

# The Role of the External Personal Assistants for Children with Profound Intellectual and Multiple Disabilities Working in the Children's Home

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**Background** Children with profound intellectual and multiple disabilities need support to function in an optimal way. However, there is a limited knowledge about the role of external personal assistants working in the children's home.

**Materials and Methods** A mixed method study was performed including qualitative data from interviews with 11 Swedish parents and nine external personal assistants and quantitative data from questionnaires answered by 60 families.

**Results** For the child, the assistant's role was one of reinforcing, meaning supportive and empowering, and the child needed a high level of assistance. For the

family, the role was one of balancing and the external personal assistant was more often found to assist in activities away from home while parents tended to assist within home and in family unit activities.

**Conclusion** In planning and implementation of external assistance, the child's needs as well as considerations of the whole family should be regarded.

**Keywords:** children, external personal assistance, home setting, profound intellectual and multiple disabilities, role

## Background

Children with profound intellectual and multiple disabilities (PIMD) are heavily dependent on others. Thus, support is considered important for the children to be able to function, particularly in the context of their families. Through the social security system in Sweden, paid personal assistance for children with certain disabilities can be conducted by either a parent who is employed as a personal assistant or an external personal assistant. To be an external personal assistant is a difficult role, in some respect being a third party in a family system (Clevnert & Johansson 2007). There is limited knowledge about the role of external personal assistants for children with PIMD working in the children's and their family's home.

### Children with PIMD and the family

Children with PIMD form a heterogeneous group in terms of the origins of the impairments as well as their level of functioning and range of behaviour. When having

PIMD, learning disabilities are combined with profound physical disabilities, sensory impairments and most often medical complications (Nakken & Vlaskamp 2002, 2007). With few exceptions, like other children in Sweden, the children with PIMD attend preschool and school, even though it in general is as part of special classes or schools for children with disabilities. Likewise, they grow up at home together with their biological family. The children should therefore be seen in the context of his/her family system (Bronfenbrenner 1986) where the child's participation in family activities is of great importance (Gallimore *et al.* 1989; Dunst *et al.* 2002). The family activities offer contexts or 'activity settings' for the child to learn about his/her own abilities and capabilities and to learn about others (Dunst *et al.* 2001). Due to the difficulties for children with having a PIMD, achieving participation in the activities can be a challenge.

### Supports and personal assistance

Supports can be described as resources and strategies aiming to promote the development, education, interests

and personal well-being of a person and to enhance individual functioning (American Association on Intellectual & Developmental Disabilities 2010). It can be seen as a bridge between what is and what could be. Support needs, conversely, are described by Thompson *et al.* (2009) as a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning. In line with this, Axelsson *et al.* (2014) have studied facilitation strategies that are used for improving participation of children with PIMD by interviewing parents of children with PIMD and the children's personal assistants. The suggested strategies were related to children's proximal environment and the individual child, respectively. Strategies related to the child's proximal environment included making the activity available and acceptable, having good knowledge about the child and a positive attitude. Strategies related to the individual child included giving the child a sense of belonging, making it possible for the child to understand, giving the child opportunities to influence and a feeling of being needed.

In the Convention on the Rights of Persons with Disabilities, the right to have access to personal assistance necessary to support living and inclusion is discussed (United Nations General Assembly n.d.; article 19). In conjunction with this, the Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments, the LSS (SFS 1993:387) and the Social Insurance Code, SFB (SFS 2010:110; chapter 51) provides support and services for people who have extensive and permanent physical or mental functional impairments. Also, in the Swedish Government Bill associated with the law of LSS (Government Bill 1992/93:159), the possibility for the families to get relief from the care of the child is stated. In the International Classification of Functioning, Disability and Health, ICF (World Health Organization 2001) and its version for children and youth, ICF-CY (World Health Organization 2007) personal assistance is defined as the amount of physical and emotional support the personal assistant provides. Personal assistance is classified as an individual, environmental factor (e 340). In addition, personal assistance includes the personal assistant's attitudes about the child in relation to attitudes that influence the child's individual behaviour and actions (e 440). The personal assistants can either be a paid relative (typically a parent of the child) or a hired, external non-relative – or both. According to Clevnert & Johansson (2007), when a parent is working as a personal assistant for his/her

own child a role conflict can be experienced by either being 'just' a parent or being a parent with the chores included in the work as a personal assistant. Among hired non-relatives working in someone's home, there are concerns that their role might create tensions due to crossing the boundary of the family's privacy. However, as found by Wilder (2008) the child him/herself often considers the external personal assistant to be a member of their family.

### Personal assistance as providers

Ahlström & Wadensten (2011) conducted an interview study in which the family member's experiences of external personal assistance given to an adult relative with disabilities were studied. The main finding was an appreciation of the personal assistance on the part of the family members – if not the encounter between the personal assistant and the relative with disabilities seemed to be negative. The trouble noted was the lack of ability to maintain a private life and the reduced choice when it came to getting an appropriate assistant due to the lack of personal assistants available. To get an appropriate personal assistant by matching assistants and users have been discussed by Guldvik (2003) and in line with this, desired qualities of a personal assistant have been studied by Roos (2009). Roos interviewed 12 adult assistance recipients about how they preferred their assistants and it was found that the assistance recipients wanted the personal assistants to be discrete and obedient, that is, to act according to the desire of the assistance recipient. The personal assistant should also be reliable, informative, alert, respectful, considerate and friendly. In addition, he/she should be pleased meaning satisfied with the user, the work and life in general, as well as being practical. Similarly, Egard (2011) as well as Ahlström & Wadensten (2012) in their studies stress the importance of good relationships between external personal assistants and adult assistance recipients.

Skär & Tamm (2001), in a study about disabled children's roles and relationships to their assistants, found certain aspects that were of importance for the interviewed children. The children, aged 8–19, had varying illnesses/disabilities but good communicative abilities. They viewed an ideal personal assistant to be younger than 25 to more easily have the ability to play and carry out different activities together with the child. In addition, a younger personal assistant was considered to provide greater opportunities to develop independence and autonomy. It was also found that the

children preferred a personal assistant to be of the same sex as the child in order to be able to help in practical, intimate care. The children stressed the importance of being able to choose their ideal assistant, one who ideally gave confidence and security, was available on the children's own terms, and was kind and cheery. In addition, it was desired that the personal assistant hold a friend role in relation to the child, which is something that can be assumed to be especially important for children with PIMD due to the severity of their disabilities (Granlund *et al.* 2013). Nevertheless, a Cochrane review about personal assistance and children aged 0–18 with both physical and intellectual impairments demonstrated that further studies were necessary to determine which models of personal assistance are most effective and efficient (Mayo-Wilson *et al.* 2008). In families with a child with PIMD, the personal assistant can be expected to have a unique role depending on the child's level of dependence on others in combination with the presence of the child's family. Regarding this, no existing studies have been found which implies that this is an area that needs to be explored.

### Aim of study

The aim of this study was to investigate the role of external personal assistants for children with PIMD in the home of the children. This article focuses on the two following questions:

- What is the role of the external personal assistant in relation to the child?
- What is the role of the external personal assistant in relation to the child's family?

### Materials and Methods

#### Design

A sequential mixed method design was used (Tashakkori & Teddlie 1998; Creswell & Plano Clark 2007) where, based on information from a quantitative cross-sectional study, a qualitative, explorative interview study was performed. The study was approved by the regional ethics committee, Linköping, Dnr 2010/324-31 and was part of a larger research project with an overall aim to investigate how child participation in family activities can be facilitated for children with PIMD. In accordance with both the Convention on the Rights of the Child (United Nations General Assembly 1989) as well as Swedish law, a 'child' is defined as being

18 years of age or less. However, this research also includes individuals between 18 and 20 years of age. For the ease of reading, they are likewise referred to as 'children'.

#### Participants and procedure

In the *quantitative* part of this study, 60 families with children, aged 5–20 years with PIMD, who made use of their right to 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) were included (Table 1a). Recruitment was done by contacting three national disability organizations: JAG, RBU, FUB in Sweden and 300 families were invited to participate. Sixty parents or other adult guardian being a member of the immediate family (Table 1a) responded by completing a comprehensive questionnaire called Child-PFA including questions about participation in 56 family activities (Axelsson & Wilder 2014). Answers about how much assistance the child needed to perform the activities and answers about the presence of (i) a personal assistant other than parent or sibling, (ii) a parent and/or (iii) a parent as an employed personal assistant were among other things studied. All answers were provided confidentially. No analysis of the attrition rate was done.

Based on this, 11 of the 60 parents who had answered the above-mentioned questionnaire were contacted after being identified as willing to be interviewed. These 11 were selected to provide a range of participants that included those having a child with severe impairment in mobility, cognition and communication and a high level of child participation. Participating parents were also asked to nominate one of their child's personal assistants whom the researcher could contact. This resulted in nine participating personal assistants (two withdrew from the study), (Table 1b). Each parent chose the location for the interview, and most interviews occurred in the families' homes. The personal assistants were interviewed over the telephone. Individual, semistructured interviews were performed using an interview guide. The questions for this study included: What is the personal assistant's task/what tasks do you have? What do you think are the most important of the personal assistants tasks/you as an assistant do? How does it feel to let others in around 'Sarah'/how do you feel about working in someone else's home? All interviews were performed by the author and audio recorded. The interviews with the parents lasted

**Table 1** Background data, (a) 60 families that answered the questionnaire Child-PFA and (b) 20 selected interviewed informants<sup>1</sup>

(a)	
Parent as paid personal assistants	In 58 of the families, one or both parents were working as a personal assistant for their child (41 mothers, 29 fathers), 2 children only had external personal assistance
External personal assistants	53 children had 1–9 external personal assistants, 6 did not have external personal assistance, 1 unknown
Number of hours of paid assistance/week	0–225 (3 children had 0 h of paid personal assistance/week, 14 children 1–50 h, 18 children 51–100 h, 18 children 101–150 hours and 6 children 151–225 h. 1 unknown)
The children with PIMD	37 boys, 23 girls. Aged 5–20 years old
(b)	
Interviewed parents	9 mothers, 2 fathers. All working as a personal assistant for their child
Interviewed external personal assistants	1 personal assistant had been working for the child for three months, 8 personal assistants had been working for the child for 3–12 years, 2 withdrew from the study
The children with PIMD the informants were caring for	8 boys, 3 girls. Aged 6–20 years old

<sup>1</sup>The informants included 11 parents and 9 external personal assistants.

for 50–110 min while the interviews with the personal assistants lasted for 20–55 min. Following this, each interview was transcribed and read through carefully several times. Statements from the interviewed parents and personal assistants were brought together in the analysis because initial review of transcripts found that their views on the role of the external personal assistant corresponded.

### Analysis

The quantitative data from the questionnaires and the qualitative data from the interviews have been integrated when answering each of the two research questions.

The role of the external personal assistant in relation to the *child* was studied by descriptively looking at the median values of the amount of needed assistance (not at all, somewhat, rather much, much) in each activity. In addition, an inductive, manifest content analysis of the transcribed interviews answering this research question was performed (Elo & Kyngäs 2008). Meaning units were searched for and labelled with a code. The various codes were then compared to identify differences and similarities and then sorted into subcategories. Following that, different subcategories were combined into categories that comprised groups of content that shared a commonality (Krippendorff 2013). The qualitative data were then viewed as a frame for the

interpretation of the quantitative data to get a richer understanding.

The role of the external personal assistant in relation to the *family* was studied by looking at the differences in the frequency of presence of an external personal assistant/parent/parent as a paid personal assistant (yes/no) in the family activities by using the Chi-squared test. Additionally, an inductive, manifest content analysis of the transcribed interviews answering this specific research question was performed in the same way as described above as well as the integration of both types of data.

The quantitative data analyses were performed by using SPSS 19.0 (IBM, Armonk, NY, USA). When using Chi-square, the *P*-value was set to  $P < 0.05$ . To support data management in the inductive qualitative data analysis, the Atlas.ti software program was used (Atlas.ti. 2012).

## Results

### A reinforcing role in relation to the child

The role of the external personal assistant in relation to the child was in the analysis of the interviews found to comprise four categories: To substitute basic functions, to support in everyday life, to support in maturation and to give relationship support (Table 2a). These categories can also be seen in relation to what was

**Table 2** (a) Qualitatively described role of the external personal assistant in relation to the child,  $N = 11 + 9^1$  (b) Quantitative description of the amount assistance<sup>2</sup> needed by the child,  $N = 60^3$ 

<i>(a)</i>			
<i>Categories</i>			
<i>Substitute basic functions</i>	<i>Support everyday life</i>	<i>Support maturation</i>	<i>Relationship support</i>
<i>Subcategories and examples of citations from the interviews:</i>			
<ul style="list-style-type: none"> <li>• Interpret the child</li> <li>• Be the child's communicator</li> <li>• Be the child's arms and legs 'Trying to talk about what we are painting and maybe to have a theme [. . .]. You have to help her hold the brush or the pen. We also use grasp crayons. You have to help her hold'.</li> <li>(Assistant 11)</li> <li>• Perform care</li> <li>• Be the child's driving force</li> </ul>	<ul style="list-style-type: none"> <li>• Support in routines '...there are those small things that also become important. It is important that "Annie", who might not be able to share her great personality with everyone, gets to be nice and clean. That you make sure there is no food left on her face, that you make sure that she is neat and clean, that she has fixed her hair'. (Parent 3)</li> <li>• Support in play and leisure activities</li> </ul>	<ul style="list-style-type: none"> <li>• Support the child's development</li> <li>• Get the child engaged '... sometimes you need to pep him up to make him willing to do stuff and that, like getting involved, because sometimes "John" is like he doesn't want to try new stuff'. (Assistant 8)</li> </ul>	<ul style="list-style-type: none"> <li>• Support to be a part of the family</li> <li>• Support the relationship with others '... is there for him as a helper so that he can participate in society like other people can'.</li> <li>(Parent 7)</li> <li>• Accentuate the child</li> </ul>
<i>(b)</i>			
<i>Family activity type</i>	<i>Activities</i>		
Indoor activities	Doing handicraft, playing board games, dancing and exercising physical therapy at home; 4 (3–4). Surfing the internet and playing with children (friends/siblings); 4 (2–4). Joking and fooling around, playing computer games, playing with you or other adult, story reading and playing instruments; 3 (2–4). Singing; 3 (1–4). Playing with pets; 2 (1–4). Listening to music; 2 (1–3, 5). Watching a movie and watching TV; 2 (2–3)		
Meals	Being together in the kitchen, cooking/baking and laying the table/cleaning away; 4 (3–4). Doing the dishes; 4 (2, 75–4). Having breakfast together; 3 (2, 25–4). Having tea or coffee together, having dinner together; 3 (2–4)		
Routines	Doing evening routines; 4 (4–4). Doing morning routines; 4 (3, 25–4). Cleaning the house, packing school bag, picking up after playing and going by car at other occasions; 4 (3–4). Going by car to and from school; 4 (2, 25–4). Lying down for rest; 3 (2–4)		
Outdoor activities	Shopping for groceries, gardening, playing outside with other children, playing outside with you or other adult, bicycling and going for a walk; 4 (3–4). Going on a swing; 4 (2, 75–4). Playing in the sandpit and playing ball games 4 (2–4)		
Organized activities	Going together to parent's leisure activity; 4 (3, 25–4). Going together to child's leisure activity, going to church and going to habilitation centre activities; 4 (3–4). Going together to sibling's leisure activity; 4 (2, 25–4)		
Outings	Going out in the nature; 4 (3, 5–4). Going to the playground, going shopping, going to the library, going to theatre/cinema/concerts, visiting friends who have children, visiting friends who do not have children, visiting relatives and going to parties; 4 (3–4)		
Vacation/holiday cottage	Going on vacation; 4 (4–4). Going to holiday cottage; 4 (3, 5–4)		

<sup>1</sup>Data from 11 interviewed parents and 9 interviewed external personal assistants. All names used in citations are pseudonyms.

<sup>2</sup>Median value (25th–75th percentile) of how much help that was needed where 1 = not at all and 4 = much.

<sup>3</sup>Data from 60 families that answered the questionnaire Child-PFA.

reported in the questionnaires about how much assistance the child needed to perform each activity: The studied children needed a great deal of help in all activities except in 14 less physically demanding activities, such as when watching TV and listening to music (Table 2b). Thus, the external personal assistant was found to have a reinforcing role in relation to the child meaning that he/she should support and empower the child within the activities which in turn was directed by the child's needs, that is what kind of assistance the child needed and how much.

Regarding the reinforcing role in relation to the child, to *substitute basic functions* included various aspects. It was described in the interviews to be needed to interpret the child's many times weak signals and to help the child to communicate. When facilitating the child's communication it was both a matter of helping the child to understand and being a spokesperson for the child. The children were likewise described as needing help to physically accomplish and control body movements in activities. Another aspect was to perform the care the child needed, for example make life safe and good for the child, give medicine and help the child with exercises. Many children also needed the assistant to be the driving force in activities; they needed to have an assistant who creatively could initiate activities. In this, depending on the type of functions that needed to be substituted, different levels of assistance were required. To *support the child in everyday life* included support in routines such as in dressing and in meals and support in play and leisure activities (Table 2a). To support the child in everyday life involved mainly physically demanding activities, which lead to the need for a high level of assistance. For instance, much help was needed when doing handicraft which in turn can be said to include both the subcategory be the child's arms and legs and the subcategory support in play and leisure activities (Table 2b). To *support maturation* included both to support the child's development by for example getting the child to do practical things him/herself to as high an extent as possible and to build the child's self-esteem by respecting the child including the child's age. It also included facilitating the child's engagement.

Moreover, *relationship support* was stressed by the informants and included supporting the child to be a part of his/her family as well as to support the child's relationship with others. This could be performed through such acts as inviting friends over for baking or playing board games. The need for assisting in accentuating the child was often stressed and depended

on the child's limitations in doing this by him/herself. An example of this could be by telling others about the child's abilities and what outings the child had accomplished (Table 2a). In themselves, these two latter categories, to support maturation and relationship support, involve mostly physically less demanding subcategories. However, the context in which they are performed controls the level of assistance needed: For example, facilitating the child's engagement when performing morning routines is more physically demanding than when watching a movie (Table 2b).

### A balancing role in relation to the family

The role of the external personal assistant in relation to the family was in the analysis of the interviews found to comprise three categories: Shared understanding, exhibit relational skills and fulfil a function (Table 3a). This can be seen in relation to what was reported in the questionnaires about who was most often taking part in the activities, where it was found that to some extent the external personal assistant do activities more often with the child outside the home, while the parents assist the child more often when having breakfast together and when visiting friends who do not have children (Table 3b). By showing sensitivity to the family's life and privacy, and at the same time being there to fulfil a function, the preferred external personal assistant was found to have a balancing role in relation to the family which directed the external personal assistant's actions.

Regarding the role of the external personal assistant in relation to the family, the informants stressed the importance of *shared understanding*. Included in this, personal assistance for a child in a home setting had to be recognized as a compromise for the family, namely the family would not have chosen to have an external personal assistant present if it had not been necessary. The external personal assistant was or sometimes felt that he/she was supposed to be there but not to be noticed. At the same time, the importance of recognizing that the relationship was something that had to be built up through time and effort was expressed.

The role of the external personal assistant included also to *exhibit relational skills* in relation to the family. It was important to be responsive towards the family's needs and to try to imagine one's self in the family's position by showing respect. It was likewise a matter of keeping an open dialogue by being open and honest in communication, partly in order to get to find out from the family what was expected. Related to the external personal assistant's behaviour, some parents expressed

**Table 3** (a) Qualitatively described role of the external personal assistant in relation to the family,  $N = 11 + 9^1$  (b) Quantitative comparison of frequency of presence<sup>2</sup> of personal assistants in the activities using Chi-square.  $N = 60^3$ 

(a)			
Categories			
Shared understanding		Exhibit relational skills	Fulfill a function
<i>Subcategories and examples of citations from the interviews:</i>			
<ul style="list-style-type: none"> <li>Recognize it is a compromise for the family 'Yes, it really is a unique situation. It is. You know that if the parents or those people in that home had been able to choose, then I wouldn't be there. That's the way it is, or, yes, since the situation is the way it is, then it's a good thing that I'm there, but it's not something that anyone would have chosen. To have someone else in their home that often, that's no ideal situation'. (Assistant 6)</li> <li>Recognize it is something to be built up</li> </ul>	<ul style="list-style-type: none"> <li>Be responsive and respectful 'I usually say, imagine yourself if someone comes to your home, you think about it. Still, you work in somebody else's home and it's their home, and it must be. When it comes to integrity and stuff, you might not look in every cabinet and drawer'. (Assistant 11)</li> <li>Be open and honest in communication</li> <li>Be a good match</li> </ul>	<ul style="list-style-type: none"> <li>Support family's everyday life 'First, making sure that "Ted's" life runs smoothly, but that in turn makes the life of the whole family run smoothly'. (Parent 2)</li> <li>Reducing the burden</li> </ul>	
(b)			
The external personal assistant significantly more often present in the activity, $P > 0.05$		The parent as a paid personal assistant significantly more often present in the activity, $P > 0.05$	
Activity	P-value	Activity	P-value
Playing computer games	0.031	Having breakfast together	0.010
Playing with children (friends/siblings)	0.010	Visiting friends who do not have children	0.007
Playing outside with other children	0.003		
Going on a swing	0.046		
Going for a walk	0.028		
Playing in the sand pit	0.027		
Going together to child's leisure activity	0.003		
Going to the library	0.008		

<sup>1</sup>Data from 11 interviewed parents and 9 interviewed external personal assistants. All names used in citations are pseudonyms.

<sup>2</sup>In the rest of the activities, there were no significant difference between presence of the external personal assistant and the parent as a paid personal assistant.

<sup>3</sup>Data from 60 families that answered the questionnaire Child-PFA.

the significance of the external personal assistant being a good match (Table 3a). These two categories, shared understanding and exhibiting relational skills, can be seen in relation to whether the external personal assistant is performing the assistance in the activity or if the parent chooses to perform it. It was found that that the personal assistants most often assisted for example when playing outside with other children or when going to the child's leisure activities while the parent most often assisted when having breakfast together and

when visiting friends who do not have children. Thus, it was more common that the parents preferred to not include a non-family member in these situations (Table 3b).

To *fulfil a function* included support in the family's everyday life but it was likewise described as reducing the parents' burdens associated with caring responsibilities so that the parents could engage in something else or rest (Table 3a). Also, this aspect can be seen in relation to who is assisting the child in

different activities. In this sense, an external personal assistant may assist in activities away from the child's home to give the parents some respite (Table 3b).

## Discussion

This mixed method study investigated the role of the external personal assistants for children with PIMD working in the children's home. The study took place in Sweden, where personal assistance is provided through the social security system. It was found that the external personal assistants had a reinforcing role, meaning a supportive and empowering role, in relation to the child, and a balancing role in relation to the family including reducing the experience of being burdened and showing sensitivity to family life and privacy.

In relation to the child, the described role of the external personal assistant included *substituting the child's basic functions* and *supporting (the child) in everyday life*. This is in accordance with the Swedish act LSS stating the goal that individuals should be able to live like others (SFS 1993:387). Due to the children having PIMD and consequently being heavily dependent on others (Nakken & Vlaskamp 2002, 2007), it was expected that the children in this research was found to need much support in almost all of the activities, such as in the morning and evening routines, when playing and when visiting other people. The aspect of performing care as a part of the assistant's work was also comprised in the role of substituting basic functions and is likewise discussed by Skär & Tamm (2001) in their interview study including children.

In addition, the parents and external personal assistants in the present study described the role of the external personal assistants in relation to the child to include *supporting maturation* and *supporting relationships with others*. Based on the knowledge that participation is important for children's development and well-being, helping a child to get engaged/involved was in the analysis interpreted as helping the child to mature. In a previous study, Axelsson *et al.* (2014) described facilitating strategies for improved participation and engagement in children with PIMD. Axelsson *et al.* found facilitating strategies related to the child's proximal environment exemplified by the importance of people in the child's environment having a positive attitude. Also, in the same study strategies related to the child him/herself were found and exemplified by the importance for the child to have opportunities to understand. The aspect of supporting relationship with others is also in accordance with the study by Skär &

Tamm (2001), where according to the interviewed children, an ideal assistant should have the role of being a friend as well as being an 'admission ticket' to peers. In this performed study about the role of the personal assistant assisting a child with PIMD, this can be expected to be especially important due to the severity of these children's disabilities (Granlund *et al.* 2013). Overall, the level of needed assistance can be assumed to be related to the child's disability and not to who is giving the assistance.

The role of the external personal assistant is not only related to the level of the child's need for assistance. As stated by Bronfenbrenner (1986), the child must likewise be seen in the context of his/her family system, where personal assistance for children with PIMD is crucial. Even though the external personal assistant is like a family member for the child, in line with earlier research (Wilder 2008), this study shows that this is not true for the rest of the family. According to the analysis of the questionnaires, the parents chose not to include any external personal assistant in the breakfast situation, a within home routine activity, and not either when visiting friends that didn't have any children, that is, a family unit activity. Furthermore, the external personal assistant was significantly more often present when it came to several outdoor activities as well as when going to the child's leisure activities, that is, activities away from home. This can be interpreted as parents not always feeling entirely comfortable with having an external person included in family life and thus may schedule the personal assistant accordingly. Inversely, this arrangement can also be interpreted as the personal assistant not always being entirely comfortable with the family in its most intimate moments and interactions. Associated with this, a *shared understanding* was in the interviews described as important. This included recognizing that having an external personal assistant in someone's home is a compromise. These results regarding the family supported previous research by Ahlström & Wadensten (2011) where the lack of ability to maintain a private life was expressed by family members to adult assistance recipients. In addition, in this study, the informants raised the question of importance of recognizing that relational aspects need to be developed by time, leading to the ideal that the external personal assistant continued his/her employment for a longer period of time. Also, this aspect is in line with the results by Skär & Tamm (2001) who reported that the interviewed children in their study recognized difficulties to introduce a new person into their lives.

Looking for desired quality attributes of an external personal assistant was not an aim of this study as described by Roos (2009) where 12 adult assistance recipients were interviewed. Nevertheless, in agreement with their results, the informants in this study also highlighted the importance of being responsive and respectful of the family. In this study, this was interpreted as aspects of the external personal assistant's ability to *exhibit relational skills*. Additionally, to be open and honest in communication was stressed. This is in agreement with what has been stated by Egard (2011) as well as by Ahlström & Wadensten (2012) in their studies about external personal assistance and assistance recipients. It may also be a question of the external personal assistant being a good match with the family, as expressed by some of the interviewed parents. Based on a survey among personal assistants in Norway, Guldvik (2003) even discussed whether matching personal assistants and users with mutual interests and similar expectations can help to reduce systemic dilemmas related to external personal assistance.

The external personal assistant's role in relation to the family was furthermore described to *fulfil a function*, mostly in a practical way. This included supporting family's everyday life as well as reducing the parents' burdens associated with caring responsibilities and is similar to what has been stated in a Swedish Government Bill associated with the law of LSS (Government Bill 1992/93:159). The analysis of the questionnaires showing that the external personal assistants' presence in activities away from home can thus be interpreted as a need to ease family life. It can also be understood as a need for the families to live more like families with typically developing children.

### Method discussion

The choice of a mixed method design allowed different ways of data collection and methods of analyses which were needed to get a comprehensive view on the subject (Tashakkori & Teddlie 1998). There are limitations in the study in spite of a pursuit for validity and trustworthiness. A few of the 60 children did not (yet) have an external personal assistant. This absence of an external personal assistant could be interpreted as an indication that the parents chose to be in the activity rather than involving an external personal assistant, and thus, the statistics have been drawn from all 60 children/families. Still, all 11 children where the parents were interviewed had one or more external personal

assistants. To reach validation of the Child-PFA questionnaire, discussions have been held in the research group and a pilot testing has been performed (Axelsson & Wilder 2014). Nevertheless, there might have been difficulties in knowing, and thereby reporting, if you are in the activity in the role of a parent or of a personal assistant. To reach credibility in the interviews, a heterogeneity of the participants was sought, and the conducted interviews gave opportunities, in an individual manner, to look into the parents' and employed external assistants' ways of considering the role of the external personal assistant. In the interviews, an asymmetrical power relation, for example, was reduced by having a small talk before the interview began. The different ways of conducting the interviews, face to face and over the telephone respectively, were chosen based on the informant's different relationship with the child and on convenience. Dependability was supported by the same researcher (the author) conducting all the interviews, and the period over which the interviews were conducted was kept as short as possible (five and a half months). Agreement in interpretation throughout the analysis processes was reached through dialogues with coresearchers. Yet, the ability to transfer the results to other families must be considered with caution, and it must be stressed that considerations must be given to the uniqueness of each child, family and personal assistant. Maybe the main issue, however, was that the children were not interviewed regarding their views about the role of the external personal assistants. This was not possible due to the severity of their impairments.

### Conclusion

By investigating the role of the external personal assistant in relation to the child with PIMD and in relation to the child's family with a mixed method design, this study has given a greater understanding to the complexity of the role of the external personal assistants for children with PIMD working in the children's home. The child needs personal assistance in everyday life and the assistance in turn eases family life. The external personal assistant could be a support for the child in a diverse set of family activities when the parents, for example, do not have enough time for the child, for example, other siblings may need attention. These findings play an important role with regard to improving personal assistance services for children with PIMD in the children's home environment where the

planning and in the implementation of external assistance ultimately the child's needs should govern choices. Nevertheless, consideration must be given to the entire family – with the aim that it will benefit the child with PIMD.

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### Conflict of Interest

No conflict of interest has been declared.

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