

School of Health Sciences, Jönköping University

Children with profound intellectual and  
multiple disabilities and their participation in  
family activities

Anna Karin Axelsson



SCHOOL OF  
HEALTH SCIENCES  
JÖNKÖPING UNIVERSITY

DISSERTATION SERIES NO. 49, 2014  
DISSERTATION SERIES NO. 61, 2014

JÖNKÖPING 2014

© Anna Karin Axelsson, 2014

Publisher: School of Health Sciences  
Print: Ineko AB, Göteborg

ISSN 1654-3602  
ISBN 978-91-85835-48-5





# Abstract

*Background.* Families are essential parts of any community and throughout childhood one's family serves as the central setting wherein opportunities for participation are offered. There is a lack of knowledge about participation of children with profound intellectual and multiple disabilities (PIMD) in family activities and how improved participation can be reached. Gathering such knowledge could enable an improvement in child functioning and well-being and also ease everyday life for families of a child with PIMD.

*Aim.* The overall aim of this thesis was to explore participation seen as presence and engagement in family activities in children with PIMD and to find strategies that might facilitate this participation.

*Material and Methods.* The research was cross-sectional and conducted with descriptive, explorative designs. First a quantitative, comparative design was used including questionnaire data from 60 families with a child with PIMD and 107 families with children with typical development (TD) (I, II). Following that, a qualitative, inductive design was used with data from individual interviews with parents of 11 children with PIMD and nine hired external personal assistants (III). Finally a mixed method design was conducted where collected quantitative data was combined with the qualitative data from the previous studies (IV).

*Results.* It was found that children with PIMD participated less often, compared to children with TD, in a large number of family activities, however they participated more often in four physically less demanding activities. Children with PIMD also participated in a less diverse set of activities. Additionally, they overall had a lower level of engagement in the activities; however, both groups of children showed higher engagement in enjoyable, child-driven activities and lower engagement in routine activities. The motor ability of the child with PIMD was found to be the main child characteristic that affected their presence in the family activities negatively and child cognition was found to be the personal characteristic that affected their engagement in the activities. The child's presence and engagement were influenced to a lesser extent by family socio-economic factors when compared to families with children with TD. Parents and hired external personal assistants described several strategies to be used to improve

participation of the children with PIMD, such as by showing engagement in the activities oneself and by giving the child opportunities to influence the activities. The role of the hired external personal assistant, often considered as a family member for the child, was described as twofold: one supporting or reinforcing role in relation to the child and one balancing role in relation to the parents/the rest of the family, including reducing the experience of being burdened and showing sensitivity to family life and privacy.

*Conclusion.* A child with PIMD affects the family's functioning and the family's functioning affects the child. Child and environmental factors can act as barriers that have the result that children with PIMD may experience fewer and less varied activities that can generate engaged interaction within family activities than children with TD do. Accordingly, an awareness and knowledge of facilitating strategies for improved participation in family activities is imperative. There needs to be someone in the child's environment who sets the scene/stage and facilitates the activity so as to increase presence and engagement in proximal processes based on the child's needs. The family, in turn, needs someone who can provide respite to obtain balance in the family system. External personal assistance includes these dual roles and is of importance in families with a child with PIMD.

# Original papers

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

## Paper I

Axelsson, A.K. & Wilder J. (2014). Frequency of occurrence and child presence in family activities: a comparative study of children with profound intellectual and multiple disabilities and children with typical development. *International Journal of Developmental Disabilities*, 60(1), 13-25

## Paper II

Axelsson, A.K., Granlund, M. & Wilder, J. (2013). Engagement in family activities: a quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development. *Child: Care Health and Development*, 39(4) 523–534

## Paper III

Axelsson, A.K., Imms, C. & Wilder, J. Strategies that facilitate participation in family activities of children with profound intellectual and multiple disabilities: parents' and personal assistants' experiences. *Disability and Rehabilitation*. Published online before print March 4, 2014, doi: 10.3109/09638288.2014.895058

## Paper IV

Axelsson, A.K. The role of the external personal assistant for children with profound intellectual and multiple disabilities working in the children's home. (submitted).

(The articles have been reprinted with the kind permission of the respective journals).

# Contents

<b>Abstract</b> .....	<b>5</b>
<b>Original papers</b> .....	<b>7</b>
Paper I.....	7
Paper II.....	7
Paper III.....	7
Paper IV.....	7
<b>Contents</b> .....	<b>8</b>
<b>Acknowledgements</b> .....	<b>10</b>
<b>Definitions</b> .....	<b>12</b>
<b>Abbreviations</b> .....	<b>13</b>
<b>Introduction</b> .....	<b>15</b>
<b>Background</b> .....	<b>17</b>
Children with profound intellectual and multiple disabilities.....	17
The family.....	18
Natural learning opportunities.....	18
Personal assistance.....	19
Participation.....	21
The concept of participation.....	21
Influences on participation.....	23
<b>Rationale</b> .....	<b>25</b>
<b>Aims of the thesis</b> .....	<b>26</b>
Specific aims of study I – study IV.....	26
Research questions for the synthesis of studies I-IV.....	26
<b>Materials and Methods</b> .....	<b>28</b>
Research design.....	28
Sample and procedure.....	28
Study I and study II.....	28
Study III.....	32
Study IV.....	34
Instruments.....	34
Child-PFA questionnaire.....	34

The interview guide.....	40
Data Analyses.....	42
Study I and study II.....	42
Study III.....	43
Study IV.....	43
Ethical considerations.....	45
<b>Results .....</b>	<b>48</b>
The actual participation of children with PIMD.....	48
Potential influences on child participation .....	53
<b>Discussion.....</b>	<b>63</b>
Discussion of results.....	63
The actual participation of children with PIMD.....	63
Potential influences on child participation .....	65
The time aspect.....	71
Methodological considerations.....	72
Choice of scientific approach .....	72
Choice of design.....	73
Participants.....	74
The Child-PFA questionnaire.....	75
The procedure and analysis .....	77
<b>Conclusions .....</b>	<b>80</b>
<b>Implications.....</b>	<b>82</b>
<b>Summary in Swedish.....</b>	<b>83</b>
<b>Svensk sammanfattning.....</b>	<b>83</b>
Barn med omfattande funktionsnedsättningar och deras delaktighet i familjeaktiviteter .....	83
<b>References .....</b>	<b>86</b>
<b>Appendix .....</b>	<b>97</b>

# Acknowledgements

First of all I would like to thank all the families that took time and energy to provide information about their family life, I would especially like to thank the parents and personal assistants who have shared their experiences and knowledge with me in the interviews. I would also like to thank Arvsfonden for financing the project on which the research is based and Stiftelsen Sävstaholm for funding the completion of my research. Additionally, thanks are due to the assistance company JAG for being part of the project and to the disability organizations FUB and RBU for their contributions.

There are also quite a few other persons that I am extremely grateful to - without your support and patience it would not have been possible to accomplish this thesis!

Professor Mats Granlund, my main supervisor, thank you for letting me be a part of your team and for guiding me with your excellent knowledge in the field! Jenny Wilder, PhD, my supervisor and the project leader, I am impressed by your courage and I am very thankful that you made me take these steps. Thank you for your support! Professor Christine Imms, my Australian supervisor. You possess such thoughtful, wise ideas and your way of communicating these has been terrific. Thank you!

Maria Kouns, my close friend since childhood who will, in a few months, obtain her PhD. I would never have achieved this without your support and all our discussions. Thank you for your friendship!

My travel companions, Lennart Christensson, Marie Golsäter and Ylva Ståhl. Thank you for the discussions and for sharing your professional knowledge on the railroads! Thanks also to Gunilla Brushammar, Joachim Göransson-Hill, Eleonor Fransson and Lilly Augustine for being there when needed.

The CHILD research group: you are such nice people! Thank you for your encouraging kindness and for reading and commenting my drafts. Special thanks to Margareta Adolfsson for the good talks we have had and for

suggestions to improve the final text, to Laura Daisy and Taylor Boren for your support in English and not least to CHILD's skilled research coordinator Cecilia Allegrind.

The Research School of Health and Welfare. Special thanks to Professor Bengt Fridlund and coordinator Paula Lernestal-Da Silva for good leadership. Also thanks to the SIDR PhD students Frida Lygnegård, Lina Magnusson, Lena Olsson, Johanna Norderyd and to Berit Björkman and everyone else for your friendship and encouraging attitude. You have meant a lot to me!

The Center for Habilitation Services in Jönköping. Thank you for supporting my decision to make this journey!

Last but most of all, my husband Per and our daughters Linnéa, Hanna and Petra. I hope you know that you are very special to me - you are in every way my most important micro system! Thank you for your patience over these years, I will be more present and engaged in family life from now on!

Jönköping 31/3 2014,  
*Anna Karin Axelsson*

# Definitions

*In this thesis:*

- Children: Children are defined as under 20 years of age. According to the Convention on the Rights of the Child, a child is a human being below the age of 18. However, in this thesis young people aged 18-20 will also be referred to as children.
- Child functioning: A child's physical, social and psychological functioning in the context of the family system. Functioning encompasses body functions, activities and participation. Child functioning is dependent on interactions with the family or other caregivers in the close environment.
- Family activities: Activities taking place in the family, something that the family does together in everyday life when two or more family members take part.
- Participation: Participation is defined as, firstly, physically being there/being present and, secondly, degree of engagement when being there. Participation in an activity is only possible if the activity occurs and is offered to the child.
- Profound intellectual and multiple disabilities (PIMD): Intellectual disabilities that are combined with profound physical disabilities, sensory impairments and commonly medical complications resulting in the children being heavily dependent on others.
- Typical development: Children that develop in typical ways, children without a diagnosis.

# Abbreviations

## *Frequently used abbreviations*

CAPE	Children's Assessment of Participation and Enjoyment
Child-PFA	Child Participation in Family Activities
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
FUB	The Swedish National Association for Persons with Intellectual Disabilities (Riksförbundet för utvecklingsstörda barn, ungdomar och vuxna)
ICF / ICF-CY	International Classification of Functioning, Disability and Health / version for Children and Youth
JAG	Equality, Assistance and Inclusion (Jämlikhet Assistans Gemenskap), a user cooperative
LSS	The Act Concerning Support and Services for Persons with Particular Functional Impairments (Lagen om Stöd och Service till vissa funktionshindrade)
PIMD	Profound Intellectual and Multiple Disabilities
RBU	The Swedish National Association for Disabled Children and Young People (Riksförbundet för Rörelsehindrade Barn och Ungdomar)
SFB	The Social Insurance Code (Socialförsäkringsbalken)
TD	Typical Development



# Introduction

Children have different resources for functioning in everyday life. This becomes apparent when working in habilitation services where I, as a physical therapist, have met a variety of children with disabilities and their families. These experiences, in particular those related to children with profound intellectual and multiple disabilities (PIMD) and their families, have had an impact on me. They have given me a curiosity for learning more in order to contribute to improved awareness and knowledge in the field.

There is agreement that participation in life situations is a prerequisite for a child's functioning, well-being and development as well as a goal in itself. The importance of participation for children is confirmed in the United Nations Convention on the Rights of the Child (CRC), Article 23:1, which states: "a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community" (United Nations General Assembly, 1989).

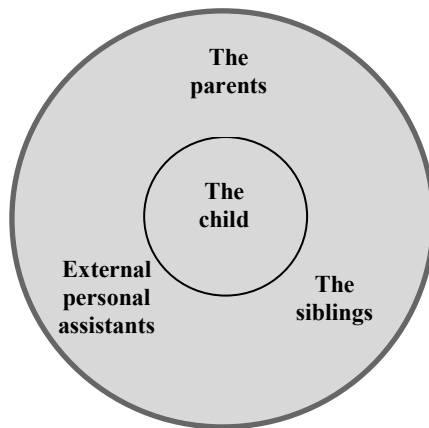
Families are essential parts of any community and throughout childhood one's family serves as the central setting wherein opportunities for participation are offered. Having a child with PIMD however challenges these opportunities. Under the terms of the Act concerning support and services for persons with particular functional impairments [Lagen om stöd och service till vissa funktionshindrade, LSS] (SFS 1993:387) and the Social Insurance Code [Socialförsäkringsbalken, SFB] (SFS 2010:110) in Sweden many families with a child with PIMD have personal assistance for their child. Personal assistance is meant to support both the participation of the child and to support the family (Government Bill 1992/93:159). In parallel with the parents, the external personal assistants play a major role in facilitating child participation in family activities. For a child with PIMD an external personal assistant is often considered a member of the child's family (Wilder, 2008).

Bronfenbrenner's bio-ecological model (1979) derived from systems theory (Bertalanffy, 1968) has served as the scientific framework for this doctoral

thesis. In this model the child's most immediate level of interaction, identified as the child's micro system, was defined as comprising the child's family and external personal assistants (Figure 1).

Although scientific studies have explored participation of children with PIMD in educational and societal settings, very little research has addressed children's participation explicitly in the home context. The intention in this thesis was to provide an exploration of these children's participation in family activities and to build evidence as to how participation can be best facilitated. In this, influencing factors acting as either facilitators or barriers to child participation in family activities such as child characteristics, frequency of offered family activities, family income, education of the mother and father, participation-facilitating strategies and the role of the personal assistant, will be explored.

**Figure 1.** The family, a microsystem in Bronfenbrenner's bio-ecological model (siblings are not studied in this research).



# Background

## Children with profound intellectual and multiple disabilities

A child is understood to have PIMD when intellectual impairments are combined with profound physical impairments, sensory impairments such as vision impairments and commonly medical complications. These make the child heavily dependent on others. Children with PIMD at the same time represent a heterogeneous group in terms of origin of impairments as well as in terms of their functional and behavioral range (Nakken & Vlaskamp, 2002, 2007). In addition, the children's level of alertness is important to their functioning (Munde, Vlaskamp, Ruijsenaars, & Nakken, 2009; Wilder, 2008). In Sweden children with PIMD, like other children, almost always grow up at home together with their biological family. They also attend preschool together with children with typical development (TD) and, thereafter, when they attend school, it is in general as part of a special class or a special school for children with disabilities.

Child functioning encompasses body functions, activities, participation and a child's individual characteristics. A child's individual characteristics are both a producer and a product of this functioning or, according to Bronfenbrenner (1999) and Sontag (1996), of the child's development. A child with PIMD, similarly to a child with TD, can be seen as a system under the influence of these personal characteristics, e.g. age, health, cognitive ability, and motor ability. All systems aim for stability and consequently disturbances provoke reactions in the systems to return to balance (Wachs, 2000). Such situations may emerge when a child with PIMD suffers medical complications, for example seizures. However, child functioning is not just influenced by the child's internal, personal characteristics but additionally by external influences at multiple levels of the child's ecology (Bronfenbrenner, 1995).

## The family

During childhood the family is the central and most important part of the child's ecology. A child cannot therefore be viewed as an isolated system but must be seen in the context of his or her family or micro system (Bronfenbrenner, 1986; Schalock, Fredericks, Dalke, & Alberto, 1994). In the micro system, the parts, i.e. the individuals, are connected and interdependent (Bronfenbrenner, 1979). Accordingly the position and roles of each part of the family must be considered in relation to the system as a whole (Nichols, 2000). As stated by Hanson and Lynch, a family is "a unit that defines itself as a family including individuals who are related by blood or marriage as well as those who have made a commitment to share their lives" (2004 p. 5). The family is influenced by personal factors of the family members, the cultural environment, socio economic status and the parents' educational levels (Bronfenbrenner, 1986). Like the child system, the family strives for self-stabilization wherein parents seek a balance between their personal desires for the family and what is possible given their circumstances. This includes the pursuit of keeping to daily routines, characterized as pursuit of "stability", which is necessary to achieve sustainability (Weisner, 2010).

## Natural learning opportunities

The family, as a social institution, provides a rich array of everyday activities within physical and social settings in which natural learning opportunities for children can be provided (Dunst et al., 2001). As explained by Spangola and Fieze (2007), everyday activities are made up of routines and rituals. Routines can be seen as regularly repeated practices, including the ordinary habits of the day, such as setting the table or going to bed. Collectively, routines provide a stable framework for everyday life and habits. Rituals, on the other hand, establish and perpetuate the understanding of what it means to be a member of the group and involve communication with a symbolic meaning. Rituals can be exemplified by annual birthday parties and celebrations such as graduation. There are likewise other

activities performed by the family which include play, social activities and outings.

These routines, rituals and the other family activities represent different activity settings. Dunst et al. (2001, p.70) describe an activity setting as a “situation specific experience, opportunity, or event that involves a child’s interaction with people, the physical environment, or both, that provides a context for a child to learn about his or her own abilities and capabilities as well as the propensities and proclivities of others”. Similarly, Gallimore, Goldenberg and Weisner (1993) describe the activity setting as the architecture of the child’s everyday life and context of his or her development. The activity settings in turn are primarily based on the family’s ecology, i.e. its resources and constraints as well as its culture (Weisner, 2002; Weisner, Bernheimer, & Coots, 1997).

Within the activity settings, proximal processes involve transfer of energy between the developing human being and the persons, objects and symbols in the child’s immediate environment (Bronfenbrenner & Evans, 2000).

These processes are by Bronfenbrenner (1993) defined as interactions which take place in an immediate external environment, on a fairly regular basis over an extended period of time, and could be exemplified by parent-child activities, play and the learning of new skills. The quality of proximal processes is of overriding importance for children’s well-being and development (Bronfenbrenner, 1993; G. King et al., 2003). According to Bronfenbrenner and Ceci (1994), the proximal processes can be said to be the engines of development while the characteristics of a person and context provide the fuel needed and do most of the steering. One such contextual factor unique to children with PIMD and their families is personal assistance.

## Personal assistance

The impairments and disabilities of children with PIMD can put stress on the family (Nichols, 2000) because of the resulting imbalance of energy in the family system. As a consequence of this, according to systems theory, there

is a quest for balance (Bertalanffy, 1968) and balance in the family system can be restored with support. In Sweden personal assistants are provided through the social security system. The Act Concerning Support and Service for Persons with Certain Functional Impairments, LSS (SFS 1993:387) and the Social Insurance Code, SFB (SFS 2010:110, chapter 51) provide support and services for people who have extensive and permanent physical or mental functional impairments causing considerable difficulties in daily life and an imperative need for support and service. The purpose of this assistance is to promote equality of living conditions and full participation in society. To obtain personal assistance, an application must be completed and a decision is made by the authorities. The laws do not specify any limitations regarding the number of hours of assistance or number of assistants to which the child is entitled.

The personal assistant can either be a paid relative (for children usually a parent) or a hired external person. For a child with disabilities an external personal assistant is usually added to the inner circle of the child's social network, which means that this assistant often becomes like a family member for the child (Wilder, 2008). The roles of children with disabilities and their relationships to their assistants have been studied. When interviewing children aged 8-19 with varying illnesses/disabilities but with good communicative abilities, Skär and Tamm (2001) found characteristics of the personal assistant that were of importance for the child. The personal assistant should ideally impart confidence and security, be available on the children's own terms, be kind and cheerful and see themselves as a friend. Younger personal assistants were considered to provide greater opportunities for the development of independence and autonomy. In the interviews, the children also stressed the importance of being able to choose their ideal assistant. This can be compared to what adult recipients in an interview study said about desired characteristics of external personal assistants (Roos, 2009). The external personal assistant should be discrete, obedient (i.e. act according to the wishes of the assistance recipient), reliable, informative, alert, respectful, considerate, friendly, pleased and practical.

Personal assistance has dual aims according to the Act: to support children's participation and to relieve parents (Government Bill 1992/93:159). Personal assistance in the child's home can, however, impinge on the family's

maintenance of private life. Being “another person” working in the child’s home might cause tension (or imbalance) due to overstepping the boundaries of family privacy (Ahlström & Wadensten, 2011; Clevnert & Johansson, 2007). On the other hand, being a parent and at the same time working as a personal assistant for one’s child can cause a role conflict for the parent due to different expectations (Clevnert & Johansson, 2007). The possibility in Sweden for parents to work as paid personal assistants affects the family’s economics in that this provides an income for the family. When the parents also have another form of paid income, their income is supplemented. To understand the importance of personal assistance for participation of children with PIMD, the concept of participation needs to be further explored.

## Participation

### *The concept of participation*

The notion of participation in this thesis is based on recent research by Granlund et al. (2012) where participation is defined as having two dimensions: firstly, physically being there i.e. *presence* and, secondly, expressions of involvement, i.e. degree of *engagement*.

Participation can be seen as a consequence of interaction between different individual aspects that could be intact or impaired and environmental aspects comprising adequate or in-adequate physical, social and psychological elements (Simeonsson et al., 2003). In the International Classification of Functioning, Disability and Health (ICF) and in its version for children and youth (ICF-CY), the importance of a person’s participation is emphasized. In these classifications, participation is defined as a person’s “involvement in a life situation”, which includes the aspect of performance i.e. what an individual does in his or her current environment (World Health Organization, 2001, 2007). Thus, in the ICF and ICF-CY the “being there” (presence) dimension of participation primarily is conceptualized. This view is questioned in a study by Hammel et al. (2008). They have described the need for persons with disabilities to be free to define and pursue participation on their own terms. Their interview study including people with

diverse disabilities likewise showed that being a part of something, social connection, choice and control were of importance. In addition, Hoogsteen and Woodgate (2010) have stated that “in order to participate, a child with disabilities must take part in something or with someone, they must have a sense of inclusion, control over what they are taking part in, and be working toward obtaining a goal or enhanced quality of life”. These views are in accordance with the view of Maxwell et al. (2012), who claim that the subjective experience of engagement should be considered, to provide a psychological perspective of participation, as well as the social aspects of being there.

Engagement can be described as occurring at the present, within a situation, at a particular moment (Granlund et al., 2012; Granlund, Wilder, & Almqvist, 2013). Engagement has been defined by McWilliam (1991) as an aspect of how activities are performed and is operationalized in the Children’s Engagement Questionnaire. This questionnaire is designed to rate children’s global engagement and comprises four engagement factors: competence, persistence, undifferentiated behavior and attention. The questionnaire emphasizes the time the child spends on certain activities. Examples of such activities are watching and listening to adults and other children, maintaining an awareness of what is going on and play. In a later study McWilliam et al. (2003) graded child engagement when observing children and their teachers: from non-engaged, defined as being unoccupied, to persistent, defined as undertaking problem solving in a goal directed way. McWilliam et al. (2003) and de Kruif and William (1999) have also stated that engagement/ persistence was not observed to be age-related.

Participation has thus multidimensional meanings, and both views of the child’s presence and engagement are consequently included in this thesis. Participation can, moreover, be described as a contribution to, as well as an outcome of, proximal processes where the child’s engagement is a snapshot of well-functioning proximal processes. According to Raghavendra (2013) practitioners need to think about participation as the ultimate goal and outcome for children with disabilities.

## *Influences on participation*

The bio-psycho-social model presented in the ICF and ICF-CY (World Health Organization, 2001, 2007) claims that the individual's participation is influenced by the person's interests and abilities, other personal characteristics such as age or gender and features of the environment that support (i.e. facilitators) or hinder (i.e. barriers) his or her efforts to participate. Environmental dimensions related to participation have been operationalized as availability, accessibility, affordability, accommodability, and acceptability (Maxwell, 2012). Other studies with participants with varying disabilities have found similar aspects to be of importance. McWilliam et al. (2003) found that children with TD and children with need of special support were more engaged when teachers addressed them individually than as a part of a group. In a systematic literature review including adolescents and adults with mild intellectual disability Arvidsson et al. (2008) found that individual characteristics, adaptive and social skills and environmental factors such as social support, choice opportunity, living conditions and physical availability were statistically related to participation. In another systematic literature review, Bult et al. (2011) found that gross motor function, manual ability, cognitive ability, communicative skills, age and gender were the variables that explained most of the variance in frequency of participation in leisure activities of children and youth of diverse diagnoses and ages. However, the level of variance explained was relatively low, which indicates that many other factors are important for frequency of participation. After studying 205 youths with cerebral palsy and their parents about factors associated with a higher intensity of participation (number of activities and how often these are performed), Palisano et al. (2011) showed that higher physical ability, higher enjoyment, younger age, female sex, and higher family activity orientation were factors associated with higher intensity of participation. Additionally, Dunst et al. (2001) states that learning opportunities that are interesting, engaging, competence-producing and mastery-oriented are associated with optimal child behavior change.

In the pursuit of child participation, Sameroff and Fiese (2000) and Sameroff (2009) have shown that the number of factors both within the child and the environment when working in the same direction over time are more important than the influence of individual factors. This emphasizes the

importance of reaching a “synergy effect” in interventions. In children with PIMD, Horn and Kang (2012) states that the individual support each child needs has to be identified to ensure that the child is an active participant in all aspects of his or her life and makes meaningful progress toward valued life outcomes. To support children with PIMD on an individual basis, personal knowledge of the child is important. Such knowledge requires long experience of interaction with the child, which is inherent in a single-case study by Hostyn and Maes (2013). Thus, personal assistants as well as parents may have important influence on children’s participation as they gain in-depth personal knowledge and the skills necessary for providing children with PIMD with opportunities for being present and engaging in proximal processes

# Rationale

Article 19th of the Convention on the Rights of Persons with Disabilities (CRPD) states the right to live independently and to be included by having “access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community” (United Nations General Assembly, n.d.). Research by Raghavendra et al. (2011) has shown that children with complex communication needs were restricted in social participation and participated in activities closer to home rather than in the community when compared to children with physical disabilities only, and children with typical development. In a study by Imms (2008) it was found that children with cerebral palsy participated in a wide variety of activities outside of school but with relatively low intensity. The children also tended to participate in activities together with the family, close to home rather than with friends in the broader community. The children with the most severe disabilities were found to participate with less intensity and in a lower variety of activities compared to the children with less severe disabilities.

The group of children included in this thesis, children with PIMD, do not have the same personal resources for functioning in daily family life as children with less severe disabilities and children with TD. To facilitate participation in family activities, the children need support from others in their micro environment, mainly by parents and external personal assistants. In turn, the activity settings provide proximal processes necessary for the child’s well-being and functioning. There is a lack of knowledge about the participation of children with PIMD in family activities and how improved participation can be reached by supporting the child or by supporting persons in the family system interacting with the child. Gathering such knowledge could enable an improvement in child functioning and well-being as well as easing everyday life for families of a child with PIMD.

# Aims of the thesis

The overall aim of this thesis was to explore participation in family activities in children with PIMD and to find strategies that might facilitate this participation (Table 1).

## Specific aims of study I – study IV

- I. To compare frequency of occurrence of family activities and child presence in two groups of families: one group of families with a child with PIMD and one group of families with children with typical development
- II. To compare child engagement in family activities in two groups of families: one group of families with a child with PIMD and one group of families with children with typical development
- III. To describe the strategies used by parents and personal assistants to facilitate participation in family activities of children with PIMD.
- IV. To investigate the role of external personal assistants for children with PIMD in the homes of the children.

## *Research questions for the synthesis of studies I-IV*

The results and discussion in this framework are based on the following research questions:

- What is the actual participation in terms of presence and engagement of children with PIMD in family activities compared to children with TD? (I, II)
- What are the potential influences on child participation in family activities? (I, II, III, IV)

**Table 1.** Studies I-IV

Study Title	I	II	III	IV
	Frequency of occurrence and child presence in family activities: a comparative study of children with profound intellectual and multiple disabilities and children with typical development	Engagement in family activities: a quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development	Strategies that facilitate participation in family activities of children with profound intellectual and multiple disabilities: parents' and personal assistants' experiences	The role of the external personal assistant for children with profound intellectual and multiple disabilities working in the children's home
<b>Design</b>	<b>Quantitative</b>	<b>Quantitative</b>	<b>Qualitative</b>	<b>Mixed method</b>
<b>Sample</b>	60 families of a child with PIMD, aged 5-20 years and 107 families of children with TD, aged 5-10 years	Same as in study I	11 parents (selected from studies I and II) and 9 personal assistants of a child with PIMD	60 families of a child with PIMD and 11 selected parents and 9 personal assistants of a child with PIMD (same as in studies I-III)
<b>Data collection</b>	Questionnaire	Questionnaire (same as in study I)	Individual interviews	Questionnaires (same as in studies I and II) and Individual interviews (same as in study III)
<b>Data analysis</b>	Mann-Whitney U, Chi square, Kruskal Wallis, Spearman's rank correlation test	Mann-Whitney U, Chi square, Kruskal Wallis, Spearman's rank correlation test	Inductive, manifest content analysis	Chi2, Descriptive quantitative analysis, Inductive, manifest content analysis

PIMD = Profound intellectual and multiple disabilities, TD = Typical development

# Materials and Methods

## Research design

The overall research was cross-sectional and conducted using different designs to obtain a comprehensive view of participation in family activities of children with PIMD. Studies I and II had quantitative, explorative and comparative designs using questionnaire data. Study III had a qualitative, explorative and inductive design using data from individual, semi-structured interviews. Study IV had a sequential mixed method design combining quantitative and qualitative data gained from the questionnaires and the individual interviews (Table 1).

## Sample and procedure

### *Study I and study II*

Two groups of families participated.

The *first group* included 60 families with a child with PIMD age 5-20 years. Of the children studied, 37 were boys and 23 girls, and their diagnoses included, among others, cerebral palsy; other syndromes where motor and intellectual disabilities were combined; and residual conditions post encephalitis. The inclusion criteria for this group were families who had a child with PIMD, aged 0-20 years, who had personal assistance according to the Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments, LSS (SFS 1993:387) and the Social Insurance Code, SFB (SFS 2010:110, Chapter 51). A sample of convenience was recruited by contacting three national disability organizations in Sweden: Jämlikhet Assistans Gemenskap, JAG, [Equality, Assistance and Inclusion], (JAG, 2014), Riksförbundet för Rörelsehindrade Barn och Ungdomar, RBU, [The Swedish National Association for Disabled Children and Young People] (RBU, n.d.) and Riksförbundet för utvecklingsstörda barn, ungdomar och vuxna, FUB, [The Swedish National Association for Persons

with Intellectual Disabilities] (FUB, n.d.). JAG works with persons with PIMD, RBU with children and youth with motor disabilities and FUB with persons with intellectual disabilities. Families may belong to more than one organization. These disability organizations mailed the questionnaires and information letters to their members in accordance with the inclusion criteria. Three hundred families fulfilled the inclusion criteria and received a questionnaire titled Child Participation in Family Activities (Child-PFA) distributed by the three organizations. The questionnaire was developed for this research and will be described below. It was then possible to return the questionnaire in confidence directly to the researchers. The researchers received sixty-five questionnaires in total. Five of these were excluded: two due to lack of completion, two because they included children < 5 years and therefore had a divergent low age compared to the rest of the children in the study, and one because the parent had completed two questionnaires. Of the remaining 60 families, 47 mothers, seven fathers and six other adults (who were close family members) had answered the questionnaire (Table 2a-b). Consequently the response-rate was 20% (22% with the excluded responses). No analysis of the attrition rate was performed in light of promised confidentiality.

Most of the 60 children in this first group had major difficulties. In the questionnaire functional mobility, cognition and communication were rated on ordinal scales between 1-5 and 1-6 respectively, where 1 was considered normal abilities when comparing with children with TD and 5/6 was considered very severe limitations. The 60 studied children were rated by the parents as follows; functional (motor) mobility 3.60 out of 5, cognition 4.73 out of 6, and communication self 5.25 out of 6 (Table 2a). The children received assistance between 0-225 hours/week. The children had between 0 and nine external personal assistants and 41 mothers and 29 fathers worked as a personal assistant for their child (Table 2b).

The *second group* included 107 families with children with TD aged 5-10 years. Of these children, 53 were boys, 53 girls and one of unknown gender. The inclusion criteria for this group were families of children with TD aged 5-10 years. This age range was chosen because at this age children and parents still engage in activities together. Data collection was completed by two students as part of an assignment on gender and socioeconomics in a

Bachelor degree in Social Work. Convenience and snow ball sampling were used, with 145 questionnaires distributed to families in three different counties in the southern part of Sweden. One hundred and seven questionnaires were returned and used in this comparative analysis. In all, 69 women and 37 men answered the questionnaire, one of unknown gender (response rate = 74%). The attrition rate was not analyzed for this group, for confidentiality reasons. (Child characteristics are presented in Table 2a, family and personal assistant characteristics in Table 2b).

The total family income in the group of families with a child with PIMD was significantly higher ( $p=.033$ ) than in the group with children with TD. There was no evidence that parents' educational level differed between the two family groups (Table 2b).

**Table 2a.** Child characteristics

	Families with a child with PIMD (N=60)		Families with children with TD (N=107)
	n (%)	Mean (SD)	n (%)
Gender			
Male	37 (62)		53 (50)
Female	23 (38)		53 (50)
Age			
5-10	16 (27)		107 (100)
11-20	44 (73)		0 (0)
Functional mobility (1-5) <sup>1</sup>	53 (88)	3.60 (1.59)	n/a
Fine motor skills (1-5) <sup>1</sup>	57 (95)	3.53 (1.47)	n/a
Cognition (1-6) <sup>1</sup>	60 (100)	4.73 (1.29)	n/a
Communication, self (1-6) <sup>1</sup>	60 (100)	5.25 (1.19)	n/a
Communication, understand (1-6) <sup>1</sup>	59 (98)	4.46 (1.37)	n/a
Behavior (1-6) <sup>1</sup>	60 (100)	3.70 (1.70)	n/a
Vision (1-6) <sup>1</sup>	60 (100)	3.43 (1.82)	n/a
Hearing (1-5) <sup>1</sup>	58 (97)	1.47 (1.11)	n/a
Health (1-4) <sup>1</sup>	60 (100)	2.15 (0.97)	n/a

<sup>1</sup> The child's ability was rated by the parents on a four to six point rating scale; normal (1) to very severe limitations (4-6 respectively). n/a = not applicable

**Table 2b.** Family and personal assistant characteristics

	Families with a child with PIMD (N=60)	Families with children with TD (N=107)
	n (%)	n (%)
<i>Responding</i>		
Mother	47 (78)	69 (64)
Father	7 (12)	37 (35)
Other adult	6 (10)	1 (1) unknown
<i>Family characteristics</i>		
Total annual income (EUR) <sup>1</sup>		
< 22 599	0 (0)	3 (3)
22 600 – 45 199	9 (15)	21 (20)
45 200 – 67 799	19 (32)	41 (39)
67 800 – 90 399	19 (32)	28 (27)
>90 400	13 (22)	12 (11)
Education, mother / father		
Grade 1-9	2 (4) / 3 (5)	3 (3) / 8 (8)
Grade 10-12	19 (33) / 23 (42)	40 (38) / 56 (55)
University	35 (61) / 28 (51)	61 (58) / 37 (36)
Other	1 (2) / 1 (2)	2 (2) / 1 (1)
Number of children at home		
1	14 (23)	6 (6)
2	25 (42)	37 (35)
3	17 (28)	51 (48)
4 or more	3 (5)	13 (12)
Working full time /part time outside the home		
Mother	13 (22) / 29 (48)	32 (30) / 55 (51)
Father	39 (65) / 11 (18)	94 (88) / 4 (4)
Working as a PA for the child		
Mother	41 (68)	n/a
Father	29 (48)	n/a
Number of hours per week a parent is working as a paid PA, n=58		
0 <sup>a</sup>	5	n/a
1-25	17	n/a
26-50	27	n/a
51-75	6	n/a
76-120	3	n/a
Number of hours per week a child has personal assistance, n=59		
0	3	n/a
1-50	14	n/a
51-100	18	n/a
101-150	18	n/a
151-225	6	n/a
Number of employed external personal assistants, n=59		
0	6	n/a
1-3	38	n/a
4-6	14	n/a
7-9	1	n/a

<sup>a</sup> The parent might be working as a paid personal assistant e.g. when the assistant is on sick leave.  
n/a = not applicable

### *Study III*

Eleven parents of a child with PIMD and nine personal assistants related to these families participated in this study. Participants were selected from the first group, i.e. parents of a child with PIMD, taking part in studies I and II. Following the completion of the questionnaire, 30 out of 60 parents agreed to be contacted for an individual interview on strategies related to improved participation in family activities and about personal assistance. The questionnaires of these 30 participants were re-analyzed to assist purposeful selection where the aim was to achieve a range of participants that included those with severe child impairment in mobility, cognition and communication and a high level of child participation. A second requirement was that the children should have external personal assistance. An interview guide was used (described below) for all interviews and each parent chose the place for the interview. The interviews were individual and were generally undertaken in the family home. Participating parents were then asked to select one of their child's personal assistants whom the researcher could contact in order to gather their perspective as well. These interviews were performed on the phone for the convenience of the personal assistants and the researcher. One personal assistant declined to participate and one interview recording was marred by repeated technical problems. Of the interviewed external personal assistants, one had worked with the child for 3 months, the remainder of the external personal assistants between 3-12 years. The interviews with the parents lasted for 50-110 minutes and the interviews with the personal assistants for 20-55 minutes. All interviews were performed by the author of this thesis and recorded.

The children of the 11 selected families with a child with PIMD were between six and 20 years. They had slightly more severe abilities than the entire (N=60) study sample (Table 2a) e.g. in terms of average functional (motor) ability (4.09 out of 5), cognition (5.09 out of 6), and communication self (5.55 of 6). (Child characteristics, family characteristics and external personal characteristics are presented in Table 3).

**Table 3.** Characteristics of 11 selected participants

<b>Child characteristics, children with PIMD (N = 11)</b>		
	n (%)	Mean
Gender		
Male	8 (73)	n/a
Female	3 (27)	n/a
Age		
5-10	2 (18)	n/a
11-20	9 (82)	n/a
Functional mobility (1-5) <sup>1</sup>	10 (91)	4.09
Fine motor skills (1-5) <sup>1</sup>	11 (100)	4.36
Cognition (1-6) <sup>1</sup>	11 (100)	5.09
Communication, self (1-6) <sup>1</sup>	11 (100)	5.55
Communication, understand (1-6) <sup>1</sup>	11 (100)	4.45
Behavior (1-6) <sup>1</sup>	11 (100)	3.00
Vision (1-6) <sup>1</sup>	11 (100)	3.75
Hearing (1-5) <sup>1</sup>	10 (91)	1.00
Health (1-4) <sup>1</sup>	11 (100)	2.18

<sup>1</sup> The child's ability was rated by the parents on a four to six point rating scale; normal (1) to very severe limitations (4-6 respectively). n/a = not applicable

<b>Family characteristics, families with a child with PIMD (N = 11)</b>	
	n (%)
Interviewed parent	
Mother	9
Father	2
Total annual income (EUR) <sup>2</sup>	
< 22 599	0 (0)
22 600 – 45 199	1 (9,1)
45 200 – 67 799	3 (27,3)
67 800 – 90 399	5 (45,5)
>90 400	2 (18,2)
Education, mother/father	
Grade 1-9	0 / 0
Grade 10-12	0 / 5
University	11 / 5
Other	0 / 0
Parent(s) as employed personal assistants	11

<sup>2</sup> Converted from SEK on February 1, 2011

<b>External personal assistants (N=9)</b>	
Interviewed external personal assistant	n
Male	1
Female	8
<i>Time that the external personal assistant has worked with the child</i>	
3 months	1
3-12 years	8

## *Study IV*

In study IV, the studied sample was the same 60 families of a child with PIMD included in study I and II (Table 2a-b) combined with the sample from study III; 11 parents selected from the 60 families together with nine personal assistants related to the selected 11 families (Table 3). Data collected in study I, II and III about personal assistance were used to conduct a sequential mixed method study (Tashakkori & Teddlie, 1998) for study IV, concluding that the quantitative data had been collected prior to the qualitative data.

## **Instruments**

### *Child-PFA questionnaire*

The Child-PFA questionnaire was developed for this study and used in studies I and II and study IV.

Part A of the Child-PFA included background questions about the child and the family, including child ability, family structure and socio economic status (SES). Child ability was measured by using a modified version of the Abilities Index (Bailey, Simeonsson, Buysse, & Smith, 1993; Granlund & Roll-Pettersson, 2001). The Abilities Index measures functional abilities and communicative complexity of children with PIMD where high ratings indicate high degree of difficulties/health problems.

Part B of the Child-PFA included 56 family activities (Table 4) and asked about:

- Frequency of occurrence of the activity
- Presence of the child, siblings, mother, father, parent as a paid personal assistant and/or external personal assistant in the activity
- Child's engagement in the activity
- The amount of assistance the child needed to perform the activity

- The use of assistive devices in the activity

The items were organized into seven activity domains: indoor activities, meals, routines, outdoor activities, organized activities, outings, and vacation and holiday cottage to provide structure to the questionnaire. Some modifications to Child-PFA questions were made when distributed to families with children with TD in order to match a sample without diagnoses. In the questionnaire for children with TD the activities “exercising physical therapy at home”, “playing in the sandpit”, “going to habilitation center activities” were removed and the activities “doing homework” and “jumping on trampoline” were added. This resulted in 53 of 56 activities being the same in both groups (Table 5). Depending on the activity domain, the respondent was asked to consider everyday life (indoor activities, meals, routines, outdoor activities), the past three months (organized activities, outings) or the past year (going on vacation and to holiday cottage) respectively.

**Table 4.** The structure of Child-PFA

<i>Questionnaires distributed to families of a child with PIMD</i>	<i>Adapted questionnaire for the families of children with TD</i>
A Background questions about the child, family and personal assistance	A Background questions about the child and the family
B Occurrence of the activity <sup>a</sup> <i>e.g. 1=never/ hardly ever, 2=monthly, 3=weekly, 4= daily</i>	B Occurrence of the activity <sup>a</sup> <i>e.g. 1=never/ hardly ever, 2=monthly, 3=weekly, 4= daily</i>
Presence of the child, siblings, mother, father, parent as a paid personal assistant and/or external personal assistant <i>yes/ no</i>	Presence of the child, siblings, mother, father <i>yes/ no</i>
Child engagement in the activity <i>1=not at all, 2=somewhat, 3=rather much, 4= much</i>	Child engagement in the activity <i>1=not at all, 2=somewhat, 3=rather much, 4= much</i>
The amount of needed assistance in the activity <i>1=not at all, 2=somewhat, 3=rather much, 4= much</i>	
The use of assistance devices (not analyzed) <i>yes/ no</i>	

<sup>a</sup> = Depending on the activity, rated with different time periods in consideration

**Table 5.** Child-PFA, section B, families with a child with PIMD

<i>Family activity type</i>	<i>Activities</i>
Indoor activities (16) <i>In everyday life</i>	Watching a movie, watching TV, joking and fooling around, playing computer games, surfing the internet, doing handicraft, playing board games, playing with you or other adult, playing with children (friends/siblings), playing with pets, story reading, singing, playing instruments, listening to music, dancing, exercising physical therapy at home.
Meals (7) <i>In everyday life</i>	Being together in the kitchen, cooking/baking, doing the dishes, laying the table/cleaning away, having tea or coffee together, having breakfast together, having dinner together
Routines (8) <i>In everyday life</i>	Cleaning the house, doing morning routines, doing evening routines, packing school bag, picking up after playing, lying down for rest, going by car to and from school, going by cars at other occasions
Outdoor activities (9) <i>In everyday life</i>	Shopping for groceries, gardening, playing outside with other children, playing outside with you or other adult, going on a swing, bicycling, going for a walk, playing in the sandpit, playing ball games
Organized activities (5) <i>During the past three months</i>	Going together to child's leisure activity, going together to sibling's leisure activity, going together to parent's leisure activity, going to church, going to habilitation center activities
Outings (9) <i>During the past three months</i>	Going to the playground, going shopping, going to the library, going to the theater/cinema/concerts, visiting friends who have children, visiting friends who do not have children, visiting relatives, going to parties, going out in the nature
Vacation/holiday cottage (2) <i>During the past year</i>	Going on vacation, going to holiday cottage

( ) = Number of activities. However, for the questionnaire for families with children with TD: the activities “exercising physical therapy at home”, “playing in the sandpit”, “going to habilitation center activities” were removed from the questionnaire. The activities “doing homework”, “jumping trampoline” were added to the questionnaire.

### *The development of Child-PFA*

A clinimetric approach was used in the development of the questionnaire (de Vet, Terwee, & Bouter, 2003) where the development was based on the questionnaire's clinical purpose and aimed to measure relevant aspects of the child's participation, defined a multiple construct, in family activities.

The Child-PFA was partly inspired by other questionnaires, such as the Children's Assessment of Participation and Enjoyment (CAPE) (G. King et al., 2005; G. King et al., 2004), the Personal Independence Profile (PIP) (Nosek, Fuhrer, & Howland, 1992) and Familjen och Habiliteringen [the Family and Habilitation] (Granlund & Olsson, 2006). As a part of the development work, discussions were held at seminars in the CHILD (Children, Health, Intervention, Learning and Development) research group.

Following the development of the questionnaire, the Child-PFA was tested in a pilot study consisting of eight parents of different children with PIMD in the county of Jönköping, Sweden. Recruitment was performed through the Children and Youth Habilitation Services and all parents were known by the researcher. After answering the first version of the questionnaire, the parents were interviewed to gain feedback on the structure and content of the questionnaire (Laaksonen, Aromaa, Heinonen, Suominen, & Salanterä, 2007; Statistiska Centralbyrån [Statistics Sweden], 2001). The pilot study resulted in some changes. In the background part of the questionnaire, Part A, clarifications were made to reduce the risk of misunderstanding. Questions about the child's physical ability, for example the ability to use the right/left leg were replaced by questions including a more functional perspective, e.g. a question about the ability to get around in a wheelchair or to walk. In Part B, the family activity part of the questionnaire, the concept family activity was clarified and defined as an activity that the family did together in everyday life where several family members took part. It was moreover clarified that a family activity could include or not include the child and that being a parent assistant meant being paid/having salary, compared to being "just" a parent. Furthermore the intervals for how often a certain family activity occurred were adjusted. Finally the layout was improved to simplify the answering of the questionnaire. No data from the pilot study was used in analysis within the main study.

A supplemental web version of the questionnaire was developed in esMaker NX2 (EnterGate) so that the members of JAG could receive a web-version of the questionnaire. This was done because electronic media comprise typical communication between the organization and its members. Members of RBU and FUB and the families of children with TD received a paper version. The families with a child with PIMD who received the web version received two reminders by the JAG organization while those who received the paper version did not receive any reminder. Among the 300 invited families with a child with PIMD, 65 responded and finally 60 included, this resulted in the same proportion, i.e. 30/web versions and 30/paper versions. Some families of children with TD received a verbal reminder from the students. All questionnaires were returned confidentially, except those received from the families of a child with PIMD who expressed a willingness to be contacted for an individual interview. A power calculation performed prior to the studies showed that 100 (50+50) participants were needed to reach a power of .80, assuming a correlation of .4 or higher.

Child-PFA factor structure was tested using exploratory one-factor analysis to investigate the underlying pattern or the variability among the 53 observed family activity variables. The factor analysis was performed on the questionnaires' responses from the families with a child with PIMD and the families with children with TD respectively. Regarding frequency of occurrence of the activities in the PIMD group, 27 factor loadings were found to be above .3 (42 above .2). In the TD group, 30 factor loadings were found to be above .3 (44 above .2). The factor analysis regarding child engagement could not be performed in the PIMD group due to a high number of activities without any variance, while 41 of the activities in the TD group loaded above .3 (49 above .2).

In addition, Child-PFA was tested for internal consistency reliability of the family activity variables. The dimension of frequency of occurrence of family activities and the dimension of child engagement in the activities were tested in both groups using Cronbach's alpha. The internal consistency of the frequency of occurrence in the PIMD group was .83, and in the TD group .84. For child engagement, the PIMD group's internal consistency was .83 and for the TD group .81, which indicates good internal consistency reliability. It was not possible to test the internal consistency of necessary

level of assistance in the activities in the group of families with a child with PIMD due to a lack of variances in responses.

The differences between the children aged 5-10 years and 11-20 years in the group of children with PIMD were explored to enable comparison of the children with PIMD with the children with TD (aged 5-10 years). Significant differences in occurrence of family activities were found in seven (13%) of their 56 listed activities. Two of the activities occurred significantly more often in the group of younger children and five of the activities occurred significantly more often in the group of older children. Significant differences between the age groups regarding engagement were found in six (11%) of the activities. In one of the activities engagement was significantly higher in the group of younger children and in the group of older children engagement was significantly higher in five of the activities. As the differences were relatively few in number, the homogeneity between the younger and older children with PIMD was deemed to be acceptable.

### *The interview guide*

An interview guide was developed and used in study III and study IV.

The interviews with the parents of children with PIMD as well as with the personal assistants was semi-structured and included open ended questions (Kvale & Brinkmann, 2009) about child involvement/engagement (III) and the role of the external personal assistant (IV). The questions were developed based on the results of the quantitative study regarding frequency of occurrence of family activities, child presence and engagement in the activities (studies I and II), and the presence of external personal assistants in the activities and/or parents as paid personal assistants. These questions enabled a comprehensive picture of participation of children with PIMD. The main purposes of the interviews were to determine the facilitating strategies used to enable child participation and to improve knowledge of the role of the external personal assistant working in the home of a child with PIMD. To pilot the interview guide, one test interview, not included in the results, was conducted with an experienced teacher at the department of education of a university, who additionally was a parent of a child with

disabilities. This pilot interview led to only minor changes in the interview guide.

Examples of interview questions:

- What do you do to help your child/the child be as involved/engaged as possible?
- Generally speaking, what makes it easier for the child to be involved/engaged?
- How can you tell that your child/the child is engaged?
- What is the (external) personal assistant's task/role?
- How does it feel to let others in around "Sarah"? / How do you feel about working in someone else's home?

# Data Analyses

## *Study I and study II*

Study I aimed to compare frequency of occurrence of family activities and child presence between the two groups of families, and study II aimed to compare child engagement in the activities. In these studies quantitative analysis was performed using non-parametric methods. To compare frequency of occurrence of family activities (I) and child engagement (II), the Mann-Whitney U test was used because responses were on an ordinal level. Child presence (I) was stated on a nominal level and was analyzed using the Chi2 test. When testing relationships between frequency of occurrence of family activities (I) / engagement (II) and selected child characteristics (health, cognition, communication and motor ability in studies I and II, together with behavior in study I, and vision and decisiveness in study II), the Spearman's rank correlation test was used. In addition, the Spearman's rank correlation test was used when testing the relationships between frequency of occurrence of family activities (I) / engagement (II) and selected family characteristics (family income, education father, education mother). To obtain an indication of the level of frequency of occurrence in relation to the level of engagement, the rated median values of the two aspects were compared descriptively. The determinant was decided to a difference of more than one step in the median values on the 4-point scales regarding each activity (II).

Family income and parent's educational level in the two studies were rated using ordinal data and Mann-Whitney U test was used. Homogeneity between the groups of children was tested to ensure that it was possible to compare them. The effect of children's age on differences in the occurrence of family activities (I) and engagement (II) within the group of children with PIMD was tested using the Mann-Whitney U test, while the Kruskal Wallis test was used to compare the age groups within the group of children with TD (I). Data analyses were performed by using SPSS (PASW Statistics 18, IBM), and the p-value was set at  $p < .05$ .

### *Study III*

Study III aimed to describe facilitating strategies related to improving the participation in family activities of children with PIMD. Inductive, manifest qualitative content analysis was used to explore these strategies (Elo & Kyngäs, 2008; Krippendorff, 2013). According to Krippendorff (2013, p. 24), content analysis is “a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the context of their use”. An inductive approach was chosen because this area has not previously been well researched (Elo & Kyngäs, 2008). To begin with, the semi-structured interviews were transcribed and read through carefully several times. The analysis was then carried out with the research question in mind, and meaning units were identified. Each meaning unit was labeled with a code. The approach of a manifest content analysis meant that obvious, unambiguous content was dealt with. The various codes were compared to identify differences and similarities and sorted into sub-categories. Finally, the different subcategories were combined into categories, i.e. groups of content that shared a commonality (Graneheim & Lundman, 2004). Statements from the parents and external personal assistants were brought together in the analysis because they talked about the same methods to assist the children’s involvement. The work of creating subcategories and combining them into categories was undertaken in collaboration with a co-researcher. Moreover, discussions were held throughout the analysis process with other researchers, until consensus was reached. The ATLAS.ti software program (ATLAS.ti Scientific Software Development, GmbH) was used to support data management in the coding process.

### *Study IV*

Study IV aimed to investigate the role of external personal assistants for children with PIMD in the home of the children. A sequential mixed method design was used where qualitative and quantitative data were integrated in the analysis to obtain a comprehensive view on the subject (Tashakkori & Teddlie, 1998).

In this study, quantitative data from the Child-PFA, group of children with PIMD, was analyzed regarding amount of assistance the child needed in the

activities. This was performed by determining the median values (1=not at all, 2=somewhat, 3=rather much, 4=much). In addition the presence (yes/no) of an external personal assistant/parent as a paid personal assistant in the different family activities was analyzed using the Chi-squared test. To further deepen the understanding of the role of the external personal assistant, qualitative data addressing the aim of this study were derived from the previously described semi-structured interviews which included questions related to the role of the external personal assistant. The transcribed data from the interviews was analyzed using inductive, manifest qualitative content analysis (Elo & Kyngäs, 2008; Krippendorff, 2013) similar to study III.

Following this, the emerging quantitative data on the amount of assistance the child needed was integrated with the qualitative data on the external personal assistant's role or duties in relation to the child. The emerging quantitative data of presence of an external personal assistant/parent as a paid personal assistant in the different family activities was integrated with the qualitative data on the external personal assistant's role or duties in relation to the family.

## Ethical considerations

The project on which this thesis is based has been approved by the Regional Research Ethics Board, Linköping, reference No. 2010/324-31.

Relevant parts of the United Nations conventions that protect the rights of children with disabilities guided this research; the CRC, Article 23:1 (United Nations General Assembly, 1989) concerning the child's right to active participation in society (where in this research the family is considered a part of society), and the CRPD, Article 19 (United Nations General Assembly, n.d.) concerning the right to inclusion. Likewise the ethical considerations comply with the Act concerning the ethical review of research involving humans (SFS 2003:460), the law amending the same act and ethical principles set by HSRF (Humanistisk-samhällsvetenskapliga forskningsrådet [the Scientific Council for the Humanities and Social Sciences] (1999). These laws stress, for example, the importance of voluntariness and confidentiality in research.

For study I, study II and study IV, all including families with a child with PIMD, questionnaires and information letters were sent by mail or e-mailed by participating disability organizations. The mailing was conducted independently of the researchers, and no names of eligible participants were consequently revealed. The information letter contained information about the project, about voluntariness in participation and about the confidentiality of the returned questionnaire. Moreover, there was information about who to contact if the questionnaire gave rise to any concerns.

If the families agreed to participate, they completed the questionnaire and returned it directly to the researchers for analysis. However, the information letter gave an option to waive confidentiality which resulted in 11 out of 30 families, being selected and contacted by phone. After further information was provided, these eleven respondents gave informed consent for an interview at a self-selected place. Similarly the telephone interviews, which were undertaken with personal assistants, were preceded by provision of information and obtaining of oral consent. Prior to these interviews the parents had given their consent for the personal assistants to talk about the child. The personal assistants were also informed that they would not be told

what the parent talked about and vice versa. This was to protect the privacy of the parents and of each external personal assistant, who was in a dependent position especially in relation to the supervisor parent. The aim was also to reduce the risk for any asymmetrical power situation (Hewitt, 2007; Kvale & Brinkmann, 2009) through the careful preparation of interviews, including the creation of questions and within the interviews themselves. Rather, it was an ambition to obtain a child perspective as well as to emphasize a salutogenic perspective (Antonovsky, 1987) where the parents' and the personal assistants' experiences and knowledge were of importance. The 19 families remaining, who expressed an interest in being interviewed, were not contacted. In retrospect this should have been done.

The use of proxy estimation in this research was considered as an important ethical and methodological dilemma. Ideally the children should have been enabled to talk about their own experiences of participation (Simeonsson et al., 2003). However, due to profound difficulties in communication, for example, the children themselves were not asked by the researchers about their views on their own participation in the research, about their participation in family activities, how participation could be facilitated, nor about the role of their personal assistants. Instead, to enable this group of children to be studied, the researchers relied on the parents and the interviewed personal assistants, both of whom knew the children very well and were deemed able to interpret the children's expressions (Coster et al., 2012; Verdugo, Schalock, Keith, & Stancliffe, 2005). In addition, the researchers had to rely on parents to imagine themselves in their child's position (Sommer, Samuelsson, & Hundeide, 2010; Söderbäck, Coyne, & Harder, 2011) as described in the introductory information in the questionnaire. Study I and study II included a comparison group, children with TD and their parents. These children were not asked directly either, but data was gathered through parent proxies. This was done to maintain consistency in data collection techniques between the two groups and because children with TD are not expected by some to be able to report about their engagement until around the age of eight or nine (Young, Yoshida, Williams, Bombardier, & Wright, 1995). Using the same method to collect information in both groups of families was considered to be of paramount importance.

The data collection for the comparison group was performed by students for their examination assignment towards a Bachelor's degree in Social Work. Anonymity was ensured by the use of snowball sampling and limited collection of background data including no names. With respect to the Act concerning the ethical review of research involving humans (SFS 2003:460) and the law amending the same act, approval from an ethical research committee concerning this comparison group was deemed unnecessary to be needed.

Given the topics addressed, participation in this research involved little, (if any), risk for the children, their families, or when included, their personal assistants. The strong link between the families of a child with PIMD and the disability organizations can be considered a dilemma due to the families' possible dependent position. As Sweden does not have any special registers for people with PIMD this method of recruitment was convenient from a methodological standpoint. It was also used to avoid any power imbalance in relation to the researchers and emphasized voluntariness.

To summarize, this thesis includes a combination of different research designs and methods, each of which raises different ethical issues as discussed above. Children with PIMD should be a primary focus within research, despite the fact that assessing abilities in a person with PIMD is extremely difficult. Each individual represents a unique pattern of abilities and constraints to functioning as well as a unique communicative repertoire (Nakken & Vlaskamp, 2007). Greater efforts should perhaps have been made to seek the children's perspective. Observing their nonverbal behavior and focus of attention within different life situations could have conveyed information about the child's level of involvement (Bedell, Khetani, Cousins, Coster, & Law, 2011; Munde, Vlaskamp, Ruijsenaars, & Nakken, 2011; Vlaskamp, 2005). On the other hand, observations might interfere with family life and personal privacy. Nevertheless, it is important to stress that improving knowledge in this area is expected to have a positive impact on the children and on their families (Maes, Vos, & Penne, 2010).

# Results

The presentation of results in this section provides a comprehensive synthesis of studies I-IV. The synthesis aims to further explore participation in family activities in children with PIMD and to find strategies that might facilitate this participation. Research questions about the actual participation in terms of presence and engagement of children with PIMD in family activities compared to children with TD are addressed (I, II), as well as potential influences on child participation in family activities (I, II, III, IV).

## *The actual participation of children with PIMD*

The results of the actual participation of children with PIMD include child presence (I) and child engagement (II) in the family activities. Frequency of occurrence of the activities (seen as opportunities for participation) and proportion of children present in an activity when it happens are viewed together to obtain insight into the relative frequency of child presence in family activities. For example, activities that occur often with a high proportion of children attending them suggest relatively high frequency of presence. Additionally, the number of different activities (diversity) in which the children were present was analyzed to further deepen the understanding of child presence. Child engagement in the activities was analyzed separately. Both presence and engagement of the children with PIMD was compared to the group of children with TD. (Detailed results about frequency of occurrence of the activities, child presence and child engagement are found in Table Aa-d in the Appendix).

### *Presence*

There were no activities where *both* the frequency of occurrence and proportion of children with PIMD who were present, were higher than in the group of children with TD. The frequency of occurrence (only) of an activity of children with PIMD was higher in four of the activities: “watching a movie”, “listening to music”, “lying down for rest” and “going for a walk”. The proportion (only) of children with PIMD present in these activities was

the same as for children with TD. In no activities was the proportion of children with PIMD present higher than in the group of children with TD (examples in Table 6).

For children with TD, 24 activities were identified where *both* the frequency of occurrence and proportion of children present were higher than for children with PIMD, e.g. “having breakfast together” and “visiting friends who have children”. For one activity, “going to church” the frequency of occurrence was higher for children with TD while the proportion of presence in the activity was the same for both groups. In ten of the activities, distributed among all domains except vacation and holiday cottage, the proportion of child presence was higher for children with TD than in the group of children with PIMD, e.g. “being together in the kitchen” and “going to theatre/cinema/concerts” (examples in Table 6).

These results, when viewed together as indirect measures of child’s frequency of presence, indicate that children with PIMD participated less frequently in 35 of the 53 activities, mainly activities away from home, while they participated more often in four, mainly non-physically active activities. The biggest differences regarding both frequency of occurrence and proportion of child presence were found in the domains of outdoor activities, organized activities, and outings, i.e. in activities that occurred away from home (I).

**Table 6.** Examples of results of frequency of occurrence of family activities and child presence, comparison group with PIMD and group with TD.

<i>Family activity</i>	<i>Group with PIMD (N=60)</i>		<i>Group with TD (N=107)</i>	
	<i>Frequency of occurrence</i>	<i>Child presence</i>	<i>Frequency of occurrence</i>	<i>Child presence</i>
	<i>Median value (25th – 75th per-centile)/ P value if family activity occurs significantly more often in the group</i>	<i>% of children present in an activity / P value if a higher proportion of the group children is present</i>	<i>Median value (25th – 75th percentile)<sup>1</sup>/ P value if family activity occurs significantly more often in the group</i>	<i>% of children present in an activity/ P value if a higher proportion of the group of children is present</i>
<i>Examples of higher frequency of occurrence of activities in combination with higher proportion of child presence</i>				
Having breakfast together <sup>a</sup>	3(2-4)	83	3(3-4) .034	98 .007
Visiting friends who have children <sup>b</sup>	2(1.75-3)	65	4(3-4) .000	94 .000
<i>Examples of higher frequency of occurrence of activities (only)</i>				
Listening to music <sup>a</sup>	4(3-4) .001	92	3(3-4)	97
Going to church <sup>b</sup>	1(1-1)	95	1(1-2) .008	99
<i>Examples of higher proportions of child presence (only)</i>				
Being together in the kitchen <sup>a</sup>	2.5(2-3.75)	85	3(2-3)	95 .021
Going to theatre/ cinema/concerts <sup>b</sup>	2(1-2)	53	2(1-2)	72 .015
<i>Examples of same frequency of occurrence of activities and same proportion of child presence</i>				
Having dinner together <sup>a</sup>	4(3-4)	98	4(4-4)	100
Visiting friends who do not have children <sup>b</sup>	2(1-2)	42	1(1-2.25)	55

<sup>a</sup>Frequency of occurrence rated on a 4 point rating scale: 1=never/hardly ever, 2=monthly, 3=weekly, 4=daily. <sup>b</sup> Frequency of occurrence rated on a 4 point rating scale: 1 = 0 times the last three months, 2=1-2 times the last three months, 3 =>every second month, 4= >once per month)

Additionally, as a part of child presence, a difference in diversity (i.e. the number of different activities the children were present in) between the two groups was found. In all domains the children with PIMD participated in a smaller number of different activities (mean value): differences were mainly found in outdoor activities, organized activities and outings (i.e. in activities occurring away from home). Overall the children with PIMD participated on average in 36 of the 53 activities in common, compared to the children with TD who participated on average in 46 of the 53 activities (Table 7).

**Table 7.** Description of child presence diversity, each domain of Child-PFA

Domain (number of activities in common)	Diversity of activities the children are present in, number of activities.			
	<i>Children with PIMD (N=60)</i>		<i>Children with TD (N=107)</i>	
	<i>Range</i>	<i>Mean</i>	<i>Range</i>	<i>Mean</i>
Indoor activities (15)	3-15	11,5	8-15	13,5*
Meals (7)	1-7	5,5	1-7	6,5*
Routines (8)	1-8	6	1-8	7*
Outdoor activities (8)	0-8	5	2-8	7,5*
Organized activities (4)	0-4	1,5	0-4	2,5*
Outings (9)	0-9	5,5	1-9	7,5*
Vacation and holiday cottage (2)	0-2	1	0-2	1,5*
All activities (53)	14-53	36	16-53	46*

\*= the mean value of diversity is significantly higher in the group of children with TD,  $p < .01$

## *Engagement*

The results of this research showed that the children with PIMD did not have a higher level of engagement in any of the 53 activities compared to the children with TD, although in 16 of the activities the children were found to be equally engaged. Consequently, in 37 of the 53 activities the children with TD were significantly more engaged. The fewest differences were found in outdoor activities, organized activities and outings. In organized activities, for example, engagement in the activities was equal in three of the four common activities (“going together to child’s leisure activities”, “going together to parent’s leisure activities” and “going to church”) and less for the children with PIMD in one of the activities (“going together to sibling’s activities”). Both groups showed a higher level of engagement in child-driven activities such as “joking and fooling around” and “playing with you or other adult”. Lower engagement was found, for example, in routine activities such as “cleaning the house” and “packing the school bag” (II).

## *Child presence and engagement in relation to each other*

When examining the relationship between child presence and child engagement of children with PIMD, it appeared that the type of activity the child participated in the least when compared to their peers with TD (i.e. outdoor activities, organized activities and outings) were the ones with the least differences between the two groups regarding child engagement, i.e. where the children with PIMD had the same level of engagement as their typically developing peers (II). However, in four routine activities; “morning routines”, “evening routines”, “packing school bag” and “picking up after playing”, the children with PIMD, on average, were not at all or somewhat engaged while the activity occurred weekly or daily. This was indicated by a rated difference between the median values above one step on the 4 point scales. The contrast indicates that the children with PIMD were only engaged to a lesser extent, even though these activities occur frequently in their families/in their home. This difference was not found in the group of children with TD.

## *Potential influences on child participation*

In this research, child participation was expected to be influenced by a number of different factors, internal and external to the child acting as either barriers or facilitators. In the following section, some examined participation-influencing factors are presented: factors related to the child with PIMD, the parents and the external personal assistants as well as specific participation-facilitating strategies used by parents and external personal assistants

### *The child with PIMD*

The child's motor ability was found to, mostly negatively, correlate to *frequency of occurrence* (and thus child presence) in the largest number of family activities. The positive correlations regarding the child's motor ability included physically demanding activities such as "going to the playground" and negative correlations were found for activities where the child could be expected to be less physically active, such as when "surfing the internet" and "story reading" (Table 8), (I).

There were also a high number of positive correlations between child cognition and *child engagement* including the activities "watching TV", "story reading", "having tea or coffee together" and "going to the library". Also, the child's motor ability and the child's health correlated with child engagement in a number of activities, mostly in a positive way. For example, motor ability correlated with engagement in "doing the dishes" and the child's health correlated with engagement in "going to the playground" (Table 8), (II). A moderate correlation between child cognition and child's motor ability was found (correlation coefficient .309,  $p=.024$ ).

### *The parents*

Factors related to the parents capable of influencing child participation were also studied. The frequency of occurrence and diversity of family activities were seen as opportunities for participation offered by the parents to the child. The frequency of occurrence of different family activities in families with a child with PIMD was, as described above, generally lower than in

families with children with TD and, in addition, the diversity of activities was lower. As described previously, four physically less demanding activities, e.g. “watching a movie”, occurred significantly more often in families with a child with PIMD while 25 more physically active activities, e.g. “cleaning the house” and “playing outside with other children”, occurred significantly more often in families with children with TD (I). Consequently it was generally found that a lower frequency and diversity of activities was offered to the children with PIMD.

The *frequency of occurrence* of family activities in families with a child with PIMD positively correlated to family income in a higher number of activities than in the families with children with TD. In contrast, the education of the father and mother in families with children with TD correlated both positively and negatively to the frequency of occurrence of family activities in a higher number of activities compared to families with a child with PIMD. Here, positive correlations regarding both mother’s and father’s education were found in “story reading”, “playing instruments”, “going together to child’s leisure activities”, “going to the library”, “going to theatre/cinema/concerts” and “going to holiday cottage” and a negative correlation regarding both mother’s and father’s education were found in “doing handicraft” (Table 9a-b), (I).

Child *engagement* in families with a child with PIMD, was negatively correlated to family income and, father’s and mother’s education. In families with children with TD, child engagement correlated to family income, education of the father and education of the mother in only a few activities and without any clear pattern. With few exceptions, the correlations which occurred between the family characteristics and frequency of occurrence of family activities and child engagement were relatively weak (Table 9a-b), (II).

At least one parent was working as a paid personal assistant for the child in 55 of the 60 families with a child with PIMD. Parents as paid personal assistants significantly more commonly assisted the child when “having breakfast together” and when “visiting friends that did not have children”, than external personal assistants (Table 10b), (IV).

**Table 8.** Relationship ( $r_s$ ) between child characteristics and participation in family activities (frequency and engagement). Families with a child with PIMD (N=60)

Family activity	Motor ability		Cognition		Health		Communi- cation	
	Fr.O	Ch.E	Fr.O	Ch.E	Fr.O	Ch.E	Fr.O	Ch.E
<i>Positive correlations</i>								
Watching movie				.44				
Watching TV		.40		.43		.35		
Playing computer games		.32		<b>.52</b>		<b>.50</b>		.36
Surfing the internet				<b>.55</b>		<b>.59</b>		
Doing handicraft		.45						
Playing with pets				<b>.60</b>		<b>.54</b>		
Story reading				.32				
Being together in the kitchen								.30
Doing the dishes		<b>.68</b>						
Laying the table/cleaning away		<b>.50</b>						
Having tea or coffee together				.36				
Having dinner together				.34				
Cleaning the house				.40				
Packing school bag				<b>.48</b>				
Picking up after playing				.43				
Gardening		<b>.48</b>		<b>.45</b>				
Playing outside with other children						.37		
Playing outs. with you or other adult	.27							
Going on a swing	.35							
Playing in the sandpit	.28							
Going to the playground	.44			<b>.65</b>		<b>.62</b>		<b>.62</b>
Going to the library				.42				
Going to theatre/cinema/concerts			.38	.41		.41		
Going on vacation			.28	<b>.52</b>				
<i>Negative correlations</i>								
Watching TV						-.28		
Surfing the internet	-.31							
Playing with you or other adult	-.34					-.32		
Story reading	-.32							
Playing instruments	-.38							
Exercising physical therapy at home	<b>-.59</b>	-.40	-.28					
Being together in the kitchen						-.31		
Laying down for rest	-.36			<b>-.45</b>		-.28		
Going for a walk				-.37				
Playing ball games							-.30	
Going to habilitation center activities	-.30							
Visiting friends who have children								-.41

Correlations with significance ( $p < .05$ ), all 53 activities tested. Fr.O = Frequency of occurrence of family activities. Ch E = Child engagement. Bold = over 20% of the variance can be explained ( $r_s = >.447$ ).

**Table 9a.** Relationship ( $r_s$ ) between family characteristics and participation in family activities (frequency and engagement), positive correlations. Families with a child with PIMD (N=60) and families with children with TD (N=107)

Family activity	Families with a child with PIMD			Families with children with TD		
	Fr.O	Ch.E	Fr.O	Ch.E	Fr.O	Ch.E
<i>Positive correlations</i>						
Playing computer games	.29					
Playing with you or other adult						
Story reading			.27		.20	.44
Playing instruments					.27	.25
Dancing	.29					
Exercising physical therapy at home			.37			
Cooking/baking	.26					
Picking up after playing						
Going by car to and from school					.25	
Gardening	.31					
Going together to child's leisure activities				.24	.25	.29
Going to the playground					.25	.23
Going to the library					.26	.24
Going to theatre/cinema/concerts	.32					
Visiting relatives	.36					
Going to parties	.30					
Going out in the nature						
Going on vacation						
Going to holiday cottage	.29					
				.31	.25	.40
				.24	.38	.22

Correlations with significance ( $p < .05$ ), all 53 activities tested. Fr.O = Frequency of occurrence of family activities. Ch E = Child engagement. Bold = over 20% of the variance can be explained ( $r_s > .447$ ).



### *The external personal assistants*

In 53 of the 60 families, one or more external personal assistants were working with the child, and in this research they were considered in different ways to influence the child's participation. The number of external personal assistants for a single child varied between 0 and 9 (Table 2b), (IV).

The external personal assistant's role or function, *in relation to the child* was described by the selected, interviewed 11 parents and nine external personal assistants to include acting as a substitute for the child's basic functions. This was done by interpreting the child, being the child's communicator, arms and legs, performing care and serving as the driving force for the child. The role in relation to the child was furthermore described as supporting the child's everyday life in routines, play, and leisure activities as well as to providing relationship support between the child and others (for example to be a part of the family) which included accentuating the child as well. The external personal assistant was also expected to support maturation by supporting the child's development and helping the child to engage (Table 10a), (IV).

The external personal assistant's role *in relation to the families* was described as having a shared understanding wherein the external personal assistant was expected to recognize that his or her presence was a compromise for the family and that their role was something to be built up or developed. The external personal assistants were, moreover, expected to exhibit relational skills by being responsive and respectful towards the family, being open and honest in communication as well as being "a good match". In addition, the need to fulfill one's function was included in the external personal assistant's relation to the parents. This was accomplished by supporting the family's everyday life and reducing their experience of being burdened. The external personal assistant was found to significantly more commonly assist the child in "playing computer games", "playing indoors with other children" (siblings included) and in activities away from home such as "going together to child's leisure activity" and "going to the library" (Table 10b), (IV).

**Table 10a.** The role of the external personal assistant in relation to the child

<i>Qualitatively described role in relation to the child. Categories and examples of citation from interviews with parents and external personal assistant (N=11+9)</i>	<i>Quantitative description of the amount assistance needed by the child (N=60). Median values<sup>1</sup> (interquartile ranges)</i>			
<i>To substitute basic functions</i> "we mostly try to listen to her verbally and the assistant helps with the interpretation" (parent 1)	Indoor activities	2(2-3)	to	4(3-4)
	Meals	3(2-4)	to	4(3-4)
	Routines	3(2-4)	to	4(4-4)
<i>To support everyday life</i> "that she should be able to do things that all 10 or 11-year-olds do, at least sometimes. Access is not always possible. The most important thing I do...is to be there. Support her and make sure she gets to do things well" (assistant 11)	Outdoor activities	4(2-4)	to	4(3-4)
	Organized activities	4(2,25-4)	to	4(3,25-4)
	Outings	4(3-4)	to	4(3,5-4)
	Vacation/holiday cottage	4(3,5-4)	to	4(4-4)
<i>Relationship support</i> "...there was Mark and I and one of Mark's classmates, it's not really the norm for them to go home with each other after school like other children of their age do, so we try to organize that for them" (assistant 6)				
<i>To support maturation</i> "...that one should help him develop as well, not just mind him and be there, I feel that there should be something in it for him as well" (assistant 8)				

<sup>1</sup>amount of assistance needed rated on a 4-point rating scale: 1=not at all, 2=somewhat, 3=, rather much, 4=much assistance is needed

**Table 10b.** The role of the external personal assistant in relation to the family

---

<i>Qualitatively described role in relation to the family. Categories and examples of citation from interviews with parents and external personal assistant (N=11+9)</i>	<i>Quantitative comparison of presence of personal assistants in the activities (where the assistance is performed), analyzed using Chi Square (N=60)</i>
<p><i>Shared understanding</i></p> <p>“...but somewhere along the line it must be allowed that its difficult, and that its a hard job for them as well, but of course it affects me that my home is my place of work” (parent 2)</p> <p><i>Exhibit relational skills</i></p> <p>”it requires a responsive assistant [...] it can’t be someone who wants to be looked after themselves. That can lead to conflicts. They must have integrity and not take over the whole house. A lot of personal chemistry and give and take from both sides” (parent 9)</p> <p><i>Fulfill a function</i></p> <p>”other family members should make the dinner and so on. The mother can’t breastfeed (the little brother) at the same time as she showers Dave...(assistant 7)</p>	<p>The <i>external personal assistant</i> significantly more commonly were present in the following activities:</p> <p>Playing computer games, Playing with children (friends/siblings), Playing outside with other children, Going on a swing, Going for a walk, Playing in the sand pit, Going together to child’s leisure activity, Going to the library (p&lt;.05)</p> <p>The <i>parent as a paid personal assistant</i> significantly more commonly were present in the activities:</p> <p>Having breakfast together, Visiting friends who do not have children (p&lt;.05)</p>

---

### *Strategies that may facilitate child participation*

The 11 interviewed parents as well as the nine interviewed external personal assistants described certain ways to facilitate child participation including child engagement. These strategies were divided into strategies related to the child's proximal environment and strategies related to the child.

Suggested strategies related to the persons in the proximal or micro environment of the child included making the activities available and acceptable for the child. This could be done by physically adapting the activity and making the activity attractive. The strategies also included the persons in the proximal environment having good knowledge about the child by knowing and interpreting the child. It also included having a positive attitude by showing one's own engagement, seeing possibilities and having an encouraging attitude. With regard to the child, it was described as important to give the child a sense of belonging by making the child feel a spirit of community and feel in focus. It was deemed important to assist children in understanding what was going on by helping them be prepared, able to recognize and by letting them receive an explanation of what is going on. Furthermore it was deemed important to give the child opportunities to influence the situation by asking questions, giving him or her chance to tell and allowing the child to decide. In addition, for the child to achieve participation/engagement the child's feeling of being needed was stressed, meaning that child needed to have a task in which to succeed (Table 11), (III).

In regard to strategies that may facilitate child participation, the group of children with PIMD in this research (N=60) was found to need much or considerable assistance to perform the activities. However the level of assistance needed was reduced in less physically activities such as "watching a movie" and "listening to music" (Table 10a), (IV). Moreover, in the group of children with PIMD the total number of hours of personal assistance ranged up to 225 per week (Table 2b), (IV).

**Table 11.** Strategies related to improved child participation: Content areas, categories and examples of citations from interviews with parents and external personal assistants (N=11+9)

<b>Facilitating strategies related to the child's proximal environment</b>	<b>Facilitating strategies related to the child</b>
<p><i>Availability and acceptability of the activity</i></p> <p>"... this morning for example he was supposed to take his medicine but absolutely didn't want to so he tried to roll away. He has a octopus cuddly toy and the octopus helped to inject the medicine and then it was OK, so it's like, making it a bit of fun" (parent 2)</p>	<p><i>A sense of belonging</i></p> <p>"If Mary and I are eating by ourselves or have grandma or grandpa here or his brothers are home and he sits next to and listens or laughs if something crazy comes up" (parent 6)</p>
<p><i>Good knowledge about the child</i></p> <p>"It is important to know about his life and what he has done and what his family situation is like and what he does...if you want to get him to communicate with other people then I need to know what he likes to do or what kind of life he has" (assistant 9)</p>	<p><i>Possible for the child to understand</i></p> <p>"...we dim the lights, sometimes we do things a bit differently, sometimes we sit down and read a story or lie down on the edge of the bed and read and talk and turn the light out, and then after a while Markus drifts off to sleep" (parent 8)</p>
<p><i>A positive attitude of people close to the child</i></p> <p>"...often you need to be active in the assistance so that she can do a bit more. Giving her a push, talk to her or helping her clap her hands (when watching sports). You should be active" (parent 1)</p>	<p><i>Opportunities to influence</i></p> <p>"She can't tell me now I want to be here with mum and dad or now I want us to go into my room, you have to ask her and if you don't get a clear answer then you have to try different things. She can let me know. And you need to try to find out what it is she really wants. If she indicates that it's not right then we leave that and go find something else. She's able to indicate no but she can also show when she is happy. If she thinks that something is fun then of course we keep at it. She gets to choose in everyday situations. When she can" (assistant 11)</p>
	<p><i>A feeling of being needed</i></p> <p>"He can't sing but he is in two choirs. Well, he likes music. Then he's the conductor instead. Then we need to be there and help hold the baton. He likes that" (assistant 10)</p>

# Discussion

In this section the results will be discussed in relation to the actual participation (presence and engagement) in family activities of children with PIMD and potential influences on child participation. Following this the methods will be considered in relation to the choice of scientific approach, the choice of design, the participants, the Child-PFA questionnaire and the procedure and analysis.

## Discussion of results

### *The actual participation of children with PIMD*

#### *Child presence*

Children with PIMD experienced a lower frequency of presence in family activities, with the biggest differences being in outdoor activities, organized activities and outings. Based on this finding, children with PIMD could be interpreted to experience both lower frequency (intensity) and a lower diversity of family activities compared to the children with TD. However, children with PIMD were found to experience four of the 53 activities more often than the children with TD. It is notable that these four were physically passive activities, and this finding was expected due to the severity of the impairment of these children's mobility. Child presence in family activities in children with PIMD has not explicitly been studied in earlier research. Nevertheless, the results of this research can be compared to the findings by Imms et al. (2008) in a study about participation of children with various levels of difficulties due to cerebral palsy. In their study the children with the most severe disabilities participated with less intensity and in a lower variety of activities, than the children with less severe disabilities. Similarly, Raghavendra et al. (2011) have found that children with physical disabilities in combination with complex communication needs participated in activities closer to home rather than in the community. Consequently, children with PIMD can be expected to experience both lower frequency and less variety

of proximal processes compared to children with TD, resulting in reduced participation.

### *Child engagement*

The lower level of engagement found in the family activities of the children with PIMD compared to the children with TD can be interpreted as the children with PIMD have weaker expressions in their proximal processes (Bronfenbrenner & Ceci, 1994). Both children with PIMD and children with TD showed higher engagement in “fun” activities, (i.e. child-driven activities) and lower engagement in routine activities. There is a dearth of studies on levels of child engagement in different activities. Imms et al. (2008), however, have reported that children with cerebral palsy have a high preference/a high level of enjoyment (which may be seen as construct related to engagement) in outside-of-school activities but a lower preference/level of enjoyment in self-improvement activities. In contrast to the current research on children with PIMD, other studies have found children with disabilities enjoy activities to the same extent as children with TD (Engel-Yeger, Jarus, Anaby, & Law, 2009; M. King, Shields, Imms, Black, & Ardern, 2013; Ullenhag, Krumlinde-Sundholm, Granlund, & Almqvist, 2014). This difference is expected to be due to the level of severity of difficulties associated with PIMD. Overall, the level of child engagement is an integral part of the child’s participation and can be seen as a contribution to, as well as an outcome of, the proximal processes. Where there are weak proximal processes there is a risk that the children cannot use and develop their limited potential, which in turn may reduce optimal functioning or development.

### *Child presence and engagement in relation to each other*

Results showed that the that the type of activities that the child was found to experience least often, compared to their peers with TD, (i.e. outdoor activities, organized activities and outings) were the ones with the least differences in child engagement, that is, the children with PIMD and the children with TD showed higher level of engagement in the same type of activities, i.e. in particular in child-driven activities. The low engagement in

some frequently occurring routines, for example “doing morning routines” and “doing evening routines” in children with PIMD, may occur because the children find these activities uninteresting and/or that the children have the opportunity to rest at these times. Alternatively, the parents or the external personal assistants may be so focused on performing the routine that they do not respond so readily to the relatively weak expressions of engagement by many children with PIMD (Iacono, Carter, & Hook, 1998).

## *Potential influences on child participation*

### *The child with PIMD*

The high number of correlations between the child’s motor ability and the frequency of occurrence of (and thus child presence in) family activities indicated the impact of the child’s motor ability on participation. The better motor ability the children had, the higher was the occurrence of physically demanding activities and children with poorer motor ability had a higher frequency of occurrence of less physically demanding activities. Thus, consistent with previous research (Bult et al., 2011), the reduced motor ability of children with PIMD can be interpreted as a barrier to the frequency of occurrence and children’s presence in the activities.

Likewise child engagement was found to be affected by factors related to the child, such as child cognition which was found to be positively correlated with a high number of activities. In most of these activities, it could be expected to be of importance for the child to understand what is going on. To a somewhat lesser extent the child’s health and motor ability can be interpreted to affect child engagement. The activities where health correlated positively with engagement such as “playing computer games” and “going to the playground” require alertness in order to enjoy the activity. The child’s motor ability did affect the child’s engagement in activities that require good motor ability, such as “doing handicraft” and “gardening”. However, these findings need to be viewed in the light of the fact that a moderate correlation was found between child cognition and child motor ability, in the children with PIMD.

Having a PIMD can be understood to act as a barrier to participation. The present research indicates, however, that different impairments associated with PIMD affect child participation in different ways. Child motor ability was found to be the main barrier to presence in family activities and child cognition was found to be the main barrier to engagement in family activities. Furthermore, the findings suggest that although children with PIMD were less present in outdoor activities, organized activities and outings compared to children with TD, there was a smaller difference in child engagement, and so it seems the children find such activities interesting. Thus, in accordance with findings described by Dunst et al. (2001), interest in an activity such as enjoyment in playing can be interpreted as a facilitator for child engagement.

### *The parents*

The family activities that occur, the frequency and diversity of the occurrence and children's presence in the activities can be considered to depend on what the parents find practical and rewarding. In this research, the frequency of occurrence of family activities was found to be generally lower in families with a child with PIMD compared to that of families with children with TD. The few exceptions found were in activities that can be considered to require less physical activity from the child, such as "listening to music" and "going for a walk" (the child is probably in a wheel chair). This can be related to Dunst et al. (2001) who found that children with different impairments participating in more diverse activity settings demonstrate more social responsiveness than children participating in less diverse activity settings. Additionally, the importance of the frequency of being in stimulating activities, or proximal processes, and the time spent in these activities (which is not studied in this research) is known to be of importance for child development (Bronfenbrenner, 1995; McWilliam et al., 2003) and consequently the child's functioning and well-being. For parents, fulfilling the needs of a child with PIMD is time-consuming and may be a reason for the family's reduced capacity to offer opportunities for participation (Tadema & Vlaskamp, 2010). Nevertheless, the results mirror what the parents consider to be the best for the family as a whole, in other words what leads to the best balance in the family system.

Children with PIMD need a supportive environment and the importance of somebody facilitating activities for children with PIMD and “setting the scene” for activities, i.e. arranging the activity settings was evident in this study. This finding can be compared to Maxwell’s view when operationalizing environmental dimensions related to participation (Maxwell, 2012). Maxwell found that frequency of attending and doing an activity related to the availability and accessibility of the activity and the degree of involvement when being in the activity related to how well adapted and acceptable the activity was for the child and others in the child’s close environment. Similarly, Dunst et al. (2001) have stressed the importance of activities being acceptable for the child and have shown that the child’s interests, engagement, competence as well as mastery can be encouraged through the activity settings.

In the families with a child with PIMD, family income was found to positively correlate to the frequency of occurrence in a higher number of activities when compared to families with children with TD. In contrast, in families with children with TD the education of the mother and father was associated with a higher number of activities compared to families with a child with PIMD. These different patterns are partly similar to what has been found by Law et al. (2006). In their study which included children with physical limitations it was found that child participation was less diverse in families reporting lower income. This could mean that family income can either be a facilitator or a barrier when it comes to the type of activities that occur in families with a child with disabilities. In the current research, we found that the higher family income, or mother’s and father’s level of education, the lower the child’s engagement. This raises the question of whether parents with children with PIMD with lower income have more time or more commonly make it their goal to engage children in different home activities than parents with higher income. However, it has to be noted that with few exceptions the correlations between the examined family characteristics and the frequency of occurrence of family activities/child engagement were low and thus conclusions must be drawn with caution.

The place or setting where the child participates and is assisted is expected to influence the outcome of participation of the proximal processes. In 55 of the 60 families one or both parents were working as a paid personal assistant for

the child with PIMD. It was found that a parents as paid personal assistants significantly more commonly, assisted the child when “having breakfast together” and when “visiting friends who did not have children”, compared to when the external personal assistants assisted the child in these activities. This can be understood to be due to the parents’ need for privacy.

### *The external personal assistants*

Except parents working as paid personal assistants, in 53 of the 60 families up to nine external personal assistants worked for the child, although never more than two at a time. The 11 interviewed parents and the nine interviewed personal assistants described the role of the external personal assistants in relation to the child as substituting the child’s basic functions, supporting everyday life, providing relationship support and supporting maturation. In this, substituting the child’s basic functions, supporting everyday life and providing relationship support can be related to the ICF’s and ICF-CY’s components: Body functions, Activities and Participation (World Health Organization, 2001, 2007). Overall, it can be understood that the external personal assistants constitute important environmental factors with a reinforcing role in relation to the child. This is in accordance with what is stated in the LSS and SFB laws (SFS 1993:387; SFS 2010:110) which state that the purpose of personal assistance is to promote equality of living conditions and full participation in society. Personal assistance can therefore be interpreted as a facilitator for child participation.

The external personal assistants not only have responsibility in relation to the child with PIMD but also to the child’s family, of which they become a third party. Their role was described by the interviewed parents and external personal assistants as including a shared understanding, to exhibit relational skills and to fulfill a function (for the family). Fulfilling a function, in combination with the need to show sensitivity to the family’s life and integrity, points to the importance of achieving a balance between these aspects.

The external personal assistants assisted the child significantly more commonly in “playing computer games”, and when “playing indoors with other children” (siblings included), compared to the parents as paid personal

assistants. It could be interpreted that in such activities, children with TD usually on their own initiative relieve their parents. This relief is also desired in families with a child with PIMD. Likewise the external personal assistants' reason for assisting the child in activities away from home, when compared to parents as paid personal assistants, can be expected to be the result of the parents' desire for respite. This relieving role of a personal assistant is provided for in the Swedish laws (Government Bill 1992/93:159). An additional reason for the external personal assistants to assist the child away from home could be that they did not always feel comfortable being a third party in the family. There are similarities to the research of Imms et al. (2008) and Raghavendra et al. (2011) which found children with severe disabilities primarily participated in activities with other family members. Consequently, if assistance is only given to the child in the child's home, the child could become even more isolated compared to children with TD. In contrast external personal assistance given to the children with PIMD provides opportunities to participate in more diverse activities and thus more diverse proximal processes.

The desired characteristics of the external personal assistants have not explicitly been studied in this research, however eight of the nine interviewed external personal assistants had been employed to assist the child for more than 3 years. They could thus be expected to harmonize with the child and the family. Desired characteristics of external personal assistants have, however, been studied by Roos (2009). In Roos' research 12 adult assistance recipients stated that they wanted the personal assistant to be discreet, obedient (i.e. to act according to the desire of the assistance recipient), reliable, informative, alert, respectful, considerate, friendly, pleased and practical. Most of these characteristics relate to the importance of being responsive and respectful as expressed by the parents and personal assistants in this research on children with PIMD.

### *Strategies that may facilitate participation*

Participants interviewed in this research described various strategies they used to facilitate child participation. They stated that availability and acceptability of the activity, good knowledge about the child and a positive attitude of people close to the child were important for improved child

participation. These strategies relate to the child's environment. The importance of availability has also been reported by Hammel et al. (2008) who found access to opportunities, unrestricted by bodily impairments or disabling physical, social and political environments, to be prerequisites for participation. Parents of children with acquired brain injuries interviewed by Bedell et al. (2005) have described organizing or modifying the activity or the physical and social environment as strategies to promote social participation for the children. Likewise, the results of this research highlights that activities have to be acceptable, i.e. fun and interesting and, thus attractive for the child. This is in line with what has been reported by Heah et al. (2007). The interviewed parents and external personal assistants in this research also stressed that assisting the child requires considerable knowledge. Given that parents know their child best, they are the main providers of this knowledge to the external personal assistants and, in turn, the external personal assistants have a responsibility to learn about the child. The importance of communicating knowledge about the child has also been reported by Horn and Kang (2012) in their research regarding guiding the team around the child with PIMD in the development of an effective and individualized educational program. Both Hostyn and Maes (2013) and Horn and Kang (2012) reported that people may need assistance to understand the communicative behaviors of these children. In line with Arvidsson et al. (2008) who identified positive attitudes as a factor related to participation, the need for a positive attitude of people close to the child became obvious in this current research.

The parents and external personal assistants moreover suggested strategies within the activity for improved participation related to the child. This included giving the child with PIMD a sense of belonging, possibilities for the child to understand, opportunities to influence the situation and giving the child a feeling of being needed. Providing or nurturing a sense of belonging was realized to be in accordance with Antonovsky's salutogenic theory about the individual, where the importance of a "sense of coherence" is stressed (Antonovsky, 1987; Eriksson & Lindström, 2005). Furthermore, according to Antonovsky (1987), a sense of coherence includes comprehensibility, manageability and meaningfulness. These constructs are related to findings of this research; possibilities for the child to understand, the child having opportunities to influence and the child gaining a feeling of

being needed. Opportunities to influence can be associated with a child's contingency awareness. This awareness is known to lead to the child's understanding that the environment can be influenced. According to Dunst et al. (2008), stimulating behaviors in children with PIMD in a non-contingent manner results in a lower rather than a higher level of responding. Whaley and Bennett (1991) in their study about promoting engagement in early childhood in children with special needs also found that providing opportunities to make choices influenced engagement. In addition, similar to this research about children with PIMD, Hammel et al. (2008) found more elements conceptualized as participation. They included meaningful engagement/being a part of, personal and societal responsibilities, having an impact and supporting others, social connection, inclusion and membership, access and opportunities and choice and control. Accordingly, an awareness of facilitating strategies for improved participation in family activities is imperative.

The amount of assistance given is another strategy that facilitates participation. Overall, the children with PIMD in this research (N=60) needed much assistance in the activities, with somewhat less in less physically demanding activities such as "watching a movie" and "listening to music". In addition the total number of hours with personal assistance varied between 0 and 225 per week. This describes the children's dependency on others in order to achieve quality in the participation. The need for much assistance was expected due to the inclusion criteria of the research and is in accordance with the definition of PIMD (Nakken & Vlaskamp, 2002, 2007). This is likewise in accordance with the Swedish laws, which support people with considerable difficulty in daily life and who require extensive support and services, in order to receive personal assistance (SFS 1993:387; SFS 2010:110).

### *The time aspect*

Over time, the reduced occurrence of family activities, child presence and engagement of children with PIMD, is expected to result in children with PIMD not experiencing the same number or the same variety of activities. Instead, they become "specialized" in a certain set of activities. This is likely

to be an important influence on the child's everyday functioning and development (Almqvist, Uys, & Sandberg, 2007; Bronfenbrenner, 1995). The child becomes familiar and engages in certain activities and becomes more skilled or able in these and less in others. In addition for children with PIMD, the proximal processes might come to a standstill due to the often slow processes of these children (Björck-Åkesson, 1992). This suggests that the quality level of the proximal processes taking place in family activities is very important. Consequently the way in which the assistance is performed becomes paramount. Finding and accumulating facilitating strategies for improved participation in family activities in children with PIMD are thus of importance. Overall, as shown by Sameroff and Fiese (2000) and Sameroff (2009), a larger number of factors when acting together (either in the child or in the environment) over time is more influential than any individual factor.

## Methodological considerations

### *Choice of scientific approach*

Bronfenbrenner's bio-ecological model (1979) in combination with general systems theory (Bertalanffy, 1968) was chosen as the theoretical framework. If a reductive approach had been used meaning either a view of positivism/naïve realism or a view of social constructivism alone, information is expected to have been lost. For example, the biomedical model/biological model was derived from positivism/naïve realism and developed by medical scientists for the study of disease. Disease is identified as a measurable deviation from normal in the biomedical model/biological model. In this model there is no space for social, psychological and behavioral dimensions, and behavioral aberrations must be explained as disordered somatic processes (Engel, 1977). In contrast, the social model and social constructivism can be interpreted as a reaction to naïve realism where the actual impairment becomes subordinate and disability is viewed as a problem located in society rather than within individuals (Bhaskar & Danermark, 2006). From a social constructivism perspective, disability is dealt with through adjustment to the social and physical environment to ensure that needs and rights of people with impairments are met.

Consequently, when it comes to studies of disabilities and the outcome of participation, a non-reductionist perspective of is needed. According to Bickenbach (2009, p. 1193), such perspectives could potentially pave the way for the “realization of the human rights in the real-world context of culture and other human differences”.

In line with Bronfenbrenner’s bio-ecological model the child’s position can be emphasized, and at the same time the child can be seen as a part of bigger systems such as the family (Bronfenbrenner, 1979). In this context, there is general agreement about the importance of the family for children. General systems theory includes slow, gradual changes in characteristics (Wachs, 2000) thus also making it a suitable framework for research about children with PIMD. The general systems theory gave the opportunity to look at the research problem from a broad, bio-psycho-social perspective (Engel, 1977). With this perspective there are at least two reasons for the interdisciplinary view taken. Firstly, the studied topic, participation, is multidimensional and thus needs to be viewed from different perspectives. Secondly, interdisciplinarity is a natural consequence of the choice of general systems theory as a theoretical framework. According to Abolela et al. (2007) interdisciplinary research should be based upon a conceptual model that links or integrates theoretical frameworks from different disciplines, uses study design and methodology that is not limited to any one field, and requires the use of perspectives and skills of the involved disciplines throughout multiple phases of the research process.

### *Choice of design*

The design was cross-sectional. Thus, the important mutual effect of context on the child and the child on context that takes place over time was not studied. The importance of time is emphasized in the transactional model by Sameroff (2009). Using the transactional model, Wilder and Granlund (in press) found that children with PIMD, over time, tend to become more isolated even within their own families. In their research the number of members in the social networks of children with PIMD seemed to stay stable or even decrease over time with several network members, for example grandparents having important knowledge about the child, becoming more

peripheral. These critical issues need to be considered in the pursuit of facilitating child participation in family activities of children with PIMD.

Participation has a multidimensional meaning and thus many factors must be involved simultaneously in studies of the phenomenon. This does not merely justify the practice of the bio-ecological model as a framework in this research but also, as a consequence, invites the use of different research methods. Accordingly both quantitative and qualitative methods were used because both objective and subjective point of views were important to answer the research questions.

### *Participants*

The most important participants in this research, however indirectly studied, were a total of 60 children aged 5-20 years with PIMD who were making use of the right to personal assistance, and 107 children aged 5-10 years in the group of children with TD. The age difference of the two groups of children needs to be elucidated. It would have been ideal to have both groups of children of the same age. However, children with TD aged 5-10 years still do activities together with their families and earlier studies have shown a significant decline in family-based activities taking place from age 10-12 years (Ullenhag et al., 2014). We therefore sought an age group that might better reflect typical family participation. In addition, Kruijff and McWilliam (1999) who included children without and with disabilities in their research found that the level of engagement was not age-related. In regard to the age differences of the two studied groups, the increasing discrepancy over time between the developmental and chronological ages of children with PIMD must also be emphasized.

The response rate in the group with a child with PIMD was low. The reason for this is unknown, but the phenomenon has been reported in other studies with similar target groups, for example, by King et al. (2009). It may indicate lack of time and energy of families of children with disabilities to be involved in surveys. The purposeful selection of participants for the qualitative part of the research was based on a high level of child engagement in selected activities from the questionnaire such as in “joking

and fooling around”, “having tea or coffee together”, in “playing with other children” and in other activities that were interpreted as examples of important activities for the child. Good examples were sought to enable rich data collection through the interviews with the parents and external personal assistants regarding strategies to facilitate child participation and engagement and thoughts about what should be included in the role (or function) of the external personal assistant.

The impact of the child’s siblings on the child has not been studied in this research. Nonetheless, it can be assumed that siblings play an important role for the participation in family activities of children with PIMD.

### *The Child-PFA questionnaire*

An existing, validated questionnaire should ideally have been used (de Vet et al., 2003). However, due to the lack of such a questionnaire measuring participation in family activities of children with PIMD, the Child-PFA was developed. By doing this, the importance of child participation as a part of the family was acknowledged in accordance with the views of McConachie et al. (2006). Nevertheless, developing a questionnaire measuring the construct of participation is a challenge (Whiteneck & Dijkers, 2009).

In developing the Child-PFA several aspects of validity had to be addressed such as construct validity and internal validity (Kazdin, 2003; Shadish, Cook, & Campbell, 2002). In a bid to reach *construct validity* of Child-PFA, theories about children with TD, children with PIMD, family activities, personal assistance and participation were studied and then discussed in the CHILD research group. This included pursuit of an understanding of the constructs, how to assess them and also how to ensure that the inferences could be warranted from the participants and settings - a comprehension of the occurring “cause-and-effects”. As a result, the background section of Child-PFA included demographic aspects expected to play a role in child participation, such as information about the child’s disabilities, support (e.g. personal assistance) and information about the family. In the participation section of Child-PFA the way of viewing and operationalizing participation as a multidimensional concept was furthermore in line with recent research

on the subject (Granlund et al., 2012; Maxwell, 2012). This resulted in frequency of occurrence of family activities (seen as opportunities for participation), child presence and child engagement being studied. The pilot study that followed was conducted to further improve the content and validity of the questionnaire. However, participation in family activities of children with PIMD is multifaceted, and the Child-PFA did not capture all aspects. For example, not only can the frequency of presence be said to be of importance for a child's participation, so too is the time spent in the activities. The Child-PFA did not include any questions about that. The questionnaire included examples of a wide range of family activities, but when, for instance, considering the high number of weak loadings ( $<.3$ ) when performing exploratory factor analysis, some of these could have been excluded, partly in order to obtain more interpretable factors.

*Internal validity* addresses how the chosen independent variables are related to the dependent variable i.e. the outcome (Kazdin, 2003; Shadish et al., 2002). The participation section of the Child-PFA began with information about what to take into consideration when answering. This was to improve clarity. However, even though it is used in the questionnaire, the concept engagement was never defined. This was not assumed to be necessary because the concept is a part of everyday Swedish vocabulary and does not appear to have any competing meanings. Likewise, none of the respondents in the pilot study reported difficulty with what would be included in the concept. However, having two versions of the questionnaire in this research, one web version and one paper version can have posed a threat to internal validity. The questions were the same, but in the web version the respondent could be forced to answer with one single alternative if that was expected, whereas in the paper version the parents had the opportunity to give more than one answer. Another threat to the internal validity was the high attrition rate, especially in the group of families with a child with PIMD. On the other hand, for those answering the questionnaire it might have resulted in too high a score as a way to appear in a more favorable light than what might otherwise emerge. A possible reason for this exaggeration could be guilt. In addition, the information letter the families received included information about the expected time it would take to answer the questionnaire, which was estimated to be 45 minutes. It was later realized that it probably took much longer, which might have affected the response rate.

The need to include a measure of the changing abilities and autonomy as the children grow older in participation instruments for children has been emphasized by McConachie (2006). The Child-PFA has only been used for this cross-sectional study and its usefulness for prospective study is not known. In conclusion, due to the lack of available instruments in the area, it was necessary to develop a questionnaire to improve knowledge about child participation in family activities in children with PIMD. However, the Child-PFA needs to be further developed and evaluated for validity and, reliability and to improve utility.

## *The procedure and analysis*

### *The quantitative part of the research*

Only a fraction of all the families with children with PIMD in Sweden answered the questionnaire, which may pose a threat to *external validity* and thus the ability to generalize the findings. The 60 families were all members of one or more of the three organizations. Asking other parents might have provided a different result and likewise in the group of families with children with TD. Knowledge of the Swedish language was required, which may have excluded some families. In general, studies using questionnaires to collect data are limited by the underlying risk that information is obtained from predominantly well-functioning families and/or those that have a preference for participation in a study. Another threat to the external validity was the given time span to consider when answering questions about organized activities and outings. This time span was three months and considering the time of the year when the questionnaire was received by the families (winter time) the response might not reflect the typical family life at other times of the year. However, both groups of families received the questionnaire at about the same time.

To reach good statistical *conclusion validity* it was important to use the right statistical methods in the analyses, which in this research meant predominantly non-parametric tests to validly assess ordinal level data. A higher number of participants would have increased the power further,

resulting in a reduced risk of making a type II error (Kazdin, 2003; Shadish et al., 2002). However, the increased risk for type I errors needs to be emphasized even more. This arose because of the large number of statistical tests that had to be performed due to the large number of listed family activities. For this reason, patterns of activities were primarily sought, not individual activities.

### *The qualitative part of the research*

The purpose of also using content analysis in this research, was to provide further, new insights, a representation of facts and a practical guide to action from data (Krippendorff, 2013). Inductive content analysis, based on Elo and Kyngäs (2008), was chosen as the appropriate method given the limited knowledge about children with PIMD and their participation in family activities in the literature.

In qualitative research the concepts of credibility, dependability and transferability are commonly used to describe different aspects of trustworthiness (Graneheim & Lundman, 2004). Trustworthiness was pursued. To enhance *credibility*, people in the child's micro environment representing good examples, found in the quantitative part of the research, were interviewed to find key factors for facilitating participation. The interviews provided opportunities to seek individual parents' and employed external personal assistants' ways of facilitating participation in the daily life of the child by asking exploratory questions as well as follow-up questions. Conducting the interviews by meeting the parents "eye to eye" made it easier to ask follow-up questions based on what the parent was telling. This sensitivity was considered less necessary in the interviews with the personal assistants where there is another kind of emotional tie to the child. Nevertheless different ways of interview data collection may have posed a threat to credibility. Credibility was also enhanced during the analysis process of finding categories answering the research question. Agreement in interpretation throughout the analysis processes was reached through dialogue with co-researchers. Furthermore, the group of informants showed heterogeneity in being parents and personal assistants respectively, by caring for boys or girls of different ages and by living in/working in different sizes of municipalities in Sweden. *Dependability* was enhanced by using the same

researcher to conduct all the interviews and an effort was made to concentrate the time period for conducting the interviews as well as the analyses to reduce any risk of inconsistency. Finally, the *transferability* of these qualitative results was improved by clarity and depth of description of the participants, settings and studied aspects. Also, the results from the qualitative studies are supported by the congruity of the findings from other studies, for example by Heah et al. (2007). However, finally it has to be stressed that considerations must be given to each child's and family's needs and uniqueness.

# Conclusions

This research was intended to improve the awareness and knowledge of participation in family activities of children with PIMD where participation is understood to have at least two dimensions, presence and engagement. These dimensions are influenced by various factors and the factors constituting the core of proximal processes. It is the total force of these factors that control a child's functioning.

A child with PIMD affects the family's functioning and the family's functioning affects the child. This involves a family with a child with PIMD functioning differently from other families in several aspects. To meet their everyday needs, families with a child with PIMD - when compared with other families - partially prioritize other family activities and allocation of their time. This is seen when certain activities occur more frequently in families with a child with PIMD compared to families with children with TD and, in turn, result in the child with PIMD being offered fewer activities in which to participate.

The influential factors partly differ between presence and engagement. The activities in which the child is present are influenced by the characteristics of the child, such as motor ability. On the other hand, the child's engagement is affected by the child's cognitive abilities, type of activities in which he or she participates and the responsiveness to the child of people in the child's environment. The child's presence and engagement are influenced by family socio-economic factors to a lesser extent than in families with children with TD.

Factors acting as barriers result in a child with PIMD experiencing fewer and less varied activities to generate engaged interaction in proximal processes within family activities compared to children with TD. Accordingly, the awareness of facilitating strategies for improved participation in family activities was found to be imperative. For example, there needs to be someone in the environment who sets the scene/stage and facilitates the activity so as to increase presence and engagement in proximal processes based on the child's needs. The family, in turn, needs someone who can

provide respite to obtain balance in the family system. External personal assistance includes these dual roles which are of importance in families with a child with PIMD.

# Implications

There remains a need for broad and continued consideration of questions regarding mutual influence between the child, the family and the external personal assistant over time. In addition, questions about the factors which pull the child away from and towards the family must likewise be taken into account. Such *awareness* and *knowledge* about the impact of transactional regulations on participation and thus development would help in the identification and implementation of interventions, such as recommendations, for the child with PIMD and his or her family needs. The goal of such interventions is to better understand and improve child participation in the proximal processes of everyday life. These interventions, in turn, would benefit from further inquiry; this could be accomplished through video observations, for example.

Furthermore, an external personal assistant becomes a third party of the family unit and his or her role in relation to the child must thus be accompanied by discussions particularly regarding the assistant's role as a support/relief for the family as a whole. Within such discussions, an understanding of and sensitivity to the family's unique needs must be included to achieve the stability desired within their family system.

## **Svensk sammanfattning**

### **Barn med omfattande funktionsnedsättningar och deras delaktighet i familjeaktiviteter**

Familjen är barnets viktigaste miljö och i denna så kallade mikromiljö erbjuds ett rikt utbud av vardagsaktiviteter. Dessa aktiviteter kan i sin tur ge barnet möjlighet till utvecklingsbefrämjande samspel, så kallade proximala processer, vilka också är av betydelse för barnets välmående och fungerande.

Att ha omfattande funktionsnedsättningar innebär att ha intellektuella svårigheter kombinerat med begränsningar när det gäller fysiska förmågor och sensorik (t.ex. synnedsättning), vanligtvis också kombinerat med medicinska besvär (t.ex. epilepsi). Detta påverkar barnets förutsättningar för delaktighet. Att ha ett barn med omfattande funktionsnedsättningar kan i sin tur leda till stress och ibland obalans i familjens vardag. För att underlätta familjers vardag och återställa balansen erbjuds personlig assistans via det svenska socialförsäkringssystemet. De utomstående personliga assistenterna, liksom föräldrarna, kan ha en betydelsefull påverkan på barnets delaktighet i familjen.

Kunskapen om delaktighet i familjeaktiviteter för barn med omfattande funktionsnedsättningar är begränsad, och detsamma gäller hur förbättrad delaktighet kan uppnås genom att stödja barnet eller genom att stödja individer i barnets familjesystem. Det övergripande syftet med denna avhandling var därför att utforska delaktighet i familjeaktiviteter för barn med omfattande funktionsnedsättningar och att hitta strategier som kan underlätta för deras delaktighet. Ett frågeformulär kallat Child-PFA besvarades av 60 familjer med ett barn med omfattande funktionsnedsättningar och av 107 familjer med barn med typisk utveckling. Efter det intervjuades 11 föräldrar från de 60 familjerna med barn med omfattande funktionsnedsättningar och nio utomstående personliga assistenter till barnen i dessa familjer. Intervjufrågorna handlade om vilka

strategier som användes för att underlätta barnets delaktighet och om den utomstående personliga assistentens roll.

Utgångspunkten i studierna var att delaktighet dels handlar om att fysiskt närvara i aktiviteter och dels om att vara engagerad i det man gör. Resultaten visade att barnen med omfattande funktionsnedsättningar var *närvarande* i familjeaktiviteter minde ofta och att de deltog i en mindre variation av aktiviteter, jämfört med barn med typisk utveckling. Undantag fanns för fyra fysiskt mindre krävande aktiviteter som t.ex. lyssna på musik och promenera. Faktorer som påverkade närvaron i aktiviteten var t.ex. barnets motoriska förmåga; ju sämre den motoriska förmågan var, desto mer sällan deltog barnet i mer fysiskt krävande aktiviteter. Dessutom fanns det ett samband mellan familjens socio-ekonomiska status och hur ofta aktiviteterna förekom. I familjer med barn med omfattande funktionsnedsättningar tycktes familjens inkomst ha en större betydelse, medan i familjer med barn med typisk utveckling var tendensen att det handlade om föräldrarnas utbildningsnivå när det gällde vilka aktiviteter man gjorde. Barnen med omfattande funktionsnedsättningar hade generellt sett ett lägre *engagemang* i aktiviteterna de deltog i och det var vanligt att en sämre kognitiv förmåga innebar ett lägre engagemang. Både barnen med omfattande funktionsnedsättningar och barnen med typisk utveckling visade dock ett högre respektive lägre engagemang i samma slags aktiviteter; engagemanget var högre i roliga aktiviteter som t.ex. i att busa och lägre i rutinaktiviteter som t.ex. att plocka undan efter sig. Dessutom var engagemanget hos barn med omfattande funktionsnedsättningar delvis högre i familjer med lägre inkomst och utbildningsnivå medan sådana samband över huvud taget var få i familjer med barn med typisk utveckling. Generellt sett var dock tendensen att familjens socio-ekonomiska status spelade mindre roll när det gäller barns delaktighet i familjer med barn med omfattande funktionsnedsättningar jämfört med i familjer med barn med typisk utveckling.

Resultaten visade också att den utomstående personliga assistenten för familjer med barn med omfattande funktionsnedsättningar hade dubbla roller. De hade dels en roll gentemot barnet som framför allt var stöttande eller förstärkande och dels en roll gentemot föräldrarna som kan beskrivas som balanserande, där att visa respekt och skapa avlastning var viktiga

innehåll. Utifrån sina erfarenheter av att samspela med barnet använde föräldrar och de personliga assistenterna sig av strategier för att underlätta barnets delaktighet. Det handlade om att göra aktiviteten tillgänglig, att själv ha ett positivt förhållningssätt och en god kunskap om barnet. Det handlade också om att ge barnet en känsla av att vara räknad med, möjlighet att förstå och påverka aktiviteter samt att ge barnet en känsla av att vara behövd.

**Sammanfattningsvis** kan det konstateras att barn med omfattande funktionsnedsättningar påverkar familjens fungerande t.ex. genom sina motoriska svårigheter samtidigt som familjens fungerande påverkar barnet, t.ex. genom de aktiviteter som de erbjuder barnet. Några få aktiviteter förekommer oftare i familjer med ett barn med omfattande funktionsnedsättningar jämfört med i familjer med barn med typisk utveckling medan flertalet aktiviteter förekommer mer sällan. Detta i sin tur resulterar i att barn med omfattande funktionsnedsättningar erbjuds färre aktiviteter att delta i. Faktorer som påverkar barnets delaktighet kan således antingen vara underlättande eller hindrande, där faktorer som är hindrande resulterar i att barn med omfattande funktionsnedsättningar jämfört med barn med typisk utveckling, är med om färre och även mindre varierande aktiviteter.

Denna forskning visar därmed på vikten av kunskap och medvetenhet om underlättande faktorer för förbättrad delaktighet i familjen. Exempel på underlättande faktorer är att någon, utifrån barnets behov, "sätter scenen", dvs. gör aktiviteten tillgänglig och rolig för att därigenom öka barnets närvaro och engagemang i de proximala processerna. Dessutom behöver familjen någon som kan ge avlastning för att skapa en balans i familjesystemet. Den utomstående personliga assistenten har dessa dubbla roller, vilket är av betydelse i familjer med barn med omfattande funktionsnedsättningar.

# References

- Aboelela, S.W., Larson, E., Bakken, S., Carrasquillo, O., Formicola, A., Glied, S.A., . . . Gebbie, K.M. (2007). Defining interdisciplinary research: Conclusions from a critical review of the literature. *Health Services Research, 42*(1p1), 329-346. doi: 10.1111/j.1475-6773.2006.00621.x
- Ahlström, G., & Wadensten, B. (2011). Family members' experiences of personal assistance given to a relative with disabilities. *Health & Social Care in the Community, 19*(6), 645-652. doi: 10.1111/j.1365-2524.2011.01006.x
- Almqvist, L., Uys, C., & Sandberg, A. (2007). The concepts of participation, engagement and flow: A matter of creating optimal play experiences. *South African Journal of Occupational Therapy, 37*(3), 10-15.
- Antonovsky, A. (1987). *Unraveling the mystery of health : How people manage stress and stay well*. San Francisco, CA: Jossey-Bass.
- Arvidsson, P., Granlund, M., & Thyberg, M. (2008). Factors related to self-rated participation in adolescents and adults with mild intellectual disability—a systematic literature review. *Journal of Applied Research in Intellectual Disabilities, 21*(3), 277-291. doi: 10.1111/j.1468-3148.2007.00405.x
- Bailey, D.B., Simeonsson, R.J., Buysse, V., & Smith, T. (1993). Reliability of an index of child characteristics. *Developmental Medicine and Child Neurology, 35*(9), 806-815.
- Bedell, G.M., Cohn, E.S., & Dumas, H.M. (2005). Exploring parents' use of strategies to promote social participation of school-age children with acquired brain injuries. *American Journal of Occupational Therapy, 59*(3), 273-284.
- Bedell, G.M., Khetani, M.A., Cousins, M.A., Coster, W.J., & Law, M.C. (2011). Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine and Rehabilitation, 92*(5), 765-773. doi: 10.1016/j.apmr.2010.12.029
- Bertalanffy, L.V. (1968). *General system theory: Foundations, development, applications*. New York: Braziller.
- Bhaskar, R., & Danermark, B. (2006). Metatheory, interdisciplinarity and disability research: A critical realist perspective. *Scandinavian*

- Journal of Disability Research*, 8(4), 278-297. doi: 10.1080/15017410600914329
- Bickenbach, J.E. (2009). Disability, culture and the UN convention. *Disability and Rehabilitation*, 31(14), 1111-1124. doi: 10.1080/09638280902773729
- Björck-Åkesson, E. (1992). *Samspel mellan små barn med rörelsehinder och talhandikapp och deras föräldrar: En longitudinell studie*. Göteborg: Acta Universitatis Gothoburgensis.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard Univ. Press.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human-development - research perspectives. *Developmental Psychology*, 22(6), 723-742. doi: 10.1037//0012-1649.22.6.723
- Bronfenbrenner, U. (1993). Ecological models of human development. In M. Gauvain & M. Cole (Eds.), *Readings on the development of children* (2nd ed., pp. 37-43). NY: Freeman.
- Bronfenbrenner, U. (1995). Developmental ecology through space and time: A future perspective. In P. Moen, G. H. Elder, K. Lüscher & U. Bronfenbrenner (Eds.), *Examining lives in context: Perspectives on the ecology of human development* (Vol. APA science volumes, pp. 619-647). Washington, D.C.: American Psychological Association.
- Bronfenbrenner, U. (1999). Environments in developmental perspective: Theoretical and operational models. In S. L. Friedman & T. D. Wachs (Eds.), *Measuring environment across the life span : Emerging methods and concepts* (pp. 3-28). Washington, DC: American Psychological Association.
- Bronfenbrenner, U., & Ceci, S.J. (1994). Nature-nurture reconceptualized in developmental perspective - a bioecological model. *Psychological Review*, 101(4), 568-586. doi: 10.1037/0033-295x.101.4.568
- Bronfenbrenner, U., & Evans, G.W. (2000). Developmental science in the 21st century: Emerging questions, theoretical models, research designs and empirical findings. *Social Development*, 9(1), 115-125. doi: 10.1111/1467-9507.00114
- Bult, M.K., Verschuren, O., Jongmans, M.J., Lindeman, E., & Ketelaar, M. (2011). What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Research in Developmental Disabilities*, 32(5), 1521-1529. doi: 10.1016/j.ridd.2011.01.045
- Clevnert, U., & Johansson, L. (2007). Personal assistance in Sweden. *Journal of Aging & Social Policy*, 19(3), 65-80. doi: 10.1300/J031v19n03\_05

- Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., & Teplicky, R. (2012). Development of the participation and environment measure for children and youth: Conceptual basis. *Disability and Rehabilitation, 34*(3), 238-246. doi: 10.3109/09638288.2011.603017
- De Kruijf, R.E.L., & McWilliam, R.A. (1999). Multivariate relationships among developmental age, global engagement, and observed child engagement. *Early Childhood Research Quarterly, 14*(4), 515-536. doi: 10.1016/S0885-2006(99)00028-9
- De Vet, H.C.W., Terwee, C.B., & Bouter, L.M. (2003). Current challenges in clinimetrics. *Journal of Clinical Epidemiology, 56*(12), 1137-1141. doi: 10.1016/j.jclinepi.2003.08.012
- Dunst, C.J., Bruder, M.B., Trivette, C.M., Hamby, D., Raab, M., & Mclean, M. (2001). Characteristics and consequences of everyday natural learning opportunities. *Topics in Early Childhood Special Education, 21*(2), 68-92. doi: 10.1177/027112140102100202
- Dunst, C.J., Trivette, C.M., Raab, M., & Masiello, T.L. (2008). Early child contingency learning and detection: Research evidence and implications for practice. *Exceptionality, 16*(1), 4-17. doi: 10.1080/09362830701796743
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107-115. doi: 10.1111/j.1365-2648.2007.04569.x
- Engel-Yeger, B., Jarus, T., Anaby, D., & Law, M. (2009). Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *American Journal of Occupational Therapy, 63*(1), 96-104.
- Engel, G.L. (1977). Need for a new medical model - challenge for biomedicine. *Science, 196*(4286), 129-136.
- Eriksson, M., & Lindström, B. (2005). Validity of Antonovsky's sense of coherence scale: A systematic review. *Journal of Epidemiology & Community Health, 59*(6), 460-466. doi: 10.1136/jech.2003.018085
- FUB. (n.d.). *FUB - Föreningen för barn, unga och vuxna med utvecklingsstörning [FUB - The Swedish National Association for Persons with Intellectual Disability]*. Retrieved 18 mars, 2014, from <http://www.fub.se/>
- Gallimore, R., Goldenberg, C.N., & Weisner, T.S. (1993). The social construction and subjective reality of activity settings: Implications for community psychology. *American Journal of Community Psychology, 21*(4), 537-560.
- Government Bill 1992/93:159. *Regeringens proposition 1992/93:159 om stöd och service till vissa funktionshindrade [Government bill 1992/93:159 concerning support and service for persons with certain functional impairments]*. Stockholm: Regeringen.

- Graneheim, U.H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112. doi: 10.1016/j.nedt.2003.10.001
- Granlund, M., Arvidsson, P., Niiä, A., Björck-Åkesson, E., Simeonsson, R., Maxwell, G., . . . Pless, M. (2012). Differentiating activity and participation of children and youth with disability in Sweden: A third qualifier in the international classification of functioning, disability, and health for children and youth? *American Journal of Physical Medicine and Rehabilitation*, 91(13), 84-96. doi: 10.1097/PHM.0b013e31823d5376
- Granlund, M., & Olsson, C. (2006). *Familjen och habiliteringen* ([Ny utg.] ed.). Stockholm: Ala.
- Granlund, M., & Roll-Pettersson, L. (2001). The perceived needs of support of parents and classroom teachers - a comparison of needs in two microsystems. *European Journal of Special Needs Education*, 16(3), 225-244. doi: 10.1080/08856250110074382
- Granlund, M., Wilder, J., & Almqvist, L. (2013). Severe multiple disabilities. In M. Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability* (pp. 452-474). New York: Oxford University Press.
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19), 1445-1460. doi: 10.1080/09638280701625534
- Hanson, M.J., & Lynch, E.W. (2004). *Understanding families: Approaches to diversity, disability, and risk*. Baltimore: P.H. Brookes.
- Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy*, 74(1), 38-47. doi: dx.doi.org/10.2182/cjot.06.10
- Hewitt, J. (2007). Ethical components of researcher-researched relationships in qualitative interviewing. *Qualitative Health Research*, 17(8), 1149-1159. doi: 10.1177/1049732307308305
- Hoogsteen, L., & Woodgate, R.L. (2010). Can I play? A concept analysis of participation in children with disabilities. *Physical & occupational therapy in pediatrics*, 30(4), 325-339. doi: 10.3109/01942638.2010.481661
- Horn, E., & Kang, J. (2012). Supporting young children with multiple disabilities: What do we know and what do we still need to learn? *Topics in Early Childhood Special Education*, 31(4), 241-248. doi: 10.1177/0271121411426487

- Hostyn, I., & Maes, B. (2013). Interaction with a person with profound intellectual and multiple disabilities: A case study in dialogue with an experienced staff member. *Journal of Intellectual & Developmental Disability, 38*(3), 189-204.  
doi: 10.3109/13668250.2013.798400
- Humanistisk-Samhällsvetenskapliga Forskningsrådet. [the Scientific Council for the Humanities and Social Sciences]. (1999). Forskningsetiska principer i humanistisk-samhällsvetenskaplig forskning. Antagna av humanistisk-samhällsvetenskapliga forskningsrådet (HSFR) i mars 1990, reviderad version april 1999. [ethical principles for scientific research in the humanities and social sciences (HSFR) in march 1990, rev. Ed. April 1990]. Retrieved Oct. 22nd, 2013, from <http://www.stringerfonden.org/documents/hsetikregler.pdf>
- Iacono, T., Carter, M., & Hook, J. (1998). Identification of intentional communication in students with severe and multiple disabilities. *Augmentative and Alternative Communication, 14*(2), 102-114.
- Imms, C., Reilly, S., Carlin, J., & Dodd, K. (2008). Diversity of participation in children with cerebral palsy. *Developmental medicine and child neurology, 50*(5), 363-369. doi: 10.1111/j.1469-8749.2008.02051.x
- JAG. (2014). *JAG - Jämlikhet Assistans Gemenskap [JAG - Equality, Assistance and Inclusion]*. Retrieved 18 mars, 2014, from <http://www.jag.se/>
- Kazdin, A.E. (2003). *Research design in clinical psychology* (4. ed.). Boston, MA: Allyn and Bacon.
- King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P. (2005). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development, 33*(1), 28-39. doi: 10.1111/j.1365-2214.2006.00613.x
- King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., . . . Young, N. (2004). *Children's assessment of participation and enjoyment (CAPE) and preferences for activities of children (PAC)*: San Antonio, TX: Harcourt Assessment, Inc.
- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M.K., & Young, N.L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics, 23*(1), 63-90.  
doi: 10.1300/J006v23n01\_05
- King, G., Petrenchik, T., Law, M., & Hurley, P. (2009). The enjoyment of formal and informal recreation and leisure activities: A comparison of school-aged children with and without physical disabilities. *International Journal of Disability, Development and Education, 56*(2), 109-130. doi: 10.1080/10349120902868558

- King, M., Shields, N., Imms, C., Black, M., & Ardern, C. (2013). Participation of children with intellectual disability compared with typically developing children. *Research in Developmental Disabilities, 34*(5), 1854-1862. doi: 10.1016/j.ridd.2013.02.029
- Krippendorff, K. (2013). *Content analysis: An introduction to its methodology* (3rd ed.). Thousand Oaks, Calif. ; London: SAGE.
- Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing* (2nd ed.). Los Angeles: Sage Publications.
- Laaksonen, C., Aromaa, M., Heinonen, O.J., Suominen, S., & Salanterä, S. (2007). Paediatric health-related quality of life instrument for primary school children: Cross-cultural validation. *Journal of Advanced Nursing, 59*(5), 542-550. doi: 10.1111/j.1365-2648.2007.04347.x
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., . . . Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine and Child Neurology, 48*(5), 337-342. doi: 10.1017/S0012162206000740
- Maes, B., Vos, P., & Penne, A. (2010). Analysis of daytime activities for children with profound intellectual and multiple disabilities in specific settings. *The British Journal of Development Disabilities, 56*(111), 123-136. doi: 10.1179/096979510799102907
- Maxwell, G. (2012). *Bringing more to participation: Participation in school activities of persons with disability within the framework of the international classification of functioning, disability and health for children and youth (ICF-CY)*. (Doctoral thesis), Jönköping University, Sweden, Jönköping.
- Maxwell, G., Augustine, L., & Granlund, M. (2012). Does thinking and doing the same thing amount to involved participation? Empirical explorations for finding a measure of intensity for a third ICF-CY qualifier. *Developmental Neurorehabilitation, 15*(4), 274-283. doi: 10.3109/17518423.2012.689780
- McConachie, H., Colver, A., Forsyth, R., Jarvis, S., & Parkinson, K. (2006). Participation of disabled children: How should it be characterised and measured? *Disability and Rehabilitation, 28*(18), 1157-1164.
- McWilliam, R.A. (1991). *Children's engagement questionnaire*: Chapel Hill, NC: Frank porter Graham Child Development Center, University of North Carolina at Chapel Hill.
- McWilliam, R.A., Scarborough, A.A., & Kim, H. (2003). Adult interactions and child engagement. *Early Education and Development, 14*(1), 7-27. doi: 10.1207/s15566935eed1401\_2

- Munde, V., Vlaskamp, C., Ruijsenaars, A.J.J.M., & Nakken, H. (2009). Alertness in individuals with profound intellectual and multiple disabilities: A literature review. *Research in Developmental Disabilities, 30*(3), 462-480. doi: 10.1016/j.ridd.2008.07.003
- Munde, V., Vlaskamp, C., Ruijsenaars, W., & Nakken, H. (2011). Determining alertness in individuals with profound intellectual and multiple disabilities: The reliability of an observation list. *Education and Training in Autism and Developmental Disabilities, 46*(1), 116-123.
- Nakken, H., & Vlaskamp, C. (2002). Joining forces: Supporting individuals with profound multiple learning disabilities. *Tizard Learning Disability Review, 7*(3), 10-15. doi: 10.1108/13595474200200023
- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*(2), 83-87. doi: 10.1111/j.1741-1130.2007.00104.x
- Nichols, W.C. (2000). *Handbook of family development and intervention*. New York: Wiley.
- Nosek, M.A., Fuhrer, M.J., & Howland, C.A. (1992). Independence among people with disabilities 2. Personal independence profile. *Rehabilitation Counseling Bulletin, 36*(1), 21-36.
- Palisano, R.J., Orlin, M., Chiarello, L.A., Oeffinger, D., Polansky, M., Maggs, J., . . . Stevenson, R. (2011). Determinants of intensity of participation in leisure and recreational activities by youth with cerebral palsy. *Archives of Physical Medicine and Rehabilitation, 92*(9), 1468-1476. doi: 10.1016/j.apmr.2011.04.007
- Raghavendra, P. (2013). Participation of children with disabilities: Measuring subjective and objective outcomes (editorial). *Child: Care, Health and Development, 39*(4), 461-465.
- Raghavendra, P., Virgo, R., Olsson, C., Connell, T., & Lane, A.E. (2011). Activity participation of children with complex communication needs, physical disabilities and typically-developing peers. *Developmental Neurorehabilitation, 14*(3), 145-155. doi: 10.3109/17518423.2011.568994
- RBU. (n.d.). *RBU - Föreningen för barn, unga och vuxna med utvecklingsstörning [RBU - The Swedish National Association for Disabled Children and Young People]*. Retrieved 18 mars, 2014, from <http://www.rbu.se/>
- Roos, J.M. (2009). *Quality of personal assistance shaped by governments, markets and cooperations*. (Doctoral Thesis), University of Gothenburg, Göteborg.

- Sameroff, A.J. (2009). The transactional model. In A. J. Sameroff (Ed.), *The Transactional Model of Development* (pp. 3-21). Washington: American Psychological Association.
- Sameroff, A.J., & Fiese, B.H. (2000). Transactional regulation: The developmental ecology of early intervention. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of Early Childhood Intervention* (2nd ed., pp. 135-159). Cambridge: Cambridge University Press.
- Schalock, M.D., Fredericks, B., Dalke, B.A., & Alberto, P.A. (1994). The house that traces built - a conceptual-model of service delivery systems and implications for change. *Journal of Special Education, 28*(2), 203-223.
- SFS 1993:387. *Lagen om stöd och service till vissa funktionshindrade (LSS) [the Act on support and service to certain disabled individuals]*. Stockholm: Socialdepartementet.
- SFS 2003:460. *Lag (2003:460) om etikprövning av forskning som avser människor [the Act (2003:460) concerning the ethical review of research involving humans]*. Stockholm: Utbildningsdepartementet [Ministry of Education and Research].
- SFS 2010:110. *Socialförsäkringsbalk [Social insurance code]*. Stockholm: Socialdepartementet [Ministry of Health and Social Affairs].
- Shadish, W.R., Cook, T.D., & Campbell, D.T. (2002). *Experimental and quasi-experimental designs for generalized causal inference*. Boston: Houghton Mifflin.
- Simeonsson, R.J., Leonardi, M., Lollar, D., Björck-Akesson, E., Hollenweger, J., & Martinuzzi, A. (2003). Applying the international classification of functioning, disability and health (ICF) to measure childhood disability. *Disability and Rehabilitation, 25*(11-2), 602-610. doi: 10.1080/0963828031000137117
- Skär, L., & Tamm, M. (2001). My assistant and I: Disabled children's and adolescents' roles and relationships to their assistants. *Disability & Society, 16*(7), 917-931. doi: 10.1080/09687590120084010
- Sommer, D., Samuelsson, I.P., & Hundeide, K. (2010). *Child perspectives and children's perspectives in theory and practice, 2* (Vol. 2): Springer.
- Sontag, J.C. (1996). Toward a comprehensive theoretical framework for disability research: Bronfenbrenner revisited. *Journal of Special Education, 30*(3), 319-344.
- Spagnola, M., & Fiese, B.H. (2007). Family routines and rituals: A context for development in the lives of young children. *Infants & Young Children, 20*(4), 284-299.  
doi: 10.1097/01.IYC.0000290352.32170.5a
- Statistiska Centralbyrån [Statistics Sweden]. (2001). Fråga rätt! Utveckla, testa, utvärdera och förbättra blanketter. from

- [http://www.scb.se/statistik/\\_publikationer/OV9999\\_2000I02\\_BR\\_X97%C3%96P0101.pdf](http://www.scb.se/statistik/_publikationer/OV9999_2000I02_BR_X97%C3%96P0101.pdf)
- Söderbäck, M., Coyne, I., & Harder, M. (2011). The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. *Journal of Child Health Care, 15*(2), 99-106. doi: 10.1177/1367493510397624
- Tadema, A.C., & Vlaskamp, C. (2010). The time and effort in taking care for children with profound intellectual and multiple disabilities: A study on care load and support. *British Journal of Learning Disabilities, 38*(1), 41-48. doi: 10.1111/j.1468-3156.2009.00561.x
- Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, Calif. ; London: SAGE.
- Ullenhag, A., Krumlinde-Sundholm, L., Granlund, M., & Almqvist, L. (2014). Differences in patterns of participation in leisure activities in Swedish children with and without disabilities. *Disability and Rehabilitation, 36*(6), 464-471. doi: 10.3109/09638288.2013.798360
- United Nations General Assembly. (1989). *Convention on the rights of the child*. New York: United Nations.
- United Nations General Assembly. (n.d.). Convention on the rights of persons with disabilities.  
from <http://www.un.org/disabilities/default.asp?id=259>
- Wachs, T.D. (2000). *Necessary but not sufficient: The respective roles of single and multiple influences on individual development*. Washington, D.C.: American Psychological Association.
- Weisner, T.S. (2002). Ecocultural understanding of children's developmental pathways. *Human Development, 45*, 275-281.  
doi: 10.1159/000064989
- Weisner, T.S. (2010). Well-being, chaos, and culture: Sustaining a meaningful daily routine. In G. W. Evans & T. D. Wachs (Eds.), *Chaos and its influence on children's development: An ecological perspective* (pp. 211-224). Washington, DC: American Psychological Association.
- Weisner, T.S., Bernheimer, L., & Coots, J. (1997). *The ecocultural family interview manual*. Los Angeles, CA: UCLA Center for Culture and Health.
- Verdugo, M.A., Schalock, R., Keith, K., & Stancliffe, R. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research, 49*(10), 707-717. doi: 10.1111/j.1365-2788.2005.00739.x
- Whaley, K.T., & Bennett, T.C. (1991). Promoting engagement in early childhood special education. *Teaching Exceptional Children, 23*(4), 51-54.

- Whiteneck, G., & Dijkers, M.P. (2009). Difficult to measure constructs: Conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical Medicine and Rehabilitation*, 90(11), S22-S35. doi: 10.1016/j.apmr.2009.06.009
- Wilder, J. (2008). *Proximal processes of children with profound multiple disabilities*. (Doctoral thesis), Stockholm University, Sweden, Stockholm.
- Wilder, J., & Granlund, M. (in press). Stability and change in sustainability of daily routines and social networks of families of children with PIMD. *Journal of Applied Research in Intellectual Disabilities*.
- Vlaskamp, C. (2005). Assessing people with profound intellectual and multiple disabilities. In J. Hogg & A. Langa (Eds.), *Assessing adults with intellectual disabilities: A service providers' guide* (pp. 152-163). Malden, MA: BPS Blackwell.
- World Health Organization. (2001). *International classification of functioning, disability and health (ICF)*. Geneva: World Health Organization.
- World Health Organization. (2007). *International classification of functioning, disability and health: Children and youth version: ICF-CY*. Geneva: World Health Organization.
- Young, N.L., Yoshida, K.K., Williams, J.I., Bombardier, C., & Wright, J.G. (1995). The role of children in reporting their physical-disability. *Archives of Physical Medicine and Rehabilitation*, 76(10), 913-918.



# Appendix

**Table Aa in appendix.** Frequency of occurrence of family activities, child presence and engagement presented in the same table, group with PIMD and group with TD

Family activity	Group with PIMD, N=60		Group with TD, N=107	
	Frequency of occurrence	Child presence	Frequency of occurrence	Child presence
	Median value (25th – 75th percentile) <sup>1</sup> / P value if family activity occurs significantly more often in the group	% of children present in an activity / P value when a higher proportion of the group is present	Median value (25th – 75th percentile) <sup>1</sup> / P value if family activity occurs significantly more often in the group	% of children present in an activity / P value when a higher proportion of the group is present
				Child engagement
				Median value (25th – 75th percentile) <sup>2</sup> / P value if child engagement is significantly higher in the group
<i>Indoor activities (never/ almost never, monthly, weekly, daily)</i>				
Watching a movie	3(2-4)	90	2(2-3)	3(3-4)
Watching TV	4(3-4)	90	4(3-4)	3(3-4)
Joking and fooling around	3,5(3-4)	95	3(3-4)	4(3-4)
Playing computer games	2(1-3)	80	3(2-4)	4(3-4)
Surfing the internet	1(1-3)	52	2(1-4)	85
Doing handicraft	2(1-3)	72	2(2-3)	3(2-4)
Playing board games	1(1-2)	62	2(1-3)	2(2-2)
Playing with you or other adult	4(3-4)	95	3(2-4)	4(3-4)
Playing with children (friends/siblings)	3(1-4)	80	3(2-4)	4(3-4)
Playing with pets	2(1-4)	62	1(1-4)	4(3,5-4)
Story reading	3(1-3)	77	3(3-4)	3(2-4)
Singing	3(1-4)	80	3(2-3)	4(3-4)
Playing instruments	1(1-3)	60	1(1-2)	3(3-4)
Listening to music	4(3-4)	92	3(3-4)	2(1,25-3)
Dancing	1(1-2)	67	2(1-3)	3(3-4)
Exercising physical therapy at home	3(1-4)	72	n/a	3(2-4)
			n/a	n/a

<sup>1</sup> = 1-4, high ratings indicate high frequency of occurrence; <sup>2</sup> = 1-4, high ratings indicate high level of engagement. n/a = not applicable. Bold when p<.01.

**Table Ab in appendix.** Frequency of occurrence of family activities, child presence and engagement, group with PIMD and group with TD.

Family activity	Group with PIMD, N=60			Group with TD, N=107		
	Frequency of occurrence	Child presence	Child engagement	Frequency of occurrence	Child presence	Child engagement
	Median value (25th – 75th percentile) <sup>1</sup> / P value if family activity occurs significantly more often in the group	% of children present in an activity / P value when a higher proportion of the group is present	Median value (25th – 75th percentile) <sup>2</sup> / P value if child engagement is significantly higher in the group	Median value (25th – 75th percentile) <sup>1</sup> / P value if family activity occurs significantly more often in the group	% of children present in an activity / P value when a higher proportion of the group is present	Median value (25th – 75th percentile) <sup>2</sup> / P value if child engagement is significantly higher in the group
<i>Meals (never/ almost never, monthly, weekly, daily)</i>						
Being together in the kitchen	2.5(2-3,7.5)	85	2(2-3)	3(2-3)	95	3(2-3)
Cooking/baking	2(1-2)	77	2(2-3)	.019	93	3(3-4)
Doing the dishes	1(1-5)	42	1(1-2)	1(1-2)	70	1(1-2)
Laying the table/cleaning away	2.5(1-4)	72	2(1-3)	3(2-4)	97	2(2-3)
Having tea or coffee together	3(2-4)	90	3(2-4)	3(2-4)	96	3(3-4)
Having breakfast together	3(2-4)	83	3(2-4)	.034	98	3(2-4)
Having dinner together	4(3-4)	98	3(2-4)	4(4-4)	100	3(3-4)
<i>Routines (never/ almost never, monthly, weekly, daily)</i>						
Cleaning the house	1(1-2)	55	1(1-2)	.000	85	2(2-2)
Doing morning routines	4(4-4)	82	2(2-3)	2(2-3)	92	3(2-3)
Doing evening routines	4(3-4)	83	2(2-3)	.030	97	3(2-4)
Packing school bag	3(1-4)	65	1(1-2)	3(2-4)	92	2(2-3)
Picking up after playing	3(1-4)	73	1(1-2)	2(2-3)	93	2(2-3)
Doing homework	n/a	n/a	n/a	n/a	n/a	3(3-4)
Lying down for rest	2.5 (1-3,7.5)	72	3(2-3,7.5)	1(1-2)	68	2(1-3)
Going by car to and from school	3(1-4)	75	3(2-3)	3(1-4)	79	3(2-3)
Going by car at other occasions	3 (2-3)	95	3(2-3,2.5)	3(3-3)	95	3(2-3)

<sup>1</sup> = 1-4, high ratings indicate high frequency of occurrence; <sup>2</sup> = 1-4, high ratings indicate high level of engagement. n/a = not applicable. Bold when p<.01.

**Table A6 in appendix.** Frequency of occurrence of family activities, child presence and engagement, group with PIMD and group with TD.

Family activity	Group with PIMD, N=60			Group with TD, N=107		
	Frequency of occurrence	Child presence	Child engagement	Frequency of occurrence	Child presence	Child engagement
	Median value (25th – 75th percentile) / P value if family activity occurs significantly more often in the group	% of children present in an activity / P value when a higher proportion of the group is present	Median value (25th – 75th percentile) / P value if child engagement is significantly higher in the group	Median value (25th – 75th percentile) / P value if family activity occurs significantly more often in the group	% of children present in an activity / P value when a higher proportion of the group is present	Median value (25th – 75th percentile) / P value if child engagement is significantly higher in the group
<i>Outdoor activities (never/ almost never, monthly, weekly, daily)</i>						
Shopping for groceries	2(1-3)	77	2(2-3)	2(2-3)	94	3(2-3)
Gardening	1(1-2)	52	1(1-3)	2(1-2)	88	2(2-3)
Playing outside with other children	1,5(1-2,75)	57	3(2-3,75)	3(3-3)	98	4(3-4)
Playing outside with you or other adult	2(1-3)	72	3(2-4)	2(2-3)	94	4(3-4)
Going on a swing	1(1-2)	58	3(2-3)	1(1-2)	71	3(2-4)
Bicycling	2(1-2,75)	63	3(2-4)	3(2-3)	98	4(3-4)
Going for a walk	3(2-4)	93	3(2-3,5)	3(2-3)	90	4(3-4)
Jumping on trampoline	n/a	n/a	n/a	n/a	82	n/a
Playing in the sandpit	1(1-1)	32	2(1-3)	n/a	n/a	n/a
Playing ball games	1(1-2)	46	3(2-4)	2(2-3)	92	3(3-4)
<i>Organized activities (0 times the last three months, 1-2 times the last three months, &gt;once per month, &gt;once per month)</i>						
Going together to child's leisure activity	4(2-4)	75	4(3-4)	4(2-4)	88	4(4-4)
Going together to sibling's leisure act.	1(1-2)	27	1,5(1-3)	2(1-4)	66	3(2-4)
Going together to parent's leisure	1(1-1)	20	2(1-3,75)	1(1-3)	52	3(2-4)
Going to church	1(1-1)	95	3(1-4)	1(1-2)	99	2(2-3)
Going to habilitation center activities	2(1-3)	57	3(2-3)	n/a	n/a	n/a

1 = 1-4, high ratings indicate high frequency of occurrence; 2 = 1-4, high ratings indicate high level of engagement. n/a = not applicable. Bold when p<.01.

**Table Ad in appendix.** Frequency of occurrence of family activities, child presence and engagement group with PIMD and group with TD.

Family activity	Group with PIMD, N=60			Group with TD, N=107		
	Frequency of occurrence	Child presence	Child engagement	Frequency of occurrence	Child presence	Child engagement
	Median value (25th – 75th percentile) <sup>1</sup> / P value if family activity occurs significantly more often in the group	% of children present in an activity / P value when a higher proportion of the group is present	Median value (25th – 75th percentile) <sup>2</sup> / P value if child engagement is significantly higher in the group	Median value (25th – 75th percentile) <sup>1</sup> / P value if family activity occurs significantly more often in the group	% of children present in an activity / P value when a higher proportion of the group is present	Median value (25th – 75th percentile) <sup>2</sup> / P value if child engagement is significantly higher in the group
<i>Outings (0 times the last three months, 1–2 times the last three months, &gt;every second month, &gt;once per month)</i>						
Going to the playground	1(1-3)	38	3(2-4)	2(1-3)	73	4(3-4)
Going shopping	4(3-4)	83	3(2-3)	4(3-4)	97	3(2-3)
Going to the library	1(1-2)	38	3(2-4)	2(1-3)	67	3(3-4)
Going to theatre/cinema/concerts	2(1-2)	53	3(2,75-4)	2(1-2)	72	4(3-4)
Visiting friends who have children	2(1,75-3)	65	3(2-3)	4(3-4)	94	4(3-4)
Visiting friends who do not have children.	2(1-2)	42	3(2-3,5)	1(1-2,25)	55	3(2-4)
Visiting relatives	3(2-4)	85	3(2-4)	4(3-4)	96	4(3-4)
Going to parties	2(2-2)	67	3(2-4)	3(2-4)	95	4(3-4)
Going out in the nature	1,5(1-4)	48	3(2-4)	3(2-4)	86	3(3-4)
<i>Vacation and holiday cottage (0 times the last year, 1 time the last year, 1-2 times the last year, more than 3 times the last year)</i>						
Going on vacation	2(1-3)	68	4(2,5-4)	3(2-3)	95	4(4-4)
Going to holiday cottage	1(1-4)	43	3(3-4)	1(1-4)	52	4(4-4)

<sup>1</sup> = 1–4, high ratings indicate high frequency of occurrence; <sup>2</sup> = 1–4, high ratings indicate high level of engagement. n/a = not applicable. Bold when p<.01.

## **Studies from the Swedish Institute for Disability Research**

1. **Varieties of reading disability**  
Stefan Gustafson  
ISBN 91-7219-867-2, 2000
2. **Cognitive functions in drivers with brain injury – anticipation and adaptation**  
Anna Lundqvist  
ISBN 91-7219-967-9, 2001
3. **Cognitive deafness**  
Ulf Andersson  
ISBN 91-7373-029-7, 2001
4. **Att lära sig leva med förvärvad hörselnedsättning sett ur par-perspektiv**  
Carin Fredriksson  
ISBN 91-7373-105-6, 2001
5. **Signs, Symptoms, and Disability Related to the Musculo-Skeletal System**  
Gunnar Lundberg  
ISBN 91-7373-160-9, 2002
6. **Participation – Ideology and Everyday Life**  
Anette Kjellberg  
ISBN 91-7373-371-7, 2002
7. **Föräldrar med funktionshinder – om barn, föräldraskap och familjeliv**  
Marie Gustavsson Holmström  
ISBN 91-7203-500-5, 2002
8. **Active wheelchair use in daily life**  
Kersti Samuelsson  
ISBN 91-7373-196-X, 2002
9. **Två kön eller inget alls. Politiska intentioner och vardagslivets realiteter i den arbetslivsinriktade rehabiliteringen**  
Marie Jansson  
ISBN 91-7373-568-X, 2003

10. **Audiological and cognitive long-term sequelae from closed head injury**  
Per-Olof Bergemalm  
ISBN 91-7668-384-2, 2004
11. **Att vara i särklass – om delaktighet och utanförskap i gymnasiesärskolan**  
Martin Molin  
ISBN 91-85295-46-9, 2004
12. **Rättvis idrottsundervisning för elever med rörelsehinder – dilemma kring omfördelning och erkännande**  
Kajsa Jerlinder  
Licentiate Degree, 2005
13. **Hearing impairment and deafness. Genetic and environmental factors – interactions – consequences. A clinical audiological approach**  
Per-Inge Carlsson  
ISBN 91-7668-426-1, 2005
14. **Hearing and cognition in speech comprehension. Methods and applications**  
Mathias Hällgren  
ISBN 91-85297-93-3, 2005
15. **Living with deteriorating and hereditary disease: experiences over ten years of persons with muscular dystrophy and their next of kin**  
Katrín Boström  
ISBN 91-7668-427-x, 2005
16. **Disease and disability in early rheumatoid arthritis**  
Ingrid Thyberg  
ISBN 91-85299-16-2, 2005
17. **"Varför får jag icke följa med dit fram?" Medborgarskapet och den offentliga debatten om dövstumma och blinda 1860-1914**  
Staffan Bengtsson  
ISBN 91-85457-06-X, 2005
18. **Modalities of Mind. Modality-specific and nonmodality-specific aspects of working memory for sign and speech**  
Mary Rudner  
ISBN 91-85457-10-8, 2005

19. **Facing the Illusion Piece by Piece. Face recognition for persons with learning disability**  
Henrik Danielsson  
ISBN 91-85497-09-6, 2006
20. **Vuxna med förvärvad traumatisk hjärnskada – omställningsprocesser och konsekvenser i vardagslivet. En studie av femton personers upplevelser och erfarenheter av att leva med förvärvad traumatisk hjärnskada**  
Thomas Strandberg  
ISBN 91-7668-498-9, 2006
21. **Nycklar till kommunikation. Kommunikation mellan vuxna personer med grav förvärvad hjärnskada och personernas närstående, anhöriga och personal**  
Pia Käcker  
ISBN 978-91-85715-88-6, 2007
22. **”Aspergern, det är jag”. En intervjustudie om att leva med Asperger syndrom**  
Gunvor Larsson Abbad  
ISBN 978-91-85831-43-2, 2007
23. **Sounds of silence - Phonological awareness and written language in children with and without speech**  
Janna Ferreira  
ISBN 978-91-85895-74-8, 2007
24. **Postponed Plans: Prospective Memory and Intellectual Disability**  
Anna Levén  
ISBN 978-91-85895-57-1, 2007
25. **Consequences of brain tumours from the perspective of the patients and of their next of kin**  
Tanja Edvardsson  
ISBN 978-91-7668-572-3, 2008
26. **Impact on participation and service for persons with deafblindness**  
Kerstin Möller  
ISBN 978-91-7668-595-2, 2008
27. **Approaches to Audiological Rehabilitation with Hearing Aids: studies on prefitting strategies and assessment of outcomes**  
Marie Öberg  
ISBN 978-91-7393-828-0, 2008

28. **Social Interaction and Participation in Activities of Everyday Life Among Persons with Schizophrenia**  
Maria Yilmaz  
Licentiate Degree, 2009
29. **Focus on Chronic Disease through Different Lenses of Expertise  
Towards Implementation of Patient-Focused  
Decision Support Preventing Disability:  
The example of Early Rheumatoid Arthritis**  
Örjan Dahlström  
ISBN 978-91-7393-613-2, 2009
30. **Children with Cochlear Implants: Cognition and Reading Ability**  
Malin Wass  
ISBN: 978-91-7393-487-9, 2009
31. **Restricted participation:  
Unaccompanied children in interpreter-mediated asylum hearings in Sweden**  
Olga Keselman  
ISBN: 978-91-7393-499-2, 2009
32. **Deaf people and labour market in Sweden.  
Education – Employment – Economy.**  
Emelie Rydberg  
ISBN: 978-91-7668-725-3, 2010
33. **Social rättvisa i inkluderande idrottsundervisning  
för elever med rörelsehinder – en utopi?**  
Kajsa Jerlinder  
ISBN: 978-91-7668-726-0, 2010
34. **Erfarenheter av rehabiliteringsprocessen mot ett arbetsliv  
– brukarens och de professionellas perspektiv**  
Helene Hillborg  
ISBN: 978-91-7668-741-3, 2010
35. **Knowing me, knowing you – Mentalization abilities of children who use  
augmentative and alternative communication**  
Annette Sundqvist  
ISBN: 978-91-7393-316-2, 2010

36. **Lärare, socialsekreterare och barn som far illa – om sociala representationer och interprofessionell samverkan.**  
Per Germundsson  
ISBN: 978-91-7668-787-1, 2011
37. **Fats in Mind**  
**Effects of Omega-3 Fatty Acids on Cognition and Behaviour in Childhood**  
Ulrika Birberg Thornberg  
ISBN: 978-91-7393-164-9, 2011
38. **”Jobbet är kommunikation”**  
**Om användning av arbetshjälpmedel för personer med hörselnedsättning**  
Sif Bjarnason  
Licentiate Degree. ISBN: 978-91-7668-835-9, 2011
39. **Applying the ICF-CY to identify everyday life situations of children and youth with disabilities**  
Margareta Adolfsson  
ISBN: 978-91-628-8342-3, 2011
40. **Tinnitus – an acceptance-based approach**  
Vendela Zetterqvist  
ISBN: 978-91-7393-040-6, 2011
41. **Applicability of the ICF-CY to describe functioning and environment of children with disabilities**  
Nina Klang  
ISBN: 978-91-7668-864-9, 2012
42. **Bringing more to participation**  
**Participation in school activities of persons with Disability within the framework of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)**  
Gregor Maxwell  
ISBN: 978-91-628-8484-0, 2012
43. **From Eye to Us.**  
**Prerequisites for and levels of participation in mainstream school of persons with Autism Spectrum Conditions**  
Marita Falkmer  
ISBN: 978-91-637-2091-8, 2013

44. **Otosclerosis, clinical long-term perspectives**  
Ylva Dahlin-Redfors  
ISBN 978-91-628-8617-2, 2013
45. **Tinnitus in Context - A Contemporary Contextual Behavioral Approach**  
Hugo Hesser  
ISBN 978-91-7519-701-2, 2013
46. **Hearing and middle ear status in children and young adults with cleft palate**  
Traci Flynn  
ISBN 978-91-628-8645-5, 2013
47. **Utrymme för deltagande, beslutsprocesser i möten mellan patienter med ospecifika ländryggsbesvär och sjukgymnaster i primär vård**  
Iréne Josephson  
ISBN 42-978-91-85835-41-6, 2013
48. **”Man vill ju klara sig själv” Studievardagen för studenter med Asperger syndrom i högre studier**  
Ann Simmeborn Fleischer  
ISBN 978-91-628-8681-3, 2013
49. **Cognitive erosion and its implications in Alzheimer’s disease**  
Selina Mårdh  
ISBN 978-91-7519-621-1, 2013
50. **Hörselscreening av en population med utvecklingsstörning  
Utvärdering av psykoakustisk testmetod och av OAE-registrering som komplementär metod**  
Eva Andersson  
Licentiate Degree. ISBN 978-91-7519-616-9, 2013
51. **Skolformens komplexitet – elevers erfarenheter av skolvardag och tillhörighet i gymnasiesärskolan**  
Therése Mineur  
ISBN 978-91-7668-951-6, 2013
52. **Evaluating the process of change:  
Studies on patient journey, hearing disability acceptance and stages-of-change**  
Vinaya Kumar Channapatna Manchaiah  
ISBN 978-91-7519-534-6, 2013

53. **Cognition in hearing aid users: Memory for everyday speech**  
Hoi Ning (Elaine) Ng  
ISBN 978-91-7519-494-3, 2013
54. **Representing sounds and spellings Phonological decline and compensatory working memory in acquired hearing impairment**  
Elisabet Classon  
ISBN 978-91-7519-500-1, 2013
55. **Assessment of participation in people with a mild intellectual disability**  
Patrik Arvidsson  
ISBN 978-91-7668-974-5, 2013
56. **Barnperspektiv i barnvårdsutredningar - med barns hälsa och barns upplevelser i fokus**  
Elin Hultman  
ISBN 978-91-7519-457-8, 2013
57. **Internet Interventions for Hearing Loss  
Examining rehabilitation Self-report measures and Internet use in hearing-aid users**  
Elisabet Sundewall Thorén  
ISBN 978-91-7519-423-3, 2014
58. **Exploring Cognitive Spare Capacity: Executive Processing of Degraded Speech**  
Sushmit Mishra  
ISBN 978-91-7519-386-1, 2014
59. **Supported employment i en svensk kontext – förutsättningar när personer med funktionsnedsättning når, får och behåller ett arbete**  
Johanna Gustafsson  
ISBN 978-91-7529-012-6, 2014
60. **Effects of Specific Cochlear Pathologies on the Auditory Functions:  
Modelling, Simulations and Clinical Implications**  
Amin Saremi  
ISBN 978-91-7519-365-6, 2014

61. **Children with profound intellectual and multiple disabilities and their participation in family activities**

Anna Karin Axelsson

ISBN 978-91-85835-48-5, 2014

# School of Health Sciences Dissertation Series

1. Linddahl, Iréne. (2007). Validity and Reliability of the Instrument DOA; A Dialogue about Working Ability. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 1. ISBN 978-91-85835-00-3
2. Widäng, Ingrid. (2007). Patients' Conceptions of Integrity within Health Care Illuminated from a Gender and a Personal Space Boundary Perspective. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 2. ISBN 978-91-85835-01-0
3. Ernsth Bravell, Marie. (2007). Care Trajectories in the oldest old. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 3. ISBN 978-91-85835-02-7
4. Almborg, Ann-Helene. (2008). Perceived Participation in Discharge Planning and Health Related Quality of Life after Stroke. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 4. ISBN 978-91-85835-03-4
5. Rosengren, Kristina. (2008). En hälso- och sjukvårdsorganisation i förändring – från distanserat till delat ledarskap. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 5. ISBN 978-91-85835-04-1
6. Wallin, Anne-Marie. (2009). Living with diabetes within the framework of Swedish primary health care: Somalian and professional perspectives. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 6. ISBN 978-91-85835-05-8
7. Dahl, Anna. (2009). Body Mass Index, Cognitive Ability, and Dementia: Prospective Associations and Methodological Issues in Late Life. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 7. ISBN 978-91-85835-06-5
8. Einarson, Susanne. (2009). Oral health-related quality of life in an adult population. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 8. ISBN 978-91-85835-07-2
9. Harnett, Tove. (2010). The Trivial Matters. Everyday power in Swedish elder care. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 9. ISBN 978-91-85835-08-9
10. Josefsson, Eva. (2010). Immigrant background and orthodontic treatment need - Quantitative and qualitative studies in Swedish adolescents. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 10. ISBN 978-91-85835-09-6
11. Lindmark, Ulrika. (2010). Oral Health and Sense of Coherence - Health Behaviours, Knowledge, Attitudes and Clinical Status. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 11. ISBN 978-91-85835-10-2

12. Pihl, Emma. (2010). The Couples' Experiences of Patients' Physical Limitation in Daily Life Activities and Effects of Physical Exercise in Primary Care when having Chronic Heart Failure. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 12. ISBN 978-91-85835-11-9
13. Nilsson, Stefan. (2010). Procedural and postoperative pain management in children - experiences, assessments and possibilities to reduce pain, distress and anxiety. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 13. ISBN 978-91-85835-12-6
14. Algurén, Beatrix. (2010). Functioning after stroke - An application of the International Classification of Functioning, Disability and Health (ICF). Doctoral Thesis.  
School of Health Sciences Dissertation Series No 14. ISBN 978-91-85835-13-3
15. Kvarnström, Susanne. (2011). Collaboration in Health and Social Care - Service User Participation and Teamwork in Interprofessional Clinical Microsystems. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 15. ISBN 978-91-85835-14-0
16. Ljusegren, Gunilla. (2011). Nurses' competence in pain management in children. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 16. ISBN 978-91-85835-15-7
17. Arvidsson, Susann. (2011). Health promoting factors in people with chronic musculoskeletal pain or with rheumatic diseases: a descriptive and interventional study. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 17. ISBN 978-91-85835-16-4
18. Berggren, Elisabeth. (2011) Identity construction and memory after Subarachnoid Haemorrhage - Patients' accounts and relatives' and patients' statements in relation to memory tests. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 18. ISBN 978-91-85835-17-1
19. Ericsson, Iréne. (2011) Välbehövande och demens - Aspekter på välbefinnande hos äldre personer med måttlig till svår demenssjukdom. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 19. ISBN 978-91-85835-18-8
20. Silén, Marit. (2011) Encountering ethical problems and moral distress as a nurse - Experiences, contributing factors and handling. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 20. ISBN 978-91-85835-19-5
21. Munck, Berit. (2011) Medical technology and its impact on palliative home care as a secure base experienced by patients, next-of-kin and district nurses. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 21. ISBN 978-91-85835-20-1

22. Jacobsson, Brittmarie. (2011) On Oral Health in Young Individuals with Foreign and Swedish Backgrounds. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 22. ISBN 978-91-85835-21-8
23. Bergsten, Ulrika. (2011) Patients' and healthcare providers' experiences of the cause, management and interaction in the care of rheumatoid arthritis. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 23. ISBN 978-91-85835-22-5
24. Wilińska, Monika. (2012) Spaces of (non-)ageing - A discursive study of inequalities we live by. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 24. ISBN 978-91-85835-23-2
25. Wagman, Petra. (2012) Conceptualizing life balance from an empirical and occupational therapy perspective. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 25. ISBN 978-91-85835-24-9
26. Golsäter, Marie. (2012) Hälsosamtal som metod att främja barns och ungdomars hälsa – en utmanande uppgift. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 26. ISBN 978-91-85835-25-6
27. Celsing Fåhraeus, Christina. (2012) Övervikt/fetma hos barn, ungdomar och unga vuxna i relation till vikt, viktutveckling och kariesförekomst. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 27. ISBN 978-91-85835-26-3
28. Åhnby, Ulla. (2012) Att möjliggöra äldre människors delaktighet i vardagen - Framtidsverkstad som idé och metod. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 28. ISBN 978-91-85835-27-0
29. Ståhl, Ylva. (2012) Documentation in Child and School Health Services Mapping health information from a biopsychosocial perspective using the ICF-CY. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 29. ISBN 978-91-85835-28-7
30. Åkerman, Eva. (2012) Assessment and tools for follow up of patients' recovery after intensive care. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 30. ISBN 978-91-85835-29-4
31. Pietilä, Sirpa. (2012) Tvillingenskap genom livet - individualitet och relation i äldre tvillingars livsberättelser. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 31. ISBN 978-91-85835-30-0
32. Gimbler Berglund, Ingalill. (2012) Nurse anaesthetist's interactions and assessment of children's anxiety. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 32. ISBN 978-91-85835-31-7

33. Fristedt, Sofi. (2012) Occupational participation through community mobility among older men and women. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 33. ISBN 978-91-85835-32-4
34. Andersson, Bodil. (2012) Radiographers' Professional Competence - Development of a context-specific instrument. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 34. ISBN 978-91-85835-33-1
35. Siouta, Eleni. (2012) Communication Patterns in Consultations Between Patients with Atrial Fibrillation and Health Professionals. Licentiate Thesis.  
School of Health Sciences Dissertation Series No 35. ISBN 978-91-85835-34-8
36. Selander, Helena. (2012) Driving assessment and driving behavior. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 36. ISBN 978-91-85835-35-5
37. Sjölander, Catarina. (2012) Consequences for family members of being informal caregivers to a person with advanced cancer. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 37. ISBN 978-91-85835-36-2
38. Anastassaki Köhler, Alkisti. (2012) On temporomandibular disorders – Time trends, associated factors, treatment need and treatment outcome. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 38. ISBN 978-91-85835-37-9
39. Berggren, Elisabeth. (2012) Daily life after Subarachnoid Haemorrhage – Identity construction, patients' and relatives' statements about patients' memory, emotional status and activities of living. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 39. ISBN 978-91-85835-38-6
40. Sigurðardóttir, Sigurveig H. (2013) Patterns of care and support in old age. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 40. ISBN 978-91-85835-39-3
41. Larsson, Ingrid. (2013) Person-centred care in rheumatology nursing for patients undergoing biological therapy: an explorative and interventional study. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 41. ISBN 978-91-85835-40-9
42. Josephson, Iréne (2013) Utrymme för deltagande. Beslutsprocesser i möten mellan patienter med ospecifika ländryggsbesvär och sjukgymnaster i primärvård. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 42. ISBN 978-91-85835-41-6
43. Strand, Anne-Sofie (2013) Truancy from student and school perspectives. An interview and document study. Doctoral Thesis.  
School of Health Sciences Dissertation Series No 43. ISBN 978-91-85835-42-3

44. Nygårdh, Annette (2013) A quality improvement project on empowerment in chronic kidney care – an interactive research approach. Doctoral Thesis. School of Health Sciences Dissertation Series No 44. ISBN 978-91-85835-43-0
45. Johansson, Linda (2013) Foodwork and meals in everyday life among persons with dementia and their partners. Doctoral Thesis. School of Health Sciences Dissertation Series No 45. ISBN 978-91-85835-44-7
46. Godfrey, Marjorie M.(2013) Improvement Capability at the Front Lines of Healthcare – Helping through Leading and Coaching. Doctoral Thesis. School of Health Sciences Dissertation Series No 46. ISBN 978-91-85835-45-4
47. Jacobsson, Brittmarie (2013) On Oral Health in Young Individuals with a Focus on Sweden and Vietnam. A Cultural Perspective. Doctoral Thesis. School of Health Sciences Dissertation Series No 47. ISBN 978-91-85835-46-1
48. Jansson, Inger (2014) On the nature of work ability. Doctoral Thesis. School of Health Sciences Dissertation Series No 48. ISBN 978-91-85835-47-8
49. Axelsson, Anna Karin (2014) Children with profound intellectual and multiple disabilities and their participation in family activities. Doctoral Thesis. School of Health Sciences Dissertation Series No 49. ISBN 978-91-85835-48-5

