Everyday functioning in six year-old children born preterm
From a child perspective towards the child’s perspective

Anna Karin Andersson
EVERYDAY FUNCTIONING IN SIX YEAR-OLD CHILDREN BORN PRETERM
FROM A CHILD PERSPECTIVE TOWARDS THE CHILD'S PERSPECTIVE

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Abstract

The overall aim of the thesis was to explore everyday functioning in six year-old children born preterm, from the children’s perspectives and from their parents’ perspectives. The relation between everyday functioning and neonatal risk factors, behavioural characteristics was studied with descriptive and correlational statistics, ANOVA and multiple linear regression (I). Patterns of everyday functioning were explored in a cluster analysis following a person-oriented approach (II). In a mixed method approach, the children’s and their parents’ perceptions on children’s competence in everyday activities were explored with a pictorial instrument and analysed with descriptive statistics and qualitative content analysis (III). The children’s perceptions of meaningful everyday life situations were explored in a photo voice study, analysed with qualitative content analysis. In total, 144 children born preterm and 222 children born at term and their parents were involved.

The results indicated that from the parents’ perspective most children born preterm and full-term were perceived with strong everyday functioning featuring strong motor, process and communication skills, a positive interaction pattern and low levels of behaviour problems. As a group, the children born very preterm were perceived weaker in their everyday functioning than the full-term group but the pattern of performance skills, interaction and behaviour varied similar to that of children born full-term. Further, it was found that preterm birth was not the main predictor, instead hyperactivity had most influence on everyday functioning. Moreover, the children born preterm perceived themselves to be overall strong performers of everyday activities. They wanted to be active and do things and for that they wanted to have skills and significant others i.e. siblings, parents, friends and pets to interact with and to feel safe and loved. Further, the children born preterm expressed a will to develop, improve and gain new skills and to have more opportunities to do meaningful things.

In conclusion, the results in this thesis indicate that young children born preterm are able to reflect on their everyday functioning, and express needs and desires for their participation in meaningful everyday life situations. Moreover, preterm birth is not the sole predictor of everyday functioning more critical is the interaction of individual, behavioural and contextual factors.
...så länge det finns ungar så finns det hopp!

(Ur Turistens klagan, text och musik C.Vreeswijk.
© Wooden Horse Music)
Abstract

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In conclusion, the results in this thesis indicate that young children born preterm are able to reflect on their everyday functioning, and express needs and
desires for their participation in meaningful everyday life situations. Moreover, preterm birth is not the sole predictor of everyday functioning more critical is the interaction of individual, behavioural and contextual factors. The results in the thesis show that clinical follow up of children born preterm should comprehend the assessment of everyday functioning including preterm risk factors, as well as behavioral and environmental factors.
List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


IV  Andersson, A.K., Harder, M., Strand Brodd, K., & Almqvist, L. (2017) Meaningful everyday life situations from the perspective of children born preterm: a photo-elicited interview study with six year-old children (In manuscript)

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<tr>
<td>BL</td>
<td>Birth length</td>
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<tr>
<td>BPD</td>
<td>Bronchopulmonary dysplasia</td>
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<td>BW</td>
<td>Birth weight</td>
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<td>DCD</td>
<td>Developmental coordination disorder</td>
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<td>FT</td>
<td>Full-term</td>
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<td>GA</td>
<td>Gestational age</td>
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<td>HC</td>
<td>Head circumference</td>
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<td>HIE</td>
<td>Hypoxic ischemic encephalopathy</td>
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<tr>
<td>ICF-CY</td>
<td>International classification of functioning, disability and health: child and youth version</td>
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<tr>
<td>IVH</td>
<td>Intraventricular haemorrhage</td>
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<tr>
<td>LPT</td>
<td>Late preterm</td>
</tr>
<tr>
<td>M</td>
<td>Mean</td>
</tr>
<tr>
<td>NEC</td>
<td>Necrotising enterocolitis</td>
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<tr>
<td>PDA</td>
<td>Persistent ductus arteriosus</td>
</tr>
<tr>
<td>PVL</td>
<td>Periventricular leukomalacia</td>
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<tr>
<td>ROP</td>
<td>Retinopathy of prematurity</td>
</tr>
<tr>
<td>SCB</td>
<td>Statistics Sweden (Statistiska centralbyrån)</td>
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<tr>
<td>SD</td>
<td>Standard deviation</td>
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<tr>
<td>SMBR</td>
<td>Swedish medical birth registry (Medicinska födelseregistret)</td>
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<td>SNQ</td>
<td>Swedish neonatal quality registry</td>
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<td>VPT</td>
<td>Very preterm</td>
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Introduction

This thesis focuses on everyday functioning in children born preterm. For most preschool children, everyday functioning involves a number of different activities such as playing, having dinner with the family, getting dressed, running fast in the playground or painting a picture. It also involves interacting with peers and adults and fulfilling social roles based on age, maturity and cultural expectations (Vohr & Msall, 1997). Thus, everyday functioning is a multidimensional construct encompassing the child’s abilities and engagement, as well as the context in which the child spends time (Adolfsson, Granlund, & Pless, 2012). By participating in activities in everyday life, children acquire skills and competences which, taken as a whole, contribute to their everyday functioning (AOTA, 2002). Different biological and contextual factors can influence the development of this everyday functioning.

It is well known that children born preterm are at risk, despite improvements in neonatal care, and the long-term outcomes of these children are now the focus of attention in research.

During my five years of research studies, I have had the opportunity to meet children born preterm for clinical follow-up, new-borns to six year-olds. With the task to assess children’s abilities from a motor function perspective, I have been caught by children’s curiosity to test and challenge their skills, their eager to learn and their competences. It is easy to see that, regardless of their prerequisites, children want to play and have fun in interaction with others. In the encounter with children we need to see the individual child beyond diagnosis and offer them opportunities instead of formulating their limitations from a normative perspective. Although the assessment of motor function is valuable, it is important to recognise that it only gives a glimpse of children’s functioning in everyday life.

The overall aim of the thesis is to explore everyday functioning in preschool children, with a focus on children born preterm. The project adopted a perspective based on functioning, a strength-based perspective, rather than on impairments and disabilities. Four studies are included in the thesis, moving from a group-based perspective to an individual one. The thesis first
draws attention to children’s everyday functioning and the factors which influence it. It then considers children’s own perceptions of how they function, and finally examines what children perceive as meaningful and important in everyday life.

For presentational purposes the terms ‘parent’ and ‘parents’ are used in the thesis as convenient shorthand for all adults with parental responsibilities.

Care sciences from a health and welfare perspective

This thesis was written in the area of Care Sciences and the research field of health and welfare. Using an overall perspective from care sciences, the thesis aims to focus on the individual child’s resources and participation in everyday life within a natural context. This perspective is in line with a holistic view of health, where individuals take actions of their own free will. Their actions are not predetermined but are dependent on the context and circumstances in which they live (Nordenfelt, 1995). From a holistic perspective, health involves having the abilities or resources to reach vital goals, though it is also dependent on the context and circumstances of life (Nordenfelt, 1995). The International Classification of Functioning, Disability and Health: Child and Youth (ICF-CY) presents a model which describes health as a multidimensional concept, and acknowledges the relation between the person and the environment (WHO, 2007). The ICF model is presented in Figure 1. The ICF–CY sees children and young people within the context of their environment and stages of development. It classifies body structures and functions, activities and participation, and environmental factors which allow young people to function in an array of everyday life situations, or which restrict them in doing so. Accordingly, health can be described in terms of functioning in the everyday life of the individual.

In agreement with this perspective, children have described health as a multidimensional construct, and as a resource which allows them to perform activities and participate in play with friends. In fact, they were even more specific in their statements, relating health to eating habits, having skills, playing with others and attending preschool and school (Almqvist, Hellnas, Stefansson, & Granlund, 2006). The present thesis is therefore based on the perspective of functioning as an expression of health, and children are understood as active and creative individuals acting within their own context.
Health and welfare in children born preterm

About 15 million children are born preterm each year throughout the world (World health organisation, 2012). The incidence of preterm birth varies widely between countries. In Sweden, about 5% of all babies are born preterm. Most of these are born between 33 and 36 weeks of gestation, and 1% are born very preterm, before the end of 32 weeks of gestation (Hjelm, 2012). Neonatal care for children born preterm is extensive and complex, but average time in the neonatal ward varies mainly by gestational age (GA): from four days for those born moderately preterm to 125 days for those born extremely preterm (Swedish Neonatal Quality Register, 2015).

Neonatal risk factors

Children born preterm are at increased risk of neonatal morbidity such as bronchopulmonary dysplasia (BPD), retinopathy of prematurity (ROP), intraventricular haemorrhage (IVH), periventricular leukomalacia (PVL) and necrotising enterocolitis (NEC), to which children born very and extremely preterm are most exposed (Fanaroff et al., 2007; Farooqi, Hagglof, Sedin, & Serenius, 2011). In a prospective study from Sweden, the combined impact of the three most serious neonatal morbidities was examined at 11 years of age (Farooqi et al., 2011). The findings show that BPD was the most prevalent neonatal morbidity with the least predictive long-term outcome, and
IVH and PVL were the least prevalent neonatal morbidities, strongly correlated with the risk of developing a poor outcome such as CP, severe visual impairment, hearing loss or mental retardation. Even without neonatal morbidity, 10% of the children born extremely preterm develop poor outcomes, and the risk increases to 19% with one morbidity, to 58% with two morbidities and to 80% with the three neonatal morbidities (Farooqi et al., 2011). Children who have suffered from multiple neonatal morbidities are also at risk of poor long-term outcomes such as low academic achievement at school (McGrath & Sullivan, 2002; Winchester et al., 2009).

**Long-term outcomes**
The cognitive outcomes of school-age children born preterm have been reported significantly lower than children born full-term (Aarnoudse-Moens, Oosterlaan, Duivenvoorden, van Goudoever, & Weisglas-Kuperus, 2011; Aarnoudse-Moens, Weisglas-Kuperus, van Goudoever, & Oosterlaan, 2009; Anderson & Doyle, 2003; Bhutta, Cleves, Casey, Craddock, & Anand, 2002). Compared to children born full-term, very preterm-born children are especially vulnerable to cognitive deficiencies and learning disabilities, including lower performance in numerical skills at preschool and in mathematics at school (Aarnoudse-Moens et al., 2011; Aarnoudse-Moens et al., 2009; Anderson & Doyle, 2003; Bhutta et al., 2002; Taylor, Espy, & Anderson, 2009). In reading and spelling, there are indications of lower performance in early school years, though they tend to catch up with peers as they grow older (Aarnoudse-Moens et al., 2011).

Neurobehavioural outcomes have been studied by several researchers, who found a higher prevalence of adverse outcomes in preterm-born children than in those born full-term. Attention problems are the most pronounced neurobehavioural factor, but internalising behavioural problems such as withdrawn behaviour has also been reported, as well as externalising behavioural problems such as hyperactivity and attentional difficulties (C. Aarnoudse-Moens et al., 2009; Anderson & Doyle, 2003; Bhutta et al., 2002). Some researchers suggest that externalising behavioural problems are negligible, and are no different from children born full-term (Aarnoudse-Moens et al., 2009; Anderson & Doyle, 2003).

Motor-skill deficiency is a common negative outcome in children born preterm who do not develop CP (Williams, Lee, & Anderson, 2010). Study results indicate that these children are on average −0.57 to −0.88 SD behind their term-born peers in motor development, measured by widely-used motor tests (de Kieviet, Piek, Aarnoudse-Moens, & Oosterlaan, 2009). These motor
tests showed deficiencies in balance skills, ball skills, manual dexterity, and fine and gross motor development, and balance skills were the most impaired. In measuring the preschool quality of motor function, children born preterm, and especially very preterm, seem to have pronounced coordination deficiencies (Hemgren & Persson, 2002). Similar to the relation between neonatal morbidity and cognitive functions, the increased degree of motor impairment is related to neonatal morbidity, and there is clear evidence of persistence in motor deficiencies from infancy to adolescence (de Kieviet et al., 2009). Most studies agree that children born very preterm perform more poorly than their term-born peers on motor assessments conducted at school age. In addition they show a higher prevalence of developmental coordination disorder (DCD), exceeding the most commonly reported prevalence of 6% in the general population (Edwards et al., 2011; Foulder-Hughes & Cooke, 2003; Williams et al., 2010). DCD is a descriptive diagnosis associated with children with minor motor difficulties, and where a child’s performance is substantially low in daily activities that require motor coordination. Children with DCD have difficulties with skills such as dressing and tying shoelaces, and skills which influence their ability to undertake activities in everyday life. They also have difficulties participating in the classroom and interacting with peers, which can also interfere with academic achievement (Edwards et al., 2011). Spittle and Orton (2014) highlight the risk of overlooking mild to moderate motor deficiencies in children born preterm, or seeing them as a maturational delay the child will outgrow. The researchers point out the probable consistency between motor problems in children born preterm and those in children with DCD, and argue for them to be assessed not only in terms of motor functions but also in terms of their performance in everyday life (Spittle & Orton, 2014). Although several studies have investigated cognition, motor function and behaviour in children born preterm using standard assessments, less is known about the functional impact of the deficiencies in terms of everyday functioning.

Theoretical framework
This thesis is based on theories in which children’s development and functioning are described in relation to their environment.
Bioecological model of human development

The bioecological system theory was formulated in response to contemporary psychological research which was often conducted in a laboratory setting and with an exclusive focus on the person (Bronfenbrenner, 1979). Bronfenbrenner (1979) argued that development should be studied in its ecological context, in the actual setting where children (humans) live their lives, and with a focus on the developmental processes involved.

“Human development takes place through processes of progressively more complex reciprocal interaction between an active ... human organism and ... its immediate external environment.” (Bronfenbrenner, 1979)

The bioecological model of child development emphasises the mutual interaction, referred to as proximal processes, between the active child and the environment in which the developing child lives (Bronfenbrenner, 1979, 1989). Child development is considered a joint function of this mutual interaction, and consequently the current outcome or the child’s current developmental status is influenced by it. For a child to develop, the proximal processes need to occur over extended periods of time and on a regular basis, be reciprocal and include activities that increase in complexity over time. The proximal processes are considered to be the primary engines of development, and their power and content will affect development. The process-person-context-time model has been suggested as a research design for investigating child development (Bronfenbrenner & Morris, 2006). Different factors can operate as facilitators and others as inhibitors for development. The characteristics of the person can have facilitating or inhibiting influences. Action-oriented characteristics like curiosity are an example of facilitating or generative characteristics, while impulsiveness and distractibility are examples of inhibitory or disruptive characteristics.

In proposing bioecological system theory, Bronfenbrenner describes the environment as four layers or systems nested within each other: the microsystem, mesosystem, exosystem and macrosystem (Bronfenbrenner, 1979). The child is seen in the centre of the model, acting and interacting with family, friends etc. in different settings or microsystems in his/her everyday life. The mesosystem describes the relationship and interactions between the individuals or entities in the microsystems, while the exosystem constitutes the social institutions which affect the child indirectly. The fourth layer, the macro system, encompasses broader cultural values, laws and governmental resources (Bronfenbrenner., 2005). The relation between these settings and the larger context in which they are embedded influences child development. Thus, for a complete understanding, the study of child development cannot be restricted
to the child in its immediate environment, but must comprehend interactions between the larger environments the child belongs to (Bronfenbrenner, 1979). The bioecological model also recognises particular settings or regions in the environment, called ecological niches, as especially favourable or unfavourable for the development of children with particular personal characteristics. The ecological niches are described by Bronfenbrenner from a socioeconomic perspective, and do not involve everyday life situations on a more concrete level, which is the focus of this thesis. The thesis mainly involves the microsystem in terms of exploring how children function, and how they perform, interact and communicate within their immediate context. The bioecological system theory has been used by e.g. Dunst and colleagues (2000, 2001 and 2002) to describe activity settings as the context for favourable learning opportunities, and as a way of studying the influence of proximal processes on the development and functioning of young children in everyday life situations.

Everyday natural learning opportunities
For most children, everyday life involves a variety of regularly occurring situations in the context of their family, relatives, teachers and friends. These everyday life situations, occurring in the natural setting, are regarded as important sources of learning opportunities (Bronfenbrenner., 2005; Dunst et al., 2001). The natural setting provides experiences and opportunities for learning, which are therefore labelled activity settings (Dunst, Hamby, Trivette, Raab, & Bruder, 2000). In several studies, Dunst et al. (see e.g. 2000, 2001, 2002, and 2006) have explored important activity settings and learning opportunities as perceived by parents of young children aged 0–5 years. Parents recognised more than 20 categories of activity settings in both family and community life, all of which involved a multitude of opportunities for learning (Dunst et al., 2000). In family life, children can experience child-based routines such as brushing their teeth, physical play like riding a bike and play activities, as well as family routines such as cooking and preparing meals. Community life includes organised sports or arts-based activities, and preschool activities. The activity settings are described as the experiences children gain through interacting with people and the environment, and which lead to new abilities and competences. The experiences derive from situation-specific events which are experienced regularly and which lead to mastering a competence. This, in turn, makes the child more interested and engaged, and encourages new experi-
ences (Dunst, 2000). Everyday life situations can therefore be regarded as natural settings with recurring opportunities for children to develop new competences and skills, and to perfect these skills. Everyday life situations involve a cluster of related activities. For preschool children, these include communicating, dressing, eating, bathing, walking and moving around, playing and family relationships (Adolfsson, 2013). Moreover, the activities require purposeful actions, referred to as skills or abilities, which increase in variety and complexity as the child gets older. Skills are goal-directed actions that a person uses to perform a task (Fisher, 1998; Kielhofner, 2009), and they contribute to a child’s competence in an everyday activity. The next section explores how children function, and the skills they need for everyday life situations.

Everyday functioning
In everyday life, children are exposed to a variety of different situations in different environments related to self-care, mobility and play, as well as moments of interaction with adults and peers, offering opportunities to develop a range of skills. These situations vary according to the child’s age and maturity, as well as normative and cultural expectations. Thus, everyday functioning involves children’s ability to adapt to new and increasingly complex activities, and to a varied context (Case-Smith, 1995), fulfilling the social roles which are expected of them based on age and social relevance. The Occupational Therapy Practice Framework (OTPF) (AOTA, 2002) defines two factors of importance in terms of a child taking part in everyday life situations: performance patterns and performance skills. Performance patterns are patterns of behaviour related to activities of everyday life, and include habits (specific, automatic behaviours), routines (sequences of activities that provide a structure for daily life) and roles which are socially agreed behaviours with an accepted code of norms. Performance skills are small units of action which have implicit functional purposes. They are the observed performance of a child who is engaging in an everyday life situation, and the result of a person-context-task interaction (Fisher & Kielhofner, 1995, in AOTA, 2002). The concept includes motor skills, process skills and communication/interaction skills. Motor skills are skills involving moving and interacting with objects, tasks and environment. Process skills involve organising, modifying and completing a task. Communication/interaction skills involve intentions and needs, and coordinating behaviour to act with other people (AOTA, 2002).
Several concepts are found in the literature with similar definitions of everyday functioning. These include *functional performance* (Case-Smith, 1995; Maggi, Magalhães, Campos & Bouzada, 2014; Wang, Tseng, Wilson & Hu, 2009), *functional skills and functional status* (Msall & Tremont, 2002; Sullivan & Msall, 2007; Vohr & Msall, 1997) and *adaptive behaviour* (Fjørtoft et al., 2015; Tassé et al., 2012). The concepts have similarities in that they describe children’s ability to perform the tasks or activities of everyday life in a natural context. All concepts emphasise the relation between children’s functional performance or skills and everyday life, as a result of a reciprocal transaction between the person and the context (Case-Smith, 1995). A focus on task performance, defined as what children actually do in their natural context in contrast to the process or method used to achieve the task, is also a perspective found in the above-mentioned concepts.

In this thesis, the definition of everyday function was essentially derived from Vohr and Msall (1997). *Everyday functioning* was defined as the ability/skills to perform activities in everyday life, to interact with people and objects in the microsystem and to fulfil expected social roles (Vohr & Msall, 1997). Everyday functioning refers not only to skills in isolation, but to the extent to which children use their skills, taking into account individual characteristics and adapting to environmental constraints. In this case, the environment includes the physical surroundings, the people, the objects they are dealing with, and the task they are performing (Kielhofner, 2009). In this environment children are actors making experiences regarding the places, people, object and activities referred to as “the social context” (Batorowicz, King, Mishra, & Missiuna, 2016). It may be assumed that children’s everyday functioning is influenced by the interaction between the environment and the social context.

As noted above, everyday functioning is a multifactorial construct (person-context-activity), and different factors such as intrinsic personal elements and external contextual circumstances influence children’s participation in everyday life. With the aim of exploring how a combination of personal and contextual factors contribute to this participation, Rosenberg and colleagues (2010) studied a group of preschool children without disabilities. The researchers wanted to explore different aspects of participation such as diversity, intensity, independence, child enjoyment and parent satisfaction. The findings show that performance skills contribute significantly to children’s independence in everyday life, but are less influential for other aspects of participation (Rosenberg, Jarus, Bart, & Ratzon, 2011). Performance skills which reflect what a child actually does have been found to be influential in
terms of children’s participation in everyday life (Rosenberg, 2015). In addition, performance skills, especially process skills, have a strong influence on children’s independence, and in children with developmental disabilities these skills may also influence their enjoyment and their parents’ satisfaction with their performance (Liberman, Ratzon, & Bart, 2013).

Measuring everyday functioning

A complete profile of children’s functioning requires a holistic approach. A framework which takes into account biological, psychological and social perspectives allows for a description of children’s developmental strengths and difficulties in everyday life situations (Msall, 2005). Everyday functioning is measured by performance, i.e. what the children actually do in their daily environment, in contrast to children’s capacity, i.e. what a child can do in a standardised environment. Clinical settings tend to use the latter as a measure (Holsbeeke, Ketelaar, Schoemaker, & Gorter, 2009). Measuring everyday functioning also involves information about the support or assistance necessary for a child’s success in everyday life situations (Msall, 2005). The conceptual frameworks used in this thesis are outlined in the following section.

International classification of functioning, disability and health

In this thesis, everyday functioning is understood as a multidimensional concept, dependent on personal and contextual factors, and factors related to activity (Adolfsson et al., 2012; AOTA, 2002). The ICF-CY offers a conceptual framework for researching everyday functioning. Everyday life situations of children include frequently occurring routines or complex activities in a societal context, described in the activity and participation components of the ICF-CY (Adolfsson, 2013). In order to describe children’s functioning in everyday life situations there is a need to consider all components in the ICF-CY: body structure and function, activity and participation, but also environmental and personal factors. Activity is usually measured as capacity, while a measure of performance describes the component ‘participation’. The relationships between the components in the ICF-CY model should not be seen as linear. Instead, the ICF-CY emphasises the interaction between the components for a comprehensive understanding of functioning (WHO, 2007). However, the processes that constitute the interaction between ICF-CY components are not entirely clear (Badley, 2008). It is argued that performance in the ICF-CY has a developmental approach and is actually describing degrees of competence.
Children’s activity competence is commonly used in research as a measure of functioning (Imms et al., 2015). In the Family of Participation Related Concepts (fPRC) framework, activity competence is described as an intrinsic person-related concept linked to participation. Activity competence is defined as the ability to execute the activity according to expected standards (Imms et al., 2017; WHO, 2007). Two additional concepts in the fPRC are related to participation: a sense of self, describing personal perceptions influenced by past participation or with a future-oriented influence on participation. The third intrinsic person-related factor involves preferences defined as interests that hold meaning or are valued (Imms et al., 2017).

To capture the whole spectrum of everyday functioning, the ICF-CY was used as a conceptual framework for data collection throughout this thesis, and study designs, methods and measurements was selected accordingly. The fPRC was presented during the course of the thesis, and the fPRC model was considered helpful in analysing the findings in Study II, III and IV.

A person-oriented approach

The multidimensional relationship between biological, behavioural and contextual factors in everyday functioning requires a study design that enables the study of patterns rather than isolated factors. The person-oriented approach derives from a holistic perspective in developmental research, where the individual is conceptualised as an integrated totality (Bergman, Magnusson, & El-Khoury, 2003; Bergman & Trost, 2006). The child is seen as an active agent in the processes interacting with the environment. Individual development takes place in complex, adaptive processes driven by nested systems of mental, biological and behavioural factors, together with social, cultural and physical factors in the environment. As a result, child functioning consists of patterns of factors dependent on a specific child’s personal and contextual characteristics. Consequently, individual functioning and development may differ between individuals. Bergman & Magnusson (1997) suggested that, theoretically, there may be as many patterns as there are individuals, but on a more global level a number of frequently observed patterns will appear which share similarities within the group and dissimilarities with other groups. A person-oriented approach is well-suited for research on everyday functioning with its dependence on a variety of factors (Bergman & Magnusson, 1997).
An usual approach in developmental research is to study the influence of one factor or variable on developmental outcome. The variable-oriented approach tends to assume a linear relationship between variables. The two approaches are to be seen as complementary. The variable-oriented approach may be suitable to investigate the relation between variables and across time by using linear statistical models (Field, 2009). The variable oriented approach may also be useful to help find operating factors to include in research with a person-oriented approach with the aim to identify patterns of e.g. everyday functioning (Bergman & Trost, 2006).

A child perspective and the child’s perspective
Everyday functioning is the result of reciprocal interaction between the person and the context (Bronfenbrenner, 1979; Case-Smith, 1995). It must therefore be evaluated within the child’s natural environment, which for preschool children is largely in the family context (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006). Parents who observe a child in different social and physical contexts are important sources of information (Glascoe & Dworkin, 1995; Rosenberg, Bart, Ratzon, & Jarus, 2013). However, this also means that researchers need to include children as active participants in research, contributing their own perceptions, experiences and understanding of the world. The child’s perspective is of particular interest in research within children’s natural settings, and aims to contribute to knowledge of children’s everyday life (Sommer, Pramling Samuelsson, & Hundeide, 2010). Including children in research is nevertheless dependent on their cognitive and communicative abilities, experiences and the level of interpretation needed to understand their narratives (Nilsson et al., 2015). Thus, for comprehensive information about everyday functioning, data need to be retrieved from both children (child’s perspective) and from close adults (child perspective) (Nilsson et al., 2015).

Everyday functioning in children born preterm
Only a limited number of studies have been found which investigate everyday functioning in children born preterm. In studies which compare children born preterm to children born full-term, lower levels of everyday functioning have been found in the preterm children (Killeen, Shiel, Law, Segurado, & O'Donovan, 2015; Maggi, Magalhães, Campos, & Bouzada, 2014; Palta, Sadeh-Badawi, Evans, Weinstein, & McGuinness, 2000; Sullivan & Msall,
Children born preterm with neurological disabilities such as cerebral palsy show most disabilities in everyday functioning. However, approximately 20% of children without neurological disabilities also display difficulties in everyday life (Palta et al., 2000; Sullivan & Msall, 2007; Verkerk et al., 2013). In preschool age groups, children born preterm show lower performance in self-care, mobility and social function, measured with the Pediatric Evaluation of Disability Inventory (PEDI), mobility functions being the most pronounced (Palta et al., 2000; Verkerk et al., 2013). In accordance with the aforementioned results, Sullivan and Msall (2007) found overall lower performance in everyday activities for the same age group of children born preterm than for those born full-term. In contrast, Sullivan and Msall (2007) found that the children born preterm presented high scores for mobility and lower scores for self-care, measured with the Functional Independence Measure for Children. In addition, children born preterm seem to require more assistance from their parent, i.e. they are less independent in terms of everyday functioning (Maggi et al., 2014). Verkerk and colleagues (2013) observed that, compared to PEDI values in the norm population, children born preterm seem to require more assistance from parents in terms of social functioning, but fall within norm values in terms of the mobility and self-care assistance scales.

Difficulties in everyday functioning seem to persist as the children grow older (Fjørtoft et al., 2015; Palta et al., 2000; Sullivan, Miller, & Msall, 2012). Although they may catch up in terms of everyday personal and domestic skills such as dressing, hygiene and helping with simple household tasks, skills in everyday community activities, play and leisure may still be affected in 10 year-olds (Fjørtoft et al., 2015). There are also inconsistencies in terms of risk factors for everyday functioning. Research indicates that preterm birth alone has an impact on everyday functioning, as disabilities in self-care, mobility and social function are also apparent in children without motor or intellectual disabilities (Killeen et al., 2015). Neonatal morbidities such as IVH, PDA, BPD and ROP have been associated with everyday functioning (Palta et al., 2000; Sullivan & Msall, 2007). Neonatal morbidities have been found to affect mostly mobility functions, but also to some extent self-care and social functioning (Palta et al., 2000). However, other studies report no association between neonatal morbidities and everyday functioning. Behavioural factors may influence everyday functioning. Internalising behaviours, such as anxiousness, nervousness, withdrawal and emotional behaviour, as well as externalising behaviours...
such as hyperactivity, conduct problems, temper tantrums and impulsiveness, have been reported to occur more commonly in children born preterm (Fjortoft et al., 2015; Mansson, Stjernqvist, & Backstrom, 2014). From a parent perspective, behavioural problems, and in particular hyperactivity and emotional problems, are found to have a negative effect on everyday life and friendships in typically developed preschool children (Fuchs, Klein, Otto, & von Klitzing, 2013). It can be assumed that behavioural problems also have an impact on everyday functioning in children born preterm. Given the limited number of studies, the different measurements used and the inconsistencies in results, everyday functioning in preschool children born preterm needs to be explored further.

Rationale

Children live and develop within everyday life situations (Dunst et al., 2001; Dunst et al., 2000). The development of functioning in these situations is dependent on the child’s inherent characteristics, biological factors and contextual factors (WHO, 2007). How these factors interact in terms of the development of everyday functioning is not clear. Children’s development is not linear, but takes place in a context of interaction with people in their close environment. There is a need to understand the nature of this interaction, especially in children at risk of disabilities. Children born preterm are a vulnerable group who may be at particular risk of deficit in everyday functioning. Studies on children born preterm have devoted attention to outcome measures such as neurodevelopment, behavioural problems, and cognitive and motor function. However the number of studies concerning everyday functioning in these children is limited. Few studies have examined how everyday functioning is influenced by the different factors to which the preterm-born in particular are exposed.

There is also a need to explore children’s own perceptions of their functioning and everyday life situations. This thesis aims to contribute to an increased understanding of everyday functioning in young children born preterm.
Aim

The overall aim of the studies included in this thesis was to explore everyday functioning in preschool children born preterm. The specific aims of the studies were as follows:

I. To explore everyday functioning and its relationship to perinatal risk factors and socioeconomic status in a group of six year-old children born preterm and at term

II. To explore patterns of everyday functioning, and to investigate the relations between these patterns and perinatal characteristics, neonatal risk factors, behaviour and socioeconomic status in a group of six year-old children born preterm and at term

III. To explore perceived efficacy in everyday activities in six year-old children born preterm

IV. To explore meaningful everyday life situations from the perspective of children born preterm
Method

The thesis used quantitative, qualitative and mixed-method designs, and several methods for data collection, to capture everyday functioning as a multidimensional concept. An overview of the aims, design, data collection and data analysis for the four studies is presented in Table 1.

**Table 1. Overview of the aim, study design, data collection and analysis methods**

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Data collection</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To explore everyday functioning and its relationship to perinatal risk factors and socioeconomic status in children born preterm and at term</td>
<td>Quantitative, cross-sectional</td>
<td>Registers, questionnaires</td>
<td>Descriptive, correlational, ANOVA, multiple linear regression</td>
</tr>
<tr>
<td>II</td>
<td>To explore patterns of everyday functioning, and the relation between these patterns and prenatal characteristics, neonatal risk factors, behaviour and socioeconomic status</td>
<td>Quantitative, cross-sectional</td>
<td>Registers, questionnaires</td>
<td>Descriptive, Ward’s cluster analysis</td>
</tr>
<tr>
<td>III</td>
<td>To explore competence in everyday activities as reported by children and parents</td>
<td>Mixed-method</td>
<td>Self-reporting, questionnaires, interviews</td>
<td>Descriptive statistics, qualitative content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>To explore meaningful everyday life situations from the perspective of children born preterm</td>
<td>Qualitative</td>
<td>Photo-elicited interviews</td>
<td>Qualitative content analysis</td>
</tr>
</tbody>
</table>

Study I used a variable-oriented group-based approach, and focused on the relation between neonatal risk factors and parent-rated everyday functioning. Based on the findings in Study I, Study II used a person-oriented approach to
studying patterns of everyday functioning. Study III included both self-reported and proxy-reported measurements. In Study IV, a qualitative design was used to capture the child’s perspective. Through the selection of different study designs, the thesis moved from a group-based perspective to an individually based perspective of everyday functioning, and from a child perspective to the child’s perspective.

Participants

The four studies were based on two sets of participants, including a total of 366 children. In Studies I and II the children were born in 2008, and the children in Studies III and IV were born in 2010. Both sets of participants were between five and seven years old at the time of data collection. Sixteen parents participated in Study III. Participants’ characteristics for the four studies are presented in Table 2.

Table 2. Participants’ characteristics

<table>
<thead>
<tr>
<th></th>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
<td>350</td>
<td>331</td>
<td>16</td>
<td>10</td>
</tr>
<tr>
<td>Parents</td>
<td>-</td>
<td>-</td>
<td>20</td>
<td>-</td>
</tr>
<tr>
<td>Boys/Girls</td>
<td>211/139</td>
<td>196/135</td>
<td>8/8</td>
<td>5/5</td>
</tr>
<tr>
<td>GA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 32 w</td>
<td>35</td>
<td>34</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>33 – 36 w</td>
<td>93</td>
<td>87</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>≥ 37 w</td>
<td>222</td>
<td>210</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Figures are presented in numbers of persons. GA = gestational age.

Studies I and II

The population-based Studies I and II were based on the same sample population. All 5-7 year-old children born preterm living in the Södermanland and
Västmanland county council areas were invited to participate in the studies. The population included children born before 37 weeks of gestation in 2008. A group of children born at term, containing two children for each one born preterm and matched for ± 1 day of birth, was also invited to participate in the studies. For reasons of confidentiality, it was not possible to control for exclusion criteria, so gestational age and day of birth constituted the inclusion criteria of the sample selection. In total, 1048 children were identified who fit the inclusion criteria: 25 of these were deceased, had emigrated or were lost for other reasons. Thus, a total of 1023 children, 586 boys and 437 girls, were eligible for inclusion in the studies, and a letter of invitation was sent out to their parents. Parents of 350 out of 1023 (34%) children, 211 boys and 139 girls, accepted the invitation to participate. Seven of the 350 children were born at < 28 weeks of gestation and 27 were born between 28 and 32 weeks of gestation. Because the number of children was limited, these two groups were merged into one group of 35 children born at ≤ 32 weeks of gestation. This group of children was labelled Very preterm (VPT). Ninety-three children were born between 33 and 36 weeks of gestation, labelled Late preterm (LPT), and 222 children were born between 37 and 42 weeks of gestation, labelled Full-term (FT) (Table 2). Data were collected during the children’s sixth year of life, and their ages ranged from 63–74 months (m = 69.34 months, SD 3.40) in the VPT group, from 62–75 months (m = 69.29, SD = 3.31) in the LPT group and from 62–75 months (m = 68.96 months, SD = 3.29) in the FT group (p = .66).

In Studies I and II, there were no significant differences in gender or residence between those who participated and those who did not consent to participate. However, among those who declined participation, significantly more had foreign citizenship than those who participated.

Procedure
Participants were recruited in collaboration with The National Board of Health and Welfare in Sweden (National Board of Health and Welfare, 2014), Statistics Sweden (SCB) (SCB, 2012) and the Swedish Neonatal Quality Registry (SNQ) (Swedish Neonatal Quality Register, 2015). Children born preterm and the matched controls were identified in the Swedish Medical Birth Registry (SMBR) administered by the National Board of Health and Welfare, and data regarding the children were sent to SCB and SNQ. SCB distributed the letter of invitation and questionnaires provided by
the research group to the parents of the eligible children. In the invitation letter, parents were informed that by responding to the questionnaires they agreed to participate in the study and consented to registry data from SCB, SMBR and SNQ being made available to the research group. Parents who agreed to participate answered the three questionnaires and sent them to the research group. The research group informed SCB about the participants, and registry data were retrieved from SCB, SMBR and SNQ and sent back to the research group on memory sticks (usb).

Studies III and IV
All children aged 5–6 years and born preterm, living in the Södermanland county council area, were invited to participate. One hundred and fifty children were identified who were born before 37 weeks of gestation in 2010, and who had been cared for at the neonatal ward. Twenty-seven of these children were deceased or had another residence. Inclusion criteria was children born preterm without neurological disabilities, hearing or visual disabilities and/or intellectual disability. Four children had been diagnosed with a disability, and were therefore excluded. The remaining 119 children and their parents were invited to participate. In Study III, 16 children and their parents accepted the invitation to participate. There were eight boys and eight girls; one boy was five years old and all the other children were six years old. The children’s gestational age at birth ranged from 26–36 weeks, four children were born at \( \leq 32 \) weeks of gestation and six children between 33 and 36 weeks of gestation. Study III also included 25 parents: 15 mothers and five fathers participated. Five couples were interviewed together, and 10 mothers and one father were interviewed alone. Parents were also present at children’s interviews to provide security for their children.

The children participating in Study III were invited to take part in Study IV. Eleven children born preterm agreed to participate. At the time of data collection, one child had to withdraw due to illness, with ten children remaining in the study: five boys and five girls. The gestational age at birth ranged from 26 to 36 weeks, with one child born at gestational age 26 weeks and nine children between gestational ages 32 and 36 weeks (Table 2). All ten children were six years old.

For confidential reasons, it was not possible to analyse any differences between those who participated in Studies III and IV and those who declined to participate.
Procedure
Participants in Studies III and IV were recruited in collaboration with the paediatric clinic at the county council. The neonatologist and the medical secretary at the neonatal ward identified children according to the inclusion criteria, and sent out invitation letters to the children and their parents in a joint process for the two studies. Parents sent their informed consent to the research group, who contacted the families for further information about the studies and to set a date for the first interview with the child. Dates for the parents’ interviews and for the children who participated in Study IV were scheduled at the first appointment. The interviews took place at a location chosen by the families: the university, at home, at work or at the paediatric clinic.

Data collection
For the project, the ICF-CY framework served as a model for exploring the multidimensional construct ‘everyday functioning’. Methods were chosen to collect data from the ICF-CY components body function and structure, activity, participation and environmental factors. Most of the data collection methods included items with a mix of the three ICF-CY components: body structure/function, activity and participation, except for registry data which only included items connected to body structure/function, and socioeconomic data connected to environmental factors. Data collection methods are presented in chronological order according to how they were used in Studies I–IV.

Perinatal data
Perinatal data were collected from the SMBR and SNQ (Studies I and II). The SMBR, managed by the National Board of Health and Welfare, contains data on pregnancies, births and new-borns reported by maternity care and neonatal care. Data were collected on sex, gestational age, birth weight, birth length, head circumference and possible twins. Data were also collected on Apgar score and morbidities during the neonatal period, BPD, hypoglycaemia, HIE, IVH, NEC, neonatal infections, PVL, PDA and ROP.

The SNQ includes data on children admitted to a neonatal ward at birth or within 28 days thereafter. The SNQ data are similar to data in the SMBR but may also contain additional data. For example, data on morbidities are registered during the whole period the child is cared for. For Studies I and II, data
from the SNQ could involve children born both preterm and at term, and these were used to supplement the SMBR data.

Performance skills questionnaire

The Performance Skills Questionnaire (PSQ) was designed to allow parents to assess their child’s skills in performing activities essential for everyday life (Bart, Rosenberg, Ratzon, & Jarus, 2010). It examines how 4–6 year-old children behave, function and organise themselves during an activity. The PSQ contains 34 items in three domains: motor skills (10 items), process skills (14 items) and communication skills (10 items). The motor skills domain measures skills which require e.g. balance, strength and persistence during activities; the process skills domain measures skills in e.g. initiating, organising, maintaining, adapting and completing an activity, and the communication skills domain measures skills in speech and interaction. The PSQ is based on the ICF and the OTPF, and describes the observed performance of the child in carrying out an activity. The PSQ was therefore considered a suitable instrument for measuring everyday functioning (Studies I and II). In the questionnaire the respondents are asked to rate how the items describe their children. Each item is scored on a Likert scale with six grades, where 1 represents “does not describe my child at all” and 6 represents “describes my child a great deal”. Three measures, one for each domain, can be yielded from the PSQ, as well as a total score. The psychometrics of the PSQ have been evaluated by the constructors (Bart et al., 2010). Internal consistency reliability for the PSQ showed an acceptable level for the three domains: motor skills, process skills and communication skills (Cronbach’s alpha 0.89, 0.92, and 0.84 respectively). Test-retest reliability indicated good agreement for the ordinal items (Kappa values ranging from 0.44-0.89) and very good agreement for the PSQ total measures (ICC 0.92-0.96). Content validity for the instrument has been established by an expert group. Construct validity was supported by factor analysis, which yielded three factors explaining almost 52% of the total variance. Significant differences were found between known groups. Convergent and divergent validity were supported by significant correlations with two standardised tests for children (Visual-Motor Integration and Movement Assessment Battery for Children) (Bart et al., 2010). For Studies I and II, the PSQ was translated from English into Swedish by the research group. The translation of the PSQ was then back-translated by an external person. To validate the accuracy of translation, the original version and the back-translated version were sent to the
constructors of the PSQ (Bart et al., 2010). The Swedish translation was approved with a minor review in one item.

The Strengths and Difficulties Questionnaire

The Strengths and Difficulties Questionnaire (SDQ) is a widely-used behavioural screening questionnaire on 4-16-year-olds, designed to be answered by parents and/or teachers (Goodman, 1997). The questionnaire includes 25 items divided into five scales, each including five items, on emotional symptoms, conductive problems, hyperactivity/inattention, peer relationship problems and prosocial behaviour. In ten items the questions are formulated to estimate positive attributes, one question is neutrally formulated and 14 questions are formulated to estimate negative psychological attributes. The items can be scored “not true”, “somewhat true” and “certainly true”, with a score of 0, 1 or 2. The scores can be summarised for each of the five scales with a total ranging from 0 to 10. The total difficulty score is generated by summing the scores from the emotional symptoms scale, conduct problems scale, hyperactivity scale and peer problems scale, giving a resultant score that can range from 0 to 40. The resultant score is classified as normal, borderline or abnormal on the SDQ record sheet, and can be used to identify possible mental health disorder (SDQinfo.org). The psychometric properties of the SDQ have been examined by several researchers (Goodman, 1997, 2001; Malmberg, Rydell & Smedje, 2002; Smedje, Broman, Hetta & von Knorring, 1999; Stone, Otten, Engels, Vermulst & Janssens, 2010). In a review study by Stone et al. (2010), the weighted mean internal consistency of the resultant score, based on 26 studies, was 0.80 (0.69-0.87) for parent ratings and 0.82 (0.62-0.85) for teacher ratings. Weighted mean test-retest reliability, based on six studies, was 0.76 (0.72-0.86) for parent ratings and 0.84 (0.55-0.90) for teacher ratings. Construct validity was examined, and supported the five-factor structure of the SDQ (Stone et al., 2010; Rothenberger et al., 2008). In terms of concurrent validity, the SDQ indicated a strong correlation with the Rutter questionnaire and sufficient correlation with the Child Behaviour Checklist (Goodman, 1997; Stone et al., 2010). The SDQ has been translated into Swedish and examined for psychometric properties (Malmberg et al., 2002; Smedje et al., 1999). The internal reliability of the total resultant score was shown to be satisfactory (Cronbach’s alpha 0.76 and 0.84 respectively), and the factor structure of the SDQ was confirmed (Malmberg et al., 2002; Smedje et al., 1999). Swedish cut-off scores have been proposed and studied, showing satisfactory sensitivity and specificity (Malmberg et al., 2002). Based on the assumption
of interacting components as presented in the ICF-CY, children’s behavioural characteristics were considered to contribute to everyday functioning. The SDQ was therefore included as a data collection method (Studies I and II).

The Interaction Questionnaire (Föälldrars upplevelse av samspelet med barnet)

The Interaction Questionnaire (henceforth InteractQ) was developed in Sweden by Granlund and Olsson (1998). The InteractQ was used in Studies I and II. The questionnaire contains 19 items, 10 of which describe the child’s ability to interact and communicate (child-initiated items), for example: *The child initiates the interaction; The child remains long enough in an activity or situation; The child is able to focus my attention on a shared objective.* Nine items describe a parent’s ability to involve the child in interaction and communication, for example: *I use appropriate language in our interaction; I know how to keep the child focused on our current activity.* The parent is asked to rate how often he/she perceives the suggested interaction takes place. The questionnaire measures the interaction pattern on a five-point Likert scale, from seldom (rated one) to most of the time (rated five). The questionnaire has been used in several studies in Sweden (Almqvist & Granlund, 2005; Almqvist, 2006; Wilder, Axelsson & Granlund, 2004). Internal consistency of the interaction scale has shown sufficient reliability (parent behaviour α=0.80, child behaviour α=0.73) (Almqvist, 2006; Wilder et al., 2004). For Studies I and II, two indexes were calculated on the mean scores: one index for the child-initiated items and one for parent-initiated items. Both indexes were used in correlation analyses in Study I. In Study II, only the child-initiated interaction index was used in the analysis, as the aim of the study focused on patterns of everyday functioning which only involved the children’s patterns of interaction.

Socioeconomic data

Registry data on socioeconomic demographics were collected from the SMBR and SCB (Studies I and II). The data included maternal age at the time of childbirth, residence, educational level and household income. Maternal age was divided into three age groups. Data on residence focused on the number of inhabitants and household income in Swedish kronor. The data on residence were used for attrition analysis. The huge range from the lowest to the highest household income made it impossible to use the data in the analyses. The SCB
registry for educational level consists of 46 levels from fewer than 9 years of education to doctoral degree, and is divided into four main categories, including an unknown category. The registry presents the highest completed educational level. In the project, data on the highest educational level were collected and categorised as follows: ≤ 9 years, 10–12 years and ≥ 12 years. In the cases of two parents, the highest educational level was used.

The Perceived Efficacy and Goal-setting System
The PEGS (Missiuna & Pollock, 2000) is a self-reporting instrument developed to measure perceived competence in everyday activities, and for setting and prioritising goals for intervention. The PEGS consists of 24 pairs of pictorial cards for use in interviews with 5–9 year-old children, a parent questionnaire and a teacher questionnaire. In the present study, the PEGS was used to measure only perceived competence in everyday activities, and questions about goals for intervention were not asked (Study III). The PEGS was used in this limited form in a study of children with DCD to give voice to the child’s perspective of his or her strengths and difficulties in fine and gross motor tasks in everyday life (Dunford, Missiuna, Street & Sibert, 2005). The PEGS consists of items related to fine motor performance (n = 12 items) and to gross motor performance (n = 12 items), including self-care, productivity and leisure activities which commonly occur in children’s everyday life. The items on self-care involve e.g. dressing, cutting food and managing self-care routines. The items on productivity involve e.g. drawing, arts and crafts activities and finishing schoolwork on time, and the items on leisure activities involve e.g. doing sports, playing video games and keeping up with others. Each item is depicted in pairs, one showing a child performing an activity competently and the other showing a child performing an activity with less/low competence. In a two-step decision-making process, the interviewer first asks the child to select the picture with the child who is most like him/her. Secondly, the child is asked to indicate whether the child on the selected picture is “a little like” him/her or “a lot like” him/her. The cards are placed in four piles and a score is given for each card: 1 corresponds to “a lot like the less competent child”, 2 corresponds to “a little like the less competent child”, 3 corresponds to “a little like the competent child” and 4 corresponds to “a lot like the competent child”. The PEGS also contains two blank cards where the child can mention additional things, not previously shown on the item cards, which the child would like to improve or
work on in therapy. In the current study, these blank cards were used to give the children the opportunity to mention any other task or activity in everyday life where they perceived themselves competent or less competent. The child was also asked to say more about the activities on the pictorial cards in the PEGS, such as why and in what way the child was competent in one activity and less competent in another, what made the activity easy/difficult, how frequently the activity was performed and about the context where the activity was performed.

The parent and teacher questionnaires involve the same 24 activities as in the child interview. Parents are asked to rate their child’s competence in each activity in the same two-step process as for children. Furthermore, there are blank cards for parents to add any task not presented in the 24 activity cards. In the present study only the predetermined items in the parent questionnaire were used in individual interviews with the parents. The sums of the child’s rating and the parent’s rating are calculated for the four-point scale. A score is given which indicates the perceived level of competent performance for children and for their parents, and similarities and differences in children’s perception and parent’s perception can be explored (Missiuna & Pollock, 2000). The constructors of the PEGS found that children aged 5-9 years were able to discriminate between items and rate their own performance in different activities (Missiuna & Pollock, 2000). Internal consistency for the scale has shown a Cronbach’s alpha reliability coefficient of 0.795 (Missiuna et al., 2006). The PEGS has been translated into Swedish and adapted to a Swedish context (Vroland-Nordstrand & Krumlinde-Sundholm, 2012a), the psychometrics of the instrument have been tested (Vroland-Nordstrand & Krumlinde-Sundholm, 2012b) and it has been used as a goal-setting instrument for intervention (Vroland-Nordstrand, Eliasson, Jacobsson, Johansson & Krumlinde-Sundholm, 2016). By courtesy of the constructors of the PEGS and the Swedish research group, a research edition of the PEGS was made available for use in Study III.

Interviews

Individual interviews with the parents were included in the data collection procedure. The interview included one or two parents, according to their own choice. The interviews were performed by the researcher (doctoral student) without the child present, to allow the parents to talk freely. The parents of children born preterm were asked how they perceived their child’s compe-
ence in everyday life situations, the support they gave their child in these situations and their child’s requirements in terms of assistance. The interview started with an open question: How do you perceive your child’s everyday functioning? Follow-up questions where posed to let parents develop and deepen their descriptions. The interviews ended with a review of parents’ answers in the PEGS and further follow-up questions were posed for a comprehensive understanding of their children’s competence in the three domains.

Photo-interviews
Photographs were used to document meaningful situations in everyday life (Study IV). The children born preterm were asked to take photographs of everyday life situations they perceived meaningful and important, and which occurred relatively regularly. They were encouraged to take photographs during a two-week period in their natural setting e.g. at home, at preschool or in a location for leisure activities. However, instructions about the photographic object remained open to avoid the risk of influencing the child’s choice of situation. The children were offered the loan of a camera by the research group to take photographs, or they could use their own if they wished. The photographs were used in individual interviews with each child to reflect on and elicit descriptions about meaningful everyday life situations.

In the individual interviews semi-structured questions were posed. The children were asked to talk about the situation depicted in the photographs, including the context where it was taken, the objects and/or people participating, why the situation was chosen, their feelings about the situation, the frequency of the situation and whether it was an important situation or not. The questions asked were:

Tell me about this everyday situation. What happens here? Where are you? Who’s with you? What do you do in this situation? Why did you choose this situation? Is this an important situation for you? How often do you do this activity? Is this an everyday situation you are good at doing? Is this a situation you consider difficult? Tell me about why you are good at/so skilled in this situation. Tell me why you think this situation is hard.

Data have been collected with children using photographs in several other studies (Almqvist & Almqvist, 2015; Einarsdottir, 2005; Mengwasser & Walton, 2013). Allowing children to take their own photographs give them power over the data collection and highlights the child’s perspective on what
Data analyses

A mixture of quantitative and qualitative analysis was used in this thesis. An overview of analysis by study is presented in Table 1. Descriptive statistics were calculated in Studies I–III. In Studies I and II, GA was categorised into VPT: children born at \( \leq 32 \) weeks, LPT: children born at 33–36 weeks and FT: children born at \( \geq 37 \) weeks of gestation. Mean and standard deviations for perinatal characteristics were calculated by category. Maternal age and parents’ educational level were each divided into three categories. Where two parents were involved, the highest educational level was used. The internal reliability of each sample was estimated using Cronbach’s alpha for the PSQ, the InteractQ, the SDQ and the PEGS. The level of statistical significance was set to 0.05.

Study I

Measures of mean and standard deviation (SD) were calculated for perinatal data. Proportions of boys/girls, number of twins and neonatal morbidities were calculated and used as nominal data. The mean and SD of the subdomains in the PSQ, SDQ and InteractQ were calculated by gestational group, and an analysis of variance (ANOVA) was performed for differences in distribution between the VPT, LPT and FT groups. Non-parametric correlations (Spearman) were calculated between perinatal characteristics, subdomains of the PSQ, the InteractQ and environmental data.

In order to use everyday functioning as an outcome variable, an index was created from the subdomains in the PSQ (34 items) and the first ten items in InteractQ which represented child-initiated interaction with the parent. A principal component analysis with orthogonal rotation, Varimax, was performed to convey any items in the index which could possibly be related. The analysis resulted in 9 factors with an eigenvalue over 1.0 accounting for 62.1% of the cumulative variance. Although the eigenvalue was higher than 1 for nine factors, the scree plot showed an inflexion that would justify retaining four factors. An oblique rotation (Oblime with Kaiser Normalization) was performed, based on the factor analysis made by the constructors of the PSQ yielding 3 factors (Bart et al 2010) and a theoretical hypothesis about the InteractQ as representing a fourth factor. With a four-factor solution that
accounted for 47% of the explained variance, it was concluded that the index
reflected the multidimensional concept in focus, everyday functioning. For
the index involving differences in distribution in everyday functioning be-
tween the VPT, LPT and FT groups, an ANOVA was performed. Effect
sizes were calculated for the ANOVAs according to eta-squared: \( \eta^2 = SS_{between}/SS_{total} \).

The inclusion of 14 twins in the preterm groups (VPT, LPT) in relation to
no twins in the control group was taken into account. This complexity of
nested data was handled for following the principles described by McCauch & Adelson (2010). This procedure indicate the degree to which the standard
error needed to increase to account for the clustering effect. The average
sample size was 1.06 and the ICC was .69. Thus the following equations
were calculated to adjust the standard errors:

\[
\sqrt{1 + \frac{.69}{1.06 - 1}} = 1.02
\]

(McCoach & Adelson, 2010).

A multiple linear regression analysis (MRA) was performed with the aim
of identifying factors which predict everyday functioning. A hierarchical
MRA was performed in three steps: perinatal characteristic variables were in-
cluded in the first step, contextual variables were added in the second and be-
havioural variables were added in the third step.

Study II
Following suggestions by Bergman and colleagues (2003), a cluster analysis
was performed using Ward’s agglomerative hierarchical method, based on the
standardised score of the variables. The cluster analysis included six variables:
PSQ motor skills, PSQ process skills, PSQ communication skills, InteractQ
child-initiated items, SDQ hyperactivity and SDQ conduct problems. The rel-
atively small sample size limited the number of eligible cluster variables. Fur-
thermore, in Study I SDQ hyperactivity and conduct problems were found to
be strong predictors of everyday functioning, and the other subscales: emo-
tional, peer-relation problems and prosocial behaviour, were not. The number
of clusters retained was determined by explained error sums of squares, cluster
homogeneity, and theoretical and practical meaningfulness. A seven-cluster
solution was chosen which explained 65.91% of the variance (explained error
sums of squares). A relocate process, i.e. a comparison between the chosen
cluster solution and a cluster analysis of 2/3 of the sample, and a centroid pro-
cess was performed to validate the cluster analysis, the cluster quality and
structural stability.
ANOVA was used for continuous variables and Chi square analyses for categorical variables in comparisons between clusters. ANOVAs were performed in relation to gender, perinatal characteristics, neonatal risk factors, maternal age and parents’ level of education.

Study III

Both descriptive statistics and qualitative content analysis were used in the mixed-method design for Study III. Quantitative and qualitative data were collected with a concurrent strategy (Creswell, 2009). Initially the data were analysed separately, and quantitative and qualitative data were integrated for interpretation and presentation of results. Perceived competence scores in the PEGS were analysed with descriptive statistics. Mean scores, SD and range for the four-point scale in the PEGS total scale and subscales were calculated for both the children and the parents. The PEGS scale was then dichotomised into competent and non-competent, and the number of children regarded as competent or non-competent was counted by item for both the children’s and the parents’ statements. Vroland-Nordstrand and Krumlinde-Sundholm (2012b) demonstrated good agreement in test-retest reliability for the dichotomised scale of the Swedish version of the PEGS, while the four-point scale showed varied agreement. It was decided that quantitative data would be calculated and presented for both scales. The interviews with children and parents were recorded and transcribed verbatim. The qualitative data involving children’s and parents’ interviews were analysed using qualitative deductive content analysis as described by Elo and Kyngäs (2008). A separate categorisation matrix was developed for children and parents according to the domains in PEGS: self-care, productivity and leisure activities. The analysis began by highlighting all text which appeared to correspond to the categories in the matrix. For the children’s interviews it involved statements regarding self-perceived competence/non-competence in everyday activities. For the parents’ interviews it involved statements regarding self-perceived competence/non-competence and the support given in the activities included in the PEGS. The highlighted text was then condensed and grouped under the corresponding category in the matrix. Similarities and dissimilarities in the data were grouped together by each item and coded. In the children’s interviews the activities mentioned on the blank card were classified into appropriate categories in the PEGS. In the parents’ interviews, data were only chosen if they fitted the aim and categories in the PEGS (Elo &
Kyngäs, 2008). To integrate quantitative and qualitative data, the identified codes and categories were quantified and presented by item in the results.

Study IV

The children’s interviews were recorded and transcribed verbatim. Qualitative content analysis was conducted using an inductive approach according to Elo and Kyngäs (2008). The qualitative content analysis took place in a joint process between the first and second author. First, all interviews were read through repeatedly and separately by the first and second authors. In the next steps of the analysis, the two authors worked together, and all text which appeared to represent the study aim and answer both the “what” and the “how” was highlighted and condensed to form codes (Elo & Kyngäs, 2008). During the process, notes and headings were written in margins to describe aspects of the content. The codes were then grouped together to form sub-categories. Similarities and dissimilarities in the sub-categories were analysed, and sub-categories were grouped together in an abstraction process, forming generic categories. In the analysis the aim was to remain close to the text by using content-related words, without over-interpreting or abstracting the categories, and by keeping the child’s perspective in focus. The photographs were used in the analysis to help understand the children’s descriptions.

Ethical considerations

The Regional Research Ethics Board in Uppsala, Sweden approved the study protocols for Studies I and II, Dnr 2012/552 and Studies III and IV, Dnr 2016/240.

The thesis draws attention to a vulnerable group of young children, and this could have a stigmatising effect. In the first two studies, comparisons between the group of children born preterm and the group of those born FT contribute to earlier research which provides a picture of the overall differences between groups. However, the strength-based perspective with a focus on functioning emphasised positive aspects and contributed to a nuanced picture of everyday functioning in this group of children. Participants in Studies I and II were recruited in collaboration with the National Board of Health and Welfare and with Statistics Sweden. The participants were assigned a code number, and the research group had no information on participants’ names, numerical codes or addresses. The participants gave their informed consent by answering
the questionnaires and sending them to the research group. In the invitation to take part, the participants were informed about confidentiality, and that they were free to withdraw without having to give a reason or be subject to compensation claims.

Recruitment of participants for Studies III and IV was also approved by medical and administrative staff at the paediatric clinic, and participants were recruited with the assistance of the neonatologist and the medical secretary on the neonatal ward. The research group had no prior information on the identity of eligible children. Written informed consent was obtained from parents. On first telephone contact, parents were encouraged to inform the children and ask them for their agreement in terms of participation. Informed consent was obtained from children as an introduction to the interviews. The unequal relation between the child and the researcher may have influenced the child’s ability to decline participation. To build a trust-inducing relationship and to mitigate the imbalance in the relationship, the researcher met the child and the parents at the entrance to the building where the interview was going to take place, in order to get to know each other. Children were then informed about the aim of the studies, and were asked for their permission to record the interview. For children who declined to be recorded, notes were taken by the researcher. Children also had the chance to look around and ask questions about the research or anything else which came to mind. The children had a parent in attendance, who remained by their side at the interview sessions. There was a risk that children would feel singled out by being invited to participate in interviews because of their premature birth. All participating children knew that they were born preterm. The risks associated with preterm birth were not highlighted. The focus was on the child’s perspective. Children were shown respect for their perceptions and experiences, and they were informed that no statement was wrong. In Study IV, children were asked to take photos of their everyday life situations, which for most children include situations in the preschool context. It was emphasised that the child could choose the context for the photographs. Those who chose not to take photographs at school still had the chance to share their meaningful situations in school, during the interview. Permission to take photographs at school was collected by the research group in advance. A teachers were asked to assist the children taking the photographs, parents of other children at school were informed of the study and had the opportunity to reject their children’s participation in the photographs. Both child and parents were reminded that they were free to withdraw from the study without any requirement to state reasons. During interviews, the children were asked if they wanted to continue, were tired, needed a break or
wanted to end the interview. The children were also encouraged to decide what and how much they wanted to say, and when to move on to the next set of pictorial cards or photograph. If required, the name and number of the neonatal team at the paediatric clinic were provided by the research group. During the final meeting for collecting data, parents were offered the chance to receive a copy of the articles when they were published.
Results

Child characteristics
Table 3 shows perinatal data for participants in Study I, including neonatal morbidities and socioeconomic data. Although 19 children were excluded for Study II, the characteristics of the groups remained essentially the same. For the children in Studies III and IV, perinatal characteristics (except for GA, Table 2) and socioeconomic data were not collected.

Table 3. Perinatal characteristics, neonatal morbidities and socioeconomic data for Study I.

<table>
<thead>
<tr>
<th></th>
<th>VPT (n = 35)</th>
<th>LPT (n = 93)</th>
<th>FT (n = 222)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GA (weeks)</td>
<td>m SD</td>
<td>m SD</td>
<td>m SD p</td>
</tr>
<tr>
<td>Min—max</td>
<td>Min—max</td>
<td>Min—max</td>
<td></td>
</tr>
<tr>
<td>29.8</td>
<td>2.5</td>
<td>35.3</td>
<td>.9</td>
</tr>
<tr>
<td>24-32</td>
<td>33-36</td>
<td>37-42</td>
<td></td>
</tr>
<tr>
<td>BW (gram)</td>
<td>1461.4</td>
<td>448.2</td>
<td>2707</td>
</tr>
<tr>
<td>683-2255</td>
<td>1545-3745</td>
<td>2275-5540</td>
<td></td>
</tr>
<tr>
<td>BL (cm)</td>
<td>39.6</td>
<td>4.2</td>
<td>47</td>
</tr>
<tr>
<td>31-45</td>
<td>40-51</td>
<td>45-56</td>
<td></td>
</tr>
<tr>
<td>HC (cm)</td>
<td>28.3</td>
<td>3.0</td>
<td>32.9</td>
</tr>
<tr>
<td>21-36</td>
<td>28-39</td>
<td>31-40</td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>n</td>
<td>n</td>
<td></td>
</tr>
<tr>
<td>Twins</td>
<td>12</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Morbidities</td>
<td>22</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>(n ≥1)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Data are given in m = mean, SD = standard deviation and n = numbers. VPT = very preterm-born, LPT = late preterm, FT = full-term, GA = gestational age, BW = birth weight, BL = birth length, HC = head circumference and p = level of significance.

The number of children in the three groups varied considerably, and as expected there were significant differences between the VPT, LPT and FT groups in terms of GA, BW, BL and HC. All children in the VPT group had a
BW below 2500 grams, while 30 (32%) children in the LPT group and eight (3.6%) children in the FT group weighed below 2500 grams at birth. Twenty-two (62.8%) children in the VPT group, 18 (19%) in the LPT group and 18 (8%) in the FT group had had more than one neonatal morbidity, including BPD, PDA, hypoglycaemia, IVH, ROP and/or neonatal infections.

Summary of results of the included studies
The findings of the four studies on preschool children’s everyday functioning are synthesised under three main headings: children’s everyday functioning, factors influencing everyday functioning and meaningful everyday life situations.

Children’s everyday functioning
The findings in Study I, II and III showed that most parents perceived their children to have strong everyday functioning.

In the everyday functioning index which included the three PSQ subscales and the InteractQ child-initiated items, parents rated their children born pre-term and FT, high (m = 5.04, SD .5, 95% CI 4.99–5.1). Mean scores for the PSQ subscales were highest in motor skills (m= 5.52, SD .48), followed by communication skills (m = 5.29, SD .66) and process skills (m = 5.07, SD .72). The mean score for the InteractQ was 4.28 (SD .42) (Study I). The cluster analysis in Study II revealed that most children displayed a pattern of strong everyday functioning, i.e. a pattern with strong motor skills, process skills, communication skills and positive interaction. In the analysis, a solution with seven clusters was selected which explained 65.91% of the variance (explained error sums of squares). A little more than half (56%) of the children showed a pattern with strong or fairly strong everyday functioning, including strong performance skills and interaction patterns, and low levels of hyperactivity and conduct problems. In four clusters, including 29.9% of the sample, children had a pattern of everyday functioning featuring weak performance skills, and were less active in interaction. These four patterns showed some differences. In one cluster, children were perceived to have pronounced motor-skill deficiencies, while the other three clusters displayed patterns featuring overall low levels in terms of performance skills and interaction.

An overview of the patterns of everyday functioning after the cluster analysis is presented in Figure 3.
There were some differences in everyday functioning between the children born preterm and the children born full-term. In the everyday functioning index, the VPT (m = 4.85 SD .45) group was rated lower (p = .038) than the FT group (m = 5.08 SD .51). The ANOVA showed that the VPT group was perceived to have lower levels of motor skills than both the LPT and FT groups, and lower levels of process skills than the FT group. There were no differences between groups in communication skills, but the VPT children were perceived less active in interaction than the LPT and FT children, as rated in the Inter-actQ. Overall, the children born preterm showed as varied patterns of everyday functioning as the children born at term. Most (64.5%) children born preterm showed patterns of strong or fairly strong everyday functioning, and about one-third showed patterns of poor everyday functioning.

In Study III, which involved only children born preterm, parents rated their children as competent performers of most everyday activities in the PEGS. Mean scores for all but three activities corresponded to “the competent child” on the pictorial cards. Tying shoe laces was perceived too difficult, and none of the children were seen as competent in the activity. Moreover, regarding skipping and organising things, half of the children were perceived not competent by their parents. In self-care, children were perceived as almost independent, needing only manual assistance in tricky tasks, and reminders or instructions in terms of the procedure for the activity. The parents suggested that their children appreciated productive activities such as drawing, colouring, writing, and arts and crafts. Some parents said that their children were disorganised and had difficulties completing an activity. Most children were perceived to have good relations with their peers and to be active in a variety of sports activities, except for skipping which few children had tried.

The children in Study III agreed with their parents about most everyday activities. The children perceived themselves to be competent, particularly in activities such as dressing, arts and crafts, drawing and running, and keeping up with friends. They also agreed with their parents that they were not competent in tying shoe laces and that they had difficulties with skipping. Five children said it was sometimes hard to complete an activity on time. The children did not agree with their parents in the sense that they perceived themselves to be organised, and said that their room could be untidy but they could still find what they were looking for.
Figure 2. Pattern of everyday functioning by cluster. Everyday functioning includes six variables: motor = motor skills; process = process skills; comm = communication skills; hyperact = hyperactivity; conduct p = conduct problems; sEF = strong everyday functioning; fsEF = fairly strong everyday functioning; fsEFhcp = fairly strong everyday functioning with hyperactivity and conduct problems; wEFh = weak everyday functioning with hyperactivity; wEFmp = weak everyday functioning with motor problems; wEFcp = weak everyday functioning with conduct problems; owEF = overall weak everyday functioning. + = high levels; - = low levels; 0 = equal to total sample mean.

Factors influencing everyday functioning

The results of Study I revealed a significant but weak relation between GA, BW, BL and the everyday functioning index. A relationship was also found between maternal age and everyday functioning, but not for neonatal morbidities or parents’ educational level and the everyday functioning index. In the hierarchical regression analysis, maternal age, parents’ level of education and GA were found to predict 1.6% and 3.2% of the variance in everyday functioning. GA, BW and BL were also found to be related to the subscales motor skills and process skills, but not to communication skills. The InteractQ was only related to GA. The weak relation between GA and everyday functioning was to some extent confirmed in the cluster analysis. There was a tendency towards a higher mean GA in the clusters with patterns of strong and fairly strong everyday functioning than in the clusters with patterns of weak everyday functioning. The ANOVA revealed a significant difference in GA between the sEFhcp cluster and the wEFh cluster. In the latter cluster, the mean GA was 36 weeks and more children born preterm than FT were included in
Gender, number of neonatal morbidities, maternal age and parents’ level of education did not differ between clusters.

Behavioural problems were included in Study I as independent variables. Due to the findings in Study I, hyperactivity and conduct problems were included in the cluster analysis in Study II, as contributors to everyday functioning. It was found that behavioural problems measured with the SDQ total scale were strongly related to the everyday functioning index and to the subscales included in the index. Further analysis showed that hyperactivity was the strongest related variable, while conduct problems, prosocial behaviour, and emotional and peer-relation problems were less related to the everyday functioning index and to its four subscales. When hyperactivity and conduct problems were added to the regression analysis, the explained variance increased to almost 50%, and hyperactivity was the main predictor of everyday functioning in the model.

Hyperactivity and conduct problems were found to be factors influencing the patterns of everyday functioning. In two clusters, involving 81% of the total sample, children had low levels of hyperactivity and conduct problems, and were fairly strong or strong on performance skills and interaction. In three clusters, involving 31.6% of the sample, children were perceived to have hyperactivity and conduct problems, and were weak on performance skills and interaction. One cluster (fsEFhcp) showed a pattern with fairly strong performance skills and interaction, and with levels of hyperactivity and conduct problems higher than the total sample mean. The wEFcp cluster had higher levels of hyperactivity and conduct problems than the fsEFhcp cluster, and had weak performance skills and interaction. The ANOVA showed a significant difference between each cluster in terms of prosocial behaviour and peer-relation problems. The sEF cluster showed higher levels of prosocial behaviour and lower levels of peer-relation problems than the wEFmp cluster and all clusters featuring hyperactivity and conduct problems.

In Study III, parents expressed behavioural aspects of their children’s functioning in the items ‘organising things’ and ‘finishing work on time’. Nine parents said that their children had difficulties finding their things, which caused anger and despair. Two children were perceived not competent by their parents in terms of finishing work on time. Parents said that they helped their children with routines and structure, and gave child-friendly information about time.
Meaningful everyday life situations

Ten children participated in the photo-elicited interviews about meaningful everyday life situations (Study IV). The children took in total 111 photographs to show and talk about. The photographs illustrated the children doing activities, or other people and objects used in activities and environments in which activities took place. Photographs were taken in the children’s homes, at school, in sports arenas, in a stable and outdoors. The photographs were used to elicit the interviews, and in the first step of the content analysis process to facilitate the analysis. The children’s descriptions of meaningful everyday life situations can be understood as being in an active and dynamic process, which interpreted as the main category. Three generic categories emerged: doing things, significant prerequisites to do things and desires of significant development. For the children in this sample, meaningful everyday life situations involve being active and doing things. The children described meaningful activities they do by themselves or together with significant others, e.g. playing games, playing cards, board games and computer games, dancing, climbing, swinging, helping with household chores, reading, drawing, arts and crafts and doing sports activities. Some activities are closely related to significant people, e.g. siblings and grandparents, or to pets and to specific places, e.g. school, sports arenas or outdoors. In the following quotation, one child express the aspect of doing things:

“[I] get up there [in the climbing frame] and then I turn, jump there, jump there, and then climb into those swings as you see. [b90]”

The children also described having prerequisites which involved significant others, skills and things for undertaking the activities. The prerequisites were described as something the children enjoyed and which were necessary for everyday life. The children said that experiencing and doing various activities increased their desire to have more pets as significant others, such as a horse or a dog. It made them want to acquire more skills and to improve their existing skills, and it made them want to undertake more activities, either by embarking on new activities, increasing the frequency of an activity or doing the activity in the future.
Discussion

In this section a summary of the results are presented followed by the discussion about the results in relation to previous research and to the theoretical and conceptual frameworks. Finally, some methodological aspects are discussed.

Summary of results

This thesis aimed to explore everyday functioning in preschool children, and to address the long-term consequences of preterm birth on everyday life. In Sweden there is a pronounced interest in the care of children born preterm. Extensive research has resulted in advances in neonatal care and great benefits for the children. Research has also addressed the consequences of immaturity and neonatal risk factors as the child grows and develops. Studies have focused on neurodevelopmental, cognitive, motor and behavioural outcomes, but less research has explored how these children function in everyday life. In order to explore children’s functioning from a variety of perspectives, and in order to approach the research from a strength-based perspective, the thesis went from a group perspective to an individual perspective and from a parent’s perspective to the child’s perspective. The group-based perspective in Study I contributed to a picture of everyday functioning in children born preterm in relation to children born full-term, as well as an understanding of factors which are important for everyday functioning. These factors were tested in Study II, and in order to explore patterns of everyday functioning a more nuanced picture of children’s functioning was presented. The focus on the individual, the children and their parents in Studies III and IV contributed an exclusive picture of each child’s functioning and what is perceived important in everyday life. In addition, parents’ opinions about their child in the parent-rated questionnaires, which had been designed from a child perspective, provided information on ICF-CY body function as well as activity, participation and environmental factors, and the child’s perspective contributed to an understanding of the child’s unique perceptions and thoughts.
The main finding in the studies included (I – III) was that, overall, the parents perceived their children born both preterm and full-term to function well in everyday life i.e. to have a strong everyday functioning. When the groups were compared, it was found that parents of children born VPT perceived their children to have slightly lower levels of everyday functioning than the children born FT. However, preterm birth was not the main predictor of everyday functioning. Instead, behavioural problems, i.e. hyperactivity and conduct problems, had the greatest influence in both children born preterm and in those born FT. Hyperactivity was found to be strongly related to everyday functioning in both children born preterm and children born full-term (Study I). In both these sets of children the patterns of everyday functioning varied in a similar way, but in cases where preterm birth and hyperactivity covaried, overall everyday functioning was weak (Study II). From the child’s perspective, the main findings were consistent with parents’ perceptions. Children born preterm perceived themselves to be overall competent performers of everyday activities (Study III). They said they want to be active and do things, and that they want to be competent in the activities of everyday life (Study IV).

The results in relation to previous research

A number of studies have investigated children born preterm, as well as long-term outcomes in terms of neurodevelopment, cognition, behaviour and motor function (Aarnoudse-Moens, Weisglas-Kuperus, van Goudoever, & Oosterlaan, 2009; Bhutta et al., 2002; Hemgren & Persson, 2002; Mansson & Stjernqvist, 2014; Williams et al., 2010). Investigating everyday functioning as an outcome measure adds a perspective to this body of research. Guided by the ICF-CY model, the findings in the thesis are mainly related to previous studies focusing on a multidimensional perspective of everyday functioning, and less to studies investigating individual factors. Consistency with earlier research will be discussed below.

Sixteen children born preterm participated in the interview study, along with their parents, and the PEGS was used for data collection. The findings from the PEGS study revealed that parents’ perceptions of their children’s competence and independence in everyday activities were not entirely consistent with earlier studies (Maggi et al., 2014; Palta et al., 2000; Sullivan & Msall, 2007). In the present study, the parents perceived the children to be competent overall in self-care activities, school productivity and leisure activities, as did the children themselves. In self-care activities, the children needed
assistance with tying shoelaces, fastening small buttons and putting on certain clothes, but they were perceived as fast and generally independent dressers. The children were also perceived almost independent in toileting and showering, more or less needing only verbal instructions and reminders. Studies using the PEDI have found that children born preterm perform worse in self-care activities and need more assistance, e.g. in dressing, bathing and toileting, than FT children (Maggi et al., 2014; Palta et al., 2000; Sullivan & Msall, 2007). Differences in findings may rely on variations in inclusion criteria, such as assessments being done at earlier ages. For example, children were 4-5 years old and had a lower mean gestational age (mean GA approx. 29 weeks) in the earlier studies.

In a meta-analysis which included 14 studies with children born preterm, with mean ages 5–17, the children showed lower academic performance in mathematics, spelling and reading than full-term controls (Aarnoudse-Moens et al., 2009). All of these studies were based on clinical assessments, in contrast to the PEGS study which is based on parent and child assessments. Caution must be observed in the interpretation of the results because of the limited study sample, still it can be of value to relate to previous studies. The children in Study III were perceived good at printing their name, and their knowledge in reading varied from children just starting to put letters together to children reading books. Although the item involving numbers was removed, some children mentioned mathematics on the blank cards as an activity they were good at. According to the Swedish school curriculum, these children had not yet begun compulsory education, so their abilities and skills in reading, spelling and mathematics were hard to assess. Moreover, the measurements are not quite comparable, as all items in the PEGS feature motor functions rather than performance which is dependent on cognitive functions. Mean scores for school productivity in the present sample were just below an Israeli sample of children with DCD (Engel-Yeger & Hanna Kasis, 2010), where motor deficiencies were prominent, but above a sample of British children with DCD (Dunford, Missiuna, Street, & Sibert, 2005). The variations in findings may be due to a cultural difference in parents’ perceptions of children’s competence, including the school curriculum and the prevailing view of young children in terms of their development and learning.

Being active in leisure activities was seen as an important and meaningful everyday life situation in this thesis (Study IV). The children said they were good at the activities they were involved in, and they expressed a desire to improve in these activities. On average in the PEGS study, the children perceived themselves to be competent in all leisure activities except for skipping
and ball games with racquets and sticks. Rated with the PSQ (Study I), the VPT children had lower mean scores in motor skills than the LPT and FT children. However, compared to their scores in process and communication skills, mean motor-skill scores were higher. There was no difference in motor skills between the LPT and the FT children, which may be an influential factor in the findings of the PEGS study, as the sample included 12 of 16 LPT children. Other factors may include the exclusion of children with disabilities from the study and the children’s age at data collection.

In earlier studies, children born preterm were found to have impaired mobility and motor function (de Kieviet et al., 2009; Hemgren & Persson, 2002; Palta et al., 2000; Verkerk et al., 2013; Williams et al., 2010). In parents’ reports using the PEDI, disabilities in the mobility domain were most frequent, and affected about one-fifth of the children (Palta et al., 2000; Verkerk et al., 2013). However, the children were rated quite independent in terms of mobility, and did not require assistance from their parents in performing the activities (Verkerk et al., 2013). It has been suggested that children born preterm perform motor activities more slowly than children born full-term (Williams et al., 2010), and may be affected by coordination problems (Hemgren & Persson, 2002). In the present studies it was found that motor skills were rated higher than the other variables in the VPT, LPT and FT children. In the wEFmp cluster, the deficiencies in motor skills were accompanied by overall weak everyday functioning. Moreover, in the wEFmp cluster, the mean GA was 37.1 weeks, i.e. predominantly involving children born FT. The deficiencies in motor skills in the wEFmp cluster may be due to confounding factors beyond control in the study. On the other hand, these varied findings indicate that no single factor is decisive in terms of everyday functioning, and an interaction between several factors is more relevant.

Low levels of process skills were found in the clusters of children who had overall weak everyday functioning. Process skills involve the ability to initiate, maintain and complete an activity, more specifically organising the steps in an activity in the right order, using appropriate tools, seeking help and learning from mistakes (AOTA, 2002; Bart et al., 2010). As described in the SDQ, hyperactivity involves restlessness, over-activity, difficulties in sitting still, deficiencies in maintaining focus and attention, and acting before thinking. It could therefore be argued that process skills and hyperactivity are opposite concepts. In Study I, the statistical analysis between process skills and hyperactivity showed a correlation between the factors. No multicollinearity was found, so it can be assumed that the concepts were not measuring the same underlying construct. In three clusters in Study II, children with high levels of
hyperactivity had weak process skills. It is likely that hyperactivity affects the development of process skills, e.g. the ability to maintain focus. However, two clusters presented other patterns: in the fsEFhcp cluster with overall strong everyday functioning and process skills, despite having hyperactivity problems. In the second cluster (wEFmp), the hyperactivity items were rated on level with total mean however the children were perceived with poor process skills. Hence, hyperactivity is probably not the sole predictor for process skills, which the patterns in the two clusters demonstrated, indicating that more factors are interacting.

Process skills have been defined as the behavioural aspect of executive functioning (Rosenberg, 2015). Deficiencies in executive functions have been connected with children born preterm (Mulder, Pitchford, Hagger, & Marlow, 2009). It is possible that children who also have poor executive functions are included in the weak everyday functioning clusters with weak process skills. In other studies, process skills have been related to participation (Liberman et al., 2013; Rosenberg, 2015). In fact, process skills have been found to be the main predictor of child independence, child enjoyment and parental satisfaction with a child’s performance, as measures of participation (Liberman et al., 2013). Process skills, along with self-perceptions of competence, contribute to child independence (Rosenberg et al., 2011). For the parents in the PEGS Study III, children’s independence was an important goal. The parents supported their children by structuring the daily routine, with instructions and reminders, and by providing clothes or cutlery adapted for children. Although process skills were not part of the aim of Study III, some parents stated that their children needed structure and reminders, that they had difficulties in completing an activity, and that they were disorganised. Delays in the development of process skills may be one explanation for these difficulties.

Most children in Study III said they most often played with friends. Their parents agreed, and some parents described their children as having an open and sociable disposition. Significant others played a prominent role in the descriptions of meaningful everyday life situations. Significant others were important in terms of feeling safe and loved, but also in terms of doing things with them. Playing games with friends or siblings was often mentioned, e.g. pretending to have a certain profession or playing at families. The LPT and VPT children who were involved in Studies I and II were perceived by their parents to have communication skills in line with FT children, but the VPT children did not display an interaction pattern in line with LPT or FT children. These results are in accordance with other studies. For instance, in a Dutch study, none of the children had disabilities in terms of social function (Verkerk
et al., 2013), where in other studies they have demonstrated these disabilities
(Killeen et al., 2015; Killeen, Shiel, Law, Segurado, & O’Donovan, 2015; Palta et al., 2000). In a study of 10-11 year-olds, the children had communication skills in line with FT but had lower scores on socialisation, and on play and leisure (Fjortoft et al., 2015). There are some differences in the measurements used in this thesis, in that the PSQ measures communication skills within a broad perspective. Parents were asked to rate their children’s skills in communicating with both their parent and other people, and parents were asked about their children’s gestures, expressions and respect for rules. The InteractQ measures the pattern of close interaction between the child and the parent, which could explain the differences in findings.

In previous studies, children born preterm have shown deficiencies in long-term outcomes such as motor function (Hemgren & Persson, 2002; Williams et al., 2010), cognition (Bhutta et al., 2002), and school achievements (Aarnoudse-Moens et al., 2011; Taylor et al., 2009). The children born preterm have a higher prevalence of behavioural problems than children born FT (Anderson & Doyle, 2003; Bhutta et al., 2002; Mansson et al., 2014). The results in this thesis presented a similar picture in the analyses comparing the VPT, LPT and FT children based on group means. However, the main results in this thesis indicated that most children born preterm were perceived with overall strong everyday functioning. Clinical assessments of children’s performances and interaction was not included in the studies which may be considered a limitation in the thesis. In line with the bioecological theory, everyday functioning is what happens in the natural setting and consequently parents, who see their child in the many natural settings and as the child grows and develops, are those who can contribute with a comprehensive description of the child’s functioning (Glascoe & Dworkin, 1995; Wilson, Kaplan, Crawford, Campbell, & Dewey, 2000). Thus, children’s everyday functioning is a research area of its own not possible to assess by clinical assessments. Furthermore, along with the definition of everyday functioning in this thesis, children’s functioning involves the interaction with others (Vohr & Msall, 1997). The children’s functioning is the result of own skills, behaviours and interaction patterns but is also dependent on parents’ interaction and adaptive behaviour towards the child (Kadlec, Coster, Tickle-Degnen, & Beeghly, 2005). What characterises strong or weak everyday functioning depends on the perceptions of the interaction outcome and the specific “norms” in the child’s microsystem.
Findings in relation to the theoretical and conceptual frameworks

The core concepts in the bioecological system theory of human development are manifested in the Process-Person-Context-Time model and in the structure of the nested systems (Bronfenbrenner & Morris, 2006). The assumptions underlying bioecological theory involve a view of human beings as active actors who take part in their own context. As actors, people have an incentive to develop, whether this development is negative or positive. It is also assumed that interaction with others is necessary for development. The bioecological system theory was used in this thesis as an ontological perspective of children’s development. The underlying assumption was that children’s development is driven by the proximal processes in the microsystem. The studies in the thesis had cross-sectional designs, which explored developmental outcomes at a particular point in time. Children of five-six years were included. This is a delicate age involving transition from home to a broader social context, which places increased demands on children (Bronfenbrenner & Morris, 2006). Deficiencies in everyday functioning may therefore be evident at these ages in children with perinatal risk factors (Spittle & Orton, 2014).

The Process-Person-Context-Time model and the concept of nested systems were both central to the thesis. Everyday functioning is by definition context-bound, as it reflects children’s developmental outcomes in everyday life. Thus, the research reflected what happens in children’s immediate context, the microsystem. The thesis focused on proximal processes, in particular between the children and their parents. The outcomes of the proximal processes are reflected particularly in the InteractQ, in which parents were asked to rate the interaction pattern between themselves and their child, including both child-initiated and parent-initiated interaction. In addition, examples of proximal processes are presented in the PEGS study (Study III). Parents noted that they supported their children’s development by encouraging them to be active, by letting them try new activities and by making increased demands. Preterm birth may have a negative influence on the proximal processes in that parents’ concerns and negative experiences in the neonatal period influence parental behaviour in terms of interaction (Hoffenkamp et al., 2015). In accordance with bioecological theories (Bronfenbrenner, 1989), skills for everyday life are related to a mother’s early stimulation and maternal directiveness, e.g. explicit instructions and maternal expectations for a child’s development (Dieterich, Hebert, Landry, Swank, & Smith, 2004). Although most
parents in Study III were unconcerned that their children’s birth had been pre-term, they said that they provided daily structure, encouraged their children to try and practise and quietly urged them to be independent.

The child’s characteristics were the focus of all four studies, i.e. perinatal characteristics, behaviour and outcomes in terms of performance skills, interaction patterns with parents, and other people e.g. grandparents, siblings and friends. The children said they acted in several microsystems, e.g. at home, at school, at the swimming pool or the sports arena and in the playground, which contributed to child development in a number of ways. Meaningful everyday life situations involve e.g. playing games, riding bikes, playing on swings and climbing trees. The children indicated that being in different settings or microsystems creates enthusiasm for development and improving their skills. A guiding principle in the thesis involved describing everyday life situations as natural learning opportunities (Dunst et al., 2000). In everyday life, specific situations appear on a regular basis, and often with increasing complexity. In the studies by Dunst and colleagues (2000, 2001, 2002), eleven different family and community activities were identified as learning opportunities (Dunst et al., 2000). Study III only included items from four of the family activities and three of the community activities described by Dunst et al. (2000), which is a limitation of the study. There is a risk that valuable information about children’s competence in important everyday life situations was not identified. Study IV provided three additional family activities which children identified as important, but they did not identify family activity involving child routines like self-care as an important activity setting. The findings from the two studies link to the child perspective–child’s perspective continuum, which means that in order to explore everyday functioning as a whole it is necessary to include both children and their parents as informants (Nilsson et al., 2015).

Socioeconomic aspects have an impact on proximal processes and on children’s development in the microsystem. Our findings showed that mean maternal age in the VPT group was lower than in the FT group, but no other socioeconomic differences were found. However, the findings may be biased by the difference between the participants and the non-respondents (the drop-outs), as the latter included more parents with foreign citizenship.

The children listed an array of activities they perceived meaningful and funny, and which they enjoyed doing. They said they performed these activities often or wanted to do them often. They also said they were good at the activities and wanted to improve their skills. This description is in accordance with the model of activity settings: children’s learning and development is promoted when they are engaged in activities and interaction which provide
opportunities to perform and practise skills, and which lead to mastering these skills (Dunst et al., 2001).

The results of Studies III and IV indicate that the association between children’s competence and their meaningful everyday life situations is not entirely clear. However, doing arts and crafts, drawing and painting, playing board or computer games and role play, e.g. playing mother-father-child, were activities mentioned as meaningful, and children were perceived competent in them. In studies I and II, children in the VPT, LPT and FT groups were perceived most competent in motor skills measured with the PSQ. Assuming that doing things is strongly connected to meaningful everyday life situations for children, motor skills are probably a strengthening factor. Thus, the total results add to the validity of the model of activity settings (Dunst et al., 2001; Dunst et al., 2000). Given that the two clusters of children displaying a pattern of everyday functioning featuring poor motor skills (Study II), further research is needed to identify development-enhancing factors for these groups. One way could be to build on children’s own statements of what they perceived meaningful situations, and to use their interests to encourage them to engage more in activities and interactions that provide opportunities to learn and master new skills (Dunst et al., 2001).

The concept of everyday functioning was based on the OTPF. This describes performance in everyday life which is dependent on performance skills and performance patterns (AOTA, 2002). The children’s performance skills were investigated in Studies I-III. The PSQ is explicitly based on the OTPF, which measures performance skills in the areas of motor skills, process skills and communication skills (Bart et al., 2010). The children’s performance patterns were the focus of Study IV, which investigated everyday life situations. The concepts ‘performance skills’ and ‘performance patterns’ are in line with the bioecological system theory, which sees the child as an active individual who contributes to his/her own development through interests and motivation (AOTA, 2002; Bronfenbrenner, 1989). The children in the thesis perceived themselves as actors. They were aware of their skills and had opinions about how to improve them. They also described their performance patterns as activities they usually performed (routines), for example their roles in play or helping out with household tasks. Routines for these children involved recurrent activities, such as playing with friends at school or activities with grandparents, e.g. a daily walk or sports activity carried out on a weekly basis. Performance skills are dependent on the interaction between the person, the activity and the context, and involve the situations which take place in everyday life, in the child’s close context, the microsystem. Consequently, measuring
performance skills and performance patterns is in accordance with the perspective on child development described in bioecological system theory.

Method discussion
To capture the overall and specific aims of the studies in this thesis, both quantitative and qualitative methods were used. The following section will discuss the strengths and limitations of the design and methods.

As discussed above, the four studies had cross-sectional designs. Consequently, the opportunity to draw conclusions about the children’s development was limited, as this would have required a longitudinal study design. Using both quantitative and qualitative designs, everyday functioning was explored from a variety of perspectives. Most studies are based on a variable-oriented approach, in that single variables e.g. risk factors and health issues are investigated with regard to a developmental outcome (L. Bergman et al., 2003). The use of a person-oriented approach (Study II) clarified the understanding of how interrelated variables influence the outcome. The person-oriented approach provided information about individual similarities and differences which form the patterns of everyday functioning, and which could be true for children born both preterm and full-term.

Including a population-based sample in the project was a strength, as it minimised selection bias. In the first two studies, the participants were recruited from two county council areas, and in Study III from one county council area in the middle of Sweden. In each county council area, about 3000 children were born in both 2008 and 2010, including approximately 1% children born ≤ 32 weeks of gestation and 5% born between 33 and 36 weeks of gestation. The proportions of children born preterm in the two counties were considered representative of the population of children born preterm in Sweden (National Board of Health and Welfare, 2014). However, the high dropout rate in all studies made it difficult to generalise the findings. Although the sample did not differ from the drop-out group in terms of parents’ gender or family residence, the sample may not have been fully representative. For example the proportion of parents with foreign citizenship was larger among the non-respondents. No data were available on perinatal anthropology or neonatal morbidities, or on long-term sequelae such as neurological, neuropsychiatric or other disabilities, which may have biased the results in Studies I and II.
Using registry data to achieve the aims of the thesis had strengths and limitations. The SMBR, SNQ and SCB collect extensive data on perinatal characteristics, neonatal morbidities and sociodemographic factors. However, the researcher had limited opportunities to control the data collection, and had to rely on the quality of the registers. Furthermore, the aim of the registers may not be compatible with the aim of the research. Collecting data from national registers in Sweden is an expensive procedure which, for reasons of confidentiality, is very time-consuming. Nevertheless, collecting data from registers was a convenient way of accessing a large amount of data and specifically data on children born preterm.

To explore everyday functioning as a multidimensional concept, the ICF-CY was used as a framework for selecting data collection methods. The data collection methods contributed to a broad perspective of everyday functioning. The four studies included five different measurements (registry data, PSQ, InteractQ, SDQ and PEGS) and covered the ICF-CY components ‘body function’, ‘activity’ and ‘participation’. However, there was a preponderance of items in the questionnaires related to activity competence and the activity component of the ICF-CY. These questionnaires did not cover the ICF-CY environmental component, which may have limited comprehensive coverage of everyday functioning. However, in Studies III and IV, environmental factors were included in parents’ descriptions of how they supported their children in everyday activities, and in children’s descriptions of meaningful everyday situations. Study II investigated sociodemographic data as part of the component ‘environmental factors’.

The measurements used in the project involved four parent reports and one self-report used for the children in Study III. Although parents have been reported to rate their children higher than clinicians, parents are nevertheless likely to have a rich source of information about everyday life situations, as they see their children in different settings over time and throughout their developmental stages (Glascoe & Dworkin, 1995; Wilson et al., 2000). Exploring everyday functioning requires an ecological perspective, i.e. exploring children’s functioning in their natural setting. The ecological perspective acknowledges multidimensional interaction between the ICF-CY components, including environmental factors (Simeonsson et al., 2003). Including parents as informants is therefore crucial, and is a strength of this thesis.

The PSQ was developed to measure parents’ perceptions of their children’s performance skills. The PSQ has mainly been used in typically developed children and to investigate the impact of DCD (Bart, Jarus, Erez, & Rosenberg, 2011; Bart et al., 2010; Liberman et al., 2013; Rosenberg, 2015; Rosenberg et
al., 2011). It is not entirely possible to determine the present study’s consistency with other studies which have used e.g. the PEDI as the instruments have diverse measurement perspectives (Bart et al., 2010; Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992). However, the PSQ is not culture-bound. It is feasible without verbal instructions and contributes to a qualitative aspect of performance which has not been examined in children born preterm. Although the PSQ is a criterion-related instrument, it was developed for 4–6 year-old children. There is a risk of a possible ceiling effect, as the children in the studies were six years old. The PSQ measures skills a child uses in an everyday life situation and as such, has a perspective on the child’s activity competence. As described in the fPRC model, activity competence is an intrinsic person factor which both influences and is influenced by children’s participation (Imms et al., 2017).

The SDQ is a commonly-used questionnaire which has been translated into Swedish and into a Swedish context, and its psychometric properties have been well investigated. The SDQ has been used in earlier research with children born preterm (Arpi & Ferrari, 2013; Elgen et al., 2012) and has contributed with important aspects of both positive and negative behaviour to the present studies.

The PEGS is a self-reporting instrument for use in interviews with young children (Missiuna, Pollock, Law, Walter, & Cavey, 2006). The benefit of the PEGS is that it facilitates the interviews by providing a common focus on the pictorial cards. The PEGS was developed to obtain the child’s perspective of perceived competence and to set goals for interventions. A disadvantage is the limited number of activities or items included. The fact that the activities are predetermined may have had a limiting effect on the children’s descriptions of their competence. Moreover, we do not know if the activities in the PEGS were perceived meaningful for the children, and consequently the child’s perspective could not be fully explored. In the PEGS interviews, supplementary questions were encouraged in terms of each activity, and the added information contributed some additional data. On the other hand, these supplementary questions extended the interviews and therefore challenged the children’s endurance and attention-span. Adding the PEGS parents’ questionnaire and an interview question about parents’ support to their children contributed to a comprehensive picture of children’s competence and independence in everyday activities, from both the child’s and the parents’ perspective.

Using photographs to elicit interviews with the children in Study IV balanced the power relationship between the child and the researcher. The
children were invited to participate by taking photos of their meaningful everyday life situations. Instructions were given both verbally and in written form. The children were informed that they themselves could decide what to photograph, but it was not possible for the research group to control this. Hindrances such as illness in the family meant that the period between the children taking the photographs and being interviewed exceeded two weeks. Hence, there was a risk that the children forgot why they had taken the photos and which everyday life situation they wanted to describe. On the other hand, the photographs served as reminders, and the children chose what and how much they wanted to describe. In studies III and IV, children’s and parents’ interviews were analysed using qualitative content analysis as described by Elo and Kyngäs (2008). In this description the text is analysed answering the “what” and the “how” simultaneously. This method was particularly convenient in these interviews where each item in the PEGS and each photograph formed short parts of the interviews. During the analysing process, there was a risk of losing the child’s perspective in the analysis of interview data. To minimise this risk, the interpretation and the descriptions remained close to the text, and as far as possible the children’s own words were used.

The thesis moved from a child perspective towards the child’s perspective across the four studies. Parents provided extensive information about their children in well-validated questionnaires. In Study III, using the PEGS was a step towards the child’s perspective, though predetermined questions were included, and this limited the opportunities for the children to express perceptions from their own perspective. A balance also had to be struck between posing further questions to elicit a child’s perspective and risking tiring the children out, which in turn risked not completing the questionnaire. To leave enough space for the children’s descriptions, a dichotomised scale can be used and there can be a break in the interview. In addition, the blank cards should be discussed openly and with interest.

In Study IV, the children were encouraged to contribute their own perspective of meaningful everyday life situations. Although there were some limitations, the study provided information about the children’s perceptions and thoughts on what they consider meaningful in their lives. This information may be particularly valuable in supporting children with deficiencies in everyday functioning. The four studies also contributed information about the intrinsic person-related factors ‘activity competence’, ‘sense of self’ and ‘preferences’ described in the fPRC (Imms et al., 2017), and therefore came closer to an understanding of how children participate.
Conclusions

The overall findings of the thesis are encouraging. Most children born pre-term are perceived by themselves and by their parents to function well in their everyday life situations. The findings indicate that perinatal factors and risk factors associated with preterm birth are not the sole predictors of everyday functioning. More critical is possibly the interaction between biological, behavioural and contextual factors. Children born preterm are at particular risk in groups of children with weak everyday functioning and behavioural problems. Young children are able to contribute information about how they function in everyday life. They have strong motivation to be active in their context and to improve their skills and interaction patterns.

Implications for future research

The findings of the thesis raise several questions with implications for future research. They show that everyday functioning is a result of the interaction between several factors involving children and their context. This interactional effect on everyday functioning was seen in the quantitative findings as well as in the qualitative ones, and from both the parents’ and the child’s perspective. However, the findings are based on cross-sectional studies, and longitudinal research is warranted for an increased understanding of the processes involved in the development of everyday functioning.

In the first two studies, a relationship became apparent between behavioural problems, in particular hyperactivity, and everyday functioning. We saw a relation between hyperactivity and process skills, which raises questions about how these factors interact with each other, with other factors and within the context of everyday life. This issue is worthy of further exploration, and may be of significance for interventions which aim to support parents in terms of parenting.

In Study IV, the children expressed the importance of being in doing, and they expressed a will to develop and improve their skills. Children’s motivation to learn and improve, along with what they think is important for everyday life, is an essential perspective for future research.
Svensk sammanfattning

Vardagslivet består, för de flesta sex-åriga barn, av en mängd situationer och aktiviteter som ofta är komplexa i sin natur t.ex. lek utomhus med kompisar, middag med familjen, simskola och TV-spel med syskon. För att fungera i dessa situationer behöver barn utveckla färdigheter, anpassade för aktiviteten och för miljön där vardags situationen äger rum. Barn behöver också fungera i interaktion med andra och uppfylla de sociala roller som förväntas utifrån ålder, mognad, social och kulturell miljö. Barn födda för tidigt har i ett flertal studier visat ökad risk för kognitiva och motoriska svårigheter och beteendeproblem vilka kan ha betydelse för vardagsfungerandet.

Det övergripande syftet med avhandlingen var att undersöka vardagsfungerande hos sex-åriga barn födda för tidigt. Avhandlingen inkluderade studier om föräldrars uppfattningar om sina barns vardagsfungerande, samband mellan riskfaktorer förknippade med för tidig födsel och vardagsfungerande (studie I), mönster av vardagsfungerande (studie II), barnens uppfattningar om egen kompetens i vardagsaktiviteter (studie III), samt barnens uppfattningar och beskrivningar av betydelsefulla vardagssituationer (studie IV). Genom insamling av data från nationella register, föräldraenkäter, ett bildbasert intervjuverktyg samt intervjuer utifrån barnens egna fotografier rörde sig avhandlingen från ett gruppbaserat perspektiv till ett individbaserat perspektiv och från ett barnperspektiv till barnets perspektiv. Totalt deltog 144 barn födda för tidigt, 222 barn födda i fullgången tid och barnens föräldrar.

Resultaten visade att de flesta föräldrar uppfattade att deras barn hade ett gott vardagsfungerande, med goda färdigheter i motorik, kommunikation och interaktion med andra och med små beteendeproblem. De barn som var mycket för tidigt födda, uppfattades ha mer svårigheter i sitt vardagsfungerande jämfört med de fullgången födda. Trots det visade resultaten att för tidig födsel har mindre betydelse för barns vardagsfungerande än beteendeproblem såsom hyperaktivitet. Barn födda för tidigt och barn födda i fullgången tid fanns representerade i de sju identifierade variationsmönster av vardagsfungerande, de flesta barn med mönster av starkt vardagsfungerande. Ett mindre antal, både barn födda för tidigt och barn födda i fullgången tid,
uppvisade mönster av svagt vardagsfungerande. Trots att olika faktorer (färdigheter, beteende, förmåga att interagera) var framträdande i mönstren, är det troligt att det är interaktionen mellan de olika faktorerna som är avgörande för barns vardagsfungerande. De barn födda för tidigt som deltog i en utav studierna, beskriver sig själva som skickliga i de flesta vardagsaktiviteter. Barnen uttryckte att betydelsefulla vardagssituationer är att göra saker, själv eller med andra och på olika platser. Barnen beskrev också vikten av ha ändamålssägna färdigheter och att ha personer eller husdjur att vara med och känna sig älskad av. De uttryckte längtan efter att få göra mer saker, få lära sig nya färdigheter och bli skickligare i andra. Resultaten i avhandlingen visar att också vardagsfungerande bör inkluderas i uppföljningen av barn födda för tidigt och omfatta riskfaktorer så väl som beteende- och omgivningsfaktorer. Förskolebarn födda för tidigt har förmågan att reflektera över sitt eget fungerande och kan uttrycka behov och önskningar för att vara delaktiga i vardagssituationer, därför bör även unga barn tillfrågas och inkluderas i planering av kliniska insatser som rör deras vardagsliv.
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