Intensive Group Training in a Local Community Setting for Children with Cerebral Palsy

Methodological Aspects and Change in Motor Functioning

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Summary

The purpose of this thesis was to examine measurement properties of three outcome measures of motor function for children with cerebral palsy (CP), and to investigate change in their motor functioning following three weeks of intensive, activity-focused and goal-directed physiotherapy in a group setting.

A portable electronic walkway has been found feasible and reliable when measuring gait parameters in adults with neurological disorders and in children with typical development, but measurement properties of the assessment tool have not been examined in children with CP. Test-retest reliability of gait parameters from the electronic walkway was investigated in 17 children with CP. A defined procedure to calculate speed dependent gait parameters at a normalised gait speed was used. In a short time span, the electronic walkway was found to be highly reliable for assessing gait parameters in children with CP.

A subsequent study examined the inter-observer and intra-observer reliability of two quality of movement measures when scored from video clips. Quality of movement measures can be challenging and time consuming to score in a clinical setting due to the complexity of the construct. The impact of quality of movement on motor development has been sparsely investigated, but good quality is presumed by many professionals to increase efficiency and safety of activities and decrease efforts in children with CP. Hence an efficient way of assessing quality of movement seems important. Twenty-six children with CP participated in a reliability testing of the Gross Motor Performance Measure (GMPM) and the Quality of Upper Extremity Skills Test (QUEST). Performance of the test items were videotaped, edited and independently scored by two assessors on two occasions. The intra-observer and inter-

observer reliability of the total scores of the two measures were found satisfactory, and the total scores can thus be recommended for research use. Reliability, however, was not satisfactory for the sub-scales and single items, and cannot be recommended for use as separate measures.

The above three measures quantify different aspects of motor functioning in children with CP and were found to be reliable and feasible for use in clinical research, including research carried out as multicentre studies.

There is little scientific knowledge about the optimal type, dosage and onset of physiotherapy for children with cerebral palsy. Recent work has indicated that more intensive, goal-directed and functional training than commonly offered by physiotherapists might be beneficial. Furthermore, there is little knowledge about the impact of movement quality on motor development in children with CP. The third study investigated change of motor functioning in children with CP who participated in intensive, activity-focused and goal-directed physiotherapy in a group setting for the first time.

Twenty-two children aged three to nine years in five training groups from different places in Western Norway participated in the study. A repeated measures design was applied with three baseline measurements before and two follow up measurements after the intervention. The intervention aimed to attain individual goals regarding basic motor abilities and motor abilities in everyday activities, and consisted of three hours of physiotherapy, five days a week for a three-week period. After the intervention period, the children had gained significant improvements in basic motor abilities assessed by the Gross Motor Function Measure (GMFM) and high attainment of predetermined individual goals was found. The children's parents reported significant improvement in the children's ability to perform self-care activities in the

home environments and a decreased need for caregiver assistance in mobility and self-care activities assessed by the Pediatric Evaluation of Disability Inventory (PEDI).

A positive trend in improved quality of movement as measured by the Gross Motor Performance Measure (GMPM) and Quality of Upper Extremity Skills Test (QUEST) was revealed, but not statistically significant. A significant improvement in movement quality was found in items of the GMFM which improved during the study period, but not in items that reminded stable. Thus, acquisition of gross motor functions seemed to be related to better quality of movement, however, more research is needed to substantiate this observation.

The intensive physiotherapy training in a group setting was experienced as fun and motivating, even though the children and their families also found the training period strenuous. Defined periods of intensive, focused training to attain specific goals seem to be a feasible way of optimising motor functioning in children with CP.

List of papers

The present thesis is based on the following original articles:

I Sorsdahl AB, Moe-Nilssen R, Strand LI.
Test-retest of spatial and temporal gait parameters in children with cerebral palsy as measured by an electronic walkway.
Gait and Posture. 2008; 27: 43-50.

II Sorsdahl AB, Moe-Nilssen R, Strand, LI.
Observer Reliability of the Gross Motor Performance Measure and the Quality of Upper Extremity Skill Test, based on Video Recordings.
Developmental Medicine and Child Neurology. 2008; 50: 146-151.

III Sorsdahl AB, Moe-Nilssen R, Kaale HK, Rieber J, Strand LI.
Change in basic motor abilities, quality of movement and everyday activities following an intensive activity-focused goal-directed physiotherapy program in a group setting for children with cerebral palsy.
BMC Pediatrics. 2009 (under review after revisions have been performed).

Table of contents

Abbreviations

AACPDM	American Academy for Cerebral Palsy and Developmental Medicine
ANOVA	Analysis of variance
CIMT	Constrained Induced Movement Therapy
CP	Cerebral Palsy
GAS	Goal Attainment Scaling
GMAE	Gross Motor Ability Estimator
GMFCS	Gross Motor Function Classification System
GMFM	Gross Motor Function Measure
GMFM-66	Gross Motor Function Measure 66-item version
GMFM-88	Gross Motor Function Measure 88-item version
GMPM	Gross Motor Performance Measure
ICC	Intraclass Correlation Coefficient
ICF	International Classification of Functioning, Disabilities and Health
ICF-CY	International Classification of Functioning, Disabilities and Health - Children and Youth Version
MACS	Manual Ability Classification System
MTSCI-1	Motor Teaching Strategies Coding Instrument
MIC	Minimal Important Change
NDT	Nevrodevelopmental therapy
OT	Occupational Therapist
PEDI	Pediatric Evaluation of Disability Inventory
PT	Physiotherapist
QUEST	Quality of Upper Extremity Skills Test
RCT	Randomised Controlled Trials
SCPE	Surveillance of Cerebral Palsy in Europe
SDD	Smallest Detectable Difference
S_w	Within subject standard deviation
WHO	World Health Organisation

Definitions

Definitions of concepts used in the thesis and/or in the articles:

Anti-spastic medication: Medication given to reduce muscle tone, e.g. Botulinum toxin type A given as injection in muscles, and Baclofen given through an infusion pump [1].

Basic motor abilities: Basic abilities like rolling, crawling, sitting and walking [2].

Bonferroni adjustment: Adjustment of the chosen level of significance due to multiple comparisons. The selected significance level is divided by the number of tests to obtain a more stringent p-value [3].

Coefficient of determination (R^2): An indication of the percentage of variance that is shared by two variables [3].

Condition-specific measure: Measurement tool designed to document the status of individuals having a specific diagnosis or condition [3].

Construct validity: The ability of a measure to converge with other indicators or measures of the same construct and discriminate unrelated indicators or measures [4].

Content validity: The extent to which the components (items) of the scale cover all aspects of the attribute to be measured, in a balanced way [4].

Criterion validity: The extent to which a measure correlates with a pre-existing one of the same concept, preferable a “gold standard” [4].

Criterion referenced measure: A measure where there is an external criterion against which people are judged [5].

Effectiveness: The extent to which a specific intervention, procedure, regimen, or service does what it is intended to do for a defined population [6].

Efficacy: The extent to which a specific intervention, procedure, regimen, or service produces a beneficial result under ideal conditions [6].

Everyday activities: Activities like mobility, self-care, social function and play in daily environments [7].

Feasibility: The ability to use the measure within its application area e.g. in terms of cost, training, equipment and respondent burden [6].

Functioning: An umbrella term encompassing all body functions, activities and participation [8].

Generic measures: Measures that have been developed to measure constructs that are relevant to the general population [5].

Habilitation: A process aimed at enabling persons with disabilities to reach and maintain their physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation [9].

Heteroscedasticity: An assumption in regression analysis that the residuals at each level of the predictor variable(s) have unequal variances [10].

Homoscedasticity: An assumption in regression analysis that the residuals at each level of the predictor variable(s) have equal variances [10].

Intra-observer reliability: The extent to which repeated observations of a single observer agree [11], often expressed as a correlation coefficient.

Inter-observer reliability: The extent to which observations of the same thing made by more than one observer agree [11], often expressed as a correlation coefficient.

Motor Function: In this thesis motor function is used as an umbrella term encompassing the motor aspects of body functions, activities and participation, including quality of movements, gross motor function and hand motor function.

Minimal Important Change (MIC): Minimal change that is seen important [12], also named Minimal Clinically Important Difference (MCID) [6]. Expressed as cut off point in measurements, or via parents, children's and/or professionals judgement [13].

Prevalence: The proportion of a given population experiencing a condition at a given time e.g. the current cases in a population [11].

Quality of movement: An aspect of a motor activity e.g. coordination or stability [14].

Rasch analysis: Using a set of items from a sample the analysis produces an interval scale that estimates the difficulties of the items (item difficulty) and the abilities associated with total raw score (child ability) [15].

Reliability: The extent to which measurements are repeatable [3]. Different types of reliability exist e.g. inter-observer, intra-observer and test-retest reliability.

Responsiveness: The ability of a measure to detect clinically important change over time, even if these changes are small [12].

Smallest detectable difference (SDD) [16]: The limit of change an individual has to exceed to say there is a change beyond measurement error [3], also named Minimal Detectable Difference (MDD)[17], Minimal Detectable Change (MDC) [6] or Smallest Detectable Change [12]. Based on S_w the SDD between two measurements for the same subject can be

calculated using the equation $\sqrt{2} \times 1.96 \times S_w = 2.77\ S_w$ for 95% of pairs of observations [18].

Sphericity: The extent to which all differences between pairs of scores are equally variable [19].

Standardised measure: A published measurement tool, designed for a specific purpose in a given population, with detailed instructions provided on administration and scoring and the results of reliability and validity testing published in peer-reviewed journals [6].

Test-retest reliability: The extent to which repeated applications of a test provide consistent results [6].

T-score: Standardised score from the raw scores, e.g. with a mean of 50 and standard deviation of 10 [5].

Validity of a measure: Concerns what a test measures and how well it does so [20]. Different types of validity exist e.g. construct, content and criterion validity.

Validity of a study: The extent to which the conclusions are believable and useful [3]. Internal validity concerns whether other than the independent variable could be related to changes in the dependent variable, whereas external validity concerns the generalizability of the results.

Within subject standard deviation (S_w): Standard deviation of repeated measurements on the same subject [18]. Also named Standard Error of Measurement (SEM) [3].

Mathematical and statistical notation is used as suggested by Altman 1991 [21].

Introduction

In developed countries, cerebral palsy (CP) is the most common disorder of movement and posture in children, with prevalence of 2.0-2.5 per 1000 live births [11]. The prevalence of CP in Norway is reported to be 2.1 per 1000 live births [22]. A large range of habilitation services might be offered to children with CP and their families including medical interventions such as anti-spastic medication and orthopaedic surgery, special education services and speech therapy. Physiotherapy is seen as an integral part of the habilitation services, and children with cerebral palsy are one of the largest groups of children receiving services from pediatric physiotherapists [23]. In a Norwegian survey, Jahnsen et al. [24] found that 92 percent of adults with CP reported to have received physiotherapy during their childhood until the age of 15. Over the years, different physiotherapy interventions have been offered to children with CP (e.g. Mayston [25] and Damiano [26] for overviews), however, the effects have been sparsely investigated, and the quality of the research has earlier been hampered by small samples, lack of sensitive measures and poor descriptions of the interventions [27,28]. Even if methodological quality has improved in recent years, there is still little scientific documentation regarding the effects of physiotherapy interventions on motor development in children with CP [29,30].

An evolving understanding in the habilitation field has emerged during recent years that theories and knowledge from the social sciences should complement the biomedical model in habilitation [31], and that children's engagement in activities and participation in kindergarten, school, home and leisure settings are important goals for habilitation efforts [26,32,33]. In the 1990s, new knowledge in the field of movement science and pediatric neurological physical therapy implied that goal-directed,

functional and family-centred interventions might be more effective than traditional neurodevelopmental focused interventions [34-36]. It has, in addition, been questioned by parents and professionals whether more intensive physiotherapy would influence motor development in children with disabilities to a larger extent. In the late 1990s an increasing number of families were seeking out more intensive habilitation and training modalities abroad, which were not offered by the Norwegian health system [37,38]. Moreover, there has been an increased requirement from official health authorities of evidence based practice in health services, including physiotherapy and habilitation services.

As a consequence of these trends and insights, and as parents of children with cerebral palsy strongly signalled that the amount and intensity of physiotherapy programs were not sufficient, a project was developed in 1998 which implied collaboration between a physiotherapy institute for children in Bergen "Barnas Fysioterapisenter" (BFS), the Physiotherapy Service in Bergen municipality and the University College of Bergen (HiB). The project had an initial phase where an intensive physiotherapy program in a group setting was developed and pilot tested [39], and a second phase where aspects of functioning in children with CP and ways of implementing intensive periods in habilitation plans were explored [40]. Finally, the project had a third and last phase in which the intervention model was communicated to professionals and parents in seminars, and physiotherapists who wanted to start similar intensive training groups were offered supervision. An article describing aspects of the intervention model was published in "Fysioterapeuten" [41] which is the main physiotherapy journal in Norway. The last phase also included a qualitative research arm aimed to explore and describe parents' experiences with the intensive group training, parents' view of the children's change, and participating physiotherapists' description of and motivations for the intervention model. The results were reported in another Norwegian publication [42].

During the period from 2002 to 2008, the Ministry of Health and Social Affairs funded developmental projects regarding habilitation in Norway [43]. Five habilitation units in Western Norway located in the cities of Stavanger, Haugesund, Bergen, Førde, Ålesund and collaborating partners from BFS, HiB and the University of Bergen (UiB) applied for grants in an umbrella project regarding intensive training and habilitation. Each of the six applicants contributed with own project plans in the joint application for grants, and had their own project leaders. Four of the five habilitation units implemented the model of intensive physiotherapy that was developed in Bergen.

The research project leading to the present thesis was conducted in collaboration with BFS and the four habilitation units in Stavanger, Haugesund (in cooperation with Gard private institute for physiotherapy), Førde (in cooperation with the municipality of Gloppen), and Ålesund; the children participating in intensive group training for the first time. The group training was carried out during the period from August 2004 to October 2005. The project was performed as a doctoral work at the Department of Public Health and Primary Health Care, Section for Physiotherapy Science at the University of Bergen. The objective of the project was to investigate whether children with CP changed their motor functioning as a result of participation in intensive physiotherapy in groups. The study was performed as a multicentre study, in a part of Norway with long travel distances, and there was a need for evaluation measures that were portable. To ease the assessment burden of children and assessors, it was intended that advanced observational measures should be scored by skilled assessors from video uptakes. The methodological part of the thesis aimed to examine reliability of three evaluation measures that seemed useful for multicentre studies including children with CP.

Background

Cerebral palsy - diagnosis and functional classifications

Cerebral palsy is a neurodevelopmental condition beginning in early childhood and persisting through the lifespan [44]. A classic definition of cerebral palsy from 1964 is "a disorder of posture and movement due to a defect or lesion of the immature brain" [45 p.9]. However, this clinical descriptive term includes a heterogeneous population with a variety of movement disorders, commonly accompanied by other impairments. A new definition of cerebral palsy that covers the heterogeneity and the complex nature of the diagnosis is proposed by an international expert group [44 p. 9]:

> "Cerebral palsy (CP) describes a group of permanent disorders of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infants' brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems"

CP is traditionally divided into subgroups based on topology of affected limbs and tone disturbances, e.g. hemiplegia, diplegia, quadriplegia, ataxia or dyskinesia, along with the degree of involvement e.g. mild, moderate or severe [11]. However, this sub grouping has been questioned because of its inaccuracy, poor reliability and lack of including functions and body parts often affected, like bulbar function and trunk involvement [44,46]. In a newer classification from a network of CP registers and surveys, "Surveillance of CP in Europe (SCPE)" [47], the subgroups bilateral and unilateral spastic cerebral palsy, ataxia and dyskinesia are used. Criteria were defined and a training manual was developed to improve reliability of sub-grouping children with CP, but considerable variation in assignment of CP subtype was revealed across the network, hence reliability is still a challenge [48]. Little additional information about the children's functional ability has been derived by using diagnostic subgroups

of CP, so in recent years rather functional classification systems of gross motor and arm/hand function have been developed and are increasingly being used in research as well as in clinical practice.

The Gross Motor Function Classification System (GMFCS) [49] has received international acknowledgement and is now a commonly used classification system of children's locomotor and sitting ability [50]. The GMFCS is a five-level age-categorized system developed to describe severity of motor involvement in children with CP based on functional abilities, need for assistive technology and wheeled mobility. Children classified to GMFCS-*level I* can walk at home, at school, outdoors and in the community. They can climb stairs, run and jump, but speed, balance and coordination are impaired. Children classified to *level V* are transported in wheelchairs in all settings, their ability to maintain head and trunk postures against gravity is limited, and their self-mobility even with the use of assistive technology is severely limited. The GMFCS has demonstrated good measurement properties when professionals as well as caregivers have classified functional abilities of children with CP [49,51-53] and high stability of the classification has been found [54,55] implying that children tend to remain in the same GMFCS-level over time. The classification system is, however, less precise in infants [49] and the GMFCS-level might be preliminary until the age of 2 years [56] An age expanded and slightly revised version of the GMFCS was released in 2007 [57]. The revised version has not yet undergone reliability testing, nor has it been systematically compared to the old version, and therefore one cannot know whether the two versions can be used interchangeably [58]. In this study, the original version was used.

The Manual Ability Classification System (MACS) [59] is in the same manner a five-level category system developed to describe arm and hand motor function in children with CP based on the children's abilities to handle objects in daily activities, their

need for assistance and adaptations. Children classified as MACS-*level I* handle objects easily and successfully, while children classified as *level V* do not handle objects and require total assistance. Good measurement properties are demonstrated when professional and families classify hand function [59-61], but for children under 2 years MACS has shown only moderate reliability. MACS has shown stable levels over 12 months [62].

Use of the GMFCS and MACS requires familiarity with the classification systems, the user instructions and the child, but requires no formal training [49,59]. The classifications have been translated into Norwegian (Appendix 1 and 2). The correlation of GMFCS and MACS levels has been shown to be moderate to high [59,62,63], indicating that the classifications are only partly built on the same construct. Recommendations are made to use both classifications systems in research since they are regarded as complementary [59, 62-64].

The distribution of the classification levels of a population of Swedish children with CP is shown in Figure 1. Approximately one third of the children were classified as GMFCS and MACS level I. Similar information about distribution of classification levels is not available for Norwegian children with CP, however, Andersen et al. [22] have estimated GMFCS levels from register data and classified 55% of a population of 374 children as GMFCS-level I or II, and 17%, 20 % and 8% as levels III-V, respectively. In the Norwegian population approximately 75% of the children were sub-diagnosed as having spastic type of CP, 6 % as dyskinesia, 5% ataxic type and 7% were not classified. The proportion of children in the different subgroups of CP is essentially similar to the proportions reported in a European population of children with CP [22]. In the Norwegian population approximately 4 % of the children had severe hearing impairments, 5 % severe vision impairments, 28% epilepsy and 31 %

general learning disabilities [22]. More severe GMFCS-levels have been found to be associated with larger proportions of accompanying impairments [65,66].

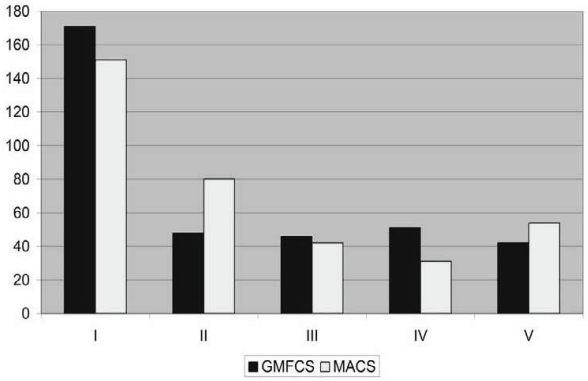

Figure 1.
Distribution of GMFCS and MACS levels in a population-based study of 359 children with CP in southern Sweden.

Motor disorders and motor development in children with CP

Abnormal gross and fine motor functioning and organisation are the core features of CP [44]. This may include problems with force generation, abnormal muscle tone, altered reflexes, poor selective control of muscle activity, and reduced ability to control posture and to learn movements [23]. The impairments should be seen as coexistent rather than isolated, and may affect each other [1]. The motor impairments can lead to difficulties in everyday activities like walking, feeding and swallowing, coordination of eye movements, articulation of speech, and secondary problems with behaviour, musculoskeletal problems, and participation in society [44].

The motor development in children with CP is delayed, and over the years clinicians and researchers e.g. Bobath [67] and Levitt [68] have described the expected motor development. Effort has been made to predict motor function, like walking ability from the age when independent sitting is achieved [69-71]. An influential contribution in this field of prediction is the creation of gross motor developmental curves for children with CP [72,73] (Appendix 3). The trajectory lines of expected development have made prediction of gross motor development from GMFCS-levels possible. According to these curves, children with CP will reach their potential in basic gross motor function in pre-school or in the first years of primary school age; children classified in GMFCS-level V, the earliest, and children classified in GMFCS-level I, the last. Similar curves for hand motor function development has been published [74], but their use is not widespread. Development of hand function according to MACS-levels in children with unilateral CP has recently been described [16].

In addition to the development of basic motor abilities, professionals and parents often pay attention to the movement patterns or "quality of movement" in children with CP. This might include aspects like stability, weight shift or the cosmetics of a movement pattern [75-77]. The construct of quality of movement is complicated [14,78], but is often referenced to an optimal or "normal" movement pattern. There is, however, little scientific knowledge about the role that movement quality plays in the development of basic motor abilities in children with CP.

In recent years the focus on motor development in CP in a lifetime perspective has increased, realizing the increasing musculoskeletal consequences, fatigue, pain and detoriation of function experienced in many adolescents and adults [24]. Whether these emerging disabilities are caused by overuse of muscles and joints, disuse, or a combination of both, is yet to be decided [79].

Measuring change in motor functioning – theoretical frameworks

The concept of measurement and the World Health Organization (WHO)'s International Classification of Functioning, Disability and Health, Children and Youth version (ICF-CY) [8] have set the framework for the studies in this thesis.

Measurement is "a process that involves an assessment, calculation, or judgment of the magnitude, quantity or quality of a characteristic or attributes" [80 p.14]. Valid measurement tools are a prerequisite in research and denotes that a tool actually measures the concept in question and that the concept is measured reliably [81]. Highly reliable measurement tools are a prerequisite for detecting true change in outcomes and ensuring that the observed change is not merely a result of measurement error [6]. Measurement tools developed for evaluative purposes are in addition required to demonstrate responsiveness to change before they can be used confidently as outcome measures [82]. This means that the measure must be able to detect change when change has occurred and show stability when no change has occurred [14]. When observational skills are required to assign scores to a measure and observers are a part of the measurement process, high observer-reliability is required to secure valid results [6]. Test-retest reliability of an assessment tool is investigated when the similarity in results in individuals who are supposed to have a stable performance is of concern [6].

The measurement property is not an invariant characteristic of a measure, but must be demonstrated in the population and setting of interest [12]. In this thesis, this means in the ages and functional levels of children with CP who were participants in the intervention study. For a measure to be declared reliable, it must demonstrate ability to differentiate among children and provide consistent values with small errors.

Relative reliability concerns the ability to differentiate between individuals and is expressed in some form of a correlation coefficient [3]. Absolute reliability concerns the absolute measurement error e.g. how close the scores on repeated measures are, expressed in the unit of the measurement scale at issue [12]. From absolute reliability values, the smallest detectable difference (SDD) can be calculated [18], and if a change exceeds the SDD, one can be 95% confident that the change is not due to measurement error. However, the SDD may not necessarily indicate a clinically important change.

The ICF-CY belongs to the family of international classifications developed by the WHO for application of various aspects of health. It provides a framework for measuring change in children with CP's functioning which incorporates biological and social perspectives [83]. The ICF-CY builds upon and contains the same components as the ICF (Figure 2), but has included a developmental perspective [8]. The ICF is divided into two parts, and the first part "Functioning and Disability" is of main interest in this thesis. This part includes three components of health: Body functions and structures, defined as the physiological functions of body systems and anatomical parts of the body, respectively; activity defined as the execution of a task or action by an individual, and participation defined as involvement in a life situation [8]. Part two "Contextual factors" contains environmental and personal factors, which also to a large extent influence a child's functioning. The group setting and the involvement of the children's parents and professionals represent this part of the ICF–CY and were considered important aspects of the intervention model. Aspects of environmental and personal factors have been addressed in a qualitative arm of the developmental project [42].

In the ICF model a distinction in the activity and participation dimensions is made between "capacity" and "performance". Capacity describes an individual's ability to

execute a task or action in a standardized environment and indicates the highest probable level of functioning. Performance describes what an individual does in his or her current environment [8]. The bidirectional arrows of the ICF-model indicate all possible interactions and influences (Figure 2) and the relations between the components on children's functioning and the relation between capacity and performance are not fully understood [84-87].

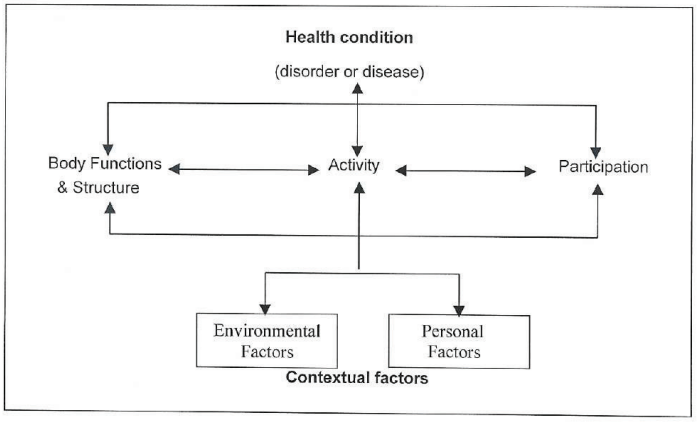

Figure 2.
Components of International Classification of Functioning, Disability and Health (ICF) [8]. Reprinted with permission.

A shift in theoretical basis of physiotherapy for children with cerebral palsy

In the past, various treatment methods have been offered to children with CP and their families. In the 1950s a common treatment method was to strengthen separate muscle groups and use orthoses, inspired by physiotherapy given to children with poliomyelitis. The building up of motion from reptilian movement patterns to primate erect walking, as recommended by Temple Fay and later followed by the Doman-Delacato system, and the training of muscle synergies in spiral and diagonal patterns, as developed by Krabat, Knott and Voss, are other examples of treatment methods [68]. In Conductive Education, originated by Andreas Petö, intensively performed

movement programs in a group setting and use of speech as a reinforcement of active movement, was put into a system [88]. Neurodevelopmental treatment (NDT), developed by Karl and Berta Bobath, was originally based on reflex inhibition and facilitation. Newer theories of motor control have been incorporated in the treatment concept [89], and the treatment is widely used internationally.

In recent years, the focus on single muscle groups, movement patterns and impairments such as increased tone and reflex activity has been followed by a system approach with emphasis on the child as a member of a family and of society. Physiotherapy as a part of habilitation services should support family and child to attain goals of importance in their everyday life [90], and a focus on task-oriented physiotherapy has evolved [35,90]. Based on information from the clinical field, an eclectic approach seemed widely used in Norway, with physiotherapy 1-2 times a week and emphasis on supervision of caregivers and professionals and also on modification of the environments e.g. by the affordance of technical equipment. In addition, physiotherapy has for a long time commonly been intensified after surgery or anti-spastic treatment. The majority of the projects regarding intensive physiotherapy or intensive multidisciplinary programs funded by the Ministry of Health and Social Affairs in Norway in the period 2002 to 2008 [43] were continued after the end of the project phases. There is, however, no published information on content and frequency of today's physiotherapy services for children with CP in Norway.

Intensive motor training approaches for children with cerebral palsy

The concept of “intensive training” or “intensive physiotherapy” has been used to describe various types of training. If not otherwise defined, the concept commonly includes an increased frequency of physiotherapy in a defined period of weeks or months, whereas the duration of each session remains the same as ordinary therapy sessions lasting mainly 45 to 60 minutes [91-95]. The Norwegian Knowledge Centre for the Health Services has reviewed international research concerning intensive training/rehabilitation of children with brain damage [30]. Their definition of intensive intervention was (p. 11): “Systematic and focused training and habilitation efforts with a minimum range of 3 times a week up to several times a day for one and more periods of time”. Seven systematic reviews and 20 separate studies met the inclusion criteria, and revealed that only studies of Constrained Induced Movement Therapy (CIMT) and early intervention with a focus on parent education had sufficient methodological strength. The two approaches revealed low to moderate evidence of effectiveness [30]. For other intensive interventions, including intensive training related to body functions such as strength training and functional activity-focused training, the review was inconclusive due to inconsistent results, few participants and methodological weaknesses in the included studies. However, a closer look at single studies regarding activity-focused interventions reveals a tendency of positive outcomes in favor of increased intensity in most studies [34, 91,92,94-96], implying that this is a subject of further investigation.

There is no consensus regarding the optimal dosage of training. Intensive physiotherapy program for children with CP have differed in frequency and duration; e.g. five sessions a week over six months [94], four sessions a week over four weeks [92], or several daily sessions over five months [97]. In two studies it was

commented that most of the motor gains seemed to appear during the first weeks or months of the intervention [94,97], and in one study with increased frequency of physiotherapy lasting six months, children and parents seemed tired after the long period of therapy [94]. Hence, shorter, focused periods of training with longer daily duration might be beneficial. There are only a few studies examining the outcome of intensive physiotherapy training in a group setting [98-100], and as group training is found useful regarding motivation and effort [98,100], this might be an advantageous way of organizing the training.

Pilot study

A pilot study [39] was conducted prior to the studies included in this thesis. The intervention model included three hours of intensive physiotherapy five days a week in a three-week period. Six children with CP aged 2 ½ to 5 years participated in two periods of intensive physiotherapy, in the spring term and in the following autumn term. The program consisted of activities in a gym and in a pool. A repeated measures design with two measurements prior to the intervention period and two measurements after was applied for four children, and one pre- and one post measurement for two children. The pilot study indicated improvement in basic motor abilities as measured by the GMFM-88, particularly in connection with the periods of intensive physiotherapy (Figure 3).

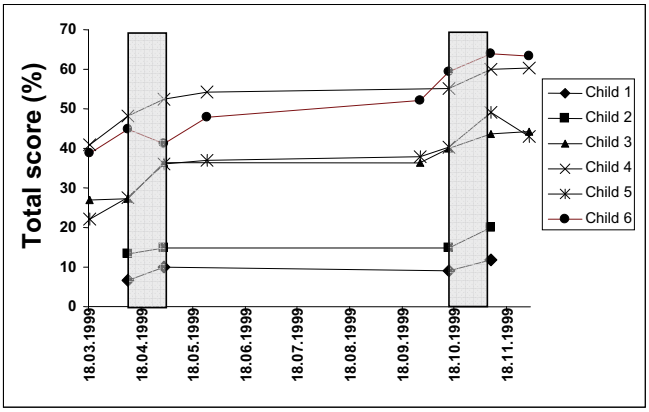

Figure 3.
Total scores of the GMFM-88 from six children with CP who participated in two periods of intensive physiotherapy [39].
Gray bars indicate intervention periods.

Aims of the present project

Results from the pilot project indicated improvement in basic motor abilities when children participated in a three-week period of intensive physiotherapy. In the present project we wanted to broaden the scope of assessments, in line with the dimensions of the ICF, and investigate change of motor functioning in a larger group of children who participated in intensive training groups for the first time.

General aims

The first overall aim of this thesis was to adapt and evaluate measurement tools. Using a multicentre approach in the intervention study where several habilitation units were invited to participate, there was a need for outcome measures that could be used reliably in different sites, and at the same time that impose as little strain on children and assessors as possible. Electronic equipment like an electronic walkway connected to a computer and video recording of parts of the assessment with subsequent editing by use of PC software and scoring from video clips, appeared to be feasible and ease the assessments. The methodological part of this thesis aimed to examine reliability of three evaluation measures that might be used in the outcome study of children with CP.

The second aim of this thesis was to investigate aspects of functional change in children with CP who participated in a course of intensive physiotherapy in their local environments.

Specific aims

- Examine test-retest reliability of gait parameters using the electronic walkway GAITRite® in a sample of children with CP (Study I).
- Examine inter- and intra-observer reliability of the Gross Motor Performance Measure (GMPM) and Quality of Upper Extremity Skills Test (QUEST) when scored from video clips (Study II).
- Investigate the impact on functioning of a 3-week period of intensive goal-directed and activity-focused physiotherapy in a group setting for children with CP (Study III).
- Examine the relationship between achievement of basic motor abilities and quality of movements (Study III).

Methods

Designs

Study I

Same-day test-retest design [6] where children with CP walked eight times over an electronic walkway at three different speeds. Retest was performed after an average of 25 minutes.

Study II

Intra-observer and inter-observer reliability design [6] where two observers independently scored video clips of the GMPM and QUEST over a one-week period. The video clips were rescored after six weeks.

Study III

Repeated measures design [3] with three baseline assessments before the intervention period and two follow up assessments after the intervention period. The baseline, intervention and follow-up phases all lasted three weeks.

Participating children

Study I

The participating children were a convenience sample of children with CP with independent gait function recruited from municipality 1 (Bergen) and 2 (Stavanger) in Western Norway. Four paediatric physiotherapists recruited the children, two working in private practice, one in a school for disabled children and one in a habilitation unit. Inclusion criteria were children with CP from 2 to 15 years of age who were able to walk without assistive walking devices (GMFCS-levels I and II).

Eighteen children with CP were referred to the study and were all included. In one child (girl, seven years, GMFCS-level II), not sufficient data from the retest were registered, and the child was excluded (Figure 4). Characteristics of the seventeen participating children are presented in Table 2. The study group represented a heterogeneous group of children with CP with different walking abilities.

Study II

The participating children were a convenience sample of children with CP recruited from municipality 1 (Bergen) and 3 (Voss) in Western Norway. Six paediatric physiotherapists working in private practice or primary schools recruited the children. Inclusion criteria were children with CP from 2 to 15 years of age. Twenty-six children were referred to the study and were all included (Figure 4 and Table 2). All levels of the GMFCS and MACS were represented in the sample. Eight of the children were also included in the sample of study I.

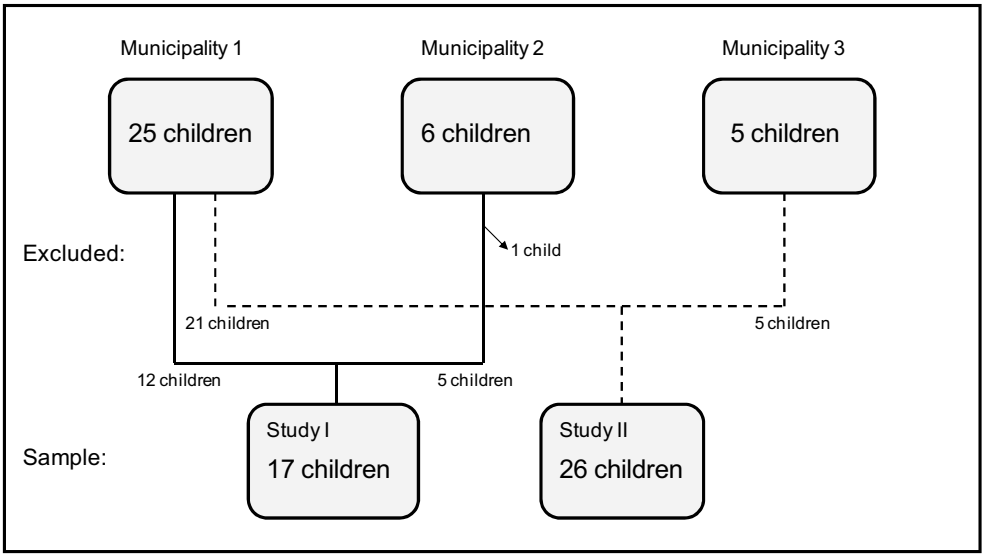

Figure 4.
Children from three municipalities were included in Study I and II.

Study III

Children with CP from four habilitation units in the cities of Stavanger, Haugesund, Førde and Ålesund in Western Norway, who were invited to participate in intensive physiotherapy training for the first time, were included in the third sample. The habilitation units recruited the children and composed the groups. The inclusion criteria were children with CP in preschool or first years of primary school living within one hour travelling time from the training location. Exclusion criteria were children with other diagnosis than CP and children who, according to the view of professionals at the habilitation units, had suffered extensive strain due to for example repeated hospitalisations or serious health problems in the past year. Twenty-five children were referred to the study and were all initially included (Figure 5). One child (girl, six years, GMFCS-level II) dropped out during the intervention period due to long travel distance. Two children were excluded: One participated in less than half of the intervention period due to illness (girl, four years, GMFCS-level III), and one was found to have another neurological condition than CP (boy, four years).

The study sample included twenty-two children with CP, who accomplished the intervention, from five training groups in four different sites of Western Norway (Figure 5). All levels of the GMFCS and MACS were represented in the sample (Table 2). Five of the children received anti-spastic medication in the study period.

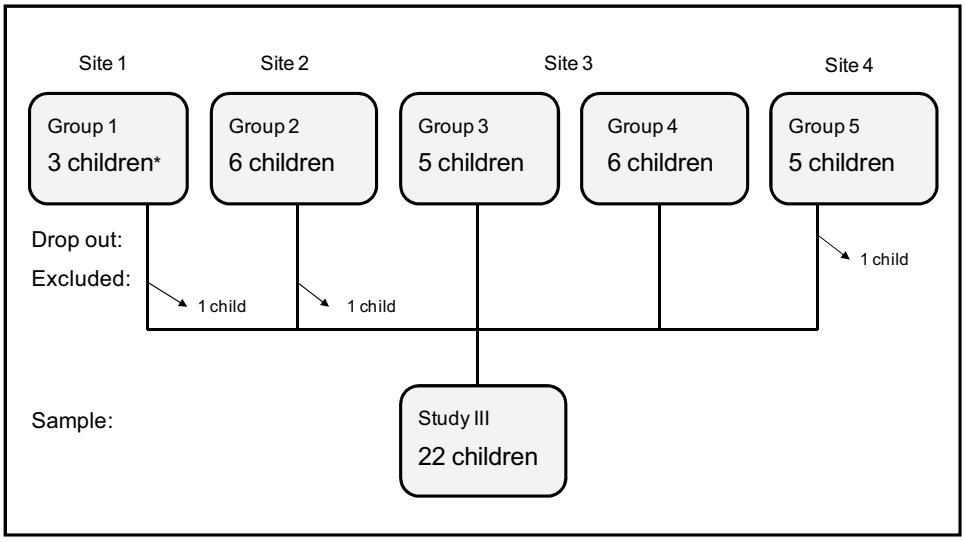

Figure 5.
Children from four sites and included in five training groups participated in Study III.

* An additional three children participated in this training group, but did not meet the inclusion criteria.

Table 2.
Demographics of participating children.

Study		Sex boys/girls	Age years	GMFCS		MACS		Diagnosis	
no	*n*	*n*	*mean; range*	*level*	*n*	*level*	*n*	*type*	*n*
I	17	8/9	7.0; 3-13	I	11			Hemiplegia	11
				II	6			Diplegia	6
II	26	14/12	7.5; 2-13	I	5	I	4	Hemiplegia	6
				II	6	II	9	Diplegia	12
				III	5	III	5	Quadriplegia	6
				IV	4	IV	5	Dyskinesia	2
				V	6	V	3		
III	22	15/7	5.5; 2-9	I	8	I	8	Hemiplegia	7
				II	2	II	7	Diplegia	11
				III	6	III	5	Quadriplegia	2
				IV	5	IV	1	Dyskinesia	2
				V	1	V	1		

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

Participating professionals

In Study I-III, two PTs administered the assessment tools and videotaped the assessment. In addition, several professionals participated in study II and III.

Study II

Four pediatric PTs participated in development of the procedure for videotaping. Two pediatric PTs with respectively 10 and 17 years of clinical experience scored the video clips.

Study III

Twelve pediatric PTs most with long clinical experience, mean 13 years, range 1 to 27 years, conducted the group training. Seven PTs and OTs from the participating habilitation units participated in the data collection, mainly performing parent interviews with the PEDI. The professionals had participated in training courses and were experienced in using the assessment tool. Four pediatric PTs from Barnas Fysioterapisenter supervised the group leaders before and during the intervention and participated in the data collection. Two pediatric PTs scored video clips of the assessments. The professionals, who collected data, did not participate in the group training, and the PT who supervised the group leaders did not participate in data collection in the groups they supervised.

Assessment tools

As functioning in children can be described using several components according to the ICF and the relationship between the dimensions of the ICF are not fully understood, a broad specter of assessment tools related to motor and everyday functioning was chosen, reflecting a range of dimensions of the ICF-CY (Tables 3 and 4).

The electronic walkway GAITRite® has demonstrated high validity and reliability in measuring temporo-spatial parameters of gait in adults with and without neurological disabilities as well as in children aged 1 to 12 years without disabilities [101-108], but the measurement properties of gait parameters have not been examined in children with CP. The walkway is portable and seemed feasible to use in the population of interest. However, concern remained as to whether children with cerebral palsy at different ages and at different functional levels could manage to follow the instructions for walking on the walkway, and whether their walking pattern could be recorded reliably in a short-time perspective when no change was expected to occur.

Measurement properties of quality of movement measures developed for children with CP have been tested by their developers or persons affiliated to the group that developed the measures and found satisfactory regarding reliability, validity and responsiveness (Table 5). However, as the measures were to be scored from video clips in the present project, the reliability of scores under such conditions had to be examined.

In the intervention study, standardized condition-specific and generic measures that had been found reliable, valid and responsive to change in children with CP were chosen (Table 5). The assessment tools were selected to cover several dimensions of the ICF-CY related to motor and everyday functioning, and the length and ease of administration were taken into consideration, as well as their feasibility for use in a multicenter study. The measures also had to be available in Norwegian or English. In addition, an individualized goal attainment measure regarded as being particularly responsive to change in children with disabilities [109] was used (Table 5), while individual goals remained a main component of the intervention model. Pilot testing of the assessment protocol was conducted with children who participated in the methodological studies. The electronic walkway GAITRite® was also included in the

protocol of the intervention study, but due to unexpected practical circumstances, the portable walkway was not applied.

Table 3.
Assessment tools used in the different studies of the thesis.

Assessment tool*	Study I	Study II	Study III
GAITRite®	x		
GMPM		x	x
QUEST		x	x
GMFM-66			x
PEDI			x
GAS			x

* For abbreviations see page xi

Table 4.
Assessment tools related to components of the ICF-CY.

Component	Functioning/disability assessed	Assessment tool*
Body function and structure	Gait pattern	GAITRite®,
	Movement functions	GMPM, QUEST, GAS
Activity and participation	Basic gross motor abilities	GMFM-66, GMPM, GAS
	Hand activities	QUEST, GAS
	Mobility	PEDI, GAS
	Self-care	PEDI, GAS
	Social function	PEDI

* For abbreviations see page xi

Table 5.
Reported measurement properties of the selected assessment tools in samples of children in pre- and primary school age with CP (condition specific assessment tools) or disabilities (generic assessment tools).

Assessment tool*	Measurement properties
GMPM	*Intra-tester reliability:* ICC = 0.92-0.96 for total score[110,111], 0.90-0.97 for attributes [110]. *Inter-tester reliability:* ICC= 0.92-0.93 for total score[110,111], 0.84-0.94 for attributes [110,112]. *Test-retest reliability:* ICC = 0.96 for total score [109,110], 0.89-0.96 for attributes [110]. *Content validity:* Evaluated by 13 international experts when the assessment tool was developed [113]. *Criterion validity:* Not established; low correlation with parents' and therapists' ratings [114]. *Construct validity:* A priori hypotheses of differences between groups of children confirmed [114]. *Responsiveness:* Change in stable and responsive groups similar to therapists' judgments [114].
QUEST	*Inter-tester reliability:* ICC = 0.90-0.96 [115,116]. *Test-retest reliability:* ICC = 0.95 for total score [115], 0.51-0.96 for domains [115]. *Content validity:* based on literature review and consultations with experts [115,117]. *Criterion validity:* Correlation with Peabody Fine Motor Scale r=0.84 [115,117]. *Construct validity:* Correlation with therapists' ratings r =0.72 and 0.58 for left and right hand, respectively. Correlation with age r= 0.33 [115,117]. *Responsiveness:* Responsiveness to change demonstrated [118].
GMFM	*Intra-tester reliability:* ICC = 0.99 [119,120]. *Inter-tester reliability:* ICC = 0.80-1.0 [119-121]. *Test-retest reliability:* ICC = 0.76 – 1.0 [119,121,122]. *Content validity:* Pilot tested by therapists [15]. Item hierarchy shown [120]. *Construct validity:* A priory hypotheses regarding change in scores in different ages and functional levels confirmed [119,120,123]. *Responsiveness:* Change correlated with change seen by parents and clinicians [119,120] and demonstrated in effect size and standardized response means [82,118].
PEDI	*Inter-tester reliability:* ICC = 0.72-1.0 [7,77,124]. *Test-retest reliability:* ICC = 0.8–0.98 [124]. *Content validity:* Evaluated by 31 experts when the assessment tool was developed [7]. *Criterion validity:* Concurrent validity with related assessment tools of motor function and self-care; r= 0.59-0.97 [7,77,125]. *Construct validity:* Support for hypotheses regarding increased scores with age [7]. *Responsiveness:* Responsiveness to change demonstrated in effect size and standardized response means [82,118]. Change correlated with changes seen by parents [77,82] and therapists [88].
GAS	*Intra-tester reliability:* ICC = 0.96 [126]. *Inter-tester reliability:* ICC = 0.51-0.96 [126,127]. *Content validity:* Supported when goals are appropriate, reasonable, relevant and complete, but reliant of clinical skills of goal setters [126,127]. Goals for children with CP supported by expert panel of experienced PTs [128]. *Criterion validity:* Low correlation with Peabody gross motor scale [128] r=0.25. *Responsiveness:* Good responsiveness for detecting meaningful clinical change [127-129].

* For abbreviations see page xi

GAITRITE (Study I)

The electronic walkway GAITRite®, (CIR Systems Inc., NJ, USA) is connected to a portable computer and constructed to record gait parameters (Figure 6). As subjects walk across the electronic walkway, sensors are activated under the pressure of the feet and deactivated when the pressure is released. The geometry and the relative arrangement of each footfall as a function of time is recorded [130]. The computer's software processes the raw data into footfall patterns and computes a large range of spatial and temporal gait parameters [130]. From clinical experience five gait parameters were chosen as clinically relevant in this study. Definitions of the spatial parameters stride length, step length and step width selected in Study I are illustrated in Figure 7. The temporal parameters cadence defined as steps per minute and stance time on one leg were also considered relevant, and two asymmetry measures of step length and stance time were in addition calculated from the gait parameters.

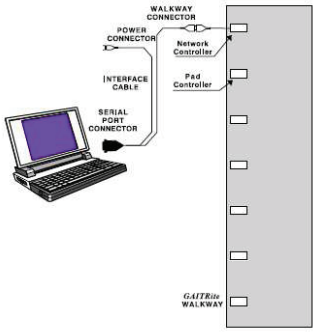

Figure 6.
Portable walkway [130] .
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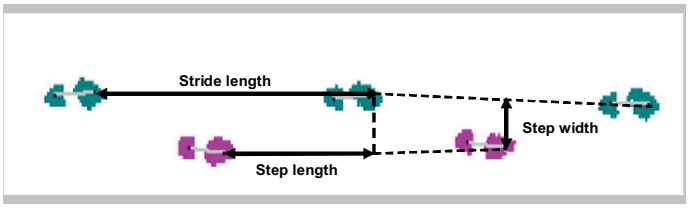

Figure 7.
Definitions of spatial gait parameters illustrated.

GMPM (Study II and III)

The Gross Motor Performance Measure (GMPM) [111] was developed to assess quality of movements in gross motor activities like walking, sitting and crawling in children with CP. The test is observational and criterion referenced, and the children are compared to themselves over repeated measurements. Twenty items derived from a sibling measure, the Gross Motor Function Measure (GMFM), are assessed on five attributes: Alignment, Coordination, Stability, Dissociated movements, and Weight shift. For items that can be performed on both left and right side, only the child's most affected side is tested and only items for which the child receives a score of 1 or more on the GMFM, is scored on the GMPM. In each item, three single attributes are scored on a 1-5 point ordinal scale (Figure 8). A score of 1 is given when no pathology is observed in three repeated trials. A score of 5 is given when severe pathology is observed. Percent scores for the attributes (scale 20-100 %) and a total score (scale 0-100%) as the average of the five attribute scores, are calculated.

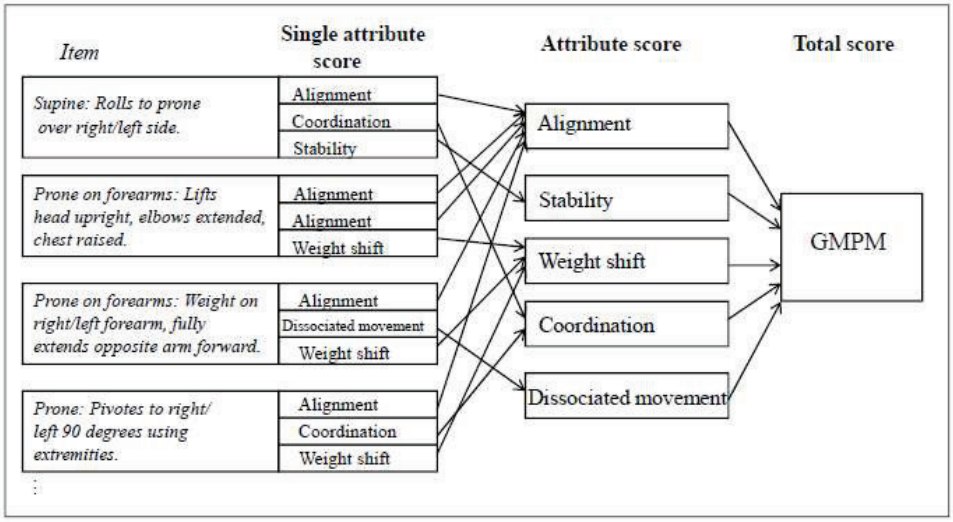

Figure 8.
Illustration of the scoring system of the Gross Motor Performance Measure (GMPM)

QUEST (Study II and III)

The Quality of Upper Extremities Skill Test (QUEST) [115] was developed to describe aspects of upper extremity quality of movement in activities like grasp, weight bearing and protective extension, to plan intervention programs and evaluate effectiveness of therapy in children who exhibit neuromotor dysfunction with spasticity. Quality of movement is assessed in four domains: Dissociated movements, Grasp, Weight bearing, and Protective extension (Figure 9). The measure includes 33 items. Each item comprises, however, several sub-items and both left and right upper extremity is assessed, so a total of 174 sub-items are scored on a dichotomous scale; "able to complete" or "not able to complete". If the movement is not administered, this is reported as "not tested". Percent scores for the domains (scale 0-100 %) and a total score (scale 0-100 %) are calculated as the mean of domains actually tested.

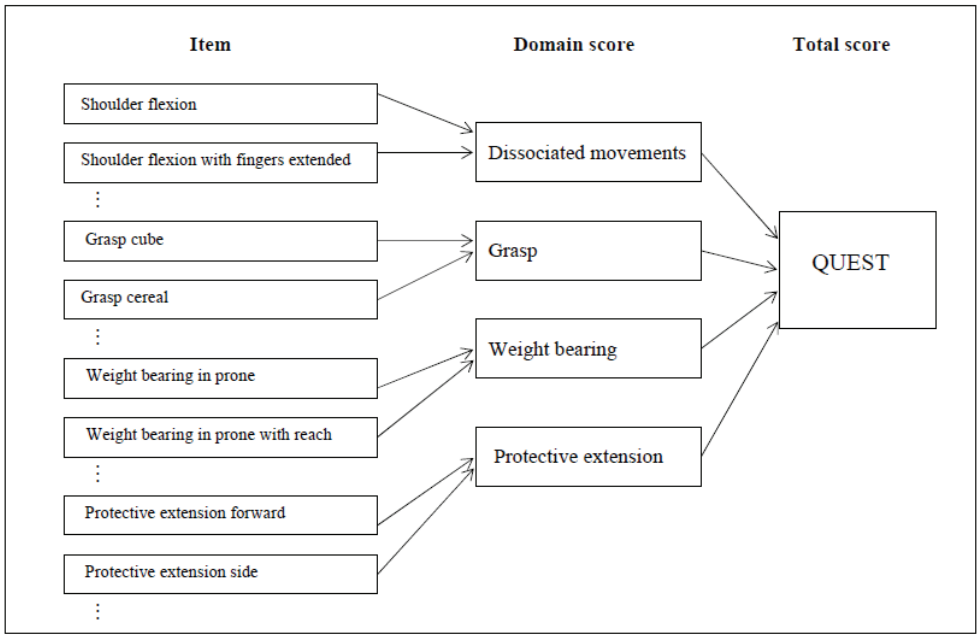

Figure 9.
Illustration of the scoring system of the Quality of Upper Extremity Skills Test (QUEST)

GMFM-66 (Study II and III)

The Gross Motor Function Measure (GMFM) [119] was developed to evaluate change in gross motor function in children with CP. The GMFM is a criterion-referenced, clinical observation tool designed to be used by all types of CP and without age restrictions. The items are grouped into five dimensions of basic motor functions: Lying & rolling, Sitting, Crawling & kneeling, Standing, and Walking, running & jumping, and scored on a 0-3 ordinal scale. A score of 0 is given when a child is not able to perform the task. A score of 3 is given when the child fully execute the motor task of the item. Two versions of the GMFM exist; the original GMFM-88 and a more recent version, GMFM-66 [15]. In the GMFM-88, percentage scores (scale 0-100 %) are calculated for each dimension and the total score (scale 0-100 %) is the average of the five dimension scores. In order to improve the interpretability and clinical usefulness, a Rasch analysis was applied to the GMFM-88, resulting in a unidimensional hierarchical scale consisting of 66 items from the original measure [120]. Using the Gross Motor Ability Estimator software [15] a total score (scale 0-100) with interval-level properties is calculated for the GMFM-66.

PEDI (Study III)

The Pediatric Evaluation of Disability Inventory (PEDI) [7] was developed to determine chronically ill children's functioning in three domains: Self-care, Mobility, and Social function. The instrument contains three theoretical dimensions: Functional skills, Caregiver assistance and Modification (environmental and technical adaptations) (Appendix 4). In this thesis the Functional skills and Caregiver assistance dimensions were applied. In the Functional skills dimension, 197 items are scored on a dichotomous scale; "able to perform the item in most situations" or "unable to perform the item in most situations". Caregiver assistance is determined for 20 items

on a 0-5 ordinal scale, where a score of 0 is given if the child needs total assistance and a score of 5 is given if the child is independent in the activity. Normative standard scores for the domains based on a sample of American children without disabilities can be derived from the measure as well as scaled scores (scale 0-100) which provides an indication of a child's ability to perform the total number of tasks of the PEDI domain. The PEDI is translated into Norwegian [131,132] and validated in Norwegian children without disabilities [133]. The Norwegian norms deviated somewhat from the original norms, implying a cultural difference, however, the scaled scores are not age related, but provide a criterion referenced measure, and is applicable in a Norwegian setting [133]. The measure is usually administered in a structured parent interview.

GAS (Study III)

Goal Attainment Scaling (GAS) [109] was developed to capture individualized goal attainment within a predetermined timeframe. For goal identified by family/child and professionals in collaboration, a scale containing five levels of outcome descriptions is constructed: Expected outcome (0), two levels of less (-2 and -1) and two levels of more (+ 1 and + 2) than expected outcome. The scales are scored in a follow-up evaluation. Example of a follow-up scale is given in Appendix 5. When used in clinical practice, usually the caregiver and professionals construct the follow-up scales. In research, however, it has been recommended that other than professionals who conduct the intervention construct the scales [134].

Goal setting process and goals

Goals for the intervention period in Study III were decided through a collaborative process including parents who made decisions about the content of the goals, and professionals who contributed to operationalize and refine the goals. A total of 98 goals were set for the training period, an average of 4 for each child. 57 goals were classified as activity goals, e.g. “Can put trousers on without help”, while 31 were classified as movement goals, e.g. “Can get the heels down when he stands supported”, and 10 were combined. GAS follow-up scales were constructed for all children, for one to three goals per child, a total of 53 scales. The follow-up scales were scored by parents and professionals in collaboration at the final follow-up assessment. The goal attainment of the remaining 45 goals was reported by parents and professionals at the last follow up assessment. Type and number of goals scored with GAS and by oral report, respectively, are listed in Table 6.

Table 6.
Attainment scoring of goals.

Attainment scoring	Number of activity goals	Number of movement goals	Number of combined goals
GAS follow-up scale 5 levels	34	14	5
Oral report	23	17	5

Videotaping and editing

Standardized procedures for videotaping performances of the GMPM and QUEST were developed, piloted and revised twice, in collaboration with the PT who later videotaped the assessments in Study II and III. The final written procedures are shown in Appendix 6. In GMPM, each item was videotaped separately, while in the

QUEST, several test items were videotaped in one sequence due to the structure of the measure.

The videos were edited using the Pinnacle Studio 8 software program (Pinnacle Systems Inc) and stored on DVDs. A fixed procedure for editing video clips was used. The duration of a video clip was for example standardized in items containing static positions where no indication of time was given in the manuals. In the final DVDs, each GMPM item was announced by the item number, while in the QUEST, since the items are performed as consecutive movement sequences and several items are scored during one sequence, the video clips were announced by the dimension name.

Intervention

The intervention model in Study III aimed to provide an intensive, but limited period of physiotherapy within the frame of the children's local environment to support their achievement of individual goals of motor and everyday activities. To ensure that the intervention could fit within the children's everyday life, a model of three hours of training, five days a week in a three-week period was chosen. The principles of the intervention model have been described in the pilot project [39] and are further outlined in a report from the developmental project [42]. The following principles have formed the base for the intervention model: 1) Functional goal directed training, implying a focus on practicing specific activities of importance to the child [35], 2) Family centered practice [36], implying that parents were involved in the goal setting process and were active participants in the training, 3) Cooperation between group leaders and parents as well as local professionals and other persons important to the child, to secure carryover of knowledge and skills to the child's everyday life, 4)

Applying recent knowledge of motor learning, using e.g. motivating activities, stimulating environments and variation [135,136]. For a more specific description of the intervention, one group training session at each site was video recorded and the amount and type of training and also the applied teaching and learning strategies, were outlined (Appendix, Paper III).

The intervention model had been applied in clinical practice for several years at a physiotherapy institute before the start of this study. To make sure that the intervention was similarly conducted, the group leaders participated in a workshop with practical and theoretical lessons, lasting two days. The workshop included observation of ongoing groups, theoretical lesions and discussions regarding planning, organization and guidance of a group, contents of the intervention and information about the assessment protocol. In addition, the group leaders were supervised three times during the course of the intensive training.

Statistical analysis

The children's background data and raw data scores were described by values of mean, standard deviation (SD), range, confidence interval (CI) and percentage. Parametric statistics were applied when i) the variables were at interval or ratio levels and in fine graded sum scores of variables at ordinal level, ii) the assumption of normality was met by inspecting Q-Q plots and by examining for normality using the Shapiro-Wilk test for small samples [21]. If the assumption of normality was not met, non-parametric statistics were applied. An overview of statistical methods is presented in Table 7.

Table 7.
Main statistical methods applied in the studies.

Statistical method	Study I	Study II	Study III
Intra Class Correlation	x	x	
Cohen's Kappa		x	
One-way analysis of variance			x
Mixed factorial analysis of variance			x
Paired T-test			x
Spearman rank correlation	x	x	
Friedman's Test			x
Wilcoxon signed rank test			x

P-values ≤ 0.05 were considered to be statistically significant, however, on repeated measurements of the GMFM, and in PEDI where the dimensions have been shown to be inter correlated [7], a stricter p-value ($p< 0.01$) was chosen. Criteria for acceptable ICC, Kappa and percent agreement values were set in advance. Sample size calculation based on results from the pilot study was performed in connection with the planning of Study III. Raw GAS scores were transformed to standardized GAS T-scores using the formula given by the developers [109].

Ethics

The studies were performed according to the Helsinki Declaration. The protocol was approved in advance by the Regional Ethical Committee in Western Norway and the National Data Inspectorate of Norway. Written informed consent was obtained from the children's parents before participation in the studies (Appendix 7), and the children were given age appropriate information about the objectives of the studies.

Summary of the papers

Methodological studies

Study I

This study examined measurement properties of an electronic walkway in a sample of children with CP. Gait parameters can be assessed in clinical observation, by using equipments such as a stop watch or inkpads, and by advanced equipment in gait laboratories. Electronic walkways are relatively new technological equipment, used to record gait parameters. They are said to be feasible in a clinical setting, with automatic exportation of gait parameters to a computer for subsequent analysis. Measurement properties of gait parameters have previously been examined in adults with and without disabilities and in children with typical development, and have shown high test-retest reliability. The objective of this study was to examine test-retest reliability of seven selected temporal and spatial gait parameters and asymmetry measures in children with cerebral palsy by an electronic walkway. Seventeen children with CP between 3 and 13 years of age participated in the study. They performed a standardized procedure of walks with different speeds along the electronic walkway. The tests were repeated after approximately 25 minutes. The scores were normalized to a walking speed of 1.1 m/sec to avoid the confounding effect of gait speed on speed dependent gait parameters. Intraclass correlation coefficients ($ICC_{1,1}$ and $_{3,1}$), within subject standard deviation (S_w) and smallest detectable difference (SDD) were calculated. The relative reliability of cadence, step length, stride length and single stance time was high to excellent ($ICC_{1,1}$ being between 0.73 and 0.95), while it was poor for step width ($ICC_{1,1}$ = 0.27 and 0.35). The relative reliability for the two asymmetry measures were high for the step length index ($ICC_{1,1}$ = 0.82) and moderate for the single stance time index ($ICC_{1,1}$ = 0.49).

The absolute reliability values for the gait parameters and asymmetry measures were also calculated and reported. All children, except one, could easily walk over the mat at different speeds, making it possible to calculate gait parameters at a normalized walking speed. In one child, the walkway failed to register sufficient footsteps, possibly due to the child's shuffling gait pattern.

Study II

In this study measurement properties of measures assessing quality of movement were examined in a sample of children with CP. Quality of movement measures for assessing motor performances of children with CP are complex and time consuming to score. Structured recordings and scoring from video clips may ease the assessment burden on children and assessors. The objective of the study was to examine observer reliability of the Gross Motor Performance Measure (GMPM) and the Quality of Upper Extremity Skills Test (QUEST) based on scores from observation of video clips. The tests were administered to 26 children with CP aged 2 to 13 years. The children's performances were recorded and edited according to fixed procedures. Two experienced paediatric physical therapists assessed the children from watching the video clips. Intra-observer and inter-observer reliability values ($ICC_{1,1}$) of the total scores varied from 0.69 to 0.97 with only one coefficient below 0.89. The ICCs of sub-scores varied from 0.36 to 0.95, finding "Alignment" and "Weight shift" in GMPM and "Protective extension" in QUEST highly reliable. The sub-scores "Dissociated movements" in GMPM and QUEST and "Grasp" in QUEST were the least reliable. Kappa coefficients of single items ranged between 0 and 1 for both measures. The video scoring was time-consuming and demanding, but offered many advantages; the possibility to review performances, to use especially trained observers for scoring (not available during the tests), and less demanding assessments for the children.

Intervention study

Study III

The objective of the intervention study was to investigate the impact on basic motor abilities and everyday activities of children with CP (n= 22) who participated in intensive activity-focused, goal-directed physiotherapy training for the first time. It was further an objective to investigate the coherence between acquisition of basic motor abilities and quality of movement during the study period. A rather stable baseline phase in the repeated measures design was demonstrated by the Gross Motor Function Measure (GMFM-66), being the main outcome measure. A main effect of time was shown after the intervention period, mean change being 3.8 ($p<0.01$) at first follow up increasing to mean 4.5 at the last follow up assessment. An interaction between time and Gross Motor Function Classification System (GMFCS) levels was found, implying that children classified to GMFCS-levels I-II improved more than children classified to GMFCS-levels III-V. There were no main or interaction effects of age or anti-spastic medication. Change scores in the Pediatric Evaluation of Disability Inventory (PEDI) ranged from 2.0 to 6.7, and the change was found significant ($p<0.01$) in the Self-care domain of the Functional Skills dimension and the Self-care and Mobility domains of the Caregiver Assistance dimension. The children's individual goals were on average attained, Mean Goal Attainment Scaling (GAS) T-score being 51.3. Video scoring by two blinded assessors gave non-significant improved scores on the GMPM and the QUEST. A significant improvement in GMPM scores was found in the same items that improved in the GMFM, but not in items that maintained the same score.

Main findings

Methodological studies

- Test-retest reliability in a short time span of gait parameters using an electronic walkway, was high in five of seven gait parameters and asymmetry indexes in children with CP who were able to walk without assistive walking devices.
- The walkway was feasible for recording gait parameters in children with CP, but reliability seemed limited in children who had difficulties in following the administration procedure or understand the task.
- Inter-observer and intra-observer reliability of GMPM and QUEST total scores were mostly satisfactory high.
- Reliability of sub-scores and single items of the two quality of movement measures differed, some showing high others low reliability.
- Video scoring was time-consuming, but was found to offer many advantages, like possibility to review performances, a less demanding assessment procedure for the children and use of especially trained observers who were not available for scoring at the time of the tests.

Intervention study

- Basic motor abilities and self-care improved in young children with CP after three weeks of intensive, activity-focused and goal-directed physiotherapy.
- Individual goal attainment was high.
- The children's need for caregiver assistance in self-care and mobility decreased.
- No significant change was found in the children's social function or in their quality of fine and gross motor movement patterns, however, in basic motor

abilities that improved during the study, significant improvement in quality of movement was found, whereas in basic motor abilities that remained stable, no significant improvement was found.

- Intensive, goal directed physiotherapy over a limited period of time, with involvement of the children's parents and local professionals seemed to be well-tolerated, motivating and instructive for the participants.
- To accomplish individualized training within a group context and at the same time take care of the group process and supervise the children's escorts, requires competence and experience.

Discussion

Methodological studies

In the two methodological studies of this thesis, different types of reliability were investigated depending on the nature and expected use of the measures.

Reliability of the electronic walkway GAITRite

Optimizing gait function e.g. the speed, effort and safety of gait is often an intervention goal in children with CP who are able to walk, and a portable walkway might be a cost-effective and user-friendly way of quantifying temporal and spatial gait parameters. Four gait parameters considered clinically relevant for children with CP (cadence, step length, stride length, single stance time) and an asymmetry index based on step length, revealed high repeatability (Table 3, Paper I). The satisfactory relative and absolute reliability of these gait parameters make them applicable in research. As variability in scores from test to retest was low, a change in the parameters could be considered mainly a result of a true change and not of measurement error. Low reliability was demonstrated for the step width, as has also been found in studies of other populations [102,103,108]. A test-retest design does not separate different sources of error, e.g. errors resulting from the instrument, the administrators or the participating children [6]. Hence, possible sources of error in the step width parameter in this study might be due to the size of the sensors as suggested by others [102], or that a hallmark of step width might be variability rather than stability in children with CP. The asymmetry index stance time also showed low reliability and this index as well as the step width parameter seem, accordingly, less applicable than the others in research.

Gait parameters in children with CP collected by use of other types of device, like data-based equipment in a laboratory setting or observational measures, have demonstrated moderate to high reliability [137-141]. However, neither the reliability values nor the gait parameter values can automatically be compared across measurement devices since they might measure different aspects of gait, and measure the parameters in slightly different ways. Footsteps computed from pressure sensitive pads under the feet may for instance give different output compared to parameters from markers over the ankle joint recorded from a sagittal plane. Hence the reliability is equipment, environmental and population specific and the gait parameter values from an electronic walkway cannot directly be compared to values from other equipment.

Concurrent with the pre-publishing on the net of Paper I, a study examining test-retest reliability of the GAITRite® in a sample of American children with disabilities was published [142]. Reliability of six temporal-spatial gait parameters in children with CP (n=16), Angelman syndrome (n=2) and arthrogryphosis (n=1), was examined in two conditions; barefoot and with shoes and orthoses. The pre determined minimum reliability coefficient criteria of ICC = 0.80 was met and supports that the electronic walkway is a reliable way of recording gait parameters in children with CP. This study expanded the scope for examination of reliability as gait with shoes and orthoses were also investigated, in contrast to our study where only the barefoot condition was examined.

A large range of spatial and temporal gait parameters are computed by the software of the GAITRite® walkway [130]. In the present study, as well as in the study by Wondra et al. [142], reliability was examined in gait parameters considered relevant as outcome measures in children with CP. In the present study and in the study of Wondra, reliability of cadence and stride length was examined. The other gait

parameters examined in the two studies can hardly be compared since different expressions of the parameter were examined, e.g. single stance time as percentage of the gait cycle in one study versus single stance time in seconds in the other. In cadence and stride length, however, our study revealed less variability by smaller absolute reliability values. The method of calculating gait parameter values at a common reference speed might be a more reliable way of expressing gait parameter values than using a single or the average of three trials, as in the study by Wondra et al. [142], where walking speed might be a confounding factor.

Reliability of gait parameters as measured by computerized gait analysis, has been found dependent upon GMFCS-level [143], children in GMFCS-level I exhibiting higher reliability than children classified in GMFCS-levels II and III. In our study, we did not find differences in reliability with respect to either GMFCS-level or age (Paper I). However, children classified in GMFCS-level III were not included. The recording of gait parameters from children who usually use crutches, canes or other walking devices are, however, possible when using an electronic walkway, but might require additional work to identify foot steps.

Feasibility and recommendations for use of the GAITRite as a research tool

The electronic walkway was tried out on two different sites during the reliability study and it was easy to transport the walkway and use it in a location familiar to the children. Furthermore, it was easy to motivate the children to walk over the walkway, the procedure of walking at three different speeds was easily understood by the children as young as three years, and the procedure required little test time; approximately five minutes for each child (Paper I). There was no requirement of placement of any devices on the child and the raw data could be stored to be analyzed by skilled professionals later.

Careful attendance of the administration procedure with observation of the child's ability and need for additional visual or verbal instructions might increase the reliability of the walkway (Paper I). Picking up toys at the end of the walk can serve as motivation for performing repeated walks, and most children found it exciting to look at their own footfalls on the computer screen when all the walks in the procedure were carried out. However, for most children, additional motivation beyond instructions seemed not needed.

The walkway seems to have limitations when children use a shuffling gait pattern, as the registration of single footsteps by the sensors inherent in the walkway is thus complicated. In a previous pilot study [144], the walkway was found to have limitations in recording footfalls in young children possibly due to their low weight. However, this was not found in the present study. The procedure of walking over the walkway at three different speeds requires vision and cognitive abilities, and will hence restrict the use of the walkway for groups of children with CP.

Compared to examination of gait parameters in a gait laboratory, the cost of the walkway equipment, the training of administrators and the time used for preparation and analysis of the gait data, are considerably less. The walkway has limitations compared to gait analysis performed in a gait laboratory, since it records neither kinetics nor kinematics of the gait pattern. However, the walkway might have advantages in investigating aspects of gait. The impact on gait parameters of different interventions like strength training [145], NDT [146], treadmill training [147] and hippotherapy [148] have been investigated in children with CP, some studies showing a large positive impact of the intervention on gait parameters [145-147], whereas in other studies such impact was not found [148]. The walkway was included in the protocol of the intervention study to investigate change in gait parameters as a result of the activity-focused, intensive physiotherapy. However, this

part of the project was not carried out due to illness of the PT who was to administer the assessment with the walkway, and practical difficulties to recruit and train another in time for the assessments of the first groups. Hence an important outcome measure is lacking in the intervention study, but the research question is of interest and will be further investigated.

Reliability of the quality of movement measures GMPM and QUEST

GMPM and QUEST are observational measures constructed to describe and evaluate quality of movement in children with CP. The scoring of the measures is complex since several aspects of movement quality are to be scored concurrently in each item; hence the observer-reliability is of concern.

Intra-observer and inter-observer reliability in items scored from video clips were examined, and the total scores on both measures were found to be highly reliable (Paper II). Scoring of the GMPM and QUEST entirely from video clips have to our knowledge not previously been performed, but the reliability of the total scores correspond to results from studies performed by the developers of the GMPM [110,111] and the QUEST [115,116] in a clinical setting, and in addition to a recent study regarding inter-observer reliability of the QUEST [149].

The sub-scores Alignment and Weight shift in GMPM and Protective extension in QUEST were likewise found highly reliable, whereas the reliability of the other domains of the measures and single items revealed a large range of reliability coefficients (Table 2, Paper II). In the sub-scores with low reliability, the ICC values were lower than ICC values found in other studies [110,112,115,116]. As the concept of movement quality and scoring of the items were seen as challenging, as also indicated by others [112,117] much effort was used to discuss the definitions and the

scoring of items, particularly in the GMPM. A total of 22 hours over a four-month period were used for training. However, the training and the practice of the scoring systems might not be sufficient, and the decision to focus on the GMFM at the cost of the QUEST (Paper II) might have been a reason for the low reliability of some the sub-scores of the QUEST. The sub-scores with the lowest reliability, Dissociated movements in both measures, require observation of several body parts and joints concurrently and seem to require good observation skills and knowledge of the scoring criteria. The sub-scores with high reliability; Alignment and Weight shift in the GMPM and Protective extensions in the QUEST, could be seen as the quality attributes most alike those clinician observe and describe in clinical practice, and hence be most familiar to the assessors.

It has been claimed that if inter-observer reliability is high, intra-observer will consequently also be high and there is therefore no need for testing this [5]. In this study, however, the inter-observer reliability in some scores was higher than intra-observer reliability, also implying that within assessors' interpretation, the scores might vary. Hence, in observer dependent measures, there might be a need for the examination of intra-observer reliability.

Feasibility and recommendations for use of the GMPM and QUEST as research tools

Quantifying quality of movement patterns is demanding and assessing quality of movement from video clips was found to have many advantages for the assessors and the children, such as the possibility to watch the video clips several times, a more efficient scoring while the assessments were edited and a less demanding test situation for the children while the assessment was not interrupted by scoring (Paper II). However, the use of video scoring is also costly in terms of training, editing and

scoring. An expanded manual and training-DVDs with examples of the scoring would have clarified the scoring options and secured the understanding of the dimensions of the measures.

The total scores of both measures demonstrated high reliability and are recommended used for research. The total scores consist, however, of several sub-scores representing different aspects of movement quality. As goal setting, intervention planning and evaluation may relate to only some aspects of movement quality and a change in a particular attribute/domain may be masked in the total score; reliability of separate domain scores should be of concern. Even if the sub-scores of the GMPM and QUEST were designed to capture clinically useful information, we recommend that only the total scores are used for research purposes to avoid measurement error obscuring the results.

Strengths and limitations of the methodological studies

Heterogeneous samples of children with CP from three municipalities in Western Norway were included in the two studies. In Study I, this secured the examination of reliability in a sample with different gait abilities. In Study II, all GMFCS- and MACS-levels were represented in the sample, which secured that all items were included in the reliability study, which is essential when examining the reliability of an assessment tool. The samples of the reliability studies were seen as representative with regards to age, GMFCS- and MACS-levels of the population of interest in the intervention study.

The number of children in the reliability studies are in line with earlier methodological studies in the field [110,112,115,116,149], but the samples are

smaller than suggested (n=50) in a recent paper on quality criteria for measurement properties [12]. The sample sizes were based on practical considerations; however, a larger sample might have given a more precise estimate of the reliability of the GAITRite®, the GMPM and the QUEST. Larger samples might also have provided better estimates for reliability of subgroups of children, and revealed differences between functional levels, which were not uncovered in the present studies.

The results of the reliability studies are limited to children with CP aged 3 to 13 years. The inclusion criteria of the studies were youths up to 15 years of age. It seemed, however, difficult for children in the final years of primary school and secondary school to participate during day-time, as is understandable, and if older children were to participate, one might consider other times of the day and other ways of recruiting the children.

In Study I, only children classified in GMFCS-levels I and II were included, but the electronic walkway may also be a possible outcome measure for children classified in GMFCS-level III. This subgroup could have been included to examine reliability in children who are able to walk with assistive devices and hence broadened the scope of reliability study. In Study I, only one PT administered the assessment with the walkway. Examining reliability with several administrators might also have revealed whether the administrator influenced on reliability of the gait parameters.

In Study II, the assessors were trained to score the measures simply on the basis of the written test manuals, without training with more experienced users of the quality of movement measures. In addition the reliability was examined on the basis of scorings from video clips, and both these conditions might have affected the reliability. A design that separated these two conditions might have revealed whether the training or the scoring from video-clips were the main source of variability in the scores. It is

evident that scoring of the quality of movement measures requires competence and experience in movement analysis in children with CP and preferably also competence in testing. Hence the results of this study can not be generalized to novice physiotherapists. The administration of the measures with video uptakes for subsequent scorings also requires good knowledge of the measures and experience in testing.

Intervention Study

When the intervention study was initiated, the body of knowledge regarding effects of intensified physiotherapy programs for children with CP was limited. Few studies had been performed and the results possibly biased by methodological weaknesses [27,28]. There were indications, however, that increased frequency and duration of training might provide more gains in basic motor abilities than common training at the time, often implying one hour of weekly physiotherapy [34,91,92,94,96,98]. The funding of developmental projects in the habilitation field in the time period of 2002 to 2008, made it possible to accomplish intensive physiotherapy training in groups for children with CP at four habilitation units in Western Norway, and to investigate the outcome in a systematic way.

Change of functioning in a capacity and performance perspective

The main outcome measure in the study, the GMFM, is considered a measure of a child's capacity, meaning what a child can do in a standardized environment [77]. The study revealed significant improvement in basic motor abilities after the intervention period as measured by the GMFM. The children with the highest functional levels (GMFCS-level I and II) obtained more gains in motor function than children

classified to Levels III to V (Paper III), which is in line with development curves for children with different GMPCS levels, constructed by Rosenbaum et al. [72]. Different abilities to change, depending on GMPCS levels, have also been shown in other intervention studies [91,93]. However, also children classified at levels III to V improved in gross motor function in the present study, implying a potential for change when the children participated in three weeks of intensive physiotherapy training.

What the child is capable of doing in a standardized setting might, however, not correspond to what the child performs in everyday life with constraints like distance, speed and safety [150]. The emphasis on assessing functioning in actual life situations has increased over the last ten years [33,86,127,151]. Tieman [86] found that children and youths with CP, well capable of walking without assistance, chose different locomotor strategies in different environments; walking without walking aids at home, with crutches or canes at school, and use of a wheelchair in the community. Children with anticipated similar functioning according to GMFCS-level, were found to use quite different locomotor methods in everyday life [152]. While children with severe functional limitations gained improved GMFM scores after an intervention, these improvements were not found to be transferred to improved abilities in home environments [153]. The intensive training in the present study was accomplished in the child's local community, but not in the everyday setting of the child, like kindergarten, school or home environments. The transference of potential achieved capacity to performance in home environments was hence of concern when planning the study, including PEDI as a supplementary measurement tool.

The PEDI is based on the parents' perception of the child's performance in everyday environments, and our results did indicate a positive change after the intervention period. The parents reported that their children had obtained increased participation in everyday activities, and that they needed less assistance in mobility (Table 4, Paper

III). This is in line with results of a 3-year longitudinal study by van Eck et al. [151] who found increased motor capacity to be significantly related to improved motor performance in children with CP. There might be several components in the intervention model, in addition to the motor practice, that contributed to these changes. The group training included extensive education and supervision of parents and local professionals to secure knowledge transition and carryover to the child's daily environments. The developing child is strongly dependent on the caregivers and the social environments, hence the influence of the environmental factors on functioning may in this phase be even greater than later in the life span [8]. Increased knowledge, skills and changed attitudes achieved through participation in the intervention period, might have influenced the children's social environments and hence their performance in daily life.

Since the intensive training was performed in a group setting, the social function domain of PEDI was also included in the assessment. In this domain, as well as in the children's functional mobility domain, some improvement was indicated, but the change was not statistically significant. In the interviews with the parents, all underscored their child's functional improvements, and exemplified change observed in the home environments within all dimensions of the ICF [42] such as; improved ability to take turns, improved self-esteem and more engagement in play in kindergarten and at home. In paper III we have discussed our experiences with PEDI which in some cases served as an educational tool for the parents at the pre-intervention assessment regarding performances of their children. Other administrations of the PEDI, like informing the parents about the contents of the items before the interview, or administration over two sessions might have improved the validity of the parent's information, particularly at the beginning of the study. An expanded assessment of the children's performances in everyday settings with more emphasis on participation e.g. by the "Children's Assessment of Participation and

Enjoyment" [154] or the "Test of playfulness" [155] might have revealed other aspects of transference between capacity and performance. In other studies of intensive therapy where PEDI has been used as an outcome measure, significant gains in approximately the same domains as we have found, have been shown [96,97]. The social domain, however, is seldom used as an outcome measure, but in one study where the children intensively performed goal directed activities in their daily environment, and in addition participated in one group session per week, significant improvements in the social dimension were demonstrated [97]. This may raise a question of whether an ecological approach is more beneficial than intensive group training, not taking improved social functioning in particular into consideration. This is a subject of further investigation, where the aim of the intervention should be further discussed.

Change of functioning in an individual and a group perspective

A principle in the intervention model applied in the present study was to emphasize the child's own goals for the training period. In the written invitation as well as in the verbal information given prior to the study, the caregivers received information about the goal setting process (Appendix 7), and were encouraged to reflect upon goals for the intervention period and discuss possible goals with the child's local professionals. During the baseline period, the children were repeatedly tested with motor assessment tools according to the protocol, and parents were interviewed regarding the children's performance of everyday activities. After the two first assessments in the baseline phase, preliminary goals were written and finally formulated at the third baseline assessment, allowing the decision of goals to be a process.

Due to the time consuming process of constructing GAS-follow up scales, such scales were only constructed for half of the goals. For the remaining goals, parents and

professionals reported orally after the intervention to what extent the goals were attained. On average the children's expected goals in the GAS scales were attained, as reported in Paper III. The individual goals were in the field of basic motor abilities, self-care and movement patterns, and probably reflected the parents' decision to participate in a physiotherapy training group. The contents and scores of the non-GAS goals were not reported, but the type of goals and the goal attainments were quite similar to the GAS follow-up scales. The participants in the groups seemed to appreciate the goal directed approach, as has also been found in other studies [34,35,97,156]. The individual goal setting approach also seemed feasible from a clinical point of view, and has been continued as a basis for training in later groups [41,42].

In the intervention study statistical significance of change scores for the total sample was of concern. However, other frameworks for examining change might have been used. Due to the heterogeneity of the population and the challenges of performing randomized controlled trials (RCT-studies) or case-control studies in the CP population, single subject approaches have been proposed [27], where children act as their own controls. A complementary evidence judgement scale for single subject research has been developed [157] and implemented in the American Academy for Cerebral Palsy and Development Medicine (AACPDM) outcome reviews. In the present study a characteristic of the single subject paradigm was used by implementing the repeated measures design. Each child acted as its own control, and variability due to heterogeneity in the sample was removed [3]. A further extension of the individual paradigm, would have been to calculate the percentage of individual children who exceeded a minimal important change (MIC) in the outcome measures, or as suggested by Terwee et al.[12], use the equation MIC/$\sqrt{n}$ to calculate a minimal important change in group studies. However, as we have discussed in Paper III regarding the GMFM, but also relevant for the other outcome tools, the distribution of

GMFCS-levels and ages in the sample would probably influence the expected MIC value. Researchers have previously proposed different change scores of the PEDI [99,118] and the GMFM [99,158] to be clinically relevant. Presently, there is no accepted value of MIC for the developing children with CP, and for some children merely the maintenance of motor and everyday function might be relevant goals, according to the motor growth curves of CP [72,73,159]. The concept of MIC will, however, be of value when more knowledge of change in different age groups and functional levels is gained.

Quality of movement and basic motor abilities

Quality of movement is a controversial term. The aim of attaining "normal" movement patterns has been a guideline for clinical physiotherapy practice, for instance in the NDT approach [89], but has been given little or no focus in task oriented therapies and measurements [7,14,77]. As quality of movement is defined and used differently, it is a demanding construct to operationalize. Different aspects of movement quality have been addressed by the two measures applied in this thesis, but the measures have been criticized for not having an underlying theoretical construct [160,161], and not including all relevant aspects of quality of movement like effort, force, timing and velocity [161]. However, to our knowledge at the start of this study, these were the only quality of movement measures developed and validated for the population of children with CP.

The results of this study indicate that quality of movement as measured by the GMPM improved when basic motor abilities as measured by the GMFM improved (Paper III); hence there seems to be a connection between quality and ability. Further studies are needed to investigate this connection, whether development of abilities is a prerequisite for development of quality, or vice versa. The impact of quality of

movement in CP on e.g. effort and prevention of secondary impairments, is also an important subject for research.

Manual guidance in therapy is often used as a tool to improve the quality of a movement. Recent theories of motor learning recommend, however, avoiding or minimizing manual guidance to support the child's own solution to a movement problem [135]. When watching video uptakes from the groups, it was evident that manual guidance served different purposes; as postural support, to increase variation in movements and joints, and to make the child able to contribute in the group activities (Appendix, Paper III). The challenge was to provide sufficient, but not too much guidance. There were examples of children who seemed irritated and disturbed in their execution of a task by the manual guidance. Hence if manual guidance is to be given, it should be necessary, adapted, and gradually reduced. The child's caregivers who provide the manual guidance need, accordingly, substantial supervision. However, in the intervention model of this study, there was no request of normal quality of movement, but variation was a principle. According to the model of Valvano [136] this could preferably be achieved through active interventions, but also through passive intervention if necessary.

Content and description of the intervention

When the goals of each child were determined, the two group leaders designed the group program based on each child's goals and also with elements aiming to prevent secondary impairments, as suggested by Valvano [136]. The "intensity" in the groups was defined as increased duration and frequency of physiotherapy in a three-week period, as well as a strong "drive" and continuous activity in the groups, with few breaks [41,42]. The number of repetitions of the activities was challenging to record due to variations between and within the children. From video uptakes of the groups,

it was evident, as discussed in Paper III, that motivation and individually tailored demands on the child was a prerequisite for high intensity of training, meaning that the child performed many focused and repeated efforts to complete a task. As a consequence, the training implied continuous adaptation of the tasks and the demands on the child, and in addition exploration of the appropriate level and type of support. The ability to perform such individualized physiotherapy in a group setting requires knowledge and experience in the group leaders.

The intervention model employed in this thesis was multifaceted and developed in accordance with recent theories of motor development and learning [135,136]. It was inspired by goal-directed and family centered practice [36,162] and by experiences from clinical practice. In the developmental phase of the intervention model, several meetings with participating parents and professionals were arranged before, during and after the first pilot groups and after subsequent groups. This strengthened the user's perspective of the intervention and resulted in a program that might be considered "best practice" as seen by professionals and parents.

The interventions of earlier research have been criticized for being poorly described [27,28,30], and not sorting out the various elements [26]. One objective of Paper III was to make a careful description of the intervention, beyond general terms described in previous articles [39,41,42]. An inductive approach was used to describe the intervention from video recordings of a group session. Several ways of describing interventions were identified [153,163,164], most describing individual interventions. The "Motor Teaching Strategies Coding Instrument (MTSCI-1)" by Larin [165] was found the most appropriate; however, substantial adaptations of the coding scheme were made in order to capture meaningful elements of a group session. One session of each of the groups had been videotaped by professionals from the habilitation unit. Each video recording lasted between two and three hours, depending on the number

of breaks, and whether dressing and undressing were recorded or not. A more united instruction for the videotaping would have secured that all activities in the groups had been captured. All video recordings were viewed and broadly described by the investigator. One group setting was selected for further description as it was seen as representative. The selected video uptake was viewed several times and described according to the adapted MTSCI-1 (Appendix, Paper III). The careful description gives an opportunity to get insight into the content of the intervention and to compare this type of intervention with other types of interventions.

Assessment tools

The use of different assessment tools in previous research has made comparison of results difficult across studies [30]. A common toolkit of measures would make it possible, despite small samples and different designs, to compare results in children with CP across different functional levels and ages [27,29]. No common toolkit has been suggested, but the GMFM and PEDI are often used.

The ICF has increasingly been used as a framework for assessment in studies of children with CP [77,118,166]. The model has been considered useful, but not able to capture all aspects of functioning addressed in habilitation services [167]. The assessment tools used in the present studies were chosen to reflect dimensions of the ICF-CY. The GMFM was used to measure activity components of the ICF [2], and items of the PEDI were mainly used to assess activity and participation components, but the environmental factor is also inherited in the measure [168]. Depending on the goal, GAS may reflect all components of the ICF-CY, and gait parameters are part of the body function component according to the coding system of ICF-CY. The two quality of movement measures, GMPM and QUEST, include aspects of movement patterns as is seen as a part of the body function component. In addition, both

measures seem to include aspects of the activity dimension, such as “stability of body positions” assessed by the GMPM and “hand function” assessed by QUEST. Hence, the quality of movement measures are more difficult to link to a particular component of the ICF-CY.

When administrating the GMFM and the QUEST, it is possible to adapt the sequence of the items to what is suitable to the child and accomplish the items in a frame of play. The GMPM, however, is less adaptable, as the items have to be administered in the order of the scoring form and each item is to be repeated three times. This requires good cognitive skills, cooperativeness and endurance from the child A new version of the GMPM, called Quality FM [169], is designed for use with children who are in GMFCS-levels I to III and focuses on quality of movement related to ambulation. This might be a simpler and more user-friendly assessment tool of movement quality.

There were few missing test data, despite the repeated and comprehensive assessments. In the last follow-up assessments, however, four of the children were tired and extremely little motivated for the assessment, and the administrator decided it was too detrimental to the children to complete the GMPM. This might have influenced the results of the last follow-up assessment negatively as the scores of the first follow-up assessment were carried forward.

There is no recommendation about the time intervals of assessments in the manuals of the assessment tools. One may question whether a change in everyday activities could be apparent after 6 weeks. A longer follow up period would have captured a change in a longer time-frame; however, the effect of maturation could then have blurred the results.

Strengths and limitations of the intervention study

In intervention studies, the internal validity, meaning the extents to which other factors than the intervention cause the change in outcome, and the external validity, the generalization of the results, is of concern [170,171]. This intervention study investigated the effectiveness of a clinical intervention offered to children in their local community. As compared to an efficacy approach, where the research environment ideally is highly controlled, a homogeneous sample is included and the treatment is highly standardized, an effectiveness study entails more threats to internal validity [172]. Maturation and learning in the participating children, the small sample size, anti-spastic medication, lack of standardization of the intervention and the lack of blinding of the assessors are sources of threat to the internal validity in the present study.

The repeated measures design that was chosen and the stable baseline phase prior to the intervention phase, control to a large extent for maturation and learning effects in the children. A power analysis was performed prior to the intervention (Paper III), and the sample size of the present study was suggested as sufficient. The effect of anti-spastic medication was investigated, but demonstrated no significant effect (Paper III). A larger sample, however, might have provided better estimates of results in subgroups of children, according to functional levels, age groups and effects of additional anti-spastic medication.

The group leaders participated in a two-day workshop and were in addition supervised three times during the three weeks intervention period to secure that the training was accomplished according to the principles of the intervention model. Assessors not involved in the intervention with experience in the use of the

assessment tools, administered and scored the outcome measures. Moreover, all the assessments were videotaped to give the possibility for validation of the clinical measures. Blinded assessors scored video clips of two assessment tools, but the change in quality of movements were less than in the other assessment tools. The blinding of the other assessors was difficult and was not performed. This might have biased the results, and the lack of blinding may be the largest limitation of this study. Hence, compared to an efficacy study, where Randomized Controlled Trials (RCT) give the highest level of evidence in group research [173], and where internal validity is strong, the results of this effectiveness study give a weaker indication of cause-relationship between the intervention and the outcome.

Despite the methodological strengths, efficacy studies might, however, have limitations in their ability to estimate treatment effects that can be expected in clinical settings [172]. Effectiveness studies evaluate treatment responses in settings that are more representative of ordinary clinical practice and hence might provide higher external validity [174]. In this study inclusion criteria were children with CP in pre- or primary school, where the parents wanted a more intensive training program. The sample was heterogeneous and seemed representative of children and families who want periods of more intensive physiotherapy. The intervention was carried out at four different sites, by different group leaders, within different organizations. In two sites, the intensive training was carried out in the habilitation units, in one site, at a private physiotherapy institute and in the last site, in a municipality physiotherapy service. The intervention model is hence applicable in different settings, and the outcomes may be generalized to other similar intensive training groups for children with CP aged three to nine years with a diagnosis of spastic or dyskinetic CP. The study can be considered the first step in providing more evidence based practice in this field.

Ethical considerations

The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects [175]. In the declaration it is stated that the well-being of the individual research subject must take precedence over all other interests, and special precaution is necessary in research populations including humans that cannot give consent for themselves, e.g. children under the age of eighteen.

The research protocol for this study contained descriptions of the ethical considerations involved and how the principles in the Helsinki declaration were addressed, and it was approved in advance by the Regional Ethical Committee. Written informed consent was obtained from the children's parents before participation in the study, and effort was made to give the children age appropriate information about the aims of the studies. The parents might feel an obligation to participate in the research study since the intervention was carried out in a group setting with close contact between the parents and professionals from the habilitation units. However, the children could participate in the group training without participating in the research study as illustrated in one of the training groups. In addition, the parents seemed to value the thorough examination of the children before and after the intervention and appreciated a scientific evaluation of the physiotherapy intervention.

In the intervention study, each assessment lasted for 60 to 90 minutes and the child was escorted by its parent(s). Effort was made to put as little strain on the children as possible, e.g. by accomplishing test items in a frame of play, and taking breaks when needed. In the methodological studies, the assessments were shorter and each child

participated in only one assessment. We discussed in advance whether and in what ways the extensive testing before and after the intervention period could put strain on the children and their parents. Four of the GMPM follow-up assessments in our study are missing due to the PTs' judgement that it would be too detrimental for the children to carry out the last GMPM assessment. These decisions ensured that the children's well-being was taken care of, and that they were prioritized before accomplishment of the assessments. Except for this, it is our experience that the assessments and also the parent's interviews were well within acceptable limits for the participating children and their parents. On the contrary, the parents appreciated the effort made to investigate and document changes in motor function.

To participate in a daily physiotherapy program over weeks may impose strain on children and parents. The two PTs who conducted each group were experienced and the training was individually tailored to the child's current state. It was a goal that every child should experience mastery of the demands and get an individually tailored program within a group frame. The group training was based on play with use of songs, stories and rhymes as motivating factors (Appendix, Paper III). However, if the parents or professionals found the intensive training too strenuous, the training would be terminated. One child with family did leave the intensive training and continued the ordinary physiotherapy program.

Intensive periods of physiotherapy in habilitation services

Children who need prolonged, combined services are entitled to an individual plan. The purpose of an individual plan is to provide a complete, coordinated and individually tailored set of services [176]. This study as well as several other studies [34,91,92,95-97] indicate that an increased amount of physiotherapy in a limited time-frame improves basic motor abilities and have positive implications for everyday life in children with CP and their families. Most models of intensive physiotherapy and multidisciplinary intensive habilitation developed with funding from the Directorate of Health and Social Affairs have been implemented in clinical practice. Short, focused, intensive periods of training may be one possible and effective way of attaining goals important to the child and the family. To secure priority, support and coordination such periods must be incorporated in the child's habilitation plan.

In older children and adolescents, the model of intensive physiotherapy presented here is not sufficient and youths might enjoy and need other types of physical intervention and leisure activities like strength training and sport. Challenges of becoming a part of working life and participating in leisure activities are reported to be more pronounced in adulthood [177]. A lifetime perspective must hence be incorporated in habilitation and physiotherapy, encouraging the possibility of performing physical activity in a lifetime perspective [24]. Possible overuse as well as disuse of the muscular and skeleton systems in different phases of the life span should also be of concern [79,178].

Conclusions and further research

The objective of this thesis was to gain increased knowledge of measurement properties of three assessment tools which were considered to be useful as outcome measures in multicentre studies including children with CP, and further investigate whether intensive physiotherapy organized as group training affected functioning of children with CP.

The measures revealed good measurement properties and are a supplement to other research methods for the population. In the intervention study, positive, significant changes in basic motor abilities and self-care, and reduced caregiver's assistance in mobility and self-care were found after a three-week period of intensive activity-focused, goal-directed group training. The intervention seemed to be motivating and well tolerated, and a feasible way of improving motor functioning in children with CP.

Further studies are already ongoing, where the outcome measures examined in this thesis are included. One study uses the electronic walkway as an assessment tool when children with CP in preschool age participate in intensive, activity-focused and goal-directed group training. The aim of the study is to examine the relationship between change in gait parameters and change in basic motor abilities. In another pilot study including six children with severe CP, change in quality of movements is examined by scoring the assessment tools from video clips. Studies examining test-retest reliability of gait parameters within a longer time frame and studies of responsiveness to important change will elucidate the value of the walkway as an evaluative measure.

Several families want to participate in repeated periods of group training. In the pilot project, further gain in basic motor abilities was found when children participated in a second intensive training period. A model containing two periods of intensive physiotherapy a year for children in pre and first years of primary school, with less focus on motor training in the periods in between, is presently being investigated.

A multicentre study in Norway where children diagnosed with CP are followed with systematic assessments for three years from the time of diagnosis, is presently being initiated. A prospective study over an extended period of time with careful registration of the children's age, functional level and habilitation services, including periods of intensive training, would give accumulated knowledge of the outcomes of different approaches regarding the child and the family in a long time perspective. To conclude, there are many challenges for further research in the field of intensive training for children with CP.

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