

From WOMEN AND CHILDREN'S HEALTH  
Karolinska Institutet, Stockholm, Sweden

# **GOAL SETTING AND SKILLS ACHIEVEMENTS IN CHILDREN WITH DISABILITIES**

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**Karolinska  
Institutet**

Stockholm 2015

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Published by Karolinska Institutet.

Printed by Eprint AB 2015

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ISBN 978-91-7676-003-1

Goal setting and skills achievement in children with disabilities

THESIS FOR DOCTORAL DEGREE (Ph.D.)

by

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*“I think that was her goal – that she would be the one who got to decide what she wanted to do.... I think that’s the reason it turned out so well, actually.”*  
*(One of the mothers in study IV)*

## **ABSTRACT**

The overall aim of this thesis was to increase knowledge about how children with different types of disabilities can identify performance issues and select goals for intervention. Furthermore, the objective was to study the effects of a goal-directed, task-oriented intervention based on children's self-identified goals from both quantitative and qualitative perspectives.

Establishing intervention goals with families, to improve the ability of children with disabilities to perform tasks that they need, want, or are expected to do, to participate in their everyday lives is a central part of paediatric occupational therapy. Within this process children's perspectives are of importance; to give greater consideration to children's needs, the children need to be involved in the goal-setting process. As goal setting is an abstract process, it can be questioned whether children with disabilities can identify goals and whether their goals are functional and achievable. Further knowledge about how the child's self-identified goals influence goal-directed intervention is sparse or even lacking. A specific interest was directed towards including the children in the goal setting, using the Perceived Efficacy and Goal Setting System (PEGS).

The PEGS is a picture-based self-report for children, developed in Canada. It uses children's self-reported performance on everyday tasks to allow them to choose and prioritize goals for intervention. To be useful in a Swedish context, the PEGS needed to be translated and adapted. In study I, five items in the PEGS required adaptation, and one new item was added. Using the Swedish version of the PEGS, 44 child-parent dyads were able to identify individual strengths and weaknesses in the child's performance of everyday tasks as well as to select goals for intervention.

Children's self-identified goals in studies I–III included improvements in self-care, and leisure and school tasks. In study II, results from 18 children showed that their goals were relatively stable over time: 78% had an absolute agreement ranging from 50% to 100%. Moreover, in studies II and III goals identified by

the children differed from those identified by their parents, and results from 31 child–parent dyads in study II, showed that 48% of the children had no goals identical to those chosen by their parents.

In studies III and IV, when goal-directed, task-oriented intervention was provided, children’s self-identified goals were achievable. There was evidence of an increase in mean goal attainment (mean T-scores) in both groups (*child-goal* ( $n=17$ ): estimated mean difference [EMD] 27.84, 95% confidence interval [CI] 22.93 to 32.76; *parent-goal* ( $n=16$ ): EMD 21.42, 95% CI 16.16 to 26.67). There was no evidence of a differences in mean T-scores post-intervention between the two groups (EMD 6.42, 95% CI -0.80 to 13.65), which indicates that children’s self-identified goals are achievable to the same extent as goals identified by parents. These results were sustained at the 5-month follow-up.

From a parental perspective, working on children’s self-identified goals was overall a positive experience. The findings revealed three categories: *Goals challenged the parents*, *The intervention demanded an intensive and flexible parental engagement*, and *The child’s personal goals gave more than anticipated*. Even though the goal-directed intervention comprehensively relied on the parents’ engagement and sometimes was challenging, the parents observed that the children’s personal goals positively influenced the children’s self-esteem, increased the children’s motivation for practice, and helped their children develop more than they as parents had anticipated.

# LIST OF SCIENTIFIC PAPERS

This thesis is based on the following papers, which will be referred to by their Roman numerals:

- I. Vroland-Nordstrand, K. & Krumlinde-Sundholm, L. (2012). The Perceived Efficacy and Goal Setting System (PEGS), part I: translation and cross-cultural adaptation to a Swedish context. *Scand J Occup Ther.* 19(6):497–505.
- II. Vroland-Nordstrand, K. & Krumlinde-Sundholm, L. (2012). The Perceived Efficacy and Goal Setting System (PEGS), part II: evaluation of test–retest reliability and differences between child and parental reports in the Swedish version. *Scand J Occup Ther.* 19(6):506–14.
- III. Vroland-Nordstrand, K., Eliasson, A-C., Jacobsson, H., Johansson, U. & Krumlinde-Sundholm, L. Can children identify and achieve goals for intervention? A randomized trial, comparing two goal-setting approaches.
- IV. Vroland-Nordstrand, K., Eliasson, A-C., Krumlinde-Sundholm, L. & Johansson, U. Parents’ experience of conducting a goal-directed intervention based on children’s self-identified goals.

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## **LIST OF ABBREVIATIONS**

ADL	Activities of daily living
CI	Confidence interval
COPM	Canadian Occupational Performance Measure
COPM-P	Canadian Occupational Performance Scale
EMD	Estimated mean difference
GAS	Goal Attainment Scaling
ICF	International Classification of Functioning, Disability and Health
OT	Occupational therapist
PEDI	Pediatric Evaluation of Disability Inventory
PEGS	Perceived Efficacy and Goal Setting System
PEO	Person-Environment- Occupation
SD	Standard deviation

# 1 INTRODUCTION

In the course of a day all children are almost constantly engaged in various tasks – tasks they need to perform, like putting on a jacket, or tasks they want to do, like riding a bicycle. This makes the doing of everyday tasks central in every child's life. Children learn and develop by performing tasks, and even as very little children they observe what others do and imitate their behaviour (Humphry, 2002). Performance of everyday tasks affects children's identity; they become who they are by what they do (Christiansen & Baum, 1997; Christiansen & Townsend, 2004), and to feel competent positively affects children's self-esteem (Christiansen, 1999).

For a variety of reasons children with disabilities often have problems performing the everyday tasks they need, want or are expected to do. This can affect their ability to develop and participate in their home and school lives, influencing their health and wellbeing (Townsend, 2007). There is therefore a need to identify children's specific problems with task performance so as to be able to develop interventions. Traditionally, interventions for children with disabilities are based on parent's perceptions of children's needs. However without knowledge about children's perspectives, we cannot know whether the interventions target areas of everyday life that are important and meaningful to the children. The primary focus of this thesis was therefore to give children a voice in goal setting and to evaluate whether children's own goals for intervention would be functional and achievable.

## 1.1 CLIENT-CENTRED PRACTICE

Client-centred practice is a central concept within occupational therapy (Fischer 2009; Townsend, 2007) and was originally introduced by Carl Rogers in 1951. In occupational therapy client-centeredness is a cornerstone of practice (Fischer 2009; Law, 1998; Law et al., 1995; Townsend, 2007) as the client's wishes and needs to perform everyday tasks should direct goal setting and intervention, it is important to consider and understand who the client is. Occupational therapy uses a broad definition of the client. The term *client* can refer to a child who has

been referred for occupational therapy, but can also be a family, organization, or other constellation or group of persons in need of occupational therapy services (Fischer 2009; Townsend, 2007).

Client-centred practice emphasizes collaboration and partnership, where the occupational therapist (OT) listens to clients, understand their priorities, and works with them in the achievement of goals that address those priorities (Law, 1998; Law et al., 1995; Maitra et al., 2006). Success of client-centred practice depends on two principal components. The first is the desire and ability of the client to take part in the decision-making process, and the second is the desire and ability of the OT's to include clients in this process (Law, 1998; Law et al., 1995; Maitra et al., 2006).

Clients can participate by actively involving themselves in discussions, specifically related to everyday tasks that they identify as meaningful and purposeful, by participating in goal setting and by demonstrating a desire and motivation to engage in their intervention session (Fischer 2009; Law, 1998; Law et al., 1995; Townsend, 2007). OT's can increase the clients' participation by meeting the clients where they are, focusing on the clients' needs and desires, and ensuring that the clients are actively involved in goal setting and intervention plans (Fischer 2009; Law, 1998; Law et al., 1995; Townsend, 2007). Two of the positive outcomes of client-centred practice are increased client satisfaction and improved functional outcomes (Law, 1998; Law et al., 1995; Maitra, 2006).

### **1.1.1 Family-centred practice**

When occupational therapy is provided within paediatric rehabilitation, the family is considered the client. Typically, in Sweden, the services are organized with a family-centred approach (Föreningen Sveriges Habiliteringschefer, 2014). Family-centred practice recognizes that each family is unique, that the family is the constant in the child's life, and that they are the experts on the child's abilities and needs (King & Chiarello, 2014; King et al., 2002; King et al., 2004; Law et al., 1998; Rosenbaum et al., 1998). As in client-centred practice, goal setting is the core concept in family-centred practice (Rosenbaum et al., 1998).

The family has an important role in collaboration with the therapists in taking responsibility for planning interventions and setting goals for the child. Family-centred practice is also recommended as a best practice (King & Chiarello, 2014; King et al., 2002; King et al., 2004).

With the family as the client, the client consists of several persons engaged in the child's life. To incorporate these different persons into the goal-setting process is essential, as each family member brings very different priorities and values. Even though family-centred practice has the best interests of the child in focus, the child's perspective is seldom prioritized in goal setting, and it can be questioned whether children with disabilities are able to identify goals that are functional and achievable.

## **1.2 GOAL SETTING**

Goals are important for several reasons. For the individual child goals that are meaningful and important can increase motivation and performance and have an impact on the outcomes of intervention. Further, with goals we can evaluate change over time, and setting goals can be the first step in establishing an intervention plan.

Studies concerning goal achievement indicate that to establish explicit, challenging goals enhances performance and motivation and improves outcomes (Locke & Latham, 2006; Locke & Latham, 2002). There are several theories describing the impact of goals on performance and motivation. Goal-setting theory is based on the hypothesis that human behaviour is purpose driven and individualized. The central issue is that goals affect performance by focusing attention, directing effort, increasing motivation, and enabling development of strategies to achieve the goal (Bryan & Locke, 1967; Locke & Latham, 2006; Locke & Latham 2002; Locke et al., 1981). According to goal-setting theory, performance and high goal achievements are affected by the commitment to the goal. The possibility of participating in goal setting, establishing goals that are meaningful and important for the individual, influences goal commitment and thereby affects performance and motivation (Locke & Latham, 2006; Locke &

Latham 2002). Recently, self-identified goals that are intrinsically motivating for the child have been recognised to be an important aspect to maximize successful outcomes after intervention (Majnemer et al., 2010). Further adopting a goal set by someone else seems to have little lasting motivational impact (Bandura 1997). There is also a relation between motivation, personal goals, and self-efficacy (Locke & Latham, 2002). Self-efficacy is the belief in one's capabilities, which influences the goal challenges we set for ourselves. This relates to our confidence and the ability to achieve a desired goal (Bandura, 1997). Personal goals and self-efficacy tend to increase motivation and thereby influence performance (Bandura & Locke, 2003). Self-efficacy is an important factor for establishing new goals and taking on new challenges.

### **1.2.1 Children's perspectives on goals**

Children's own perspectives on goals are of importance as they add a personal view. Several studies indicate that children can contribute their own perspectives on goals (Dunford et al., 2005; Missiuna & Pollock, 2002; Missiuna et al., 2006; Costa 2014). This is also seen for other constructs like quality of life (Bouman et al., 1999; Fayed, et al., 2015; le Coq et al., 2000), physical performance (Young, 1995), technical aids (Hemmingsson et al., 2009), and play (Sturges & Zivanni, 1996). When self-reports for children use, for example, concrete stimuli such as pictures, a simplified language, and clear response options, children's ability to reflect about their competence and their personal views are valid and stable over time (Sturges, 2002). Further, there is evidence that children's own perspectives differ from those of the adults around them (Bouman et al., 1999; le Coq et al., 2000; White- Koning et al., 2007). This is also likely to be the case for goal setting: studies comparing adolescents' perspectives on goals with their parents' show that their perceptions of important goals differ (McGavin, 1998; Schiariti et al., 2014), indicating that goals established by parents and adults around the child might not be perceived as meaningful and important by the child itself.

It is also important to give children their own voice in goal setting as involving children in decision-making increases participation. This aspect of participation,

giving children the opportunity to express their opinions and be heard, is contained in international conventions and national laws. The UN Convention on the Rights of the Child declares that every child has the right to express their meaning and that it should be accounted for in matters concerning the child, according to maturity (United Nations, 1989). The convention makes it the responsibility of caregivers and professionals to find ways to actively involve and listen to children's views. Since January 2015 children's right to express their intentions and actively participate in their healthcare is also regulated by the Swedish Patient Safety Act (SFS nr: 2014:821 4 kap §3). There it is stated that the healthcare professionals and caregivers should facilitate children's participation in their healthcare. Children shall have an opportunity to express their opinions about their current care or treatment and information shall be adapted according to the age and maturity of the child.

As children have the right to express their perspectives (United Nations, 1989) and hold firm views about themselves (Sturgess, 2002), their perspectives can be used to achieve motivation. The process of acquiring skills and participating in interventions can become more motivating, if based on performance issues and goals the child finds important and meaningful.

### **1.2.2 The Perceived Efficacy and Goal Setting System (PEGS)**

Goals are only meaningful if asked for in a correct way. Children's cognitive ability, insight, or difficulty in comparing with peers can influence their ability to reflect on their performance, self-evaluate, and select goals. When goals are established, it is therefore important to use instruments that support children in expressing their views. The literature describes a few instruments, the Child Occupational Self Assessment (Kielhofner, 2008; Kramer et al., 2010), the Canadian Occupational Performance Measure (COPM) (Law et al., 2005), the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (King et al., 2004; Ullenhag et al., 2012), and the PEGS (Missiuna et al., 2004), that can be used to facilitate goal setting with children. However, it is only the PEGS (Missiuna et al., 2004) that is designed for younger children and has goal setting with children as its main objective.

The PEGS is a picture-based self-report for children from five years of age, developed in Canada. It can be used with children with a variety of disabilities, in a variety of clinical and community settings (Missiuna et al., 2004). The children rate their perceived performance of daily tasks, including self-care, and leisure, and school/productivity tasks – tasks that would typically be performed by children at home, in school, or in the community. The tasks the children have rated as difficult to perform are then used to help them choose and prioritize goals for intervention (Missiuna et al., 2004).

The PEGS is a further development of the instrument the All About Me (AAM) (Missiuna, 1998). The AAM was developed to assess young children's self-efficacy regarding motor performance of daily tasks (Missiuna, 1998). The PEGS items derive from the AAM, removal and addition of items to and from the PEGS occurred through pilot testing, as well as expert review (Missiuna & Pollock, 2000). Studies using the PEGS have shown that children are able to report their perceived performance of daily tasks and to set and prioritize intervention goals. Goals set and prioritized using the PEGS were stable across two test occasions over a two-week period (Dunford et al., 2005; Missiuna & Pollock, 2002; Missiuna et al., 2006).

#### *1.2.2.1 Cross-cultural validity*

To capture performance issues and goals established by children with disabilities in a Swedish context, which is the focus of this thesis, the PEGS needed to be translated and adapted. When translating an assessment or self-report for use in a new context a simple direct translation is unlikely to be completely equivalent, owing to language and cultural differences (Beaton et al., 2000; Guillemin et al., 1993; Schmidt & Bullinger, 2003; Sousa & Rojjanasrirat 2010). In most cases, to be applicable and valid for use in a new context, an instrument requires adaptation. Four different components need to be established during the translation and adaptation process: the *semantic* component – the meaning of the words; the *idiomatic* component – finding expressions that are equivalent to or can replace items that include idioms, as idioms are rarely translatable; the *experiential* component – ensuring that situations described or depicted in the

original version are suitable in the new context; and the *conceptual* component – the meaning of the concepts (Beaton et al., 2000; Guillemin et al., 1993; Schmidt & Bullinger, 2003; Sousa & Rojjanasrirat, 2010).

Cross-cultural adaptation of an instrument therefore involves two phases, translation and adaptation (Guillemin et al., 1993). To ensure that the translated version of an instrument correctly reflects and is equivalent to the original, and is applicable in the new context, Guillemin et al., (1993) proposed guidelines for cross-cultural adaptation. The following steps are of importance: forward translation by several translators, backward translation by an independent professional translator, comparing the different versions and reaching consensus about a final version, and pilot testing of the final version (Guillemin et al., 1993).

Further to be clinically useful aspects of validity and reliability needs to be considered. The validity of an instrument is the degree to which an instrument measures what it is supposed to measure (Polit & Beck, 2004; Streiner & Norman, 2008). According to Standards (2004) five different types of validity evidence have been described, evidence based on; test content, relations to other variables, internal structure, response processes and the consequences of testing. The reliability of an instrument assesses its accuracy and express agreement of outcomes between different raters (inter rater reliability), agreement of outcome for the same rater repeating the assessment (intra rater reliability) or how stable the outcome is over two occasions close in time when no change is expected to occur (test-retest reliability) (Polit & Beck, 2004; Streiner & Norman, 2008). In this thesis, evidence of validity concerning the Swedish version of the PEGS have been collected related to test content and since the PEGS is a child and caregiver reported instrument evidence of reliability have been investigated only for stability over time through test-retest evaluation.

### **1.3 PERFORMANCE OF EVERYDAY TASKS IN CHILDREN WITH DISABILITIES**

Children with disabilities might have different medical diagnoses but they often share problems in performing everyday tasks. Their development is generally

slower than in children without disabilities and some children will always be dependent on support from the environment. It is known that performance of everyday tasks in children with cerebral palsy is influenced by age and severity (Ostensjo et al., 2003; Smits et al., 2011). Children at MACS levels I-II, achieved independence in self-care and mobility at a later age compared to children without disabilities (Ohrvall et al., 2010). Children with autism and children with intellectual disabilities have lower levels of ADL performance compared to children without disabilities (Kao et al., 2012). Further children with disabilities participate less frequently and have lower levels of involvement in community activities than children without disabilities (Bedell et al., 2013). Internationally compared to peers without disabilities, children with cerebral palsy participate in fewer leisure activities; engage more in informal rather than formal activities; spend more time with their families than with friends; and participate in more passive, home-based activities (Engel-Yeger, et al., 2009; Majnemer, et al., 2008; Shikako-Thomas et al., 2008). In a Swedish context, children with disabilities participated in leisure activities with a higher diversity but still with less frequency than children without disabilities (Ullenhag et al., 2014).

Through children's performance of everyday tasks, children progress in development, acquire new skills, and master tasks (Humphry, 2002). Moreover children's ability to perform and participate in everyday tasks also influences their identity (Christiansen & Baum, 1997; Christiansen & Townsend, 2004) and self-esteem (Christiansen, 1999). This makes it important to support children in acquiring new skills and competencies, improving their performance of everyday tasks.

### **1.3.1 Occupational performance**

The aim of occupational therapy is to increase occupational performance. Occupations are the ordinary things that people do every day (Townsend, 2007). Occupations have performance-related, contextual, temporal, psychological, social, symbolic, and spiritual dimensions (Kielhofner, 2008; Townsend, 2007). Occupational performance has been described as the outcome of a dynamic

relationship between the person, the environment, and the occupation over a lifespan and refers to the act of doing (Townsend, 2007). This means that occupational performance changes with the environment, the society, and the culture. It develops over time as, for example, when a child's habits, roles, routines, and interests change according to age and independence (Humphry, 2002). It is generally agreed that occupational performance is achieved when the environmental support, the person's abilities, and the occupational demands interact (Law, 1996).

The concept of occupational performance is closely related to the concept of participation as defined in the International Classification of Functioning, Disability and Health (ICF). Both concepts have in common that they cover the doing of everyday tasks. In the ICF, participation is defined as involvement in a life situation (WHO, 2007) and is viewed as performance in a natural environment or person-specific context. However, the concept of occupational performance and participation differ in one important aspect. The concept of participation as defined by the ICF does not cover the subjective experience of doing, whereas the concept of occupational performance does (Hemmingsson & Jonsson, 2005).

#### *1.3.1.1 The PEO model*

There are a number of practice models within the field of occupational therapy that explore aspects of occupational performance (Fischer, 2009; Kielhofner, 2008; Law, 1996; Townsend, 2007), one being the person–environment–occupation (PEO) model (Law, 1996). The PEO model consists of the person, the environment, and the occupation and views occupational performance as the outcome of the interaction between these factors. Change in any of these factors affects the others and thus impacts occupational performance. Optimal occupational performance is achieved when there is a balance, a fit, between the task requirements, the support of the environment, and the child's abilities. The performance analysis provides a framework for choosing which changes in the environment, the task, and/or the child can be used to improve the fit between these factors and thereby influence occupational performance (Law, 1996).

Goal-directed intervention is one example of an intervention that uses the PEO model as a practice model to organize the intervention (Mastos et al., 2007).

### **1.3.2 Goal-directed, task-oriented intervention**

Goal-directed intervention is based on a goal that is meaningful to the child and family. It has a family-centred practice framework and uses a learning approach to intervention. The objective is to increase the child's ability to perform tasks, with accuracy, consistency, and flexibility (Smith & Wrisberg, 2008). The task and the environment can be adapted according to the child's individual strengths and weaknesses, so that learning can occur (Smith & Wrisberg, 2008). The child is actively involved in the daily practice. With support from the adults around the child, the child practises in the day-to-day environment the tasks they selected for improvement.

As the objective with a goal-directed intervention is to increase the child's ability to perform meaningful tasks, the method used for goal setting is important, as it will influence whether the intervention target goals that are meaningful and important. The goals should be formulated such that they are challenging, specific, measurable, achievable, and relevant over a specified time-period (Bovend'Eerd et al., 2009). As goals are individual and depend on individual circumstances, changes that are linked to goals can be small and are usually not visible within a standardized assessment (Steenbeek et al., 2011). Individualized assessments like the GAS and the COPM can be used to evaluate different types of goals; they are sensitive to change (King et al., 2000; MacLaren & Rodger, 2003; Steenbeek et al., 2007) and are therefore valuable within goal-directed, task-oriented interventions (Mastos et al., 2007).

The intervention is organized using the PEO model (Law, 1996). The child's performance of the goal-specific tasks is analysed, so that factors within the task, the environment, and the child that facilitate or hinder task performance are identified. The performance analysis gives ideas for modifications and adaptations of the task and the environment as well as strategies appropriate to enhance the child's abilities.

Key features of goal-directed intervention are repetition and practice, organized at just the right level of challenge in relation to the specific child, and feedback, encouraging the child to be an active problem solver (Eliasson & Rösblad, 2008; Mastos et al., 2007; Valvano, 2004). To adjust the degree of challenge according to a specific child's strengths and weaknesses, the practice can be organized in different ways. For complex tasks like tying shoes, it can be helpful to organize the practice in part versus whole practice (Smith & Wrisberg, 2008). At first the child practises parts of the task, and then when the child has an idea of the task in question, the child moves to practising the whole task. Another ways of organizing the practice is in constant and variable practice (Smith & Wrisberg, 2008). Using constant practice, the child practises the same task in the same order over and over again, for example, buttoning the same button in the same trousers every time. As performance improves, the practice can be organized in a variable way, using, for example, different buttons in different trousers, all to enhance the learning process (Smith & Wrisberg, 2008).

The process of learning new skills, include three stages: the cognitive/verbal, the associative, and the autonomous (Fitts & Posner, 1967). These can be used to organize feedback. At the verbal stage the child is trying to understand and get an idea of the task in focus. At this stage the main idea is to help the child to find the most efficient way to accomplish the task. Cues to help the child remember what to do, feedback about the results of the performance, and demonstration and/or guidance can be used to help the child find a way to accomplish the task (Smith & Wrisberg, 2008). When the child enters the associative stage, the child can perform the task but with variations in outcomes, and the main focus is on increasing accuracy. At this stage the child should be provided with opportunities to practise the task. The environment should be arranged so that performance is enhanced, and support and encouragement to the child is important (Smith & Wrisberg, 2008). At the autonomous stage the child can perform the task and no longer needs to pay attention to what he or she is doing.

### *1.3.2.1 Evidence for goal-directed interventions*

Studies in which the effect of goal-directed interventions has been investigated report positive results (Novak et al., 2013; Sakzewski et al., 2014; Tilderhult et al., 2014; Smitts-Engelman et al., 2013). Goal-directed intervention showed to be more effective in improving task performance than intervention addressing underlying impairments (Ketelaar et al., 2001). Children's goal achievement was generally high (Novak et al., 2009; Novak et al., 2007; Ostensjo et al., 2008). Their performance of self-care and mobility tasks increased, and their need for caregiver assistance decreased (Lowing et al., 2009; Sorsdahl et al., 2010; Vinje Strovold & Jahnsen, 2010). Parents' perceptions and satisfaction with their children's task performances increased (Dunford et al., 2011; Rodger & Brandenburg, 2009), and when outcomes were followed up over time, children sustained or improved their task performance (Ekstrom-Ahl et al., 2005; Law et al., 2011; Lowing et al., 2010; Missiuna et al., 2010). Moreover from a parent perspective, studies show the importance of parents' involvement, provision of ongoing support, substantial goals and adjustment for individual circumstances, which increased the parents' feelings of motivation, competency and participation (Novak, 2011; Wiart et.al 2010; Öien et.al 2010).

To conclude, even though goal-directed interventions are evidence based and well evaluated, most results are based on parents' perceptions of important goals for their child. Since children's involvement in the goal-setting process is sparse, interventions addressing children's self-identified goals are rarely explored. A specific interest in this thesis was therefore to evaluate whether children's self-identified goals were achievable and whether the outcomes were influenced by who established the goals, the child or the parent.

## **2 AIMS OF THE THESIS**

Using the PEGS, the overall aims of this thesis was to increase knowledge about how children with different types of disabilities can identify performance issues and select goals for intervention. Furthermore the objective was to study the effects of a goal-directed, task-oriented intervention based on children's self-identified goals from both quantitative and qualitative perspectives.

The specific aims were as follows:

### **Study I**

To translate, adapt, and evaluate the applicability of the Perceived Efficacy and Goal Setting System for use in Sweden.

### **Study II**

To evaluate the test–retest reliability of children's perceptions of their own competence in performing daily tasks and of their choice of goals for intervention using the Swedish version of the Perceived Efficacy and Goal Setting System.

A second aim was to evaluate agreement between children's and parents' perceptions of the child's competence and choices of intervention goals.

### **Study III**

To compare the efficacy of children's self-identified goals and goals identified by parents on a goal-directed, task-oriented intervention.

### **Study IV**

To explore and describe parents' perceptions and experiences of conducting a goal-directed intervention based on children's self-identified goals.

### 3 METHODS

As this thesis includes both quantitative and qualitative studies, it had a multi-methods approach (Tashakkori & Teddlie, 2003). Study I describes the development of the Swedish version of the PEGS. Applicability in a Swedish context and evidence based on test content was evaluated. Study II investigated test–retest reliability of the Swedish version of the PEGS and agreement between child and parental reports. Study III, a randomized trial, compared the efficacy of children’s self-identified goals (*child-goal* group) with goals identified by parents (*parent-goal* group) on a goal-directed, task-oriented intervention. Study IV, a qualitative study, explored parents’ perceptions of a goal-directed, task-oriented intervention based on children’s self-identified goals; for an overview of the studies, see Table I.

Table I. Overview of the four studies

Study	Design	Data analysis
I	Cross-sectional, cross cultural validation	Descriptive
II	Cross-sectional, instrument evaluation	Descriptive, absolute agreement, Kappa statistics, Wilcoxon signed rank
III	Experimental, randomized two group parallel trial	Descriptive, Fishers exact, Mann-Whitney U, mixed linear model
IV	Qualitative, descriptive	Content analysis

### 3.1 PARTICIPANTS

The participating children in studies I–III fulfilled the following inclusion criteria: enrolment in paediatric rehabilitation, age between 5 and 12 years, and any type of disability but functioning at or above a five-year-old level in receptive language. In study III an exclusion criteria was involvement in another intensive intervention during the study period. Children for studies I–III ( $n=98$ ) were recruited via OTs at eight local paediatric rehabilitation centres from three different county councils in Sweden.

Table II. Participants' characteristics

	Study I	Study II	Study III	Study IV
Children $n$	64	45	34	
Age mean years (SD)	8 y (2y)	8 y 6 mo (2y)	9 (1y 4 mo)	
Gender $n$				
Girls	29	24	21	
Boys	35	20	13	
Disability $n$				
Movement disorder	36	26	20	
Autism spectrum disorder	17	9	5	
Learning disabilities	11	10	9	
Parents $n$	63	44		9
Mothers	41	28		8
Fathers	17	11		1
Both	5	5		
Therapists $n$	19			

The participants in study IV were nine parents (8 mothers, 1 father), whose children participated in the *child-goal* group in study III. Inclusion criteria for study IV were that the parent and his or her child had been randomized to the *child-goal* group, the parent had participated actively in the intervention, and the ability to communicate in Swedish. The nine parents were invited by the author to participate, after their children had ended their goal-directed interventions. For a description of participants characteristics see Table II.

The overlap of participants that participated in more than one study is reported in Table III.

Table III. Number of participants overlapping between studies

	Study I	Study II	Study III
Study I (n=64)			
Study II (n=45)	45		
Study III (n=34)	2	2	
Study IV (n=9)			9

## 3.2 DATACOLLECTION

### 3.2.1 Instruments

The data for studies I–III in this thesis were collected using self-reports, standardized interviews, and observations of task performance. An overview of the instruments used in the different studies is presented in Table IV.

Table IV. Overview of included instruments

Instruments	Objective	Study I	Study II	Study III
PEGS	Goal setting	X	X	X
GAS	Goal attainment			X
COPM	Goal setting			X
COPM-P	Occupational performance			X
PEDI	Caregiver assistance			X

### 3.2.1.1 The Perceived Efficacy and Goal Setting System(PEGS)

The PEGS uses children’s self-reported performance of everyday tasks to allow them to choose and prioritize goals for interventions (Missiuna et al., 2004). It consists of an interview set for the child with pairs of picture cards (items), a caregiver questionnaire, and a teacher questionnaire.

When administering the child interview, each item in the PEGS is presented as sets of two cards with pre-drawn pictures. One of the pictures shows a child performing the task competently and the other a child with less competence; see Fig.1.

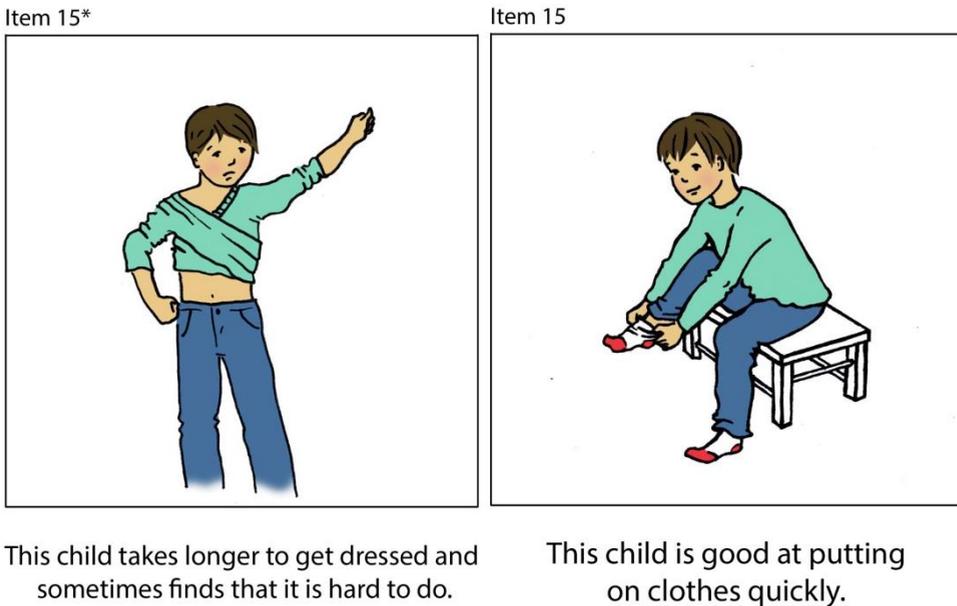


Fig. 1. PEGS item number 15, Getting dressed. Reprinted with permission of the original authors.

The statement under each picture is read to the child. The child is asked to select the picture (competent/non-competent) that is most like him or her. The child then indicates whether the selected picture is a lot or a little like him or her. Based on the child’s answers, the cards are sorted into four piles reflecting the child’s perceived performance on a 4-point scale: 1, a lot like the less competent child; 2, a little like the less competent child; 3, a little like the competent child;

4, a lot like the competent child. When all items have been administered, a pair of blank cards is used to add any additional daily tasks that the child finds difficult to perform (Missiuna et al., 2004).

The items for which the child has indicated less competence are used to set and prioritize goals for intervention. These picture cards are placed in front of the child and questions are asked regarding, for example, what makes the task difficult and where and how frequently the child performs the task. The child is asked to indicate which of these tasks he or she would like to perform better, and these are used as goals (Missiuna et al., 2004).

The caregiver and teacher questionnaires can be used to understand the perspectives of the adults around the child. These questionnaires contain the same items as the child interview set. The caregivers and/or the teacher rate the child's competence using the same 4-point scale. Additional space is provided on the questionnaires for the caregiver and the teacher to identify additional performance issues and tasks the child is not able to perform and to suggest intervention goals for the child (Missiuna et al., 2004).

In study I, the translation of the PEGS into Swedish was based on guidelines for cross-cultural adaptation of self-reports (Guillemin et al., 1993) and performed in several phases involving translation and back-translation, pre-testing, development of adjusted items, and finally, field testing of the proposed Swedish version of the PEGS.

In study II, using the Swedish version of the PEGS, children with disabilities and their parents rated the child's competence and identified goals for intervention. A retest session was completed with the children approximately two weeks after the first administration. At the retest session the children were allocated into one of two groups: (A) for evaluation of perceived competence (n=18) or (B) for evaluation of choice of goals (n=18).

In study III the Swedish version of the PEGS was used in the *child-goal* group to establish goals for intervention; see Fig. 2.

### 3.2.1.2 Goal Attainment Scaling (GAS)

The GAS is an individualized, criterion-referenced outcome measure that can be used to evaluate change in individuals or change in groups (King et al., 2000; Kiresuk, 1994). It consists of a 5-graded scale from -2 to +2, where -2 is baseline performance, 0 the expected goal, and +2 much more than the expected goal; see Table V. The procedure involves describing baseline performance and specifying a range of outcomes for a specific goal, using the scale to evaluate the individual change. When multiple goals are evaluated, ratings of goal achievement can be summarized and calculated into an overall goal attainment score, T-score. A T-score of 50 corresponds to achievement of the expected goal (level 0) and indicates a clinically significant change in goal attainment (Kiresuk, 1994).

Table V. Goal Attainment Scaling

Grade	Definition
2	Much more than the expected outcome
1	More than expected outcome
0	Expected outcome
-1	Less than expected outcome
-2	Baseline

In study III the GAS was the primary outcome measure. It was used to define and grade the goals established by the parents or the children and to evaluate each child's goal achievement post-intervention (8 weeks) and at follow-up (5 months); see Fig. 2. The GAS for each goal was constructed by the OTs responsible for the individual children, in collaboration and with supervision from the research group, and presented to the parents. Each scale was evaluated from video observations by an OT not involved in the intervention and blinded to group allocation.

### 3.2.1.3 *Canadian Occupational Performance Measure (COPM)*

The COPM is an individualized outcome measure (Law et al., 2005) designed to establish goals for intervention and to measure an individual's perception of occupational performance and satisfaction for a specific task. It uses a semi-structured interview format to encourage individuals to talk about an ordinary day and to identify occupational performance issues and tasks they have difficulties performing, within the areas of self-care, productivity, and leisure. Identified performance issues are prioritized, and the most important issues are selected as goals for intervention (Law et al., 2005).

Performance and satisfaction are rated separately on a 10-graded scale where 1 means not able to do it and 10 means able to do it extremely well for the performance scale (COPM-P), and 1 means not at all satisfied and 10 means extremely satisfied for the satisfaction scale (COPM-S). A change of two points on the performance and satisfaction scales indicates a clinically significant change in task performance and satisfaction (McColl et al., 2000).

In study III the COPM was used to establish goals for intervention in the *parent-goal* group. The COPM-P was used in both the *child-goal* and the *parent-goal* group to measure parents' perceptions of their children's task performance over time; see Fig. 2.

### 3.2.1.4 *Pediatric Evaluation of Disability Inventory*

The PEDI is a norm- and criterion-referenced measure that evaluates functional skills (the Functional Skills Scale) and caregiver assistance (the Caregiver Assistance Scale) within the domains of self-care, mobility and social function (Haley et al., 1992). The child is assessed by a standardized interview with parents. The Functional Skills Scale of the PEDI describes the child's capability in his or her environment, and the Caregiver Assistance Scale of the PEDI, describes the child's need for assistance in everyday tasks (Haley et al., 1992).

In Study III, the Swedish version of the Caregiver Assistance Scale of the PEDI (Nordmark, 1999) was used to measure the children’s need for care-giver assistance at baseline; see Fig. 2

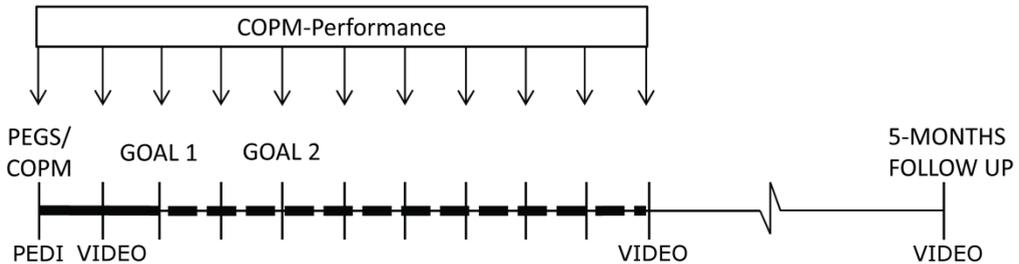


Fig. 2. Illustrates the timeline of the data collection in study III. At the first session three goals were established, and the parents rated their children’s need for caregiver assistance. At the second session the children’s baseline performance was video-recorded. During the 2-week baseline and the 8-week intervention period the parents rated their perceptions of their children’s performance weekly for every goal. Post-intervention and at 5-months’ follow-up the children’s performance was video-recorded. To control for possible effects of simply putting a focus and an increased awareness on the goals in question, the order of introduction of the goals was decided by random draw; intervention was provided for goals 1 and 2, whereas goal 3 was monitored for changes in performance but no intervention was provided.

### 3.2.2 Interviews

In study IV the data were collected through individual interviews with the nine parents (8 mothers, 1 father). Each parent was interviewed once by the author six to eight weeks after their child had ended the goal-directed intervention. This time frame was chosen considering the parents’ ability to objectively reflect on their experiences of the intervention. Each interview lasted between 36 and 53 min. The interviews were performed at the child’s local paediatric rehabilitation centre. The interviews were semi-structured, based on an interview guide with open-ended questions. The data collection focused on the parent’s thoughts, reflections, and experiences of (i) the goal-setting process, where the children identified their own goals for intervention; and (ii) the subsequent goal-directed, task-oriented intervention. To encourage the parents to give more detailed replies, follow-up questions like “What do you mean?” and “Can you tell me

more about this, please?” were used. All of the interviews were recorded and transcribed verbatim.

### **3.3 INTERVENTION**

In study III all children undertook an intensive 8-week, goal-directed, task-oriented intervention. The overall aim of the intervention was to increase the child’s ability to be engaged in meaningful tasks and to change performance by targeting the task to be achieved rather than the impairments thought to limit performance (Eliasson & Rösblad, 2008; Mastos et al., 2007).

The intervention included goal setting with the child or the parent to establish meaningful goals. The selected goals were graded using the GAS (Kiresuk, 1994) and thoroughly analysed with respect to actual performance, using the Person-Environment-Occupation model (Law, 1996). Questions were asked to try to identify aspects that influenced the child’s task performance. Further, by observation of the child’s performance of the selected goals, factors were identified within the task, the environment, and/or the child that limited or strengthened the child’s performance. To enhance successful performance, the environment and the task were adapted using modifications and adaptations in relation to the child’s strengths and limitations.

The intervention was delivered using individualized home programmes developed by the OTs. The home programmes were organized based on principals of motor learning; for a more detailed description, see the introduction. The home programmes included adaptations and modifications, repetition, and daily structured practice of tasks having just the right challenge and creating situations that encouraged the child to be an active problem solver (Smith & Wrisberg, 2008; Valvano, 2004).

Subsequently, the intervention was integrated into the child’s everyday environment, using the parent-delivered home programmes. The parents were encouraged to use the home programmes daily, and once a week the children and their parents had follow-ups with the OTs. The purposes of the weekly follow-ups were to sustain motivation for the home programmes, to follow up on

progress or plateaus of performance, and to provide support for the parents in carrying out the daily training.

### **3.4 DATA ANALYSIS**

#### **3.4.1 Statistical analyses**

Several different statistical methods were used to analyse the data from studies I–III. The statistical methods were chosen based on the aim of the study as well as whether or not the data fulfilled the assumptions for parametric tests. In study I outcomes were summarized and reported as descriptive statistics. In study II nonparametric statistics were used. In study III, to compare the efficacy of the *child-goal* group with the *parent-goal* group, a mixed linear model was used.

##### *3.4.1.1 Agreement (study II)*

In study II stability of children’s perceived competence was evaluated using absolute agreement and Cohen’s kappa (Cohen, 1968) for children’s dichotomized response option (competent/non-competent) and absolute agreement and weighted kappa (Landis & Koch, 1977) for the 4-point rating scale. As the kappa coefficient itself does not indicate whether disagreement is related to random or systematic differences, the Wilcoxon signed rank test was used to investigate possible significant systematic differences between outcomes. Kappa values were interpreted according to Landis and Koch (Landis & Koch, 1977).

Absolute agreement was calculated to compare children’s and parents’ ratings of perceived competence, to evaluate the stability of the children’s goals, and to compare the children’s goals with those of their parents. To compare goals established by parents and children, the goals were categorized as (i) self-care, (ii) play/leisure, or (iii) schoolwork.

The kappa statistics were complemented with absolute agreement, as kappa has its limits in being sensitive to the marginal distribution of the outcome. This sensitivity for the distribution of a sample’s rating is a weakness in kappa (Feinstein & Cicchetti, 1990). To interpret agreement by using the kappa alone

could indicate an agreement weaker than by chance between the ratings of, for example, the child and the parent, although an absolute agreement is quite high.

#### *3.4.1.2 Differences between groups (study III)*

A mixed linear model was used to test for differences between groups in overall goal attainment (T-scores) at different time points and changes in COPM-P scores for every goal at different time points. For a description of the models, see study III.

A mixed model was preferred for the analysis of this longitudinal dataset to the repeated measures ANOVA, since the latter handles missing data using listwise deletion (Brown & Prescott, 2006). Listwise deletion would have reduced the sample analysed in our study, as it excludes data from the analysis if any single value is missing.

T-scores and changes in COPM-P were both seen as continuous variables. Model assumptions were verified by visual inspection of various graphs. Effect size was reported using estimated mean difference (EMD) with 95% confidence intervals.

#### **3.4.2 Content analysis**

In study IV the individual interviews with the parents were analysed with qualitative content analysis (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). Qualitative content analysis attempts to identify core consistencies and meanings as well as to emphasize differences and similarities (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005).

All transcribed interviews were compared with the digital recordings to verify the accuracy of the transcribed texts. The data were coded using the aim of the study as a guide. Meaning units related to the aim that captured the parents' thoughts, experiences, and reflections of the goal-setting process and the following intervention were highlighted and labelled with codes. The codes that emerged from the different interviews were compared in order to identify

similarities and differences within and across interviews. In this phase categories that were on a more abstract level were developed and more thoroughly described in subcategories. As categories and subcategories were developed, these were presented to and discussed with first the authors' group and later the research group to enhance different possible interpretations of the text.

## **4 ETHICAL CONSIDERATIONS**

All children and their parents gave informed consent to participate in the studies. They received oral and written information about the aims of the studies; they were informed that participation was voluntarily, that confidentiality was assured, and that they could withdraw at any time without explanations.

For the benefit of the children in studies I-II, the goal setting with the PEGS was followed by an intervention period. A summary of the goals, the child had identified and prioritised was reported to the OT, responsible for the individual child, who developed an intervention plan.

Study I and II were approved by the Regional Ethics Board of Karolinska Institutet in Stockholm, Sweden and study III and IV was approved by the Regional Ethical Review Board in Uppsala, Sweden.

## 5 RESULTS

### 5.1 THE SWEDISH VERSION OF THE PEGS

To be useful in a Swedish context some changes of the original PEGS items were required. The most noticeable difference concerned four school-related items that were not applicable to the five- to six-year-olds, due to a later school start in Sweden. Therefore, the Swedish version of the PEGS has two versions of both the child interview set with the picture cards and the caregiver questionnaire, one for children between five and six years of age and one for children from seven years. For the younger children one item, “organizing numbers on a page”, was removed. In total, five items were adapted for all children, and one new item was added for children who did not use mobility aids; see Table VI. For a more detailed description, see pp 502 in study I.

Table VI. PEGS items with changes made for the Swedish version of the PEGS

PEGS item	Category	5–6 years old	7+ years old
Playing ball games	Leisure	Picture changed	Picture changed
Finishing schoolwork	Productivity	Statement changed	
Keeping desk tidy	Productivity	Picture and statement changed	Statement changed
Organizing numbers	Productivity	Removed	
Printing/writing	Productivity	Picture and statement changed	
Toileting	Self-care	Added new item	Added new item

## 5.2 CHILDREN CAN IDENTIFY GOALS FOR INTERVENTION.

Using the Swedish version of the PEGS, which is described in studies I and II, all children in studies I–III who participated in a PEGS interview (n=62) could identify both strengths and weaknesses in their own performance of everyday tasks. No child identified himself or herself solely with the less competent child or with the competent child on all items. Further, all except three children were able to indicate on which tasks they wished to improve their performance and why. In total, the children in studies I–III selected and prioritized 186 goals for intervention. The goals included improvements in self-care and leisure and school tasks; see Fig. 3. Some examples of goals identified by the children were *bicycling, hopscotch, skipping rope, scoring a goal in basketball, keyboarding faster when using the computer, learning more English words, writing my name, writing a birthday card, telling time, tying shoes, buttoning jeans buttons, showering, and toileting independently.*

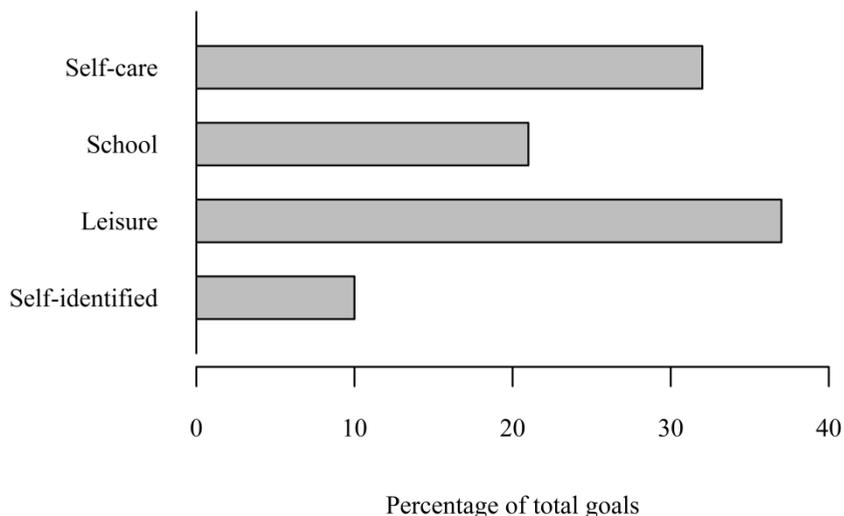


Fig. 3 *Distribution of children's goals by category.*

In study I the goals identified by the children varied, and all of the 25 items in the Swedish version of the PEGS were chosen as a goal by at least one child.

The most common goals were *riding a bicycle, tying shoes, using scissors, and skipping rope*. This strengthens the relevance of the items for a Swedish context as well as it indicates that children's goals are personal and varied.

In study II the children's chosen goals for intervention were found to be relatively stable over time; 14 out of 18 children (78%) had an absolute agreement ranging from 50% to 100%.

That children can identify goals for intervention when using the PEGS was also perceived by parents. In study IV, in the category "*The child's personal goals gave more than anticipated*", some parents expressed that it was new knowledge for them that their child could take part in goal setting. This was something they had not thought about before as being possible.

### **5.3 CHILDREN ADD A UNIQUE PERSPECTIVE**

In Study II, when describing perceived performance of the everyday tasks in the PEGS, there was poor agreement between the 44 child–parent dyads. Absolute agreement between the children and their parents ranged from 0% to 62%, and a weighted kappa value over 0.40 was seen in 5 out of the 25 items. This indicates that children have their own perceptions of their performance that are different from those of their parents.

Moreover, children showed themselves to have very different goals from their parents. In both study II and study III the children's goals differed from the goals identified for them by their parents. The parents' goals mainly concerned self-care, with the aim to increase the child's independence, whereas the children's goals were more varied and involved achievements that improve both, self-care, school tasks, and leisure tasks. Further, in study II, results showed that from 31 child–parent dyads, 48% of the children had no goals identical to those chosen by their parents.

Children's unique perspectives on goals were also acknowledged from a parent perspective. In study IV, in the category "*The child's personal goals gave more than anticipated*", the parents reported that they had expected their child's goals

to be more like their goals for the child and were surprised over their child’s own perspective on goals. They remarked that they had thought about their child’s goals as too easy or not of importance. This difference in perspectives was new knowledge for the parents. In the category “Goals challenged the parents” a few parents remarked that their child’s goals did not seem meaningful. This was challenging, and they found that it negatively influenced their own motivation for the goal-directed intervention.

### 5.4 CHILDREN’S SELF-IDENTIFIED GOALS ARE ACHIEVABLE

Both study III and study IV showed that children with disabilities are capable of reaching their self-identified goals. In study III, in the *child-goal* group, 16 out of 17 children reached or exceeded the expected goal on the GAS for at least one of the two practised goals. In total, in the *child-goal* group, 27 out of 34 (79%) practised goals were reached to level 0 or higher on the GAS at post-intervention, and 24 out of 34 (70%) at follow-up; see Fig. 4.

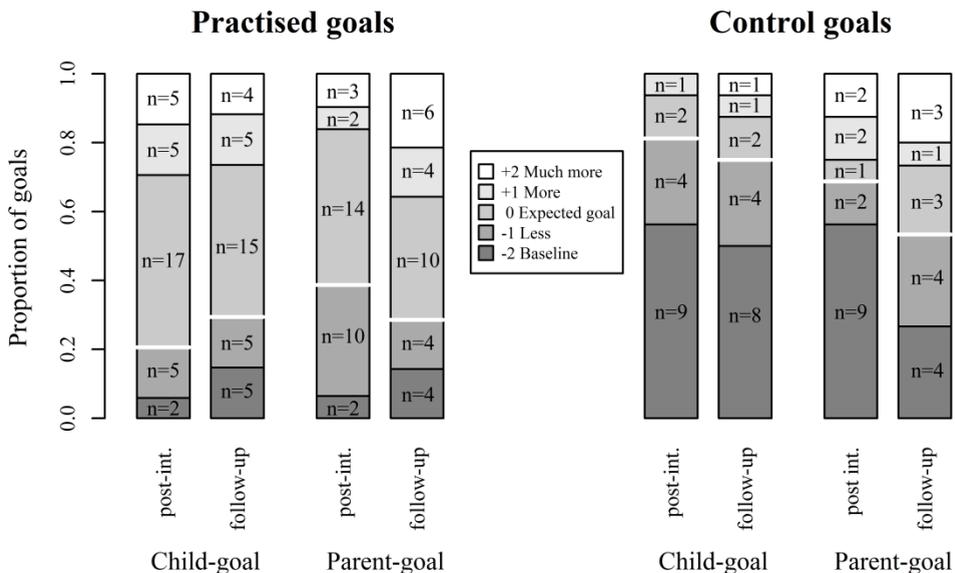


Fig. 4 The bars represent the number of goals attained at the different levels of the GAS, for practised and control goals in each group, at post-intervention (8 weeks) and at follow-up (5 months). The numbers above the white vertical lines represent goals attained to the expected level (0) or higher on the GAS.

Moreover, the findings indicate that children's goals are achievable to the same extent as parent-identified goals. The goal-directed intervention was effective in both groups. There was evidence of an increase in mean goal attainment (mean T-Score) in both groups (*child-goal*  $p < 0.001$ , *parent-goal*  $p < 0.001$ ) from baseline to post-intervention; see Fig. 5. Mean T-scores post-intervention were 52.19 (95% CI 48.09–57.91) for children's goals and 47.67 (95% CI 41.31–51.82) for parents' goals. The EMD of 6.42 was, however, not significant ( $p = 0.08$ ).

Children's goal-specific performance remained stable; see Fig. 5. There were no evidence of a difference in the mean T-scores within groups between post-intervention and follow-up (*child-goal*  $p = 0.34$ , *parent-goal*  $p = 0.45$ ).

The parents' perceptions of their children's task performance rated on the COPM-P improved gradually for the two practised goals when the intervention started. In both groups there was evidence of a differences in changes in mean COPM-P between practised and control goals that were significantly higher for practised goals. The EMD between goals was 3.41 (95% CI 2.15–4.66) in the *child-goal* group and 2.27 (95% CI 0.97–3.57) in the *parent-goal* group. The difference between practised and control goals was also evident on the GAS, as the control goals were only attained at level 0 or higher for a few cases; see Fig. 4. This indicates that goal setting per se contributes little to the actual changes of task performance, and goals are not automatically achieved.

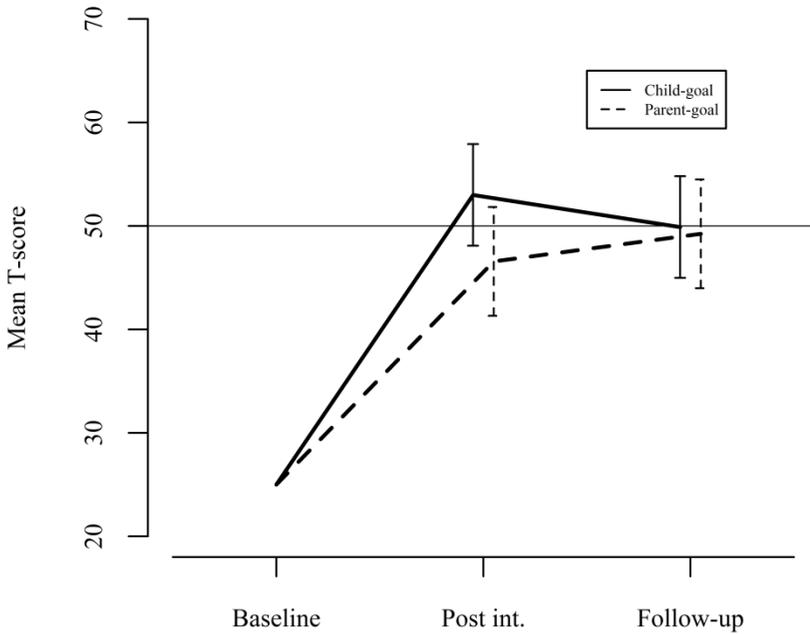


Fig. 5 Mean T-scores for the two practised goals in each group, at baseline, at post-intervention (8 weeks), and at follow-up (5 months). The error bars represent the 95% CI.

That children’s self-identified goals are achievable was confirmed by the parents in study IV. In the category “*The child’s personal goals gave more than anticipated*”, all the parents were positively surprised about how much their children actually were able to learn and described their children’s improved task performance as something they did not believe was possible. According to the parents, it was their child’s self-identified goals that had a positive impact on their child’s task performance. Further they reported that the child’s personal goals positively influenced the child’s self-esteem and motivation for practise. The parents’ believed that having goals and fulfilling them helped the child grow as a person.

## **6 DISCUSSION**

The research questions in this thesis have derived from clinical practice within children's paediatric rehabilitation. In this work the intention was always to adopt the child's perspective and to acknowledge children's right to have their own voices heard in goal setting and intervention planning. However, it is hard for children to express their performance issues and to identify personal goals. Goal setting is an abstract process, and to the best of my knowledge, there was no systematic, child-centred instrument available for children living in Sweden. The COPM had been used successfully with parents and teenagers, but often it did not provide enough support for children to make the goal-setting procedure understandable to them. As a result, even though children were asked to identify goals, the interventions commonly focused on issues suggested by the parents. Thus, to make it possible to evaluate whether children could identify their own performance issues and set goals that were achievable, the first step was to find a potential instrument and to test its cross-cultural validity for use in a Swedish context.

### **6.1.1 The Perceived Efficacy and Goal Setting System (PEGS)**

With its family-centred approach the PEGS is a valuable instrument for goal setting and intervention planning within paediatric rehabilitation. The PEGS has the ability to capture the perspective of the child as well as the perspectives of the family members engaged in the child's life and each person can bring their priorities and values to the goal setting. These aspects were the main reason for choosing the PEGS. Moreover, of the instruments described in the literature that can be used for goal setting with children, it is only the PEGS which is designed mainly for goal setting and can be used with children as young as five years of age.

The subsequent question was whether the PEGS needed to be cross-culturally adapted. Conceptually, children living in Sweden could identify themselves with the majority of the depicted daily tasks in the PEGS because these tasks were familiar and well known in their own context. However, there were differences,

especially for school related tasks, due to differences in school start and educational plans. Some issues of semantic, experiential, and conceptual aspects had to be addressed before the PEGS was found to be valid for use in a Swedish context. This corresponds well with results from other countries, where minor adaptations of the PEGS have been suggested due to cultural differences (Costa, 2014; Missiuna et al., 2010). It is important to point out that the PEGS is not an outcome measure. If so, it could be debated if outcomes based on different versions of an instrument could be comparable. The PEGS is meant to serve as a base for identifying possible performance issues and goals that children, parents and/or teachers would like to see improvements on. As such, the relevance of the content is the most important aspect of the instrument making the cross-cultural adaptation essential.

All four studies in the thesis demonstrated in different ways that the Swedish version of the PEGS, is useful for goal setting and can support children with a variety of disabilities to set and prioritize goals for intervention. All but 3 of the 62 children who participated in PEGS interviews in studies I–III were able to identify strengths and weaknesses in their own performance of daily tasks, and their prioritized goals for intervention were personal and varied. Moreover, the parents in study IV reported that using the PEGS their child could take part in goal setting.

To be clinically useful, the Swedish version of the PEGS had to satisfy an important question concerning whether children with disabilities were stable in their perceptions of prioritized goals for intervention. In study II, 14 of 18 children (78%) had an absolute agreement of goals that ranged from 50% to 100%, indicating that the Swedish versions of the PEGS can support children in setting and prioritizing goals for intervention that are relatively stable over time. In the PEGS some of the items are very generally presented, referring to many different situations in which tasks can be performed with different degrees of success; the child's response and goals may therefore differ over time. Depending on the task and/or the environment that comes to mind when the child responds to the item, the child may find the items difficult or easy to

perform. For example, the item cutting up food can be performed with varying success depending on the type of food served. The item sports and the item playing ball games are both very general and could refer to many different sports and ball games played at different levels of competence. It was therefore never expected that the test-retest reliability of the Swedish version of the PEGS would be very high, but to be useful as goals for intervention, it was important that the goals have an acceptable stability, which also was obtained.

It could also be discussed whether the results of the validity and reliability of the Swedish version of the PEGS could be generalized for use across Sweden. Studies I-III included a limited number of participants and the studies were conducted in only one geographical region of Sweden. However, the PEGS is not a norm-referenced instrument, and the participating children in studies I-III represented children with different kinds of disabilities, all treated at paediatric rehabilitation centres throughout Sweden. The adapted items mostly concerned tasks that do not relate to a specific disability or to this particular geographical region. For example, school start and educational plans are directed by laws established by the national government and are generally the same in all of Sweden. Moreover, the findings in studies I-III correspond well with the findings from other studies (Costa, 2014; Dunford et al., 2005; Missiuna & Pollock, 2002; Missiuna et al., 2006), which strengthens the assumption that the Swedish version of the PEGS is useful for goal setting with children between 5 and 12 years of age, with a variety of disabilities, in all of Sweden.

### **6.1.2 Goal setting**

An important finding confirmed in all the studies in this thesis was that children and parents prioritize different goals for intervention (Dunford et al., 2005; Missiuna et al., 2006; McGavin, 1998; Schirati et al., 2014). Irrespective of whether the goals were established with the use of the caregiver questionnaire in the PEGS or the COPM, the parent's goals mainly concerned self-care, with the aim to increase the child's independence, results corresponding well with other studies (Miller et al., 2015; Pollock et al 2014; Schirati et al., 2014). The goals established by the children concerned self-care, but in addition had a broader

perspective that included participating with peers in leisure and schoolwork. For example, more often than their parents, the children in studies I-III identified goals around recess activities, like skipping rope, hopscotch, and catching balls. Even though it was the children's task performance that was addressed in study III, the parents in study IV reported that the increased task performance in the recess activities made their peers more willing to participate with their child in the activity. This could indicate that by using children's self-identified goals our interventions more often may indirectly influence and increase children's participation with peers. This adds to the importance of including children in goal setting, and needs to be further investigated. This aspect is important, as increasing participation is perhaps the most important goal of paediatric rehabilitation (Law, 2002) and of greatest importance for every child's well-being, health, and development (WHO, 2007).

### **6.1.3 Goal-directed task-oriented intervention**

The results of studies III and IV show that children with different kinds of disabilities are capable of reaching their self-identified goals and that their goals are achievable to the same extent as parent-identified goals. This has not previously been shown. Also, in study III there was a tendency of higher goal achievements in the *child-goal* group. At post-intervention, 79% of the practised goals were reached to the expected level or higher on the GAS in the *child-goal* group, while 61% were achieved in the *parent-goal* group. Further, individual goals in the *child-goal* group more often than individual goals in the *parent-goal* group attained higher levels on the GAS; see Fig. 4. Even though not significant, this tendency of higher goal achievement in the *child-goal* group could indicate that interventions based on children's self-identified goals are reached to a higher extent, than goals identified by parents. Further, the maintained high goal achievements at follow-up indicate that children's goal-specific task performance is sustained and stable over time, which is in line with previous research (Ekstrom- Ahl et al., 2005; Law et al., 2011; Lowing et al., 2010; Missiuna et al., 2010).

There are several possible reasons for the positive results of the goal-directed, task-oriented intervention in this thesis. One being that the meaningful goals established by the child increase the child's motivation (Majnemer et al., 2010; Majnemer, 2011). Motivation is an important factor for successful task performance (Bartlett & Palisano, 2002; Miller et al., 2014), which is in agreement with the findings in study IV, where the parents expressed that their children's self-identified goals increased the motivation for practice and made the goal-directed intervention more successful than anticipated. Other reasons for the positive results could be the individualized intervention, assuring that the child is practising at just the right level of challenge, thus supporting the child's learning process (Smith & Wrisberg, 2008; Valvano, 2004). The intensity in the daily practice is significant, as repetition is an important factor when learning new skills (Gentile, 1992; Smith & Wrisberg, 2008; Valvano, 2004). The intervention was integrated into the child's day-to-day environment, where the daily practice became embedded in the context in which the child needed to accomplish the task. This fact could explain the children's task performance being sustained at follow-up. The weekly follow-ups with the OTs could also have contributed to the child's learning by supporting the parents and adults around the child in carrying out the daily practice. However, these factors are not related to the goal-setting process and were similar in both the *child-goal* group and the *parent-goal* group. One could therefore speculate that the increase in motivation for practice, which the parents observed in study IV, might have influenced the results of the goal-directed intervention and been one of the reasons for the tendency of higher goal achievement in the *child-goal* group. Further research exploring the role of children's goals in relation to other aspects, like children's motivation and self-esteem, would inform deepened knowledge of this question.

Questions have been raised about the impact of goal setting per se on task performance (Brewer et al., 2014; Brogren-Carlberg & Lowing, 2013). In study III, in both groups there was evidence of a difference in mean performance between practised and control goals that were significantly higher for practised goals. Moreover, on the control goals only a few children attained the expected

level or higher on the GAS indicating that goal setting is not enough to impact task performance, and that practise is needed.

As goal-directed interventions are intensive and comprehensively rely on the engagement of parents and children, knowledge about dose of practice is important. It is generally suggested that a higher intensity is better (Sakzewski et al., 2014) and that intensity may be a critical component of a successful intervention (Law et al., 2011). From the findings in study III it was not possible to determine a specific minimal dose of practice, since this was not investigated. In study III no information was collected about when exactly the goals were achieved; this may have occurred before the end of the intervention period. Furthermore, the relationship between dose of practice and goal achievement can be expected to vary greatly between children and tasks. Further research is needed to assist decisions about what dose of practice is efficient but not overly time consuming.

#### **6.1.4 Methodological considerations**

In studies I-III, all the PEGS interviews with the children were conducted by the author. Outcomes could therefore potentially be biased and dependent on the skills and knowledge of the interviewer. However, as administration of the PEGS interview is standardized with clear instructions and efforts were made to keep strictly to the administration protocol, the potential role of such bias should be minimal.

As the goal-directed intervention in study III, was highly individualised and would target specific goals, effects of the intervention was unlikely to be captured on standardised assessments, as the goals established by the children and the parents concerned many various types of goals. Therefore the GAS was chosen as the primary outcome measure, which might have influenced the results. Concerns about aspects of validity and reliability are always connected with the use of the GAS. Bias that influence the results can occur if the goals are too easy to attain, the scale steps have different levels of difficult or development is overestimated when scales are evaluated (King et al., 1999; MacLaren &

Rodger 2003; Steenbeek et al., 2007; Steenbeek et al., 2010). To increase validity and reliability of the GAS, it is important that each step of the scale reflects a meaningful difference, is established in discussion by a group or under supervision, and is being evaluated by a person not involved in the development of the scales (King et al., 2000; Steenbeek et al., 2008). In study III these steps were all considered. Moreover the raffled intervention order of the goals possibly protected against the possibility of selecting the more easy goals for intervention.

The individualized nature of the GAS (Kiresuk, 1994) may be one reason for the similar results for the *child-goal* group and the *parent-goal* group in study III. GAS implies that goals are constructed to ensure that the expected goal level (0) is achievable, realistic and relevant for each child, regardless of who established the goals. Another reason for the lack of differences between the two intervention groups could be the small sample size. Owing to the similar goal-directed intervention it was never really expected to be differences in outcomes between the *child-goal* group and the *parent-goal* group. However the option to choose another intervention for the control group was limited. To only compare with no intervention did not seem reasonable, as we already know that goal-directed interventions are more effective than no intervention (Novak et al., 2009). Another option could have been to compare to usual treatment which is commonly based on goals identified by the parents. But as neither the content nor the intensity of usual treatment is described or defined for children within paediatric rehabilitation in Sweden. Usual treatment would probably vary greatly, influencing the results and inflicting bias.

In study III, it was mainly the mothers who had participated actively in the intervention, and for study IV it was therefore only one father, who was interviewed. This is a potential limitation. Mothers and fathers can have different perspectives and views, therefore a more even distribution would have been desirable as it probably had captured a more diverse picture of parents' perceptions and experiences of goal-directed intervention based on children's self-identified goals. However as an inclusion criterion was that the parents had participated actively in the intervention, it was decided to not include more

participants, when no additional knowledge emerged in the interviews. Another potential limitation in study IV was the author's pre-understanding of the topic which always to some extent influence the direction of the interviews. This however can also be seen as a strength of the study as this meant that the author had the experience needed to ask adequate follow up questions to get a deeper understanding of the parent's perceptions and experiences of goal-directed task-oriented intervention based on children's self-identified goals.

## 7 CONCLUSION

This thesis reports that the Swedish version of the PEGS can discriminate between strengths and weaknesses in children's performance of daily tasks and can be used for goal setting with children with a variety of disabilities, and with their parents.

More importantly, in this thesis children with disabilities contributed a unique perspective on what is important to them; their goals were varied and functional and involved achievements that improved both ADL and interaction with peers in leisure and school tasks. Children's self-identified goals were achievable to the same extent as parent-identified goals, and remained stable over time. Furthermore in the parents' experience, goal-directed intervention based on their child's personal goals gave them and their child more than they could have anticipated.

These findings show that the knowledge and consideration of children's own perspectives on goals is of great value for goal-directed intervention and highlights the importance of letting children participate in goal setting, trusting them to have a true influence on goals for intervention.

## 8 ACKNOWLEDGEMENTS

I would like to express my sincerest gratitude to all people who have contributed to this thesis, especially to

All the children, parents, and occupational therapists who willingly participated in the studies.

My principal supervisor, Lena Krumlinde-Sundholm, and my co-supervisors Ann-Christin Eliasson, and Ulla Johansson, for guiding me through the PhD years. It has been an interesting and developing journey filled with great challenges, experiences, and enthusiastic discussions. Thank you for your support and inspiration, and for sharing your extensive knowledge in research.

My mentor, Anette Johansson, for support and inspiration.

My co-author, Helén Jacobsson, for sharing knowledge in study III.

Hans Forsberg, for providing an inspiring research environment at the Neuropediatric Unit.

Cheryl Missiuna and Nancy Pollock, for your support in the process of translating the PEGS into Swedish.

Ann-Marie Öhrvall and Marie Peny-Dahstrand, for valuable and inspiring discussions about children and their everyday occupations.

Per Liv and Hans Högberg, for invaluable help and consultation in statistics. You did not only help me with the analysis; you helped me to better understand, through our discussions.

Inga-Lill Stenlund, for always being helpful and knowledgeable, and for ringing the bell, reminding me about coffee breaks.

Marie Holmefur, Linda Nordstrand, and Linda Ek, for extensive support and good company at conferences; all other PhD students and researchers at the Neuropediatric Unit, Linda H, Johan, Mumin, Sermin, Anna, Annika, Kristina L,

Anna-Klara, Marie, Cecilla, Jenny, Ulrike, Ann-Kristin, Gunvor, Katarina, Dan, Lena and Britt-Marie, for interesting discussions, support, and encouragement.

All former and present PhD students and researchers at the Center for Research and Development, Uppsala University/Region Gävleborg. Thank you for your support during the years with my PhD. A special thanks to Lennart Fredriksson for encouragement, and to Eva Swing and Catrine Björn for long discussions, encouragement, and inspiration, and for being exceptional roommates.

Colleagues at Barn och Ungdomshabilitering Gävle, Bollnäs and Huddiksväl, for your encouragement and interest during these years.

My mother, Kerstin, who is no longer with us. I know you would have liked to follow my journey, supporting me in the best way. My father, Lars, for all the interest and support you have shown, especially this last year, and for always providing us with excellent food and wine whenever you are visiting. My sister, Malin, and David, and all other close relatives and dear friends.

My children, Simone and Ida, for bringing music and laughter to my life. I'm proud of being your mum. Finally, to Tony, my husband, for your love, patience, and encouragement during these years.

This thesis was supported financially by the Centre for Research and Development, Uppsala University/Region Gävleborg; the Uppsala-Örebro Regional Research Council; the Sven Jerring Foundation; the Norrbacka-Eugenia Foundation; the Sunnerdahls Foundation, and the Foundation Majblomman.

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