Ways to improve participation for children with disabilities in family settings:

Parents’ and external personal assistants’ perceptions of support characteristics

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ABSTRACT

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Purpose: Participation in niches within family settings provide children with social and non-social experiences that may lead to enhanced learning and development which may later promote increased participation in many other activities. Therefore, there is a need to identify about ways how to facilitate participation of a child with disabilities in families’ everyday life.

Method: The qualitative, explorative, inductive design was performed using focus groups. The data was used from the focus group interviews done in 2013-2014.

Results: The semi-structured interviews revealed four ways of how participation for children with disabilities could be enhanced in family settings. They were: to adapt as a parent; to find an external personal assistant that suits family’s needs; to develop a connection among family and external personal assistant; to find suitable activities for children with disabilities.

Conclusions: Environmental aspects were identified as the ones that could be modified to enhance participation in family settings for children with disabilities.

Keywords: children with disabilities, external personal assistant, parents, family settings, siblings
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1. Introduction

Participation is an important aspect to ensure. The literature suggests that participation in life situation helps to improve functioning, well-being, and development (Bronfenbrenner, 1999; Axelsson, 2014). Also, United Nations Convention on the Rights of the Child (UNCRC) states the importance of participation for children with disabilities (Article 23, United Nations General Assembly, 1989).

Bronfenbrenner’s bioecological model (1979) supports the idea that family settings and people that are around the child in the microsystem are the most important for development and well-being. A transactional theory states that there is a bidirectional influence. Therefore it is vital to utilize the closest people’s impact on participation.

Families are a significant part of children’s lives, and it is a setting where participation opportunities are offered for children from the small age. However, while having a child with a disability, these opportunities can be challenged. In Sweden for children with the developmental disorder, autism or autism-like conditions, for significant and permanent disability after a brain injury and people with other permanent physical or mental disability when they cause substantial difficulties in daily life, external personal assistants can be provided (SFS 1993:387).

Since external personal assistants can spend much time with a child and the family, it is essential to understand how external personal assistants work in family settings and what both parents and external personal assistants find beneficial in helping children with disabilities to participate in family settings.
2. Background

2.1 Disabilities

Disability is an umbrella term and a complex phenomenon. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines disability as: “those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN, n.d., p. 4). Therefore, disability is not only related to health problems; it is related to interactions a person has with society and with the features of one’s body (WHO, 2017).

Severity of impairment make children heavily dependent on others, such as permanent disability after a brain injury, profound intellectual and multiple disabilities (PIMD) and others. For example, PIMD is intellectual disability that is combined with profound physical disabilities. It is a chronic and life-long condition. Moreover, people that have PIMD most often have other impairments such as sensory impairments and medical complications. Therefore, having PIMD may result in dependence on others (Vlaskamp & Puten, 2008). People with PIMD need a high level of support to participate, and they require high levels of personal care too (Axelson, 2015; Jansen, Putten, & Vlaskamp, 2013). However, people with PIMD not always have the level of support they need. They can spend more time disengaged and isolated which leads to less participatory opportunities that are a central aspect of quality of life (Talman, Gustafsson, Stier, & Wilder, 2017).

2.2 Participation

Participation is a multi-dimensional construct and is defined as an involvement in a life situation (WHO, 2007), feelings of belonging and engagement in the activity (Eriksson & Granlund, 2004), and frequency of attending an activity or presence (Black-Hawkins, 2010). Participation can be looked at from two perspectives: a social and a psychological. The social perspective talks about participation regarding availability and accessibility and is related to the frequency of attending. The psychological perspective talks about participation regarding acceptability and accommodability and is related to the intensity of involvement and engagement (Adolfsson, 2011; Maxwell, Alves, & Granlund, 2012; Maxwell & Granlund, 2011). Participation can be measured by the qualifier performance which stands for acting in the current environment. However, participation includes involvement (sense of belonging) aspect too and per-
formance is not the most suitable qualifier to measure this part of participation. There are suggestions to introduce new qualifier – subjective experiences of involvement which would help to measure participation better (Granlund, 2012).

Participation occurs across many locations, such as environments for work, school, family, play, sport, entertainment, etc. (Law, 2002). It can have a positive impact on health, development, and well-being of a child. It is through participation children acquire specific skills, develop social networks (Anaby et al., 2014; Law, 2002). However, some may not have possibilities to participate to the same extent than others.

Participation can be looked at from two different perspectives. It can be seen as an outcome or as a process (Imms, et al., 2017). For a child with a disability, participation is an outcome in this study, however, for others in the environment participation can be a process to reach that outcome for a child with a disability. For example, the engagement of family members can be critical to the success of interventions (King, Desmarais, Lindsay, Piérart & Tétérault, 2015).

2.3 Environment

2.3.1 Family

Development of a child is dependent on interactions among child and social contexts (Sameroff & Fiese, 2000). The primary social setting for a child is family. A family is being defined as a unit that identifies itself as a family, which includes people related by blood, marriage or commitment (Hanson & Lynch, 2004; Wachs, 2000). It is interdependent and influence each other’s development. A family is not merely a collection of individuals but rather a dynamic system with certain needs and characteristics composed of individuals with their needs and characteristics. The presence of a child with a disability can have multiple and profound effects on a family. Some families may adapt successfully to having a child with a disability while others do not, e.g. do not include a child in participatory opportunities (Knox, 2000).

2.3.2 Family activities

Everyday family settings can provide opportunities for a child to participate which can enhance learning and development by providing social and non-social experiences which in turn may promote participation in more and different activities (Dunst, Hamby, Trivette, Raab, & Bruder, 2002). Such opportunities to participate can be found in routines and rituals. Routines
and rituals refer to repeated practices with two or more family members. Routines have no particular meaning, have momentary time commitment and are regularly repeated. Examples of routines are household chores, cooking/preparing meals, doing errands, having a bath time, brushing teeth, picking toys, dressing (Axelsson, 2015; Bronfenbrenner, 1995; Dunst et al., 2002). Rituals, on the other hand, involve symbolic meaning and portrays what it means to be in a particular group, are repeated among generations (Spagnola & Fiese, 2007; Weisner, Bernheimer, & Coots, 1997). Examples of rituals are family meetings, saying grace at meals, celebrations such as holiday dinners, birthdays, traditions, etc. (Bronfenbrenner, 1995; Dunts et al., 2002).

2.3.3 Influences of participation for children with disabilities in family settings

Children with disabilities initiate participation less than typically developing peers. Participation for children are influenced by child characteristics such as age, sex, severity of conditions, and functional abilities (Anaby, et al., 2014) and environment such as adult sensitivity, responsiveness, and arrangement of activities (Dunst et al., 2002). Attitudes in a family, socio-economic status, psychosocial support are yet another influences that can enrich or hinder participation (King et al., 2006; Law, 2002). Meaning that how a child function depends not only on child’s characteristics, such as disability but also on the external influences in the environment (Bronfenbrenner, 1995). For example, previous research about PIMD and participation have shown that families who have children with PIMD offered some activities less often and children participated less frequently in the activities offered compared to families with typically developing children (Axelsson & Wilder, 2014). Once in an activity, children with PIMD were less engaged (Axelsson, Granlund & Wilder 2013). The number and type of activities are being influenced when having a child with PIMD (Axelsson & Wilder, 2014) and the kind of activity affects the engagement level, meaning that routine activities were less engaging (Axelsson, Granlund & Wilder, 2013). However, there are some strategies identified by Axelsson, Imms, and Wilder (2014) that could help with enhancement of participation. For example, proximal environment influenced participation. Strategies to facilitate participation included to have a positive attitude and knowledge about child/adolescent and for the activity to be available and acceptable.

Also, when there is a child with a disability in a family siblings may have to take a different role and act as a caretaker, manager, teacher, helper for that child with a disability. They can play a significant role in the development of children with disabilities which can
sometimes be equal in the influence that of parents (Knox, 2000). Knowing that siblings can have an impact on, for instance, identity development of the child with a disability (Serdity & Burgman, 2012) the influence of siblings on the participation of the children with disabilities also needs to be acknowledged. Another influence can come from external personal assistants.

### 2.4 External personal assistants

Depending on the severity of the impairment children can be heavily dependent on others for their physical care, education, stimulation, etc. In Sweden, disability policy is based upon universal equality of dignity and rights. Persons with a disability can apply for consultation, companion service, contact person, short-term stays away from home, external personal assistance among other things (Clevnert & Johansson, 2007; SFS 1993:387). External personal assistants are provided to facilitate participation and equality of living conditions for those with a developmental disorder, autism or autism-like conditions, for significant and permanent handicapped disability after a brain injury and with other permanent physical or mental disability if they cause substantial difficulties in daily life (SFS 1993:387). Such challenges can be an inability to meet basic needs, e.g., dressing/undressing, eating, hygiene, and communication. If person needs help with these issues then one also has a right to get assistance with life activities such as shopping or leisure time activities. There are no restrictions on hours or on how many personal assistants one could have. It all depends on the unique needs of the person in need of personal assistance (Clevnert & Johansson, 2007; Talman et al., 2017).

The personal assistant can be relatives or non-relatives. Therefore, a personal assistant can be a parent too (SFS 1993:387). As Matthias and Benjamin (2008) identified having relative or friend as an assistant can bring benefits in a sense that they already know the person and what help they may need help with. Moreover, a user can feel more satisfied with the services (Kramer et al., 2012). Axelsson (2015) and Boren, Granlund, Wider and Axelsson (2016) in their article talked about external personal assistants’ and parents’ differences in activities they provide for children with PIMD. External personal assistants take children from home thus providing more socially integrated activities and giving parents a chance to rest while parents provide children with more non-socially integrated activities. Respite is essential for parents that have children with disabilities. Parents do not have the same amount of rest compared with parents of typically developing children, which influence the well-being the whole family (Luijkx, Putten, & Vlaskamp, 2017).
Moreover, an external personal assistant may become a considerable part of the inner circle of the social network of a child (Wilder, 2008). Axelsson (2015) stated that having an external personal assistant at home is a compromise. For a child, an external personal assistant can become a family member, while for the family external personal assistant can still feel like outsider and family may not feel comfortable in having an external personal assistant around all the time (Wilder, 2008). In addition, according to the research done by Roos (2009) external personal assistants must have certain qualities that suits family’s needs, such as being respectful, considerate, and friendly.

For this thesis environment aspects such as parents, siblings and external personal assistants and their influence in family settings are being looked at. Mainly how a child with a disability, having external personal assistance, can be influenced to participate more in family settings by parents, siblings and external personal assistants.
3. Theoretical framework

3.1 Bio-ecological model

The bio-ecological systems theory is a model of an interaction between biological and environmental factors in human development. Development of the child is shaped as a result of the different environmental systems surrounding the child and also the interaction among these systems (Bronfenbrenner, 1994). The most recent bio-ecological model of interactions is Process-Person-Context-Time (PPCT) (Bronfenbrenner & Evans, 2000)

Process refers to interactions (or proximal processes) between the child and close surroundings that are responsible for the child's well-being. These interactions change and affect both child and environment. They need to occur frequently and over the extended period, and should become more complex for development to occur (Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 1998). Proximal processes can be influenced by environment (e.g., economic status), individual systems characteristics (e.g., impairments) or culture (e.g., gender beliefs) (Wachs, 2000).

Person aspect takes into account characteristics of the one in focus, which is divided into demand, resource, and force. Demand characteristics are those that are apparent and influence initial interactions, such as age, gender, and ethnicity. Recourse characteristics are not immediately apparent. It relates to mental and emotional characteristics, such as past experiences, skills, intelligence and social and material resources, such as access to food, housing, educational opportunities, etc. Force characteristics are such as temperament, motivation, persistence, etc. Different characteristics explain why children when having the same environmental conditions perform differently (Bronfenbrenner & Morris, 1998).

The context in which the person lives contains four different systems. Each system has a direct or indirect effect on the development. Microsystem refers to the system closest to the person with direct contact e.g. family settings. Relations in microsystem are bi-directional between child and his/her microsystem. The microsystem is the most powerful level of the bio-ecological systems theory. Mesosystem consists of the interactions between the different parts of a child’s microsystems, e.g., relationships between caretakers and external personal assistant. Exosystem refers to a setting that does not involve the child as an active participant but still affects them, e.g., parents working schedule. The exosystem affects microsystem and mesosystem. Macrosystem is the cultural environment in which the child resides, and it refers to the
role the environment plays in child’s development, e.g., attitudes in society (Bronfenbrenner & Morris, 1998).

Then there is time aspect which is divided as well: micro-time which occurs during specific activity or interaction, meso-time which is the consistency of the interactions or activities and macro-time or chronosystem which means that developmental processes can vary due to historical events (Bronfenbrenner & Morris, 1998).

Certain events, such as the presence of a disability in a child can cause changes in all other systems and affect the person’s development (Bronfenbrenner, 1979).

3.2 Niches

According to Wachs (2000) niches are an expansion of microsystem that goes beyond physical settings. It adds cognitive aspects, skills, interpersonal characteristics and attitudes of a person. There is the bidirectional relation between individual and niches, especially when the person has an extreme trait. A child with disabilities influences their niches based on their specific needs, limited abilities and unusual circumstances. The number of niches depends on an individual abilities: it can be limited based on characteristics of the individual, and each individual can reach different potential in specific niches. Some factors can result in opening more niches while some factors can result in closing niches. The examples of factors can be parents’ jobs and connections, or child’s abilities, characteristics. Children with disabilities may not have a huge amount of niches to choose from depending on their abilities or other factors in the environment. Niches can be homogenous or heterogeneous. Homogenous may lead to maintain individual’s goals while heterogeneous niches may lead to more optimal development since an individual has to learn to adapt to many different contexts. Exposure to an only limited amount of niches may restrict individual’s ability to change even when change is possible. Being in one niche can open opportunities to other niches. Niches are not only neutral. They can be positive or negative depending on social and cultural context. Also, depending on ages some niches can be more critical and change with time, like for smaller children family niche can be more salient while for adolescents the more salient can be peer group (Wachs, 2000). Consequently, not only a child can choose niches based on the goals, preferences, but niches also can influence child resulting in development through proximal processes. The child with a disability may not have a vast majority of niches to choose from. However, participation in family settings can provide some niches that may lead to increase in well-being and development and even result in the opening of more niches if a child participates.
3.3 Transactional model

The transactional model stresses the idea that development occurs from interplay with processes in the individual’s context over time. The core idea is on the bidirectional, interdependent effects of the child and environment. The child influences the environment and environment affect the child. Development may not occur due to a failure in the environment or in a child to become more complex. For children with disabilities, there are restrictions on the range of contexts that can be experienced, however as history showed, those with disabilities can reach more than once believed. Consistency in individual behavior may come not only from the unique traits but in the consistency of the transactions between child and environment. Transactions are those activities that change the usual activity of the element. It can be qualitative by increasing or decreasing a level of response or quantitative by eliciting or initiating new responses (Sameroff, 2009; Sameroff & Fiese, 2000). Examples of a transaction could be as indicated in Figure 1.

**Figure 1** Transactions

Since impairment is present in children, other factors need to be found that is mouldable and can be worked on and improved which will result in improvement in participation. The example of the factors that can be changed to reach better participation for children with disabilities could be child’s participation in family niches (Sameroff & Fiese, 2000). For this thesis, the environmental aspects such as family and personal assistant are seen as the ones that can be influenced to help children with disabilities to participate more in niches of family settings. Microsystem such as family settings are considered to provide niches where proximal processes happen through which changes may occur. Through being included in everyday life, a child learns how the world functions, such as through transactions with family a child can learn about interpersonal relationships or role in a specific culture. Therefore, niches in family settings and opportunity to participate in them for children with disabilities can result in development and
participation in more and various niches which can be opened with the development of new skills (Axelsson, 2014; Imms et al., 2017; Wachs, 2000, Wilder, 2008).

In addition, as the bioecological and Transactional model states, proximal process and transactions should be increasing in demand for the development to occur (Bronfenbrenner & Morris, 1998; Sameroff, 2009). For this thesis, merely the opportunity to participate in everyday family settings was an understanding of opportunity for further development which does not necessarily mean that demands will be increasing with time.
4. Rationale

**Rationale:** Child development has multiple contributors. A theme that is visible in the literature is that participation in niches of family settings provides children with social and non-social experiences that may lead to enhanced learning and development which may later promote increased participation in many other activities (Dunst et al., 2002). Even though there are opportunities to participate in specific activities in family settings for children with disabilities, parents and external personal assistants may not be aware of ways how to increase participation of children with disabilities to the best way possible (Axelsson, et al., 2015). Also, the parents and the external personal assistants may have negative attitudes towards the ability of a child to participate (Bigby, Knox, Beadle-Brown, & Clement, 2015; Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012, Talman et al., 2017). Therefore, it is essential to have people in family settings that can believe in the ability of a child with a disability to take part in family activities and know how to make the child be more included in the family’s everyday activities such as various routines and rituals.

However, up to date, there is no study performed that looks into how to help a child with disabilities from the parents’ and external personal assistants’ perspectives by taking into consideration how having a sibling can affect the social side of participation in family settings.

The aim is to explore parents’ and personal assistants’ perceptions of support characteristics about ways to make a child with disability to participate in family’s everyday life.
5. Methodological framework

5.1 Research design

A qualitative, explorative, inductive design was performed using focus groups. The data was used from the focus group interviews done in 2013-2014.

This design was used to help to answer the study's aim. Qualitative approach study experiences of people, their values, opinions, behaviors (Mack et al., 2005). Exploratory research “is a methodological approach that is primarily concerned with the discovery and with generating or building theory” (Jupp, 2006, p.111). Focus groups are one of the examples that can be used in qualitative research to get the experiences of people related to topics of interest which are complex and sensitive (Carey, 2015; Krueger, & Casey, 2015).

5.2 Sample and procedure

This study was performed using four focus groups at the Jämlikhet Assistants Gemenskap (JAG) which is social services organization in Stockholm for the equal community. Groups consisted of parents and external personal assistants. The participants came from different parts of Sweden, and all were connected to the organization JAG. The parents were recruited from the association JAG, and then they chose the personal assistants. In total there were 17 participants: 11 parents and six external personal assistants. Parents and external personal assistants represented children with disabilities of different gender and ages. In total five boys (age varied: 9, 12, 12, 14, 15) and four girls (age varied: 4, 6, 13, 18) were represented. Children had various multiple disabilities among which: autism, severe epilepsy, blindness, brain injury, motor disability, paralysis, learning problems, gross development disorder, and muscle injury.

According to Krueger and Casey (2015), and Carey (2015) focus groups have to have specific characteristics, such as sample size in a group, time the interviews last, specific interview guide. In total six focus groups were performed of which four group interviews were used in this study. Due to some technical errors that occurred during the two interviews it was decided to not to use them in this thesis. The number of participants in these four groups varied from three to five participants. Two groups consisted of five participants, one group consisted of four participants, and one group included three participants. Interviews were performed in JAG organization premises and followed a focus group guide with semi-structured interviews.
WAYS TO IMPROVE PARTICIPATION FOR CHILDREN WITH DISABILITIES

(see Appendix A). During focus groups, two people were present: researcher and a person representing JAG organization. There were two researchers involved, which meant that either of them could interview groups. The researcher was the one leading the focus group interviews by asking questions. A person from JAG organization was taking notes and summarizing the answers at the end of the focus group interviews to make sure that what was said was understood in the right way. First introduction questions were asked, then two central interview questions that answered the aim of the study. Finally, some closing up questions were asked. The interviews were held in Swedish and were recorded. Focus group interviews lasted from 70 to 105 minutes. Groups were homogeneous in a sense that all people involved had to take care of the child, so all knew what could work to offer the best assistance for a child with a disability to participate in family settings.

5.3 Analysis

The inductive qualitative content analysis was used, and a manifest analysis chosen (Carey, 2009). Inductive means that the aim is to discover and not test explanatory theories. Content analysis can be described as a tool to analyze text. The content analysis uses systematic coding and categorizations that helps to explore a significant amount of textual data and identify trends (Vaismoradi, Turunen & Bondas, 2013). Manifest means that analysis is going to talk about what the text is saying and be close to the text (Bengtsson, 2016; Elo & Kyngäs, 2008; Hsieh & Shannon, 2005).

The text was transcribed verbatim. Since the interviews were held in Swedish before translating one of the two researchers that performed focus groups interviews took the first step in data analysis. The researcher removed all information not related to family settings specifically after reading through the text several times to ensure the correct information was left in. The rest of the text was translated by a professional translator. After this, the data was read through several times and analysis performed by master's student. To perform the analysis, meaning units were chosen, and codes were created which best portrayed the meaning of the unit. Later, similar codes were grouped into sub-category and named. Finally, after grouping sub-categories, the categories emerged and were named (Hsieh & Shannon, 2005; Elo & Kyngäs, 2008) (See Table 1). All the way through the process the aim served as a guide. It guided the meaning units chosen, name of sub-categories and categories. Discussion with the supervisor was held through all coding process to ensure the trustworthiness.
### Table 1. Examples of the process of content analysis

<table>
<thead>
<tr>
<th>Meaning units</th>
<th>Code</th>
<th>Sub-category</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is only to find things to do, but it needs to be on his conditions</td>
<td>Things to do on CWD&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Participate in activities based on CWD&lt;sup&gt;1&lt;/sup&gt; abilities</td>
<td>Find suitable activities for CWD&lt;sup&gt;1&lt;/sup&gt;</td>
</tr>
<tr>
<td>During this year that’s been this way, I’ve actually sat down and done a handbook on how to handle [her].</td>
<td>Handbook of how to handle CWD&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Be involved as a parent</td>
<td>Adapt as a parent</td>
</tr>
</tbody>
</table>

<sup>1</sup>CWD- child with disability

### 5.4 Ethical considerations

Ethical approval was acquired by the Regional Research Ethics Board, Linköping, reference No. 2010/324-31 before the focus-group interviews started.

Relevant parts of the United Nations conventions that protect the rights of children with disabilities guided this research; the Convention on the Rights of the Child (CRC), Article 18 which calls to provide appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities; Article 23:1 concerning the child’s right to active participation in society (where in this research the family is considered a part of society), Article 23:2 concerning special care (United Nations General Assembly, 1989) and the Convention on the Rights of People with Disabilities (CRPD), Article 10, right to enjoy life (United Nations General Assembly, n.d.). Likewise, the ethical considerations comply with the Act concerning the ethical review of research involving humans (SFS 2003:460) such as voluntary participation and right to withdraw whenever a participant wants, etc.

Participants agreed verbally to participate before arriving at the premises of JAG. Before the focus group interviews started parents and external personal assistants gave their informed consent to participate in writing too. The parents also agreed in writing that their child's personal assistants commented on the child they were working with. Furthermore, the fact that the participation was voluntary, and that participants had a right to withdraw whenever they wanted was clearly explained. It was not possible to ensure anonymity, because there were three to five participants in groups. Confidentiality was explained in groups and asked that information would not be leaked elsewhere (Bengtsson, 2016; King & Horrocks, 2010). In addition, the person responsible for monitoring the group i.e. the moderator was cautious about noticing discomfort levels of the participants in the group and was ready to offer support if needed. (Carey, 2015).
Furthermore, storage of data is vital; data was stored in Jönköping University in a place that people not related to this research had no access to. Once the analysis started, the transcripts had names changed, that nobody could identify the children families and external personal assistants talked about. Careful consideration of which information was being given about the participants, and which examples of the interview were provided was made if a person said something specific only to him/her, because other family members can recognize the person once the study is published (Greene & Hogan, 2005; Greig, Taylor, MacKay, & Krentz, 2013; King & Horrocks, 2010).
6. Results

In the focus group, interviews informants described ways that help participation of children with disabilities. The content analysis resulted in 16 sub-categories and four categories which answered the aim of ways to make a child with disabilities to participate in family’s everyday life. These different ways found to make a child with a disability to participate indicated by informants are presented below (see Table 2).

Table 2. Ways to make child with disability to participate in family’s everyday life

| Categories       | Adapt as a parent | Find EPA$^1$ that suits family’s needs | Develop a connection between family and EPA$^1$ | Find suitable activities for CWD$^2$
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Sub-categories</td>
<td></td>
<td>-EPA$^1$ should fit a family</td>
<td>-Family and EPA$^1$ have to get to know each other</td>
<td>-Provide opportunities for CWD$^2$ to try new activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-EPA$^1$ should have certain qualities</td>
<td>-EPA$^1$ should be able to adapt to new family</td>
<td>-Participate in activities based on CWD$^2$ abilities</td>
</tr>
<tr>
<td></td>
<td>-Accept child’s disability</td>
<td>-EPA$^1$ should have certain qualities</td>
<td>-EPA$^1$ should be able to adapt their content of the role</td>
<td>-Allow siblings to involve CWD$^2$ in activities</td>
</tr>
<tr>
<td></td>
<td>-Have EPA$^1$</td>
<td>-EPA$^1$ should have certain qualities</td>
<td>-Family and EPA$^1$ learn to work as a team</td>
<td>-Have EPA$^1$ focused on CWD$^2$</td>
</tr>
<tr>
<td></td>
<td>-Allow siblings to take care of CWD$^2$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Be involved as a parent</td>
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<td>-Have possibilities to rest as a parent</td>
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$^1$EPA – external personal assistant; $^2$CWD – child with disabilities

Adapt as a parent

This category is about what parents themselves had to do to help their children with disabilities. Parents adaptations can result in children’ with disabilities improved participation.

- Accept child’s disability

One of the ways how parents were able to help their children was to accept that they had a disability and that some assistance was needed, but that assistance was not anything abnormal or troublesome.

I don’t see it as something troublesome; this is a part of us. (Parent F)

- Have an external personal assistant

External personal assistants and parents indicated that assistance is vital for the participation of children with disabilities, for helping to get the role for a child in a family and that it would not work without personal assistance at all. With support, parents could be parents for all children and did not have to share and divide their attention to other children in the family.
With assistance it makes mom and dad just as much to both him and his little brother. Because otherwise it is if one needs to be his assistant. That possibility isn’t possible to give and share the attention. So we have solved it so that the assistants are there. (Assistant A)

-Allow siblings to take care of children with disabilities

As extra help parents could allow siblings to take care of a child with disabilities since from interviews parents and external personal assistants indicated that siblings could be capable of providing this type of help.

...he suddenly became a participant, an involuntary participant in a game that didn’t include me or an assistant (Parent H)

-Be involved as a parent

Even when having an external personal assistant, parents still had to be involved in creating opportunities for their child with disabilities to participate. They were the ones that could help new external personal assistants to get to know the child by, for example, introducing a handbook how to handle their child, securing a safe working and living environment, helping out when assistant asks for help or by merely trying to involve child themselves.

Yes, exactly. During this year that’s been this way, I’ve actually sat down and done a handbook on how to handle [him]. In part because for him it’s important that things are repeated in exactly the same way so that you say the same things in the same way with the same words. There are a lot of routines and things like that. In part because of his autism and in part because it is the repetition that teaches him the situation. He needs to learn basically everything. (Parent H)

-Have possibilities to rest as a parent

Another aspect that was found necessary for the parents was to take a break when needed for parents and let external personal assistant take care of a child with a disability because sometimes it got too much for parents.

Because he is active all of the time, we feel that we need a little break too so that you can also do something like with other children. (Parent E)

Find external personal assistant that suits family’s needs

External personal assistants had to suit family’s needs to help children with disabilities. If personal assistant did not fit the family, then it was harder to involve a child with a disability in various activities.
An external personal assistant should fit a family

Family and external personal assistant had to feel comfortable while working in a family setting with a child with a disability. It was hard to find the assistant whose chemistry would work with families', but it was necessary since it could help with including children in participatory opportunities.

…you need to click with each other and it can help to get involved with family activities. (Assistant B)

An external personal assistant should have certain qualities

Parents and external personal assistants identified that only certain people with certain attributes could be a good external personal assistant. Qualities that were mentioned were passion, flexibility, adaptability, openness, sensitivity, flexibility, persistence, etc. Education was not the only quality families looked for.

I can feel sometimes that too much experience and education here and there can also be a disadvantage. That you need to come into the new job as it is for the assistant, without any preconceptions. …… That you come with new eyes, and even then it is good to maybe know a little basically about autism if you are going to work with someone who has autism. But maybe not that it is entirely scheduled either because it is still a new individual and person we are talking about. (Assistant A)

Develop a connection between family and external personal assistant

Once in a family, external personal assistant and family members had to find a way how to adapt and work with each other to make the child with disabilities a part of family life. From the interviews, it became clear that it was not only about child-assistant relationships but as well about parents-assistant relationships and how they worked together to improve child’s with disability participation.

Family and external personal assistant have to get know each other

For families and external personal assistants to get to know each other was a process which could take a long time, but it was worth the struggle since without assistance child with disabilities would have fewer opportunities to participate.

At the same time as the child and the family the whole time learn to live with the assistance because it isn’t something that you know about just because you have assistance. The whole time you have to see it as a process and to develop it. (Parent D)

An external personal assistant should be able to adapt to new family
For external personal assistants, it was described not only to be essential to get to know the family but as well to adapt to a family, their routines and activities because all families had different ways they do certain things. It was not easy to figure it out, nevertheless vital.

People handle it very differently, and you should have respect for that, but we have handled its up until now and think that it would feel strange to do it in another way, that we cook and are together, and someone should stand and eat out of a plastic bowl in the next room. (Parent D)

-An external personal assistant should be able to adapt their content of the role

With every new family, external personal assistant started to work with new requirements may come up due to the severity of a disability. Therefore, roles of an external personal assistant could change. For the disabilities that require personal assistance in Sweden, specific roles were visible in the interviews. For instance, the external personal assistant had to be invisible but always there and monitoring to be able to give support when a child needed it.

You must be able to react to all of these signals that are there in the person who needs them, and at the same time you shouldn’t help too much. (Parent F)

-Family and external personal assistant should have a good communication

It was expressed as really vital to communicate well with each other. It made easier to understand everyone and to know what everybody was expecting. It stressed the idea that it was allowed to ask questions and ask for advice.

And it is also something. I think that it is really important that you talk a lot about this both for the assistant’s sake, from my view, and then from the assistance user’s sake, the child’s sake. That you talk about it so that everyone understands what you are doing and that everyone thinks alike. That you are dealing with the same points. Then, it becomes easier for everyone involved to take the situation if you know what the thought behind it is when you behave in a certain way. (Assistant A)

-Family and external personal assistant learn to work together as a team

Family and external personal assistant had to cooperate in one aspect – the child with a disability. Parents had not only to work together but had to be in sync all the time with what child could or could not do to convey this information to an assistant.

We are the heads so to speak. Then, it is important that we assistants and parents work as a team for the child. It is like a normal child, how you raise a child, the parents first must be in agreement because children sense what’s going on. Dad says you don’t get any candy, but you go to Mom and you get candy.

.... And it took a long time before I understood that it wasn’t [hers] communication that needed to be wholehearted. It was we parents who should work together with the assistant and have the same idea of [the child]. (Parent C)
Find suitable activities for children with disabilities

The activities that children with disabilities participated in had to be suitable for them. Activities provided in accordance to child abilities increased participation according to the participants.

- Provide opportunities for children with disabilities to try new activities

Usually, representatives of a child with a disability decided what activities a child could or could not participate in. Some parents were afraid for others to find out about child’s inabilities to take part in various activities that they did not involve their children in activities. Nevertheless, children needed to feel talented in something and to know that they could do something. Sometimes it could be tempting to perform activities that everybody was used to, but parents and external personal assistants indicated that it was essential to push children and find new activities all the time in which children with disabilities could participate in.

But to dare to do things, I also think that is good. Challenge, challenge different situations, challenge him to do things. (Parent B)

- Participate in activities based on child’s abilities

Once in activities parents or external personal assistants described that they had to find balance in how long a child could participate in activities. Some children could get exhausted in activities sooner than others. Therefore, it was vital to monitor and once noticed that child could not participate in the activity anymore to change settings, e.g., move to a different activity or find a place to relax and re-charge again. Some problems were found to arise due to children’s age, e.g. teenagers did not want to be involved in certain activities, or younger children did not want to spend more time with family. Therefore, this needed to be considered too. Even though families could become split in this situations since one of them had to leave the activity with the child if there was no external personal assistant, parents and external personal assistant identified participation in activities based on child’s abilities as vital, since it was better to be involved for a shorter time, than not to be involved at all.

You just have to adjust. To try to be involved in as much as possible but to realize that you may have to do it a little bit differently, go away maybe five, ten minutes, maybe help and then come back, I would think. (Assistant B)

-Allow siblings to involve children with disabilities in activities
Siblings were a part of a family and therefore could influence family members. For children with disabilities in this study, parents and external personal assistants indicated that indeed siblings could be a source of help while including children in more and various participatory activities. For instance, siblings could have the same interest and help to include a child with disabilities in activities. Also, children close in age could have more activities of the same interests. Finally, siblings wanted to include children with disabilities in activities.

And then the siblings discussed it and came back and said that we are taking him in our hotel room and we will take care of him the entire weekend. You don’t need to take care of him. We want him to come, too. So I said that we wouldn’t be able to go to a restaurant in the same way, we can’t do this and this and it won’t be the same trip, but “he’s coming.” And it was the best present I could ever have had. Because you don’t believe that they, just like we said before, this thing with the siblings. That they have a problem with this. (Parent C)

-Have external personal assistant focused on children with disabilities

Majority of the time for a child with disabilities to be involved in activities a personal assistant had to be involved. Once in an activity with external personal assistant siblings may want to be involved too. This rise issue of what personal assistant should do – pay attention to a sibling or only to a child with a disability. According to our participants, it was a tricky situation. External personal assistant made children less calm compared to when external personal assistant was not present, but at the same time siblings without disabilities could walk away and chose not to be involved in activities. However, if they decided to be involved, an external personal assistant could pay attention to siblings as long as parents agree with the level they wanted external personal assistants to be involved in siblings’ lives.

But it can be good that the assistant knows about it, too, because then he can say, yes but you have to run and ask Mom. That they still can set up limits if there would be something, that you talk about that they have that opportunity. (Parent G)
7. Discussion

In this section, the results will be discussed in accordance with other research in ways how to improve children participation in family settings. Following this, the methods will be considered in relation to the choice of scientific approach, the choice of theoretical approach, design and method, analysis and trustworthiness. Finally, the limitations and future research are addressed.

7.1 Discussion of the results in relation to research

After conducting focus group interviews and content analysis with the aim of exploring parents’ and personal assistants’ experiences about ways to make a child with disabilities to participate in families’ everyday life four categories were found. These categories were: to adapt as a parent, to find an external personal assistant that suits family’s needs, to develop a connection among family and external personal assistant, and to find suitable activities for children with disabilities.

*Adapt as a parent:* The findings of this study indicated that one of the ways of getting children with disabilities to participate in family settings was to adapt as a parent. For instance, accepting child’s disability and not seeing disability as an issue. Importance of having a positive attitude is in line with Anaby et al. (2014), Axelsson, et al. (2014), King et al. (2000), Law (2002) who identified attitudes impact on a possibility to participate as well. Additionally, King et al. (2010) found that when parents thought that they lived in is unsupportive environment such as where policies, services, attitudes, and assistance were inaccessible or not facilitating then children participated less in formal and informal activities. According to Maxwell and Granlund (2011) acceptability is one of the environmental dimensions of conditions for participation. It supports the notion that beliefs of parents can affect a child, therefore parents have to adapt to facilitate participation.

Additionally, in this study participants identified that siblings were allowed to take care of children with disabilities. As Knox (2000) recognized roles of siblings of children with disabilities could become those of caretaker, manager, teacher, or helper, which is in line with the findings of this study. Moreover, according to Matthias and Benjamin (2008) having a family member to assist in everyday tasks is more beneficial since they already might know what the user needs or how they like things done.

Moreover, having a personal assistant is in accordance with Swedish laws such as SFS 1993:387. The law states that personal assistant is to promote equality of living conditions and
full participation in society. In this study participants acknowledge the importance of having external personal assistant too.

Not only this law allows to have a personal assistant for those that met specific requirements, it as well enables parents to take a rest, since personal assistant can assist in relieving role for parents (Wilder, 2008). As Luijkx, Putten, and Vlaskamp (2017) identifies, parents with children with PIMD have on average 1.5 h less free time than parents with typically developing children. As they wrote, having free time for parents’ impact well-being, and therefore it is vital to have respite. In addition, rested parents can be more engaged in helping a child with disabilities to participate. It is vital since engagement of parents were identified to be vital for interventions (King et al., 2015).

Furthermore, parents themselves should be involved in taking care of a child with a disability not only when working as a paid personal assistant, but also by helping the external personal assistant if needed and when needed. As Bedell, Dohn, and Dumas (2005) recognized in their study, parents were the ones that knew their child the most and could modify interventions or suggestion about strategies from practitioners to fit family’s routines. Additionally, parents may already know certain aspects of what was working participation vise for their children and could inform external personal assistant about this instead of letting re-invent the wheel (ibid). Parents’ participation was viewed as a process to the child’s outcome of increased participation in family activities.

Find external personal assistant that suits family’s needs: The other way to enhance participation was to find the right assistants. An external personal assistant should fit a family they work in. This could lead to a child with a disability, external personal assistant and parents being involved together in family settings and thus increasing child’s with disability participation.

Another aspect identified was external personal assistant’s qualities. These were in line with the findings by Roos (2009) who stated that there are some attributes of an external personal assistant that is desired by family. However, Roos (2009) also described that different users desired different qualities and qualities were dependent on situations. Therefore, different families with different needs may require different qualities from assistants. In this study about ways to make a child with disability to participate in family settings education or a lack of it was also discussed. Some of the parents identified that education is not necessary, because every case is individual. Likewise Ahlström and Wadensten (2012) identified knowledge as an issue in their article. Personal assistants expressed their need to get more information. However, the
debate is ongoing about who makes decisions and who feels empowered: user or personal assistant. If the user is in charge then education is not necessarily needed, which is in line with the findings of this study. Overall, if a family is satisfied with an external personal assistant, then the family can spend more time together with an external personal assistant and child with a disability gets to participate in family settings more too.

Develop a connection among family and external personal assistant: Yet another way to help children with disabilities to participate in family settings was described by having a good connection among those involved in caring for the child. The finding indicated that to increase participation of children with disabilities in family settings, an external personal assistant should know the content of his/her role. For instance, be able to be there but be invisible and help only when needed. This finding is in line with Roos (2009) who found out that there were situations in which external personal assistant should be discreet, almost disappear, became invisible, but still helping out when needed. The ability to adapt by external personal assistant was viewed as a way to help a child with a disability to participate.

Additionally, the excellent knowledge about family and external personal assistant is needed. Knowing whom one is working with can make a job easier. In this research both family, meaning parents and children, should get to know external personal assistant and external personal assistant should get to know family since all families can be different and require different things. This finding partly is in accordance with Axelsson, et al. (2014) findings that having a good knowledge about the child is needed since it can help in understanding children’s with PIMD needs better. The study by Kramer et al. (2012) indicated that knowing about abilities and limitations of the child can help with decision making, e.g., what adaptations may be needed and thus, help to increase participation of a child with disabilities.

This study takes it further by identifying that parents as well should get to know assistant and learn to work with them in a team. According to Wang et al. (2004), a collaborative partnership can lead to parents feeling more empowered, knowledgeable and motivated. In this research, participants talked about the importance of working together with and for the child and having the same ideas how to help the child with disabilities to participate more.

Also, communication in medical care is identified as vital aspect according to Leonard, Graham, and Bonacum (2004). In the study by Blue-Banning et al. (2004) communication was one of the prerequisites of a successful collaboration among parents and professionals. This means that several studies support the findings of this study where participants recognized that
communication and teamwork are essential in family settings among parents and external personal assistants too.

All identified sub-categories in this category stress the importance of participation as a process of parents and external personal assistant to improve the outcome of a child with a disability – to participate more in family settings.

*Find suitable activities for children with disabilities:* this meant to involve children with disabilities in activities that were suitable for them. Maxwell and Granlund (2011) state that availability was one of the five prerequisites of participation. Axelsson and Wilder (2014) indicated that the occurrence of family activities where children with disabilities participated happened less often and these children participated less frequently when compared with families with typically developing peers. Which indicates that the activities are scares for these children. As Bedell, Cohn, and Dumas (2005) recognized that for children with brain injury to increase social participation it was vital to create opportunities to participate. Additionally, Heah et al. (2006) found that it is essential to provide enjoyable activities for children with disabilities. Therefore, opportunities to participate in activities should be created for children with disabilities. Parents and external personal assistants should provide opportunities for children with disabilities to try new activities in hope to expand their niches and find activities children with disabilities enjoy doing.

Another finding was that activities have to be based on abilities of children with disabilities. Kramer et al. (2012) in their meta-analysis found out that children with disabilities experienced meaningful engagement when adults paid attention to limitations and capacities of the child. It is in accordance with the findings of this study that abilities of the child should be considered. These two sub-categories identified that parents and external personal assistants have to be involved, engaged in monitoring of what a child can or cannot do and act accordingly to ensure the desired outcome for the child with a disability - increased participation in family settings.

Furthermore, children with disabilities and siblings should participate in activities together. This finding is in accordance with King et al. (2010) who showed that family cohesion was one important aspect for participation when children have physical disabilities. Family cohesion means the degree of commitment, help, and support that family members provide to one another. Cohesive families are interested in doing things together. Therefore, siblings and children with disabilities spending time together could result in availability of more activities a
child with disability could participate. This is an example of how involving siblings to be engaged with children with disabilities works as an outcome for children with disabilities and helps them to participate more.

Finally, external personal assistant should focus on a child with a disability mainly. Participants identified that sometimes siblings may start asking help from external personal assistant instead of asking a parent. Participants stated that while it is nothing harmful to help the sibling while in the same activity as with a child with a disability, e.g. making snack for a child with a disability and make a snack for sibling too, but limits have to be set how much a sibling can ask for help from an external personal assistant by parents.

7.2 Discussion of the results in relation to theory

7.2.1 Bronfenbrenner’s theory

In the bio-ecological model, children are being seen in relation to others. The primary context where children develop is family settings. Opportunities to participate in family settings is vital for the development of children and especially for children with disabilities. Even though the focus of this thesis was the microsystem – the family- the findings indicate that more context plays a role in making a child with disabilities to participate in family settings.

External personal assistants and parents relationships were identified as important for participants and children they represented. The relationships among microsystems the child with disabilities is involved in can be found in the mesosystem of Bronfenbrenner’s theory. How the systems work together have an impact on the person, in this case, a child with disabilities. For example, if there is no good communication between parents and external personal assistant or if they do not work as a team then a child’s participation in family settings could suffer. When parents talked about letting siblings to help out with and involve a child with disabilities in various activities they also talked about mesosystem – the parents-siblings relationships and how they affect a child with disabilities.

Exosystem appeared when participants talked about the ways to increase participation. For example, parents’ possibility to have a rest can have a positive influence on child’s participation. Rested parents might have more energy to devote to their child’s participation opportunities in various activities.
Opportunity to have external personal assistant comes from the laws. If a country does not have a specific law that allows certain people to receive an extra help, then families themselves can pay for an external personal assistant for instance. However, it can be too expensive and not all families can get a chance to do so. Therefore macrosystem has an indirect influence on child’s participation.

Person aspect comes into play too. Child’s characteristics affect activities the child is or could be involved in. Therefore, participation should be based on a child with disabilities abilities according to participants.

Chronosystem was mentioned by participants as well. It was identified that family and external personal assistant have to get to know each other. In the interviews, participants identified that this process can take a long time, but that it was worth the effort for the child’s better well-being.

As equifinality states similar outcomes can be reached through different pathways (Bornman & Granlund, 2007), therefore there is more than one way to look at the issue and children with disabilities can be influenced by other levels of the bio-ecological model which can still lead to a similar outcome. However, as Imms et al. (2017) identified participation restrictions cannot always be solved by addressing only environmental barriers. Body level or society level interventions also may be needed, however, in this study, only environmental barriers were identified.

7.2.3 Transactional theory

Transactional theory stresses the idea that there is a bidirectional effect between person and environment (Sameroff, 2009). Mancini et al. (2000) indicated that disability limits participation possibilities for children and Dunst et al. (2002) showed that comparing children with and without disabilities those with disabilities initiate participation less. Knowing this, the effect of how participation can be helped by external personal assistant, parents, and siblings was researched in this thesis. From the results the transactions that could increase child’s participation can be visible. To illustrate, the following examples could be used:

Figure 2 Transactions

- CWD\(^1\) with a few responses
- Opportunities to try new activities are provided
- CWD\(^1\) tries to initiate new responses

\(^1\) CWD

Figure 2 Transactions
WAYS TO IMPROVE PARTICIPATION FOR CHILDREN WITH DISABILITIES

This is the example of a quantitative transaction, when the amount of responses are being increased.

**Figure 3** Transactions

| CWD\(^1\) shows low response levels in activities | Participation based on CWD abilities |
| CWD\(^1\) increases level of responsiveness |

This is an example of qualitative transaction when the level of responses increases.

Overall, when the identified ways for children with disabilities in family settings are being used by parents and external personal assistant it might help to increase participation of children with disabilities.

7.3 Methodological considerations

7.3.1 Design and method

A cross-sectional approach was used for this study. The research using cross-sectional method was performed at one moment in time thus providing only a snapshot of the situation (Marshall & Rossman, 2006). A qualitative approach helped to understand more about the phenomenon rather than to measure it (Marshall & Rossman, 2006). Out of all possibilities available for the qualitative study, the focus groups were chosen to be performed.

These choices have an effect on the study. Having chosen cross-sectional study (which is commonly used in focus groups interviews) the influence of time is not taken into considerations which are mentioned as necessary in both Bronfenbrenner’s bio-ecological model (i.e. chronosystem) and Transactional model. However, as it was looked at the experiences of the participants, it means that it is based on longitudinal aspect since the participants talk about what they think would work based on their experiences through time. With qualitative study approach only the specific type of questions which helps to understand and explore the topic in more depth can be raised. The focus groups interviews help, hopefully, to explore and evoke ideas how assistance can be provided for children with disabilities. While performing focus
groups, the interactional nature can have both positive and negative aspects. Positive aspects already had been talked above. However, the negative elements must be considered too. Firstly, the impact of first impressions. If one person is perceived as dominant, the others can become more submissive and contribute less to the discussion. The second issue can be censoring and conformity. Some people in groups tend to withhold information if they do not trust people in the group or the usage of the data. Some tend to censor information to be in line with the groups or leaders perceptions. Thirdly, people may misunderstand the nature of focus group and may try to come up with consensus which is not the point of the focus group. Furthermore, participants can exaggerate their experiences (Morse, 1994). Lastly, group facilitator may not be experienced enough to manage the group. (Carey, 2015; Miller et al., 2012). Therefore choosing this method researcher has to be aware of the issues and try to work and minimize them as much as possible.

7.3.2 Analysis

There are numerous approaches for analyzing qualitative data of which one is content analysis. It can be used to analyse written, verbal or visual data (Cole 1988). The content analysis allows the researcher to test theoretical issues and understand the data through distilling content into fewer content-related categories (Cavanagh 1997). The inductive approach has been chosen for this analysis since the knowledge is still fragmented (Lauri & Kyngäs 2005). Guided by the aim, transcriptions, and translations only manifest analysis has been performed. The chosen analysis method let to perform the analysis only on the written text. Much additional information could have been lost not using observations or not paying attention to verbal cues. It could be essential to use more than one source for analysis since what people say and do in real life can differ.

7.3.3 Trustworthiness

The trustworthiness of qualitative study looks at whether the intended outcome is being measured in the study. In qualitative studies, trustworthiness is being looked at through the concepts of credibility, dependability, transferability, and confirmability.

According to Graneheim and Lundman, (2004) credibility deals with the focus of the study and how well-chosen method and analysis help to reach the focus of the study. Additionally, it deals with ensuring that all data is included in the analysis. The way to ensure credibility is to ask another person, like the researcher or even informants whether all information are
covered in the analysis. To ensure *credibility* in this research parents and external personal assistants have been chosen to be interviewed since they usually are the closest to the child and therefore believed to have the best knowledge to answer the study’s aim. Moreover, while in the focus groups when the interviews were done, the assistant taking notes read through the notes to make sure that what had been said was understood in the right way. Additionally, the supervisor helped to ensure credibility through constant interactions during the coding process. It was not possible to ensure credibility through triangulation of different methods (Asplund, 2017; Creswell, 2000). *Dependability* or stability is concerned about data and possible changes over time. For this research *dependability* was ensured by keeping the time for data gathering and analysis process respectively short. It took four months to gather all the data and around two months to analyze it. Issues of dependability can arise from the translations and the fact that focus-group interviews were performed by two researchers. To help reduce the risk of different researchers performing interviews, the interview guide was created and followed. *Transferability* talks about to what degree the results can be generalized to other situations and settings with another sample. For this research *transferability* was strived for by giving the thick description of the settings as well as all the process of data collection and analysis. Additionally, the results were supported by providing the quotations from the interviews. However, since the qualitative study is concerned more about particular rather than general (King & Horrocks, 2010) and because the sample sizes are usually small (Bengtsson, 2016) these type of studies claim of generalizability can be problematic. However, as Graneheim and Lundman (2004) stated it is for readers to decide whether findings can apply to their situation based on the descriptions. *Confirmability* is objectivity and neutrality of the data (Bengtsson, 2016; Graneheim & Lundman, 2004). One way to ensure *confirmability* in this research can be reached by having a research team to do all the analysis instead of one person (Asplund, 2017; Creswell, 2000). The supervisor and Master’s student have both been involved in the analysis process.

### 7.4 Limitations

The performed study has some drawbacks. According to Bronfenbrenner and the Transactional models, time aspect is of importance (Bronfenbrenner & Morris, 1998; Sameroff, 2009). For this thesis time aspect was not studied. For time to be considered the design of the study would have to be different, e.g., longitudinal study. Moreover, children’s experiences could have been taken into consideration too. Their opinions about how to improve participation in family settings could have added additional categories and broadened understanding.
However, due to disabilities present in children some of which was severe, only parents and personal assistants were interviewed. This was done because they were the closest people to the children and knew the best what could work for them (Bedell, Cohn, & Dumas, 2005). Furthermore, the text selected for the analysis were translated by the professional translator. Nevertheless, some meanings could have been lost in translation. Having in mind that only manifest analysis was performed this could result in different findings (Marshall & Rossman, 2006). In addition, size and the number of focus groups. There were only four focus groups in total since two had to be eliminated due to technical issues while recording. Also, the size of the groups was on the lower side (three to five). The size of the groups may have been due to various reasons such as participants were not able to show up, changed their minds, etc. Nevertheless, it could have an impact on the study. In theory, the number of participants is recommended to be between four and 12. If it is too large (more than 12) or too small (less than 4) groups may inhibit conversation – in a large group not everyone can have a chance to talk, while in a small group not enough of a variety of opinions can be expressed. The group size can be determined by the purpose of the study. If the objective is to get experience or expertise, then fewer people is better. Another issue is the complexity of the topic. The more complex the topic, the fewer people in a group is advised (Carey, 2015; Krueger & Casey, 2015; Miller et al., 2012). Consequently, the issue can be addressed from two sides. Finally, not a lot of information is known about children, parents and personal assistants. This affects the possibility to adapt the findings to other populations since comparison is not possible.
8 Conclusions

Children with disabilities need to have the same opportunities to participate in various activities as do peers without disabilities to be able to experience the same benefits that participation can provide. However, children with disabilities do not participate to the same extent as typically developing peers do. It is due to not only the disability of the child but also due to various other impacts coming from the environment the child lives in. Therefore, the environment’s influence is vital to identify and find out how it can be improved to ensure higher participation. The chosen environment was microsystem. More specifically niches of family settings, where a child with disability engage in proximal processes with parents, personal assistants, and siblings. From the focus group, interviews participants identified that environment could be modified to help a child with a disability participate more. Parents, siblings and external personal assistants can modify their behaviors, attitudes, activities or can choose different people to suit family’s needs to help the child with disabilities to participate in family settings. Therefore, working in family settings everybody involved with a child with a disability influence child in a way: parents through their attitudes and the way they provide support and choose the activities, external personal assistant in how they adapt or fit family, siblings in how they help or require help from external personal assistant. Thus, to ensure participation in family settings many aspects have to be considered.

8.1 Future research

For the future research, longitudinal study to find out whether and how the findings would change over time could be done since time is an essential aspect of both the models used. Furthermore, not many information was known about how long the external personal assistant worked with the child, therefore, after working more time with the child the perceptions of support characteristics may change. Additionally, multidimensionality of participation concept could be researched, like the engagement of children in the activities that parents and personal assistants involve children but taking siblings impact in consideration. Furthermore, observation could be performed in a hope to find more ways how to improve participation. Finally, interventions based on the findings could be performed to see whether it could be used on different samples.
References


WAYS TO IMPROVE PARTICIPATION FOR CHILDREN WITH DISABILITIES


with physical disabilities: A structural equation modeling analysis, *Children's Health Care, 35*(3), 209-234, DOI: 10.1207/s15326888chc3503_2


DOI:10.1080/08856257.2011.563610


Appendix A

Genomförande

Fokusgruppssamtal genomförs i blandade eller enskilda grupper för personliga assistenter och föräldrar beroende på antal och vilka personer som deltar under träffen.

Vi sätter oss bekvämt i rummet för samtalet och placerar ut mikrofonen i mitten på bordet, testar den så att vi är säkra på att den fungera och att alla känner sig avslappnade.

Även här upprepar/säger vi att:

- Fokusgruppssamtal är ett gemensamt samtal där alla får komma till tals och där det inte finns några rätt eller fel åsikter.
- Samtalet kommer att handla om hur man kan göra för att underlätta barnets delaktighet i det familjen gör, hur kan man vara personlig assistent på bästa sätt i det?
- Snarare är det era idéer och erfarenheter som är det intressanta. Det är inte heller viktigt vem som säger något utan vad som sägs. Det är genom era reflektioner som vi kan bygga och föra vidare.
- Ha på papper som läggs på bordet:
  Tema: Barns delaktighet i familjeaktiviteter
  "I den bästa av världar: Hur tycker du att personlig assistans ska utföras för att barnet ska kunna vara delaktig i det familjen gör?"

Övergång:

På bordet finns ett papper. På det står en fråga som vi i detta samtal kommer att röra oss omkring på olika sätt. Ni kan titta på pappret om ni kommer bort er i tanken.

Öppningsfrågor:

För att starta upp oss i samtalet tänkte jag börja lite mjukt med att fråga:

- Hur bor ni, hur ser familjen ut?
- Hur gammalt är barnet?

Ni kan väl ha den fråga i huvudet och pappret är där för att vi ska kunna gå tillbaka till fokus om vi tappar tråden.

Introduktionsfråga:

- Hur länge har ni haft personlig assistent? Hur länge har ni varit personlig assistent?
(Temat för dagens träff är barnet delaktighet i familjens aktiviteter och hur personliga assistenter kan arbeta med det😊)

- Vad brukar ni göra tillsammans i familjen? Hur brukar ni göra ni för att barnet ska kunna vara med i det familjen gör?

**Nyckelfrågor:**

- Hur tycker du att personliga assistenter kan arbeta med barnet och i familjen för att barnet ska kunna vara med?
  (Personlig assistans – på bästa sätt – för att få barnet delaktigt i familjekaktiviteter?)
  Om vi lyfter fram syskonens perspektiv:

- Om det finns syskon, hur påverkar det barnets delaktighet i familjekaktiviteter och hur personliga assistenter arbetar?
  Om man tänker ur personliga assistenters perspektiv:

- Hur gör ni föräldrar för att assistenten ska kunna arbeta smidigt hemma hos er?(så att hon/han känner att de gör ett bra arbete)

  **Hjälpfrågor möjliga följdfrågor:**
  
  Var finns möjligheterna?
  
  Hur har ni löst det – hur har ni gjort då?

**Avslutningsfråga:**

- Av allt som vi har diskuterat, vad känns viktigast för dig?

  Medsittaren/observatören för nu möjlighet att komma in med en sammanfattnings, och vi har möjlighet att kommentera den: Maggan/Helena, jag tänkte att du nu kan berätta för oss och sammanfatta det vi pratat om. …. 

- Stämmer sammanfattningen av samtalen enligt hur ni har uppfattat det? Några andra funderingar som ni vill lägga till, och som vi kanske har glömt?

  Då stänger jag av inspelnningen

SLUT
Informal translation

Implementation

Focus group calls are conducted in mixed groups of personal assistants and parents with a various number of participants involved in the meeting. Everybody sits comfortably in the room where interviews are held and microphone is placed in the middle of the table. The test is made to make sure it is working and made sure everyone is relaxed.

From here all information is repeated:

- Focus Group Calls are a common call where everyone can speak, and there are no right or wrong answers.
- The conversation will be mainly about how to facilitate the child’s involvement in the family, and how can a personal assistant work in the best way possible?
- My task is to make sure the conversation is held in the area of interests. A researcher does not take a stand and is not an expert. The researcher asks some questions to start the conversation and have some follow-up questions.

Instead, it’s the ideas and experiences of parents’ and personal assistants’ that are interesting. Neither is it essential who says something, but it is essential to what is said. It is through these reflections that we can build ideas.

- Paper is kept on the table with the following info:

  **Theme:** Children’s participation in family activities

  “In the best of worlds: How do you think that personal assistance should be carried out for the child to be involved in what the family does?”

  **Transition:**

  On the table, there is a paper. There is a question that we will talk about in this conversation in different ways. You can look at the paper if you get lost in your mind.

  **Opening Questions:**

  To start us up the conversation, we are going to start with the following question:

  - Where do you live, what does the family consist of?
  - How old is the child?

  You may have that question in your mind, and the paper is there for us to remind us the focus if we lose it.

  **Introduction Question:**

  - How long have you had a personal assistant for? How long have you been a personal
assistant?
(The theme for today’s meeting is the child’s participation in family activities and how personal assistants can work with it).
- What do you usually do in the family? What do you usually do for the child to be part of that family?

**Key Questions:**
- How do you think personal assistants can work with the child and with the family for the child to be involved?

If we highlight the sibling’s perspective:
- If there are siblings, how does it affect the child’s participation in family activities and how personal assistants work?

If you think of personal assistants’ perspective:
- How do you as a parent, make the working environment appropriate for the personal assistant to work smoothly in your home/with you? (So that he/she feels they are doing a good job).

**Closing Questions:**
- Of all we have discussed, what feels the most important to you?

The moderator/observer is now able to come up with a summary, and we have the opportunity to comment on it: Maggan / Helena, I thought you can tell us now and summarize what we were talking about. ….
- Is the summary of the conversation consistent with how you perceived it? Any other thoughts you want to add, and as we may have forgotten?

Then the recording is turned off.

**FINAL**

**Interview questions:**
- How do you think personal assistance should be carried out for the child to participate the most in what the family does?

**Follow-up questions:**
- What do you usually do for the child to be able to participate in the family activities?
- If there are siblings in the family, how does it affect the child’s participation in family activities and how the personal assistant should work then?
- What can parents do regarding the relationships with the personal assistant to work together smoothly?