Intensive training in group for children with Cerebral Palsy

Evaluation from different perspectives

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To my family Sven,
Jakob, Ina and Sissel

What is wanted is not the will to believe, but the wish to find out, which is the exact opposite.
Bertrand Russell 1928
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ABSTRACT

The general aim of this thesis was to evaluate the effectiveness of intensive training in groups (ITGs) with a habilitation approach and a conductive education approach. In addition, this thesis explored different meanings of participation in ITGs to parents from a parent perspective. This thesis consists of two parts, a quantitative evaluation of the effectiveness of two ITGs (paper I-III) and a qualitative study exploring parents’ different ways of experiencing ITGs (paper IV). Fifty-four children, 3-16 years old, with different types of CP, intellectual capacity and level of gross motor function, participated together with their parents in a four weeks ITG with a short-term and a one-year follow-up (paper I-III). The second sample was strategically composed of parents to 15 children with CP with experiences of ITGs in different settings.

The results showed that the proportion of clinically significant change in gross motor capability, functional skills or self-reported individualized goal measure didn’t show any major differences between the two ITGs. One period of ITG facilitated small clinical and parent reported improvements in functioning short-term. Nine children out of 54 made a clinically significant improvement in gross motor capability (GMFM-88 total score), 36 children improved if an improvement in any dimension A-E was counted for. Twenty-two children out of 52 improved in one of the domains self-care, mobility and social function (PEDI functional skills). Twenty-eight parents out of 54 perceived a clinically significant improvement on the self-reported individualized goal measure. Most individualized goals dealt with motor activities and movement-related body functions in both ITGs. The self-reported individualized goal measure was not found to be more sensitive to change than the clinical measures.

The one-year follow-up showed that children had a stable level of functioning. No child deteriorated on the clinical measures short-term and at the one-year follow-up. A higher proportion of change was seen in the social function domain at the one-year follow-up indicating a better potential to change in social function than in gross motor function. The majority of children had a high consumption of training delivered by the Child and Youth Habilitation and merely half of the group continued with repeated ITGs. The differences in
functional outcome between children continuing with repeated ITGs compared with only customary Child and Youth Habilitation were limited to a higher proportion of improvements in social functioning.

Parents perceived a high service quality in both ITGs. Fulfilment of health care needs was as important as functional outcome to parents. The probability for high service quality was associated with previous experience of the ITG, high expectations of improvements, if expectations and improvements in gross motor capability were achieved and if the child participated in the ITG with the habilitation approach. Therapists in the habilitation approach were more involved in discussions with parents about expectations for the ITGs and knowledge exchange than conductors were, indicating more family-centeredness.

The qualitative study points to a variety of parental needs that may be met at ITGs but also indicates some problems that should be addressed. Five overarching meaning categories of ITGs were described: ITGs as knowledge promotion, as a complementary training resource, as a bracket to ordinary life, as building up relations with therapists, and as a leisure-activity. An additional category – “ITGs as risk for ill-being” – subsumed different kinds of problems that may arise. Conceptions suggest that ITGs contribute to parents’ improved knowledge, support and well-being but ITGs could also be experienced trying for family-functioning.

Professionals and parents need to discuss parents’ previous experiences of ITGs, expectations of functional improvements, the functioning of the child and health care needs in order to individualize goals for ITGs and make the objectives for participation clear. There were no major differences in effectiveness between the two ITGs, a habilitation approach and conductive education approach. Various training approaches should be chosen depending on the child’s and family’s needs. In the choice between different training approaches it is of equal importance to acknowledge functional needs of the child as well as health care needs of the child and parent.
LIST OF PAPERS


II. Ödman P, Öberg B. Effectiveness and expectations of intensive training – a comparison between child and youth habilitation and conductive education. Disability and Rehabilitation 2006; 28 (9): 561-570


IV. Ödman P, Richt B, Öberg B. Parents’ conceptions of intensive training in group. The case of Cerebral Palsy. Submitted
# Abbreviations

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<th>Description</th>
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<tr>
<td>ITGs</td>
<td>Intensive training groups</td>
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<tr>
<td>rITG</td>
<td>Group receiving repeated periods of intensive training</td>
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<tr>
<td>Cust-group</td>
<td>Group receiving customary amount of training</td>
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<td>CE</td>
<td>Conductive Education</td>
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<td>GMFCS</td>
<td>Gross Motor Classification System</td>
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<td>BMFM</td>
<td>Bimanual Fine Motor Function Scale</td>
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<td>EP</td>
<td>Epilepsy</td>
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<td>FCS</td>
<td>Family Centred Services</td>
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<td>GMFM</td>
<td>Gross Motor Function Measure</td>
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<tr>
<td>PEDI</td>
<td>Pediatric Evaluation of Disability Inventory</td>
</tr>
<tr>
<td>PEDI FS</td>
<td>Pediatric Evaluation of Disability Inventory - Functional Skills</td>
</tr>
<tr>
<td>PEDI CA</td>
<td>Pediatric Evaluation of Disability Inventory - Caregiver assistance</td>
</tr>
<tr>
<td>GAS</td>
<td>Goal Attainment Scale</td>
</tr>
<tr>
<td>PSFS</td>
<td>Patient Specific Functional Scale</td>
</tr>
<tr>
<td>COPM</td>
<td>Canadian Occupational Performance Measure</td>
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<tr>
<td>NDT</td>
<td>Neuro-developmental treatment</td>
</tr>
<tr>
<td>SRIGM</td>
<td>Self-reported Individualized Goal Measure</td>
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<tr>
<td>SMR</td>
<td>Severe Mental Retardation</td>
</tr>
<tr>
<td>MMR</td>
<td>Mild Mental Retardation</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Diseases (ICD-10)</td>
</tr>
<tr>
<td>POCR</td>
<td>Patient perspective on Care and Rehabilitation process</td>
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<tr>
<td>MPOC</td>
<td>Measurement of Process of Care</td>
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## DEFINITIONS

Definitions of key terms in the WHO’s International Classification of Functioning, Disability and Health (ICF) [1];

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<tr>
<td>Functioning and disability</td>
<td>Umbrella terms conceived as a dynamic interaction between health conditions (eg. diseases, disorders, injuries) and contextual factors (environmental and personal factors).</td>
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<tr>
<td>Functioning</td>
<td>In the present study functioning was conceptualized and confined to embrace aspects of body function, activity and participation.</td>
</tr>
<tr>
<td>Body Functions</td>
<td>The physiological functions of body systems (including psychological functions).</td>
</tr>
<tr>
<td>Body structures</td>
<td>Anatomical parts of the body, such as organs, limbs and their components.</td>
</tr>
<tr>
<td>Impairments</td>
<td>Problems in body function or structure, such as deviation or loss.</td>
</tr>
<tr>
<td>Activity</td>
<td>Execution of a task or action by an individual.</td>
</tr>
<tr>
<td>Participation</td>
<td>Involvement in a life situation.</td>
</tr>
<tr>
<td>Activity limitations</td>
<td>Difficulties an individual may have in executing activities.</td>
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**Definitions**

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<tr>
<th>Definition</th>
<th>Description</th>
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<tr>
<td>Environmental factors</td>
<td>The physical, social and attitudinal environment in which people live and conduct their lives.</td>
</tr>
<tr>
<td>Personal factors</td>
<td>The particular background of an individual’s life and living, composed of features of the individual that are not part of a health condition or health state (note that personal factors are described but not classified).</td>
</tr>
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**More definitions**

<table>
<thead>
<tr>
<th>Definition</th>
<th>Description</th>
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<tr>
<td>Capability</td>
<td>Best possible performance of a task in either a standardized or an ideal situation [2 p. 7].</td>
</tr>
<tr>
<td>Performance</td>
<td>Refers to measurements of functional behaviours as they actually occur in the environment [2 p. 7].</td>
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INTRODUCTION

There is a high demand for physiotherapy indicating a need for parents to children with Cerebral Palsy (CP) of more support with the child’s training [3] and different treatment/training approaches reappear periodically [4, 5]. Parents who perceive that the child does not receive enough training tend to look for alternative therapies [4]. Several reasons have been put forward why parents in general look for alternative or complementary training approaches; uncertainty about the effectiveness and utility of existing treatment/training methods [5, 6]; absence of definitive treatment [5]; and desire to find an effective intervention [7].

Conductive Education (CE) is a well-known Hungarian programme that integrates education and habilitation goals into one programme [7-11]. The method has gained interest from professionals and parents and was spread from Hungary to other countries such as Great Britain, Australia, New Zealand, United States in the late 1980s [7, 10] and in the 1990s the programme was spread to Canada [10]. Many variations of delivery models have evolved in educational and health-care settings or camps and children with different diagnoses and severity levels are included [11].

In the mid 1990s, CE was gaining public interest in Sweden among adults with CP, parents and professionals. It was introduced by parents as a training-camp led by a Hungarian conductor who introduced a slightly adapted CE approach called Move&Walk. Since 1997, the Scandinavian Move&Walk Institute delivers intensive training groups (ITGs) during 4-week intensive training periods [12, 13].

Several reasons for introducing CE in Sweden have been suggested: curiosity, potential for improvements or failure to support parents and finding satisfactory services of treatment/training for their children’s habilitation [12, 14]. At the time there was a worry that optimal functioning of the child was restrained due to a liberal use of technical aids and environmental adaptations to support the child in the context of daily life. The Move-Walk Institute emphasised that the goals for CE were active training for improved capacity not only achievement through assistive devices [15 p. 48].
Introduction

When CE was introduced a controversy existed whether the proponents of CE parents and conductors regarded the training approach as an alternative or complementary service. Statements about a more restricted view of assistive devices and environmental adaptations and a priority of training physical capacities in favour of participation and modifications for accessibility in the child’s ordinary environment indicated differences in perspective on health and learning [16].

In response to parents’ demand of more support with training for their children and for group-activities the Child and Youth Habilitation in the county of Östergötland introduced intensive training groups (ITGs) led by physiotherapists and a special educational needs teacher in 1997. ITGs were considered to support parents with the training of the child and complement the service-provision in the ordinary life of the child provided by therapists having a more consultant role. Parents asked for more professionally guided training especially regarding communicative and motor activities. The group-setting was also considered to facilitate the child’s motivation for training and improve knowledge exchange between the participants in the group: children, parents, assistants and professionals. The increased demand for intensive training was supported by emerging evidence for positive effects of more intensive and goal-directed training for children with CP [17, 18], strength-training [19-22] and a recognition of positive effects of practice and repetition for the learning process [23]. The demand for intensive training in groups contributed to professionals and stakeholders interest in financing, developing and evaluating intensive training in groups within the context of the Swedish Child and Youth habilitation Services.

Cerebral Palsy

Definition

Cerebral Palsy (CP) covers a wide range of different clinical presentations and degrees of functional limitations [24]. The term CP is not an etiologic diagnosis, but a clinical descriptive term [25]. Until recently, there was a standard international definition for CP: “CP is an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes
secondary to lesions or anomalies of the brain arising in the early stages of development” [26].

The definition and classification of CP have recently been reassessed and revised. In the new definition common accompanying disorders were identified to emphasise that children with CP have multi-dimensional needs and that the management of these needs requires a multidisciplinary setting. The following is the proposed definition [25]:

“Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.”

Common to all definitions is the insult to an immature brain leading to motor impairment, the non-progressiveness of the lesion and the multi-factorial aetiology [25, 26].

Classification and associated impairments

Different classifications have been developed to describe subgroups of CP. Type of CP depends on what body parts are affected, the topographical distribution [26, 27] hemiplegia, diplegia or tetraplegia. Most recently the term unilateral (hemiplegia) or bilateral (diplegia or tetraplegia) has been recommended until a more precise terminology for diplegia and tetraplegia evolves [25]. CP is also classified according to the predominant neuromotor abnormality spastic, dyskinetic (dystonic, choreoathetoid) or ataxic [25, 26, 28]. Hagberg et al. did a further subgrouping of ataxic CP into diplegic or congenital/ simple [26, 27]. In the present study the definition of Hagberg et al. was used and spastic tetraplegia was defined as severe involvement of all four limbs, the upper limbs at least as much involved as the lower limbs [27]. All cases where the lower limbs were more affected than the upper were classified as diplegia.

The influence of changing concepts about functioning and disability [1] in practice have facilitated the need for acknowledging functional consequences
of different health states in CP. This has facilitated the need for development of functional classification systems [24]. Based on the underlying construction of self-initiated functional abilities in sitting and walking and the need for assistive devices a reliable and valid measure the Gross Motor Classification System (GMFCS) was developed and assessed (Table I) [29-32] The GMFCS is an internationally agreed upon classification of the severity of motor disability in children with CP [33, 34].

Table I. Headlines for description of gross motor function level for children aged 6-12 years as classified by the Gross Motor Function Classification System (GMFCS) (Palisano et al. 1997)

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<thead>
<tr>
<th>Level</th>
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<tr>
<td>I</td>
<td>Walking without restrictions; limitations in more advanced gross motor skills</td>
</tr>
<tr>
<td>II</td>
<td>Walking without assistive devices; limitations walking outdoors and in the community</td>
</tr>
<tr>
<td>III</td>
<td>Walking with assistive mobility devices; limitations walking outdoors and in the community</td>
</tr>
<tr>
<td>IV</td>
<td>Self-mobility with limitations; children are transported or use power mobility outdoors and in the community</td>
</tr>
<tr>
<td>V</td>
<td>Self-mobility is severely limited even with the use of assistive technology.</td>
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Prevalence and functioning in CP

Cerebral palsy (CP) is the most common neuro-developmental condition beginning in early childhood and persisting through life. The prevalence of CP is about 2/1000 live births [35-37]. The actual prevalence of types of CP were 79% spastic of which 38% hemiplegia, 35% diplegia and 6% tetraplegia, 15% dyskinetic, 6% ataxia [36].

The relationship between pathophysiology in CP and components of body function/structure, activity and participation are often complex [38]. One generally accepted classification of clinical motor features in CP is the categorization into positive and negative features. Positive motor features are defined as those leading to involuntarily increased frequency or magnitude of muscle activity, movements and movement patterns such as hypertonia and retained transient infant reactions. Negative features describe insufficient muscle activity or central dyscoordination [38, 39]. There are four negative aspects of central mechanisms for the motor disorder frequently seen in CP, recently put forward and defined; weakness, impaired selective motor control, ataxia and apraxia/developmental apraxia [38].
Understanding of posture and movement problems in CP involves sorting out movement behaviours that are related directly or secondarily to the original CNS lesion. Moreover, movement behaviours related to compensatory motor strategies also need to be understood. Compensatory strategies are regarded as CNS best attempt to compensate for the lesion. Compensatory strategies are alternative approaches to sensing and moving used to accomplish the goal of maintaining the body’s position in space [40].

For a long time spasticity was considered the primary factor that hinders the development of normal postural control and movements [41]. A combination of spasticity with reduced activity may lead to secondary problems such as failure of longitudinal muscle growth with contractures and deformities as a consequence [42]. Common acquired deformities are contractures, dislocated hips or scoliosis [42, 43].

These secondary problems also contribute to the postural behaviour seen in CP [44]. The negative features of weakness, impaired balance and poor selective motor control and problems with posture and movements may influence the child’s activity level more than spasticity and deformities [39, 45, 46]. Another prevalent secondary problem is pain of musculoskeletal origin [47, 48].

More than 50% of children with CP have associated impairments that may have as great impact on functioning as the motor impairments [49, 50]. Common associated impairments are epilepsy (EP), communication problems, cognitive deficits, hearing and visual impairments. In children with CP learning disabilities (defined as IQ<70) were reported in 40%, epilepsy (defined as active epilepsy at 4 to 8 years of age) in 33%, severe visual impairment (defined as functional blindness or an acuity after correction of refraction errors of no more than 0.3 in the better eye) in 19% [50].

The heterogeneity of clinical manifestations leads to large variety of functioning in CP. Reported prevalence of different levels of gross motor function in epidemiological studies of children with CP in Sweden showed 32%-41% of the children were classified GMFCS I: walking without restrictions but having limitations in advanced gross motor skills. Nineteen to 29% were classified GMFCS II representing children walking without assistive devices with limitations walking outdoors and in the community. Eight to 14% were children classified GMFCS III walking with assistive device and with
limitations walking outdoors and in the community. Eleven to 15% of the children were classified GMFCS IV representing children with self-mobility limitations who get transported or use power mobility outdoors and in the community. Sixteen percent were children classified GMFCS V with severely limited self-mobility even with the use of assistive technology [49, 50]. More severe GMFCS levels correlate with larger proportion of associated impairments [50].

Reported prevalence of different levels of upper limb function of children with CP with Bimanual Fine Motor Function Scale (BMFM) have shown that 31% were classified level I: one hand manipulates without restrictions and the other hand manipulates with restrictions or limitations in more advanced fine motor skills. Thirty-two percent were classified level II: one hand manipulates without restrictions and one hand has only ability to grasp and hold. Manipulation with both hands shows limitations in more advanced fine motor skills. Twelve percent of the children represented level III: children having one hand that manipulates without restrictions and the other hand has no functional ability or one hand limitations in more advanced skills and the other hand has only ability to grasp or worse. Twelve percent of the children had severe restriction in manipulative skills level IV, which is defined as the ability to grasp with both hands or one hand only ability to hold and the other hand only ability to hold or worse. Fourteen percent of the children were only able to hold or worse with both hands [50].

Motor impairments and associated problems have various impact in the accomplishment of activities in daily life and social roles. Limitations in accomplishment of activities in daily life and social roles are associated with both reduced level of gross motor function and presence of associated impairments [51-55].

Reduced levels of gross motor function also lead to increasing degree of caregiver assistance and environmental modifications. Environmental modifications are prevalent among children with CP and most often used for self-care, mobility and social function skills. Children with the most severe gross motor function disabilities classified GMFCS IV and V stood for 80% of the environmental adaptations. Children classified GMFCS I used few modifications [56].
Lepage et al. found that performances related to social roles linked to school and social integration showed the highest disruption level indicating a poor social integration of children with CP. Even if children with mild hemiplegia showed the least disruption in life habits significant problems in social integration in recreational habits were also found for mild CP [51]. There are some associations between pain, fatigue and school functioning in children with CP [57, 58].

Advances of knowledge about the life-long course of disabilities in CP have provided support for the need of more long-term prevention programmes [59-62]. Deterioration of physical functioning in adult populations has been described as stiffness, reduced range of movements, pain from musculoskeletal origin and fatigue [59, 60, 62-66]. Increased limitations of walking [60, 62] and of activities of daily living [62] have also been found in adolescent and adult populations.

**Contexts for and conceptual ideas of treatment/training approaches**

**Child and Youth habilitation**

Intensive training groups (ITGs) exist as one treatment/training approach in a comprehensive set of services delivered by a multi-disciplinary team at the Child and Youth Habilitation.

Child and Youth Habilitation is the organisation within the publicly financed health care system in Sweden supplying services for children with CP. The major goals for the Child and Youth Habilitation are to promote health, well-being and functioning of children with CP in ordinary life [67, 68].

Children with CP and their families have different needs and changing needs as the child grows up [69-71]. To meet the different needs the Child and Youth Habilitation is build up around a multi-disciplinary team with medical, psychological, social and pedagogical competences. The management of functional developmental assessment and problem solving should address
needs of the child and family as well as accommodate the child’s home, school and community [69, 72, 73].

Family-centred services (FCS) are an integral part of the service delivery philosophy and inspire professionals to include parental involvement in decision-making, reinforce collaboration, respect and the acceptance of family choices, share information, individualize intervention and enhance parents to feel competent in their role as parents [74].

A biopsychosocial perspective on health is widely accepted by professionals and researchers and the International Classification of Health and Functioning (ICF) serves as a framework for conceptualizing functioning and disability [1]. ICF acknowledges a holistic perspective on health. In a holistic perspective health is judged by the individual in contrast to the particularistic biomedical analytic perspective where health is considered as absence of statistical deviation from normality [75 p.12, 15-16]. In a holistic theory “a person is healthy if he feels well and can function in his social context” [75 p.35]. A change from the biomedical analytic to a holistic perspective of health is advocated as it is of vital importance to move beyond the effort to promote normal function in children with CP toward achievement of abilities and facilitation of independence [77].

The recognition of the child environment interaction reflects that broader perspectives are needed for defining not just health and functioning of the individual but also the role of the environment [70, 78-80]. A key concept in a holistic health theory is ability. Abilities are determined by factors internal in the agent’s body or mind. A combination of the abilities and opportunities for action constitutes what is called a practical possibility, actions that are practically possible for a person to perform if, and only if, he is able and has the opportunity to perform it. To do this, presupposes a situational background. This situational background varies and a tacit knowledge between places and cultures define various “accepted circumstances”. It means that a person with certain abilities may succeed in performing activities in one environment but not in another. This implies an important relativization of the notion of ability [75 xvi]. The relativization of abilities depending on the environment support interventions that focus on adequate

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1 Health defined in action-theoretic terms by Nordenfelt: A is completely healthy if, and only if, A is in a bodily and mental state which is such that A has a (second-order) ability to realize all his or her vital goals, given accepted circumstances [76 p.9].
training and exercises of the person as well as on modifications of environmental factors to facilitate functioning.

New suggestions for clinical practices in physiotherapy with an emphasis to promote functioning of the child in ordinary life have been inspired by changing theoretical foundations based on family-centeredness and holistic health theories but also based on theories of motor control/learning [73, 81-85].

Motor control development theories were inspired by the neuromaturationists (Gesell and Amatruda, Mc Graw ) in the first half of the twentieth century and have been replaced by theories of dynamic system (DST) derived from Bernstein’s work on the coordination and regulation of movements and recently the Neuronal Group Selection Theory (NGST). Simplified the theories developed by the neuromaturationists hypothesized that the regularities of developing motor milestones represented regularities of brain maturation which was genetically driven. Changes in motor behaviour were primarily assigned autonomous changes in the nervous system and the child’s exploration of the environment as a contributor to development was secondary [86, 87].

Contemporary theories of motor control as the dynamic system theory (DST) and the Neuronal Group Selection Theory (NGST) put forward the equal importance of multiple subsystems intrinsic to the individual (biomechanical, anthropometric, cognitive) and extrinsic to the environment for child development and learning [87, 88]. Active problem-solving and exploration of tasks become important for development and learning [89].

According to the NGST there is a repertoire of genetically determined neural networks at the onset of development. These networks show substantial variation through the dynamic epigenetic regulation of cell division, adhesion, migration, death and neurite extension and retraction. Development proceeds with selection on the basis of afferent information produced by the movement and the most favourable networks are retained. Little is known about the selection itself but the theory is encouraging as it emphasises development as the result of a complex interaction between the environment and genes [39].

The most extensively used concept for management of children with CP is the Bobath-approach also known as the neuro-developmental treatment method (NDT). The Bobaths were contemporary with the neuromaturationists and
theories for management consequently focused on brain maturation and on support of the child development and modifying symptoms of the brain lesion [41 p.4, 77]. NDT has been criticised for its emphasis on normalization and quality of movements and focus of positive neurological features. NDT focused on inhibition of spasticity and prevention of secondary impairments. The influence of negative features, such as weakness and deficits of central mechanisms for control of movements are features that have been underestimated as a major factor for difficulties in functioning. However, Bobaths also recognised the importance of people’s own activity and repetition for learning. To achieve the child’s own activity parents and assistants learn useful techniques how to handle and manage the child to assist the child’s own performances and participation with and without the use of equipment [90]. Bobath considered the term management more appropriate than treatment, as dealing with a child with CP meant not only to deal with the motor handicap but the totality of the child and especially a good mother-child relation [41 p.3]. The management of CP in NDT is met by a multi-disciplinary team working together to address functional needs from motor, sensory, perceptual and cognitive perspectives [90 p.149].

The dynamic system theory and the idea that behaviour emerges spontaneously from cooperation between multiple subsystems have facilitated the development of activity-focused and functional training approaches. It is believed that enhanced activity is achieved through identifying and “manipulating” constraints in the functioning of the child, the task or the environment (e.g., size of toys and furniture; less noise) [80, 82]. In practice the focus is widened from a focus on the functioning of the child in traditional NDT-approaches to also include analyses and manipulation of the task and the environment. Exercises of activities incorporated into daily activities provide increased opportunity to find solutions for functional motor challenges [73, 80, 82, 91]. Parents are considered the best resource for identifying functional goals and therapists should cooperate with the child and family in order to identify periods of change and meaningful needs originating from ordinary life experiences by the parent and/or the child [80, 82, 83, 85, 104]. This also connects to the idea of vital goals in holistic health theory [76]. Moreover, goal-setting and goal-oriented task specific repetitive practice are believed to enhance active participation and learning [80, 82, 83, 85, 104].

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2 Health could be considered as ability to reach vital goals and vital goals are considered as preconditions for the subject’s minimal happiness [76 p.67].
The frequency and degree of functional limitations in daily activities in children with CP support a top-down clinical decision process of first addressing needs within the components of activity and participation in ICF. However, the emphasis on identifications of problems and needs within components of activity and participation needs to be complemented with a thorough assessment of resources and constraints of the individual child within the body function and structure components [56 p.47, 80, 82]. This means that enhanced activity is not only achieved through identifying constraints in the task and the environment but also through identifying constraints in the individual, such as impairments that include muscle weakness, poor endurance, reduced joint motion, fatigue, cardio-pulmonary function [61, 73, 80, 82]. Activity-focused intervention needs to be complemented with impairment-focused interventions depending on the child’s needs at the time.

Lately, the term “packaged treatment/training approaches” has been introduced for therapeutic approaches based on a treatment/training philosophy with the objective of meeting multiple needs with the services [92]. The term will be used in the present thesis. Neuro-developmental treatment, activity-focused or functional therapy approaches and conductive education are examples of more comprehensive treatment/training approaches based on different treatment/training philosophies.

Packaged treatment/training approaches can also be described as the opposite to targeted training, which focuses on functioning such as muscle strength or body parts or acceptance of parts in different treatment/training philosophies. Another existing term is “eclectic” approaches reflecting acceptance of parts of different treatment/training philosophies and with an emphasis on implementation of treatment/training strategies based on current best scientific evidence [92].

Conductive Education

Conductive Education (CE) was introduced during the 1940-50s in Hungary and the Institute of the Motor Disabled (the Peto Institute) was established in Budapest in 1952 by its founder Dr Andras Peto. CE was originally delivered in a residential setting and provided education for non-ambulatory children who were excluded from mainstream school at that time [7]. Originally, the
primary aim of CE was to stimulate the developmental process [8] assisting non-ambulatory children to attain “orthofunction” in order to make participation in mainstream school possible [8, 11]. In CE, CP is described to be a learning problem that requires educational principles [8, 10, 11].

Peto believed that the dysfunction, due to the CNS lesion, was not static and strategies for better and more appropriate functioning could be achieved through development and learning. Rather than improving coordinated movements in a biological sense, CE’s primary aim is to develop the whole personality by helping the child adopt an active life and encourage self-realization and a problem solving personality “an orthofunctional personality” [9]. Objectives for developing an “orthofunctional personality” encompass a wide range of functional domains including physical, psychological, social, language and academic skills to support child functioning and participation in daily activities [10, 11, 93].

“Orthofunction” is central in CE, but there is more than one explicit definition; there are a number of closely related definitions [93]. One description of “orthofunction” is “the ability to function as a member in the society, to participate in normal social settings appropriate to their age without assistive device and environmental adaptations” [93 p.36]. According to Petö, “orthofunction” was defined as the opposite of dysfunction [8 p.28] and includes integration of subtasks that have been learned, the optimal performance of the individual without use of assistive devices, environmental adaptations, avoidance of stereotyped pathological behaviour and adoption of healthy behaviour. Reddihough has provided a more pragmatic and contemporary description of “orthofunction” “the child’s ability to function in society despite his or her disability” [94] reflecting an adaptation towards a relativization of the disability concept from earlier definitions.

The spread of CE to different countries has led to a variety of modified CE approaches and ways of managing children with disabilities [10, 11, 93, 95, 96]. These variations might be due to intensity [96], residential, day- to –day programmes, attitudes about use of technical equipment [11] diagnosis and severity level [10, 11]. CE is also diverse and conductors may work in clinical health care or educational settings that are publicly or privately funded. Although, there are differences between CE approaches some common features of the intervention are suggested to lay ground for CE. These are that
training is performed in a group using a highly structured framework, the use of task series, rhythmical intention and specific equipment [11].

Unlike the multi-professional team that meets the needs of the child and family at the Child and Youth Habilitation the conductors’ role is to unite the competences of therapeutic/pedagogical needs met by the multi-professional team [8-11].

The philosophy of CE resonates with contemporary thinking in that it advocates a variety of ways to achieve functional goals, addressing the child’s specific abilities and environmental context [11]. CE, unlike habilitation approaches is more restricted towards the use of assistive devices, a restriction that indicates a different perspective on health. However, modified forms of CE use external support for enhanced functioning of the child [10, 11].

**Previous evaluations of treatment/training approaches**

Comparisons between different “packaged” treatment/training approaches on the outcome of functioning have not provided enough evidence for recommendations of one treatment/training approach over another [11, 83, 96-102].

Previous comparisons of CE have been in relation to typical educational settings [95, 97-100] and treatment/training approaches in health care settings [96, 102]. These studies included children with CP, ranging 1-9 years [96-100, 102] and with normal to mild intellectual disabilities [96-99, 102]. Children with a wider range of intellectual disabilities from mild to severe intellectual capacity were included in one of the studies [100]. Evaluations included a broad range of outcome dimensions as gross- and fine-motor, social and communicative skills and daily living activities [94, 97-100]. Outcomes of academic skills were included in three of the studies [96-100]. Stiller et al. reported the only short-term approach (5 weeks) [102]. The other studies lasted 6 months [96, 100] or 12 months [97-99].

One study compared the outcome between a functional treatment/training approach with traditional neuro-therapies (NDT and Vojta). The children in
the functional approach improved more in self-care and mobility functional skills and required less caregiver assistance. There were no differences with respect to gross motor capability. The children were between 2-7 years, and had mild to moderate CP. The evaluation-period lasted for 18 months [83]. These results give some support and optimism for implementing functional approaches based on current ideas of family-centeredness, disability research and motor learning principles.

Other studies of “packaged” training approaches conclude that intense neurodevelopmental treatment/training approaches improve gross and fine motor activities short-term [17, 18, 103]. The impact on gross motor change was further enhanced when goals for training were negotiated and defined [17]. However, studies did not find that fine motor activities and quality of upper extremity movement improved with intense training and casting in comparison with a regular occupational approach [101]. Studies have not found that increased intensity of training improved gross motor skills over the long-term [104].

Trahan et al. found that intermittent periods of intensive physiotherapy (4 weeks) followed by a rest-period of no treatment/training (8 weeks) for 6 months enhanced gross motor function and consolidated the improvements between training periods [105]. Unfortunately, the study did not have a control group, leaving the question open whether intermittent periods of intensive training is more effective than regular amount of physiotherapy (once a week/once a month).

In the above studies, positive changes over time regardless training approach were found in gross motor capability [17, 83, 96, 102-104], mobility and self-care functional skills [83, 102], communicative, social skills [96, 100], hand-and upper limb function [100, 101] and academic skills [96, 100].

Only two of these comparisons between “packaged” treatment/training approaches addressed parents’ perceptions of the outcome on functioning. Law et al reported no difference between intensive training plus casting and regular occupational therapy with respect to fine motor activities and quality of upper extremity movement on parents’ perception of the child’s performance or satisfaction. Parents in both groups reported changes in performances and satisfaction with clinical significance [101]. Stiller, using an unstructured approach, found that parents perceived functional gains
irrespective of the training programme – CE, intensive therapy in a health care setting or a special education group [102].

Few studies have included outcomes related to parents’ needs for the intervention of different treatment/training approaches for children with CP; the results are inconclusive [106]. Reddighough et al. found no differences between CE or conventional treatment/training (individual and in group with the caregiver) with respect to parents’ stress although they did find a slight decrease of parental stress after 6 months intervention of CE. The comparison reported a better outcome of parents’ perceptions of coping after CE than after conventional treatment/training [96]. Hur et al. reported no difference in maternal stress between the two groups among parents of children in a CE-educational approach versus traditional special schools [97].

Differences in parents’ perceptions of the service quality between treatment/training approaches are contradictory. Hur et al. reported a higher satisfaction among parents of children in the CE-educational approach versus traditional special schools [97]. Catanese et al. and Reddihough et al. on the other hand found, no significant difference in parents’ satisfaction towards CE or conventional training [96, 100]. Bower et al. found that parents perceived no difference of the rehabilitation process whether they got intensive physiotherapy or routine amount of training [104].

In summary, outcome dimensions for evaluations of “packaged” treatment/training approaches to date have mainly focused on clinical outcome of the functioning of the child. There is less knowledge about self-reported outcome of functioning, health and well-being, parental outcome and the impact of environmental changes. In addition, research about parents’ perceptions of the quality of training/treatment approaches is needed.

This research project was initiated as there is a need to evaluate different treatment/training–approaches for children with Cerebral Palsy. Because many perspectives influence the impact of the intervention and outcome, it is challenging to evaluate different treatment/training approaches. Stakeholders and professionals need more knowledge about the effectiveness of different treatment/training approaches to improve the foundation of a more evidence-based Child and Youth Habilitation. Improved knowledge will also help parents/children to make informed choices and prioritize between different
treatment/training approaches in order to meet the needs of the child and family in the best way.
AIMS OF THE THESIS

General aims

There is a need for more evidence of different treatment/training approaches for children with Cerebral Palsy (CP). The first aim was to evaluate the effectiveness of two intensive training groups (ITGs) - a habilitation approach and a conductive education approach.

The second aim was to explore different meanings of participation in intensive training in groups (ITGs) to parents from a parent-perspective since there is scarce knowledge about parents’ lived experiences.

Specific aims

To evaluate the effectiveness of the two ITGs with clinical and self-reported outcomes on functioning short-term and after one year and to add outcome of parents’ perceptions of the service quality (paper I-III).

To describe parents’ expectations on outcome of functioning with the type of goals expressed in the two training approaches and to relate the self-reported to the clinical outcome (paper II).

To explore the association between previous experiences, expectations on outcome of functioning, achieved expectations, severity of disability, achieved outcome of functioning, the training approach and parents’ perception of the service quality (paper III).

To explore parents’ conceptions of what needs ITGs fulfil in the lives of parents to children with CP and what problems that may arise (paper IV).
MATERIAL AND METHODS

This thesis consists of two parts: a quantitative evaluation of the effectiveness of the two intensive training groups and a qualitative study exploring parents’ qualitatively different ways of experiencing ITGs.

Subjects

The study consists of two samples. In the effectiveness study subjects consisted of a convenient sample of children representing the ordinary consumer of intensive training groups (ITGs). Thus, children who were considered to benefit from ITGs were invited. Matching of the children in the two training approaches were performed with predefined inclusion and exclusion criteria.

Inclusion criteria were children with a diagnosis of CP, ages 3-16 years and who were considered to benefit from intensive training in a group. None of the children participated in any form of intensive training 3 months before the research-period.

Exclusion criteria: severe mental retardation (SMR) defined (<IQ 0-20) according to International Classification of Diseases [107] and severe visual impairment.

Figure 1 provides an overview of included children and completed measurements.

Number and characteristics of children according to gender, age, diagnosis, intellectual capacity and gross motor function level is presented for Study I-III (Table II). Background data showed that CP diplegia was the most common diagnosis. Most of the children (63%) were classified GMFCS level 4 and 5; i.e., they had extensive movement disorders. More children were classified GMFCS 5 and with severe mental retardation (SMR) in the ITG with the CE approach (Table II).
The only difference between the rITG and Cust-group in the one-year follow-up was a lower mean age (9 years, s.d 4.0 versus 11 years s.d 4).

In Study IV, the sample was strategically composed of parents to 15 children with CP. Fifteen interviews were performed with eleven mothers and two fathers; two interviews were performed with both parents. Parents had previous experiences or they were in a process of participating in repeated periods of ITGs together with their child or their child participated in ITGs. To optimize the number of different conceptions a strategic sample of parents to children with different gender, ages, diagnoses, functional levels according to the gross motor classification system (GMFCS) [30], intellectual capacity were invited to participate in the interview. Parents’ experiences of ITGs were based from different settings in the middle and south-east of Sweden (Table III).
Figure 1. An overview of included subjects in the effectiveness study and completed measurements
Table II. Background characteristics for the total group, the two ITGs, the habilitation approach (Lemo) and the CE approach (Move&Walk). Background characteristics for subgroups from the same sample formed on the basis of consumption of repeated periods of intensive training groups (rITG) or customary training (Cust-group) during the one-year follow-up. Background characteristics of children of parents interviewed using the Patient perspective On Care and Rehabilitation process for the total group and for the two ITGs Lemo and Move&Walk.

<table>
<thead>
<tr>
<th></th>
<th>Paper I-II Total group n=54</th>
<th>Paper I-II Lemo n=24</th>
<th>Paper I-II Move&amp;Walk n=30</th>
<th>Paper I-II rITG n=22</th>
<th>Paper I-II Cust n=29</th>
<th>Paper III Total group n=50</th>
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GMFCS, Gross Motor Function Classification System. MMR, mild mental retardation. SMR, severe mental retardation. Intensive training groups (ITGs) with a habilitation approach labelled Lemo and with a CE approach labelled Move&Walk.
Material and methods

Table III. Background characteristics for the 15 children of parents who participated in the interview about parents’ conceptions of intensive training groups.

<table>
<thead>
<tr>
<th>Study IV number</th>
<th>Male:female ratio</th>
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<th>Learning disabilities</th>
<th>Level of gross motor function (GMFCS)</th>
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<td>Hab- approach</td>
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<td>dyskinetic</td>
<td>II</td>
<td>CE -approach</td>
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<td>Hab+CE approach</td>
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Gross Motor Function Classification System (GMFCS) [29].
Hab - child and youth habilitation-approaches. CE – conductive education-approaches.

Intensity and character of the ITGs in the effectiveness study

The overarching description of the two ITGs in the effectiveness study from a professional perspective revealed many similarities between the two training approaches. The main objectives of the two ITGs were described as increasing the child’s functional independence in mobility and self-care domains through active training. The group-setting was considered a stimulating learning environment with positive influence on motivation, social interactions and communication. Parents/close relatives or personal assistants were actively involved in the training as a means to improve their knowledge how to
Material and methods

support the child in ordinary life circumstances. The main differences between the two ITGs were that the approaches have emerged from and are delivered in different contexts. The composition of the professionals leading the ITGs and their educational background differs.

In the ITG with the habilitation approach physiotherapists and a special educational needs teacher were responsible for the training. Because the ITG was situated in the same facilities as the ordinary Child and Youth Habilitation, consultation and cooperation with other members of the multi-disciplinary team representing medical, social, psychological and pedagogical perspectives were available.

The ITG with a habilitation approach was an eclectic approach that used the best current scientific evidence and a number of therapy-approaches [82, 91] based on motor learning theories [82, 89, 91, 108]. The use of technical aids is encouraged in a context of the Child and Youth Habilitation. The ITG with the habilitation approach were labelled Lemo and acronym for “learning of motor function”.

At the ITG with the CE approach conductors with a 4-year education from the Peto Institute in Hungary with an additional 6 months Move&Walk course led the groups together with conductor-assistants. Families and children are offered accommodation during the ITGs or visit the centre on a day –to –day basis. The programme works well with the common characterization and description of techniques used in CE approaches as described by Bourke-Taylor et al. and Darrah et al. [10, 11]. The role of the conductor, rhythmic intention with the use of songs, task oriented structured activities, and special equipment may help define interventions and improve comparisons between different CE approaches [10, 11, 96].

Some modifications of the Move&Walk method to Swedish circumstances are addressed. Originally CE did not encourage assistive devices, but there are “modified forms”, as the Move&Walk method, that allow for a restraint use. Originally children with a higher level of functioning and walking capability were addressed [7]. The Move&Walk method have broadened criteria for inclusion of intervention to embrace more diagnoses as well as different severity levels in CP.
Material and methods

Measurements in the effectiveness study

Clinical measures

The main outcomes of functioning were within the activity and participation component of ICF for both training approaches. Representatives from the two ITGs agreed upon the choice of the measurement dimensions.

Gross Motor Function Measure (GMFM) is a condition-specific criterion-referenced measurement developed to assess effectiveness of interventions on gross motor function outcomes for children with Cerebral Palsy. The items were clinically relevant and with the potential to show change in gross motor function. Items are accomplished by typically developing children at the age of 5. The performances of the child are compared against a defined criterion for 88 gross motor activities. The GMFM total score ranges from 0-100% achievement of motor function. Every item was scored on a 4-point ordinal scale from; 0 = does not initiate, 1 = initiates (<10% of the motor activity), 2 = partially completes (10 to >100% of the motor activity) and 3 = completes the movement [109-111].

In the present study the GMFM total score and the scores for the five dimensions A. Lying and Rolling, B. Sitting, C. Crawling and Kneeling, D. Standing and E. Walking, Running and Jumping were calculated.

GMFM total score has shown to be highly reliable, valid and sensitive to change [109-113]. Both researchers accomplished the criterion test to ensure reliability of testing GMFM. A further development of GMFM with a Rash-analysis (changing from ordinal to interval scale) has improved the measurement properties. The Rash-analysis resulted in GMFM-66: 66 hierarchically ordered items according to difficulty [114]. GMFM-66 is tested for reliability, validity and sensitivity to change [115]. In the present study the original version of GMFM was used and labelled GMFM-88 to distinguish from GMFM-66.

Pediatric Evaluation of Disability Inventory (PEDI) is a generic measurement developed for evaluating changes of functional skills and caregiver assistance for children with disabilities in relation to expected maturational change in typically developing children in the domains of self-care, mobility and social
function between the ages 6 months and 7.5 years. In addition to normative scores, scaled scores have been developed from the normative sample for the Functional skills and Caregiver assistance scales. Scaled scores are criterion-referenced and item difficulty has been hierarchically arranged through Rasch analyses from low ability to high ability. Scaled scores can be used for evaluating functional skills and caregiver assistance for children above the age of 7.5 years as long as the child’s abilities don’t exceed the abilities obtained by a typically developing child of 7.5 years.

PEDI includes three sets of measurement scales: Functional Skills (FS), Caregiver assistance (CA) and Modifications. Each individual scale illustrates different aspects of the child’s capability and performance in self-care, mobility and social function. PEDI FS is designed to measure meaningful subtasks of a set of complex functional skills versus PEDI CA, which measures the amount of help the child needs to carry out functional skills.

In the present study a Swedish manual supplement [116] of the American PEDI administration manual [2] was used as an interview guide. Judgement of the child’s performances was based on parents’ perceptions of the child behaviour in ordinary life. The interviews were scheduled for 60 minutes.

In the present study GMFM is considered to measure gross motor capability and PEDI FS performances of functional skills. Capability has been defined as the best possible performance of a task in either a standardized or an ideal situation whereas performance refers to measurement of functional behaviours as they occur in the environment [2 p.7].

PEDI FS consists of 197 items, each scored "unable" (0) or "able" (1) by the interviewer. Raw aggregate scores were transformed to scaled scores and were used to identify change in performance. Scaled scores represent increasing degrees of functional performance along a scale from 0-100 without reference to age [2, 116, 117]. In the present study scores for Functional skills (PEDI FS) were presented. Scores for the PEDI CA and Modification scales were not presented. Reliability, validity [2, 117] and responsiveness to change [118] for the PEDI are reported to be good.

The lowest level accepted as a clinically significant change was considered to be the ± 4% on GMFM-88 total score and the dimensions A-E and ± 4 scaled scores on PEDI. The decision of the level of minimal clinically relevant change
for GMFM-88 total score and PEDI scaled score was based on previous reports. Based on parents’ judgement a minimal important change has been recommended to be 1.825 % [109]. Bower et al. recommended 4 % as the lowest level of clinical significance [104] and recently, Wang et al. supported 4% to be a clinically significant change based on therapists’ judgement of a great improvement. A lower level was not recommended due to an increased risk of measured false positive changes. If there is a need to understand individual motor progress either version of GMFM may be used [113]. Mc Carthy et al. reported 3 scaled scores as a minimal clinically relevant change on PEDI [119].

Self-reported individualized goal measures

In addition to measure outcome with clinical measures it was considered important to evaluate outcome of functioning from a perspective of the child or parent with a self-reported individualized goal measure (SRIGM). In most cases, parents rated the SRIGM as proxies for the child. Self-reports have been proposed to be more valid as parents might be considered the best judges of the outcome [120, 121].

In the present study the interview with the SRIGM was performed in concordance with the Swedish version of the Canadian Occupational Performance Measure (COPM) with some adaptations [122]. Parents were asked to describe what activities the child was presently involved with in ordinary life. Parents were also asked to describe what activities the child had problems performing at present and what they as parents believed could be improved from training at the ITG. Parents were asked to formulate activities that the child wanted, needed or expected to perform and what they thought might be improved over 4 weeks. The interviewer was careful to remind parents to estimate goals as attainable. As with COPM the concept activities were used, but the two interviewers did not suggest any preconceived activity domains or interfere if goals were formulated within the body function component of ICF. The goal formulation was kept as open-ended as possible to achieve parents’ own preferences.

After the interview parents were giving the five most important goals priority. The pre-set goals were rated on an importance scale (not important at all – to extremely important) to gain knowledge about parents’ priorities of the
importance of the ability to perform the activity. Parents also rated the performance (cannot perform at all-performs extremely well) to achieve parents’ conceptions of the child’s performances. Importance and performance were scored on a Likert scale of 1-10. The same goals were re-evaluated on the performance scale two weeks after the intensive training period (Figure 1). Reliability, validity, and sensitivity have been reported good values for self-reported individualized goal measures (SRIGMs) as COPM [123-128] and Patient Specific Functional Scale (PSFS) [129, 130].

To describe parents’ expectations and compare the content of the intervention in the two training approaches the individualized goals were classified according to the International Classification of Functioning and Health (ICF) – child and youth version [131].

The information in ICF is organized in two parts; components of functioning (body functions, body structures and activities and participation) and environment (environmental and personal factors). The components are further classified in domains which are subdivided in categories. The individualized goals were compared with nominal definitions of labels defined with three numbers as categories in the component of functioning in ICF – child and youth version [131] in order to decide the appropriate domain. In the description and analysis of the individualized goals the domain level with one number served as a unit of analysis.

Goal-attainment was analyzed between the two training approaches and between the different domains in ICF, regardless of the training approach. The outcome of SRIGM was presented as proportion of clinically significant improvement and represents the difference in performance between the rated score before and after the period in the ITG.

An improvement of clinical significance was predefined as ≥ 2 points for two preset goals on the performance scale. Earlier publications have suggested 2 points as a minimal change of clinical importance [124, 125, 129, 132, 133].

Consumption of training

A structured questionnaire was constructed to describe the amount of additional consumption of ITGs or customary training following the ITG to
the one-year follow-up (Table IV). Customary training was defined as treatment/training and/or counselling at the Child and Youth Habilitation Centre, at home, in school, at the after school recreation-centre or at any place during leisure time.
Table IV. Quantity of training and frequency of children who participated in one or more additional repeated periods of intensive training groups (ITGs) and/or customary training during the one-year follow up for the total group n=51.

<table>
<thead>
<tr>
<th>Questions as stated to the parent</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did your child attend any form of intensive training programme after the ITG at Lemo or Move&amp;Walk one year ago?</td>
<td>22 (43%)</td>
<td>29 (57%)</td>
</tr>
<tr>
<td>Quantity of training if yes;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One ITP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 weeks</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3 weeks</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4 weeks</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Two ITP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3+3 Weeks</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3+4 Weeks</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Three ITP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2+3+3 Weeks</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3+3+3 weeks</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>3+4+4 weeks</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Does your child attend any regularly activity/training which may be seen a direct follow-up of the ITG at Lemo or Move&amp;Walk one year ago?</td>
<td>23 (45%)</td>
<td>28 (55%)</td>
</tr>
<tr>
<td>Quantity of training if yes;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Once a week</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Once a month</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Does your child do any activities or training on its own that you see as a direct follow-up of the ITG at Lemo/Move&amp;Walk one year ago?</td>
<td>37 (73%)</td>
<td>14 (27%)</td>
</tr>
<tr>
<td>Does your child participate in any regular activities at the habilitation centre such as take part of support, training/treatment or other activities?</td>
<td>29 (57%)</td>
<td>22 (43%)</td>
</tr>
<tr>
<td>Quantity of training if yes;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once a week</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Every second week</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Once a month</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Does your child take part in any other regular activity other than the habilitation, at home, in school, at the after school recreation centre, or other things as you see as training or treatment activities?</td>
<td>42 (82%)</td>
<td>9 (18%)</td>
</tr>
<tr>
<td>Quantity of training if yes;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Every day</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Once a week</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>Several times a week</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Every second week</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

ITGs with the habilitation approach was labelled Lemo. ITGs with a conductive education (CE) approach labelled was Move&Walk.
Service quality evaluation

Data were also collected using the Patient Perspective on Care and Rehabilitation Process (POCR) instrument. This is a reliable and valid multi-dimensional instrument based on a theoretical framework measuring patients’ perspectives regarding quality of care [134]. The instrument was developed to reflect needs and perceived health outcome from elderly people in a geriatric health care setting. The POCR was chosen instead of the more commonly used Measurement of Process of Care (MPOC) developed and used for measuring parents’ perceptions of service quality in a paediatric health care context. POCR was chosen instead of the MPOC, because an evaluation period of 4 weeks was considered too short for the questions asked in MPOC based on previous experiences [104].

The face validity for POCR in another care and rehabilitation context was judged based on the fact that the dimensions and questions included in POCR measured aspects of service–quality described as important to parents with disabled children in MPOC [135, 136]. An expert panel of professionals representing the two treatment/training approaches agreed upon the choice of measurement.

POCR investigates parents’ perceptions of the rehabilitation process in relation to five phases: preadmission, arrival, treatment, discharge and post-discharge. Patients’ perceptions of service quality includes perceived health outcome [134]. The POCR contains two measurement scales: fulfilment and importance of perceived health care needs including health outcome. It measures seven dimensions: A. Need for adequate care, B. Need for orientation in the care context, C. Need for knowledge and control, D. Need for support and autonomy, E. Medical and interactional needs, F. Need for preparedness before discharge, and G. Situation post-discharge.

The interviewer rated parents’ answers to questions using a 4-point response format: (1) no, not at all; (2) yes, to some extent; (3) yes, for the most part; and (4) yes, definitely. A follow-up question also assessed parents’ perceptions about the importance of the health care needs using a 4-point response format: (1) of no importance; (2) of some importance; (3) of great importance; and (4) of greatest importance.
In the present study the questions in POCR were slightly adapted to fit the context and parent population. Five questions were omitted, one question each in dimension B, C, D, E, and G. One question was added in dimension E. The adapted POCR comprises a total of 21 questions.

Predefined complementary data on parents’ experiences and expectations before and after the ITG, child-characteristics, outcome on functioning and the training approaches were analysed with a logistic regression model to investigate parents’ perceptions of the service quality. Details presented in paper III. Two independent researchers collected the complementary data before and after the intensive training period (Figure 2). Defined cut-off values see (Table V).

Table V. Criteria of and cut-off values for the predefined factors and group allocation (n).

<table>
<thead>
<tr>
<th>Predefined factors</th>
<th>Criteria of cut-off level</th>
<th>Outcome_label</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous experience of ITG</td>
<td>yes:no</td>
<td>1 yes: 2 no</td>
<td>14:36</td>
</tr>
<tr>
<td>Previous experience outcome hab</td>
<td>&gt; md 7 IQR (2)</td>
<td>1 positive: 2 less positive</td>
<td>20:29</td>
</tr>
<tr>
<td>Expectations of outcome</td>
<td>&gt; md 6 IQR (4)</td>
<td>1 high: 2 low</td>
<td>18:32</td>
</tr>
<tr>
<td>Fulfilled expectations</td>
<td>&gt; md 8 IQR (4)</td>
<td>1 yes: 2 no</td>
<td>15:33</td>
</tr>
<tr>
<td>Severity of disability</td>
<td>GMFCS V:GMFCS I-IV</td>
<td>1 most severe: 2 less severe</td>
<td>12:38</td>
</tr>
<tr>
<td>Outcome GMFM-88</td>
<td>&gt; 4 points any dimension</td>
<td>1 improved: 2 not improved</td>
<td>35:15</td>
</tr>
<tr>
<td>Outcome PEDI FS</td>
<td>&gt; 4 scaled scores any domain</td>
<td>1 improved: 2 not improved</td>
<td>21:28</td>
</tr>
<tr>
<td>Outcome SRIGM</td>
<td>&gt; 2 points for 2 goals</td>
<td>1 improved: 2 not improved</td>
<td>26:24</td>
</tr>
<tr>
<td>Training approach</td>
<td>Lemo or Move&amp;Walk</td>
<td>1 Lemo: 2 Move&amp;Walk</td>
<td>20:30</td>
</tr>
</tbody>
</table>

ITG-intensive training group, hab = Child and Youth Habilitation, GMFM-88 = Gross Motor Function Measure, PEDI FS Pediatric Evaluation of Disability Inventory-Functional Skills, SRIGM = Self-reported Individualized Goal Measure, Lemo= habilitation approach, Move&Walk = conductive educational (CE) approach.
Material and methods

Design

**Paper I-III**

Effectiveness of the two training approaches was evaluated with a prospective quasi-experimental design. The functioning of the studied group of children was followed with repeated clinical and self-reported measures in accordance with a prospective single case experimental design. Each child was examined before (phase A1), during (phase B) and after (phase A2) one period of intensive training in group (ITG) and at one year.

Short-term outcome (phase A1-A2) was analysed in relation to the one-year outcome (phase A2-1y). One-year outcome was also analysed in relation to additional consumption of training (Figure 2). The evaluation of the effectiveness of the two training approaches also comprised parents’ perception of the service quality. Parents’ perceptions of the service quality were also investigated in relation to a number of predefined factors previously found to be associated with patients’ evaluations of service quality [137] (Figure 2).
One-year follow up

<table>
<thead>
<tr>
<th>Phase A1</th>
<th>Phase B</th>
<th>Phase A2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals E1</td>
<td>Goals E2</td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>I</td>
<td></td>
</tr>
</tbody>
</table>

0 4 8 12

64 weeks

8 measurement points

Clinical test with GMFM at measurement points 1-8

Interview with PEDI FS at measurement points 1, 7 and 8

Goals

Interview and rating of the SRIGM at measurement points 2 and 6

E1

Interview about previous experiences and expectations

E2

Interview about achieved expectations

Consumption of additional training was measured for the period between measurepoint 7 and 8 at the one-year follow-up

I

Telephone interview with POCR one to two weeks after the ITG

Figure 2. Measure-points before (phase A1), during (phase B), after the period of intensive training in group (ITG)(phase A2) and after one year. GMFM-88 –Gross Motor Function Measure, PEDI FS – Pediatric Evaluation of Disability Inventory – Functional Skills. SRIGM- Self-reported Individualized Goal Measure. E1 - Interview about previous experiences and expectations on the ITG and E2 - follow-up of expectations after the ITG. POCR – Patient perspectives On Care and Rehabilitation process.

Paper IV

A qualitative study with a phenomenographic approach was added to the effectiveness study to get an improved understanding of parents’ different
ways of experiencing ITGs. Different categories of understanding i.e. conceptions constitute the essential outcome of the analysis and describe how the phenomena, in this case ITGs, are apprehended, thought about or perceived [138, 139].

Procedures

Paper I-III

The same researcher performed all the tests and interviews with the clinical and self-reported measures within one of the two training approaches due to geographical reasons.

Telephone interviews with POCR were performed 7-14 days after the period of ITG by one of the researchers (PÖ).

The telephone-interviews to describe the consumption of training were performed by two specially trained physiotherapy students and one of the researchers (PÖ) at the one-year follow-up (Figure 2). The interviews were distributed in equal proportions between the interviewers and the training approaches.

None of the researchers were involved in delivering the ITGs and or in the care of the families or children. Both training approaches were free from fees during the evaluation.

Paper IV

Data was collected with interviews. The interview was conversational and questions were open-ended. All interviews started by asking the parent; What ITGs mean to the child? What ITGs mean to them as parents? Are there any problems related to participation in ITGs? Aspects as the group-setting, parent participation and intensity of training were predefined phenomena introduced during the interview. The sequence of questions varied and parents’ answers
to the basic questions were followed up with further questions. Rephrasing and probing were used to obtain a deeper understanding [140 p.162]. The interviewer was not involved in delivering any of the ITGs but had previous experience as a physiotherapist working with disabled children in different settings and experiences from the evaluation presented in paper I-III.

**Statistical analyses**

**Paper I-III**

Descriptive statistics were used to present background characteristics for the children, quantity of continued consumption of training during the one-year follow-up after the ITG, description of individualized goals classified according to ICF, distribution of overlapping or separate clinically significant improvements on the SRIGM and the clinical measures GMFM-88 and PEDI FS.

Changes on GMFM-88 total score and the dimensions A-E represent the differences between the mean of the three measure-points before (phase A1) and after the period of ITG (phase A2) and the measure-point at one year. Changes on PEDI FS scaled scores represented the difference between the first and seventh measure-point before and after the period of ITG. Changes at one year represent the difference between the seventh and eight measure-points. Mean, standard deviation (s.d.) and ranges were presented.

Changes on SRIGM represented the difference between the second and sixth measure-point before and after the period of ITG. Level of importance and performance on the SRIGM were presented with the median and interquartile range (IQR).

Change and group differences were analysed within groups with Wilcoxon Signed Rank test and between groups with Mann-Whitney U-test and Kruskal-Wallis Test.

Proportions of clinically significant predefined change at an individual level of the clinical measures GMFM-88 total score or the dimension A-E and PEDI FS
self-care, mobility and social function and the self-reported individualized goal measure (SRIGM) were compared within and between groups with Chi-2 Squared test.

The proportion of clinically significant predefined improvement at an individual level of GMFM-88 total score, PEDI FS self-care, mobility and social function domain or with any dimension on GMFM-88 or domain in PEDI FS were compared with the proportion of clinically significant improvement of the SRIGM. Proportion of improvement for clinical and self-reported individualized measures was also compared between groups with Chi-2 Squared test.

Proportion of improvement within the ICF-domains; Neuromusculoskeletal and movement-related functions, Mobility and Self-care was compared between the training approaches with Chi-2 Squared test.

The distribution of differences for the POCR fulfilment and importance scales was analysed using the Wilcoxon Signed Rank Test.

A stepwise ordinal logistic regression model was used to investigate the association of the predefined independent factors with the dependent outcome variables, the POCR fulfilment and importance scales. Each question was analysed separately regardless of the dimensions. Correlation analyses were performed to exclude collinearity between the predefined factors. The range of the correlation coefficients for the predefined factors was $r = 0.004-0.320$.

Probability for statistical significance was set at $p$-value $\leq 0.05$.

**Analyses in the qualitative study**

**Paper IV**

The interviews were tape-recorded and transcripts constituted the empirical material for the qualitative analyses. A phenomenographic approach was used in order to circumvent the potential problems for parents to express and pinpoint needs in a somewhat artificial situation as an interview. It was assumed
that needs can be inferred from conceptions in such a way that positive conceptions of ITGs are direct expressions of underlying needs, and negative conceptions also express needs but in an invert order.

The analyses were performed in different steps as previously described [141]. In the first step each interview was listened to and transcripts were read several times to get well acquainted with the content of the interviews. In the second step conceptions of importance for the research questions were identified and compiled. The third step is condensation of the individual conceptions to find central parts of significant elements of the conceptions. The fourth step was grouping of the conceptions for the question. The fifth and sixth step concerned preliminary comparisons and naming between groups trying to establish categories with borders between them. The seventh step and last step is contrastive comparison between categories, with an objective to describe the unique character of every category and resemblances between categories [141, 142]. The categories and conceptions were labelled and relabelled in a process of analyses to reflect their essence from the second to the seventh step [141, 143]. Analyses of the interviews were also performed by the second author to increase credibility.

**Ethical considerations**

All parents received written and oral information about the aim of the studies how data were treated and kept in part I and II. The Child and Youth Habilitation sent the information letter and consent form. The information letter emphasised that participation in the study was purely voluntary and discontinuation from participation was accepted at any time during the research-period without explanation or consequences for their participation in ITGs or ordinary health care services. The researcher was not involved in the treatment/training of the child and there was no reason to believe that parents accepted participation out of politeness. All parents gave their written consent to the Child and Youth Habilitation.

The project did not place participants at any risks. In part I the design with repeated measures and interviews during a 3 month period and a one-year follow-up was time consuming and this was clearly explained to the parents. In part II the interviews took place where it was most comfortable for the
Material and methods

Parent and the length of the interviews was scheduled for approximately 1-hour. Information about data collection procedures were considered especially important as it is known that parents to children with CP already live in a demanding life-situation.

In part I, the benefit of being offered a treatment/training alternative that was not supplied by the Child and Youth Habilitation under usual conditions was one ethical consideration. The majority of children with CP were invited, but children who did not fit the inclusion criteria were excluded. The procedure is comparable with ordinary clinical decisions of choices between different treatment/training alternatives.

This research project provides more evidence-based knowledge of different treatment/training approaches for children with CP a benefit that needs to be addressed. Because scientifically based knowledge of the effectiveness of different treatment/training approaches is not sufficient to give a holistic perspective of interventions, part I complemented with part II, provides parents’ lived experiences of ITGs regardless treatment/training approaches.

The research project was expected to contribute to valuable knowledge for stakeholders, professionals and parents about the effectiveness of the two training approaches and whether the CE approach is more effective than the habilitation approach. The qualitative study was expected to add further knowledge to the effectiveness study about parents’ lived experiences and increase understanding of what needs and problems might arise from participation in ITGs.

The research project was approved by the ethic committee at the Faculty of Health Sciences, Linkoping University, Sweden, date 000110 Dnr 00-016 (Study I-III) and date 200606 Dnr 65-06 (Study IV).
RESULTS

Effectiveness of intensive training in groups (ITGs) - a habilitation approach and a CE approach

Paper I-III

Outcome of clinical measures

Short-term outcome
There were initial differences in pre-test values on mean GMFM-88 total score, PEDI FS mobility and social function domain showing a higher level of function among children in the ITG with the habilitation approach than in the CE approach. There were no differences in pre-test values on GMFM-88 and PEDI FS if children classified GMFCS 5 or SMR were excluded.

After ITG, small improvements occurred on the clinical measures. The mean GMFM-88 total score and dimension A-E ranging 1.1-3.0% (sd 2.6-5.4) and for the mobility and social function domain mean PEDI FS scaled scores ranging 0.9-1.4 (sd 3.2-4.0) for the total group. A better result was shown for the ITG with the habilitation approach than for the CE approach after the ITG on the GMFM-88 total score, dimension B and E and no differences on PEDI FS. The difference disappeared when children classified GMFCS 5 or with SMR were excluded except in dimension B.

The proportion of clinically significant changes on GMFM-88 total score, the dimensions A-E or PEDI FS showed no differences between approaches except a higher proportion of improvement on the GMFM-88 total score in the habilitation approach (8 out of 24 cases versus 1 out of 30 cases) short-term.
Results

The difference disappeared if children with SMR or younger than 9 years were excluded.

One-year outcome
There was no improvement on mean GMFM-88 total score or the dimensions A-E at the one-year follow-up except for improvements in crawling and kneeling (dimension C). The mean PEDI FS scaled scores improved in the self-care 2.1 (4.0) and social function domain 4.0 (7.6) for the total group.

A comparison of the proportion of clinically significant change at one-year in relation to after the ITG showed that of the 8 children that improved after the ITG on GMFM-88 total score (range 3.7-10.3% total scores) three children further improved, 4 children retained and 1 child lost the improvement after one year.

Thirty-four children improved in at least one dimension A-E (mode 1 dimension) after the ITG. No child deteriorated on GMFM-88 total score or in dimensions A-E after the ITG and at the one-year follow-up.

A comparison of the proportion of clinically significant change for each dimension A-E showed that there was a low proportion of improvement in each dimension (6-14 out of 51 cases) after the ITG and a higher proportion of deterioration was seen in the GMFM-88 dimensions A, D and E at the one-year follow-up, irrespective training approach (Table VI).

The proportion of changes on PEDI FS after the ITG and at the one-year follow-up for the total group did not differ (Table VII). However, 25 out of 51 cases improved in the social function domain (range 3.9-26.6 scaled scores) at the one-year follow-up compared with 9 out of 51 cases (range 3.7-24.5 scaled scores) after the ITG. Twenty children improved in at least one domain (30 domain improvements, mode 1 domain) after the ITG. Of the eight improvements in the self-care domain 3 further improved and 5 were retained, of the twelve improvements in the mobility domain 2 were further improved, 7 retained and 3 were lost, and of the nine improvements in the social function domain 6 further improved, 2 were retained and one lost (Table VII). Two cases deteriorated in the PEDI FS self-care and social function domain after the ITG and at the one-year follow-up.
The total group of the sample in the effectiveness study was divided in two groups depending on further consumption of training during the one-year follow-up (Figure 1). There were no initial differences in pre-test values on GMFM-88 total score or PEDI FS between the group of children who continued with repeated periods of intensive training in groups (rITG) to children receiving customary amount of training (Cust-group).

The result showed no differences between the rITG and Cust-group during the one-year follow-up in the mean difference of change GMFM-88 total scores or dimensions A-E at the one-year follow-up. The mean difference of change on PEDI FS social function was larger for the rITG compared with the Cust-group 6.3 scaled scores (sd 6.0) compared with 2.2 scaled scores (sd 8.5) at the one-year follow-up.

A higher proportion of children in the rITG compared with the Cust-group improved on PEDI FS social function at one year (15 out of 22 cases compared with 9 out of 28 cases). An alternative analysis of the clinical measures excluding children with SMR and GMFCS 5 didn’t alter the differences in outcome on the clinical measures between the rITG and Cust-group.

The rITG and the Cust-group were each further divided in two subgroups depending on the quantity of customary training. Low quantity of customary training was defined as less than 2.5 hours/week and high quantity of customary training was defined as ≥ 2.5 hours/week: Group 1.) rITP + low quantity of customary training (n=9); Group 2.) rITP + high quantity of customary training (n=13); Group 3.) No rITP + low quantity of customary training (n=12); and Group 4.) No rITP + high quantity of customary training (n=17). The quantity of intensive training was 4.4 weeks (s.d. 2.6), range 2.0-9.0 weeks.

Differences between the rITG and the Cust-group were further analysed according to low or high quantity of customary training. A higher number of children classified GMFCS 4 and 5 received a high mean quantity of customary training with or without additional rITGs. Children with a low quantity of customary training in addition to rITGs showed a better outcome on PEDI FS social function than children with a high quantity of customary training in addition to rITGs at one year.
**Results**

Table VI. A comparison of the proportion of change on GMFM-88 total score and the dimensions A-E after the period of intensive training in group with the proportion of change at one year for the total group n=51.

<table>
<thead>
<tr>
<th>GMFM-88</th>
<th>Change</th>
<th>After ITP</th>
<th>At one year</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total score</td>
<td>Improvement</td>
<td>8</td>
<td>10</td>
<td>n.s</td>
</tr>
<tr>
<td></td>
<td>Unchanged</td>
<td>42</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Deterioration</td>
<td>1</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Dimension A</td>
<td>Improvement</td>
<td>13</td>
<td>12</td>
<td>0.03</td>
</tr>
<tr>
<td>Lying and rolling</td>
<td>Unchanged</td>
<td>38</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Deterioration</td>
<td>0</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Dimension B</td>
<td>Improvement</td>
<td>14</td>
<td>12</td>
<td>n.s</td>
</tr>
<tr>
<td>Sitting</td>
<td>Unchanged</td>
<td>35</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Deterioration</td>
<td>2</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Dimension C</td>
<td>Improvement</td>
<td>10</td>
<td>13</td>
<td>0.05</td>
</tr>
<tr>
<td>Crawling, kneeling</td>
<td>Unchanged</td>
<td>39</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Deterioration</td>
<td>2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Dimension D</td>
<td>Improvement</td>
<td>13</td>
<td>8</td>
<td>0.01</td>
</tr>
<tr>
<td>Standing</td>
<td>Unchanged</td>
<td>38</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Deterioration</td>
<td>0</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Dimension E</td>
<td>Improvement</td>
<td>6</td>
<td>9</td>
<td>0.002</td>
</tr>
<tr>
<td>Walk, run, jump</td>
<td>Unchanged</td>
<td>45</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Deterioration</td>
<td>0</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>

A clinically significant change was defined as ± 4%. Proportion of change was analysed with the Chi-2 squared p-value.
Table VII. A comparison of the proportion of change on PEDI FS after the period of intensive training in group compared with the proportion of change at one year for the total group n=51.

<table>
<thead>
<tr>
<th>PEDI FS</th>
<th>After ITP</th>
<th>At one year</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care</td>
<td>Improved</td>
<td>8</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Unchanged</td>
<td>39</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Deteriorated</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Mobility</td>
<td>Improved</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Unchanged</td>
<td>35</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Deteriorated</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Social function</td>
<td>Improved</td>
<td>9</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Unchanged</td>
<td>39</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Deteriorated</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

A clinically significant change was defined ± 4 scaled scores on PEDI. Proportion of change was analysed with the Chi-2 squared p-value.

**Outcome of the self-reported individualized goal measure**

In total, 248 goals were formulated, regardless of training approach. Of these, 104 individualized goals were judged as clinically significant improvement. The median level of importance showed a high ranking for the three most important individualized goals ranging 9-10 (IQR 1-3) points on a Lickert scale 1-10 (not important at all - to extremely important) irrespective of training approach. Before the ITG, the median level of performance was rated low to moderate, ranging from 3 (IQR 2-3) points on a Lickert scale 1-10 (cannot perform at all - performs extremely well).

Twenty-eight parents out of 54 perceived clinically significant improvements on the performance for two preset individualized goals (SRIGM), and there were no significant differences between the habilitation approach and the CE approach. Subgroup analysis for age, level of gross motor function, and learning disability did not change the comparison between the two training approaches.

The proportion of preset individualized goals within the different components and domains in ICF did not differ between the two training approaches.
Results

(Figure 3). There was no difference between the habilitation approach and the CE approach with respect to the improvements in the three domains with the highest numbers of preset individualized goals: Neuromusculoskeletal and movement-related functions, Mobility, and Self-care.

The highest number 115 out of 248 individualized goals was within the activity and participation component in the Mobility domain. The second highest number 64 out of 248 individualized goals was within the Body function component in the domain of Neuromusculoskeletal and movement-related functions.

![Figure 3. Comparison of the proportion of individualized goals in the two training-programmes (total n =248 goals) classified according to the International Classification of Functioning, Disability and Health (ICF) into the two components Body Functions and Activity and participation with belonging subordinate domains.](image-url)
Comparison of the outcome on the SRIGM compared to the clinical measures.

Compared to the clinical measures, there was a higher proportion of children who improved according to the SRIGM (28 children out of 54): GMFM-88 total score (9 children out of 54), the single domains PEDI FS self-care (8 children out of 52), mobility (12 children out of 52), and social function (10 children out of 52).

There was no difference in the proportion of changes between the SRIGM compared with the clinical measures, if an improvement in any dimension A-E on GMFM-88 or in any domain on PEDI FS was considered.

The comparison of improvements on the SRIGM and the clinical measures showed that most of the parents who perceived an improvement on the SRIGM also showed a concurrent clinical improvement. The measurement domains as measured with SRIGM and classified with the ICF were to a high degree overlapping with the dimensions and domains measured with the clinical measures GMFM-88 and PEDI FS.

Parents´ perception of the service quality

Parents perceived a high degree of fulfilment (mean 3.4; s.d. 1.0), of health care needs and the aspects investigated were considered highly important (mean 3.5; sd 0.9) (Table VIII).

The parents expressed several important needs: gaining knowledge about abilities and disabilities and knowing where to find continued help after the intensive training period if needed. Parents also perceived it highly important that the therapists had time for communication, treated the child with respect, considerate towards the child, and understood the child’s most important problems and needs (Table VIII).
Results

The least fulfilled needs were to be asked about expectations, to learn about abilities and the training and to get support and help before conclusion of the intensive training period (Table VIII).

All predefined factors were associated to some extent with the perception of the service quality. Factors that were most frequently associated with the outcome on the fulfilment scale were: the training approach, severity of disability, achieved expectations and gross motor function outcome (GMFM-88) (Table IV in paper III). Factors that were most frequently associated with the outcome on the importance scale were: the training approach and previous experience of the ITG (Table V in paper III).

Significant regression coefficients are shown in Table IV and V in paper III. All response variables in the POCR (Table VIII) were investigated except for 13_child and 13_parent, due to a low response rate as few children and parents felt uneasiness during the ITP.

Fulfilment scale

The probability of parents perceiving a high fulfilment of needs increased if parents had previous experiences with the intensive training approach, high expectations regarding improvements, expectations were achieved, gross motor capability was improved and the child participated in the habilitation approach. The probability of parents perceiving a high fulfilment of needs decreased for parents of severely disabled children (classified as GMFCS 5) (Table IV in paper III).

The probability of parents perceiving functional improvements increased if parents had high expectations regarding improvements and the child improved according to the self-reported individualized goal measure (SRIGM) and decreased for parents of severely disabled children (classified GMFCS 5) (Table IV in paper III).

Importance scale

The probability of parents perceiving that needs were important increased if the child participated in the habilitation approach and gross motor capability improved and decreased if parents had previous experience with the ITG or if they were parents of severely disabled children (classified GMFCS 5) (Table V in paper III).
Parents whose children participated in the habilitation approach and who had previous experience with the ITG perceived that participating for the sake of the child was of less importance. This was in contrast to parents who perceived that expectations and improvements on the SRIGM were achieved; they perceived that parent participation was more important (Table V in paper III).
### Table VIII. Parent-perceived outcome on the Patient perspective on Care and Rehabilitation Process (POCR) for the total group. c=child, p=parent

<table>
<thead>
<tr>
<th>A. Need for adequate care</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Fulfillment Mean (sd)</td>
<td>md</td>
<td>Importance Mean (sd)</td>
<td>md</td>
<td>Mean difference (sd)</td>
<td>p-value</td>
</tr>
<tr>
<td>1. Did you want NN to participate in the training-programme?</td>
<td>50</td>
<td>3.8 (0.5)</td>
<td>4</td>
<td>50</td>
<td>3.5 (0.6)</td>
<td>4</td>
<td>0.3 (0.6)</td>
</tr>
<tr>
<td>2. Did you, already at the beginning of the programme, know the purpose of the training-programme?</td>
<td>50</td>
<td>3.0 (1.0)</td>
<td>3</td>
<td>50</td>
<td>3.0 (0.9)</td>
<td>3</td>
<td>0 (1.1)</td>
</tr>
<tr>
<td>3. Is there anything in connection with your child’s training that you wonder about?</td>
<td>50</td>
<td>3.7 (0.8)</td>
<td>4</td>
<td>12</td>
<td>2.0 (1.3)</td>
<td>2</td>
<td>0.6 (2.2)</td>
</tr>
<tr>
<td>B. Need for orientation in the care context</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Did the therapists ask you, early in the ITP, what help and support was important for NN?</td>
<td>48</td>
<td>2.8 (1.4)</td>
<td>4</td>
<td>48</td>
<td>3.2 (1.0)</td>
<td>4</td>
<td>-0.4 (1.3)</td>
</tr>
<tr>
<td>5. Did the therapists tell you and NN, early in the ITP, about routines like training-breaks, where to eat lunch etc.?</td>
<td>49</td>
<td>3.5 (0.8)</td>
<td>4</td>
<td>48</td>
<td>3.2 (0.9)</td>
<td>3</td>
<td>0.4 (1.0)</td>
</tr>
<tr>
<td>6. Did you get to know, early in the ITP, who was the responsible therapist for NN?</td>
<td>50</td>
<td>3.9 (0.4)</td>
<td>4</td>
<td>50</td>
<td>3.7 (0.7)</td>
<td>4</td>
<td>0.2 (0.8)</td>
</tr>
<tr>
<td>7a. Did you get to know enough about NN’s difficulties?</td>
<td>48</td>
<td>3.0 (1.2)</td>
<td>4</td>
<td>50</td>
<td>2.8 (1.2)</td>
<td>3</td>
<td>0.1 (1.4)</td>
</tr>
<tr>
<td>7b. Did you get to know enough about NN’s skills?</td>
<td>49</td>
<td>2.8 (1.1)</td>
<td>3</td>
<td>50</td>
<td>3.0 (1.1)</td>
<td>3</td>
<td>-0.2 (1.2)</td>
</tr>
<tr>
<td>7c. Did you get to know enough about the training NN performed?</td>
<td>49</td>
<td>2.9 (1.3)</td>
<td>4</td>
<td>49</td>
<td>3.5 (0.8)</td>
<td>4</td>
<td>-0.6 (1.1)</td>
</tr>
<tr>
<td>8. Did the other children get the help and training they needed from your point of view?</td>
<td>47</td>
<td>3.9 (0.4)</td>
<td>4</td>
<td>47</td>
<td>3.4 (0.9)</td>
<td>4</td>
<td>0.5 (1.0)</td>
</tr>
<tr>
<td>C. Need for knowledge and control</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Did you get informed in time if there were any changes in the training-programme, staff etc.?</td>
<td>35</td>
<td>3.5 (1.0)</td>
<td>4</td>
<td>35</td>
<td>2.5 (1.3)</td>
<td>3</td>
<td>0.8 (1.5)</td>
</tr>
<tr>
<td>10a. Do you have enough knowledge about your child’s difficulties?</td>
<td>50</td>
<td>3.6 (0.6)</td>
<td>4</td>
<td>50</td>
<td>3.8 (0.4)</td>
<td>4</td>
<td>-0.3 (0.8)</td>
</tr>
<tr>
<td>10b. Do you have enough knowledge about your child’s skills?</td>
<td>50</td>
<td>3.7 (0.6)</td>
<td>4</td>
<td>50</td>
<td>3.9 (0.2)</td>
<td>4</td>
<td>-0.2 (0.6)</td>
</tr>
<tr>
<td>D. Need for support and autonomy</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>11_c Did the therapists have time to communicate and listen to NN’s wants and wishes as a child?</td>
<td>45</td>
<td>3.3 (1.0)</td>
<td>4</td>
<td>46</td>
<td>3.8 (0.5)</td>
<td>4</td>
<td>-0.4 (0.8)</td>
</tr>
<tr>
<td>11_p Did the therapists have time to communicate and listen to your wants and wishes as a parent?</td>
<td>50</td>
<td>3.4 (0.9)</td>
<td>4</td>
<td>50</td>
<td>3.7 (0.6)</td>
<td>4</td>
<td>-0.3 (1.0)</td>
</tr>
<tr>
<td>12. Did you as parent participate together with NN in the ITP?</td>
<td>49</td>
<td>3.8 (0.6)</td>
<td>4</td>
<td>49</td>
<td>3.3 (0.9)</td>
<td>4</td>
<td>0.5 (1.1)</td>
</tr>
<tr>
<td>13_c Did NN get support when worried?</td>
<td>14</td>
<td>2.9 (1.4)</td>
<td>4</td>
<td>14</td>
<td>3.3 (1.1)</td>
<td>4</td>
<td>-0.4 (1.7)</td>
</tr>
<tr>
<td>13_p Did you, as a parent get support when worried?</td>
<td>9</td>
<td>2.2 (1.4)</td>
<td>2</td>
<td>9</td>
<td>3.7 (1.0)</td>
<td>4</td>
<td>-1.4 (1.4)</td>
</tr>
</tbody>
</table>
Table VIII continued.

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E. Medial and interactional needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Did the staff treat NN the way NN needed?</td>
<td>50</td>
<td>3.6 (0.8) 4</td>
<td>50</td>
<td>3.9 (0.3) 4</td>
</tr>
<tr>
<td>15. Did NN receive the training NN needed?</td>
<td>49</td>
<td>3.5 (0.8) 4</td>
<td>49</td>
<td>3.7 (0.6) 4</td>
</tr>
<tr>
<td>16. If you review the ITP in retrospect did the therapists behave respectfully to NN?</td>
<td>50</td>
<td>3.8 (0.6) 4</td>
<td>50</td>
<td>3.9 (0.2) 4</td>
</tr>
<tr>
<td>17. Do you believe the staff understood what were NN’s most important problems and what was most important for you to get help and support with?</td>
<td>50</td>
<td>3.5 (0.9) 4</td>
<td>50</td>
<td>4.0 (0.2) 4</td>
</tr>
</tbody>
</table>

F. Need for preparedness before discharge

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>18_c Did NN get enough support and help at the end of the ITP e.g. how to continue the training?</td>
<td>31</td>
<td>2.9 (1.2) 3</td>
<td>32</td>
<td>3.3 (1.1) 4</td>
</tr>
<tr>
<td>18_p Did you as a parent get enough support and help at the end of the ITP e.g. how to continue the training for NN?</td>
<td>48</td>
<td>3.4 (0.9) 4</td>
<td>49</td>
<td>3.6 (0.7) 4</td>
</tr>
</tbody>
</table>

G. Situation post-discharge

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>19. Were you prepared for the situation after the ITP?</td>
<td>50</td>
<td>3.3 (1.1) 4</td>
<td>49</td>
<td>2.9 (1.1) 3</td>
</tr>
<tr>
<td>20. Do you know where to turn if you need continued help with the training for NN?</td>
<td>50</td>
<td>3.7 (0.9) 4</td>
<td>50</td>
<td>3.8 (0.6) 4</td>
</tr>
</tbody>
</table>

Mean differences between fulfilment and the importance-scale were analyzed with the Wilcoxon Signed Rank Test. D. 12* importance for the parent 3.7(0.6) 4, mean difference 0.1 (sd 0.7) n=49
Parents’ conceptions of different meanings of intensive training in groups (ITGs) to the parent.

Paper IV

Five overarching meaning categories describing what needs ITGs may fulfil for parents were identified: ITGs as knowledge promotion, as a complementary training resource, as a bracket in ordinary life, as building up relations with therapists and as a leisure-activity. One additional category described the possible problems that may arise: “ITGs as risk for ill-being”. Each category is in turn subdivided into a number of conceptions. All together 13 conceptions of ITGs were identified.

ITGs as knowledge promotion
A means to explore the present functioning of the child
According to this conception, ITGs are a means for parents to improve knowledge of their child’s present functioning. Three roads to increased knowledge are described. Knowledge is gained through explorations of the child’s upper limit of functioning, by comparisons with other children in the group and by symbolic means such as listening to the therapist’s explanations of why particular tasks may be difficult to perform.

A means to improved anticipation
According to this conception, ITGs are a means to insights regarding changes in functioning to be expected in the close or distant future. Anticipation of functioning can either be reached through personal experiences or by listening to other people’s experiences, especially the opinions and experiences of therapists.

A means to learn how to support the functioning of the child
According to this conception, ITGs are a means to improve knowledge about how to support the child’s functioning. Four roads to increased knowledge are described. ITGs contributed to parents’ need for knowledge about how to use hands while assisting their child, to learn a way of thinking and behaving that meant to encourage the child’s own activity in favour of assisting the child
with hands, to modify tasks to enhance functioning and gain knowledge about technical aids as a means to support functioning.

*A means to share experiences with other parents*
According to this conception, ITGs are a means to share experiences with other parents having a child with similar needs. Parents share their experiences and feelings about having a child with CP and a broad range of other topics from social rights to practical issues in daily life such as choices of practical clothes.

**ITGs as a complementary training resource**
*A means to get relief from the training-responsibilities*
According to this conception, ITGs may serve as a means to get relief from the child’s training.

*A means to mobilize others in training*
According to this conception, ITGs are a means for parents to find support with the transference of knowledge to close relatives, assistants or staff in school about the functioning of the child and how to support the child in ordinary life.

*A means to get the child motivated in the training*
According to this conception, ITGs are a means for parents to stimulate the child’s involvement in the training. ITGs are described as doing training with playfulness, songs, joy, competitiveness and togetherness in a group and in a room prepared for training. Parents holding this conception believe that the group and the environment facilitate concentration and motivation of the child.

**ITGs as a bracket in ordinary life**
*A means to get time together with the child*
According to this conception, ITGs are a means to leave ordinary life demands and to get time to focus on the child.

*A means for temporary “normalisation”*
According to this conception, ITGs offer an environment knowledgeable and understanding toward disabled children where the child is met as a person without stigmatizing. ITGs became a means to relax and experience a temporal normalisation as a parent.
Results

A means to get a widened perspective
According to this conception, ITGs are a means to widen one’s perspective on the disabilities of the child by comparison with other children in the group. This conception included feelings of ease and comfort.

A means to gain increased vitality and strength
According to this conception, ITGs are a means for increased psychological vitality and strength.

ITGs as building up relations with therapists
According to this conception, ITGs are a way to establish a better relationship with therapists. A more personal relation is attained through participation in the ITGs.

ITGs as leisure activity
According to this conception, ITGs are a means for parents to arrange spare time for their child. ITGs compensate for difficulties finding formal leisure activities adapted to the child’s needs of training and social togetherness in ordinary life. It is a means for the parent and child to share an interest in the same way parents share interests with the other siblings.

ITGs as a risk for ill-being
A contributor to feelings of insufficiency
According to this conception, ITGs are a contributor to feelings of insufficiency of not living up to the role of being a good parent. Two main problems were described. Feelings of insufficiency emerged in the encounter with other parents or transference from therapists/conductors of unrealistic goals for training in the ordinary life environment.

An intruder in ordinary life
According to this conception ITGs interfere with ordinary life and place extra burdens on the family. It requires extra work to plan for the intensive training period both at home and at work. The family suffers from one parent being absent at home.
DISCUSSION

Main findings

Conductive education (CE) was neither more nor less effective than intensive training in a group at the Child and Youth Habilitation concerning the impact on functioning measured with clinical and self-reported measurements. According to parents’ goals both training approaches would be described as interventions which primarily focus on movement-related body functions and activities [144].

One intensive training period facilitated small clinically significant improvements, mainly in gross motor capability and mobility performance. The one-year follow-up reinforced the conclusion that short-term improvements mainly dealt with gross motor function and mobility skills but indicated a better potential of change in self-care and social function long-term. Outcome on functional skills after the intensive training-period indicated scarce and questionable changes transferred to the ordinary life setting. The self-reported individualized goal measure (SRIGM) confirmed the results of the clinical measures [144, 145].

Parents perceived a high service quality in both training approaches [146]. In addition to functional improvement, time for communication, considerate and appropriate treatment, and understanding of the child’s needs and problems all reflected needs that were highly valued. There was a complex interaction between parents’ perceptions of the service quality and the presumed influential factors. High service quality was associated with previous experience of the training approach, high expectations of improvements, whether expectations and improvements in gross motor capability were achieved and whether the child participated in the habilitation approach. Moreover, parents’ perceptions of functional improvements were associated with high expectations of improvements and achieved improvements on the self-reported individualized goal measure (SRIGM). One interpretation from the quality evaluation in the present study was that other needs than improvement in functioning needed to be shed light upon as fulfilled
Discussion

expectations were rather associated with perceptions of high service quality than functional improvements [146].

Conceptions of ITGs in general implied that ITGs fulfil a variety of needs to parents of children with CP. The identified conceptions implied that ITGs might contribute to parents’ feelings of enhanced competence as a caregiver, of being supported and well-being. Conceptions also showed that there were various meanings of what it meant to be supported. The present thesis provides a description of the expected outcome on functioning and parents’ perceptions of the service quality of the two ITGs. Furthermore, the qualitative study describes a variety of different needs that might be supplied from participation in ITGs with respect to parents’ needs and problems that might arise.

Description of the two intensive training group (ITGs) approaches

In evaluations of outcome of therapeutic interventions within the paediatric field there is a need of more knowledge of the actual performances of interventions [11, 147]. When trying to describe the intervention in the present study emphasis was made to describe the intervention from a professional and parent perspective.

Professionals’ objectives with the intensive training groups (ITGs) were difficult to describe with theories and had to be described in general terms. It’s also recognized that there is no coherent theory underlying contemporary physiotherapy or CE [93, 148]. Moreover, it was not within the scope of this study to evaluate whether the training approaches implement theories in practices. The description of the two ITGs from a professional perspective was therefore overarching and revealed many similarities.

Common features of the two ITGs that might have similar impact on the outcome of this evaluation were the group that meets in a segregated setting adapted for training, participation of parents, close relatives or personal assistants; the length of the training period and amount of training. The emphasis on learning and creating of an environment to motivate the child’s involvement in the training were also common features between the ITGs.
The main difference between the two ITGs was the background and composition of the professionals leading the groups. The evaluation of parents’ perception of the process of care in the present study added pieces of knowledge indicating that therapists in the habilitation approach were to a greater extent involved in discussions with the parents about their expectations on the ITG and of knowledge exchange. This indicated a closer collaboration with parents and a more family-centred approach than in the CE approach [146]. In contrast, the conductor’s role is described as a leader of a group, guiding and supervising the participants from professional experiences [10, 149]. The differences in professional background may reflect differences between the two ITGs concerning attitudes on professionals’ and parents’ roles in planning and performances of interventions.

Another strategy to describe the intervention was to use the evaluation of the individualized goals for training as descriptions of parents’ goals (expectations) for the training-period in the two ITGs. The results of the self-reported individualized goal-measure (SRIGM) revealed that most goals for training were directed towards improvement of gross and fine-motor functions primarily within the activity and secondary within the body function component. Both interventions could partly be regarded as “functional approaches” as most goals were activity-focused, complemented with impairment-focused interventions as a large amount of goals also were defined within the body function component [145]. It could have been expected that a larger proportion of goals had been formulated within other domains such as self-care and communication according to how the ITGs were presented by the professionals. The individualized goals for training showed that parents’ expectations on the training were similar between the two training approaches.

In conclusion the two ITGs as described by professionals and parents were similar in many aspects. The evaluation of parents’ perceptions of performances of service delivery indicated more collaboration between parents and therapists in the habilitation approach. Because there were limitations in describing the ITGs, detailed information about the received input of treatment/training at an individual level as well as a group-level is scarce. For instance, it would have been of great interest to study the implementation of theories in practice (whether we do what we say) or to measure how much each individualized goal was targeted with the training.
In this study, both training approaches were referred to “packaged treatment/training approaches” as the objectives for interventions were that of meeting multiple needs with the services [92]. One reason for evaluating the outcome of the two ITGs, even though there are many aspects of the intervention that remain to be described, is the need for a better description [150 p.68-69].

Interpretation of outcome on functioning with the clinical and self-reported measures

Comparison between treatment/training approaches

In this study, comparison of the outcome on functioning in relation to previous evaluations of CE approaches call for careful interpretation of results since there are differences in inclusion criteria for children, the training setting, and the time for intervention and outcome dimensions and measures.

The present study confirmed the results of previous evaluations of CE [96, 102]. In this study, the setting for the CE approach was more compatible to a health care setting than an educational setting. Therefore, comparisons of outcomes were made with studies performing CE in similar settings [96, 102] and in relation to studies using comparable outcome measures on functioning [95, 96, 102]. There were no differences in outcome of functioning between the training approaches, the habilitation approach and the CE approach delivered in a health care setting [144, 145]. Neither, have previous evaluations shown differences in child-outcome between interventions in traditional educational settings versus CE in educational settings [93, 97, 98, 100].

Outcome of gross motor capability and functional skills

The magnitude of change on gross motor capability after the ITG was compared between the present study and CE approaches delivered in health-
Discussion

care settings [95, 96, 102]. A larger magnitude of change in gross motor capability was achieved by Reddihough et al. and Wright et al. [95, 96] than in the present study. In comparison Reddihough et al. reported changes of 7% and 8% on GMFM-88 mean total score over a 6 months period with CE versus customary training [96]. Wright et al. reported a combined change score on GMFM-88 mean total score of 6.5% after two subsequent years of 8 months follow-ups [95]. In the present study a change on GMFM-88 mean total score was 3% in the habilitation approach and 1% in the CE approach after a 4 week ITG. The larger magnitude of change reported in Reddihough et al. and Wright et al. studies might to a large extent be explained by the younger age group targeted and a longer follow-up period.

The two ITGs in the present study offered increased intensity of training compared to regular amount of training offered by the Child and Youth Habilitation services. Therefore, comparison of outcome was also performed with other “packaged- approaches” investigating the impact of more intensive training. Only two other studies were regarded as feasible comparisons with the present study including a wider age-group and children with similar functional levels [17, 103]. The comparisons showed that similar magnitude of change was reported in gross motor capability over the short-term, a result that was also evident in the present study. In comparison Bower et al. reported changes on GMFM-88 mean total score on 3% after two weeks’ intensive training [17] and Tsorlakis et al. reported changes on GMFM-88 mean total score (GMFM-66) of 3% (2%) after 4 months’ intensive training [103].

It was concluded that increased intensity of training enhanced gross motor capability short-term [17, 103] and an added value of collaborated and well-defined goals were advocated [17]. In the present study the comparison of outcome after the intensive training period in relation to the one-year outcome revealed no statistical changes in gross motor capability but a small change on GMFM-88 total score short-term supports effects of intensive training in gross motor capability after the ITG [144].

Differences of GMFM total mean scores are small and individual differences in the groups need to be investigated to interpret whether some children benefit more than others. From a rehabilitation perspective, it is also suggested that the individual should be the unit of evaluation [151]. The use of the preset definition of minimal clinically significant change showed that 9 children made clinically significant improvements in favour for ITGs with the
habilitation approach versus the CE approach (8 out of 24 cases vs 1 out of 30, range 4-10% on GMFM-88 total score) after a 4-week intensive training period. As many as 36 children out of 54 improved if an improvement of 4% in one dimension (A-E) was considered. A stable level of gross motor capability was reinforced when comparing proportion of clinically significant changes, three of the children that improved after the ITG made further improvements and no child deteriorated on the GMFM-88 total score or the dimensions A-E after the intensive training period and at the one-year follow-up [144].

In the present study, the consumption of training was pragmatically investigated in retrospect at the one-year follow-up, allowing for a comparison between children receiving repeated periods of intensive training in groups (rITGs) and customary amount of training (Cust-group). In a single case study of repeated intensive training periods (4 children 3-4 years of age), Trahan et al. showed that the children improved 5-11% on GMFM total mean score after a 4-week intensive training period and continued to change 3-16% after a new 4-week intensive training period following a rest-period of 8 weeks [105]. The results in the present study did not confirm that repeated intensive training periods reinforced motor development. As in Bower et al., it was concluded that repeated intensive training periods did not lead to larger improvements in gross motor capability than customary amount of training [104, 144].

The development of gross motor developmental curves have improved the premises for relating the added value of different interventions to prognostic changes in gross motor capability of children with CP receiving customary Child and Youth Habilitation services. The small changes on mean GMFM total score in the present study confirmed the magnitude of change that could be expected in relation to the patterns of prognostic gross motor developmental curves [152, 153]. It’s been estimated that children with CP have on average reached 90% of their gross motor capability at the age of 5. There’s also a tendency that children with lower functional level reach their potential development limit more quickly [153]. More than seventy-eight percent of the children in the present study were older than 6 years and 63% of the children included were classified GMFCS 4-5 contributing to explain the small changes in gross motor development.

Pediatric Evaluation of Disability Inventory (PEDI) was used to widen the dimensions of evaluation to include functional skills in self-care, mobility and social function domains and to explore whether changes were transferred to
Discussion

an ordinary life context. Both interventions targeted a wider scope of dimensions in functioning than capability in basic gross motor activities as measured with GMFM-88. The results in the present study did not show any differences in functional skills between the two ITGs - short-term and transference of functional changes to ordinary life was limited [144].

At a group level there were small improvements in the mobility (0.9 mean scaled scores) and social domain (1.7 mean scaled scores) after one intensive training period and the magnitude of improvements was larger in self-care (2.8 mean scaled score) and social function (4.3 mean scaled scores) for the total group after one year [145]. Small improvements were expected as the intervention period was only 4 weeks. It was ventured to use a level of 4 scaled scores as a clinically significant change at an individual level. Twenty-two children out of 52 made a significant improvement after the ITG if a change in any domain in PEDI FS was noted and every task that improved might be considered valuable for the child. Most children improved in the mobility domain after the intensive training period, reinforcing the interpretation that short-term improvements mainly dealt with gross motor changes [144].

The one-year follow-up showed a larger proportion of clinically significant changes for the total group in self-care and social function domains 17 respectively 25 children (n=51). The larger proportion of improvements in the self-care and social function domains and the stable level of gross motor function at the one-year follow-up showed that the potential for change was better for these domains than the mobility domain. The question might be raised whether interventions targeted in the ITGs focus too much on gross motor function and mobility needs in favour of self-care, communication, and social function needs. Children who continued with repeated intensive training periods in groups showed a larger mean change and higher proportion of clinically significant changes in the PEDI FS social function domain after one year than children who received customary amount of training [144].

However, interpretations need to be taken cautiously; according to the measurement properties of PEDI, the standard error of measurement for the particular score should be considered. Unless the amount of change exceeds two standard errors, there is uncertainty whether a real change has occurred in the child’s performance [2]. According to this recommendation, only one child
Discussion

in each ITG in the present study made clinically meaningful changes after one intensive training period.

Because few studies have reported outcome on PEDI, it is difficult to interpret the magnitude of change in relation to other therapeutic interventions. Ketelaar et al. reported mean changes after customary compared to functional training in self-care: 3 compared to 4 scaled scores after 6 months and 4 compared to 8 scaled scores after one year and in mobility: mean change of 1 compared 2 scaled scores after 6 months and 4 compared to 8 scaled scores after 1 year [83]. Ekström-Ahl et al. reported median changes in self-care of 5.2 scaled scores, mobility 2.5 scaled scores and social function 2.6 scaled scores after 5 months’ intervention using an ecologically functional approach [85]. The larger magnitude of changes might partly be explained by the interventions targeting younger ages and the longer intervention periods [83, 85]. Whether the better result of the two studies by Ketelaar et al. and Ekström-Ahl et al. was due to the implementation of the interventions being more functional remains to be proven [83, 85]. A similar magnitude of change was reported after 6 weeks’ neuro-developmental treatment in self-care (mean changes 1.8 scaled scores) for children with comparable ages and functional levels as in the present study [154].

Most previous studies have only valued the clinical relevance of change at a group level, and comparisons of the proportion of clinically meaningful changes of GMFM-88 and PEDI FS are scarce when evaluating other “packaged approaches”. Stiller et al. reported several meaningful changes on subscales of GMFM-88 dimensions, Peabody Developmental Motor Scales (Fine-motor subscales), and PEDI FS. A clinically significant change was defined as a 10% change on each standardized tests. One-fourth of the subscales improved for the children participating in the CE (special education group), whereas 1/3 of the subscales improved for children participating in the intensive training group [102]. The results in the present study show clinically significant changes in about 1/2 of the children [145]. The two studies indicate short-term effects of the intensive training [102, 145].

Changes in self-care, mobility, and social functioning in an ordinary life context with the use of adapted technology may be more responsive to changes in older ages than gross motor capability as measured with GMFM-88 [152]. This was supported in the one-year follow-up in the present study because a higher proportion of improvements was seen in the self-care or
social function domains. The higher proportion of improvements in social function for the group continuing in repeated ITGs must be interpreted with cautiousness because parents were able to choose whether their child continued or discontinued with ITGs. Parents who wanted their child to continue with ITGs probably experienced that their child benefited from the intervention; whether changes in social function were related to the ITGs or natural development remains inconclusive.

In addition this study evaluated the added value of ITGs to the customary services delivered by the Child and Youth Habilitation, the relatively small changes that occurred over short-term and at the one-year follow-up showed that the included children already were functioning close to their upperlimit. These results might strengthen parents’ and professionals’ confidence that customary habilitation approaches fulfil the needs of supporting the child’s development of gross motor capability and mobility skills based on professional judgement (clinical measurements).

Addition of a self-reported individualized goal measure for interpretation of changes in functioning from a parent-perspective

The use of a self-reported individualized goal measure (SRIGM) was threefold. Firstly, it was believed to widen the perspective of what are important goals for intervention and outcome of the two training approaches from parents’ perspectives. Secondly, instruments evaluating change from a client-perspective have also been recommended for use in clinical practice as more sensitive measures to detect change after intervention due to the individualization of the specific goal for the training [128-130, 155, 156]. Thirdly, there is also a discussion which outcome that matters to the child [157, 158] and who should judge whether an outcome is successful. Self-reports have been proposed to be a more valid outcome measurement due to the belief that the patient is the best judge of the outcome [120, 121, 157, 158]. Parents are considered the best resource for identifying functional goals, and therapists should cooperate with the child and family to address meaningful needs/goals that originate from ordinary life experiences of the parent or the child [80, 82, 83, 85, 104]. Because the two objective assessors were not involved and had no own experiences of the two ITGs, collaboration about
goals was not intended. To interview parents about the goals for training without collaboration was a way to avoid transference of professional values on the individualized goals [145]. On the other hand, the sensitivity to change of the SRIGM might have been reduced since formulating measurable goals is difficult [95, 154]. It was believed that the SRIGM would result in individualized goals being more sensitive to change than standardized and criterion-referenced measures as GMFM-88 and PEDI. It was also expected that the SRIGM would capture individualized goals/needs addressed in measurement areas outside the dimensions and domains in GMFM-88 and PEDI.

The SRIGM, however, was not more sensitive to change than the clinical measures in the present study. The proportion of meaningful improvements, such as the ones measured with the SRIGM, agreed with the clinical measures if using the definitions in the present study [145]. Due to the results, it was questioned whether self-reported individualized goal measures are more sensitive to change than clinical measures. Previous studies evaluating change with clinical and self-reported individualized goal measures (COPM or Goal Attainment Scales) have reported similar results with the clinical and self-reported measures [85, 154, 159, 160]. One of the studies reported somewhat larger improvements on the self-reported goals [101]. The somewhat widened scope of evaluation with the SRIGM, which included body function, did not increase the sensitivity to change of SRIGM compared to the clinical measures.

The present study showed that parents often formulated goals in the same dimensions/domains as the clinical measures GMFM-88 and PEDI [145]. The same experience was done when evaluating neuro-developmental treatment with clinical measures and a goal attainment scale [154]. From this, it could be concluded that parents’ judgement of outcome on functioning agreed with the professionals’ judgement.

A parent’s choice of dimensions for goals could reflect their conceptions of vital goals (needs) for the individual child and their expectations of what might be influenced by the intervention. Two factors might influence how parents individualize their child’s goals: experience with the Child and Youth Habilitation and experience with the ITGs. Recently, it was reported that 60% of the treatment goals set by therapists were covered by GMFM-88 and PEDI [161].
Until now, the discussion has concentrated on the effects of functioning. This was also the most discussed reason for participation in ITGs by both parents and therapists. The concern that children may not receive enough support with the child’s development from customary services at the Child and Youth Habilitation Service or that training of the child’s capacities might suffer from too much compensation with technical aids seems unjustified. Still, parents’ concern about the child’s development, worry that needs are not met, and discontent with customary services called for a broader evaluation perspective to improve the understanding of what needs ITGs with a CE approach fulfil in relation to a habilitation approach. An important target with interventions is also to enhance parents’ well-being [162] and feelings of competence in supporting the child [83, 85].

**Parents’ perception of the quality and interpretation of outcome in relation to previously defined influential factors**

The next step taken in the effectiveness study was to investigate whether there were differences in parents’ perceptions of the service quality between the two ITGs. An important factor for parents’ well-being is satisfaction with service quality [78, 163]. Based on previous knowledge, it was conceived that interpretation of parents’ perceptions of the quality of care could be improved if the outcome of service quality was related to previous experiences, expectations, and perceived outcomes [137].

The comparison of parents’ perceptions of service quality showed that parents at the ITGs with the habilitation approach were to a greater extent involved in discussions with professionals about their expectations of the intensive training period and exchanged knowledge with the therapists, two factors that indicate a family-centred approach [146].

The conductors’ guidance and supervision don’t seem to correspond with the close collaboration and involvement of parents as emphasised with a family-centred habilitation approach, which emphasises empowerment of parents and increased self-efficacy. Parents might have appreciated a more professional-based leadership, but in the present study the results supported
Discussion

the family-centred approach as parents’ involvement and knowledge exchange were considered of high importance [146].

When evaluating service quality of different treatment/training approaches a generally high level of satisfaction with the service quality has been reported [85, 96, 104] as in the present study [146]. It suggests that parents are in general satisfied with services when services are available. The interpretation might be exaggerated due to bias in selection of treatment/training approaches being evaluated as these approaches might be considered more well-organized and led by therapists with high ambitions. The other way around the quality-evaluation as such might stimulate and enhance the quality of the interventions.

Another interesting finding was that parents’ expectations of improvements and the outcome on the self-reported individualized goal measure were associated with parents’ perceptions of improvements after the ITGs. This suggests that positive expectations of outcomes exaggerated parents’ perceptions of improvements measured with POCR and the self-reported individualized goal measure (SRIGM). The results indicate that the SRIGM measured improvements, which to a greater extent than the clinical measures were perceived by parents. Goals were also chosen with respect to what parents believed were changeable components of functioning. The clinical measures were based on assumptions that represent important goals of intervention from a general perspective of typically developing children – that is, a less individualized approach. Parents may have overlooked changes on the clinical measures. Importantly, perceived improvements encourage and strengthen parents’ well-being, an important goal from a parent perspective and for family-centred services [162, 164, 165].

Previous studies have shown that favourable clinical outcome has positive effects on patients’ perceptions of the service quality [137]. This was supported by the present study since a favourable outcome on GMFM-88 increased the probability that parents perceived a higher service quality. This was also taken as an added contribution of evidence that small clinical improvements in gross motor function were achieved in the present study [146].

An important consideration was that the highest proportion of low fulfilment of needs was within the dimension measuring parents’ perceptions of improvements. Almost one-fourth of the parents did not perceive
improvements in functioning. Still, most parents perceived a high service quality [146]. Another finding was that parents’ perceptions of achieved expectations of the ITGs were associated with parents’ perceptions of fulfilment of needs rather than whether they perceived that the child improved [146]. The evaluation of service quality demonstrated that most of the health care needs explored with POCR were important and the most highly valued needs were having time for communication, being considerate, and providing respectful treatment and understanding from professionals of the child’s needs and problems. This underlines that ITGs fulfil other needs in addition to or instead of changes in functioning.

The probability of parents perceiving a lower service quality increased if the child was afflicted with severe disability, indicating a need for more knowledge about the needs of ITGs for parents and children in different subgroups according to age, severity of disability, etc. Children with multiple health care needs have previously been found less satisfied with the quality of health care services. Multiple health care resources are not recommended for this subgroup [166]. Service quality evaluations are important to improve the information and knowledge about different training approaches and thereby facilitate parents’ informed choices of what might be of value to the child and parents. Service quality evaluations may also facilitate quality improvements if steps are taken by professionals to adapt interventions to the needs of parents and children.

**Parents’ conceptions of intensive training in groups**

In the qualitative study no difference was made whether the ITGs were performed with a habilitation approach or a CE approach. ITGs were seen as one phenomenon based on previous knowledge of the similarities in outcome on functioning and parents’ perception of service quality regardless of treatment/training approaches [144-146]. Other common attributes included the segregated setting from ordinary life, parent participation, and intensity; these were preconceived phenomena (rather than the treatment/training approaches as such) believed to influence parents’ conceptions of ITGs.
The identified conceptions pointed to a variety of parental needs that may be met, but also indicated some problems that should be noticed. Conceptions showed that there were various meanings of what it meant to be supported. One consideration was whether parent participation in ITGs provided support for parents. Children with CP and their families are confronted with multiple health care needs, needs that change during development depending on the child and family as well as on environmental factors [167]. Parents’ need for more physiotherapy has been suggested to be greater when the child’s disorder is still undefined [168 p.84]. Following the grief associated with realizing the child’s disability, parents enter a second phase associated with a strong wish for seeking information about how to help their child and a strong desire to participate in training [169, 170].

As a means to be supported, ITGs might be described from different positive aspects. Conceptions inferred that parents valued therapists as models that show how to afford learning opportunities by different means such as using hands, verbal instructions, structuring physical spaces, and use of materials to promote child participation. Opportunities for observation and imitation of the therapist have previously been reported as an effective [171] and valued [172] method for parents’ learning. Conceptions revealed that transference of knowledge could be perceived as a way to help parents handle and support their child. Selected activities that are doable and easy to integrate into daily routines and interactions are reasonable training activities at home [171, 172]. More knowledge is needed about the effects and characteristics of home training on functioning [173] and how it affects the parent-child relationship and family life.

Conceptions also inferred that ITGs as a meeting place for knowledge exchange contributed to parents’ confidence in themselves as caregivers. Sharing information and experiences from different sources – parents, children, professionals, and the environment at the ITGs – were important ways to gain knowledge. Gained knowledge from ITGs helped parents identify, formulate, and ask for different kinds of support from the child and youth habilitation services. Parents expressed an increased self-confidence as perceived needs were reassured from shared experiences with other parents. Knowledge transference is difficult to achieve [136, 174, 175] and an important aspect of service quality that must be addressed to optimize parent involvement. An important issue is good cooperation and knowledge exchange between professionals (therapists and conductors) delivering ITGs
and professionals serving in the child and youth habilitation team. This collaboration helps parents implement services in the home environment. The ecologically functional approach, as described by Ekstrom-Ahl et al., uses a combination of group and individual goal-directed intervention in the child’s ordinary life environment, strategies that help parents and children implement services in ordinary life [85]. Being open about different treatment/training options is also important. It has been described difficult for parents to get information about conductive education from professionals at the Child and Youth Habilitation Service [10, 14, 176]. A supportive environment should acknowledge additional sources of information [177].

Importantly, cautiousness needs to be taken of demands on parents who already have a much higher caregiver burden than that of non-disabled children. A negative aspect of transference of knowledge how to support the child is that it might put high demand on parent participation. Professionals’ expectations of parents being their extended therapeutic arm have been described as overwhelming and demanding [172]. Conceptions also inferred that expectations of parents’ performing home-training might be perceived demanding and there was a risk for feelings of insufficiency transferred from therapists or other parents at the ITGs. Siebes et al. found that parents want to be involved in goal-setting and treatment/training as their involvement is important to find the best fit of meeting needs in daily life [177]. A sensitivity and cautiousness of expectations of parents participating in the child’s training are supported as decreased caregiver demands have shown to be associated with increased physical and psychological well-being [162].

Conceptions also showed that parent participation in ITGs could enhance parents’ well-being as ordinary life demands were left behind by providing an opportunity for time together with the child, feelings of togetherness, joy, comfort, and feelings of doing good for the child. Conceptions also revealed experiences of the child being met with respect, appreciation, and encouragement. The conception a temporal normalisation illustrated that being in the group in an environment knowledgeable and understanding of the child’s behaviour might be a source for relaxation and help parents to experience their children with “other eyes” without having to pay attention to the child’s behaviour problems or need for support and protection. Behaviour problems of the child have been found to be a source of ill-being among parents of disabled children [162, 164]. Perceived respect of the value of the child and the engagement from professionals have been suggested as an
important way for strengthening parents’ experiences of being supported and inducing feelings of hope. Hope is strengthened by professionals who help parents see the potential abilities and help them understand their child’s development [178-180]. Hope and support enhance parents’ feelings of doing good and help them find ways to support the child [180]. Hope should not be mistaken for denial or unrealistic expectations [179]. In this sense, ITGs might be a contributing factor of parents’ needs of building up psychological resources of well-being and adaptation in the parental role.

On the contrary, conceptions also inferred that there were different opinions whether parent participation was a means to be supported. All parents did not have needs of participation for themselves and it was preferred that the child’s training was supported by others during the period of ITG. In this sense, ITGs were perceived as a period of ease and relief from training responsibilities.

Parent participation might be counter productive for parents that already feel competent to handle the child in ordinary life [106]. Conceptions inferred that ITGs met the child’s needs of well-being by providing professional support with training and peer interaction. ITGs were an adapted training activity; ITGs are often seen as a prerequisite for the child being able to participate and as a way to address their specific physical, communicative, and social needs. It was a leisure activity in the sense that it gave the child an activity to do with other children. Another conception was that ITGs were a way to normalize life as the child had an activity after school. It suggests a need for formal activities for older children with disabilities and for physiotherapists to take on a role to find sports and activities suitable for older children with CP [168 p. 84, 181]

Formal activities where the child may participate on its own (or together with its assistant) might support the child and parent in their needs of changing role during child-development. Role expectations are determined by the external world and professionals have a responsibility to be sensible to parents’ and children’s separate needs in the process of changing roles when the child gets older. More, knowledge is needed about processes of adaptation but it’s known that experiences of parenting a child with CP changes over time [182].

Discussion
The dialogue and choice of treatment/training approaches

ITGs are one of many different intervention strategies. All interventions intrude in the child’s daily life [71]. Children participating in the effectiveness study had intensive training [144]. The groups were labelled intensive training groups and conceptions revealed positive experiences of the added extra activity to explore the child’s possibility for change and to improve functioning; however, conceptions related to intensity from a parent-perspective also had to do with extra work at home, in school, and at work depending on the child’s age and parents’ situation. Conceptions also inferred that the family might suffer from one parent being absent at home. Clearly, parents need support with the child’s training. Parents are aware of the positive benefits of activity in general. They experience developmental problems of the child and reduced activity levels, which in turn leads to reduced experiences for learning. Moreover, parents experience progressiveness of what Graham called the “short-muscle disease” – the race between the growth of spastic muscles and the long bones, which is always won by skeletal maturity leading to contractures and deformities [43]. Multidisciplinary prevention programmes of secondary musculoskeletal problems as contractures, scoliosis, and hip luxation have shown to be successful in preventing hip luxation [183]. Prevention programmes and service quality evaluations are proactive and help parents and professionals find warning signals and evaluate whether implemented services provide high quality services supporting the children’s and families’ needs.

If one considers other treatment/training approaches with increased amount of training for a well-defined period, there is evidence for more targeted intervention strategies compared to “packaged treatment/training approaches”. There is evidence for strength training for children with CP [19-22, 184, 185]. More studies are needed to investigate the impact of improved strength on activities in daily life [186, 187]. Another treatment/training approach for children with hemiplegic cerebral palsy is constraint induced movement therapy (CIMT), a strategy that shows significant treatment/training effects over traditional interventions on upper limb functioning [188-191]. Evaluations of these methods focus on functioning and the setting for implementation varies. Targeted interventions and packaged
treatment/training approaches might be delivered individually as well as in a group setting.

The present study showed that there is still inconclusive evidence of effectiveness of different “packaged” treatment/training approaches of one method over the other on functioning [83, 96, 98-100, 102, 144, 145]. There is some evidence that short-term effects of intensive training improve gross-motor activities [17, 102, 103, 144]. The added value of intensive training periods in relation to customary child and youth habilitation on long-term effects on functioning has not been proven in the present study [144] or previous studies [104].

Importantly, packaged approaches also address important health care needs of the child and family other than functional outcomes. Parents of children with CP and the child have many different and complex needs. Prevention programmes, service quality evaluations, and research-based knowledge about the objectives and outcome of different intervention strategies give therapists and families improved support in making decisions about interventions that meet individual needs. Packaged treatment/training approaches, such as the ITGs in the present study, have a broader scope for intervention and include training of the child’s functioning as well as support for the parent.

The evidence of treatment/training approaches of outcome on functioning supports the effectiveness of various intervention strategies. As advocated in a family-centred practise, best practice requires a careful dialogue with parents and children to choose the best compromise for supporting the children’s and families’ needs. Factors such as parents’ previous experiences of different treatment/training approaches, expectations regarding the functional outcome, and the child’s disability might help parents and professionals adapt training approaches to individualize needs. Such a dialogue will support parents in making informed choices concerning different training approaches.

Methodological considerations

The design in the present study was a before and after comparison prospective quasi-experimental design with repeated measures [150]. Although the study
was not randomized, a large number of participants, the methodology with repeated measures, and use of multi-dimensional measurements have contributed to strengthen the conclusions drawn in this research-project.

Defined inclusion and exclusion criteria were used to delimit eventual bias in outcome between the ITGs due to differences between the included children or families in the two samples. As effectiveness of the two interventions was evaluated, the choice of inclusion and exclusion criteria was made to include children and families with regard to “typical” consumers of the ITGs. This together with the accessibility of children with CP led to relatively wide inclusion criteria in the present study. One of the exclusion criteria was that children were obliged to have a wash-out period of three months of intensive training before the start of the baseline measurements. At the time, intensive training was highly advocated by parents and the obliged wash-out period hampered accessible children in one of the regions.

The wide inclusion criteria of children resulted in an imbalance of children’s characteristics in the two samples, a result that showed that a proportion of children in the CE approach had more severe CP afflicted with severe mental retardation (SMR) and severe limitations in gross motor function level (GMFCS 5) that had to be controlled for. The development of motor growth curves for children with CP [152] has improved the prerequisites for estimating the development of gross motor capability by the gross motor function level and age [152, 153]. Motor development is invariably associated with a range of other disabilities [28]. The gross motor function level, according to GMFCS and age, were therefore chosen as important variables defining subgroups. Intellectual capacity was also considered an important variable to control because it is associated with presence of increased severity of disability [52] and has also been found to be a contributing factor for particularly self-care and social function [54].

The design was chosen due to the heterogeneity of the group of children and it was decided to present the results as proportion of individual changes and definitions of significant clinically relevant changes – i.e., meaningful changes to the child were defined. Because few studies have reported changes as a proportion of changes at an individual level, it was decided to report mean changes on the clinical outcome and self-reported measures and allow for comparison with previous studies using the same outcome measures. At the time of the study, GMFM-66 was not available. The use of GMFM-88 instead
of GMFM-66 can be recommended when including severely disabled children and when measuring individual change over time as in the present study [111] p. 131 [113]. The use of GMFM-88 instead of GMFM-66 allowed for measuring changes within dimensions and rather small changes could only be expected after 4 weeks of intensive training. The reliability and validity for dimension scores are not as high as for the whole measure [109, 111 p. 25]. Changes in any of dimensions (A-E) were supported as parents’ perception of high service quality was associated with measured clinically significant improvements on the dimension scores as hypothesized [146]. There were small changes at a group level and the comparison of mean differences between the two training approaches would not show any large differences by using GMFM-66, which could have been more appropriate for a between group comparison analysis [114].

In addition, repeated measures of gross motor capability according to an ABA-design were performed during the short-term evaluation to control for eventual variations in functioning when interpreting change due to the intervention [192-195]. As the intervention was as short as four weeks, there was only one measure point during the intensive training period. The result of this examination was not included in the analyses. Instead, statistics were used to compare mean changes at baseline (A1) with mean changes after the intensive training period (baseline A2).

It was not considered appropriate to repeat the comprehensive PEDI interview with a smaller temporal interval than the 12 weeks or to repeat rating of the individualized goals more than once before and after the intensive training period. The risk for bias, such as getting socially desired answers or exaggeration of ratings, was believed to be less if parents did not have the opportunity to memorize questions and ratings.

A bias that may have afflicted the result is the risk that the evaluation with the repeated measures with GMFM-88 contributed to enhance motor capability through learning and thus influencing the result in addition to the intervention. However, a lower performance from the child could be expected due to the boredom of repeating the measurement every fortnight for 12 weeks. Both assessors perceived that a lot of enthusiasm made it possible to explore the child’s capability at every assessment.
The conclusion that there were no differences in outcome on functioning between the two ITGs was based on analysis of outcome after controlling for age, severe mental retardation, and severe limitations in gross motor function. There is a complex interaction between associated impairments, and the sample was too small for purposes of comparing outcome on subgroups. Different properties in family support may also have relevance for changes in functioning, but family characteristics were not evaluated. There was no reason to believe that possible differences in family functioning would influence the short-term outcome, which was the foundation for comparison between the two ITGs.

A limitation in the present study as well as in other studies comparing different treatment/training approaches was the inability of the researchers to evaluate outcome in relation to no intervention. The method of comparing changes in functioning between different intervention approaches hampers possibilities of finding differences as both influence the child (and family). Moreover, children with CP in Sweden have received services from the Child and Youth Habilitation Services since being very young and probably function close to their optimal level of functioning, a finding that was also apparent in the present study. The result of changes represents the added value of the ITGs to customary Child and Youth Habilitation Services. It is unethical to use a control group in this type of study since such a strategy would withhold services from children with severe disabilities. This limitation means that it was difficult to determine whether improvements were due to the interventions or the child’s natural development.

Another methodological question was the measurement dimensions and tools. The clinical evaluation tools GMFM-88 and PEDI could be considered the best choice because they are reliable, valid and sensitive to change [196]. Furthermore, they targeted the dimensions on functioning expressed as dimensions addressed by the two ITGs. The comparison between parents’ goals for training categorized in the ICF components showed that most goals were agreed with measured dimensions and domains in GMFM-88 and PEDI, supporting the view that the clinical measures targeted aims/goals for intervention [145].

The use of Process of Care and Rehabilitation (POCR) as an evaluative tool could be methodologically supported because the dimensions included in POCR measured needs recognized as valuable needs within the framework of
a family-centred approach. Another advantage was that POCR in addition to health care needs also includes parents’ perceptions of the functional outcome and contributed to added information about the perceived outcome on functioning. The argument for choosing POCR instead of the more commonly used Measurement of Process of Care (MPOC) within a paediatric context was that an evaluation period of 4 weeks was considered too short for the questions asked in MPOC based on previous experiences [104].

The qualitative study was performed to add knowledge about what needs were fulfilled and what problems might arise from participation in ITGs from parents’ lived experiences. Needs might be difficult to pinpoint and express, and a phenomenographic approach investigating conceptions about ITGs were believed to circumvent the problem of answering direct questions about needs and problems of participation in ITGs.

A single phenomenographic study might not capture all possible conceptions pertaining to the subject area. It is believed that a reasonable amount of conceptions were identified as emphasis was laid on interviewing parents with experiences from various ITGs and of children with different needs depending on their age and functioning. A methodological limitation was that no parents without experiences of participation in ITGs were interviewed, which might have reduced the number of different conceptions. A similar limitation is that socio-demographic background was not especially considered when selecting informants. The imbalance between positive and negative conceptions of the ITGs is another somewhat problematic area and could perhaps better be interpreted as an eagerness to communicate positive aspects rather than as an indication of an enterprise without complications and problems. When selecting the strategic sample for the interviews, an emphasis was made to find parents known to have different points of views, negative as well as positive; however, it turned out that parents who were interviewed were positive participants. More studies are needed to test these findings. It is, however, believed that the present study has given a fairly good picture of a variety of subjective (and to a certain extent shared) conceptions of ITGs. In addition, studies need to examine the kinds of unacknowledged needs ITGs address. Several interviews were also performed after the interviewer had experienced saturation.
CONCLUSIONS

There were no major differences in effectiveness between the ITGs - a habilitation approach and a CE approach according to outcome on functioning. Parents’ expectations of targets for interventions were also similar between the two ITGs. The only difference was that parents in the habilitation approach were to a greater extent involved in discussions about expectations and knowledge exchange with the therapists, indicating a more family-centred approach.

One training period in an intensive training group (ITG) facilitated small clinical and parent-reported improvements in functioning for the short-term. Improvements were mainly motor activities and movement related body functions in line with parents’ expectations.

The majority of the children had a high consumption of training during the one-year follow-up and the added value of repeated ITGs to customary Child and Youth Habilitation services was limited to a positive effect in social function.

Parents perceived a high service quality. Fulfilment of health care needs was as important as functional outcome to parents. Parents’ conceptions of what needs ITGs fulfil suggest that objectives for interventions should also embrace parents’ needs of enhanced competence as a caregiver, of being supported and their well-being. Professionals and parents need to discuss parents’ previous experiences, expectations of functional improvements and health care needs in order to individualize goals for ITGs and make the objectives for participation in ITGs as clear as possible.

Parents’ conceptions revealed that participation in ITGs might be difficult for family functioning. It calls for a need of different available intervention strategies for families so they can choose the best compromise between meeting needs of the child and family.
SAMMANFATTNING

Det övergripande syftet med den här avhandlingen var att utvärdera effekter av två intensiv träningsprogram i grupp (ITG). Det ena ett alternativ som ingår i Barn och Ungdomshabiliteringens (BUH) utbud och det andra ett privat alternativ som erbjuder konduktiv pedagogik (artikel I-III). Syftet var också att beskriva vilka olika betydelser ITG har för föräldrar till barn med Cerebral Pares (CP), vilka behov som tillgodoses och vilka problem som kan uppstå i ett sammanhang som omfattar barnets och familjens hela tillvaro (artikel IV). Avhandlingen omfattar en kvantitativ och en kvalitativ del. I den kvantitativa delen ingick femtiofyra barn, 3-16 år, med olika typer av CP, begåvningsnivå och grovmotorisk funktionsnivå som tillsammans med sina föräldrar deltagit i utvärderingen av en fyra veckors intensivträningsperiod och en ettårsuppföljning (artikel I-III). I den kvalitativa intervjustudien ingick ett strategiskt urval av föräldrar, till 15 barn med CP, som har erfarenhet av ITG i olika miljöer på Barn och ungdomshabilitering och/eller av konduktiv pedagogik (Artikel IV).


Ettårsuppföljningen visar att barnens grovmotoriska förmåga och funktionella färdigheter var stabila. En större andel barn förbättrade sina sociala förmågor jämfört med grovmotorisk kapacitet och rörelseförmåga. Majoriteten av barn hade en hög konsumtion av träning. En jämförelse mellan barnen som fortsatt att delta i ITG och barnen som hade sedvanliga träningsåtgärder på BUH och i
Föräldrarna upplevde en hög servicekvalitet i båda ITG. Sannolikheten för att föräldrarna upplevde en hög servicekvalitet ökade om barnet hade tidigare erfarenheter av träningsalternativet, positiva erfarenheter av BUH, höga förväntningar på funktionsförbättring, om förväntningarna hade uppnåtts, den grovmotoriska förmågan förbättrats och om barnet deltog i ITG på BUH. Föräldrarna upplevde att de i högre grad blev tillfrågade om förväntningar och att informationsutbytet var bättre i ITG på BUH. Det visar på ett mer familjecentrerat förhållningssätt. Upplevelsen av god servicekvalitet var i högre grad associerat till uppnådda förväntningar på träningsprogrammet än om barnets funktionsförbättringar uppnåddes.

Den kvalitativa studien visar att ITG uppfyller en mängd olika behov för föräldrarna men också att deltagande i ITG kan ge upphov till problem för familjen. Fem övergripande kategorier identifierades; ITG som kunskapsbfrämjare, träningskomplement, parentes i tillvaron, relationskapande till terapeuterna och fritidsaktivitet. En ytterligare kategori ITG som ”risk för illabefinnande” innefattar olika problem som kan uppstå i samband med deltagande i ITG. De olika uppfattningarna visar att ITG kan bidra till ökad kunskap, stöd och ett förbättrat välbefinnande hos föräldern även om det också kan innebära påfrestningar för familjen att delta i ITG. Uppfattningarna visar också att innebörden av vad som utgör ett bra stöd och vilken föräldramedverkan man har behov av skiljer sig mellan föräldrarna. Föräldrarnas välbfinnande kan påverkas på två sätt dels genom att egna behov tillgododes, dels genom att de uppfattar att barnens behov blir tillgodosedda.

En dialog mellan professionella och föräldrar om deras tidigare erfarenheter av ITG, förväntningar på funktionsförbättringar, barnets fungerande och habiliteringsbehov kan tydliggöra och individualisera målen med att delta i ITG. En sådan dialog kan underlätta beslut om olika strategier för att stödja barnet och familjen. Resultaten visar att det inte var några skillnader på effekter avseende funktionsförbättringar mellan de båda ITG. I valet mellan olika träningsstrategier är det viktigt att beakta barnets och föräldrarnas skilda behov samt att ta hänsyn till såväl aspekter av servicekvalitet som barnets fungerande.

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