskä N, Sipari S, Jeglinsky I, Lehtonen K, Kinnunen A. Co-development of the CMAP Book: A tool to enhance children’s participation in pediatric rehabilitation. *Disability and rehabilitation* 2022;44(9): 1709–1719. (ePub 25.5.2021). doi: 10.1080/09638288.2021.1921061

© **copyright # 2024**, reprinted by permission of Informa UK Limited, trading as Taylor & Taylor & Francis Group, <http://www.tandfonline.com>

