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# Please cite the original article:

Kinnunen, A.M. & Holopainen, L. 2023. A Journey of Discovery: Modelling Participation to Enhance Multifunctional Collaboration among Children with Disabilities. Scandinavian Journal of Disability Research, 25 (1), 256-268.

DOI: https://doi.org/10.16993/sjdr.976







# A Journey of Discovery: Modelling Participation to Enhance Multifunctional Collaboration among Children with Disabilities

**RESEARCH** 

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# **ABSTRACT**

Children's participation refers to involvement in interaction with others together with attendance in family and community activities. There is an urgent need to develop actions that promote participation of children with disabilities, but there is still limited understanding of processes that may enable it. This study focuses on how the participants (five parents, two teachers, three therapists) enhance participation of Finnish children with neurological disabilities at school, home, and in the therapy and how participants develop multifunctional collaboration to promote participation. Participants were interviewed five times in group interviews for one year. The data were analysed with a qualitative grounded theory approach. Three central factors enhancing participation were found: factors preparing and building participation and factors promoting participation in action. A participatory multifunctional collaboration model enhancing participation showed that collaboration is built up through a child-centred approach by sharing information and know-how and by transcending adults' prejudices and fears.

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### **KEYWORDS:**

children; disability; multifunctional collaboration; participation

# TO CITE THIS ARTICLE:

Kinnunen, Anu Maarit, and Leena Holopainen. 2023. "A Journey of Discovery: Modelling Participation to Enhance Multifunctional Collaboration among Children with Disabilities." Scandinavian Journal of Disability Research 25(1):256–268.DOI:https://doi. org/10.16993/sjdr.976

# INTRODUCTION

Participation is equated with agency, the right to be heard, and the right to self-determination (Adair et al. 2015). Special attention should be paid to strengthening participation when it comes to children with disabilities (Imms, Granlund et al. 2016; Law et al. 2007; Webster & Carter 2007). The concept of participation is widely used but not clear. Namely, participation holds relationships between attendance and involvement. Attendance is related to availability, accessibility, and affordability of activities, and involvement is related to how accommodating and acceptable the activity setting is both to the individual and to others (Imms, Adair et al. 2016). Strengthening participation means, above all, focusing on children's physical, social, attitudinal, and interactive environments rather than their (dis)abilities and skills (Anaby et al. 2013; Karlsson 2020; Kinnunen et al. 2021, Mercerat & Saïas 2021).

Participatory practices build children's confidence in their own actions and allows them to become aware of their right to participate (Teleman et al. 2021). In this regard, it is important to not only focus on children's current participatory activities but also on the possibilities and decisions for their future life course. Focusing on future aspects of the child's possibilities to participate helps the child to grow as a member of society (Rosenbaum & Gorter 2012). One of the best-known and most widely used models for examining child participation through childadult interaction is Shier's (2001) pathways to participation model. The model aims to increase the child's participation linearly, and the relevant point in the model is that it is not a question of whether children participate but to what extent and how (Larsson et al. 2018; Andersen & Dolva 2015; Shier 2001). Adults play the most crucial role in strengthening a child's participation in daily life, and the child's experience of participation is formed in these everyday situations (Imms, Granlund et al. 2016; Madsen, Handberg & Nielsen 2019). Accordingly, the aim of this paper is to explore the issues raised by teachers, parents, and therapists in developing a multifunctional collaboration to enhance possibilities for children with disabilities to participate in their own at-home activities, as well as in education, therapy, and society. In addition, as current research has gleaned only a limited understanding of the processes that may facilitate these children's participation in different environments (Whiteneck & Dijkers 2009), our aim is to build a comprehensive model of the collaborative participation process.

# CHALLENGES AND FULFILMENT IN PARTICIPATION AT HOME, SCHOOL, AND THERAPY OF CHILDREN WITH NEUROLOGICAL DISABILITIES

Internationally, the publication of the Convention on the Rights of the Child (UN 1989) and the Salamanca Statement (UNESCO 1994) gave rise to the development of policies and practises of children's participation across the world. Moreover, the Convention on the Rights of Persons with Disabilities (UN 2016), specifically Article 24, which points to 'the right of persons with disabilities to education' and the right to 'an inclusive education system at all levels and lifelong learning', started in many countries the development of strategies and practises to enable children's educational participation or inclusive education. Concerning education, Finnish legislation underlines that schools must promote every student's participation and ensure that all students can participate in the operation and development of the school and express their opinion on matters related to the status of them (Ministry of Education and Culture 2019). The move to inclusive education in Finland has been going on for decades; however, there are still challenges in its implementation (Nikula, Pihlaja & Tapio 2021). In addition, Articles 29 and 30 (UN 2016) recognise the right of persons with disabilities to participate in community. In Finland, according to Article 6 in the Constitution of Finland (731/1999), persons always have the right to receive information about matters concerning them and the right to express their own views on them. The above-mentioned follows that in many countries, also in Finland, the child's right to participate is reasonably supported by legislation but realised with varying degrees (Ketola 2011; Maciver et al. 2019; Vetoniemi & Kärnä 2021).

In this study, the participation of children with developmental neurological and motoric disabilities is inspected. These children experience several difficulties that may impact their ability to communicate and interact actively. It has also been reported that children's neurological disabilities are especially negatively correlated with physical independence and mobility (Rosenbaum 2003). Disabilities may also incur prejudice and stigma, as well as low expectations for how children with disabilities can contribute to making decisions affecting their own lives (McConachie et al. 2006). These children can be seen, therefore, to be at high risk for experiencing difficulties in actively participating at school and in society (Majnemer et al. 2008). Kinnunen and Holopainen 257 Scandinavian Journal of Disability Research DOI: 10.16993/sjdr.976

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Previous studies have shown many challenges in active participation at home, school, leisure time, and society for children with disabilities. Parents of children with disabilities have reported a high level of desire to change their children's participation patterns at home and in community (Jeong et al. 2017). For example, parents see that participation in 'unstructured physical activities' and 'getting together with other children' as the most important activities aiding their children's participation (Bedell et al. 2013). Challenges to participation raised by parents also include the child's dependency on the family and their concern about the child's ability to change and be autonomous as they grow older (McConachie et al. 2006). Listening to families and utilising their expertise helps uncover solutions that support the child's everyday life, learning, and functioning (Chiarello et al. 2010).

Politicians, researchers, and practitioners perceive inclusive education differently concerning, for example, what schools can and should do to help inclusive education succeed (Göransson & Nilholm 2014). From a sociological point of view, this desire to adapt the education system to the needs of all is in line with the understanding of disability as a social and environmental relationship. One barrier to educational participation of children with physical disabilities is the traditional 'Medical Model thinking' of teachers and other professionals, which views a disability as a defect within the individual that must be cured, fixed, or even eliminated (Cameron & Lingwood 2020). In this view, children are not seen as individuals actively participating with their disabilities. In several countries, the challenge of enhancing educational participation has led professionals to reflect on and evaluate their own practises and collaboration (Imms, Granlund et al. 2016). Children participating in the school community as full members, playing and working with classmates, are at the beginning of their participation in society. In addition, at-school participation can be strengthened by a teacher's knowledge of the needs, the possible diagnosis, and the background of the child with disabilities (Kurniawati et al. 2014).

The starting point of support and rehabilitation is at its best in family orientation. This means that a child's support cannot be planned without considering the entire family's everyday life. Moreover, the support the child needs should be integrated into the child's natural growth environment because the child learns by participating in everyday activities at home and at school (Rapp & Corral-Granados 2021). Children's rehabilitation practises require a working approach based on participation, which is based on everyday experiences and enables children to learn and develop new skills while strengthening the family and the child to participate in society as a full member (Palisano et al. 2019). Children have their own important role to play in enhancing participation in their rehabilitation, and an adult's actions towards that are essential (King et al. 2009). It has also been recognised that the adult's actions for making the child's arowth towards an independence are meaningful. Making this possible is also connected to meaningful goals in daily activities (Palisano et al. 2019; Rosenbaum & Gorter 2012).

# TOWARD MULTIFUNCTIONAL COLLABORATION AROUND CHILDREN WITH **NEUROLOGICAL DISABILITIES**

In this study, we use the concept of multifunctional collaboration to emphasise the roles of children and family working together alongside professionals (Palisano et al. 2019). Underlying this is the idea of partnership, which defines a common role and division of responsibilities in which professionals and parents are equal. Parental involvement in their child's affairs is essential, as they possess knowledge of the child, while professionals have special expertise in the situations of similar children through their respective professions. Multifunctionality entails the involvement and expertise of children and families as the best experts on their own lives. Shared expertise requires a relationship of trust, shared involvement, and collaboration (Adair et al. 2015).

The significance of an open and receptive professional culture and the willingness to collaborate and communicate openly is recognised in the research (D'Amour & Ontasan 2005; Nancarrow et al. 2013). In collaboration between professions, professionals represent different practises and perspectives that define what kind of goals and activities they focus on, but identifying the needs of the family, shared responsibility, and family empowerment are the key principles of multifunctional collaboration (An & Palisano 2013). Studies have shown that collaboration between parents and teachers positively affects, for example, students' academic progress (Azad & Mandell 2016; Mazon et al. 2021; Minke et al. 2014) and information sharing, being heard, and collaboration with family in all phases of the rehabilitation process is meaningful (Järvikoski 2013). Still, more research is needed on how collaboration in supporting schoolaged children with disabilities is executed.

A teacher's main goal is to ensure optimal learning for all students, but other professionals can support them in their work teaching children with disabilities (Barnes 2008). Because of the need for teachers to receive such outside support, it is important to find ways to develop collaboration. It has been shown in previous studies that hindering elements of collaboration in school settings creates tension in collaboration, including lack of time and poor understanding of roles (Wintle et al. 2019). Promoting factors, including shared understanding and respect for each other's roles and expertise, have been shown in studies from Campbell, Camden, and Missiuna (2016) and Missiuna et al. (2012). Moreover, a cross-professional approach at school can provide a child-centred pedagogical approach whereby a child's individual needs are acknowledged. It has also been reported that working cross-professionally can be perceived as enhancing inclusive education by comprehensive assessment of individual strengths and needs through identification (Barnes 2008).

The model of participation designed by Shier (2001) describes the strengthening of participation by climbing from one level to another; however, Shier notes that it is beneficial to occasionally descend to a lower level. Through observation, the adult learns to take advantage of these levels and strengthens the child's participation according to his or her level of development. Now, however, this does not appear to be a consistent approach for adults to take either when working with disabled children or when participating in life that is seen as 'a process [that] is situated, that is relational and that is uniquely linked to young people's individual lifetrajectories' (Cahill & Dadvand 2018).

In the last five years, major social and healthcare reform has been carried out in Finland and in many other countries (Kangas & Kalliomaa-Puha 2022). The needs and wishes of the entire family along with the child—not just on existing services or professionals—have been recognised as key principles in planning and implementing services (An & Palisano 2013; Kennedy-Behr, Lowe & Teo 2018). Thus, in Finnish context, the governmental aim is to ensure more family-oriented services in the social and healthcare sectors. Combining the knowledge and skills of different sources provides the family with a comprehensive set of services that accommodates the requirements and the lifestyle of that family—not the other way around (Kennedy-Behr, Lowe & Teo 2018). Families, and especially children, should be seen as equal partners who set service goals and evaluate the quality of the services they want and need (Morgan et al. 2016). In Finnish reform of services for children and families, the goal has been to consolidate the service package for children and families in such a way that the quality, accessibility, and timeliness of the services offered to children and families would be possible (Aula 2019). This requires closer multidisciplinary collaboration and new operating models. Therefore, the main aim of this study is to analyse the different roles of participants (i.e., parents, teachers, therapists) in multifunctional collaboration and in enhancing participation at school, home, and in the therapy of children with neurological disabilities. The specific research questions (RQs) are as follows:

RQ 1. What are the participants' perceptions of the concept of participation, and what are the factors enabling the child's participation in education, therapy, and society?

RQ 2. What types of acts, procedures, and multifunctional collaboration amongst adults promote the child's participation in education, therapy, and society?

# **METHODS**

# PROCEDURE AND PARTICIPANTS

The study participants were obtained through the rehabilitation counsellors of the North Savo region in the middle of Finland, which has about 250,000 inhabitants. The rehabilitation counsellors work in the university hospital and participate in rehabilitation planning with families and professionals. The rehabilitation counsellors were introduced to the study and received information about the study orally and in writing from the researcher. They passed this initial information about the study to parents. The researcher's contact information was found in the research bulletin, based on which participants contacted the researcher either by phone or email. When the parents contacted the researcher, they were again given information about the research and research process. The parents who participated in the study submitted a signed consent form at the meeting at the beginning of the research process. Parents provided information about the study verbally and in writing to their child's teacher and therapist, who considered whether to participate in the study. Interested teachers and therapists contacted the researcher by phone or email. The teachers and therapists who participated in the study received the same information again and the research consent form after contacting them. At the beginning of the study, they submitted a signed consent form to the researcher. The group of participants was rather small, but participants represented the groups of adults commonly found around children with neurological disabilities. The data was based on and built around conversations with people who understand the phenomenon under study. Of course, a larger group of participants could have produced more perspectives on the topic.

The prerequisite for participating in the study was that the participant be a parent, teacher, or therapist of a child with special support needs receiving intensive rehabilitation. The participants had to actively participate in the child's everyday life. The middle-aged parents (three mothers and two fathers, mean age 50.3 years) of three children in primary school (ranging in age from 8 to 12) participated in the study. In addition, two teachers (one class teacher and one special education teacher, male and female, mean age 28 years) participated in the study. Moreover, three therapists (male and two females, mean age 41.3. years) participated in the study. The therapists were either physiotherapists or occupational therapists by profession, and their working environments were the home and the therapy facilities of the hospital and schools. They operated in both the public and private sectors as professionals.

## **DATA COLLECTION**

The data were collected through individual and group interviews. After obtaining each participant's consent, the in-depth interview process was conducted. Intensive conversations allowed different perspectives to open and deepen. Also, individual questionnaires were used to collect background information (e.g., age). The interviews were audio recorded with the participants' agreement. The data collection process was carried out from from the August 2015 to May 2016 in five-step process. Process included thematic interviews, such as perceptions of participation, promoting and preventing actions of participation, and collaboration between parents and other adults enhancing participation. During the research process, a total of 13.5 hours of discussion material was accumulated.

### **ETHICAL ASPECTS OF THE STUDY**

This study has sought to adhere to the ethical principles of good research. The principles of informed consent have been applied to participation in the research (Kohonen et al. 2019). Participants in the study received instructions orally and in writing. Their participation in the study could have been suspended at any time, and additional information was available to them. Interviews and discussions provided by participants were treated anonymously and confidentially. The research material remains with the researcher and is used only in this research and in any scientific articles related to this research. According to the instructions of the Committee on Research Ethics at the University of Eastern Finland, an ethical review statement was not required from a human sciences ethics committee, as this research does not involve intervening in the physical integrity of research participants. The participant group of the study consisted of parents of children under the age of 15 who had given their consent to the study. Participation in the study did not pose an immediate danger or threat to their safety or exposure to strong stimuli. Finally, participating in the study did not cause mental harm beyond the limits of normal everyday life for the people who participated in the study. Moreover, only participants' personal data have been collected and not been combined with data from several different sources.

# **DATA ANALYSIS**

The grounded theory approach (Charmaz 2014), including coding data, writing memos, and theorising the data, was used in this study (see Table 1). The principles of theoretical sampling were applied, and the concentration of the analysis process on categories and making comparisons continued until the saturation point was reached. Data analyses were conducted via an inductive process. By the principles of grounded theory, the method of constant comparison

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**Table 1** Data analysis process.

was used. Data were compared within and between transcripts using single codes to build codes
which were cross-analysed to build categories. Open coding was completed, while related codes
were grouped together. Memo writing was used to understand the relationships between codes
and categories. When theoretical saturation was reached, which is the point in the analysis
when the core category of this study was formulated, data analysis was ended. At the end of the
research analysis process, the aim was to derive a substantive theory, a combined model about
the reality of the participation of a child with disabilities and the collaboration that reinforces it.

LEVEL	NAME	PURPOSE	RESULTS
Phase I	Open coding	To generate concepts (codes) related to building up the inclusion/participation of a child with disabilities.	Concepts and category names were created, and properties identified.
Phase II	Axial coding	To generate concepts related to building up the inclusion and participation of a child with disabilities and to find categories amongst concepts.	Concept and category connections located and described. Duplicate categories merged, hierarchy formed, and upper categories identified.
Phase III	Selective coding	To find the core category of inclusive and participation activities.	Creating a model that builds up the participation of a child with disabilities.

# **RESULTS**

### ADULTS' PERCEPTIONS OF THE PARTICIPATION OF A CHILD WITH DISABILITIES

The research results, based on descriptions by parents, teachers, and therapists, are presented according to the order of the research questions. RQ 1 is addressed in the sections Recognition of factors preparing participation and The child as key actor in building participation through the categories and subcategories. RQ 2 is answered in the section Participation promotion in action.

# Recognition of factors preparing participation

A prerequisite for participation is that participation itself is seen as a starting point for action. 'Participation is human dignity,' said one therapist in the interview. In the data, 'participation' meant the child's presence in the meetings; for another participant, it meant listening to the child. The equality of participation came up in the parents' discussions. One parent said, 'The child is equal to others, who, despite the disability, is not pitied.' The parents also emphasised that participation means the child being included in everything, with support measures offered to enable participation. Therapists emphasised that participation means that the child is the main actor in the activity. Teachers emphasised the child's participation amongst his/her peers, which is influenced by the opportunity to interact with others. In the opinion of all participants, the value of the activity was strongly related to participation. Everyone believes that valuing the child's own opinion and respecting their decision-making power are important factors in participation.

Participation is being allowed to be yourself, especially now that you are getting older. Saying your own opinions, because he is the best expert on his own issues. (Parent 1)

Every adult has their own role and task in a child's life. Children are given their own roles and responsibilities. Parents appear in the data as experts on their own children, sharers of information and, above all, as partners for the child and other adults. The adult is also seen as a supporter of the development of the child's social relationships with their own activities. From time to time, the adult must also take the role of the decision-maker, in which case the child is, as it were, an object in action. For therapists and teachers, a significant factor was whether the adult was familiar to the child. Teachers and therapists were seen as important adults in the lives of children with disabilities.

Village educator ideas—parents together with all those involved in the child's life. (Parent 5)

In the research, the operating environments are society, home, school, therapy, and leisure environments. The environment can have limiting or promoting physical properties. The limitations of the physical environment are reflected in the child's everyday life in a significant way. A child's ability to participate in normal everyday activities can be significantly reduced due to physical barriers.

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On the other hand, the environment can also be seen as an enabling factor. The child's familiar environment, such as the home, was seen to have positive effects on the child's and family's voice being heard. The parents described that it is easier for the child and the family to share information in their own home, for example, in collaboration meetings. The therapy of a child in need of special support appears to take place in varying operating environments. However, it is an important part of a child's everyday life, and it is linked to home, school, and leisure activities. School is seen as an important operating environment for a child who needs special support. The school also appears as a meeting place that enables friendships. According to the participants, children also need leisure activity environments where they can naturally develop their own skills and experiences of success. Leisure activity environments also enable activities with peers.

In the study, the most significant barrier was people's attitudes towards a child in need of special support. Adults' attitudes matter in encounters with children; they also affect the way adults collaborate with others. Parents described an example where a teacher had a negative attitude towards the child because the child created more work for him. The parents also described the way some professionals work as 'contract work', where there is no time to stop for the child's individual issues and needs. In addition, poor information flow, lack of a common language, or lack of understanding of the other's role can lead to dysfunctional collaboration between adults.

Teachers may have fears because they feel that they do not have enough information about disabilities. They may therefore withdraw from cooperation because they do not have sufficient means to work with the child. (Teacher 1)

# The child as key actor in building participation

In the data, the child's role in building participation was seen as crucial. Participants see the child as an individual actor with their own personality and temperament. According to the participants, the child should be seen 'beyond their disability and aids, and at the same time, the child's individual characteristics and support needs should be understood'. The data highlight experiences of success connected to the development of the child's self-esteem and how they participate in different situations. When it comes to a child who needs special support, recognising their strengths is especially important during everyday challenges. Identification of what is meaningful to the child enables motivation and transition to everyday life.

If I say to the child what has to be done and why is important to her at the moment, but there's no interest in doing what I am telling, we'll hardly reach the goal. That has to come from the child. What is important to her and what is meaningful goes through the child. (Therapist 3)

The child themselves should play a central role when their activities are planned. It would be good to focus on the child's strengths and interests. In the data, the conditions for participation were strongly related to the presence of the child in the processing of matters concerning them, mutual discussion, and the child feeling heard. Valuing the child's own opinion and respecting their decision-making power are important qualifications for participation. The child's right to self-determination is made concrete in everyday activities. Adults should try to understand the child's world from his/her point of view. Values and worldview influence any way of working, and this is significantly reflected in the child's opportunities to participate.

We should listen to that child. Yes, we should respect the child. Could it be possible for a therapist or professional to jump in there on the children's side, so as not to always change that environment from an adult's world? (Therapist 1)

The child's own perspective and experiences should be used in the planning of an activity. In the data, the participants identified a fear that the child would not be allowed to act or experience but would be passively treated as an individual in the institution. Equality is seen as a prerequisite for participation. When implemented, it gives the child an equal opportunity to participate in various everyday situations as themselves and with their own abilities and skills. Equality is described as personal experiences amongst other people's children. Equality is an experience—a feeling of belonging amongst others, equals. That experience is very empowering and motivating for the child.

Adults should also look at their own behaviour and actions through a child's eyes. According to the results, a journey of discovery by adults into the child's world is essential.

It is a journey of discovery into the world of a child. Not always [of] a child into the adult world, but an adult [into the] child world. (Parent 2)

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### Participation promotion in action

Adult practises should be child-centred and enhance friendships with other children. The teacher described how critical it is to get the child involved in activities according to their own strengths. This requires professionals to work together as well as understand the value of the child's participation in activities. One teacher described how important it is to obtain permission from a therapist to allow the child to participate in exercises in class, even in poor operating environments. On the other hand, there is not always enough time to help a child who needs support to participate equally. Peer support from another child with disabilities is also related to friendships.

Peer support gives the child strength and alternatives, to see that some others have done this and others have done that. And what has followed from those decisions. (Parent 2)

Open interaction and collaboration are key to enabling participation. In open interaction, the adult should be willing to listen to what others have to say. In addition, the participants should appreciate the opinions of others, including the child and other actors around the child. Empathetic encounters were considered essential. Collaboration requires trust building and commonly agreed-upon rules and procedures. When working with a child, the adult and child should have a common language that helps the adult adapt to the child's world of experience and meaning.

Knowing the family's everyday life is also essential. For example, parents felt it was challenging if the therapist could not comprehend the family's everyday life. Without this, rehabilitative actions could not become part of everyday activities. The professionals, on the other hand, stated that sometimes the parents did not have enough resources to focus on collaboration, and that made it difficult.

The participants expressed that sharing information improves collaboration and the child's opportunities for participation. Shared information makes it possible to plan actions and material appropriately and in a timely manner. One teacher described how incorrect information about a child's material needs affects the child's participation at school. Moreover, misinformation about the diagnosis and its implications for a child's functioning causes difficulties for participation in everyday life at school. Misinformation is also thought to affect preconceived attitudes and fears, thereby limiting the conditions for a child's effective participation.

Based on the data analysis, a substantive theory was derived on how collaboration strengthens the participation and agency of a child with disabilities. Collaboration that enhances participation is built up through the preparatory factors of participation and recognition of the child as an actor in participation, followed by participation promotion in action. In addition, the dimensions of participation are based on adults' collaboration, promotion of the child's agency, and participatory policies. This collaboration is built on common operating principles. Every child is seen to play an important role in working together. Transparency and clear roles in the division of labour are also crucial. Moreover, the process assets of the activity appear to be a dimension of the collaboration that enhances participation.

# **DISCUSSION**

The results of this study were explored from a two-phase analysis process resulting in three dimensions of participation. Dimensions were the recognition of factors preparing participation, the child as a key factor in building participation, and participation promotion in action. The child as a key builder of her/his own participation included identification of individual characteristics, strengths and needs, equality, and things that are meaningful to the child. Participation promotion in action is constructed through supporting the child, having common language, childlike action, peer actions, and open interaction between adults in collaboration. In the final phase, a participatory multifunctional collaboration model combining all three dimensions was constructed.

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It was clear to all participants that the child's participation should be the starting point for all collaboration, but at the same time, the participants expressed that negative attitudes affecting participation can be seen in their own and others' everyday actions, for example, how much they give space to a child's own initiatives. This also shows that in Finnish context, more actions should especially be focused on everyday activities. For example, therapists and teachers could collaborate more actively in classroom situations instead of working independently at the school and in the hospital, which is the most common situation. Namely, participation includes the power to influence one's own operations, growth, and operating environment, which contribute to strengthening growth, learning, and well-being. All involvement happening at school age also has a strong influence on the control of the individual's own life in the future (King et al. 2009). Making this development towards independence possible should be one quiding factor for all adults working with children. A child needs support to find their own meaningful goals towards adulthood (Palisano et al. 2019; Rosenbaum & Gorter 2012).

It has also been established that services for children with special needs should move to evidence-based activities that guide the provision of services to continuously achieve community participation and quality of life (King et al. 2009). In this study we show that a child's quality of life derives from the child's agency and their own key role in participation promotion. Another important result is that a child with disabilities can provide reliable and important information him/herself and be an active participant when an assessment process is adapted to them. It follows that the active involvement of children and families is necessary to ensure, for example, by strengthening the role of the child and parents in school and therapy (Anaby et al. 2013; Karlsson 2020). By this, it could be possible to create participation-focused activities that are meaningful, motivating, and contextually relevant for children (Palisano et al. 2019). This also means that measures and actions assessing the needs of the children with disabilities should be developed in collaboration with the children, parents, and professionals (Granlund & King 2021; Piškur 2013).

Participation-focused practice reflects a paradigm shift in interventions for children with disabilities or long-term health conditions, as the issue to be addressed becomes participation in everyday activities rather than problems with body function (King et al. 2009, Cahill & Dadvand 2018). Our results highlight participation-enhancing actions in multifunctional collaboration. Practises focused on participation require the introduction of new methods and new ways of working. One important change is to use child-centred approaches, emphasised in the collaborative model in this study. In our results, we point out that it would be crucial for the adult to be genuinely present in the interaction with the child and to indulge in listening to and understanding the child's message. Identifying and reinforcing a child's strengths and minimising limitations will optimise the child's opportunities for participation in decision-making. Here, different digital solutions can play a key role (Vinblad et al. 2019). Vänskä et al. (2021) showed in their research that children's own views and voices were heard, and meaningful things in their daily lives were shared with adults, which empowered children and made their world more transparent.

In our research, factors hindering participation, such as stigma, parental worry, overprotection, and financial stressors, were detected. In the case of children who need special support, the stigma resulting from the disability and negative system practises can isolate non-disabled and disabled children from each other (Anaby et al. 2013). In Finland, the move from segregation of children with disabilities to inclusive education has been going on for decades, but there is still work to do (Nikula, Pihlaja & Tapio 2021). Moreover, parents' lack of support or the negative attitudes of peers and other persons can be barriers to the child's participation (Zheng et al. 2016; Cairns & McClatchey 2013). Other studies have a shown that society's bureaucracy and the poor availability of services can weaken opportunities to participate (e.g., Lach et al. 2008). Finnish society has a multidimensional healthcare system which has gone through major changes in this decade. The system is challenging because the services are scattered in the system, so it can be difficult for parents to find them. Service guidance is also not systematic: therefore, the multidimensional collaboration is quite unstructured, which was also brought up in this study.

The journey of participation described in the present study can be compared, for example, to the model developed in another geographic place and culture over two decades ago by Shier (2001). At the lowest levels in that model, where individuals have few or no opportunities for decision-making, listening to a child is a key starting point for enhancing participation. Adults around the child begin to plan how and to what extent the child with disabilities can participate. The model of enhancing collaborative participation in this study was based on the dialogue between all participants. To adopt it fully into practice, a new operating culture in Finland is required. Although the built model of participatory collaboration does not include an element of performance evaluation, it could be used in planning and implementing participatory collaboration. Moreover, it would be important to continue to develop the model with larger and different groups of adults and with different groups of children with disabilities.

# **CONCLUSIONS**

The results demonstrate the importance of recognising all actors' individual attitudes, knowledge, and practises enabling or hindering collaboration to build up a participatory collaboration model. The key enabling elements were the mutual sharing of expertise and information between all actors in the integration of everyday practical activities in different environments, an open and appreciative atmosphere, and hearing the child's voice in his/her own everyday environment. The results further indicate that adults' prejudices and fears about disabilities, short of information about children's disabilities, and concrete physical barriers in the environment are the main hindering factors. Considering the results, this requires new skills and new ways of working. This also needs management support, systematic change in organisational procedures, further training for professionals, and collaboration between the basic training programmes. Our findings contribute to a contextualised conception of children's participation, looking at the participation as a model that could be used, for example, as a checklist for planning joint activities in the phase of starting or implementing inclusive collaboration. Moreover, when further developing this model, an evaluation piece should be added for quality verification of the process.

### DATA ACCESSIBILITY STATEMENT

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

# **ACKNOWLEDGEMENTS**

We extend our warm thanks to the parents and professionals who took part in the research process.

## **COMPETING INTERESTS**

The authors have no competing interests to declare.

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### TO CITE THIS ARTICLE:

Kinnunen, Anu Maarit, and Leena Holopainen. 2023. "A Journey of Discovery: Modelling Participation to **Enhance Multifunctional** Collaboration among Children with Disabilities." Scandinavian Journal of Disability Research 25(1):256-268.DOI:https://doi. org/10.16993/sjdr.976

**Submitted:** 12 October 2022 Accepted: 09 August 2023 Published: 11 September 2023

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Scandinavian Journal of Disability Research is a peerreviewed open access journal published by Stockholm University Press.

