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Exploring participation in family and recreational activities among children with cerebral palsy during early childhood: how does it relate to motor function and parental empowerment?

Runa Kalleon^a , Reidun Jahnsen^b  and Sigrid Østensjø^a 

^aOsloMet – Oslo Metropolitan University, Oslo, Norway; ^bOslo University Hospital (OUS), University of Oslo (UiO), Oslo, Norway

ABSTRACT

Purpose: To explore participation in real-life activities during early childhood, compare children's participation based on motor function and investigate relationships between participation and parental empowerment.

Methods: Data derived from the Cerebral Palsy Follow-up Program (CPOP) in Norway and the research registry Habilitation Trajectories, Interventions, and Services for Young Children with CP (CPHAB). Fifty-six children (12–56 months, GMFCS levels I–IV, MACS levels I–V) and their families were included. Frequency and enjoyment of participation were assessed by the Child Engagement in Daily Life Questionnaire and parental empowerment in family and service situations by the Family Empowerment Scale at least twice during the preschool years. Differences between groups based on motor function were explored by the Kruskal–Wallis tests. A linear mixed model was conducted to explore relationships between child participation and parental empowerment.

Results: Similarities and differences in participation between children at different motor function levels varied between the activities explored. Fluctuations in frequency and stable enjoyment scores over time were most common. A statistically significant relationship was revealed between child participation and parental empowerment in family situations, but not in service situations.

Conclusions: Child participation appears as context-dependent and complexly influenced by both motor function and parental empowerment. This supports a focus on transactional processes when exploring and promoting child participation.

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Child participation; real life contexts; parental empowerment; transactional processes; cerebral palsy



► IMPLICATIONS FOR REHABILITATION

- Family and recreational activities represent real-life contexts providing opportunities for interactions and experiences supporting development and learning.
- Children with CP appreciate a wide range of activities in the home and community, which emphasizes the importance of providing opportunities for such participation in order to fulfill their desires and interests.
- Child participation appears as complexly influenced by the unique activity setting, motor function and characteristics of the family environment, requiring attention to transactional processes when aiming to explore and promote participation.

Introduction

A paradigm shift has recently been outlined within the context of pediatric rehabilitation transferring the focus from traditional rehabilitation settings toward children's real-life contexts and situated experiences [1]. This substantiates assessing and exploring child participation in family and recreational activities as relevant concerns both in research and practice. The paradigm shift implies moving beyond considering personal characteristics and environments as different points of entry when aiming to facilitate development and well-being, and instead turning attention to the transactions taking place among people situated in real-life contexts [1]. This is in line with a bioecological model highlighting ongoing reciprocal interactions involving the child and other

persons, objects, and symbols in the immediate environment (termed proximal process) as the very engine of human development [2]. Involving a child in a variety of daily activity settings provides opportunities for such ongoing interactions, thus constituting important contexts for learning, development, and personal growth [1]. However, it is worth noting that pediatric rehabilitation according to the new paradigm incorporates more than just promoting development and new skills, rather, it involves supporting children to realize meaningful lives [1]. This corresponds well with the definition of rehabilitation as a process of living well with a disability instead of being fixated on optimizing function [3]. As an extension of that, Gibson [4] encourages professionals to avoid a one-sided focus on a future developmental course and

CONTACT Runa Kalleon  runaka@oslomet.no  Department of Physiotherapy, Faculty of Health Sciences, Oslo Metropolitan University, P.O. Box 4, St. Olavs plass, Oslo N-0130, Norway

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instead acknowledge the enjoyment and engagement in the here and now in a child's life. Wenger [5] expands the understanding of participation in real-life contexts by pointing to participation in activities as more than simply doing or improving; it involves a sense of belonging and being in the world. Thus, exploring and providing opportunities for participation in real-life activity settings is considered an important subject both from a developmental perspective and as a recognition and caretaking of the child's current situation.

Imms et al. [6] identified two essential elements of participation: attendance and involvement. Attendance involves being present in an activity setting and can be measured as frequency of participation or diversity of activities, as well as a mapping of where and with whom the child participates. From a developmental perspective, frequency is essential because proximal processes are to take place on a fairly regular basis to be effective [2]. Participation in diverse activity settings is considered important because each activity represents a unique opportunity to participate in a community of practice that may expand the child's experiences and provide a valuable setting for learning [5]. Furthermore, the activities involve interaction with different partners, which in turn influence both the activities and role patterns taken [7]. Different activities lead to an exposure to varied physical environments that may affect opportunities for participation, particularly among children with motor limitations [8].

Involvement refers to the subjective experience of participating [6]. Experiences while engaging in interactions with persons, objects, and symbols are, in more recent versions of the bioecological model, included as a driving force of development [2]. Emotionally and motivationally loaded experiences affect preferences for activities and the children's sense of self, both posing intrinsic factors influencing and being influenced by participation [6]. Enjoyment represents an important subjective aspect of participation embedded in the involvement dimension. The extent to which a child enjoys attending an activity may thus both explain a current participatory pattern and give directions for future participation.

Participation is according to the framework presented by Imms et al. related to both characteristics of the person involved, the specific activity setting and the physical and social environment [6]. Previous research indicates that children with an early onset health condition like cerebral palsy (CP) participate less often in activities in their homes and communities compared to children without disabilities [9–11], and it has been revealed that parents perceive restrictions in family activities due to their child's CP diagnosis [12]. CP is a complex condition characterized by large variations in motor function as well as disturbances in perception, sensation, cognition, and behavior and other health conditions such as epilepsy [13]. Previous empirical studies, including young children with CP, have revealed differences in total scores of frequency and enjoyment in family and recreational activities related to levels of gross motor [10,14] and hand functioning [14], indicating that motor competence plays a role in a child's participation in activities. What has been less explored is participation as it appears in unique activity settings for children representing different levels of motor function, which has the potential to reveal nuances that otherwise may remain undetected in presentations of total scores. There is also a need for longitudinal research including both frequency and enjoyment of participation, thus providing two complementary perspectives on participation as it develops during early childhood.

Environmental and contextual dimensions affecting participation include availability (the objective possibility to engage in a

situation), accessibility (the perceived access to a situation or context), affordability (the financial costs and time and energy expenditure of being engaged in a situation), adaptability (how well a situation can be adapted), and acceptability (the person's acceptance of a situation and other persons' acceptance of a person's presence) [15]. Furthermore, child participation is shaped by the different ecological systems surrounding the child [2]. For young children, the family constitutes the immediate and most important system influencing child development and well-being [2]. Previous research has identified family ecology, operationalized as parents' perceptions of their family life and expectations of their child, as a determinant of participation [16]. Family empowerment represents another aspect of family functioning. Empowerment is defined as the experience of holding power or gaining control and mastery over life, and it can be expressed as skills or abilities, self-perception, and actions [17]. Parental empowerment has previously been operationalized into a measure of attitudes, knowledge, and behaviors expressed within different contexts [18]. Up to now, little research has explored the relationship between parental empowerment in family situations and child engagement in activities in real-life contexts.

The rehabilitation service system and collaboration between parents and service providers constitute a more remote ecological system surrounding the developing child. Previous research indicates that an intervention approach specifically focusing on the parent/service provider collaboration and coaching of parents has the potential to increase child participation in activities [19]. How frequency of child participation relates to parents' perceptions of empowerment when interacting with services and service providers during their child's early years, has, to the best of our knowledge, not previously been explored, and may thus add new knowledge about the relationship between the child and the surrounding ecological systems.

Therefore, this study aimed to explore participation in real-life activity settings among young children with CP during early years and in relation to motor function and family empowerment. The specific research questions were:

1. How frequent do children with CP participate in family and recreational activities in overall and in specific activity settings during their early years, and how much do they enjoy the activities?
2. How do the frequency and enjoyment of participation during early years relate to the child's gross motor function and hand function?
3. Do the children's frequency and enjoyment of participation change over time, and how do the participation trajectories relate to their gross motor function and/or hand function?
4. How does the frequency of child participation over time relate to parental empowerment in family and service situations?

Materials and methods

Study design and participants

The study was based on longitudinal registry data from two CP registries in Norway: the Cerebral Palsy Follow-up Program (CPOP) and Habilitation Trajectories, Interventions, and Services for Young Children with CP (CPHAB). CPOP is an ongoing registry that systematically maps primary and secondary impairments related to the CP diagnosis, gross motor and hand function, communication skills, and interventions. CPHAB is an additional research registry that includes parent-report questionnaires mapping extended

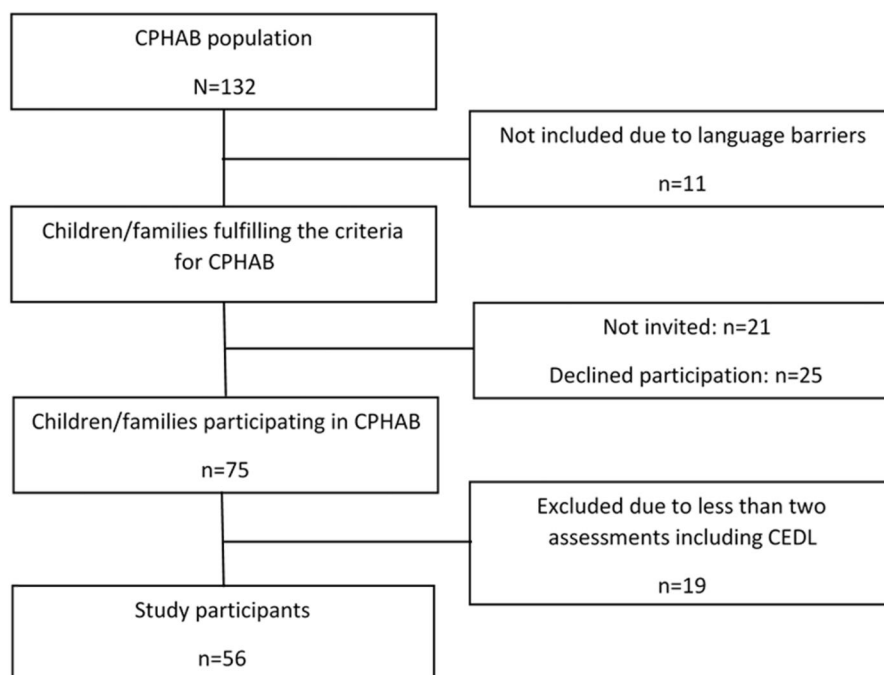


Figure 1. The inclusion/exclusion process.

child functioning, family characteristics, and services received. Thirteen out of the 21 child pediatric rehabilitation units in Norway participated in the CPHAB project running from 2012 to 2016. Questionnaires were completed at the regular follow-up consultations at these units once or twice a year according to the families' preferences.

Families included in the CPHAB were those raising a child four years or younger when first registered in the CPOP or Cerebral Palsy Registry in Norway (CPRN) between January 2012 and December 2014 and who were able to complete questionnaires in Norwegian or English. For the current study, only participants completing the questionnaire measuring child participation at least twice were included. Parents of children with the most severe mobility limitations according to the Gross Motor Function Classification System (GMFCS level V) [20] were provided with alternative questionnaires and were by that excluded from the study. Finally, 56 children and their families were included. The inclusion/exclusion process is illustrated in Figure 1.

Participation in the CPHAB project was voluntary and written consent was obtained from the parents of all participating children prior to the study. The study was approved by the Regional Committee for Medical and Health Research Ethics of South-Eastern Norway (registration number 2017/782).

Measure of participation

Child participation was measured by the Child Engagement in Daily Life (CEDL) Questionnaire [10], which is a parent-completed questionnaire aiming to assess participation in play and family routines [10]. The questionnaire consists of 18 items each representing a broad category of activities within the two domains, *family and recreational activities* (11 items) and *self-care* (seven items). In the present study, only the first domain was included. The 11 items included represent different activity settings of family and community life. Two dimensions of participation, frequency and enjoyment, were both scored on a five-point Likert scale ranging from 1 (never) to 5 (very often) and from 1 (not at all) to 5 (to a great deal) for each of the 11 activity settings

included. Based on the Rasch analysis, a scaled score for the overall frequency of participation is available by converting the summed scores for all the 11 items included using a conversion table [10]. Such a table does not exist for enjoyment. As a guide for interpretation of overall enjoyment, it is recommended to calculate an average of the raw scores on the 11 items [10]. For the domain family and recreational activities, internal consistency is reported as moderately high and test-retest reliability as acceptable. Children's participation varied by motor ability and age, supporting construct validity [10].

Classification of gross motor and hand function

Gross motor function was classified according to the five levels of the Gross Motor Function Classification System (GMFCS) [21]. The classification is mainly based on mobility performance. Children classified at level I are expected to walk independently indoors and outdoors, but with some limitation regarding speed and balance. Children classified at level II are expected to walk independently, but with some limitations outdoors. Prior to age 4, children might use a handheld mobility device. Children at level III may walk short distances with mobility aids but use wheelchair in the community. At level IV, self-mobility is limited, and the child is transported in a manual wheelchair or using powered mobility [20]. The GMFCS has demonstrated good reliability, predictive validity, and stability [21–23].

Hand function was classified according to the five levels of the Manual Ability Classification System (MACS/mini-MACS) [24,25]. The classification is based on typical use of both hands and upper limbs [24]. Children classified at level I are expected to handle most objects easily. Classified at level II, the children will handle most objects successfully, however, with somewhat reduced quality or speed. Children classified at level III are expected to handle objects slowly, requiring assistance or modification of the activity. At level IV, children can only handle a few easily managed objects in adapted situations, and children at level V do not have the ability to handle objects [24]. Reliability and validity of the MACS

and mini-MACS are considered good [24–27]. MACS and mini-MACS levels are for simplicity referred to as MACS in this paper.

Measure of parental empowerment

Parental empowerment was assessed using two of the subscales in the Family Empowerment Scale (FES): *family* and *service situations* [18]. The first subscale includes 12 statements referring to parents' perception of empowerment in their own handling of the immediate situation at home, while the *service situations* subscale includes 12 statements encompassing parents' perception of empowerment in collaboration with service providers and the service system. The statements reflect attitudes (what a parent feels or believes), knowledge (what a parent knows or potentially can do), and behavior (what a parent actually does) and are scored on a five-point Likert scale ranging from 1 (not true at all) to 5 (very true). A summary score for each subscale is calculated. High summary scores indicate a higher level of perceived parental empowerment in the given context. In a systematic review of empowerment measures, FES is rated as a high quality questionnaire in terms of item development, internal consistency, test–retest reliability, and content and construct validity [28]. The measure has recently been used as a main outcome in another CPHAB study [29].

All questionnaires were completed from two to six times during the child's early years with a median of four assessments completed.

Statistical analyses

Statistical analyses were performed using IBM SPSS Statistics 26 (Armonk, NY). CEDL employs a Likert-type scale providing data on ordinal level, and for that reason, median and range scores and non-parametric statistics were primarily used to analyze and report results. The statistical analyses performed are presented in relation to the four research questions in the study.

In order to explore child participation in family and recreational activities, median and range scores were calculated for each of the participants across their longitudinal assessments, thus representing the children's average participation during early years. Scores were calculated both as total scores across all the 11 activity settings (overall participation), and as separate scores for each of the 11 activities (question 1).

How frequency and enjoyment of participation relate to the child's gross motor function and hand function were explored using the median scores representing average participation across the longitudinal assessment. The children were divided in groups based on three levels of gross motor (GMFCS) and hand function (MACS). For GMFCS, the levels were: level I (minimal restrictions in walking), level II–III (restrictions in walking outdoors or in need of walking aids), and level IV (mostly using wheelchair for mobility). For MACS, the levels were: level I (handle most objects easily), level II (handles most objects, but with reduced quality), and level III–V (dependent on adaptations and/or assistance to handle objects). Differences in participation between the groups were analyzed using the non-parametric Kruskal–Wallis test followed by post-hoc pairwise comparison adjusted by the Bonferroni correction (question 2).

To explore potential changes in participation over time, median scores for overall frequency and enjoyment were calculated for each child at each of their longitudinal assessments. These scores were used for identification of participation trajectories. We further explored how the different trajectories were

distributed between groups based on the children's GMFCS and MACS levels (question 3).

How child participation during early years relate to parental empowerment was explored using scaled scores of overall frequency of participation. The scaled scores were determined based on the summed raw scores from all the 11 items included in CEDL using a conversion table [10]. Such a table is not available for enjoyment. The scaled scores available from all participants' longitudinal assessments were used as the dependent variable in the analyses of relationships using a linear mixed model. Summarized scores from the two FES subscales family and service situations were included as co-variables estimating fixed effects. The child's age and GMFCS level were adjusted for by including these variables as random effects in the analyses. *p* Value less than 0.05 was considered statistically significant (question 4).

Results

Characteristics of participants

Participants included children with CP of both genders classified across GMFCS levels I–IV and MACS levels I–V (see Table 1). Children's age at first assessments ranged from 12 to 56 months. Parental empowerment scores were overall high both in the context of family situations and in service situations. The follow-up period for the participants varied from 6 to 43 months, with a median follow-up time of 24 months.

Frequency and enjoyment of participation during early years

Median and range scores for the overall frequency and enjoyment of participation during the child's early years are presented in Table 2. The overall frequency of participation in family and recreational activities was high, with most children participating often or very often (median 4, range 2.5–5) and enjoying participation very much or to a great deal (median 5, mean 4–5).

The frequency of participation in each of the activity settings during early childhood is presented in Table 3. The children participated most frequently in family activities at home and in the

Table 1. An overview of child characteristics and parental empowerment scores.

Child characteristics	
Gender, <i>n</i> (%)	
Male	34 (61)
Female	22 (39)
Age in months, median (range)	30 (12–56)
Subtype CP (<i>n</i> , %)	
Unilateral	25 (45)
Bilateral	30 (53)
Other	1 (2)
GMFCS level (<i>n</i> , %)	
Level I	28 (50)
Level II	7 (12)
Level III	11 (20)
Level IV	10 (18)
MACS level (<i>n</i> , %)	
Level I	16 (28)
Level II	25 (45)
Level III	11 (20)
Level IV	3 (5)
Level V	1 (2)
Parental empowerment	
FES family (mean, SD)	51.3 (5.4)
FES service situations (mean, SD)	50.3 (6.6)

GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System; FES: Family Empowerment Scale.

Table 2. Overall frequency and enjoyment in relation to GMFCS and MACS levels.

Frequency				Enjoyment			
Median (range)	GMFCS and MACS levels	Median (range)	<i>p</i> Value	Median (range)	GMFCS and MACS levels	Median (range)	<i>p</i> Value
4 (2.5–5)	GMFCS I	4 (3–5)	0.023*	5 (4–5)	GMFCS I	5 (4–5)	0.003*
	GMFCS II–III	4 (2.5–5)			GMFCS II–III	5 (4–5)	
	GMFCS IV	3.5 (3–5)			GMFCS IV	5 (4–5)	
	MACS I	4 (4–5)	0.012*		MACS I	5 (4–5)	0.001*
	MACS II	4 (2.5–5)			MACS II	5 (4–5)	
	MACS III–V	3.5 (3–5)			MACS III–V	5 (4–5)	

GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System.

* $p < 0.050$.**Table 3.** Frequency of participation in family and recreational activity settings in relation to GMFCS and MACS levels.

Family and recreational activities	Median (range)	GMFCS levels	Median (range)	<i>p</i> Value	MACS levels	Median (range)	<i>p</i> Value
Family activities at home such as chores, mealtime, watching TV	5 (3.5–5)	GMFCS I	5 (4–5)	0.955	MACS I	5 (4–5)	0.223
		GMFCS II–III	5 (4–5)		MACS II	5 (4–5)	
		GMFCS IV	5 (3.5–5)		MACS III–V	5 (3.5–5)	
Family outings in the community such as shopping, going to religious services or the library, visiting family and friends	4.5 (2.5–5)	GMFCS I	4.5 (4–5)	0.621	MACS I	4.75 (4–5)	0.225
		GMFCS II–III	4.75 (2.5–5)		MACS II	4 (2.5–5)	
		GMFCS IV	4.25 (3.5–5)		MACS III–V	5 (3.5–5)	
Indoor play with adults	4.5 (3–5)	GMFCS I	4.5 (3–5)	0.754	MACS I	4.75 (4–5)	0.765
		GMFCS II–III	5 (4–5)		MACS II	4.5 (3–5)	
		GMFCS IV	4 (3–5)		MACS III–V	5 (3–5)	
Indoor play with children	4 (2–5)	GMFCS I	4 (3–5)	0.374	MACS I	4.25 (3–5)	0.898
		GMFCS II–III	4 (2–5)		MACS II	4 (2–5)	
		GMFCS IV	4.25 (3–5)		MACS III–V	4 (3–5)	
Outdoor play with adults	4 (3–5)	GMFCS I	4 (3–5)	0.123	MACS I	4 (3–5)	0.329
		GMFCS II–III	4 (3–5)		MACS II	4 (3–5)	
		GMFCS IV	4 (3–5)		MACS III–V	4 (3–5)	
Outdoor play with children	4 (1–5)	GMFCS I	4.25 (3–5)	0.016*	MACS I	4.25 (3–5)	0.107
		GMFCS II–III	3.25 (1–5)		MACS II	4 (1–5)	
		GMFCS IV	4 (3–5)		MACS III–V	3.5 (2.5)	
Quit recreational activities such as coloring, card games, reading books	4 (1.5–5)	GMFCS I	4 (1.5–5)	0.571	MACS I	4.25 (3–5)	0.173
		GMFCS II–III	4 (2.5–5)		MACS II	4 (2.5–5)	
		GMFCS IV	4 (3–5)		MACS III–V	4 (1.5–5)	
Organized lessons, adapted sports, and arranged play groups such as swimming, dance/creative movement, parent and me classes	3 (1–4)	GMFCS I	3 (1–4)	0.541	MACS I	3 (1–4)	0.878
		GMFCS II–III	2.25 (1–4)		MACS II	2.5 (1–4)	
		GMFCS IV	3 (1–4)		MACS III–V	3 (1–4)	
Active physical recreation such as riding a tricycle, swimming, running outside, climbing on playground equipment	3.5 (1–5)	GMFCS I	4 (3–5)	0.001*	MACS I	4 (3–5)	0.040*
		GMFCS II–III	3 (1–5)		MACS II	4 (2–5)	
		GMFCS IV	3 (1–4)		MACS III–V	3 (1–5)	
Entertainment outings such as going to the zoo, a children's museum, the circus, concerts	3 (1–5)	GMFCS I	3 (1–5)	0.045*	MACS I	3 (1–4)	0.026*
		GMFCS II–III	3 (1–4)		MACS II	3 (1–5)	
		GMFCS IV	2.25 (1–3)		MACS III–V	2 (1–4)	
Social activities such as play date, going to parties	3 (1–5)	GMFCS I	3 (1–5)	0.621	MACS I	3 (2–5)	0.054
		GMFCS II–III	3 (1–5)		MACS II	3 (1–5)	
		GMFCS IV	3 (1.5–4)		MACS III–V	3 (1–4)	

GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System.

* $p < 0.050$.

community and in indoor play with adults (median 4.5–5). They participated least frequently in organized lessons/groups, entertainment outings, and social activities (median 3).

Median and range scores for enjoyment of participation in the different activity settings during early childhood are presented in Table 4. The majority of the children enjoyed all the activities very much or a great deal (median 4–5).

Child participation in relation to gross motor and hand function

Overall frequency and enjoyment scores based on the children's GMFCS and MACS levels are presented in Table 2. There was a statistically significant difference in the distribution of median overall frequency scores between children classified at GMFCS level I and IV ($p = 0.038$) and between children classified at MACS level I and III–V ($p = 0.015$), revealed by post hoc pairwise

comparisons, with lower mean ranks among the children with the most limited gross motor and hand function. There was also a statistically significant difference in the distribution of overall enjoyment scores between children classified at GMFCS level I and levels II–III ($p = 0.002$) and between children classified at MACS level I and level II ($p = 0.001$) and levels III–V ($p = 0.044$), respectively, with the highest mean ranks revealed in the group of children with the least severe limitations in mobility and hand function.

Frequency scores in the different activity settings based on GMFCS and MACS levels are presented in Table 3. A significant difference in the distribution of median scores was found for outdoor play activities with children, physically active recreation and entertainment outings. Post hoc pairwise comparisons revealed a difference in the category "outdoor play with children" between children classified at GMFCS level I and levels II–III ($p = 0.049$), with lower mean ranks found among children with moderate

Table 4. Enjoyment of participation in family and recreational activity settings in relation to GMFCS and MACS levels.

Family and recreational activities	Median (range)	GMFCS levels	Median (range)	<i>p</i> Value	MACS levels	Median (range)	<i>p</i> Value
Family activities at home such as chores, mealtime, watching TV	5 (3–5)	GMFCS I	5 (4–5)	0.606	MACS I	5 (4–5)	0.300
		GMFCS II–III	5 (3.5–5)		MACS II	5 (3.5–5)	
		GMFCS IV	4.5 (3–5)		MACS III–V	5 (3–5)	
Family outings in the community such as shopping, going to religious services or the library, visiting family and friends	5 (3–5)	GMFCS I	5 (4–5)	0.289	MACS I	5 (4–5)	0.286
		GMFCS II–III	5 (3–5)		MACS II	4.5 (3–5)	
		GMFCS IV	4 (4–5)		MACS III–V	5 (4–5)	
Indoor play with adults	5 (4–5)	GMFCS I	5 (4–5)	0.153	MACS I	5 (4–5)	0.109
		GMFCS II–III	5 (4–5)		MACS II	5 (4–5)	
		GMFCS IV	5 (5–5)		MACS III–V	5 (4–5)	
Indoor play with children	5 (3–5)	GMFCS I	5 (4–5)	0.220	MACS I	5 (4–5)	0.526
		GMFCS II–III	4.75 (3–5)		MACS II	5 (3–5)	
		GMFCS IV	5 (4–5)		MACS III–V	5 (4–5)	
Outdoor play with adults	5 (3.5–5)	GMFCS I	5 (4–5)	0.807	MACS I	5 (4–5)	0.026*
		GMFCS II–III	5 (3.5–5)		MACS II	5 (3.5–5)	
		GMFCS IV	5 (4–5)		MACS III–V	5 (4–5)	
Outdoor play with children	5 (3–5)	GMFCS I	5 (3–5)	0.052	MACS I	4 (4–5)	0.232
		GMFCS II–III	5 (3.5–5)		MACS II	5 (3–5)	
		GMFCS IV	5 (4–5)		MACS III–V	5 (3–5)	
Quit recreational activities such as coloring, card games, reading books	4.5 (3–5)	GMFCS I	4.5 (3–5)	0.062	MACS I	4.5 (4–5)	0.555
		GMFCS II–III	4.75 (3–5)		MACS II	4 (3–5)	
		GMFCS IV	4 (3–5)		MACS III–V	4 (3–5)	
Organized lessons, adapted sports, and arranged play groups such as swimming, dance/creative movement, parent and me classes	4.5 (2–5)	GMFCS I	4.5 (2–5)	0.859	MACS I	4.25 (2.5–5)	0.986
		GMFCS II–III	4 (2.5–5)		MACS II	4 (2–5)	
		GMFCS IV	4.75 (3.5–5)		MACS III–V	4.5 (2.5–5)	
Active physical recreation such as riding a tricycle, swimming, running outside, climbing on playground equipment	5 (3–5)	GMFCS I	5 (3–5)	0.069	MACS I	5 (3–5)	0.869
		GMFCS II–III	4.5 (3–5)		MACS II	5 (3–5)	
		GMFCS IV	5 (4–5)		MACS III–V	5 (3–5)	
Entertainment outings such as going to the zoo, a children's museum, the circus, concerts	4.75 (2.5–5)	GMFCS I	5 (3–5)	0.208	MACS I	5 (3–5)	0.102
		GMFCS II–III	4.5 (2.5–5)		MACS II	4 (2.5–5)	
		GMFCS IV	4 (3–5)		MACS III–V	4 (3–5)	
Social activities such as play date, going to parties	4.5 (2–5)	GMFCS I	5 (3–5)	0.085	MACS I	5 (3–5)	0.083
		GMFCS II–III	4 (2–5)		MACS II	4 (2.5–5)	
		GMFCS IV	4.25 (3–5)		MACS III–V	4 (2–5)	

GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System.

* $p < 0.050$.

mobility limitations. In “physically active recreation”, a difference was revealed between children classified at GMFCS level I and both levels II–III ($p = 0.008$) and level IV (0.001), and likewise between children classified at MACS levels I and II ($p = 0.024$) and between level I and levels III–V ($p = 0.003$). In the activity setting, “entertainment outings”, a significant difference was found between children classified at GMFCS levels I and IV ($p = 0.013$) and between children classified at MACS level I and levels III–V ($p = 0.039$).

Children's enjoyment while attending the different activity settings based on gross motor and hand function is presented in Table 4. The only statistically significant difference in distribution of median scores was found for “outdoor play with adults” ($p = 0.026$), with post hoc pairwise comparisons revealing a significant lower mean rank among children classified at MACS level II compared with those at level I.

Trajectories of participation

By mapping individual median scores of overall frequency and enjoyment at each of the longitudinal assessments, four participation trajectories were identified: *increasing* (constantly increasing scores across the longitudinal assessments), *decreasing* (constantly decreasing scores), *stable* (no changes in scores), and *fluctuating* (both increasing and decreasing scores across the assessments). The number of participants representing each of the trajectories is presented in Figure 2 (frequency) and Figure 3 (enjoyment). Among children representing all motor classifications except MACS level II a fluctuating trajectory of frequency with both increases and decreases in median scores across the assessments

were found to be most common. A trajectory representing stable median scores was the second most common pattern, while only a few children had trajectories representing constantly increasing or decreasing scores.

When it came to enjoyment, stable median scores across time represented the most common trajectory independent of motor function, followed by trajectories representing fluctuating scores. Constantly increasing enjoyment median scores across time were more common than a decreasing trajectory among all groups of children except for the children with the most severe limitations in mobility and hand function (GMFCS level IV and MACS levels III–V).

Relationships between frequency of participation and parental empowerment in family and service situations

Table 5 provides an overview of the relationships between overall frequency of child participation during early childhood and parental empowerment. A positive relationship was found between frequency of participation and parental empowerment in family situations ($p = 0.003$); no statistically significant association was seen for parental empowerment in service situations ($p = 0.617$). The estimates indicate an average change in frequency scores by a one-point increase in empowerment scores.

Discussion

This study explored children with CP's participation in family and recreational activity settings during early childhood in relation to gross motor function, hand function and parental empowerment in family and service situations. The activity settings represent

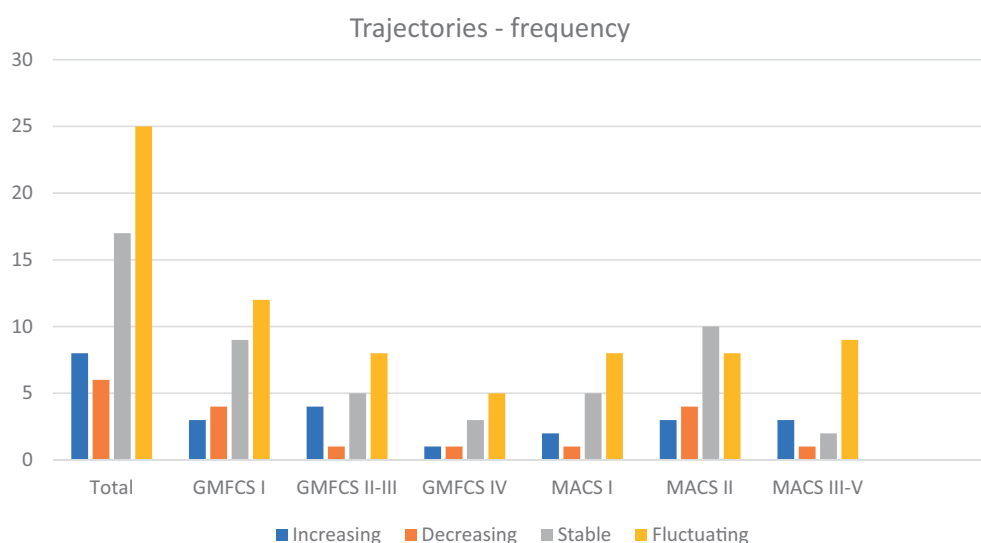


Figure 2. Number of children representing different trajectories of frequency in relation to gross motor and hand function. GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System.

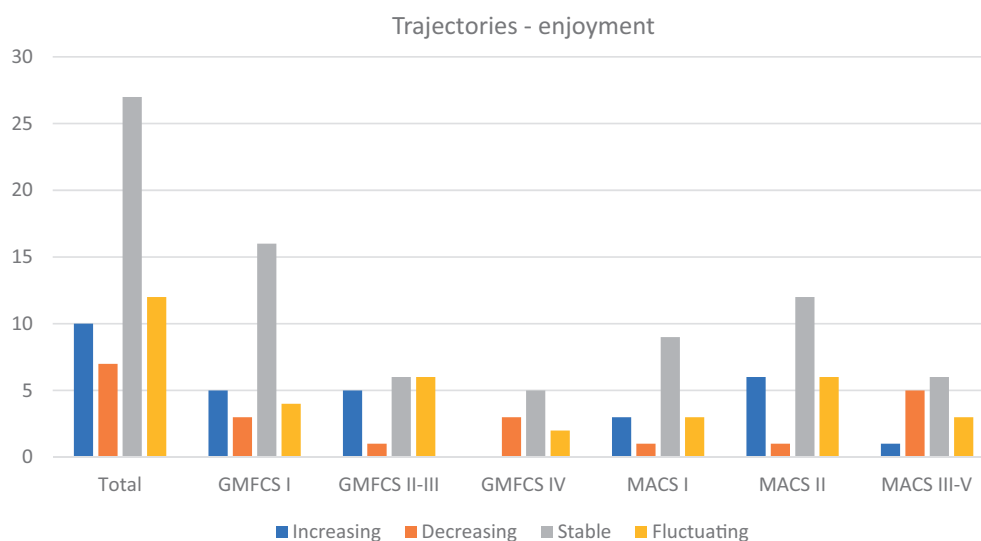


Figure 3. Number of children representing different trajectories of enjoyment in relation to gross motor and hand function. GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System.

Table 5. Relationships between overall frequency of participation and parental empowerment in family and service situations.

Subscales of the Family Empowerment Scale (FES)	Estimates	95% CI	<i>p</i> Value
Family situations	0.487	0.258–0.716	0.000*
Service situations	0.049	–0.144 to 0.242	0.617

**p* < 0.050.

real-life contexts with opportunities for interactions and experiences supporting learning, development, and well-being [1].

Frequency and enjoyment of participation in family and recreational activities

When looking at the activity settings together, the frequency of participation during early years appears high, with a median score of 4 representing children participating “often” in the activities. This corresponds well with previous studies of children with CP from Canada and the USA [10,14]. Moreover, the majority of the

children enjoyed the activities very much or a great deal (median 4.5–5). The subjective experience while attending activities is considered an essential part of participation and may contribute both to explaining current participatory patterns and set directions for further attendance [6]. It also captures important aspects of the children’s well-being and experience of meaningfulness while attending activities. The high enjoyment scores in the current study indicate that participation in family and recreational activities are deeply appreciated by most children, thus highlighting the importance of making such activities available in order to fulfill their desires and interests.

When looking at the unique activity settings, both similarities and differences in frequency of participation between activities were found. All children participated once in a while or more frequently in “family activities at home” and in “indoor and outdoor play with adults”, and most of them attended these activities often or very often (median score 4–5, range 3–5). This finding highlights the home as the main learning context for young children and reflects their dependence on parents and other well-known adults in the early processes of development. Interactions

with persons and objects in a familiar environment are seen as important for children to acquire knowledge and skills that enable them to engage in more complex and varied activities both with others and on their own on later occasions [2]. Thus, facilitating opportunities for participation and by that provide situated learning experiences has the potential to promote a child's capacity and adaption to diverse activity settings and socialization into new roles [1].

The majority of the children also participated often to very often in "family outings in the community", "indoor and outdoor play with children", and in "quiet recreational activities". However; the frequency of attending these activities varied more among the participants, with some children participating less frequently than "once in a while" (lowest median scores 1–2.5). In different ways, participation in these activity settings represents a further developmental step since community activities often involve broader and more unfamiliar environmental contexts and/or other types of interactional partners. Regarding quiet recreational activities, a possible explanation of the variation is that such activities place greater demands on attention and cognitive skills compared with other activities going on in the family. Such skills are often affected among children with CP [13]. The above-mentioned activities may therefore represent the *zone of proximal development* for some children, which means that their participation opportunities are dependent on appropriate guidance and encouragement from primary caregivers [30]. Facilitating such activities and providing sufficient support may by that create more advanced learning opportunities, thus promoting further development.

"Entertainment outings", "organized lessons and groups", and "social activities" were the activity settings with the least frequent participation (median 3, range 1–4/1–5) and appear with the widest range of enjoyment scores (2–5/2.5–5). Participation in these activity settings depends to a large degree on opportunities provided by the community or by people from outside the immediate family and may thus restrict the frequency of participation. Interacting with more peripheral persons and attending activities at unfamiliar locations require more advanced adaptive behavior skills, which may represent a challenge for some children with CP [13]. Such challenges may explain both the wide variations in enjoyment scores and the less frequent participation among some of the children in these activities. This explanation is supported by previous research identifying adaptive behavior as a determinant of participation [31]. It further emphasizes the importance of exploring the subjective experiences and promoting enjoyment through support and modifications enabling mastery. This may, in turn, promote participation and thereby provide varied experiences and access to new communities of practice [1,5].

Participation in relation to gross motor and hand function

Understanding how motor abilities may affect attendance and enjoyment in activities is essential in order to facilitate equal participation opportunities for all children regardless of their disabilities. When all the activity settings included in CEDL are seen together, children with the most severe limitations in gross motor and hand function participated less frequently than children with the mildest motor restrictions. Children with only minor limitations in motor function (GMFCS level I, MACS level I) enjoyed the activities more than children with moderate mobility restrictions (GMFCS levels II–III) and more than children with moderate and severe limitations in hand function (MACS levels II and III–V). These findings at least partly correspond with previous research

revealing differences in frequency and enjoyment based on levels of motor functions [10,14]. However, when looking at the activity settings separately, the relationships between severity of motor limitations and participation appear as more complex, being influenced by and dependent on the specific context.

Most differences based on levels of gross motor and hand function were found in the activity setting "active physical recreation". In this setting, children with only minor limitations (GMFCS level I and MACS level I) seem to participate more frequently than children with both moderate and severe motor limitations (GMFCS levels II–III and level IV, MACS levels II and levels III–V). This is in line with previous research revealing progressively more sedentary behavior among young children classified at GMFCS levels III–V, making them less likely to meet recommendations for physical activity [32,33]. In CEDL, active physical recreational activities are exemplified as riding a tricycle, swimming, running outside, and climbing on playground equipment. Participation in these activities will often depend on motor skills that might not have been acquired by some participants due to their young age and/or disability. However, assistive devices might compensate for motor limitations and offer alternative ways of participating in physically active recreation. Previous research from Norway has shown that children do not care about performing activities differently from their peers, for example, sitski on the alpine slope, as long as the device makes them able to participate along with family and friends [34]. The importance of adaptations made corresponds with accommodability as an environmental dimension affecting participation [15], and supports an early introduction of assistive devices in order to provide opportunities for participation in varied activities and thereby promote increased physical activity among children with motor limitations.

In what way environmental adaptations and assistive devices are successfully implemented in a child's real-life contexts may also explain differences in participation in the activity setting "outdoor play with children". In this setting, a difference in the distribution of scores was revealed between children with the least restricted gross motor function (GMFCS level I) and children with moderate limitations (GMFCS levels II–III), indicating less frequent participation among children classified at GMFCS level II–III. No similar difference was found between children with the least and the most severe gross motor limitations (GMFCS levels I and IV). These findings may reflect some specific challenges experienced by children with walking abilities being dependent on the environment. Children at GMFCS level I are expected to have minimal walking limitations regardless of the physical environment, while children at GMFCS levels IV most likely will be using wheeled mobility both indoors and outdoors. The predictable need for mobility aids in the group of children with most severe mobility restrictions may lead to early and appropriate adaptations directed at outdoor play, which may explain why no differences in frequency of participation were found compared with children with only mild motor limitations. Children functioning at GMFCS levels II and III are, on the other hand, supposed to have some walking abilities, and thus their need for mobility devices may be more dependent on the environmental context. The lower frequency of participation in this group compared with children with only minor limitations could be explained by challenges when it comes to compensating for motor limitations in the context of outdoor play. By having a potential for independent walking with or without a handhold assistive device, introduction of wheelchair may be delayed if parents are clinging to walking as "normal" as long as possible [35]. The children may also be more unfamiliar with a manual or powered wheelchair since they are not necessarily

dependent on them in other contexts. How children use and interpret their use of an assistive device in outdoor play are in previous research described to be affected both by the activity setting, the child's self-determination and how the device is embedded in the child's body schema [36]. A device incorporated in one situation was not necessarily relevant for use in another [36]. This implies a need for individual and contextualized assessments and adaptations in order to consider how assistive devices may promote participation in real-life activities.

Another difference in frequency of participation was found between children with the most severe motor limitations (GMFCS level IV, MACS levels III–V) and children with the least severe limitations (GMFCS level I, MACS level I) in the activity setting "entertainment outings". This difference may be explained by central dimensions concerning the environment [15], such as reduced objective opportunities for participation (availability) and the perceived access for children in need of extensive help and assistive devices. Given that many of these activities involve costs for the families (affordability), less frequent participation may also reflect their financial and practical situation.

In the other activity settings, no statistically significant differences in frequency were found between children classified at different levels of motor function. This indicates that appropriate adaptations of activities are possible regardless of motor limitations and that opportunities for participation thus seem to be more dependent on environmental factors than on children's abilities.

Further, the motor abilities seemed to be of little importance when it comes to differences in enjoyment in specific activity settings. The only statistically significant difference found was between children classified at MACS levels I and II in "outdoor play with adults". However, taking into account that the median value in both groups represents children enjoying the activities "a great deal" and the relatively small range of scores (3.5–5/4–5), the clinical importance of this differences is considered small.

Trajectories of frequency and enjoyment of participation across time

A fluctuating trajectory with both increases and decreases in median scores across time was by far the most common frequency pattern. Such a fluctuation may reflect variable opportunities for attending activities, for instance, due to seasonal changes and available community programs. In Norway, the weather conditions vary considerably according to the season, and the two-month summer holiday for schools often implies changes in family and community activities.

The second most common trajectory revealed was a stable pattern, while only few children had a constantly increasing or decreasing frequency scores. The variations in frequency across time and the differences in trajectories revealed corresponds well with a recent study exploring longitudinal changes in participation among young children with CP in Canada and in the USA, highlighting substantial variations among individuals [37].

How enjoyment of participation changes or remains stable across time may contribute to the interpretation of the frequency patterns. In the current study, enjoyment of participation was found to be stable across time among most children regardless of limitations in gross motor and hand function. When looking at the trajectories of frequency and enjoyment in context, the findings indicate that changes in frequency of participation do not primarily relate to how much a child appreciates an activity. Consequently, the findings support that participation in the first

years seems to be influenced by other aspects of the activity settings than the children's preference and motivation.

Even though the number of participating children is small, it is worth noting that decreases in enjoyment across time are more common than increases among the children with the most severe limitations in gross motor and hand function (GMFCS level IV, MACS levels III–V). This may reflect children who have experienced falling short due to their limitations in motor skills, inadequate adaptations of activities and the environment, or lack of social support. The subjective experiences of attending activities among this group of children may therefore be in need of extra attention in order to facilitate a favorable participatory pattern in the long run.

Relationships between frequency of child participation and parental empowerment in family and service situations

A positive relationship was revealed between children's frequency of attending activity settings during early years and parental empowerment in family situations. This indicates that families perceiving themselves as in control of their daily situation provide a favorable environmental context for child participation in real-life activities. This result corresponds well with previous research documenting a positive association between frequency of participation and family ecology, operationalized as parents' perception of their family life and their expectations of the child [16]. The finding further highlights the importance of supporting parents of a child with a disability to remain in control of their family life and supports individually tailored interventions anchored in a family's real-life context [1].

As opposed to empowerment in family situations, no statistically significant relationship was revealed between frequency of child participation and family empowerment in service situations. According to a bioecological model of human development, interactions between parents and service providers and systems represent a more remote ecological system surrounding the child compared with the immediate family context [2]. The influence on participation as an aspect of child functioning may therefore be less explicit. Additionally, empowerment in service situations as measured by the FES reflects how parents perceive themselves in control when navigating in the pediatric rehabilitation system and does not capture to what extent the service system adapts to contexts of relevance for the families. Thus, we are not fully able to expose the potential that lies in collaboration between parents and service providers corresponding with the new paradigm, which implies leaving a traditional rehabilitation setting and rather focusing on the opportunities of real-life contexts.

Study limitations and future directions

The relatively small number of participants, variations in the children's age when included and differences in the regularity and number of assessments limited the potential for more sophisticated analyses of participation trajectories. Due to the study design, no causal relationship could be revealed, only associations. The study primarily explores two dimensions of participation (frequency and enjoyment), and thus left out other important aspects such as intensity and diversity. Furthermore, even if participation is explored in relation to different activity settings, we have limited information about more specific characteristics of the environment which may influence children's opportunities for participation. The limitations point to the need for larger and more comprehensive studies to increase knowledge about young

children's participation in family and recreational activities in a longitudinal perspective.

Conclusions

Young children with CP participate quite frequently in most family and recreational activities during early childhood, and they like the activities very much. Similarities and differences in participation based on levels of gross motor and hand function varied between the unique activity settings, indicating that child participation is context dependent and complexly influenced by more than just motor function. By that, the study supports approaches to exploring and promoting participation that take into consideration transactional processes unfolding in real-life situations [1].

The relationship revealed between child participation and parental empowerment in family situations outlines the immediate family environment as the pivotal point in a young child's life in line with what is accentuated in bioecological models [2]. It further supports empowering approaches facilitating family control in daily situations. The fact that no significant association was found between child participation and parental empowerment in service situations indicates a remaining potential in the parent-service provider collaboration. Therein lies a call for further innovative thinking about how to develop service systems facilitating participation in meaningful contexts for children and families in the years to come.

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ORCID

Runa Kalleson  <http://orcid.org/0000-0003-1335-1793>

Reidun Jahnsen  <http://orcid.org/0000-0002-0694-0410>

Sigrid Østensjø  <http://orcid.org/0000-0002-7418-2973>

Data availability statement

The data underlying this study are available from the Cerebral Palsy Follow-up Program (CPOP) in Norway. Restrictions apply to the availability of the data, which were used under license for the current study, and are not publicly available. However, data are available from the authors upon reasonable request and with permission of CPOP.

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