Facets of life in families caring for a young child with cerebral palsy

A longitudinal cohort study exploring parental empowerment, child participation in real-life activities and services received by the families

Runa Kalleson

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Department of Physiotherapy
Faculty of Health Sciences
OsloMet – Oslo Metropolitan University

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Universitetsbiblioteket
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Oslo, August 2021 ***Runa Kalleson***

Summary

Background: Cerebral palsy (CP) refers to a group of childhood motor disorders caused by abnormal development or damage to the brain. Children with CP and their families often face some extra challenges in their daily lives, which usually require involvement of extended services. The extent to which parents perceive having control over daily situations with their child and interactions with service providers and service systems is considered important, both for the parents' own sake and by virtue of families constituting the most influential environment in their child's life. Empowerment has thus emerged as an area of interest in the context of paediatric rehabilitation. Another area that is receiving increasing attention is children's participation in play and family activities, which represent an important context for promoting skills and facilitating learning and development, as well as being considered a primary goal of rehabilitation services. To create opportunities for participation among children with CP from an early age, knowledge is needed regarding the activity settings in which young children participate and about how participation can be related to motor limitations. Furthermore, the complex and chronic nature of the CP diagnosis commonly implies long-term multidisciplinary follow-up, which highlights coordination and continuity as important aspects of the services provided to children with CP and their families. Knowledge of what services the families receive is necessary both to expand the understanding of the family's situation and to gain knowledge about the current service provision.

Aims: The overall aim of this study was to gain knowledge about some key areas in the lives of children with CP and their families: Parental empowerment, children's participation in real-life activities and services received by the families. The sub-aims of the study included gaining knowledge of the current situation, increasing understanding of relationships with characteristics of the child, the family and the services they receive, and outlining changes or developments that may occur over time.

Methods: The study was designed as a prospective cohort study using data from two Norwegian CP registers: (1) the Cerebral Palsy Follow-up Programme (CPOP), which is now part of the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP), and (2) the associated research register Habilitation Trajectories, Intervention and Services for Preschool Children with CP (CPHAB). Fifty-eight families with a child diagnosed with CP aged four years or younger registered between 2012 and 2015 were included. In the first sub-study, parental empowerment in the contexts of family, service situations and community was explored by analysing repeated measurements with the Family Empowerment Scale (FES). In the second sub-study, the children's participation in real-life activities was described and analysed based on the Child Engagement in Daily Life questionnaire (CEDL). Services received by the families as mapped by the Habilitation Services questionnaire (HabServ) were explored in the third sub-study. The data were analysed using quantitative methods in all three sub-studies.

Results: Parental empowerment levels were high and stable in the contexts of family and service situations, but lower in the context of influencing the service system on a community level. The relationships between empowerment and characteristics of the child and the family and services received varied depending on the context. The children participated frequently in several activity settings, and they greatly appreciated the participation. Less frequent participation was found among children with moderate and severe motor limitations in some activity settings, such as active physical recreation and outdoor play with children. A statistically significant relationship was found between parental empowerment in family situations and the frequency of child participation. Most families received services aimed at both the child and the parents, including health, educational, social and coordination services. The number of services received and the reception of a service coordinator varied with different gross motor levels. The longitudinal reports on some services, such as individual service plan and coordinator, indicated that service delivery interruptions were common.

Conclusion: The study's results provided a generally positive impression of the families' situations. However, some challenges were also indicated, such as limited parental involvement in the improvement of services, differences in participation based on motor limitations and interruptions and varying use of coordination services.

Sammendrag

Bakgrunn: Cerebral parese (CP) er betegnelsen på en gruppe motoriske funksjonsforstyrrelser hos barn forårsaket av avvikende utvikling eller en skade i hjernen. Barn med CP og familiene deres vil kunne møte noen ekstra utfordringer i hverdagen, og vanligvis vil de ha behov for utvidede tjenester. Hvordan foreldre opplever å ha kontroll i daglige situasjoner med barnet sitt og i samhandling med tjenesteytere og tjenestesystemer fremstår som viktig, både for foreldrenes egen del og i kraft av at familiene utgjør den mest innflytelsesrike omgivelsesfaktoren i et barns liv. Empowerment har dermed seilt opp som et sentralt tema innen barnehabiliteringsfeltet. Et annet området med økende interesse er barns deltakelse i lek og familieaktiviteter, hvilket anses som en viktig arena for trening av ferdigheter og tilrettelegging for utvikling og læring, i tillegg til å utgjøre et mål for habiliteringstiltak i seg selv. For å kunne skape gode muligheter for deltakelse hos barn med CP fra tidlig alder trenger vi kunnskap om aktiviteter der små barn deltar og om sammenhenger mellom deltakelse og barnets motoriske begrensninger. Som en kompleks og kronisk tilstand innebærer CP-diagnosen ofte at tverrfaglige tjenester er involvert i oppfølging over lengre tid, hvilket retter søkelys mot koordinering og kontinuitet som sentrale aspekter ved tjenesteytingen til barn med CP og deres familier. Kunnskap om hvilke tjenester familiene mottar er nødvendig både for å øke forståelsen av familienes situasjon og for å få kunnskap om tjenestesystemets fungering.

Mål: Det overordnede målet med studien var å fremskaffe kunnskap om noen sentrale områder i livet til små barn med CP og deres familier: Empowerment hos foreldre, barns deltakelse i dagliglivets aktiviteter og tjenester som mottas av familiene. Delmål i studien inkluderte det å fremskaffe kunnskap om den nåværende situasjonen, øke forståelsen av sammenhenger med forhold knyttet til barnet og familiene og tjenestene de mottar, samt skissere eventuelle endringer eller utvikling som skjer over tid.

Metode: Studien var utformet som en prospektiv kohortstudie basert på data fra to norske CP-register: (1) Cerebral parese oppfølgingsprogram (CPOP), som nå inngår i Norsk kvalitets- og oppfølgingsregister for cerebral parese (NorCP), og (2) det tilhørende forskningsregisteret Habilieringsforløp, tiltak og tjenester for førskolebarn med CP (CPHAB). 58 familier med et barn diagnostisert med CP fire år eller yngre ved registrering mellom 2012 og 2015 ble inkludert i studien. I den første delstudien ble foreldrenes empowerment i familiesituasjoner, tjenestesituasjoner og på samfunnsnivå utforsket gjennom analyser av gjentatte målinger med Family Empowerment Scale. I den andre delstudien ble barns deltakelse i lek, familie- og fritidsaktiviteter beskrevet og analysert basert på spørreskjemaet Barns deltakelse i dagliglivets aktiviteter. Tjenester mottatt av familiene kartlagt gjennom et spørreskjema for registrering av habiliteringstiltak (HabServ) ble utforsket i den tredje delstudien. Data ble i alle delstudiene analysert ved bruk av kvantitative metoder.

Resultater: Foreldrene skåret høyt på empowerment i familie- og tjenestesituasjoner, men langt lavere i sammenheng med det å påvirke tjenestesystemer mer generelt på et samfunnsnivå. Sammenhengen mellom empowerment og forhold ved barnet, familiene og tjenestene de mottok varierte avhengig av konteksten. Barna deltok hyppig i en rekke forskjellige typer aktiviteter, og de likte aktivitetene godt. Barn med middels og store begrensinger i motorikk deltok noe sjeldnere i enkelte aktiviteter, slik som fysisk aktivitet og utendørs lek med andre barn. Det ble funnet en statistisk signifikant sammenheng mellom foreldres empowerment i familiesituasjoner og hyppighet av barns deltakelse i lek, familie- og fritidsaktiviteter. De fleste familiene mottok tjenester rettet både mot barnet og foreldrene, og inkluderte helsetjenester, pedagogiske tjenester, sosiale ytelser og koordineringstjenester. Antall tjenester og det å ha en koordinator varierte avhengig av barnets grovmotoriske funksjonsnivå. De gjentatte kartleggingene av enkelte tjenester mottatt av familiene, slik som individuell plan og koordinator, indikerte at avbrudd i tjenesteytingen var vanlig.

Konklusjon: Studien ga et generelt sett positivt inntrykk av familienes situasjon. Den ga imidlertid også indikasjoner på enkelte utfordringer, slik som begrenset foreldreinvolvering i utbedring av tjenestesystemer, ulikheter i barns deltakelse relatert til motoriske begrensninger, samt utbredte avbrudd og varierende bruk av koordinerende tjenester.

Table of Contents

LIST OF APPENDICES

Appendix I

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Appendix II

Ethical approval

Appendix III

Questionnaires included in the study:

- Bakgrunnsinformasjon om familien og barnet (Norwegian version of the Parental Account of Children's Symptoms)
- Quality of Life Scale – norsk versjon (Quality of life Scale – Norwegian version)
- Family Empowerment Scale
- Barns deltakelse i dagliglivet, del 1 (Child Engagement in Daily Life, part 1)
- Registrering av habiliteringstiltak del 1, 3 og 4 (Habilitation Services questionnaire, part 1, 3 and 4)

LIST OF ARTICLES

Article I

Kalleson R, Jahnsen R, Østensjø S. Empowerment in families raising a child with cerebral palsy during early childhood: Associations with child, family, and service characteristics. *Child: Care, Health and Development*. 2020;46(1):19-27.
DOI: **https://doi.org/10.1111/cch.12716**

Article II

Kalleson R, Jahnsen R, Østensjø S. 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? *Disability & Rehabilitation*. 2021.
DOI: **https://doi.org/10.1080/09638288.2021.1894608**

Article III

Kalleson R, Jahnsen R, Østensjø S. Comprehensiveness, coordination and continuity in services provided to young children with cerebral palsy and their families in Norway. *Child Care in Practice*. 2021.
DOI: **https://doi.org/10.1080/13575279.2021.1898934**

LIST OF FIGURES

LIST OF TABLES

ABBREVIATIONS

ADHD: Attention deficit and hyperactivity disorder

APCP: Assessment of Preschool Children's Participation

CEDL: Child Engagement in Daily Life

CP: Cerebral palsy

CPHAB: Habilitation trajectories, intervention and services for preschool children with CP

CHARM: Research Centre for Habilitation and Rehabilitation Models and Services

CPOP: Cerebral Palsy Follow-up Program

CPRN: Cerebral Palsy Registry in Norway

FES: Family Empowerment Scale

fPRC: The family of participation-related constructs

GMFCS: Gross Motor Function Classification System

GMFM: Gross Motor Function Measure

HabServ: Habilitation Services questionnaire

ICF: International Classification of Functioning, Disability and Health

ICF-CY: International Classification of Functioning, Disability and Health: Children and Youth version

ISP: Individual Service Plan

MACS: Manual Ability Classification System

NAV: Norwegian Labour and Welfare Administration

OsloMet: Oslo Metropolitan University

OUS: Oslo University Hospital

PEDI: Pediatric Evaluation Disability Inventory

PEDI-CAT: Pediatric Evaluation of Disability Inventory Computer Adaptive Test

PACSNO: Parental Account of Children’s Symptoms: Norwegian version

QOL: Quality of life

QOLS-N: Quality of Life Scale: Norwegian version

REC: Regional Committees for Medical and Health Research

SCPE: The Surveillance of Cerebral Palsy in Europe

SD: Standard deviation

SED: Severe emotional disabilities

TSD: Services for Sensitive Data

UiO: University of Oslo

WHO: World Health Organization

YC-PEM: Young Children’s Participation and Environment Measure

1. Introduction

Cerebral palsy (CP) is a condition that has captured the interest of clinicians and researchers since ancient times. In fact, the first description of CP can be traced back to Hippocrates, around 400 B.C. (1). CP is considered the most widespread motor disorder in childhood, with a prevalence of about 2 per 1,000 live births internationally (2). The condition is caused by an abnormality or lesion in the immature brain of a foetus, infant or toddler that affects the child's movement and posture (3). Motor limitations are commonly accompanied by other developmental problems and impairments, which complicate the condition considerably (4). The complex and chronic nature of CP implies that children with this diagnosis almost always need some kind of long-term rehabilitation follow-up (4).

From the mid-1900s, interventions targeting children with CP mainly focused on correcting abnormal postural reflexes and locomotion (1, 5). In contrast, more contemporary interventions are directed at functional goals related to everyday tasks and include family-centred approaches that focus on educating and supporting parents (5). Rehabilitation goals have shifted from "fixing" the condition to incorporating other "f-words": family, function, fitness, fun, friends and future (6).

This new paradigm of rehabilitation views disability as contextual and societal (7). Particularly in the early years, families are uniquely positioned in the child's life and constitute the most important context for learning, development and well-being (8). Thus, **family empowerment** is a key area of interest for both clinical practice and research (7). In Norway, empowerment has been highlighted in national guidelines as an important perspective related to involvement of patients, clients and families in rehabilitation processes. Nevertheless, research on empowerment in relation to characteristics of children, families and rehabilitation services has been surprisingly limited.

Another shift in the field of paediatric rehabilitation is the increased attention on **children's participation in real-life activities,** as opposed to assessments of function and interventions carried out in more constructed professional contexts (9, 10). Participation in play and family activities has been presented both as an important context for learning and development and as a main goal for rehabilitation interventions (11). Additionally, social participation is now widely accepted as a main dimension of human functioning (12).

Families caring for a child with CP are most likely to encounter an extended service system that includes various organisational structures and service providers representing different professions. The **services received by families** represent an aspect of the environment with the potential to influence the children’s situation both directly and indirectly through family support (13, 14). The focus on coordination services in rehabilitation has increased over the past two decades, both in Norway (15) and internationally (16). However, broad mappings of health, education and social services received by families raising children with CP, as well as explorations of coordination services using a quantitative research approach, seem to be lacking.

This PhD study explored all these above-mentioned facets of life in families raising a young child with CP. The research was made possible by access to register data from two Norwegian CP registers: (1) **the Cerebral Palsy Follow-up Program (CPOP)**, which merged with the Cerebral Palsy Registry in Norway (CPRN) in 2021, forming the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP), and (2) the associated research register, **Habilitation Trajectories, Intervention and Services for Preschool Children with CP (CPHAB)**. In combination, these registers contain data on a wide range of issues related to children’s disability, including family characteristics and services received. This data could increase the understanding of how to develop services and service systems that promote favourable upbringing conditions and developmental opportunities for children with disabilities, such as CP.

At present, the PhD study has resulted in three articles published or accepted for publication in three peer-reviewed journals. An overview of the articles is provided in Table 1.

Table 1. An overview of the articles originating from the PhD study

Article number	**Title**	**Main theme**	**Journal**	**Publication state**
I	Empowerment in families raising a child with cerebral palsy during early childhood: Associations with child, family and service characteristics	Parental empowerment	*Child: Care, Health and Development*	Published 2020
II	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?	Child participation in real-life activities	*Disability & Rehabilitation*	Published 2021
III	Comprehensiveness, coordination and continuity in services provided to young children with cerebral palsy and their families in Norway	Services received by the families	*Child Care in Practice*	Published 2021

2. Background

This chapter includes an overview of the clinical aspects of CP diagnosis, a presentation of the main theoretical frameworks underpinning the current study and an outline of key constructs and previous research related to the main themes explored by the study: Parental empowerment, child participation in real-life activities and services received by the families.

2.1 Cerebral palsy: An overview

More than an etiological diagnosis, CP is a descriptive clinical term comprising a number of non-progressive motor disorders occurring during pregnancy, birth or in the child’s first years (4). Prepartum risk factors associated with CP include multiple pregnancy, placental abnormalities and maternal infections, and the diagnosis is inversely associated with premature birth and low birth weight (3). Intrapartum and neonatal risk factors include meconium aspiration, emergency caesarean section, birth asphyxia, hypoglycaemia, neonatal seizures, respiratory distress syndrome and neonatal infections (3). In about 10% of cases in which CP is diagnosed, the condition has occurred in the post-neonatal period; these instances are most frequently caused by head injuries or infections in the central nervous system (3). More recently, genetic factors have been highlighted as possible causes of CP (3). Globally, the prevalence of CP has remained stable (2); however, a considerable decrease has been seen in Norway, from a prevalence of 2.62 live births in 1999 to 1.89 in 2010 (17). This decrease is most likely associated with advances in maternal and neonatal care (17).

CP is a very heterogeneous condition. The severity, location and expression of the motor problems vary significantly, and many children have additional developmental disorders related to sensing, perception, cognition, communication and behaviour (4). The diagnosis is also associated with primary and secondary musculoskeletal problems and may be accompanied by other serious health conditions, such as epilepsy (4). A registry study of children and adolescents receiving specialist health care between 2008 and 2017 identified an increased risk of medical, neurological and mental/behavioural disorders among those diagnosed with CP compared to the general population, with comorbidities recorded in 95% of CP patients (18).

While some children with CP are minimally affected, others have extensive need for help in most areas. These wide variations in symptoms and functional limitations emphasise the need for further classifications to describe CP and enable meaningful comparisons in clinical practice and research. The Surveillance of Cerebral Palsy in Europe (SCPE) network recommends classifying CP according to the following subtypes: spastic unilateral, spastic bilateral, dystonic, choreo-athetotic, ataxic and non-classifiable (19). These subgroups are all characterised by an abnormal pattern of movement and/or posture, with main differences in the localisation and primary expression of the motor symptoms.

Spastic CP is diagnosed when increased muscle tone is seen and/or pathological reflexes are detected. This is, by far, the most common type of CP, accounting for more than 85% of the cases in Norway, with approximately equal distribution between the two subcategories, unilateral and bilateral (20). *Unilateral* means that limbs on one side of the body are involved, while *bilateral* implies an involvement of limbs on both sides. *Ataxic* CP accounts for about 4% of the cases in Norway (20) and is characterised by limitations in muscle coordination that lead to disturbances of rhythm, force and accuracy. *Dystonic* and *choreo-athetotic* CP are *dyskinetic* forms of CP that display different characteristics in involuntary movements (19). Together, these dyskinetic types account for about 7% of cases in Norway (20).

Moreover, the motor abilities and limitations of children and youth with CP can be classified based on different functional dimensions, such as gross motor function (21) and manual abilities (22). The Gross Motor Function Classification System (GMFCS) categorises children's function and limitations at five different levels based on motor performance in an everyday environment (23). Children at level I usually walk (or are expected to walk) without limitations. At level II, the children walk independently, but with some limitations outdoors. Children at level III may walk with hand-held mobility devices but are likely to prefer wheelchairs for longer distances. At level IV, children's self-mobility is limited, and they may move around using powered mobility. Finally, children classified at level V have no means of independent movement and are expected to be transported in a wheelchair (21).

Similarly, the Manual Ability Classification System (MACS) classifies hand function at five levels based on the child's handling of objects in daily life (22). At MACS level I, children handle objects easily and successfully, and hand function does not restrict their independence in daily activities. At level II, objects are handled with somewhat reduced quality and/or speed, and certain activities are avoided or achieved with some difficulty or by using alternative strategies. Children at MACS level III handle objects with difficulty and will need help to prepare and/or modify the activity. At level IV, children will need continuous support and assistance and/or adapted equipment to handle objects and perform an activity. Children at level V have severely limited ability to perform even simple actions and need total assistance (22).

Since abnormal movement patterns constitute a core symptom of the CP diagnosis, these two classification systems have been extensively used in professional practices and in research to stratify children into clinically meaningful groups (23). Research has revealed a strong relationship between children's GMFCS level and associated impairments (24); therefore, the GMFCS level may serve as an overall indication of the severity of the child's disorder. In Norway, 53% of children with CP born between 2008 and 2013 were classified at GMFCS level I, 15% at level II, 7% at level III, 10% at level IV and 15% at level V (20).

Both clinical follow-up and research on children with CP are significantly influenced by two overarching theoretical frameworks: the International Classification of Functioning, Disability and Health (ICF) (12) and the bioecological model of human development, as described by Urie Bronfenbrenner (8). These overarching frameworks are presented in the next section, followed by a review of the literature related to the main themes explored in this study.

2.2 Theoretical frameworks

As stated above, the two main theoretical frameworks underpinning CPHAB and, therefore, this PhD study are the ICF (12) and Urie Bronfenbrenner's bioecological model of human development (8). The two frameworks hold several similarities. Both emphasise participation as an essential aspect of human functioning and development and recognise the importance of the relationship between the individual and the environment. However, while the ICF is grounded in a biopsychosocial perspective on health and focuses on functioning and disability as an outcome, Bronfenbrenner's bioecological model is more concerned with processes driving an ongoing development. These two frameworks are outlined in the following sections.

2.2.1 The International Classification of Functioning, Disability and Health

The ICF was launched by the World Health Organization (WHO) in 2001 and provides a standard framework and language for describing health and health-related states (12). In 2007, a derived child and youth version (ICF-CY) was presented, with some adaptations capturing the developmental aspects of functioning (13). However, the ICF-CY later merged into the ICF, which then addressed all aspects of functioning throughout the life span. Therefore, the framework is only referred to as the ICF heretofore.

The ICF is divided into two main parts: 1) functioning and disability and 2) contextual factors (12). The first part includes the components *body functions and structures* and *activity and participation*, while the latter comprises the components *environmental factors* and *personal factors*.

Body functions refer to physiological and psychological functions, and *body structures* to anatomical parts of the body. *Activity* is defined as the execution of a task or action, and *participation* is described as involvement in a life situation. *Environmental factors* refer to factors external to the individual and include physical, social and attitudinal aspects of the environment. These environmental factors are divided into two levels: an individual level representing the immediate environment of an individual (such as the family) and a societal level referring to, for instance, overarching services and systems in a community. *Personal factors* relate to the individual's particular characteristics or background and comprise features of that individual that are not part of a health condition or health state, such as gender, ethnicity and age (12).

According to the ICF framework, environmental factors interact with body functions and structures and activity and participation; therefore, disability is described as an outcome of the complex relationship between a person's health condition, personal factors and aspects of the environment in which he or she lives (12). By integrating biological, individual and social perspectives, the ICF represents a biopsychosocial approach that aims to describe and map functioning and disability (12).

The relationships between the different components included in ICF are visualized in a diagram that is frequently referred to in the literature. Multiple arrows between all the entities emphasise the complex, dynamic interactions and potentially bidirectional influences between the components (12). The model highlights environmental factors, such as family characteristics and services, as important for functioning and health and illuminates how participation both constitutes an important dimension itself and has the potential to influence other aspects of function. Figure 1 illustrates how the main themes explored in the present study (throughout the three sub-studies) and the variables included in the statistical analyses are linked to the ICF components.

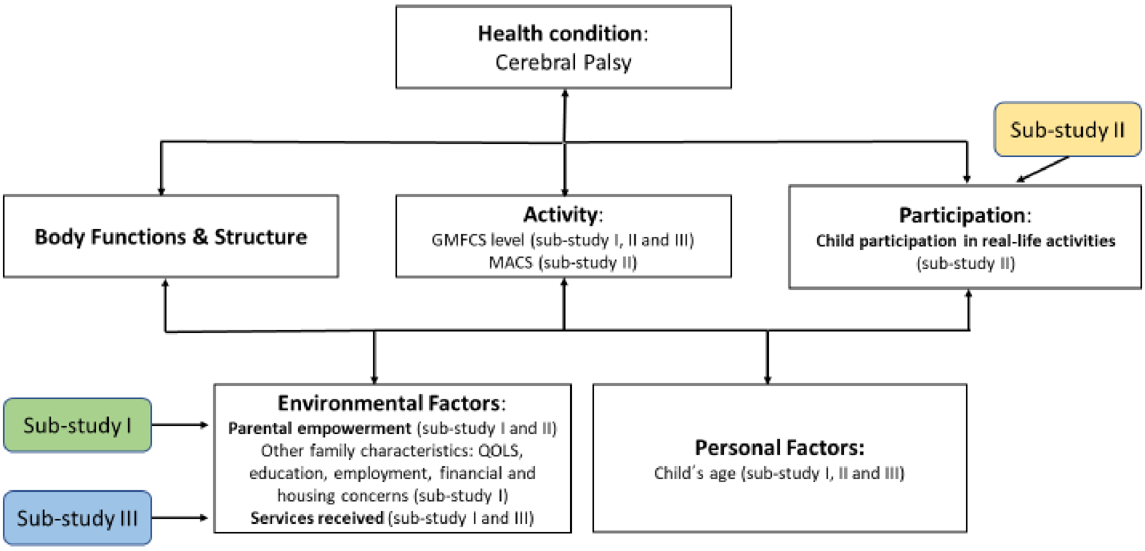

Figure 1. The ICF components including the main themes explored in the three sub-studies (in bold) and the other variables included in the statistical analyses

2.2.2 Bioecological model of human development

While the ICF is rooted in a health perspective, the bioecological model of human development originates from a psychologist and is grounded in the field of social sciences. However, due to its interdisciplinary and cross-sectoral focus on child development, the model has been considered of great importance to professionals and researchers concerned with children's development and well-being in the fields of both health and social and educational services. In the literature, the model has been commonly visualized with the developing child in the centre, surrounded by concentric circles representing different ecological systems. Bronfenbrenner described the surrounding environments as nested systems ranging from micro to macro that enclose each other like Russian dolls (14).

The *microsystem* represents the child's immediate environment, where face-to-face interactions, activities and the unfolding of social roles occur (8, 14). Particularly for young children, the family constitutes the most influential microsystem. The *mesosystem* expands the environment surrounding the child and comprises the relationships and connections between two or more microsystems, such as the family and kindergarten (8, 14). This level may include collaborative practices and encounters between representatives from different microsystems. The *exosystem* represents an environmental system where processes and interactions take place and may influence child development even though the child is not directly present (8, 14). Family network, workplace flexibility and services supporting parents are examples of systems or contexts that indirectly influence a child's situation. In fact, Bronfenbrenner specifically advocated such systems and services that support families to facilitate favourable conditions for child development (25). Finally, the outer ecological system is referred to as the *macrosystem* and entails aspects of the culture, ideologies and other characteristics of the wider society (14).

Bronfenbrenner's model has evolved over time from an ecological to a bioecological model. The prefix *bio* refers to the increased recognition of biologically based characteristics that influence processes and developmental outcomes (8). Such characteristics include the presence of a disability, which constitutes biologically based "baggage" that will most likely influence child development (25). Descriptions of a child's motor function thus seem relevant in analyses of developmental or participatory trajectories over time.

Furthermore, the emphasis of the model has gradually shifted from the environments toward an increased focus on processes (8). *Proximal processes*, described as reciprocal interactions between the person in focus and other persons, objects and symbols in his or her immediate external environment, are highlighted as the very driver of human development (8). Examples of settings where proximal processes take place include participation in play activities with children or adults, athletic activities, problem-solving tasks and activities for skill development. Participation in such interactive processes has the potential to generate the abilities, motivation, knowledge and skills necessary for involvement in progressively more complex interactions with others and individually. To be effective, such processes have to occur on a fairly regular basis over extended periods of time (8). Thus, frequency of participation and longitudinal participatory patterns should be examined when aiming to increase knowledge about children's opportunities for learning and further development.

The bioecological model incorporates four essential elements that have synergistic interconnections; these are proximal processes, personal characteristics, context and time (8). This structure supports research that integrates all of these elements while aiming to explore and increase the understanding of facilitating favourable conditions for child development and well-being.

Bronfenbrenner's model highlights three types of biopsychosocial characteristics as particularly influential for the direction and power of proximal processes and their effects on development: *dispositions*; *bioecological resources of abilities, experiences, knowledge and skills*; and *demand characteristics* (8). The characteristics not only relate to the child in focus but also to persons in the child's microsystem, such as parents or others who interact with the child on a fairly regular basis and over an extended period of time (8). This perspective builds on the argument of exploring parental empowerment as an important part of gaining knowledge of childhood matters.

Inspired by Bronfenbrenner's bioecological model, Figure 2 illustrates the child enclosed in a family context, with services representing a more remote ecological system surrounding the entire family. The main themes in the sub-studies and other variables included in the analyses are incorporated into the child's microsystem and into a surrounding ecological level, respectively.

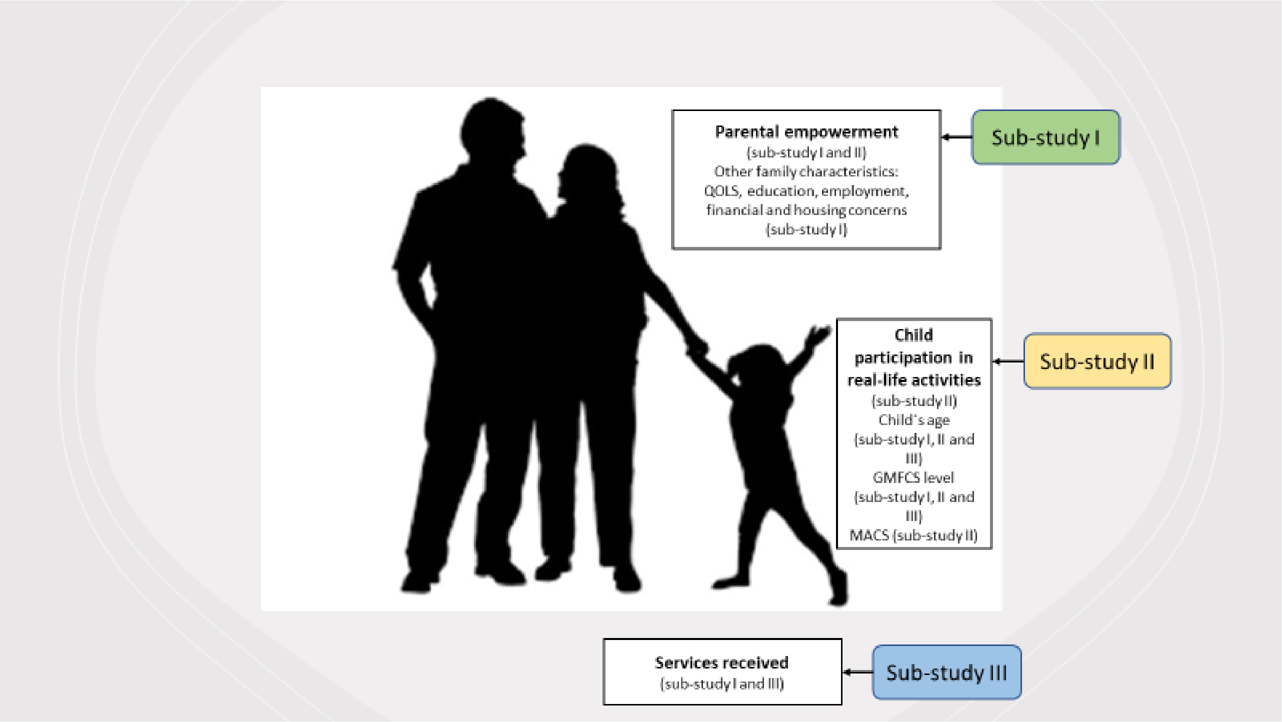

Figure 2. The main themes of the sub-studies (in bold) and other variables included in the analyses visualized in a family context, which represents the child's microsystem, and at a surrounding ecological level, which includes services received.

2.3 Parental empowerment

The importance of measuring and exploring parental empowerment in the context of childhood rehabilitation can be argued for several reasons. Primarily, family constitutes the most influential context for young children with disabilities. Therefore, measuring empowerment can identify the family's resources and needs and provide direction for further follow-up of the child. More indirectly, measuring parental empowerment can also provide information about aspects of the service provision and the extent to which parents are involved in the development and quality improvement of service systems. The next section presents the theoretical underpinnings of empowerment, followed by an outline of the operationalisation of the construct into a measurement instrument. This outline is accompanied by a review of previous research based on the instrument.

2.3.1 Theoretical underpinnings

Empowerment is described as a multidimensional construct that incorporates processes, outcomes and values (26). Empowerment processes refer to mastering and gaining control over important issues and include elements such as raising critical awareness of the environment and participating in decision-making processes (26). Empowerment can also refer to an individual's current ability to exercise power (27) as well as his or her control over elements important to his or her destiny (27) and quality of life (28). The value dimension of empowerment refers to a belief system and approach that govern the collaboration between professionals and clients, and it includes attention to competence and skill development, as well as independence and involvement in society (26).

Empowerment can be expressed in various settings and at various ecological levels, such as individual, organisational and community levels (29). The concept includes components of recognising, promoting and enhancing abilities that enable people to cope with their needs, solve their problems and mobilise resources necessary for gaining control of their lives (30). From the perspective of professionals, empowerment can involve creating a relationship in which the client or user takes control of change processes and decides both goals and means to achieve them (28). The construct incorporates both intrapersonal (psychological) and interpersonal (relational) components, which seem to be closely intertwined (30).

Although empowerment is often discussed as a theoretical rather than practical construct (31), measurement instruments have been developed that enable research on empowerment among caregivers. One of the most widely used instruments is the Family Empowerment Scale (FES) (32), which is presented in the next section.

2.3.2 The Family Empowerment Scale

The FES was developed as a brief, self-administrated questionnaire that provides a snapshot of caregiver empowerment in families caring for a child with serious emotional disabilities

(32). The FES consists of 34 statements (items) representing two main dimensions of empowerment: the ecological level or context in which empowerment is expressed and the way it is expressed. The first dimension includes three distinct contexts: *family* (12 items), representing the immediate situation at home and parental management of daily situations; *service situations* (12 items), reflecting interactions with service providers and the process of obtaining access to services; and *community* (10 items), representing parental influence and advocacy for bettered services for families in general (i.e., not aimed merely at the specific child and family). Within these three contexts, empowerment is expressed as *attitudes* (what parents feel and believe), *knowledge* (what parents know and have the potential to do) and *behaviour* (what they actually do). The items are scored on a Likert scale ranging from 1 (not true at all) to 5 (very true), with higher scores indicating higher levels of empowerment (32). Scoring is accomplished by summing up each item's score in each of the three subscales (family, service situations and community).

The original structure of the scale describing empowerment in the three contexts (family, service situations and community) has been confirmed as meaningful by subsequent empirical studies (31, 33-35) and is widely used for reporting research results. However, based on a statistical factor analysis and conceptual considerations, Singh and colleagues (36) developed an alternative four-factor structure to interpret results that included the following components: system advocacy, knowledge, competence and self-efficacy. This structure has been used to report parental empowerment scores based on the FES in several studies (36-40). Additional studies have reported only total scores (41-43), while others have used only parts of the questionnaire (44, 45). Even with this complexity in the reporting of results, research based on the use of the FES has provided valuable information on parental empowerment in different populations and contexts. The most relevant studies on parental empowerment in relation to the current study are presented in the next section.

2.3.3 Previous research on family empowerment

The FES has been used in research studies measuring caregiver empowerment in several countries, such as the USA (32, 34, 36-38, 40-42, 44, 46-49), Canada (45), Australia (41, 50, 51), the UK (52), Israel (43, 53), Japan (54-57), Korea (39), India (50), Finland (33, 58, 59), Serbia (60), Iran (35) and the Netherlands (61, 62). The following caregivers were assessed: those representing families with children without disabilities (31, 33, 58-60), families caring for children with a chronic health condition (43) and a wide variety of disabilities (31, 32, 34-37, 39, 40, 44, 46-48, 50, 51, 53-57, 60) and families caring for a child receiving palliative care (52). Furthermore, the FES has been used to explore empowerment levels and associations with different characteristics of the child, family or services received (31-41, 50, 51, 53-55, 59, 60) in studies that used empowerment as an intervention outcome (44, 46, 47, 49, 52) and in research in which empowerment was included as a family characteristic (38, 43, 61).

The mean scores of parental empowerment as reported in the context of family situations vary considerably, from 2.9 among caregivers of children with developmental delays in Japan (54, 55) to 4.4 among parents with young children both with and without disabilities in Finland (58). In most studies, the empowerment scores reported in the context of service situations were almost as high as or higher than in family situations. Similar to empowerment in family situations, the lowest scores for service situations were found among Japanese caregivers raising a child with a developmental disability (mean score, 2.8) (54). The highest mean scores of empowerment in service situations were found among American parents of a child diagnosed with an autism spectrum disorder who participated in a support group (mean score, 4.5) (47). With very few exceptions, the mean scores of empowerment in the community context were considerably lower than those of the other two subscales. Mean scores at the community level were reported from 2.0 in Japanese families raising a child with a developmental disability (55) to 3.7 among families with a child with autism in the USA (48). No previous studies have reported parental empowerment scores among caregivers in Norway or among parents of children with CP as a distinct group.

Research exploring associations between levels of parental empowerment and children's disabilities has yielded inconsistent results and considerable variations between different contexts and dimensions of empowerment. In the context of family situations, a Canadian study found no statistically significant differences in the empowerment scores of families with and without children with developmental disabilities (31). In contrast, significantly lower levels of empowerment in the family subscale were found among Finnish families raising a child with a disability compared to families with children without disabilities (33), while no statistically significant differences were found in the contexts of service situations or community (33). These findings corresponded with those of a Serbian study that found statistically significantly lower empowerment scores on a single-item level among families with children with disabilities versus those without disabilities (62). This difference was found in almost half of the items included in the family subscale but in only one item in each of the contexts of service situations and community (60). While these studies indicate equal or somewhat lower empowerment in families with children with disabilities compared to those without, an American study reported higher empowerment scores on the self-efficacy dimension in families including children with severe emotional disabilities (SED) combined with attention deficit and hyperactivity disorder (ADHD) compared to families with children with SED alone (37). This added finding highlights the complexity of the relationship between parental empowerment and children's disability. To the author's knowledge, no research papers have reported comparisons of parental empowerment scores based on the severity of the child's mobility limitations according to GMFCS classifications for children with CP.

Inconsistency has also been revealed in research exploring associations between empowerment and family characteristics. In a Finnish study exploring empowerment among caregivers of young children with and without disabilities, higher empowerment scores were found among parents with education from a college or university compared to parents with fewer years of education (60). However, this was true only for the community subscale (58). In contrast, the American study including parents with children with SED and ADHD found higher empowerment scores regarding the knowledge dimension of empowerment among parents with no higher education compared to parents reporting more years of education (37). Regarding family resources besides education, a good financial status has been correlated with higher empowerment scores (43, 58). How parental empowerment may relate to other family concerns, such as the housing situation, when raising a child with mobility limitations has not previously been explored.

Research on associations between empowerment and service characteristics has indicated a positive relationship between empowerment and the family-centeredness of the services (51). In intervention studies using the FES as an outcome measure, increases in empowerment scores were seen over time after the intervention (44, 47, 48, 52). Whether, and if so how, empowerment levels change over time regardless of specific interventions, as well as the possible relationships between empowerment levels and the receipt of concrete coordination services (e.g., coordinators, individual plans and multidisciplinary teams), have been less explored.

2.4 Child participation in real-life activities

Participation in play and recreation is considered a fundamental right for all children and is solidly anchored in article 31 of the United Nations Convention on the Rights of the Child (63). Participation in subjectively important activities provides value in and of itself by bringing joy and meaning into the child’s life, and it is thus considered a desirable outcome or goal for rehabilitation services (11). Furthermore, participation in real-life activities is recognized as an important context for promoting skills and facilitating learning and development (8, 11, 13).

One of the most commonly used definitions of participation stems from the ICF, which broadly defines participation as “involvement in a life situation” (12). Participation appears to be a multidimensional construct (11) influenced by and affecting both individual and environmental factors (11, 12). The next sections will present a model of participation and participation-related constructs, followed by an outline of how participation can be operationalised to measure child participation in real-life contexts, such as in family and recreational activities. Finally, literature stemming from previous research on young children’s participation will be presented.

2.4.1 A framework for exploring participation

Based on a review of literature, Imms et al. presented a framework valuable for understanding and exploring participation as it emerges in real-life situations (11). Their framework includes two essential and embedded components of participation—attendance and involvement—as well as personal, contextual and environmental factors that may both influence and be influenced by participation. Combined, these elements are referred to as *the family of participation-related constructs* (fPRC). The different elements and their interplay are illustrated in Figure 3.

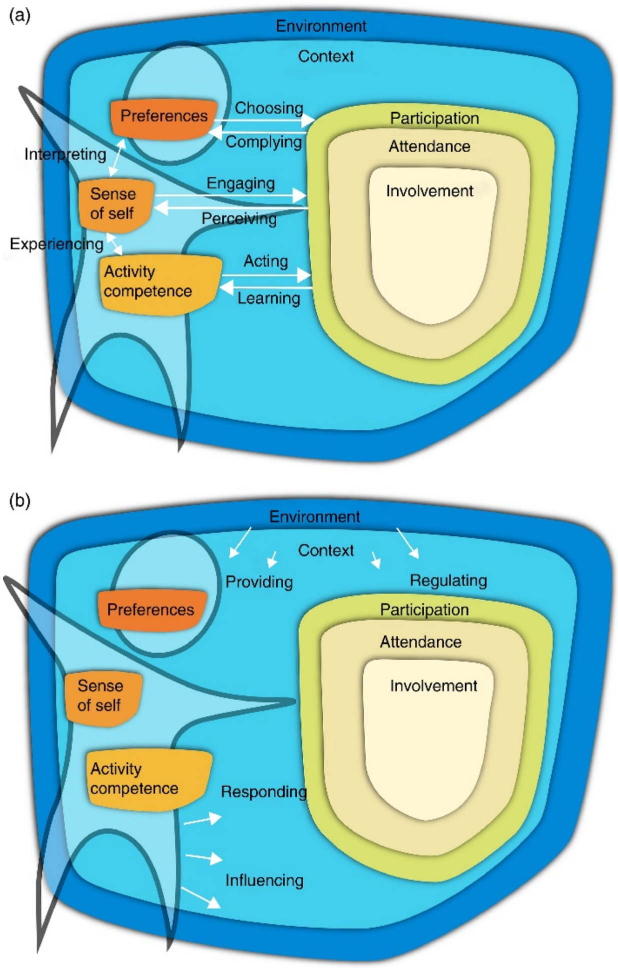

Figure 3. The family of participation-related constructs (fPRC) model (11), which illustrates a) person-focused processes and b) environment-focused processes.

The participation component of *attendance* illustrated in Figure 3 refers to being present in a situation, and it can be measured as frequency and/or diversity in activities in which a child participates. *Involvement* (*engagement* may be used interchangeably) captures the subjective experience of the child while attending. This component includes the cognitive elements of motivation, attention and focus; behavioural characteristics, such as effort and persistence; and emotional reactions, such as enjoyment, eagerness or a sense of belonging. Attendance and involvement are both considered essential for understanding, exploring and describing participation (11).

The model categorises within-person factors into *activity competence, sense of self* and *preferences*. *Activity competence* refers to a child's physical, cognitive and affective skills and abilities that influence the execution of an activity. These skills and abilities can be measured as capacity (what a child has the potential to do at his or her best), capability (what a child is able to do in a standardised environment, for instance, a test situation) or performance (what the child usually does in his or her natural environment) (11). The child's *sense of self* refers to intrapersonal characteristics, such as confidence, satisfaction, self-esteem and self-determination. These characteristics may influence engagement in activities, and they are also shaped by participation experiences (11). Finally, *preferences* refer to interests and activities that are valued and considered important from the child's point of view. These preferences are established through interactions and experiences and are likely to affect the child's choice of activities in which to participate (11).

Each of the within-person factors has, in different ways, the potential to influence and explain participation *in the present* and provide direction for *future* participation, and these factors can be influenced and explained by participation in the *past* (11). This potential elucidates the dynamic and complex interplay that occurs between participation and multiple individual characteristics, as well as between participation in the past, present and future.

Moreover, according to the fPRC model, participation is regulated by the *context* and the *environment* (11). The *context* represents participation as it emerges for an individual child and may include, for instance, people, activities, places, objects and time spent on an activity. The *environment* refers to a broader external environment and may include both objective physical properties and social conditions (11). Different dimensions of the context and the physical and societal environment of participation can be described by the "a-words": availability, accessibility, affordability, accommodability and acceptability (64). *Availability* represents the objective possibilities for engaging in a situation and may relate to facilities or resources. *Accessibility* refers to whether people can, or perceive that they can, access the context for participation. *Affordability* represents the balance between costs (both financial and time and energy spent) and rewards (i.e., whether engaging in the situation is worthwhile). *Accommodability* refers to whether a situation is or can be adapted through modifications or adjustments. Finally, *acceptability* represents a person's acceptance of the situation, thus constituting a more subjective dimension (64).

The multiple and complex interconnections between the subjective and objective components of participation, different characteristics of the person and aspects of the context and the environment pose certain challenges for measuring and exploring participation using quantitative questionnaires. The next section presents and discusses a questionnaire developed to measure participation in family and recreational activities among the youngest children.

2.4.2 Measuring child participation: The Child Engagement in Daily Life questionnaire

There are several arguments for measuring child participation. On an individual level, measuring participation may document a current state, provide direction for goal setting and planning interventions and can be used for evaluating intervention outcomes. In a research context, measuring participation may contribute to the knowledge of an important aspect of child functioning. More specifically, research based on measurements of participation may contribute to an increased understanding of how participation appears at a certain stage of life and how it may change over time. Measuring participation also enables detection of children in need of extra attention, and explorations of a potential empirical relationships between participation and characteristics of the child and his or her environment.

According to the fPRC model, an instrument that includes the two main components of participation—attendance and involvement/engagement—should be used. However, a study looking into instruments assessing participation among preschool children revealed that subjective aspects were emphasised in only a minority of the available instruments (65). A recent systematic review of participation instruments aligned with the fPRC framework identified the Child Engagement in Daily Life (CEDL) questionnaire (66) as 1 out of 12 instruments incorporating both attendance and involvement/engagement and 1 out of 7 instruments with psychometric properties supporting its use with children with CP (67).

The CEDL questionnaire was developed to provide a short and user-friendly questionnaire for assessing participation in play and family routines among young children with and without disabilities (66). The questionnaire was originally tested on children with CP 18 to 60 months of age (66), with intentions to be used among children up to the age of 8 years (68). It was also used in a recent study including children as old as 12 years (69).

The CEDL questionnaire includes items referring to broad categories of activity settings and is divided into two parts: family and recreational activities (11 items) and self-care (7 items). Only the family and recreational activities part was included in the CPHAB project (and thereby this study). For this reason, only this part is discussed further in the text. The 11 activity settings included are *family activities at home* (such as chores, mealtime, watching TV), *family outings in the community* (such as shopping, going to religious services or the library, visiting family and friends), *indoor play with adults, indoor play with children, outdoor play with adults, outdoor play with children, quiet recreational activities* (such as colouring, card games, reading books), *organised lessons, adapted sports and arranged play groups* (such as swimming, dance/creative movement, parent-and-me classes), *active physical recreation* (such as riding a tricycle, swimming, running outside, climbing on playground equipment), *entertainment outings* (such as going to the zoo, a children's museum, the circus, concerts) and *social activities* (such as a play date, party). Further, two dimensions of participation—frequency and enjoyment—are assessed for each of the 11 activity settings. Both dimensions are scored on a 5-point Likert scale with frequency of participation scores ranging from 5 (representing "very often") to 1 (representing "never") and enjoyment scores ranging from 5 (reflecting that the child likes the activity "a great deal") to 1 (the child likes the activity "not at all").

Previously, most participation instruments have been directed at children of school age and adolescents, which has led to a dominance of these age groups in systematic reviews exploring participation. However, in the last couple of years, the CEDL questionnaire and some other instruments have been developed to enable research on participation among the youngest children. Results from these studies are presented in the next section.

2.4.3 Previous research on young children's participation in real-life activities

The most widely used measurement instruments for exploring young children's participation in addition to the CEDL questionnaire (66) are the Assessment of Preschool Children's Participation (APCP) (70) and the Young Children's Participation and Environment Measure (YC-PEM) (71). As previously described, the CEDL questionnaire assesses the frequency and enjoyment of participation in 11 broad categories representing different activity settings (66). The APCP assesses attendance in the form of diversity and intensity of participation in the areas of play, skill development, active physical recreation and social activities; it does not include the involvement component (70). The YC-PEM includes assessments of frequency, involvement and desire for change as well perceived environmental support in activity settings at home, in day-care/preschool and in the community (71).

Independent of the instrument used to assess participation, the research has indicated that participation differs between children with and without disabilities. Research based on the CEDL questionnaire has revealed less frequent participation in children with CP compared to children without any disability (66). Similarly, research using the APCP has indicated that children with physical disabilities participate less often and in fewer activities than children without such disabilities (72). Additionally, research based on the YC-PEM has revealed less participation among children with disabilities and developmental delays compared to their typically developing peers in the context of day-care/preschool (71, 73), as well as lower levels of involvement in the activity settings of home (71), day-care/preschool (71, 73) and the community (71).

In addition to the revealed differences in participation between children with and without disabilities, the research has indicated that the more specific ability levels of children with disabilities are associated with aspects of participation. Among children with CP, frequency of participation as measured by the CEDL questionnaire was found to be the highest among children with the least restricted mobility (GMFCS level I), and it decreased with more limited mobility as classified by the GMFCS (66, 69, 74). Furthermore, another study using the CEDL questionnaire identified children's gross motor function capacity, measured by the Gross Motor Function Measure (GMFM) (75), as a determinant of participation among children with more severe limitations to self-mobility (GMFCS levels III to V) (68). These findings were in line with results from research that used the APCP and revealed that children classified at GMFCS levels I to III participated more frequently and in a greater range of activities than children at GMFCS levels IV and V (70). Furthermore, positive associations have been revealed between functional capabilities and performance in the areas of daily activities, mobility and social/cognitive functioning as measured by the Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) (76), as well as levels of involvement in activity settings at home, in day-care/preschool and in community, as measured by the YC-PEM (71).

Research has indicated that aspects of the relationships between gross motor abilities and frequency of participation may differ between activity settings. When it comes to physically active recreation, the frequency of participation seems to decrease with decreasing gross motor function, and children with the most restricted mobility seem to participate less frequently in family activities at home compared to children with milder mobility limitations (66). In contrast, in the activity setting of entertainment outings, the most frequent participation is seen among children classified with severe mobility limitations, while children with only minor limitations in mobility (GMFCS level I) were found to participate less frequently in indoor play with adults compared to children with more severe gross motor limitations (66).

Research on the associations between participation and the abilities of young children with CP has, to a large extent, focused on gross motor function, leaving relationships between participation and manual abilities far less explored. One previous study indicated that children at MACS levels I and II participate more frequently in family and recreational activities overall compared to children classified at MACS levels III, IV and V (69). However, how the frequency of participation in different activity settings relates to hand function has not been previously explored.

Studies on the relationships between young children's participation in family and recreational activities and the characteristics of the family have been limited. In a study including young children with CP and their families, a statistically significant direct connection was found between the frequency of child participation and the family ecology, operationalised by measures of the family's expectations of their child and family relationships, personal growth and system maintenance (74). Another study—including children with a wider spectrum of disabilities—identified family functioning in terms of problem solving and communication as a variable that could explain aspects of participation, such as involvement in the community and desire for change in the home setting (77). How child participation relates to parental empowerment has not yet been explored.

Another area of scarce research is the subjective experiences of participation among the youngest children. Previous research has indicated that children without disabilities enjoy participation more than children with mobility limitations (66) and that enjoyment is negatively associated with functional levels, as classified by the GMFCS (66, 69) and MACS (69). However, how enjoyment relates to differences in motor abilities in different activity settings has not been explored.

Research on how aspects of participation may change over time in the early years has also been limited. Research based on the use of the APCP has indicated that children above the age of 4 participate more frequently and in a broader range of activities compared to children who are younger (70, 72). Results from studies using the CEDL questionnaire have been more inconsistent. One study including children from 18 to 60 months found that children younger than 31 months participated less often in family and recreational activities compared to older children (66), whereas no difference between age groups was found in a study including children with CP aged 1.5 to 12 years (69). A recent study exploring the frequency of participation over time among young children with CP concluded that trajectories were generally relatively stable, with great individual variability, however (74). The trajectories of enjoyment over time have yet to be explored.

2.5 Services directed to children with disabilities and their families

Whereas the family constitutes the immediate and most influential environment for young children, interventions, services and service systems represent other aspects of the environment that surround children and their families. Thus, gaining knowledge about the services received by families is important for understanding the families' situation and identifying the strengths and limitations of the service system. The next sections will present the organisational structures of services directed at children with disabilities in Norway, as well as the research exploring some of the key characteristics of services in a paediatric rehabilitation context.

2.5.1 Organisation and anchoring of services in legislations

Health and social care in Norway is based on a welfare model dominated by public funding and provision of universally available services (78), and the responsibility for services is divided between the state and municipalities (see Table 2). Specialist health services are governmental and are administered by four Regional Health Authorities (North, Mid-Norway, West and South-East) (15). Within each of these Regional Health Authorities, specialised follow-up of children with disabilities is offered in a paediatric rehabilitation unit based on the families' residential address. The municipalities are responsible for primary health care services, including physical and occupational therapy (15). Furthermore, the municipalities are responsible for adapting day-care facilities for children with disabilities, which commonly include the provision of a kindergarten assistant and special education support, as well as supporting families by offering respite care services. Some financial benefits directed at families with a child with disability are provided by the state, while others are provided by the municipalities. Furthermore, the services and benefits are anchored in different legislations (for more details, see Table 2).

Table 2. Organisational level of services and legislations

Service category	Organisational level	Legislation
Specialist health services	State (Regional Health Authorities)	The Specialist Health Services Act
Paediatric rehabilitation (specialist level)	State (regional paediatric rehabilitation units)	The Specialist Health Services Act
Primary health care services: Physiotherapy, occupational therapy	Municipalities	The Municipal Health and Social Services Act
Adaptations of day-care facilities: Kindergarten assistant, special education	Municipalities	The Kindergarten Act
Respite care services: Respite care home, personal assistant, support contact	Municipalities	The Municipal Health and Social Services Act
Financial benefits:		
Training allowance	State (NAV[*])	The National Insurance Act
Attendance allowance	State (NAV)	The National Insurance Act
Basic benefit	State (NAV)	The National Insurance Act
Caregiver benefit	Municipalities	The Health and Care Services Act
Car subsidies	State (NAV)	The National Insurance Act
Housing grants	State (The Norwegian State Housing Bank)	

[*] NAV: The Norwegian Labour and Welfare Administration

With responsibilities distributed between the state and the municipalities, differences in the legal basis for the services provided, and a wide range of professions involved, continuity and coordination stand out as important aspects of the service delivery for children with disabilities and their families. How these aspects are addressed in the Norwegian service system and internationally is presented in the next section.

2.5.2 Continuity, coordination and family-centredness in services

Continuity and coordination of care have been presented as global priorities for improving services provided to people with chronic conditions and complex needs (16). Continuity refers to the extent to which services and events are perceived as coherent and interconnected over time and are in accordance with the family’s needs and preferences (16). Service coordination is described as organising multiple involved services to avoid fragmentation and ensure that services are provided consistently and continuously across the different service systems (79). Thus, both continuity and coordination are considered essential for ensuring coherent and individual tailored services both over time and across organisational borders.

Coordination has particularly gained increased focus in the Norwegian health care system during the last decades (15), and two organisational tools for coordination were incorporated into the health and social legislation in 2001. These were the individual service plan (ISP) and the personal service coordinator (80). The aims of the ISP and the coordinator are to provide coordinated and individually tailored services to those in need of long-term, multidisciplinary services; to ensure patient and user participation; and to strengthen the collaborative interactions between service providers and the patient and his or her family (80). The ISP is intended as a tool for cooperation between different actors involved in a child's or family's situation and is supposed to include an overview of goals, interventions and services received, as well as responsibilities for follow-up (81). The service coordinator is assigned the responsibility of developing and following-up the child's ISP (80). Additionally, the coordinator has a key role in helping families navigate a complex service system (82), advocating for the family in encounters with the welfare system (81) and being a close and trusted contact person for the family (81).

Multidisciplinary support teams represent another kind of service coordination widely used within the context of paediatric rehabilitation. Such teams are not statutory in Norway; however, they are often combined with other provided coordination services, such as the ISP and service coordinator. To a large extent, multidisciplinary teams, the ISP and service coordinators appear intertwined; the ISP constitutes a concrete basis for working in multidisciplinary teams (83), and the coordinators are responsible for chairing the team meetings and developing and updating the plan accordingly (81). In this way, the coordination services constitute an organisational framework for collaboration, as illustrated in Figure 4.

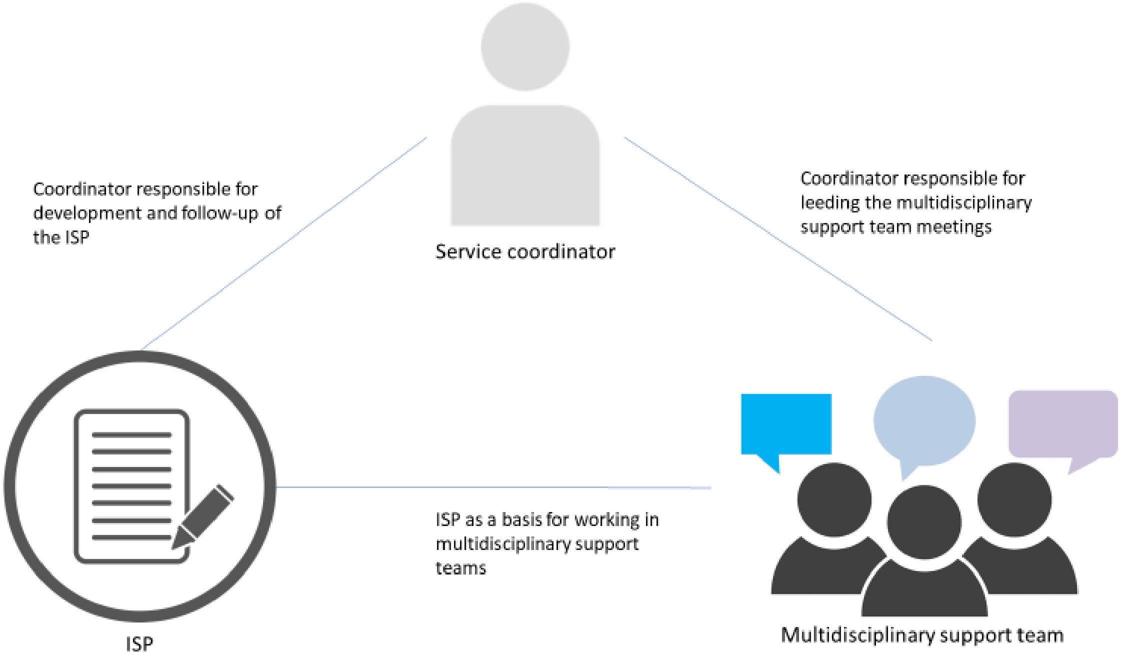

Figure 4. Coordination services as an organisational framework for collaborative practices; links between the coordinator, the individual service plan (ISP) and a multidisciplinary support team.

Collaborative practices and service coordination are presented as cornerstones of family-centred services (82), which are fundamental in the field of paediatric rehabilitation (84). The roots of family-centred practices can be traced back to the USA, where a shift in the 1970s moved from focusing solely on the child toward viewing the family as a unit for intervention (85). In the paradigm of family-centred care, families are recognized as pivotal in their child's life, constituting the most important ecological environment (85, 86). According to family system theories, the well-being of families is essential to the well-being of the child (86), which argues for implementation of services that support the family as a whole. Moreover, family system theories emphasise the family's resources and capabilities, which can further strengthen and provide active involvement in the follow-up of their children (85, 86). The values and processes embedded in the empowerment construct (26) thus appear to be closely intertwined with key aspects of family-centred care (85).

The next section presents previous research exploring how the abovementioned aspects of service provision are implemented in real-life contexts of children with disabilities and their families.

2.5.3 Previous research on services directed to children and their families

A Norwegian report published in 2016 included a literature review of parents' experiences with public health and social services and interviews with parents raising a child with a disability (94). This report concluded that both subjective experiences and objective aspects of the service delivery vary greatly and emphasised the need for coordination, preferably in the form of an individual service coordinator (87).

The value of a being entitled to a coordinator has been highlighted for years (88); however, several challenges have been revealed for implementing this kind of service in the follow-up of children with special needs. From the perspective of professionals, being appointed the coordinator role without knowing the child and family well has been pointed out as a major challenge (81). Furthermore, some coordinators report irregular and infrequent contact with the user, while some families are not even aware that a professional has been appointed to the role (81). This highlights the blurring roles experienced by professionals who are appointed as a family's coordinator (39); coordinators may struggle to balance their basic professional role (for example, being a physiotherapist) and being a coordinator, and to combine the administrative and relational aspects of working with families (39). Furthermore, some coordinators experience that demands associated with the coordinator role are on the margins of their professional competence (39).

A number of challenges related to the use of ISPs as tools for coordination have also been described, with critical voices raised both in Norway (89) and in countries with a similar service system (90). Barriers to the implementation of ISPs are identified in relation to individuals, service providers, organisations, management and policies (91). From a service provider perspective, working with ISPs has been described as challenging due to conflicting roles and heavy workloads (92). Furthermore, research on collaborative practices related to young children with special needs has revealed the risk that the ISP ends up as a “desk document” in the drawer of a coordinator instead of being a live and informative document (81). Challenges related to the implementations of ISPs in Norway have also been revealed in the context of mental health services (91) and rehabilitation after brain injuries (93). However, the ISP has also been described as a useful tool that forms a basis for structured meetings between families and professionals, thereby promoting collaboration and coordination of services (83). Large differences in collaborative practices have been identified in research (94), and both ISPs and coordinators may serve either as facilitators or barriers to collaboration, depending on the context (81).

Multidisciplinary teams seem to be less controversial and have also been discussed less in the literature. Such teams have been described as valuable platforms for engaging parents in shared practice where knowledge is exchanged and common ground for negotiating meaning is established, thereby promoting collaboration (95). Other research has highlighted multidisciplinary teams as more effective for coordination and collaboration than ISPs (90), and working in teams has been outlined as the most efficient context for providing family-centred services (86).

Providing family-centred services has widely been agreed upon as a best practice within paediatric rehabilitation and has consistently been associated with positive child and family outcomes, as seen in parents’ appraisals of services (96), parental self-efficacy beliefs (97, 98) and parental empowerment (99). Two distinct dimensions of family-centred practices have been identified: relational and participatory (85, 100). Relational practices are interpersonal behaviours; these include empathetic listening and non-judgmental attitudes. Participatory practices include families’ active involvement in decision-making and planning of further follow-up (85). Both dimensions are essential for establishing solid partnerships between the family and service providers, which is a key aspect of family-centred practices (84, 100).

Help-giving practices, which focus on both relational and participatory aspects of the service approach (101) and the establishment of strong collaborative relationships have been revealed as favourable for enhancing family empowerment (101, 102). However, research has indicated that professionals struggle to enhance empowerment in families caring for children with disabilities (103). Large differences between practices are seen both in terms of the power balance between service providers and families (104) and user involvement in collaborative processes that include a coordinator and involve working with an ISP (105). Research has even indicated that planning processes (e.g., based on ISPs) can have a negative effect on empowerment processes (89).

The relationship between received coordination services and parental empowerment, as examined through quantitative methods, has not been explored in previous studies. Research capturing the broad picture of services received across organisational and professional borders is also lacking. Furthermore, the continuity in services provision over time has been explored only to a small extent and thus constitutes an area in need of research.

2.6 Summary of knowledge gaps

The review of literature on parental empowerment, children’s participation in real-life activities and services aimed at children with disabilities and their families has revealed some existing knowledge gaps. First, empowerment has been highlighted both as a favourable process and an outcome of collaborative practices involving parents and service providers. However, little is known about empowerment in families caring for a young child with a disability like CP in a Nordic context. Hence, research that explores parental empowerment in connection with the characteristics of the child and the family and the services received, as well as how empowerment develops over time, is needed. Such research will provide new knowledge valuable for rehabilitation practices and will generate additional hypotheses that may be tested in subsequent studies.

Second, children’s participation in real-life activity settings constitutes an important context for learning, development and the fulfilment of a meaningful life. To facilitate opportunities for participation among young children with disabilities, knowledge about how functional limitations can affect both subjective and objective aspects of participation in different activity settings is needed. Information is also needed on how these aspects may change over time. However, little research has been conducted on these topics among the youngest children with CP in the Nordic countries. More knowledge about participation in this group of children will have value for informing rehabilitation practice and for increasing the focus on participation as a primary outcome of rehabilitation services.

Finally, children with a complex health condition, such as CP, will need long-term multidisciplinary follow-up in most cases, and in line with a family-centred approach, child-directed services should be accompanied by services aimed at supporting the whole family. However, little research has described the specific services received, and how widespread these services are and how they relate to the characteristics of children's disability has not been explored. Such knowledge is important for increasing the understanding of what families with children with disabilities encounter in their everyday lives and for identifying areas in need of further research or quality improvements.

These main knowledge gaps presented above form the basis for the research questions addressed in the current PhD study.

3. Aims of the thesis

The overall aim of the PhD study was to elucidate and explore some important facets of the life of families caring for a young child with CP. More specifically, the study aimed to 1) describe parental empowerment, child participation in real-life activities and services received by families during early years; 2) outline how these abovementioned aspects of the families' situation can be linked to characteristics of the child and family, as well as the services received; and 3) reveal whether and how empowerment, participation and service provision change over time or relate to increasing age. Through these aims, the study will contribute to strengthening the knowledge base for paediatric rehabilitation and will form the basis for further development of services and service systems that create good upbringing and development conditions for children with complex health conditions, such as young children with CP.

An overview of the specific aims and research questions included in each of the sub-studies is provided in Table 3.

Table 3. An overview of the main themes and specific aims and research questions included in the PhD study

Sub-study	**Main theme**	**Aims of the study/research questions**
I	Parental empowerment	*Aims:* • To describe trajectories of parental empowerment in the family, service situations and community from enrolment in a systematic follow-up program for children with CP throughout early childhood • To explore longitudinal associations between parental empowerment and characteristics of the child and family and the services they receive
II	Child participation in real-life activities	*Research questions:* • How frequently do children with CP participate in family and recreational activities both overall and in specific activity settings during their early years, and how much do they enjoy these activities? • How do the frequency and enjoyment of participation during the early years relate to the child's gross motor function and hand function? • Do the children's frequency and enjoyment of participation change over time, and how do the participation trajectories relate to the children's gross motor function and/or hand function? • How does the frequency of child participation during the early years relate to parental empowerment in the family and service situations?
III	Services received by the families	*Research questions:* • What kind of *child- and family-directed services* do young children with CP and their families receive, and is there a relationship between the number of services received and the child's age and severity of mobility limitations? • What kind of *coordination services* do the families receive, and does the type of service differ based on the severity of the child's mobility limitations? • How *continuous* is the provision of services during early childhood?

4. Methodology and methods

This chapter includes an overview of the study's overarching research design and a description of the methods used in the study. Most aspects of the methodology and methods were common to the entire PhD study and are therefore described together, except for the statistical analyses, which are presented separately for the three sub-studies.

4.1 Study design and organisational anchoring

The main objectives of the study were to empirically explore parental empowerment in families raising a young child with CP, to expand the knowledge about children's participation in real-life activities and to examine services received by families during early childhood. The study was designed as a registry-based prospective cohort study anchored in two Norwegian CP registers: the CPOP and the associated research register, CPHAB. Both registers include data that, when combined, enabled an exploration of the chosen themes with a quantitative research approach.

The **CPOP** is a nationwide, ongoing program that includes systematic assessments of motor function and a register of physiotherapy and occupational therapy interventions directed at children with CP from an early age. The CPOP was established in 2006 as a three-year project in the South-Eastern Norway Regional Health Authority and was continued and implemented in the remaining regional health authorities in Norway in 2010 (106). The CPOP's regular mappings of impairments and interventions targeting motor function follow standardised protocols and are completed by physiotherapists and occupational therapists at regional rehabilitation units, sometimes in collaboration with colleagues in the municipalities. This regular monitoring enables early detection of secondary impairments and unfavourable motor development as well as an identification of needs for specific interventions. Thus, the CPOP forms a valuable platform for systematic follow-up of children with CP and constitutes a unique register for longitudinal research of CP-related topics, either alone or in combination with other research registers, such as the CPHAB. In 2021, the CPOP was merged with the CPRN, becoming the NorCP.

CPHAB was established as a research project from 2012 to 2016 as part of the Research Centre for Habilitation and Rehabilitation Models and Services (CHARM). The CHARM network group is funded by the Norwegian Research Council and has an overall purpose of strengthening research in rehabilitation services across the different levels of health care services and other societal institutions. The CPHAB project was rooted in a biopsychosocial and ecological understanding of child development and functioning and aimed to expand the perspectives of CP beyond a sole focus on motor function. More concretely, CPHAB entailed an extended mapping of child and family functioning as well as contextual factors that may affect their lives. More information about CPHAB and related research projects is available on the CPHAB website (https://www.med.uio.no/helsam/english/research/projects/cp-rehab-children/index.html). For this specific PhD project, the most relevant information from CPHAB were questionnaires assessing parental empowerment as expressed in different contexts and those assessing child participation in real-life activities, as well as reports on services directed at both children and their families.

4.2 Recruitment procedure and the inclusion process

In Norway, 21 regional rehabilitation units are responsible for CPOP registrations. Based on comparisons with the Norwegian Patient Registry, more than 90% of all children with CP in Norway are included in the CPOP/CPRN registers (17). All the regional rehabilitation units were invited to take part of the CPHAB project as an extension of the CPOP follow-up, and 13 units agreed to participate. According to the other rehabilitation units, the main reason for not participating was a lack of capacity to recruit participants and administer the package of questionnaires included in CPHAB.

For the families and children belonging to the participating rehabilitation units, the inclusion criterion was raising a child who was first registered with CP in the CPOP/CPRN at 4 years or younger between 01 January 2012 and 31 December 2014. This amounted to 132 families. Families who were not able to complete written questionnaires in Norwegian or English were excluded from the study, and 11 participants were excluded due to this criterion. Furthermore, 21 families were not invited to participate in the CPHAB study either because of capacity limitations at the rehabilitation units, or because professionals considered the burden of participation too large for the families. An additional 25 families declined to participate in CPHAB.

Due to the explorations of longitudinal aspects, families with only one assessment were excluded from all three sub-studies, and families with less than three assessments were excluded from sub-study III, which explored continuity in service provision over time. Families of children with the most severe gross motor limitations (GMFCS level V) completed a slightly different package of questionnaires that did not include the CEDL, and these few families were excluded from sub-study II, which explored child participation. A small number of families were also excluded from each of the sub-studies due to incomplete questionnaires that served as main variables in each of the studies (i.e., the FES, CEDL and Habilitation Services questionnaire [HabServ]). In total, 58 participants were included in the first sub-study, 56 in the second and 57 in the third. A flow chart illustrating the inclusion/exclusion process in CPHAB and the sub-studies is presented in Figure 5.

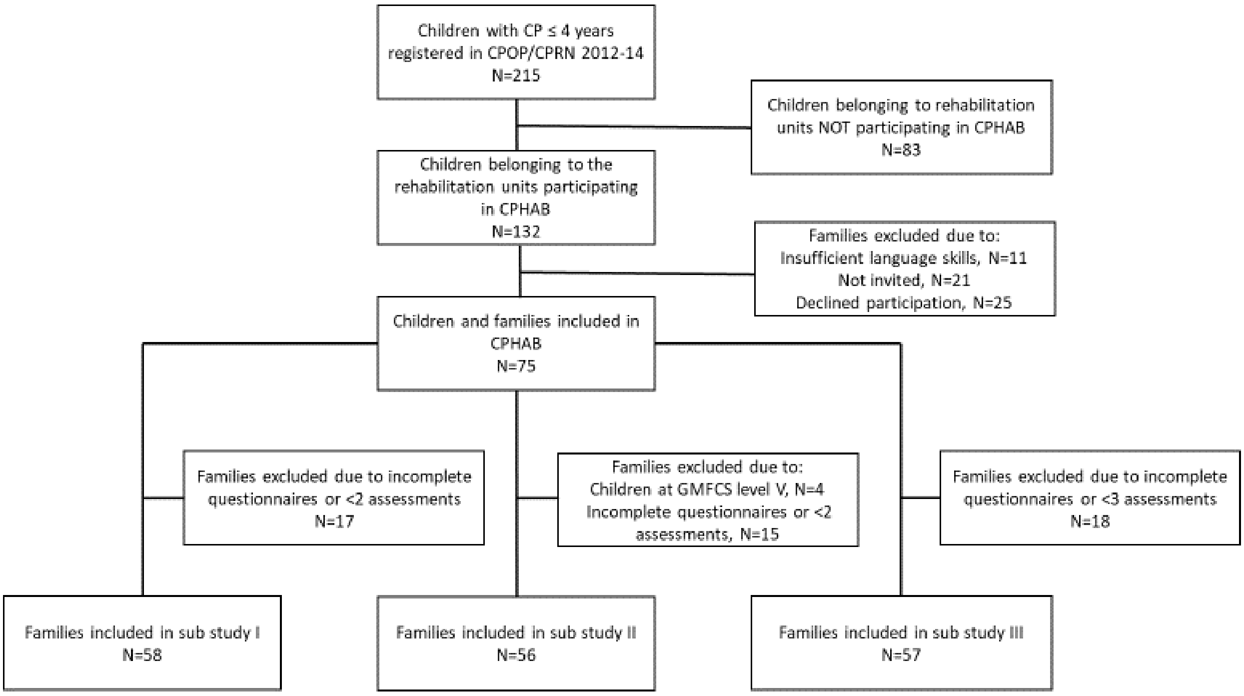

Figure 5. Flowchart illustrating the inclusion/exclusion process in CPHAB and the sub-studies.

4.3 Participants

The participants were recruited from the same population and largely consisted of the same families. Characteristics of the children and families included in the studies are presented in each of the three papers, which each focused on slightly different aspects of the child and family.

4.4 Data collection

Assessments and registration of information included in the CPOP were performed as part of the regular follow-up of children with CP at the regional paediatric rehabilitation units. The collection of data included in CPHAB took place at the units participating in this additional research project. The questionnaires included in CPHAB were completed by the parents, with an interval of approximately 6 months following the regular rehabilitation consultations. Some parents preferred an interval of approximately 12 months between the consultations instead. Participating families completed the questionnaires between two and six times (between three and six times in sub-study III), within a time period of 6 to 43 months (12 to 43 months in sub-study III). The median number of assessments in all three sub-studies were four.

4.5 Classifications and measuring instruments

The *child characteristics* examined in the study included gender, age (in months), subtype of CP, and classifications of gross motor and hand function retrieved from the CPOP register. The **subtype** of CP was classified according to the SCPE guidelines (107) as spastic unilateral, spastic bilateral, dyskinetic or ataxic.

Gross motor function was classified using the GMFCS (21). The GMFCS represents a system for classifying and describing motor abilities among children with CP by focusing on sitting, walking and the use of mobility devices in four age groups: less than 2 years, 2 to 4 years, 4 to 6 years and 6 to 12 years of age (21). The distinction between GMFCS level I and II includes some limitations in walking long distances, balancing, walking stairs, running and jumping experienced by children at level II but not among those at level I. Children at level II are expected to be capable of walking without a hand-held mobility device after age 4, while children at level III are likely to need a hand-held mobility device to walk indoors and may use wheeled mobility outdoors and in the community. Among children at level IV, self-mobility is more limited and these children usually need support in sitting. Children at level V have more severe limitations in head and trunk control; they need extensive assistance, and self-mobility is achieved only if the child can learn how to operate a powered wheelchair (21).

Studies on the reliability and stability of the GMFCS have concluded that interrater reliability is high for classifying children above the age of 2 (21, 108, 109). These studies have also found that future motor function is well predicted by the classification system (108, 110). Comparisons with the Pediatric Evaluation Disability Inventory (PEDI) have revealed strong associations between the GMFCS levels and self-care, mobility and social abilities among children with CP aged 2 to 6 years; these comparisons support the concurrent validity of the instrument (109). Furthermore, the number of additional impairments experienced by a child with CP is associated with the child’s GMFCS level (24), which supports the use of the GMFCS as an indicator of the overall severity of CP.

Manual abilities were classified based on the child’s use of his or her hands when handling objects in daily life using the MACS/Mini-MACS (22, 111). The distinction between levels I and II includes reduced quality of movements and slower performance among children at level II compared with those at level I; this reduced performance may limit the effectiveness of object handling. Children at level III have limitations that commonly require adaptations of the environment and help preparing the activity. At MACS level IV, children need more continuous help, and they are likely to participate only in parts of an activity. In comparison, children at level V might only participate in simple movements in special situations, such as pushing a button (22).

Interviews with professionals and parents have supported the content validity of the MACS, and interrater reliability has been found to be high for children above the age of 2 (22, 112, 113). Recent adaptions of the MACS have resulted in a version specifically directed at children younger than 4 years, which is referred to as the mini-MACS (111). The mini-MACS has demonstrated good interrater reliability and content validity (111). Manual abilities and gross motor function are not highly correlated in all subtypes of CP, which means that use of both the GMFCS and MACS is recommended to obtain a complete clinical picture of motor functioning among children with CP (114).

The *family characteristics* included in the study were retrieved from the CPHAB register and included parents’ level of education, employment, financial concerns, perceived housing problems, parental quality of life (QOL) and parental empowerment. With the exception of QOL and parental empowerment, this information was mapped by the Norwegian version of the Parental Account of Children’s Symptoms (PACSNO) (115).

Parental QOL was assessed using the Norwegian version of the Quality of Life Scale (QOLS-N) (116). The QOLS-N measures overall QOL based on parent-reported satisfaction within 16 life domains rated on a 7-point scale, where high total scores indicate a high QOL (116). Face and content validity of the QOL-N have been reported as acceptable by experts on the construct, as well as professionals and patients within the field of dermatology, and test-retest results have been reported as satisfactory (116). However, the psychometric properties of the QOLS-N have not been reported in the context of paediatric rehabilitation.

Parental empowerment was mapped by the FES (32). As described in the background chapter, the FES is built on a two-dimensional framework, with items reflecting the expression of empowerment as attitudes, knowledge and behaviour in three contexts: the immediate family situation at home, gaining access to services and interacting with service providers, and influencing the service system aimed at children and families beyond their own family at a political or community level. Each of the 34 items included in the FES are scored on a 5-point Likert scale, where a higher score indicates higher levels of empowerment (32). Mean scores can be calculated for each of the three subscales: family (12 items), service situations (12 items) and community (10 items). The development of the items was based on literature review, use of an expert panel and empirical studies (32). FES is in a previous review highlighted as one of the few empowerment instruments that have included all three of these steps in its development (117).

How well the FES reflects the underlying theoretical framework of empowerment (see the background chapter for more details) has been explored among 25 professionals within the field of child mental health (32). The Kappa coefficients for each of the subscales were reported as 0.83 (family), 0.70 (service system) and 0.77 (community/political) (32), which indicated that the professionals largely agreed with the structure. Factor analysis also supported this division into the three subscales (32). The internal consistency of the original FES subscale scores have been reported as high, with an alpha coefficient ranging from 0.87 to 0.88 (32), and the three context structure has been supported in other studies (34, 45, 53, 58, 118). The construct validity of the FES, which reflects the instrument’s ability to differentiate between groups, has been explored by analysing associations between parents’ participation in activities and empowerment scores in each subscale. The results of these explorations indicated that the FES discriminated those who were actively involved in activities that were indicative for empowerment in the community (32). Discrimination based on activities focusing on the family and service context has been explored to a lesser extent (32). The test-retest reliability of the FES, which reflects the stability or constancy of scorings across time, has been reported as adequate, with a Pearson correlation coefficient ranging from 0.77 to 0.85 (32). The FES was translated into Norwegian as part of CPHAB, using forward-back translation with harmonization followed by cultural adaptation using interviews, as described by Wild et al. (119).

Child participation in real-life activity settings was mapped by the part of the CEDL questionnaire that addressed the frequency and enjoyment of participation in family and recreational activities (66). Pilot testing among children with CP 18 to 60 months of age confirmed that the questionnaire was applicable for use in a community context, was easy to score and was well accepted by parents (66). The internal consistency of the CEDL questionnaire has been reported as high, with Cronbach's alpha coefficients of 0.86 (frequency) and 0.91 (enjoyment); this indicates that the instrument reflects a common construct of participation (66). Furthermore, its construct validity was supported by findings that were consistent with previous empirical research based on the APCP measure, such as less frequent participation among the youngest children and children with CP compared to children without CP (66). The CEDL questionnaire's test-retest reliability was considered acceptable, with inter-class coefficients of 0.70 for both the frequency and enjoyment dimensions (66). Changes in participation over time as assessed by the CEDL questionnaire have been reported to be small; therefore, its appropriateness for evaluating change following interventions remains unclear (120).

Services received by the families were mapped by the HabServ. This questionnaire was developed by an expert group during the planning of the CPHAB project, and it was pilot-tested on 19 parents raising a young child with CP in three rounds (121). The HabServ contains questions about services directed at the children and families including coordination services. The services explored in the current PhD study included the primarily child-directed services of physical therapy, occupational therapy, special education, kindergarten assistance and attendance in an intensive training program; the family-directed services of respite care service and financial services and benefits; and the coordination services of a multidisciplinary support team, ISP and service coordinator. Parents answered whether they had received these services in the preceding 6 months. The HabServ has been used in several other CPHAB studies (121-123); however, psychometric properties of the questionnaire have not been reported.

4.6 Statistical analysis

All statistical analyses were performed using the IBM SPSS version 26.

For child and family characteristics, interval-level data (age in months) were presented as median and range, whereas categorical data were presented as numbers and percentages. The remaining analyses differed between the sub-studies due to the differing study aims, questionnaires that formed the basis for analyses and methodological considerations made along the way. Table 4 provides an overview of the main variables explored, additional variables included in the analyses and type of statistical analyses performed.

Table 4. An overview of main variables explored, variables included in the analyses and statistical analyses performed in the three sub-studies.

Sub-study	Main variables explored	Variables included in the analyses	Statistical analyses performed
I	**Family Empowerment Scale (FES)** Family subscale Service situations subscale Community subscale	Age GMFCS level Parental education Parental employment Parental QOL Financial and residential concerns Coordination services Intensive rehabilitation Parent training	*Descriptive statistics*: Age: Median (range); FES scores: Means (SD) *Exploring relationships*: Linear mixed model *Trajectories*: Means at enrolment and after approximately 6, 12, 18, 24 and 36 months
II	**Child Engagement in Daily Life (CEDL) questionnaire** *Frequency*: Overall (summarized and scaled score), single item scores *Enjoyment*: Overall (summarized score), single item scores	Age GMFCS level MACS level FES (family and service situations)	*Descriptive statistics*: Median (range) *Exploring relationships:* Linear mixed model, Kruskal Wallis test *Trajectories*: Changes and/or stability in individual median scores for overall frequency and enjoyment of participation over time
III	**Habilitation services questionnaire (HabServ)** Child-directed services Family-directed services Coordination services	Age GMFCS level	*Descriptive statistics*: Age: Median (range); Services received: Mean (SD); Families receiving services: Number and percentages *Exploring relationships:* Chi-square test for independence, Fischer's exact test *Trajectories:* Identification of interruptions in service reports

4.6.1 Sub-study I

In the first sub-study, levels of parental empowerment during early childhood in the contexts of the family, service situations and community were presented as mean scores (with SD) for each of the three subscales family, service situations and community.

For each subscale, a linear mixed model with random intercept was used to explore the relationship between parental empowerment and characteristics of the child (age, CP subtype, GMFCS level), family (maternal and paternal education and employment status, parental QOL, financial and residential concerns) and services received (parent training, ISP, coordinator, multidisciplinary team, intensive rehabilitation program). The linear mixed model is a statistical method for exploring relationships between variables that handles correlated data in a repeated measure design and allows for an unequal number of repetitions with disparate time intervals between the assessments. The identification number of the participants was set as a random effect that contributed to the covariant structure of the data, while the characteristics of the child, family and services received were set as fixed effects and explored one by one in separate analyses. The potential effect of child age and GMFCS level were adjusted for in the analyses by setting these as random effects.

Trajectories of parental empowerment were explored by calculating mean scores for each of the three FES subscales—family, service situations and community—at six points of time: at enrolment and after approximately 6, 12, 18, 24 and 36 months.

4.6.2 Sub-study II

In the second sub-study, the frequency and enjoyment of child participation during early childhood were explored and presented as median scores (with range) representing participation based on all items included in the CEDL questionnaire. Frequency and enjoyment were also explored for each of the 11 activity settings included in the CEDL questionnaire separately.

The Kruskal-Wallis test was used to explore differences in participation based on the children's gross motor function and manual abilities by analysing differences in the distribution of medians between groups of children classified at GMFCS levels I, II to III and IV, as well as between children classified at MACS levels I to II, III and IV to V. This procedure was carried out for both frequency and enjoyment of participation. For frequency of overall participation, a conversion table was available to convert raw scores (calculated across all 11 items) into scaled scores (66). These scaled scores were used to explore relationships between participation, the children's age and the parents' level of empowerment in the contexts of family and service situations utilising a linear mixed model. No conversion table was available for enjoyment scores, so these analyses were performed only for frequency. The participation trajectories were explored by investigating changes and/or stability in individual overall frequency and enjoyment scores over time. The number of children representing the identified trajectories was calculated for the total sample and in the different groups based on the children's GMFCS and MACS levels.

4.6.3 Sub-study III

In the third sub-study, the services received by the families were explored by calculating the number and percentage of families that received each of the included child- and family-directed services and benefits, as well as the three coordination services—coordinator, ISP and a multidisciplinary team—during the study period. Furthermore, the mean number of services received during early childhood was calculated for all participants based on their longitudinal assessments. The relationships between the number of services reported by families at each assessment and the children's age and GMFCS level were explored using a linear mixed model. The relationships between the type of coordination service received and the children's GMFCS level were explored by performing a chi-square test for independence, as well as Fischer's exact test (when a number in the cross table was less than 5).

Continuity in the service delivery over time was explored by identifying interruptions in the service reports, which appeared when a previously received service or benefit was not reported by the parents on the following assessment(s) of services received. The number and percentage of participants with interruptions in their reports were calculated and presented for each of the services and benefits that were expected to be delivered continuously.

4.7 Ethical considerations

The study was approved by the Regional Committees for Medical and Health Research (REC) for the south-east region of Norway (REC registration number 2017/782). Oral and written information about the project was provided to the parents by appointed project co-workers in conjunction with planned follow-up consultations at the regional paediatric rehabilitation units, and a written consent was collected from the parents prior to the first assessment. The data were pseudonymized by replacing personal identifiable information with an identification number before hand-over to the researcher. The key to restore the information back to its original state was stored at the Oslo University Hospital (OUS). A data-handling agreement was made between Oslo Metropolitan University (OsloMet) and the OUS, and all data were stored and handled within the Services for Sensitive Data (TSD) delivered by the University of Oslo (UiO).

Although the questionnaires included in CPHAB were completed in conjunction with the regular follow-up consultations at the regional rehabilitation units, some extra effort was required from professionals and particularly from the parents to complete the questionnaires included in CPHAB repeatedly. Therefore, the material had to be used in such a way that the knowledge gained would benefit both families and those involved with the follow-up. The themes explored in this study are considered important for the further development of services and the service system and can thus hopefully be of benefit to children with CP and their families in the long run.

In general, cohort studies do not include any harmful exposure to participants beyond being measured (124). This study also avoided extra effort from the participants by using existing register data to explore the main themes.

5. Summary of the main results

This chapter provides a brief overview of the main results that stemmed from each of the three sub-studies. Details, such as specific measurement scores and p-values, are available in the attached articles. The aims of the sub-studies are included to contextualise the results.

5.1 Sub-study I: Parental empowerment in the contexts of family, service situations and community

The first sub-study addressed parental empowerment as one important facet of life in families caring for a young child with CP. The overall aims of the sub-study were to explore how parental empowerment in family situations, service situations and on a community level was expressed during the children's early years and to investigate how empowerment in the different contexts was associated with characteristics of the child, family and the services they received. To the best of the author's knowledge, this was the first study to examine the relationships between parental empowerment and the severity of the child's CP as expressed by the GMFCS level and, so far, the only study to explore the relationships between empowerment as measured by the FES and coordination services received.

The findings of the study indicated that most parents felt in control of situations throughout their child's early childhood in the family context and when interacting with service providers and the service system. The parents appeared to feel far less empowered when it came to influencing the service system on a community level; however, a positive trend was indicated over time.

Empowerment in family situations was found to be associated only with some family characteristics (maternal education and employment status, parental QOL), not with any child characteristics or services received. In contrast, empowerment in service situations was associated with both child (GMFCS level) and family (maternal education, parental QOL) characteristics, as well as one of the coordination services received (multidisciplinary support team). Finally, empowerment on a community level was associated with child characteristics (age, GMFCS level) and some services received (multidisciplinary support team, intensive rehabilitation programme) but not with any family characteristics.

In sum, the sub-study revealed that parental empowerment seem to differ according to the contexts and was, to varying degrees, associated with child and family characteristics, as well as services received.

5.2 Sub-study II: Child participation in real-life activities

The second sub-study aimed to explore multiple aspects of child participation in real-life activities during the early years. More specifically, the aims were to 1) describe the frequency and enjoyment of child participation in family and recreational activities, both overall and in different activity settings; 2) detect whether and how differences in participation relate to gross motor and hand function; 3) explore trajectories of frequency and enjoyment of participation in relation to gross motor and hand function; and 4) examine the potential relationship between frequency of child participation and parental empowerment in the context of family and service situations.

The study revealed that young children with CP seemed to participate frequently in a wide range of activities, with some differences found based on GMFCS and MACS levels. Enjoyment ratings were high for all the activity settings mapped. Overall, children with the least severe limitations in gross motor and hand function (GMFCS and MACS level I) participated more frequently in family and recreational activities compared to children with more severe limitations, and they enjoyed these activities more. The differences in participation between children classified at different levels of gross motor function and manual abilities varied to some extent between the activity settings with statistically significant differences found in some settings, such as active physical recreation and outdoor play, but not in others.

For participation over time, four different trajectories of frequency and enjoyment were identified in the study. These were trajectories characterised by 1) constantly *increasing* scores, 2) constantly *decreasing* scores, 3) *stable* (unchanged) scores and 4) *fluctuating* scores, which included both increases and decreases in the scores over time. Regardless of motor limitations, a fluctuating trajectory was the most common for frequency, while a stable trajectory was most common for enjoyment.

Finally, a positive and statistically significant relationship was found between frequency of child participation and parental empowerment in the context of family situations. No such relationship was revealed between participation and empowerment in service situations. In sum, the sub-study revealed that participation appeared to be dependent on the specific activity setting and additionally influenced by both the child’s motor functioning and parental empowerment.

5.3 Sub-study III: Services received by the families

The third sub-study explored the services directed at children and their families longitudinally across organisational borders. The sub-study's overall aim was to increase knowledge about the comprehensiveness, coordination and continuity of services received. More specifically, the aims were to 1) describe the services children and families received during the children's early years, 2) explore whether the number and type of services were associated with the children's gross motor function and 3) examine the longitudinal continuity of the services provided.

The study revealed that most families received comprehensive services that involved both health and educational services as well as social services and benefits. Receipt of coordination services was frequently reported, especially a multidisciplinary support team and ISP. Receiving some of the financial benefits or a service coordinator was less widespread. Families raising a child with minor gross motor limitations (GMFCS level I) received fewer services than families with children with more severe limitations. Furthermore, having a service coordinator was more common among families raising a child with the most severe gross motor limitations (GMFCS levels IV and V) compared with those with milder limitations.

Interruptions in the delivery of services over time were identified in a large proportion of families. The interruptions were most noticeable for occupational therapy, some of the financial benefits and the coordination services having a service coordinator and an ISP.

Overall, this study confirmed that young children with CP in Norway were supported by a comprehensive welfare system that recognized the complex needs of children and families. However, frequent interruptions in the longitudinal reports of services received and a noticeably low proportion of families who reported having a service coordinator indicated that some areas of the service provision still may need some quality improvements.

6. Discussion of the methodology and main results

This chapter includes reflections on aspects related to the methodology that form the basis for exploring the main themes of parental empowerment, child participation and services received by the families. The chapter also includes discussions of the actual results that stemmed from the study.

6.1 Methodological considerations

The methodological considerations that were made both during the study and in retrospect were linked to the overall study design, the properties of the measurement instruments used in the analyses and the statistical choices that were made. The following sections include reflections on issues relevant to assessing the internal and external validity of the study.

6.1.1 Reflections on the overarching methodology

The study was based on data from two different CP registers in Norway: the CPOP and CPHAB. Combining data from these registers had several advantages. The CPOP represents a well-established follow-up program that is solidly anchored in specialist health services and includes almost all children diagnosed with CP in Norway. This facilitated systematic recruitment and continuous participation among families included in the study. CPHAB was specially developed to obtain supplementary information on a wider range of issues considered important for both parents and children. It provided opportunities to explore issues where prior knowledge was lacking. The two registers complemented each other in a valuable manner and constituted a significant strength of the study.

The study was designed as a prospective longitudinal cohort study that followed young children diagnosed with CP and their families over time in early childhood. Cohort studies are a favourable design for exploring the natural course of a condition or phenomenon (124), which in this study included parental empowerment, child participation in real-life activities and services received by the families. Repeated measurements using standardised questionnaires enable investigations of relationships and identification of longitudinal patterns and thus appeared to be useful for broad explorations of questions of interest. A limitation of such a design is that confounders may arise over time and influence the main variables explored (124). In general, great care should be taken when causal explanations are discussed for findings of associations between variables (124). However, analyses of relationships in cohort studies can be of great value when exploring a relatively new field, not least by generating new hypotheses for investigations in further studies.

A potential challenge in using a cohort design with repeated measurements using standardized questionnaires lies in the predefined options for answers. The options may not be sufficiently comprehensive to capture all aspects of a phenomenon under investigation (125). As outlined in the background section, the two main phenomena explored in the study—parental empowerment and child participation—both appeared to be complex and multifaceted constructs. Services directed at children and families may also vary considerably, both in terms of content and how they are delivered. The standardisation of the questionnaires limits the possibilities for more in-depth and individually adapted answers, and valuable information may thus be omitted.

The following sections include a discussion of further questions of importance to the study's internal validity, considerations of the generalizability of the results and a summary of the study's methodological solidity.

6.1.2 Properties of the main measurement instruments

The psychometric properties of the measurement instruments are crucial to the trustworthiness of the results, i.e., the internal validity of the study (125). The **FES** has been rated as a reliable and valid instrument for measuring empowerment among caregivers (117). This questionnaire has a strong and explicit foundation in empowerment theory and is highlighted as one of the few empowerment instruments that have included the three steps of a literature review, use of an expert panel and empirical studies to develop the questionnaire (117). The FES was originally developed and tested for use among caregivers of children enrolled in mental health services in the USA (32) but was later used in a wide range of international studies of caregivers of children with different conditions and characteristics. However, no studies have yet validated the instrument for use in the Norwegian paediatric context, and the availability of comparable data for this population is thus lacking. This limited, to some extent, the possibilities for interpreting the results. Furthermore, clarification of what can be considered a clinically meaningful difference between groups or change over time based on FES scores is lacking.

The **CEDL** questionnaire was developed and tested for a population very similar to that targeted in the current study, both in terms of functional limitations and age. The CEDL questionnaire has not been validated for use in Norway; however, the items representing broad categories of activity settings were developed to allow for cultural differences (66). The psychometric properties of the instrument are considered sufficient, except for its responsiveness, which is still inconclusive (67). Similar to the FES, an overarching challenge is the persistent uncertainty associated with what a clinically meaningful difference or change over time entails for both frequency and enjoyment of participation as measured by the CEDL questionnaire.

The **HabServ** questionnaire was developed in the planning process of CPHAB and thus is specifically directed at mapping a comprehensive set of services relevant for young children with CP and their families in a Norwegian context. Thus, the instrument was well suited for use in the current study. The HabServ was in the planning of the CPHAB project pilot-tested on 19 parents of young children with CP in three rounds, which resulted in one modification of the questionnaire as well as clarifications of some questions. However, the properties of the instrument have been explored and discussed only to a limited extent, which implies that some uncertainty is still associated with the use of the instrument in a research context.

6.1.3 Considerations and choices made regarding statistical methods

The statistical choices made may have affected the internal validity of the study. Even with the predetermined research design and the given data available for analysis, the work on the three sub-studies included various considerations and statistical choices. These choices were influenced by the characteristics of the main variables and by ongoing reflections on balancing benefits and pitfalls. The ambiguity arising in encounters between common practice and literature on methods and methodology was challenging to face and resulted in some inconsistencies in data-handling across the sub-studies, e.g. the use of both parametric and non-parametric statistics.

In sub-study III, most data were on a nominal level and formed the basis for non-parametric descriptive statistics and a limited number of statistical analyses of relationships. Sub-studies I and II appeared far more open to considerations and choices. These two studies explored complex and multidimensional constructs based on data stemming from parent-reported questionnaires that used a Likert-type scale. One of the fundamental differences in data-handling was that analyses in sub-study I were based on parametric statistics, whereas analyses in sub-study II were primarily based on non-parametric statistics. Thus, levels of parental empowerment were presented as means and SD, while levels of child participation were presented as medians and range. Ambiguity on how to handle Likert-scale data in the literature and research community contributed to this inconsistency.

Likert scales provide data on an ordinal level. This means that the responses are ranked but the interval between the scored categories is unknown, as opposed to interval-level data, for which the actual distance (intervals) between the scores is the same across the entire scale. Strictly speaking, ordinal data should not be averaged or arithmetically manipulated (125). However, data originating from Likert scales are frequently analysed based on means (SD). This may be due to the fact that non-parametric statistics appear less powerful than statistics developed for use with scaled or metric data (125). Moreover, in the context of publishing papers, parametric analyses are often requested, even if the data are derived from Likert scales (125). Researchers may face a dilemma between following requests and the tradition of the field or being true to acquired methodological knowledge.

Another assumption underlying the use of parametric statistics is that the obtained values are based on a normal distribution in the population of interest. However, this assumption is not always present, especially not in studies with a small number of participants. Additionally, values based on certain types of questionnaires tend to be skewed (in a positive direction). This was the case for both the FES scores (in the subscales of family and service situations) and CEDL scores in the respective studies. Therefore, the use of parametric statistics could be argued against when analysing FES data. However, all relevant empowerment studies based on the FES have used parametric statistics, making comparison of results across populations of interest easier.

Sub-study II utilised non-parametric analyses, which are more in line with the methodological literature, but these analyses are not commonly used in research based on the CEDL. The choice to use these analyses reflected an increased awareness raised during the work with the studies both in terms of the properties of the measurement scales and the prerequisites that formed the basis for data-handling. In retrospect, whether common practice in the research field should have been given greater weight (thus, calculations of means and SD should have been added) could be discussed.

Another difference in the analyses and reporting of results between sub-study I and II was the presentation of results based on total scores of the three subscales in the first sub-study, whereas the second sub-study presented results based both on total scores and a single-item level. Psychometric analyses of the FES have shown an acceptable internal consistency, which means that each scale reflects the same underlying construct; the structure of three subscales (family, service situations and community) has been supported as meaningful in several empirical studies (31, 33-35). However, some information may be lost in the calculations of total dimension scores as similar scores can arise from different combinations of responses (125). A calculation and presentation of scores on a single-item level could thus have revealed more detailed information when exploring parental empowerment.

In quantitative research, research reports should focus on a small number of endpoints that are specified in advance rather than a broad investigation of all variables available (125). Limiting the number of comparisons minimizes the risk of making type I errors (125). In sub-study I, associations between parental empowerment and a large number of variables were explored. A total of 15 variables representing child, family and service characteristics were selected based on findings from previous studies and/or theoretical assumptions of relationships, and they were each included in analyses exploring association with empowerment scores for the three subscales (family, service situations and community). Considering the relatively large number of analyses performed, some statistically significant relationships may have appeared by chance, representing type I errors. However, statistically significant results are less likely to be obtained in small samples (like in this study), and a factor large enough to produce statistically significant differences is therefore considered more worthy of attention than it would be in a larger sample (125). The analyses and interpretation of the results can thus still be defended.

Another objection to the interpretation of the results concerns the limited number of participants. The relatively small sample size may have led to type II errors, referring to a situation in which statistically significant associations are not revealed even if a relationship exists (125). A larger number of participants would have added greater strength to the results and may have enabled more sophisticated multivariate analyses and the building of statistical models. Additionally, the GMFCS levels had to be collapsed in the analyses due to the small number of participants in the study and nuances in differences and relationships may thus have been overlooked.

Relationships were explored using a linear mixed model in both sub-studies I and II. In non-experimental studies, bias and confounders represent considerable challenges (125). When using a linear mixed model, potential confounders can be adjusted for; this represents a major advantage of this specific statistical method. In both sub-studies I and II, the children’s age and GMFCS level were included in the analyses as random effects to avoid an unintended confounding effect from these variables.

Analyses of the longitudinal aspects of the main themes differed considerably between sub-studies I, II and III. In sub-study I, trajectories of parental empowerment were explored by averaging scores at enrolment in the CPOP/CPHAB and thereafter at assessments given at approximately 6, 12, 18, 24 and 36 months. In retrospect, this method appears questionable. Comparing averaged scores may have been misleading, as individual slopes taking different directions may have balanced each other and masked underlying changes (125). In sub-study II, a different approach was chosen: exploring individual trajectories as different slopes (increasing, decreasing, fluctuating and stable). A similar approach could have been applied in sub-study I to decipher whether other patterns could be detected.

A common challenge to the results interpretation from the longitudinal analyses in sub-studies I and II included the lack of clarity surrounding statistical and clinically meaningful changes in the FES and CEDL questionnaire. The longitudinal patterns must therefore be cautiously interpreted. In sub-study III, the longitudinal focus was directed at the continuity of service provision based on reports. By identifying interruptions in the repeated reports, unique information on an important service aspect was obtained, which highlighted the great value of a longitudinal research design. However, results from the longitudinal analyses of the service delivery must be interpreted with caution since no information was given about causes for the interruptions, e.g., changed child and family needs, parental preferences or circumstances related to the service systems.

6.1.4 External validity: Generalizability of the results

The external validity of a study refers to the extent to which the results can be applied beyond the sample included in the study, i.e., the generalizability of the results (125). The population targeted by the PhD study consisted of children 4 years or younger with CP who were registered in the CPOP/CPRN for the first time between 2012 and 2015, as well as their families. This population was close to identical with a “theoretical” population as more than 90% of children with CP are registered in the CPOP/CPRN (126). Unfortunately, only 13 out of the 21 paediatric rehabilitation units involved in the CPOP had the capacity to participate in the CPHAB project. This resulted in a lower number of participants than originally planned. However, the participating units represented a good spread across the country, which supported the generalizability to children with CP and their families regardless of geographic location.

Sub-study I compared the characteristics of participating children to those registered in the CPOP but not included in CPHAB. To make this comparison, available variables of child characteristics (gender, age, subtype of CP and GMFCS level) were used. No statistically significant differences regarding age and gender were revealed, but differences were found for type of CP and GMFCS level. The proportion of children with spastic bilateral CP was somewhat higher among the participating children than the non-participating children, with a corresponding lower proportion diagnosed with spastic unilateral, dyskinetic and ataxic CP. Additionally, a higher proportion of children were classified at GMFCS levels II, III and IV compared with non-participants, and correspondingly fewer were classified at levels I and V. The differences between participating and non-participating children may be explained by a lower perceived need for broader follow-up among families raising children with the least severe motor limitations (GMFCS level I), as well as a lack of perceived resources for participation among families raising a child with the most severe disabilities (GMFCS level V). The differences in distribution may have influenced some of the results, such as the number of services received (as discussed in sub-study III). However, all three sub-studies performed analyses and reported results based on the children's GMFCS level. This implies that these results may be valid even if the studied sample differed somewhat from the non-participants when it comes to functional gross motor levels.

Unfortunately, data were not available for comparisons between participants and non-participants regarding family characteristics, and reasons for declining participation or not being invited due to professionals' judgment were not documented. Therefore, the basis for identifying selection bias and estimating to what extent the participants reflected the population based on family characteristics was limited.

6.1.5 A summary of the methodological solidity of the study

Combined, the CPOP and CPHAB registers formed a unique database for exploratory research on important aspects of life in families caring for a young child with CP. The longitudinal cohort design enabled explorations of relationships and patterns over time. However, the relatively small sample constituted a limitation for certain analyses and affected the strength of the results. Thus, more studies including a larger sample are needed. However, even with some critical reflections related to the study methodology, the three sub-studies, both individually and collectively, contribute to increased knowledge about the complexity of childhood disability in a family and service context. The main findings are discussed in more detail in the following sections.

6.2 Discussion of main findings

Overall, the PhD study found several encouraging aspects regarding the situation of children with CP and their families in Norway. However, it also revealed some persistent challenges, especially related to the service system.

One of the positive findings was the high parental empowerment scores in the context of the immediate family situation. This indicated that, to a large extent, parents perceived having control over their everyday lives and coped well with daily situations with their children. The finding corresponds well with previous research on empowerment processes among mothers of children with chronic neurodisabilities in the UK, which revealed that the participants adapted well to their situation and rapidly started to develop a sense of control (30). The sustained process of empowerment was attributed by the researchers to the mothers' commitment to bond with and love their child. The mothers felt a great responsibility to ensure the best possible care for the child, and they expressed that they had no other choice but to deal with the situation (30). These feelings are most likely universal among caregivers worldwide and may explain why differences in empowerment scores among caregivers in countries with different socio-economic conditions are not as apparent as expected (50). The fact that no statistically significant association was found between parental empowerment score and the reporting of financial and housing concerns, supports empowerment as a construct that appears to be relatively robust under different material conditions. Nevertheless, the empowerment scores among Norwegian parents correspond with findings from a previous Finnish study (58) and appear very high compared to, for example, families raising a child with disabilities in Japan (56) or Serbia (60). This may indicate that high levels of empowerment, at least in part, can be attributed to a generally favourable economic situation and a well-established Nordic welfare system.

The high empowerment scores in the context of the family situation were a favourable finding in that the family constitutes the most influential microsystem in a young child's life forming a unique context for child development, learning and well-being (14). The positive association between parental empowerment in family situations and the frequency of child participation in real-life activities supports the significance of family functioning in facilitating good upbringing and development conditions for children. The finding also corresponds well with the ICF framework that highlights connections between child participation and the family as an important environmental factor (13), as well as with the bioecological model of human development, which emphasises the importance of characteristics of persons involved in the children’s microsystem (8). The finding further supports a family-centred service approach aiming at strengthening the family’s capabilities and involving parents in rehabilitation processes (84). However, it should also be noted that there may be a risk of placing too much responsibilities on parents and providing too little support to families who are considered well empowered (30).

Parental empowerment scores in the context of service situations were also high among the Norwegian parents. The high scores indicate that most families perceived having knowledge of and access to needed services, and that the parents seemed to manage interactions with service providers quite well. Individual processes, including the acquisition of knowledge, competence and self-efficacy, have been emphasised as crucial for developing relational participatory competence, which in turn could ensure appropriate use of services and strengthen the parents’ influence in collaboration with service providers (30). The intra- and interpersonal empowerment processes, which have been described as closely intertwined (30), may explain the correspondence between empowerment levels in the two contexts family and service situations. High levels of empowerment in family situations may lay the foundation for favourable empowerment processes in service situations (32). However, given that promoting parental empowerment is a concern for service providers, the influence can potentially also work in the opposite direction with well-functioning services and collaborative processes facilitating increased empowerment in family situations.

However, as opposed to empowerment in family and service situations, low parental empowerment scores were revealed on the community level, i.e., the more general context of parents influencing the service systems for children with disabilities and their families. The low scores may indicate that parental competencies were not recognized and valued in the service system and/or that the parents had little experience with how to collaborate with service systems in a community context. These results might reflect a greater challenge for the service systems than for the families themselves, as the families’ expertise is undermined rather than optimally utilised as a resource for improving services and follow-up systems. However, non-optimal development of services can also have a negative effect on families in the long run in those cases where they are dependent on long-term extra support. Furthermore, the low empowerment scores in the community subscale may reflect a gap between user involvement as a statutory right and how it is experienced by families in real-life situations.

A promising finding in the study was that young children with CP seemed to participate frequently in a wide range of activity settings in their daily lives. This indicated that children have favourable access to important arenas that facilitate learning and development (8, 11). Additionally, high enjoyment scores indicated that involvement in activity settings included in the CEDL questionnaire was perceived as fun and meaningful for the children. This finding supports the use of participation in real-life contexts as a starting point for service planning and interventions in paediatric rehabilitation, as a means of promoting skills (9, 11) and, more importantly, as a source of well-being and quality of life (127).

However, the study also revealed a somewhat worrying association between limitations in children's gross motor and hand function and less frequent participation in some of the activity settings, such as outdoor play with children, active physical recreation and entertainment outings. This association indicated that aspects of the context or environment may act as barriers to participation for children with certain motor limitations. The reasons for these differences in participation were not specifically revealed in the study; however, the high level of enjoyment indicated that the children's preferences or motivation were not limits to participation. On the contrary, the consistently high enjoyment scores indicated that children valued their involvement in a wide range of activities independent of their motor abilities. The lower frequency of participation among children with the most severe limitations in mobility and hand function may thus have been related to other within-person factors, such as activity competence (as indicated by the GMFCS and MACS levels), and/or to the physical or social environment (11).

Less frequent participation should be considered as resulting from an interplay between a child's motor limitations and properties of the context and environment. It may relate to the *availability* (referring to objective possibilities for participation related to facilities or resources), the *accessibility* (the actual or perceived access to the participation context), the *affordability* (representing the balance between costs and rewards) and the *accommodability* (referring to whether a situation is sufficiently adapted through modifications or adjustments) (64). The findings of differences in participation in some activity settings between children with various motor limitations indicate a persistent need to identify potential barriers and to further discuss how to overcome these barriers to increase participation opportunities for all children with CP, regardless of motor limitations.

As a positive finding, most families seemed to receive services not only targeting the children's motor limitations but also including extra educational services in kindergarten, as well as services and benefits aimed at supporting the life of the whole family. This holistic approach to service delivery corresponded with a contemporary understanding of childhood disabilities as contextual and societal (7) and was in line with the key principles of family-centred care (84). The many services across organisational borders confirmed the need for coordination tools to ensure collaboration and coherence in the services provided. This need seemed to be met to some extent, as a high proportion of families received one or more coordination services during their children's early years. However, a mismatch between the number of families who reported having an ISP and a coordinator and the frequent interruptions in the longitudinal reports on these services indicated some persistent challenges for the provision of coordination services. This was further indicated by the fact that no relationship was found between parental empowerment and families receiving an ISP or a coordinator. The findings add to previous research that has revealed challenges for implementing these coordination services (39, 81, 89, 91, 92, 94). In contrast, higher empowerment scores in service situations and in the community were found among families who had a multidisciplinary support team compared with those who had not, which support previous research that has highlighted working in teams as a favourable collaborative practice (86, 90, 95).

Comparison of the findings from the three sub-studies revealed some complex patterns (see Figure 6). First, and not surprisingly, the severity of the children's motor limitations appeared to be associated with both parental empowerment, child participation and the number and type of services received by the families. However, the relationships were not consistently linear. The lowest empowerment scores in the context of service situations were not, as might be expected, found among families raising a child with the most severe gross motor limitations (GMFCS levels IV and V), but among parents of children with moderate mobility limitations (GMFCS levels II and III). This latter group of children also participated less frequently in the activity setting of outdoor play with children. The challenges faced by children with moderate disabilities and their families may be underestimated in the service system, as indicated by the less widespread use of a coordinator among these families compared to families with children with more severe motor disabilities. The findings thus highlight a group of children and families that may need greater attention, both in research and practice.

Another question raised by comparison of the three sub-studies' results is whether services provided to families are as effective as intended. No service characteristic was found to be related to empowerment in the family situation, nor were the statutory coordination services (ISP and coordinator) associated with higher empowerment scores on any subscale. Furthermore, no significant association was found between the frequency of child participation and parental empowerment in service situations, which may indicate that the availability of services and interactions between families and service providers was not necessarily transferrable to favourable child outcomes. Thus, the extent to which today's service approaches succeed in facilitating children's participation and parental empowerment is still unclear.

Another important pattern revealed was that both parental empowerment and children's participation seemed to depend on a given context, and that the associations with child and family characteristics varied according to these different contexts. The direct and indirect connections between characteristics of the child and family and the services received, as visualized in Figure 6, support approaches in research and practices that consider children and their families as situated in complex real-life contexts instead of viewing the person and the environment as separate and demarcated entities (8, 9).

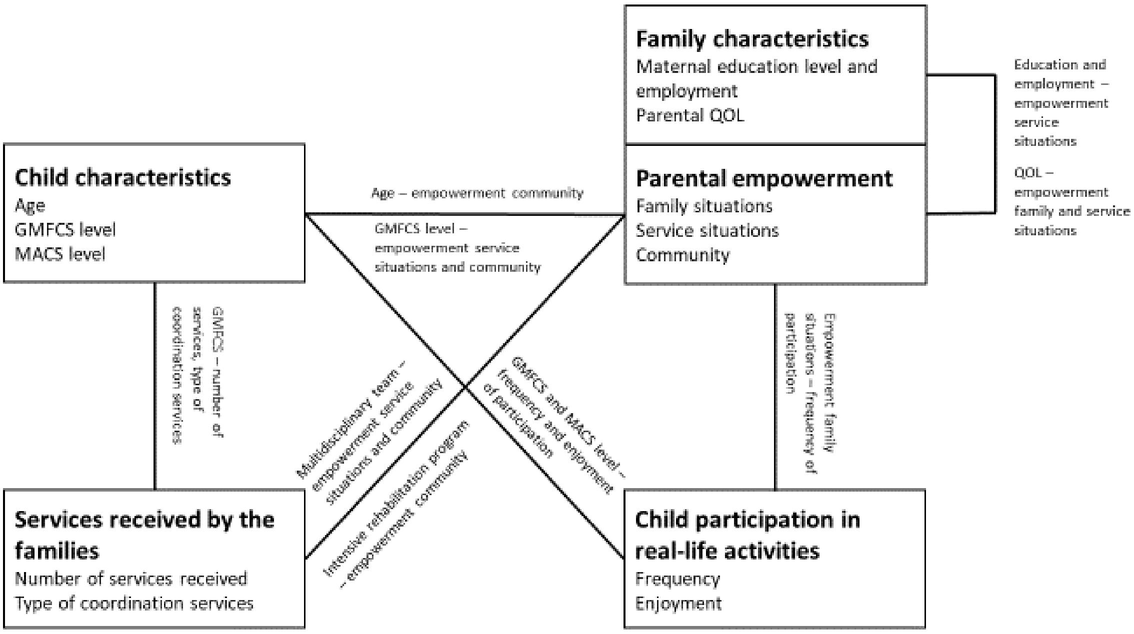

Figure 6. Connections between results from the three sub-studies exploring parental empowerment, child participation in real-life activities and services received by the families.

7. Conclusion: Implications for practice and further research

This study elucidated some facets of life in families caring for a young child with CP, more specifically parental empowerment, child participation in real-life activities and services received by the families. The study obtained new knowledge that is considered important for the field of paediatric rehabilitation and also raised some new questions and concerns.

The results from the study provided a generally positive impression of the child's and family's situation in terms of high levels of parental empowerment in family and service situations, frequent and valued child participation in varied activity settings and a wide range of services provided to support children and their families. However, some challenges were also identified, not least related to limited involvement of parents in the development of services (as indicated by low empowerment scores in the community subscale), the relationship between motor limitations and less frequent child participation in some activity settings (such as physical active recreation and outdoor play with children), and extensive interruptions in the provision of the coordination services ISP and coordinator.

The study confirmed both parental empowerment and child participation as context-dependent phenomena complexly influenced by characteristics of the child and the family. This affirmation highlights the importance of looking at child and family issues as unique and contextualized in real-life situations (9). The complexity of the relationships between child and family characteristics and the services provided should be recognised in clinical practice, and further explorations of the relationships should be targeted in future research. The low parental empowerment scores in the community context may indicate limited use of first-hand user experiences for improving services, suggesting an untapped potential for further development of service systems benefitting children with CP and their families.

The research conducted in the study was based on families caring for a young child with CP. How the results correspond to situations in families who raise children with other disabilities or children in other age groups remains unexplored.

Furthermore, the study explored parental empowerment, child participation and services received by families using a quantitative approach, and relatively few participants were included. Future research could advantageously explore the same topics in a larger sample and include the use of qualitative or mixed methods to further expand the knowledge of the complex interplay between children, families and services provided.

In conclusion, the study supports parental empowerment, child participation in real-life activities and services received by families as relevant themes to explore in the field of paediatric rehabilitation. The findings can thus be used as a basis for further clinical discussions, development and quality improvement of services, as well as inspire future research projects.

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Forskningsansvarlig: Høgskolen i Oslo og Akershus
Prosjektleder: Runa Kalleson

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 04.05.2017. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektomtale
Cerebral parese (CP) er en kompleks tilstand som krever oppfølging og tiltak fra flere faggrupper og nivåer i tjenesteytingen. Hovedmålet med prosjektet er å fremskaffe systematisert kunnskap om barnet, familien og tjenesteytingen som kan ha betydning for barnets og familiens fungering. Prosjektet er designet som en kvantitativ prospektiv longitudinell kohortstudie. Dataene baseres på halvårlige kartlegginger av barnets og familiens fungering, samt tiltakene de omfattes av, gjennom førskolealder. Det vil spesielt fokuseres på variabler som er mulig å endre i et habiliteringsforløp. De konkrete forskningsspørsmålene som ønskes besvart er 1) Hvordan endrer barnas funksjon og deltakelse i dagliglivet seg gjennom førskolealder? og 2) Hvordan endrer foreldrenes opplevelse av empowerment og livskvalitet seg? Variabler som vil kunne forklare endringer omfatter karakteristika ved barnet, familien og mottatte habiliteringstiltak. Statistiske analysemodeller for gjentatte målinger vil benyttes.

Vurdering

Komiteen har ingen innvendinger til designet i studien, men påpeker at prosjektleder står oppført med mastergrad i søknaden, og således ikke innehar den formelle prosjektlederkompetansen som kreves etter helseforskningslovens § 4. Komiteen krever derfor at prosjektlederrollen overføres en person med forskerkompetanse. Av tekniske grunner må denne overføringen meldes REK på skjema for prosjektendring, for at vårt system skal kunne oppdateres.

Ut fra dette setter komiteen følgende vilkår for prosjektet:

1. Prosjektlederansvaret må overføres en person med tilstrekkelig forskerkompetanse.

Vedtak

Prosjektet godkjennes under forutsetning av at ovennevnte vilkår oppfylles, jf. helseforskningslovens §§ 9 og 33.

I tillegg til vilkår som fremgår av dette vedtaket, er tillatelsen gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 31.12.2021. Av dokumentasjonshensyn skal prosjektopplysningene likevel bevares inntil 31.12.2026. Opplysningene skal lagres atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Komiteens avgjørelse var enstemmig.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. Forvaltningslovens § 28 flg. Eventuell klage sendes til REK Sør-Øst. Klagefristen er tre uker fra mottak av dette brevet.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK sør-øst på eget skjema senest 31.10.2021, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK sør-øst dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Med vennlig hilsen

Britt- Ingjerd Nesheim
prof. dr. med
leder REK sør-øst C

Tor Even Svanes
seniorrådgiver

Kopi til:
fou-hf@hioa.no
Høgskolen i Oslo og Akershus ved øverste administrative ledelse: postmottak@hioa.no

BAKGRUNNSOPPLYSNINGER OM FAMILIEN OG BARNET

Barnets familie

1. **Mors oppvekstland** ……………………………………………………… (første utfylling)

2. **Fars oppvekstland** ……………………………………………………… (første utfylling)

3. **Barnets boforhold**
Kryss av for omsorgspersonen(e) som barnet bor mest / like mye sammen med:

☐ Mor og far	☐ Mor og ektefelle/samboer
☐ Mor	☐ Far og ektefelle/samboer
☐ Far	☐ Andre omsorgspersoner

4. **Utdanning til omsorgspersonen(e) som barnet bor mest / like mye sammen med**
Kryss av for den <u>høyest fullførte utdanningen</u>

	Mor	Far	Andre	Andre
Grunnskole	☐	☐	☐	☐
Videregående skole	☐	☐	☐	☐
Høgskole /universitet	☐	☐	☐	☐
Annen	☐	☐	☐	☐

5. **Tilknytning til arbeidslivet til omsorgspersonen(e) som barnet bor mest / like mye sammen med**
Kryss av for nåværende arbeidstilknytning:

	Mor	Far	Andre	Andre
Arbeider mer enn heltid	☐	☐	☐	☐
Arbeider heltid	☐	☐	☐	☐
Arbeider deltid (50% eller mer)	☐	☐	☐	☐
Arbeider deltid (under 50%)	☐	☐	☐	☐
Er ikke i arbeid	☐	☐	☐	☐

6. Dersom omsorgspersonen(e) som barnet bor mest / like mye sammen med ikke arbeider heltid, skyldes det……

Sett kryss for det som er aktuelt

	Mor	Far	Andre	Andre
Arbeidsledig	☐	☐	☐	☐
Trygd	☐	☐	☐	☐
Utdanning	☐	☐	☐	☐
Ønsker å være hjemme med barna	☐	☐	☐	☐
Barnets funksjonsvansker/sykdom	☐	☐	☐	☐
Egen sykdom	☐	☐	☐	☐
Annet, beskriv……………………	☐	☐	☐	☐

7. Går barnet i barnehage?

☐ Nei ☐ Ja, ………….. antall dager i uka.

8. Har barnet søsken / stesøsken?

☐ Nei ☐ Ja, antall ……… alder ……. ,……. ,……., …….,…….,……

9. Har barnet hjemmeboende søsken / stesøsken som får ekstra tiltak (som medisinske, spesialpedagogiske)?

☐ Nei ☐ Ja

10. Oppleves familiens økonomi som et problem?

☐ Nei ☐ Ja, på hvilken måte ……………………………………………………………

………

………

11. Oppleves familiens bolig som et problem (som størrelse, utforming)?

☐ Nei ☐ Ja, på hvilken måte……………………………………………………………………………

………

………

Barnet

12. Har barnet noen tilleggsvansker som følge av CP diagnosen?

Typer av vansker	Nei	Ja	Vet ikke
Syn	☐	☐	☐
Hørsel	☐	☐	☐
Lungeproblemer	☐	☐	☐
Kognitiv funksjon	☐	☐	☐
Språk og kommunikasjon	☐	☐	☐
Utfordrende adferd	☐	☐	☐
Andre ………………………..	☐	☐	☐
Andre ………………………..	☐	☐	☐

13. Har barnet epilepsi?

☐ Nei ☐ Ja ☐ Vet ikke

14. Har barnet andre alvorlige sykdommer?

☐ Nei ☐ Ja, hvilke(n) ………………………………………………………………….

Ref: Taylor et al. Parental Account of Children's symptoms (PACSNO). Copyright 1986. Norsk oversettelse ved P. Zeiner 1989, rev. T.Nøvik, V.Tufte 1992, rev. T.Diseth 1992, 2003. Omarbeidet av S. Østensjø og H.T. Myrhaug til bruk i CPHAB.

QUALITY OF LIFE SCALE – NORSK VERSJON

Vennligst les gjennom hvert punkt og sett en ring rundt det tallet som best beskriver hvor fornøyd du er for tiden. Selv om du for tiden ikke deltar i noen aktivitet eller har noe forhold, ber vi deg besvare hvert punkt. Du kan være fornøyd eller misfornøyd uten å delta i aktivitet eller ha noe forhold.

		Svært fornøyd	**Fornøyd**	**Stort sett fornøyd**	**Blandet**	**Stort sett misfornøyd**	**Misfornøyd**	**Svært misfornøyd**
1.	Materielle goder: hjem, mat, bekvemmeligheter, økonomi, trygghet	7	6	5	4	3	2	1
2.	Helse: fysisk i form og energisk	7	6	5	4	3	2	1
3.	Forholdet til foreldre, søsken og andre slektninger: kontakt, besøk, hjelp	7	6	5	4	3	2	1
4.	Ha og oppdra barn	7	6	5	4	3	2	1
5.	Forhold til ektefelle/samboer eller tilsvarende	7	6	5	4	3	2	1
6.	Nære venner	7	6	5	4	3	2	1
7.	Hjelpe og gi oppmuntring til andre, delta i frivillig engasjement, gi råd	7	6	5	4	3	2	1
8.	Deltakelse i organisasjoner eller offentlig virksomhet	7	6	5	4	3	2	1
9.	Studier: skolegang, øke din forståelse, utvide dine kunnskaper	7	6	5	4	3	2	1
10.	Egenforståelse: kjenne dine sterke sider og begrensninger - vite hva livet dreier seg om	7	6	5	4	3	2	1
11.	Arbeid: yrkeslivet eller i hjemmet	7	6	5	4	3	2	1
12.	Skapende aktiviteter: musikk, kunst, poesi, etc	7	6	5	4	3	2	1
13.	Sosial omgang: møte med andre mennesker, gjøre ting, festligheter, etc	7	6	5	4	3	2	1
14.	Lese, lytte til musikk eller se på underholdning	7	6	5	4	3	2	1
15.	Fysisk aktiv fritid: sport, reiser, dans, turer	7	6	5	4	3	2	1
16.	Uavhengighet, gjøre noe på egenhånd	7	6	5	4	3	2	1

ref:Wahl et al: The Norwegian Version of the Quality of Life Scale (QOLS-N); Scand J Caring Sci 1998;12:215-222.
Burckhardt et al: Quality of life of adults with chronic illness: A psychometric study; Res Nurse Health 1989;12: 357-354

FAMILY EMPOWERMENT SCALE

Spørsmålene kartlegger en rekke områder i ditt og familiens liv, tjenestene som barnet ditt mottar og kommunens organisering av tjenester. Spørsmålene inkluderer ulike aktiviteter som foreldre kan gjøre, men ikke alltid gjør. Dersom det er spørsmål som ikke passer for deg, sett en ring rundt "Aldri".Andre personer kan være involvert i omsorgen og beslutninger som gjelder barnet ditt, men vi ber deg svare på spørsmålene ut fra din situasjon. Skriv gjerne tilleggskommentarer på slutten av skjemaet.

Sett en ring rundt det som passer best for hver påstand

Om deg og din familie …	**Aldri**	**Sjelden**	**Av og til**	**Ofte**	**Alltid**
1. Når det oppstår problemer med barnet mitt håndterer jeg dem ganske bra.	1	2	3	4	5
2. Jeg føler meg trygg på at jeg er i stand til støtte mitt barns vekst og utvikling.	1	2	3	4	5
3. Jeg vet hva jeg skal gjøre når det oppstår problemer med barnet mitt.	1	2	3	4	5
4. Jeg føler at familielivet mitt er under kontroll.	1	2	3	4	5
5. Jeg er i stand til å innhente informasjon som gjør at jeg kan forstå barnet mitt bedre.	1	2	3	4	5
6. Jeg tror at jeg kan finne løsninger når det oppstår problemer med mitt barn.	1	2	3	4	5
7. Når jeg trenger hjelp med problemer i familien min, er jeg i stand til å be andre om hjelp.	1	2	3	4	5
8. Jeg prøver å lære meg nye måter å hjelpe barnet mitt til å vokse og utvikle seg.	1	2	3	4	5
9. Når jeg er sammen med barnet mitt har jeg fokus på både det som er bra og på vanskene.	1	2	3	4	5
10. Når jeg møter et problem som har med barnet mitt å gjøre, bestemmer jeg meg for hva jeg vil gjøre og så gjør jeg det.	1	2	3	4	5
11. Jeg har god innsikt i mitt barns funksjonsproblemer.	1	2	3	4	5
12. Jeg føler at jeg er en god forelder.	1	2	3	4	5
Om tjenestene som ditt barn mottar…	**Aldri**	**Sjelden**	**Av og til**	**Ofte**	**Alltid**
13. Jeg føler jeg har rett til å godkjenne alle tjenester som barnet mitt mottar.	1	2	3	4	5
14. Jeg vet hva jeg skal gjøre når jeg er bekymret for at tjenestene som barnet mitt mottar er for dårlige.	1	2	3	4	5
15. Jeg forsikrer meg om at fagfolk forstår hvilke tjenester jeg mener barnet mitt trenger.	1	2	3	4	5
16. Jeg er i stand til å ta avgjørelser om hvilke tjenester barnet mitt trenger.	1	2	3	4	5
17. Jeg er i stand til å samarbeide med tjenesteapparatet og fagfolk for å beslutte hvilke tjenester barnet mitt trenger.	1	2	3	4	5
18. Jeg passer på at jeg har jevnlig kontakt med fagfolkene som yter tjenester til barnet mitt.	1	2	3	4	5
19. Min mening er like viktig som fagfolks når det gjelder beslutninger om hvilke tjenester barnet mitt trenger.	1	2	3	4	5

20. Jeg forteller fagfolk hva jeg mener om tjenestene som blir gitt til barnet mitt.	1	2	3	4	5
21. Jeg vet hvilke tjenester barnet mitt trenger.	1	2	3	4	5
22. Når det er nødvendig tar jeg initiativ til å finne et egnet tjenestetilbud til barnet mitt og familien.	1	2	3	4	5
23. Jeg har god kjennskap til det tjenesteapparat barnet mitt får hjelp fra.	1	2	3	4	5
24. Fagfolk bør spørre meg om hvilke tjenester jeg ønsker til barnet mitt.	1	2	3	4	5
Om din involvering i kommunens tjenestetilbud …	**Aldri**	**Sjelden**	**Av og til**	**Ofte**	**Alltid**
25. Jeg opplever at jeg kan delta i å forbedre tjenestetilbudet til barn i min kommune.	1	2	3	4	5
26. Jeg tar kontakt med lokale politikere når viktige utredninger og saker som vedrører barn er under behandling.	1	2	3	4	5
27. Jeg vet hvordan tjenestetilbudet til barn er organisert.	1	2	3	4	5
28. Jeg har tanker om hvordan tjenester til barn ideelt skulle vært organisert.	1	2	3	4	5
29. Jeg hjelper andre familier med å få de tjenestene de trenger.	1	2	3	4	5
30. Jeg tror at andre foreldre og jeg kan påvirke tjenestetilbudet til barn.	1	2	3	4	5
31. Jeg forteller folk i tjenesteapparatet og forvaltningen hvordan tjenester til barn kan forbedres.	1	2	3	4	5
32. Jeg vet hvordan jeg kan få folk i forvaltningen og lokale politikere til å høre på meg.	1	2	3	4	5
33. Jeg kjenner foreldre og barns rettigheter når det gjelder spesialundervisning.	1	2	3	4	5
34. Jeg føler at min kunnskap og erfaring som forelder kan brukes til å forbedre tjenestetilbud til barn og familier.	1	2	3	4	5

Kommentarer……

……

……

……

……

Barns deltakelse i dagliglivet

Child Engagement in Daily Life

Beskrivelse: Barns deltakelse i dagliglivet er et selvrapporterings skjema som fylles ut av barnets foreldre for å beskrive og evaluere barnets deltakelse i familie- og fritids aktiviteter og i egenomsorg.

Instruksjon for foreldre:
Vi er interessert i ditt barns deltakelse i daglige aktiviteter i samspill med andre, lek og egenomsorg.
Vi ønsker at den som fyller ut spørreskjemaet er barnets foreldre eller pårørende som har den daglige omsorgen for barnet, slik at hun/ han kjenner barnet godt.
Det er to tabeller for hver oppgave. For hver oppgave i tabellen krysser du av for de to svaralternativene som passer. Beskrivelsene av definisjonene for svaralternativene er en veiledning for å hjelpe deg til å velge det beste svaret for barnet ditt.

Del en: Deltakelse i familie- og fritidsaktiviteter

Vi ber deg om å gradere hvert spørsmål i **Deltakelse i familie- og fritidsaktiviteter** på to skalaer: 1) Hvor ofte barnet ditt deltar og 2) Din opplevelse av hvor godt barnet ditt liker det. Det gis flere eksempler på aktiviteter under «familie aktiviteter i hjemmet». Barnet behøver ikke delta i alle disse eksemplene, men grader barnets deltakelse ved å se på den brede kategorien «familie aktiviteter i hjemmet»

Hvor ofte:	**Hvor godt tror du barnet ditt trives med aktiviteten:**
Svært ofte – Barnet ditt deltar alltid i aktiviteten (ved enhver mulighet)	**Kjempegodt -** Barnet ditt elsker aktiviteten
Ofte – Barnet ditt deltar ofte i aktiviteten	**Veldig godt –** Barnet ditt liker aktiviteten veldig godt
Av og til – Barnet ditt deltar av og til i aktiviteten	**Sånn passe** – Barnet ditt liker aktiviteten
Nesten aldri – Barnet ditt deltar sjelden i aktiviteten	**Mindre godt –** Barnet ditt aksepterer aktiviteten
Aldri - Barnet ditt deltar aldri i aktiviteten	**Ikke i det hele tatt –** Barnet ditt misliker aktiviteten

Oversatt til norsk, Bjørg Fallang, Høyskolen i Oslo og Akershus.

	Hvor ofte?					Hvor godt tror du barnet ditt trives med aktiviteten:				
Hvor ofte deltar barnet ditt i	svært ofte	Ofte	av og til	nesten aldri	aldri	kjempegodt	veldig godt	sånn passe	mindre godt	ikke i det hele tatt
	5	4	3	2	1	5	4	3	2	1
Familieaktiviteter hjemme, slik som plikter, måltider, se på TV										
Familie utflukter i lokalmiljøet som shopping, biblioteket, religiøse aktiviteter, besøke familie og venner										
lek innendørs med voksne										
lek innendørs med barn										
lek utendørs med voksne										
lek utendørs med barn										
fritidsaktiviteter som å fargelegge, spille kort, lese bøker										
organiserte aktiviteter, tilpasset idrettsaktivitet og arrangerte lekegrupper som svømming, dansing/kreativ bevegelsesaktivitet, foreldre -barn grupper										
fysisk aktive fritidssysler slik som å klatre i lekestativ, sykle på trehjulsykkel, svømme, løpe ute										
fornøyelses utflukter som å gå i dyreparken, barnemuseum, konserter, teater, på sirkus										
sosiale aktiviteter som avtalt lek med venner, gå i selskap										

Oversatt til norsk, Bjørg Fallang, Høyskolen i Oslo og Akershus.

Scoring Instructions and Conversion Tables

For Frequency of Participation in Family and Recreational Activities: Sum the raw scores on the 11 items and use the following chart to determine the scaled score relevant for young children with cerebral palsy.

Summed Raw Score	Scaled Score	Summed Raw Score	Scaled Score	Summed Raw Score	Scaled Score
55	100.0	40	54.1	25	37.7
54	88.2	39	52.8	24	36.6
53	80.9	38	51.7	23	35.3
52	76.6	37	50.6	22	34.0
51	73.2	36	49.5	21	32.6
50	70.5	35	48.4	20	31.3
49	68.2	34	47.4	19	29.7
48	66.1	33	46.3	18	28.1
47	64.2	32	45.3	17	26.4
46	62.5	31	44.3	16	24.4
45	60.9	30	43.2	15	22.2
44	59.4	29	42.2	14	19.5
43	57.9	28	41.1	13	16.1
42	56.6	27	39.9	12	10.3
41	55.3	26	38.9	11	0.0

For Enjoyment of Participation in Family and Recreational Activities: Calculate the average of the raw scores on the 11 items and use the response options as a guide for interpretation of overall enjoyment.

REGISTRERING AV HABILITERINGSTILTAK

Hensikten med dette skjemaet er å samle informasjon om hvilke habiliteringstiltak barnet har mottatt i løpet av de **siste 6 månedene**.
I habiliteringstiltak inngår alle ekstra tiltak og støtteordninger som kan ytes til barn med CP for å støtte opp under barnet og familien.

Skjemaet omhandler 4 grupper av tiltak og tjenester

1. **Trening og stimulering** (motorikk, kommunikasjon, hverdagsferdigheter mm)
2. **Tekniske hjelpemidler** (forflytning, kommunikasjon, trening, bading, bil, rampe mm)
3. **Kurs og opplæring** (i regi av kommunen, spesialisthelsetjenesten, brukerorganisasjoner mm)
4. **Tjenester og ytelser** (fysioterapi, spesialpedagogikk, individuell plan, avlastning, stønader mm)

På neste side finner dere et eksempel på hvordan dere fyller ut skjemaet. Se godt på dette før dere starter.

Utarbeidet av B. Fallang, R. Jahnsen, G. Størvold, A.B. Sørsdahl, I. Vestrheim, S. Østensjø.

1. Trening og stimulering

Hva har barnet trent på i løpet av de siste 6 månedene?		**Hvilke fagpersoner har deltatt i treningen?**	**Hvordan har dere deltatt i treningen**	**Hvor lenge har treningen pågått?**	**Hvor ofte har treningen foregått?**	**Hvor har treningen foregått?**	**Hvordan har treningen vært organisert?**	**Har det vært mål for treningen?**	**Hvor stor nytte har barnet hatt av treningen?**
Kryss av for de områder som har vært i fokus for treningen. Der du har krysset av (x) skriver du inn de aktuelle tallene i hver celle bortover.		1=fysioterapeut 2=førskolelærer 3=spes. ped 4=assistent 5=ergoterapeut 6=andre 7=vet ikke	1= ikke deltatt 2=sett på 3=utført	1= 1-2 uker 2=3-4 uker 3=1-2 mnd 4=3-4 mnd 5=hele perioden 6=vet ikke **Skriv ett tall**	1= 1g/uke 2=2g/uke 3=3-5 g/uke 4=6-7g/uke 5=flere ganger daglig 6=vet ikke **Skriv ett tall**	1=hjemme 2=barnehage 3=skole 4=hos fysioterapeut 5=hab. tjenesten 6=svømmehall 7=ridesenter 8=annet sted, angi	1=individuelt 2=i gruppe 3=del av daglige aktiviteter 4=vet ikke	1=ja 2=nei 3=vet ikke **Skriv ett tall**	1=liten nytte 2=noe nytte 3=stor nytte 4=svært stor nytte 5=usikker **Skriv ett tall**
Vanlig trening	**x**								
Grovmotoriske ferdigheter (sitte, reise seg, stå, gå mm)									
Tøyninger									
Håndmotoriske ferdigheter (gripe, slippe, klippe mm)									
Språk og tale									
Alternativ kommunikasjon (ved talevansker)									
Spise og drikke									
Kle av og på seg									
Bli renslig									
Lekeferdigheter (bygge, pusle, lek med biler/ dokker)									
Sosiale ferdigheter (lek med barn/voksne mm)									
Fysisk aktivitet (svømme, ri, allidrett, sykle, ake mm)									
Annet, angi									
Deltatt i spesielle trenings-/habiliteringsprogram (f.eks. PITH, PIH, BIP, Petø, FHC, Vojta) i løpet av de siste 6 månedene?									
Nei ☐ Ja ☐ Angi program:									

3. Kurs og opplæring

Hva har vært tema på kurset/opplæringen som dere har deltatt på i løpet av de siste 6 månedene?		**Hvilken instans sto for opplæringen?**	**Hvor mange ganger foregikk opplæringen?**	**Hvor mange timer per tema varte opplæringen?**	**Hvordan forgikk opplæringen?**	**Hvor stor nytte har dere hatt av opplæringen?**
Hvis dere har deltatt, kryss av for de temaene som har vært i fokus i kurset/opplæringen. Der du har krysset av (x) skriver du inn de aktuelle tallene i hver celle bortover.		1=kommunal tjeneste 2=spesialisttjeneste 3=lærings- og mestringssenter 4=interesse-organisasjon 5=andre, angi	1=1 gang 2=2 ganger 3=3-4 ganger 4=> 4 ganger **Skriv ett tall**	1=1-7 timer 2=8-15 timer 3=16-25 timer 4=26-35 timer 5=>35 timer **Skriv ett tall**	1=forelesning 2=demonstrasjon 3=praktiske øvelser 4=gruppediskusjon 5=nettbasert 6=samtale 7=andre måter, angi	1=liten nytte 2=noe nytte 3=stor nytte 4=svært stor nytte 5=usikker **Skriv ett tall**
Diagnosen CP	☐					
Å være foreldre til funksjonshemmet barn	☐					
Rettigheter	☐					
Likemannsarbeid	☐					
Individuell plan	☐					
Målsetting	☐					
Motorisk trening	☐					
Lek og stimulering	☐					
Alternativ/supplerende kommunikasjon	☐					
Epilepsi	☐					
Ernæring og spising	☐					
Fritidsaktiviteter	☐					
Datateknologi	☐					
Annet, angi	☐					
Annet, angi:	☐					

4. Tjenester og ytelser

Hvilke økonomiske og andre ytelser har barnet og familien mottatt i løpet av de siste 6 månedene? Kryss av for de ytelsene som barnet eller dere har mottatt fordi barnet har CP. Der du har krysset av (x) skriver du inn de aktuelle tallene i hver celle bortover		**Hvor fornøyd er dere med omfanget eller størrelsen på ytelsene?**
		1=ikke fornøyd 2=ganske fornøyd 3=godt fornøyd 4=svært godt fornøyd **Skriv ett tall**
Fysioterapi		
Spesialpedagogisk hjelp		
Ergoterapi		
Assistent i barnehage		
Psykologhjelp		
Legehjelp		
Helsestasjon		
Individuell plan		
Personlig koordinator		
Ansvarsgruppe		
Grunnstønad		
Hjelpestønad		
Omsorgspenger ved barns sykdom		
Omsorgslønn		
Avlastning		
Støttekontakt		
Brukerstyrt personlig assistanse		
Bilstønad		
Boligtilskudd		
Opplæringspenger		

Annet, angi		
Annet, angi		

Er det noe dere har savnet eller bedt om og ikke fått?

Her kan dere skrive alt dere syns er viktig å få formidlet om tiltak og tjenester til barnet og familien, og som vi ikke har spurt om.

Articles

Article I

Kalleson R, Jahnsen R, Østensjø S. Empowerment in families raising a child with cerebral palsy during early childhood: Associations with child, family, and service characteristics. *Child: Care, Health and Development*. 2020;46(1):19-27. DOI: **https://doi.org/10.1111/cch.12716**

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RESEARCH ARTICLE

WILEY

Empowerment in families raising a child with cerebral palsy during early childhood: Associations with child, family, and service characteristics

Runa Kalleson[1] | Reidun Jahnsen[2] | Sigrid Østensjø[1]

[1] Department of Physiotherapy, Faculty of Health Sciences, OsloMet – Oslo Metropolitan University, Oslo, Norway

[2] Department of Clinical Neuroscience for Children, Oslo University Hospital and Institute of Health and Society, University of Oslo, Oslo, Norway

Correspondence
Runa Kalleson, PT, MSc, Department of Physiotherapy, Faculty of Health Sciences, OsloMet – Oslo Metropolitan University, PB 4, St. Olavs plass, 0130 Oslo, Norway.
Email: runaka@oslomet.no

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Abstract

Background: Insight into family empowerment is important in order to develop and offer services that support and strengthen parents caring for a child with disability. The aims of this study were to describe empowerment trajectories among parents caring for a young child with cerebral palsy (CP) and to explore associations between parental empowerment and characteristics of the child and family and the services they receive.

Methods: 58 children (median age at first assessment 28 months, range 12–57) and their parents were included in a longitudinal cohort study based on registry data from follow-up programmes for children with CP in Norway. Parental empowerment trajectories were described by averaging scores in the three subscales of the Family Empowerment Scale (FES; family, service situations, and community) at enrollment and at semiannual/annual assessments. A linear mixed model was used to explore associations.

Results: Parental empowerment scores on the FES in family and service situations were high and stable during early childhood, although considerably lower in the community context. In service situations, perceived empowerment was significantly associated with both child, family, and service characteristics, whereas empowerment in family situations was only associated with family characteristics. The service factor *having a multidisciplinary support team* was positively associated with perceived empowerment in both service situations and in the community.

Conclusion: Knowledge about parental empowerment in different contexts and associations with characteristics of the child and family and the services they receive can contribute to further reinforcing family empowerment and identifying parents in need of additional support.

KEYWORDS
cerebral palsy, cohort study, early childhood, parental empowerment trajectories

1 | INTRODUCTION

Raising a child with a disability like cerebral palsy (CP) requires high levels of knowledge and access to resources, information, and services. Children with CP present with a range of permanent motor impairments, and the disorder often affects other developing functions such as cognition and communication (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). As a consequence, most children with CP and their caregivers will have to prepare for life-long interaction with an extended service system.

A family-centred approach to service delivery is considered best practice in early childhood interventions (King, Teplicky, King, & Rosenbaum, 2004). Facilitating parental empowerment represents a major component of family-centred interventions with the intent to promote child development and wellbeing (Dunst, Trivette, & Hamby, 2007). Empowerment is described both as a multidimensional process (gaining greater control and mastery over life) and an outcome (holding power; Staples, 1990), reflected on different levels: personal (personal power and self-efficacy), interpersonal (influencing others), and political (social action or social change; Gutiérrez & Ortega, 1991). Another dimension reflected in the literature is the way empowerment is expressed; as skills or abilities, self-perception and actions (Staples, 1990). These two dimensions are incorporated and operationalized in the Family Empowerment Scale (Koren, DeChillo & Friesen, 1992), measuring empowerment expressed as attitudes, knowledge, and behavior in the context of family, service situations, and community.

Previous research on associations between caregiver empowerment, measured by the FES, and child and family characteristics has resulted in inconsistent findings across countries and child disorders (Nachshen & Minnes, 2005; Singh et al., 1997; Vuorenmaa, Perälä, Halme, Kaunonen, & Åstedt-Kurki, 2016; Wakimizu, Fujioka, Yoneyama, Iejima, & Miyamoto, 2011; Wakimizu, Yamaguchi, & Fujioka, 2017). Research on the impact of service-provision on parental empowerment is still scant, and even though empowerment has been used as an outcome in some intervention studies involving children with physical disabilities (An et al., 2017; Burton et al., 2018), little is known about the trajectories of parental empowerment across time.

So far, no study has explored empowerment among parents raising a child with CP as a distinct group. The aims of this study were to describe trajectories of parental empowerment in the family, service situations, and community from enrollment in a systematic follow-up programme for children with CP throughout early childhood and to explore longitudinal associations between parental empowerment and characteristics of the child and family and the services they receive.

Key messages

- Parental empowerment ratings on the FES in family and service situations were high and stable during early childhood, indicating strong family resources.
- Low empowerment ratings in the community context indicate an insufficient utilization of family resources in the quality improvements of services.
- Having a multidisciplinary support team was associated with higher empowerment ratings in service situations and in the community, reinforcing the potential of service providers to enhance parental control over the children's services and strengthen their capability to influence the service systems.
- More research on how services can affect parental empowerment over time is needed to further facilitate family involvement in child rehabilitation.

2 | METHOD

2.1 | Participants and procedure

In Norway, all children with CP are offered a systematic follow-up through the Cerebral Palsy Register of Norway and the Cerebral Palsy Follow-up Program, based in the regional paediatric rehabilitation units. An associated research registry, Habilitation Trajectories, Interventions, and Services for Young Children with CP (CPHAB) was established to expand the follow-up by including information about the family and the service provision. Thirteen of the 21 regional paediatric rehabilitation units nationwide took part in the CPHAB. Inclusion criteria were children registered in Cerebral Palsy Register of Norway or Cerebral Palsy Follow-up Program when aged 4 years or younger, between January 2012 and December 2014, with caregivers capable of answering questionnaires in Norwegian or English. During the first 2 years of follow-up, the children and their families were assessed twice a year, thereafter once or twice a year according to the families' own preferences, at least three times. The questionnaires were completed by one of the parents in conjunction with the child's regular consultation at the rehabilitation unit.

The present study has a longitudinal cohort design using data from the CPHAB and the CPOP. The inclusion process is presented in Figure 1. Of the 132 children who fulfilled the age criteria, 11 were not invited in the study due to parental language barriers. 21 families were not invited to participate because of lack of resources in the rehabilitation units but also because service providers considered the strain of some families to be too large to participate. Furthermore, 25 families declined participation, and 17 were excluded due to incomplete questionnaires. A total of 58 families participated in the current study. The study was approved by the regional Committee for Medical and Health Research Ethics of South-Eastern Norway (registration number 2017/782).

2.2 | Measures

Parental empowerment was assessed using the Family Empowerment Scale (Koren, Dechillo, & Friesen, 1992). The FES has three subscales representing different contexts where empowerment can be expressed: (a) Family (12 items), referring to the immediate situation at home; (b) Service situations (12 items), referring to the parents' collaboration with the service system to obtain services addressing the needs of the child and family; and (c) Community (10 items), referring to parents' advocacy for improved services for children with disabilities in general rather than specifically for his or her child. Within each of these contexts, three

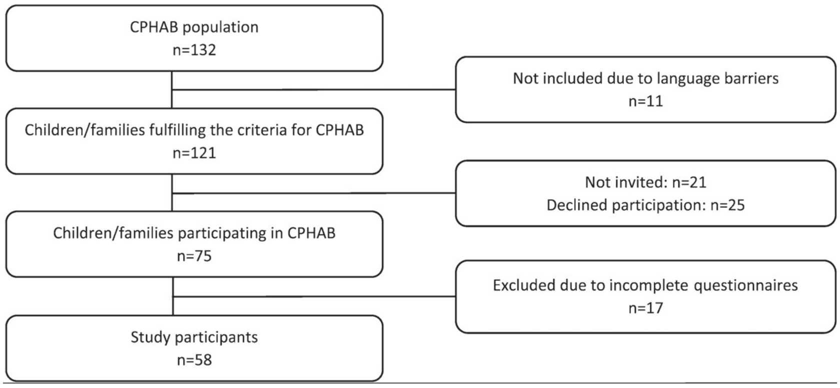

FIGURE 1 The inclusion process. CPHAB, Habilitation Trajectories, Interventions, and Services for Young Children with CP

ways of expressing empowerment are reflected: Attitudes (what a parent feels or believes), knowledge (what a parent knows or potentially can do), and behaviour (what a parent actually does). "I believe that other parents and I can have an influence on services for children" is an example of an item reflecting attitude (on the community level). "I know the steps to take when I am concerned my child is receiving poor services" reflects knowledge (in service situations), while "When faced with a problem involving my child, I decide what to do and then do it", is an example of an item expressing behaviour (family level). The FES has a five-point Likert scale (1 = *not true at all*, 5 = *very true*), where a higher score indicates a higher level of perceived empowerment. A systematic review of empowerment instruments has reported that FES is a valid and reliable measure of caregiver empowerment (Cyril, Smith, & Renzaho, 2016). It was originally developed for parents whose children had emotional disabilities (Koren et al., 1992), with later studies confirming sufficient content validity for parents of young children in general (Vuorenmaa et al., 2014) and for parents of children with a chronic condition (Segers et al., 2019). The FES was translated into Norwegian as part of the CPHAB, using forward–back translation with harmonization followed by cultural adaptation using interviews, as described by Wild et al. (2005).

Child characteristics included age, subtype of CP, and gross motor abilities. Subtype was classified as spastic (unilateral or bilateral), dyskinetic, or ataxic CP (Surveillance of Cerebral Palsy in Europe, 2000). Gross motor abilities were classified according to the five levels of the Gross Motor Function Classification System (GMFCS; Palisano et al., 1997). The GMFCS has demonstrated good predictive validity and reliability (Palisano et al., 1997; Palisano, Hanna, Rosenbaum, & Russell, 2000; Wood & Rosenbaum, 2000) and is widely used as an indicator of the severity of CP (Level I representing the lowest severity, Level V the highest).

Family characteristics included parents' education, employment, financial concerns, residential problems, and parental quality of life (QOL). The characteristics, except for QOL, were included in the Norwegian version of "*Parental Account of Children's Symptoms*" (Taylor, Schachar, Thorley, & Wieselberg, 1986). Parental QOL was assessed using the Norwegian version of the Quality of Life Scale (Wahl, Burckhardt, Wiklund, & Hanestad, 1998). The questionnaire consists of 16 items where answers are rated on a 7-point scale and where a higher score indicates a higher level of QOL.

Service characteristics included two means of service coordination (service coordinator and individual service plan; ISP), multidisciplinary support team, parent training, and participation in an intensive rehabilitation programme, and were collected from the HabServ questionnaire. The questionnaire contains information about interventions and services provided to the child and the family during the preceding 6 months and has previously been used in three studies (Klevberg, Østensjø, Elkjaer, Kjeken, & Jahnsen, 2017; Myrhaug, Jahnsen, & Østensjø, 2016; Myrhaug & Østensjø, 2014).

2.3 | Data analyses

Data were analysed using the IBM SPSS Statistics version 25. Participant characteristics were summarized descriptively and compared with characteristics of non-participants by the use of a chi-square test (categorical variables) and two-sample *t*-test (age). Averaging empowerment scores were calculated for each of the three FES subscales at six points of time (enrollment, 6, 12, 18, 24 and 36 months after). A linear mixed-effects model with random intercept was used to explore associations between parental empowerment mean scores and child characteristics (age, CP-subtype, and GMFCS level), family characteristics (maternal and paternal education and employment, parental QOL, and financial and residential concerns), and service characteristics (parent training, ISP and/or coordinator, multidisciplinary team, and intensive rehabilitation programme). This statistical method handles correlated data in the repeated measure design and allow an unequal number of repetitions with disparate time intervals between the assessments. The identification number of the participants was set as a random effect contributing to the covariance structure of the data. The characteristics of the child and family and the services they received were set as fixed effects and explored one by one. Analyses of associations with the child's age were adjusted for the GMFCS level, and vice versa, whereas analyses including family and service characteristics were adjusted for both the child's age and GMFCS level. Due to the small sample size, the categories of some variables were collapsed.

3 | RESULTS

A total of 58 families participated in the study, representing 48% of the cohort (See Figure 1). Child and family characteristics are presented in Table 1. There was a significant difference between participating and non-participating children with respect to CP subtypes and GMFCS levels, with a greater proportion of children with spastic bilateral CP and children at GMFCS Levels III and IV participating in the study.

Services provided to the families during early childhood are presented in Table 2. More than 80% of the families have received support from a multidisciplinary team, a service coordinator or an ISP. About three fourth of the parents have participated in some kind of training, and more than 50% of the children have attended an intensive rehabilitation programme (see Table 2).

3.1 | Parental empowerment trajectories

Figure 2 illustrates the parental empowerment trajectories on the FES in the family, service situations, and community subscales. Empowerment ratings in family and service situations were high and stable during early childhood (mean 4.1, *SD* = 0.5 to mean 4.3, *SD* = 0.4) and considerably lower in the community subscale (mean 2.4, *SD* = 0.7 to mean 2.7, *SD* = 0.8).

3.2 | Associations between parental empowerment and child, family, and service characteristics

In the family context, parental empowerment was significantly associated with three family characteristics: maternal education and employment and parental QOL (see Table 3). Full-time maternal employment was associated with higher empowerment ratings, whereas high level of maternal education was associated with lower ratings. QOL and empowerment were positively associated. No child or service factors were significantly associated with parental empowerment in the family subscale.

In service situations, empowerment ratings were significantly associated with one characteristic of the child, two characteristics of the family, and one characteristic of the services. Caring for a child with moderate gross motor limitations (GMFCS II or III) was associated with lower ratings compared to caring for a child with less severe limitations (GMFCS I). A high level of maternal education was associated with lower empowerment ratings, whereas higher parental QOL and having a multidisciplinary team were associated with higher ratings.

In the community context, parental empowerment was significantly associated with two child and two service characteristics. Ratings were positively associated with the child's age, whereas caring for a child with moderate gross motor limitations (GMFCS II or III) was associated with lower ratings compared to children at GMFCS Level IV or V. Having a multidisciplinary support team and attending an intensive rehabilitation programme were associated with higher empowerment ratings (Table 3).

Four family characteristics, paternal education and employment, financial concerns, and residential problems, were not significantly associated with parental empowerment in any context. This was also the case for the service characteristics *having a service coordinator or an ISP* and *attending parent training*.

4 | DISCUSSION

Parental empowerment ratings on the FES in family and service situations were high and stable during early childhood, whereas considerably lower in the community context. These results indicate that most parents of young children with CP in Norway feel competent and empowered when it comes to issues related to their family and their child's services but less so when dealing with service systems. These findings are consistent with results from other Western countries including young children in a primary health care setting (Vuorenmaa et al., 2016), children receiving early childhood interventions (Fordham, Gibson, & Bowes, 2012), and children with developmental disabilities (Banach, Iudice, Conway, & Couse, 2010; Burton et al., 2018; Minjarez, Mercier, Williams, & Hardan, 2013). The relatively low ratings in the community context may indicate that family capabilities are insufficiently utilized in quality improvements of services for children with disabilities at a system level.

Intervention studies have shown an increase in parental empowerment ratings on the FES from pretests to post-tests (An et al., 2017; Burton et al., 2018), indicating a positive effect of interventions designed to increase family empowerment. In the present study, empowerment scores on the FES were stable from the entering of a systematic follow-up programme and throughout early childhood. The stability of the FES scores might reflect that attending a general follow-up programme focusing on assessments and measures is less efficient in improving parental empowerment than specific goal-directed interventions targeting family empowerment.

By exploring associations between parental empowerment and child, family, and service characteristics, we found different patterns of associations for each of the three FES subscales. Empowerment in the family context was only associated with family characteristics. In the community context, empowerment was associated with both child and service characteristics. Empowerment in the service situations appears to be the most complex context, associated with characteristics within all the three groups: child, family and services.

Previous studies exploring associations between child characteristics and parental empowerment reveal inconsistent results. In a study of families attending an early intervention programme in the United States or Australia, no significant association between perceived empowerment and children's age was found (Dempsey & Dunst, 2004). In the context of primary health care in Finland, children's age was associated with maternal empowerment in service situations, but not in the family and community contexts (Vuorenmaa et al., 2016). In the present study, the children's age was associated with parental empowerment only in the community context. Together, these findings indicate that the child's age alone is not a strong predictor of parental empowerment.

Associations between child functioning and parental empowerment have previously been found in the context of mental health services (Resendez, Quist, & Matshazi, 2000; Weiss, Cappadocia, Macmullin, Viecili, & Lunsky, 2012). No previous study has explored associations between parental empowerment and the gross motor limitations (GMFCS levels) of children with CP. In the present study, we

TABLE 1 Child and family characteristics

Characteristics	Participants (*n* = 58) *n* (%)	Non-participant (*n* = 63) *n* (%)	Sig.
Child's gender			*p* = .13
Female	22 (38)	30 (48)	
Male	36 (62)	33 (52)	
Age at first assessment (months)			*p* = .15
Median (min–max)	28 (12–57)	30 (10–48)	
CP subtype			*p* = .01*
Spastic unilateral	23 (39)	30 (48)	
Spastic bilateral	34 (59)	23 (36)	
Dyskinetic and ataxic	1 (2)	9 (14)	
Not classified	0 (0)	1 (2)	
GMFCS level			*p* = .00*
I	26 (45)	34 (54)	
II	6 (10)	6 (10)	
III	11 (19)	6 (10)	
IV	11 (19)	4 (6)	
V	4 (7)	10 (16)	
Not classified	0 (0)	3 (4)	
Mother´s country of origin			
Norway	51 (88)		
Other	7 (12)		
Father´s country of origin			
Norway	50 (86)		
Other	8 (14)		
Primary caregivers			
Mother and father	50 (86)		
Mother	5 (9)		
Father	1 (2)		
Other	2 (3)		
Maternal education			
≤12 years (high-school)	18 (31)		
>12 years (college, university, other)	39 (67)		
Unknown	1 (2)		
Paternal education,			
≤12 years (high-school)	24 (41)		
>12 years (college, university, other)	31 (54)		
Unknown	3 (5)		
Maternal employment			
Full time	28 (48)		
Part-time ≥50%	14 (25)		
Part-time <50%	6 (10)		
Not employed	10 (17)		
Paternal employment			
Full time	50 (86)		
Part-time ≥50%	2 (3)		

(Continues)

TABLE 1 (Continued)

Characteristics	Participants (*n* = 58) *n* (%)	Non-participant (*n* = 63) *n* (%)	Sig.
Part-time <50%	1 (2)		
Not employed	1 (2)		
Unknown	4 (7)		
Parental quality of life			
QOLS total score, mean (*SD*)	86.7 (13)		
Siblings			
Yes	51 (88)		
No	7 (12)		
Financial concerns			
No	38 (66)		
Yes	20 (34)		
Residential problems			
No	31 (53)		
Yes	27 (47)		

Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; QOLS, Quality of Life Scale; *SD*, standard deviation; Sig., significance.

*Significant at $p < .05$.

TABLE 2 Services received by the families during early childhood

Services	Participants (*n* = 58), n (%)
Parent training	
Yes	44 (76)
No	14 (24)
Individual service plan/service coordinator	
Yes	47 (81)
No	11 (19)
Multidisciplinary support team	
Yes	48 (83)
No	10 (17)
Intensive rehabilitation programme	
Yes	32 (55)
No	26 (45)

found no significant association between GMFCS levels and perceived empowerment in the family context. In service situations, empowerment ratings were significantly lower among parents caring for a child with moderate motor limitations (GMFCS II and III) compared to parents of children with less severe limitations (GMFCS I). In the community context, parents caring for a child at GMFCS Level II or III showed significantly lower empowerment ratings than the caregivers of children with the most severe motor limitations (GMFCS IV and V). This non-linear pattern of associations is not easily explained. However, while Level I children are expected to walk with minor difficulties and children at Level IV and V are expected to use a wheelchair, the expected mobility and gross motor function of children at Level II and III may be more unpredictable. This situation may in turn affect parental feelings of empowerment. Parents of children at GMFCS IV and V will be aware earlier of their need for comprehensive services, which may motivate them to make an effort to improve the service systems. This may explain their high ratings in the community subscale and are in line with findings from a study of children with serious emotional disturbances and attention deficit hyperactivity disorder (Singh et al., 1997).

Maternal educational and employment were two family characteristics that were significantly associated with perceived empowerment. Working full time was associated with higher ratings in the family context, whereas higher education was associated with lower ratings both in family and service situations. The same relationship between maternal education and empowerment is observed in two other studies including caregivers of children with emotional and behavioral problems (Curtis & Singh, 1996; Singh et al., 1997). No significant association was found between empowerment and paternal employment or education level.

Family empowerment and parental QOL are two areas of concern in paediatric rehabilitation services. In previous studies of children with disabilities, a significant association between parental health-related QOL and caregiver empowerment has been revealed (Wakimizu et al., 2016; Wakimizu et al., 2017). In the present study, parental global QOL was significantly associated with empowerment in both family and service situations. This positive association substantiates the importance of strategies to reinforce parental empowerment.

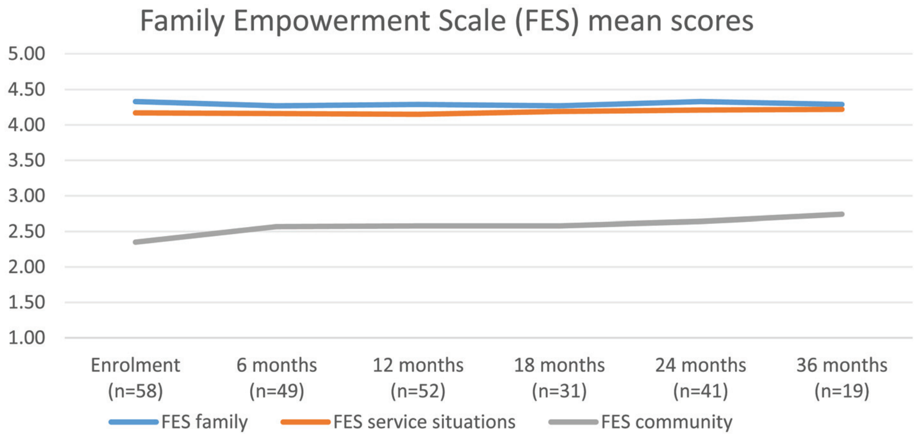

FIGURE 2 Mean FES scores in the subscales family, service situations, and community from enrollment in CPHAB and throughout early childhood. CPHAB, Habilitation Trajectories, Interventions, and Services for Young Children with CP [Colour figure can be viewed at wileyonlinelibrary.com]

TABLE 3 Associations between longitudinal FES mean scores and child, family, and service characteristics in the context of the family, service situations and community during early childhood

	FES family			FES service situations			FES community		
Subscale	**Estimate**	**95% CI**	***p*-value**	**Estimate**	**95% CI**	***p*-value**	**Estimate**	**95% CI**	***p*-value**
Child characteristics									
Age[a] (month)	-5×10^{-4}	-4×10^{-3}, 0.33	.708	1×10^{-3}	-3×10^{-3}, 5×10^{-3}	.574	0.01	2×10^{-3}, 0.01	.003*
GMFCS level[b]									
I	0.16	−0.09, 0.42	.197	0.28	0.02, 0.55	.037*	0.26	−0.11, 0.62	.162
II–III (reference)									
IV–V	0.04	−0.24, 0.33	.771	0.19	−0.11, 0.49	.216	0.48	0.06, 0.89	.025*
Family characteristics									
Maternal education[c]									
≤12 years (reference)									
>12 years	−0.16	−0.31, −0.01	.041*	−0.30	−0.47, −0.13	.001*	−0.13	−0.37, 0.12	.311
Maternal employment[c]									
Full time (reference)									
Part-time/no work	−0.16	−0.27, −0.4	.007*	−0.05	−0.18, 0.07	.423	−0.03	−0.22, 0.15	.739
QOLS[c]	0.01	0.01, 0.02	.000*	0.01	0.01, 0.02	.000*	0.01	-2×10^{-3}, 0.01	.188
Service characteristics									
Multidisciplinary support team[c]									
No (reference)									
Yes	0.01	−0.10, 0.12	.872	0.14	0.02, 0.27	.025*	0.23	0.05, 0.40	.011*
Intensive rehabilitation programs[c]									
No (reference)									
Yes	0.02	−0.08, 0.12	.640	0.05	−0.07, 0.17	.394	0.18	0.01, 0.35	.038*

Note. The estimates represent the differences in mean FES scores when the continuous variables increase with 1 month (age) or point (QOLS) and when scores are compared with the reference values (categorical variables). GMFCS level II–III was set as a reference value because the lowest empowerment mean scores were revealed in this category.

Abbreviations: CI, confidence interval; FES, Family Empowerment Scale; GMFCS, Gross Motor Function Classification System; QOLS, Quality of Life Scale.

[a] Adjusted for the child's GMFCS level. [b] Adjusted for the child's age. [c] Adjusted for the child's age and GMFCS level.

*Significant at $p < .05$.

Previous research on caregiver empowerment has revealed a positive correlation between empowerment ratings on the FES and how parents perceive the coordination and comprehensiveness of care (Fordham et al., 2012). In the present study, we explored associations between empowerment and different types of rehabilitation services provided to the families. Families having a multidisciplinary support team perceived themselves as more empowered than parents without such a team, both in interaction with service providers and in their advocacy for services for children with disabilities. Interestingly, having a service coordinator and/or ISP was not significantly associated with perceived empowerment in any context. A child's ISP should be based on family-identified needs and goals, and the role of the service coordinator includes facilitation of family involvement (Norwegian Directory of Health, 2018). With that in mind, the lack of positive associations between coordinated services and parental empowerment is somewhat disappointing—but not surprising, because previous studies have identified multiple challenges when coordinated services are to be implemented in practice (Bjerkan, Richter, Grimsmo, Hellesø, & Brender, 2011; Holum, 2012; Høyem, Gammon, Berntsen, & Steinsbekk, 2018).

Parent training is another service provided to families aiming to strengthen competence and confidence. Providing families with information is found to be strongly correlated with parental empowerment in the family, service situations, and community contexts (Fordham et al., 2012). In the present study, however, no significant associations were found between perceived empowerment and participation in courses and training. As opposed to parent training, attending an intensive rehabilitation programme was associated with higher empowerment ratings in the community context. Such rehabilitation programmes provide a setting where parents of children with CP meet and spend time together, which may positively affect their confidence and motivation for involvement in quality improvements of services. This is in line with previous findings of positive outcomes of peer support for parents of children with a chronic disabling condition (Shilling et al., 2013).

4.1 | Limitations

This exploratory registry-based study described longitudinal associations between parental empowerment (FES scores) and child, family, and service characteristics. Because of the limited number of participants, it was not possible to conduct multivariable analyses besides adjustments for the child's age and GMFCS level. Due to the study design, no causal relationships could be revealed, only associations. In the CPHAB registry, no information was available on which caregiver filled out the forms. By that, we missed the opportunity to differentiate between mothers and fathers.

5 | CONCLUSION

Most parents perceived themselves as empowered in family and service situations, but less so when it comes to influencing the service systems. The associations between parental empowerment and characteristics of the child and family and the services they received varied across contexts. Knowledge of factors associated with parental empowerment can contribute to further facilitating empowerment in families and identifying parents in need of additional support. The positive association between empowerment and having a multidisciplinary support team indicates that some services have a potential to reinforce parental control over service situations and strengthen their capacity to influence the service systems.

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ORCID

Runa Kalleson https://orcid.org/0000-0003-1335-1793
Reidun Jahnsen https://orcid.org/0000-0002-0694-0410
Sigrid Østensjø https://orcid.org/0000-0002-7418-2973

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Article II

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ORIGINAL ARTICLE

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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 Kalleson[a], Reidun Jahnsen[b] and Sigrid Østensjø[a]

[a]OsloMet – Oslo Metropolitan University, Oslo, Norway; [b]Oslo 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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➤ 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 Kalleson runaka@oslomet.no Department of Physiotherapy, Faculty of Health Sciences, Oslo Metropolitan University, P.O. Box 4, St. Olavs plass, Oslo N-0130, Norway

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

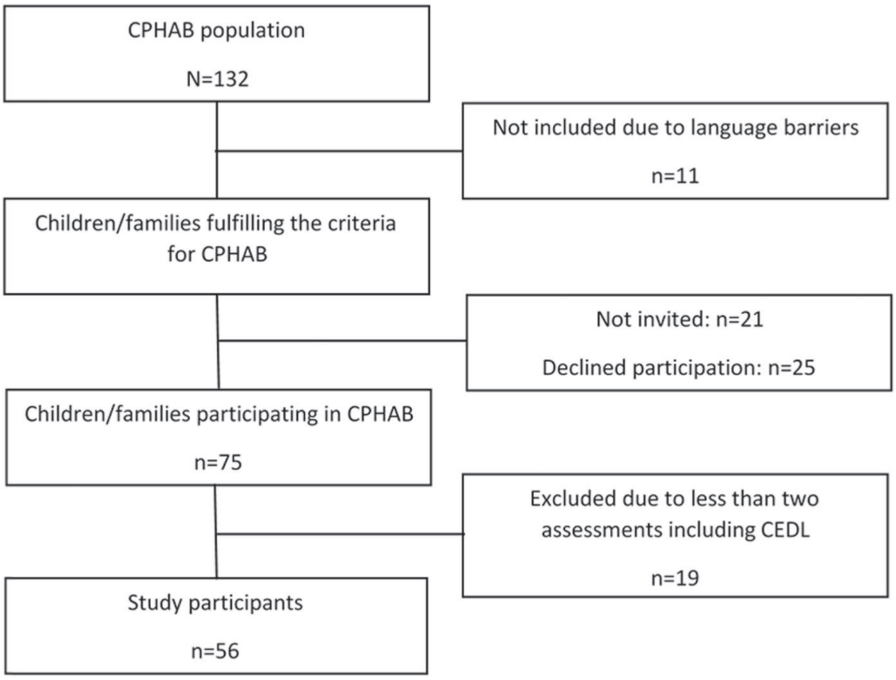

Figure 1. The inclusion/exclusion process.

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 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-variates 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, *n* (%)	
Male	34 (61)
Female	22 (39)
Age in months, median (range)	30 (12–56)
Subtype CP (*n*, %)	
Unilateral	25 (45)
Bilateral	30 (53)
Other	1 (2)
GMFCS level (*n*, %)	
Level I	28 (50)
Level II	7 (12))
Level III	11 (20)
Level IV	10 (18)
MACS level (*n*, %)	
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)	*p* Value	Median (range)	GMFCS and MACS levels	Median (range)	*p* 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 GMCFS and MACS levels.

Family and recreational activities	Median (range)	GMFCS levels	Median (range)	*p* Value	MACS levels	Median (range)	*p* 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 (3–59		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)	*p* Value	MACS levels	Median (range)	*p* 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

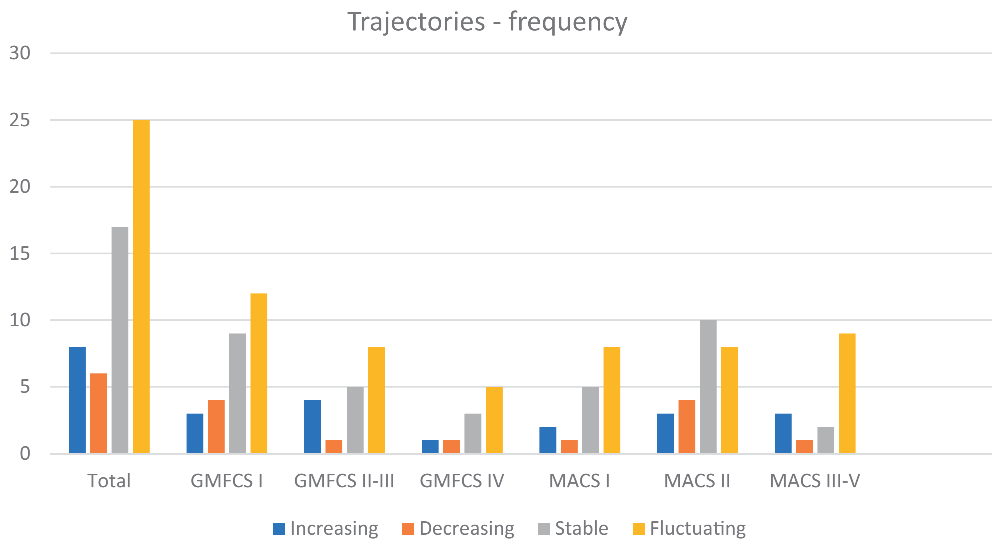

Figure 2. Number of children representing different trajectories of frequency in relation to gross motor and hand function. GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System.

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	*p* 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 adaptions 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 adaptions 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 adaptions 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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Article III

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Comprehensiveness, Coordination and Continuity in Services Provided to Young Children with Cerebral Palsy and Their Families in Norway

Runa Kalleson [a], Reidun Jahnsen [b] and Sigrid Østensjø [c]

[a]Faculty of Health Sciences, Department of Physiotherapy, OsloMet – Oslo Metropolitan University, Oslo, Norway; [b]Oslo University Hospital (OUS), University of Oslo (UiO), Oslo, Norway; [c]OsloMet – Oslo Metropolitan University, Oslo, Norway

ABSTRACT

Background: Cerebral palsy (CP) is one of the most common childhood disorders requiring comprehensive and coordinated care over time. This study aimed to add knowledge about health, educational and social services received by children and families throughout early childhood, with special attention on coordination services provided.

Methods: The study was designed as a prospective longitudinal cohort study utilising data from two CP registers in Norway. Fifty-seven families with children with CP aged 12–57 months with different levels of mobility limitations classified according to the Gross Motor Function Classification System were included. Services were mapped via the parent-reported Habilitation Service questionnaire at least three times. The relationships between mobility limitations and the number of services and type of coordination services were explored using a linear mixed model and Chi Square/Fischer's exact test. Continuity in the provision of services was explored by identifying interruptions in the longitudinal reports on services received.

Results: Most of the families received both health, education and social services as well as some types of coordination services. The number and type of services received varied to some extent depending on the children's mobility limitations. Multidisciplinary team and an individual service plan were widespread coordination services, while having a service coordinator was most common among the families raising a child with severe mobility limitations. Interruptions in the longitudinal reporting of services were frequent, especially in the receiving of coordination services.

Conclusion: The comprehensiveness of the provided services emphasises the need for coordination services. The relatively low proportion of families provided with a coordinator and the frequent interruptions in the longitudinal reports on services indicate some persistent challenges in the service system.

KEYWORDS
Cerebral palsy; early childhood; service provision; child-directed services; family-directed services and benefits; comprehensive care; coordination; continuity of care

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

Introduction

Improving the quality of care for children with complex disabilities and their families is a persistent objective in rehabilitation services. Cerebral palsy (CP) is the most common childhood motor disorder, characterised by impairments in movement and posture that lead to varying degrees of mobility limitations (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). Several additional conditions are commonly seen, including disturbances of sensation, cognition, communication and behaviour, as well as seizure disorders and musculoskeletal complications (Rosenbaum et al., 2007). This implies that most children with CP require long-term multidisciplinary care involving both health and educational services. The family holds a unique position in the follow-up of young children with disabilities, and in line with a family-centred approach, child-directed services are expected to be accompanied by services aimed at supporting the entire family.

When the multiple services provided for children with disabilities exceed organisational boundaries, there will be a need for service coordination in order to effectively provide family-centred care (G. King & Chiarello, 2014) and ensure coherence and continuity in the provision of services (Reid et al., 2002). In Norway, two types of coordination services have been established as statutory for everyone in need of coordinated long-term services: being entitled to a service coordinator and an individual service plan (ISP) (Ministry of Health and Care Services, 2011). A service coordinator plays a key role in childhood rehabilitation by helping families navigate a complex service system (Trute, 2007), and he or she is assigned the responsibility for the child's ISP (Ministry of Health and Care Services, 2011). A well-functioning ISP has proven to have the potential to increase empowerment (Holum, 2012) and participation in collaborative processes (Hedberg et al., 2018; Holum, 2012) and may provide an efficient way of working in multidisciplinary teams (Hedberg et al., 2018). Such teams have long traditions in Norway beyond statutory services and have been associated with high levels of parental empowerment (Kalleson et al., 2019). However, the extent to which families raising a child with CP receive these services and the way in which the type of coordination service relates to child age and mobility have not been previously explored.

Another important aspect of quality of care is the sustained continuity of services over time (World Health Organization, 2018). Even though there is general agreement that continuity is a quality indicator for rehabilitation services (World Health Organization, 2018), there is a striking lack of studies exploring the provision of services for children with disabilities and their families within a longitudinal perspective.

As far as we know, this is the first study that systematically maps health, education, social and coordination services provided to children with disabilities and their families over time. The study aims to increase knowledge about the comprehensiveness, coordination and continuity of care for children with CP and their families during early childhood. Three specific research questions are addressed:

(1) How comprehensive are the child- and family-directed services that young children with CP and their families receive, and is there a relationship between the number of services received and the child's age and the severity of mobility limitations?
(2) What kind of coordination services do the families receive, and does the type of service differ based on the severity of the child's mobility limitations?
(3) How continuous is the provision of services during early childhood?

Methods

Study Design and Participants

The study was designed as a prospective longitudinal cohort study based on 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). The CPOP is an ongoing national registry monitoring motor function and related interventions, and CPHAB was developed as an additional research registry conducted as a project from 2012 to 2016. It included parent-report questionnaires mapping extended child functioning, aspects of the family situation and the child- and family-directed services received. The inclusion criteria of CPHAB, and thus this study, were children with CP who were four years or younger when registered for the first time in the CPOP between January 2012 and December 2014, as well as parents capable of answering questions in Norwegian or English. Thirteen of the twenty-one pediatric rehabilitation units in Norway participated in the CPHAB project, which represented small, medium and large units spread over large parts of the country. A total of 132 children were registered in these units during the inclusion period of CPHAB. Of these, eleven families were excluded due to language barriers. Twenty-one families were not invited to participate in CPHAB, mainly due to a lack of resources at the rehabilitation units. Twenty-five families declined participation, and 18 families were excluded from the present study due to returning incomplete questionnaires or completing fewer than three assessments. Ultimately, 57 families were included in the study (see Figure 1). The families completed the CPHAB questionnaires in conjunction with their child's regular follow-up at the rehabilitation units twice a year during the first two years of follow-up, and thereafter once or twice a year according to the families' own preferences.

Questionnaires

Child characteristics, including age, subtype of CP and gross motor functioning, were retrieved from the CPOP registry. The subtypes of CP were spastic (unilateral or bilateral), dyskinetic and ataxic (Cans, 2000). Gross motor functioning was classified according to the five levels of the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997), where level I represents the least severe mobility limitations and level V represents the most severe limitations. According to the GMFCS children at level I are expected to be able to walk without limitations, children at GMFCS level II will be able to walk in most settings, but with some limitations for instance on uneven surfaces and in crowds, children at level III may walk with a hand-held mobility device and prefer to use a wheelchair or powered mobility outdoor and in the community, at level IV children use wheeled mobility in most settings, while children at level V have severely limited self-mobility and a need for extensive help in most areas. The GMFCS has demonstrated good reliability, predictive validity and stability (Alriksson-Schmidt et al., 2017; Palisano et al., 2000; Wood & Rosenbaum, 2000).

Family concerns about their financial situations and housing and information about children attending kindergarten were retrieved from the Norwegian version of the "Parental Account of Children's Symptoms" questionnaire (Taylor et al., 1986) included in the CPHAB registry.

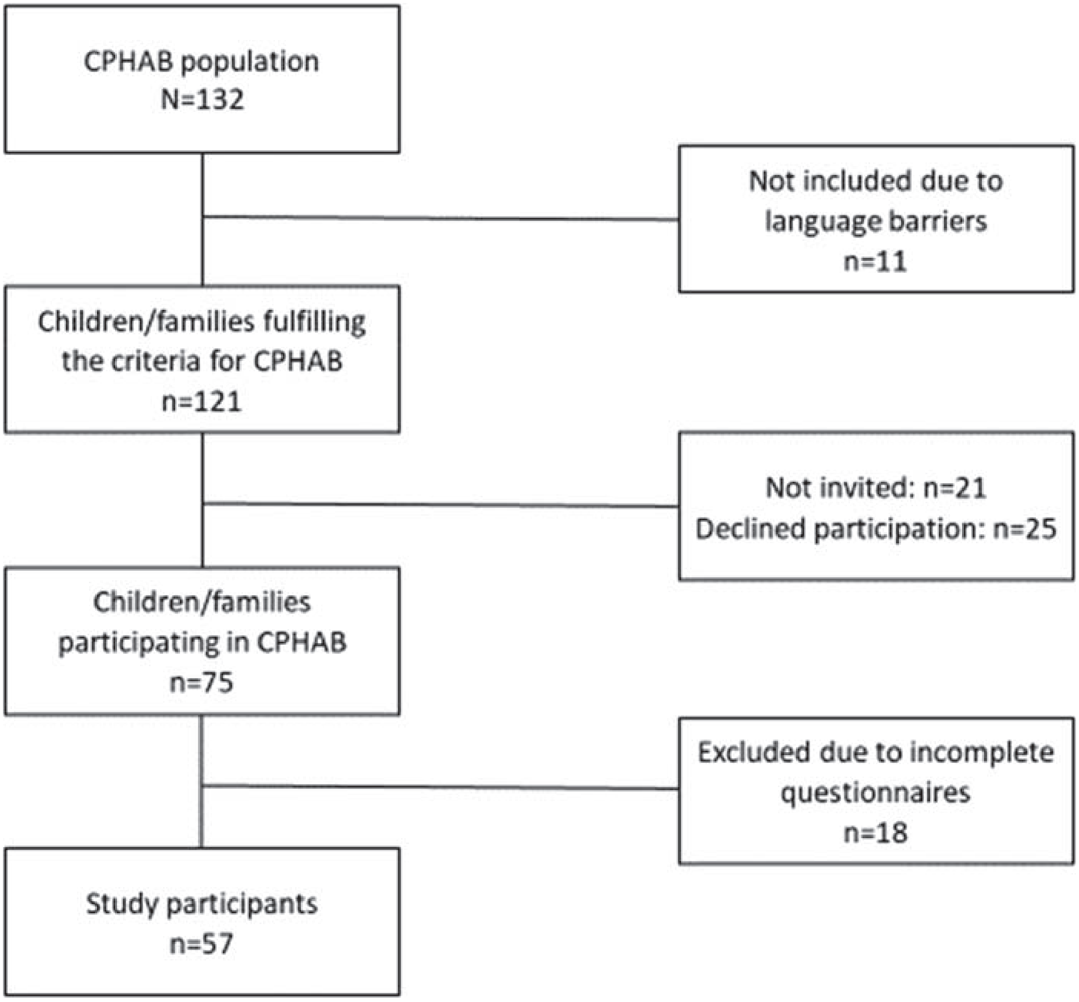

Figure 1. The inclusion process.

Information about services received was retrieved from the Habilitation Service questionnaire (HabServ) included in the CPHAB registry. This questionnaire has previously been used in four studies (Kalleson et al., 2019; Klevberg et al., 2017; Myrhaug et al., 2016; Myrhaug & Østensjø, 2014). In the present study, parental reports on the child- and family-directed services received in the preceding six months were utilised. A description of the Norwegian social services and benefits included in the questionnaire is provided in Table 1.

Statistical Analysis

All analyses were performed in IBM SPSS Statistics 26. Descriptive statistics were compiled for the relevant child characteristics and aspects of the family situation. The number and percentage of families receiving each of the included child- and family-directed services and benefits during the project period were calculated. Due to a small number of families receiving personal assistant ($n = 3$) and support contact ($n = 1$), these services were merged into the category “respite care services”, together with respite care home. A linear mixed model was used to explore the relationships between the number of services reported at each assessment and the child’s age and mobility limitations, which

Table 1. Overview of social services and benefits for families raising a child with chronic illness or disability.

Respite care home:	Planned temporary care provided to families with heavy care loads, taking place in private homes, in the home of the client or in sheltered housing or institutions. Applied for in the municipality. Legislation: The Health and Care Services Act.
Personal assistant:	A person, working for an individual user (or family), where the user/family works as the manager, deciding the form and content of the service. Applied for in the municipality. Legislation: The Health and Care Services Act.
Support contact:	A person aiming to help clients have meaningful leisure time and social contact by accompanying the client to leisure-time activities. Applied for in the municipality. Legislation: The Health and Care Services Act.
Training allowance	Allowance aiming to compensate for loss of income if parents must attend a course or other training necessary to care for a child with a chronic illness or disability and arranged by a health institution and special education competence center. Applied for at The Norwegian Labor and Welfare Administration (NAV). Legislation: The National Insurance Act.
Attendance allowance	Allowance universally available to families with a child in need of extra care and supervision due to illness, injury or disability. The extent of care needed will determine the rate granted. Applied for at NAV. Legislation: The National Insurance Act.
Caregiver benefit	Benefit aiming to compensate the caregivers for the extra care load by raising a child with disability. The benefit is considered and decided in connection with other services provided to the families. Applied for in the municipality. Legislation: The Health and Care Services Act.
Basic benefit	Benefits aiming to compensate for costs incurred due to the child's disability. Applied for at NAV. Legislation: The National Insurance Act.
Car subsidies	Subsidies available to persons experiencing problems with public transport due to a severe motor disability. Applied for at NAV. Legislation: The National Insurance Act.
Housing grants	Grants aiming to improve accessibility in the homes of persons with disability. Applied for at The Norwegian State Housing Bank.

could be grouped as mild (GMFCS level I), moderate (GMFCS levels II and III) or severe (GMFCS levels IV and V).

The number and percentage of families receiving each of the three coordination services, coordinator, ISP and multidisciplinary team, were calculated. The relationships between the type of coordination service received and the child's mobility limitations were explored by performing a Chi-Square test for independence and Fischer's exact test.

Most services and benefits were expected to remain continuous throughout preschool age. When a previously received service or benefit was not reported by the parents on the following assessment(s), this was identified as an *interruption*. For each of the services and benefits for which continuity was expected, the number and percentage of participants with interruptions in their follow-ups were calculated. Intensive rehabilitation programmes; parent training/courses; and some financial benefits, such as training allowances, car subsidies, and housing grants, were all expected to be periodic in nature and were, in consequence, excluded from these analyses.

Results

Participating families completed the questionnaires between three and six times (median four) within a time period of 12–43 months (median 27 months). Table 2 shows that the child's age at the first assessment ranged from 12 to 57 months (median 27). Almost half of the children was classified at the GMFCS level I, which indicates the least restricted mobility, while the functioning of the remainder of the children was distributed across GMFCS levels II–V. The number of additional impairments ranged from zero to seven, with about half of the children having at least one additional impairment. All children except one were attending kindergarten at least three days per week. More than one-

Table 2. Child characteristics and family situation.

Child characteristics, *n* = 57	
Age in months at first assessment, median (range)	27 (12–57)
Gender, n (%)	
Male	37 (65)
Female	20 (35)
CP subtype, n (%)	
Spastic unilateral	23 (40)
Spastic bilateral	33 (58)
Ataxic	1 (2)
GMFCS level, n (%)	
I	25 (44)
II	6 (11)
III	11 (19)
IV	11 (19)
V	4 (7)
Additional impairments, median (range)	1 (0-7)
Additional impairments: Distribution of types, n (%)	
Communication	24 (42)
Vision	22 (39)
Cognition	19 (33)
Epilepsy	10 (18)
Behaviour	8 (14)
Hearing	5 (9)
Respiration	4 (7)
Any other serious condition	7 (12)
None	29 (51)
Children attending kindergarten 3–5 days a week, n (%)	
Yes	56 (98)
No	1 (2)
Financial concerns, n (%)	
Yes	22 (39)
No	35 (61)
Concerns about the housing situation, n (%)	
Yes	28 (49)
No	29 (51)

third of the families reported financial concerns, and almost half of them reported concerns about their housing situation during the child's early years. Thirty-two families (56%) reported having concerns about either their financial situation or housing at least once during their children's early years.

Child-directed and Family-directed Services Received

Regarding child-directed services, all the children reported receiving physiotherapy (PT), the great majority received help from a kindergarten assistant and/or special education teacher and about two-thirds received occupational therapy (OT). More than half of the children attended intensive rehabilitation programmes during their early years (see Figure 2).

Among family-directed services, the most common services were parent training and courses, which were received by more than three-quarters of the parents during the children's early years. The training and courses were centred around the CP diagnosis and its consequences, child-directed interventions (motor training, play and stimulation, augmentative/supplementary communication), working processes (goal setting, ISP) and family issues (parenting, rights of families with a disabled child). Among potential

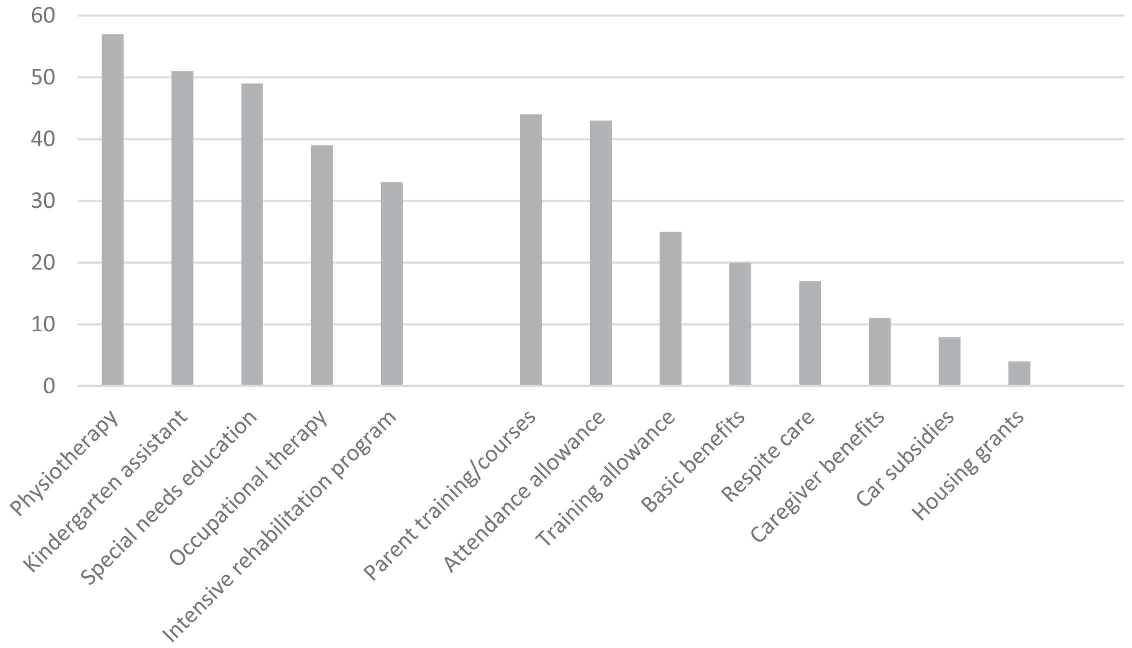

Figure 2. Number of families receiving child- and family-directed services and benefits during early childhood.

financial benefits, an attendance allowance was the most frequently reported service, followed by a training allowance and basic benefits. Less than one-third of the families received respite care services, and only a small minority received caregiver benefits, car subsidies, or housing grants.

In total, 49 out of the 57 participating families (86%) received both child- and family-directed services, while eight families received only child-directed services during the child's early years. Number of services and benefits received in the preceding six months ranged from zero to fourteen per assessment, with an average of 5.6 (SD 2.7). No association was found between the number of services received and the child's age (see Table 3). In contrast, the results showed that child mobility was associated with the number of services provided. Families raising a child classified at GMFCS level I (least limitations) received significantly fewer services than families having a child with moderate (GMFCS levels II–III; $p = 0.02$) and severe mobility limitations (GMFCS levels IV–V; $p = 0.00$). *Post-hoc* analyses setting families with children classified with the most severe mobility limitations (GMFCS levels IV–V) as redundant revealed no statistically significant differences between this group and the group of families raising children with moderate mobility limitations (GMFCS levels II–III; $p > 0.05$).

Table 3. Relationship between number of services received and the child's age and GMFCS level.

Child characteristics	Estimate	*P*-value	95% CI
Child's age (in months)[1]	0.01	0.55	−0.01–0.03
GMFCS level			
GMFCS level I (reference)			
GMFCS level II–III	2.00	0.02*	0.76–3.24
GMFCS level IV–V	2.56	0.00*	1.28–3.85

[1] Adjusted for the child's GMFCS level.
*$p < 0.05$.

Coordination Services

In total, 52 out of 57 families (91%) reported receiving one or more coordination services. Having a multidisciplinary support team and an ISP were the most widespread type of coordination services and were received by about 80% of the families, while only about one-third reported having a service coordinator (see Figure 3). Eighteen families (31%) received all three types of coordination services, 25 families (44%) received a combination of a multidisciplinary team and an ISP, nine families (16%) received only a multidisciplinary team or an ISP as the only coordination service and five families (9%) received none of the services.

The families receiving an ISP and a multidisciplinary support team were quite evenly distributed across the children's mobility levels. Fischer's exact test indicated no significant associations between the child's mobility limitations and families receiving an ISP ($p = 0.55$) or multidisciplinary team ($p = 0.12$). Regarding having a service coordinator, however, a Chi-Square test for independence revealed significant association between the child's mobility limitations (classified according to GMFCS levels) and having a coordinator ($p = 0.01$). Two-thirds of the families raising children with the most severe mobility limitations (GMFCS levels IV–V) reported having a coordinator, while less than one-third of the families with a child classified with less severe limitations (GMFCS levels I, II or III) reported the same.

Interruptions in the Continuity of Services and Benefits

Interruptions in coordination services were widespread among those having a service coordinator (70% of the families) and an ISP (60%), whereas they were less frequently identified in those receiving a multidisciplinary support team (33%). Regarding family-directed services and benefits, the interruption rate was highest among those receiving basic benefits (45%). Among the child-directed services, interruptions were most commonly identified among those receiving OT (almost half of the families) and

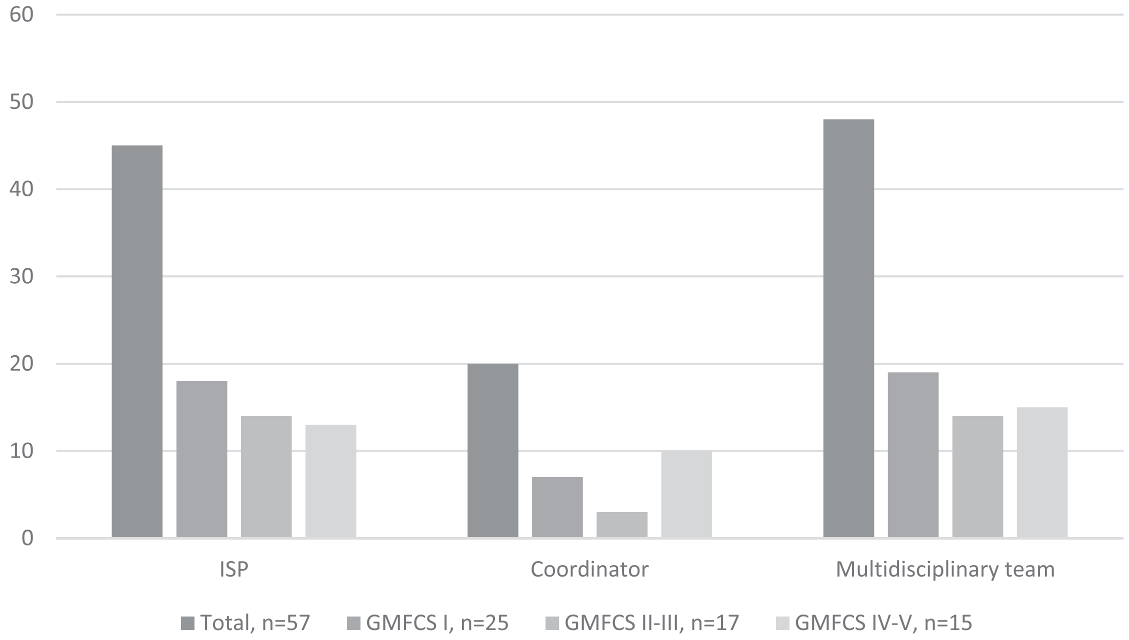

Figure 3. Number of families receiving coordination services based on the child's GMFCS level.

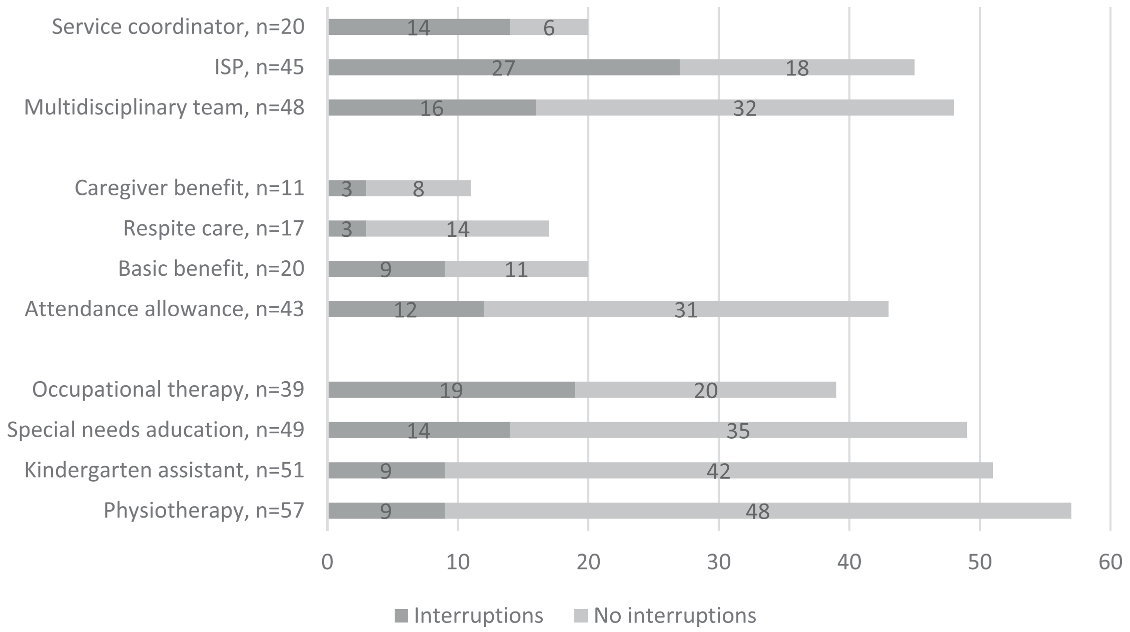

Figure 4. Number of families with interruptions in the longitudinal reporting of coordination services, family-directed services and child-directed services.

special education (more than one-fourth). Regarding family-directed services and benefits, the interruption rate was highest in those receiving basic benefits (45%) (Figure 4).

Discussion

This study confirms that children with CP are supported by a welfare system recognising the complex needs of children and families. The comprehensiveness of services corresponds well with a bio-ecological perspective on child development (Bronfenbrenner & Morris, 2006) and a family-centered approach to childhood rehabilitation (Dempsey & Keen, 2008). However, some challenges were revealed regarding the coordination of services and longitudinal continuity in service provision.

Most families reported receiving a variety of child- and family-directed services. However, the number of services received varied greatly. Families raising children with minor mobility limitations (GMFCS I) received significantly fewer services than families raising children with moderate (GMFCS II–III) or severe limitations (GMFCS IV–V). This may indicate that the burden of caring for a child with mild mobility limitations does not differ much from of care what is expected for all families raising young children, whereas more extra services are needed when the child´s disability is more pronounced. The severity of mobility limitations is found to be associated with several additional impairments, such as disturbances of cognition, vision, hearing, speech, and epilepsy (Delacy & Reid, 2016), which may reinforce the need for more comprehensive services among families raising a child with mobility limitations classified at GMFCS levels II–V compared with those at level I. However, the lack of difference in the number of services received between children with moderate and severe mobility impairment indicates that service needs are affected by more than motor function. Thus, the interplay between motor functioning and additional impairments and aspects of the family situation must be considered when services are planned and provided in a rehabilitation context.

The finding that there was no significant association between the number of services received and the child's age indicates that the need for services persists through the child's early years. While children without disabilities increase their mobility and independence relatively quickly, this is not the case for children with complex disabilities. This difference may explain why some children with disabilities will continue to need more extensive help in everyday situations in a long-term perspective.

Regarding child-directed services, all children received physiotherapy (PT), the great majority reported receiving special education and a kindergarten assistant and more than two-thirds received occupational therapy (OT). This finding highlights the need for cooperation across organisational boundaries in order to efficiently promote child development, learning and well-being.

When it comes to family-directed services, training and courses were the most widespread and were received by more than three-quarters of the families. This corresponds well with a family-centred approach in pediatric rehabilitation, focusing on parent competence and involvement in interventions (S. King et al., 2004). Almost as widespread was the receipt of the financial benefit known as an attendance allowance, which aims to compensate for the need for extra care and supervision due to the child's limitations in performing everyday activities and expectations of parental involvement in different interventions. The finding draws attention to the burden of raising a child with a disability like CP. As many as one-third of the parents received respite care, which indicates that even families with a young child must be relieved of their care situations sometimes.

Although some family-directed services appear to be quite widespread, it is worth noting that the percentage of families receiving some of the available financial benefits was low. The most striking example was the low number of families receiving housing grants, especially considering that almost half of the families reported concerns about their housing. Whether this is due to lack of information or an application being rejected could not be revealed by the study. It has been documented that a large percentage of municipalities do not offer housing grants, even if they have been allocated funds by the Norwegian State Housing Bank (Proba Research, 2014). Housing grant in Norway is a means-tested benefit based on an assessment of the family's overall financial situation. In Sweden, where subsidies for housing adaptations are right-based instead of means-tested, it seems that such services are more widespread in use (Proba Research, 2014). In any case, the frequent reporting of concerns about finances and housing during the child's early years emphasises the need for social services to support and strengthen parents in caring for their child.

The multiple services involved in caretaking for children with CP and their families highlight the need for coordination services to support collaboration among service providers within and across organisational units (Reid et al., 2002). The coordination of services is considered a prerequisite for providing effective family-centred care (G. King & Chiarello, 2014) and has been a prioritised area of health policy in Norway for nearly two decades (Ringard et al., 2013). This is reflected in the study, revealing that most families receive one or more types of coordination services, independent of the severity of the child's mobility limitations. However, compared to having an ISP or a multidisciplinary team (about 80%), being assigned a coordinator is far less widespread (35%). This difference is notable because the coordinator is assigned the responsibility for the planning and follow-up for the ISP (Norwegian Directorate of Health, 2015). The discrepancy between reporting having a coordinator and the other types of coordinating services may be substantial; however, it could also be seen an under-reporting due to unclear boundaries and overlapping roles, for instance, when the child's physiotherapist also holds the role of coordinator (Appleton et al., 1997), as has been identified as a problem in previous studies (Hannigan et al., 2018; Alve et al., 2013; Nilsen & Jensen, 2012).

In contrast to having a multidisciplinary team and an ISP, being assigned a service coordinator was significantly related to the child's mobility limitation severity. Two-thirds of families raising children with the most severe limitations (GMFCS IV–V) reported having a coordinator, as compared with less than one-third of the families raising children with mild to moderate limitations (GMFCS I–III). This indicates a more pronounced need for a dedicated person to help families navigate the service system when the child's motor limitations are extensive, especially given the relationship between the severity of mobility limitations and the number of additional impairments (Delacy & Reid, 2016).

Another important aspect of coherent and integrated care is sustained continuity in service provision over time (World Health Organization, 2018). Some rehabilitation services included in the study were expected to be periodic during early childhood, such as an intensive rehabilitation programme, parental training and grants for the current home or car. Other services were expected to be provided more or less continually. Among those, relatively few interruptions were identified in PT and kindergarten assistant, while interruptions were more frequently seen for OT and special education services. The interruptions may be explained by planned periodic involvement, and they thus do not necessarily represent a problem or a challenge in the service system. However, previous research indicates that continuity in the provision of therapies seems to be the preferred service model from a parental perspective (Beresford et al., 2018).

Frequent interruptions were also identified for several of the family-directed services and benefits. As Demiri and Gundersen (2016) have documented in a review of the familieś experiences with health and social services in Norway, there are several challenges associated with the process of gaining access to services, such as the need for repeated applications. From the parents' perspective, repeated applications were perceived as both time-consuming and demanding, and expressed as an ongoing struggle (Demiri & Gundersen, 2016). Such negative experiences may have prevented some families from applying for social services and benefits on some occasions.

Interruptions were surprisingly widespread among coordination services, being identified in one-third of the families with a multidisciplinary support team, more than half of the families with an ISP and more than two-thirds of the families with a service coordinator. Previous research has revealed multiple barriers when service coordination is to be implemented in healthcare (Hannigan et al., 2018; Holum, 2012; Nilsen & Jensen, 2012). In a Norwegian context, one previously identified challenge is the ISP ultimately becoming a "desk document" instead of a "live document" (Nilsen & Jensen, 2012). The existence of an inactive plan may explain why some parents did not report having an ISP in the six months preceding an assessment. Challenges are also reported regarding the implementation of a service coordinator (Nilsen & Jensen, 2012). In some cases, the coordinator does not have sufficiently in-depth knowledge of the child and family situation or is not actively involved in the regular follow-up, leading to more irregular and infrequent encounters with the families (Nilsen & Jensen, 2012). The interruptions in coordination services recognised in the present study complement previous research and support a call for quality improvements in such services (G. King & Chiarello, 2014).

The study was exploratory in nature and aimed to increase the understanding of the complex services offered to young children with CP and their families in a longitudinal perspective. However, the study has certain limitations. First, by using registry data based on a mapping of services, information that went beyond descriptions of services received was not available. For instance, the questionnaires included were not designed to reveal the reasons for *not* receiving a service, which restricted possibilities for linking perceived needs to the services received. Further, whether parents perceived the interruptions in services received as a lack in continuity in care was not possible to explore with the available data. This points to the need for further research to deepen the knowledge about the service provision and how it is experienced by the families.

Another limitation was that 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 service trajectories. This limitation implies the use of larger samples in forthcoming quantitative studies.

It should also be noted that the percentage of children at each GMFCS level differed somewhat from the total population of children with CP in Norway, with fewer participants being classified at GMFCS I (44% compared with 53%) (CPRN/CPOP Annual Report 2019). Because the study indicates that families raising children at GMFCS level I receive fewer services than other families, the average number of services and the percentages of families receiving each of the services may have been slightly higher than would have been expected with a more representative sample in terms of GMFCS levels.

In conclusion, the widespread provision of child- and family-directed services indicates a holistic approach in the service system. Multiple services crossing organisational borders indicate the need for the coordination of services to ensure family-centred and coherent care. While multidisciplinary teams and ISPs were frequently reported, the low proportion of families reporting having a service coordinator raises concerns about the implementation of this service in a rehabilitation context. Furthermore, the frequent interruptions in several services draw attention to longitudinal continuity as a persistent concern in childhood rehabilitation. Thus, both coordination and continuity in service provision appear to be areas in need of quality improvement and further research.

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Ethics and Consent

Participation in the CPHAB project was voluntary. 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).

Notes on contributors

Runa Kalleson, PT, M.Sc, ph.d. student.

Reidun Jahnsen, PT, ph.d., professor.

Sigrid Østensjø, PT, ph.d., professor.

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

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