

RESEARCH PAPER

Strategies that facilitate participation in family activities of children and adolescents with profound intellectual and multiple disabilities: parents' and personal assistants' experiences

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Abstract

Purpose: Participation throughout one's life plays a significant role for development and emotional well-being. For this reason, there is a need to identify ways to facilitate participation in family activities for children and adolescents with profound intellectual and multiple disabilities (PIMD). **Methods:** The study design was qualitative and explorative, based on semi structured interviews with 11 parents and 9 personal assistants of children with PIMD. **Results:** The interviews revealed participation-facilitating strategies relating to the children's/adolescent's proximal environment, such as "Availability and acceptability of the activity", "Good knowledge about the child" and a "A positive attitude of people close to the child", as well as strategies related to the children/adolescents themselves: "Sense of belonging", "Possible for the child/adolescent to understand", "Opportunities to influence" and "Feeling of being needed". **Conclusions:** Children and adolescents with PIMD are dependent on support obtained through their environment. The identified strategies, individually adapted through awareness and knowledge by the parents and the personal assistants, provide important evidence to assist our understanding in gaining understanding about how to improve participation in family activities of children and adolescents with PIMD.

Keywords

Children and adolescents, parents, participation, personal assistants, profound intellectual and multiple disabilities, qualitative

History

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► Implications for Rehabilitation

- Participation-facilitating strategies related to the child/adolescent and his or her proximal environments are identified to improve participation in children and adolescents with profound intellectual and multiple disabilities (PIMD).
- Examples of strategies for the child's/adolescents' proximal environment include "good knowledge about the child/adolescent", and, for the child/adolescent, include creating "sense of belonging" and "opportunities to influence".
- Identifying and making these strategies explicit may assist in enhancing the participation of children and adolescents with PIMD in family activities.
- People in the child's/adolescent's proximal environment need to set the scene for participation.

Introduction

Participation in various social contexts is of great importance for an individual's development and emotional well-being. However, attaining successful participation in family activities for children and adolescents with profound intellectual and multiple disabilities (PIMD) is a challenge. There are many opportunities for participation in everyday life [1], it is therefore important that care providers are aware of strategies that can enhance participation of children and adolescents with PIMD.

Children and adolescents with profound intellectual and multiple disabilities

Children and adolescents with PIMD are a heterogeneous group, both in terms of the origin of impairments as well as in functional and behavioral range. PIMD can be defined as profound intellectual impairment combined with physical impairments, sensory impairments and, usually, other medical complications [2,3]. People who have PIMD are typically very dependent on others. Like other children in Sweden, children with PIMD usually grow up at home, with their biological family. In addition, they are usually supported by personal assistants and almost always attend preschool or special school. According to the Convention on the Rights of the Child (and in accordance with Swedish law), a "child" is defined as being <18 years of age [4], which includes adolescence. In this study, only two of the

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involved individuals were slightly above age of 18 years and for the ease of reading all individuals are predominantly referred to as children.

In Sweden, the Support and Service for Persons with Certain Functional Impairments Act (LSS) [5] and the Social Insurance Code (SFB) [6] provide for personal assistance to facilitate equality of living conditions and social participation for people with disabilities. These acts apply to, among others, people with intellectual disabilities, as well as people who have a substantial, permanent physical or mental impairment that causes considerable difficulty in daily life and, who in turn, require extensive support and services. Within the laws, there are no restrictions on the number of hours of personal assistance granted; rather, the unique needs of the person serve as a guide. In addition, there are no explicit limitations on the number of assistants to which the person is entitled, which means that individuals may have several assistants. The personal assistants can either be paid relatives (for children, usually a parent) or hired non-relatives and are referred to as “personal assistants” throughout this article.

For children with PIMD, a personal assistant often becomes a part of the inner circle of the social network and the personal assistant is sometimes considered a family member [7]. Within families, routines and meaningful rituals predict and crystalize a structure that frames family life. Family *routines*, according to Spagnola and Fieze [8], can be defined as practices repeated regularly and are characterized by a communication that is instrumental. Family routines include ordinary habits throughout the day, from laying the table to going to bed. Family *rituals*, on the other hand, establish and maintain an understanding of what it means to be a member of this family group, invoking communication with a symbolic meaning. These rituals can be exemplified through such examples as birthday parties and graduation celebrations [8]. Collectively, through routines, rituals and other family activities, which may include games as well as social activities and excursions, natural learning opportunities are provided [9]. When children have PIMD participation may become a challenge to attain and, consequently, parents and personal assistants within the child’s proximal environment have the responsibility to “set the scene” for participation by arranging the environment and by helping the young person to become a part of the family’s social community at, e.g. the dinner table [10].

Participation

In the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), participation is defined as a person’s “involvement in a life situation” [11]. Participation has been conceptualized by several authors as containing two dimensions: (1) the individual’s presence in the activity and (2) the individual’s engagement in the activity while being there [12–14]. Being present can be seen as the frequency, diversity and duration of taking part. Engagement can be seen as the individual’s expression of involvement or degree of involvement within a situation [15]. Engagement has been operationalized as comprising four engagement factors: Competence, persistence, undifferentiated behavior (repetitive interaction with environment with a simple low-level behavior) and attention [16]. Of these factors, attention and persistence are particularly important to consider in relation to children with PIMD.

Participation in family activities provides the primary, and critical, setting for children and in which they learn about how the world functions. Axelsson and Wilder [17] studied the frequency of occurrence of family activities (which are opportunities for participation) and child presence in these activities. In families

with a child with PIMD, some family activities occurred less often and children participated less frequently in comparison to families of children with typical development (TD). This suggests that having a child with PIMD influences the number and type of experiences offered to the child. Axelsson and Wilder [18] also found that the children with PIMD were generally less engaged in family activities, than children with typical development (TD), however, the pattern of levels were similar across the groups. That is, engagement was higher (e.g. in joking and fooling around) or lower (e.g. in doing the dishes), in the same kind of activities for children in both groups. It was evident that child-oriented and play-centered family activities were more engaging than routine activities. In addition, this research has shown that for children with PIMD age has a limited influence on the type of activities that occur in families [17] and whether or not children exhibit high engagement [18]. McWilliam et al. [19] have also reported that observed engagement/persistence was not correlated to developmental age and Kramer et al. [20] found engagement, but not age, to be of importance for competence when studying children with cerebral palsy.

King et al. [21,22] perceive engagement as the affective or motivational aspects of enjoyment and preference. These dimensions are utilized in King et al.’s instruments, designed to assess participation, called Children’s Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC). This broad perspective of engagement means that participation can be seen from an observable standpoint as engaged behavior as well as from a subjective perspective of the individual [13,23]. The child’s engagement when present in an activity is a subjective experience of engagement ideally reported by him/herself [24]. However, for children and with PIMD, proxies have to be asked due to the children’s severity of impairment. Proxies may include a parent of the child or another close person in the child’s proximal environment, e.g. a personal assistant. Alternately, observation studies can be undertaken to capture subjective expressions of engagement. In this study, parents and personal assistants were interviewed about child engagement as an expression of the child’s participation.

Facilitators of participation

Children with PIMD often need support to participate in family activities due to their functional difficulties. Horn and Kang [25] identified that it was important for professionals and families to work together to identify the support necessary for each child with PIMD to become an active participant within his/her life. To our knowledge, specific ways to support or facilitate participation in family activities in children with PIMD have not yet been studied. However, how to facilitate participation has been studied in children with less severe disabilities, and different strategies have been identified to improve these children’s participation. For example, Heah et al. [26] studied children who had a range of physical disabilities and the ability to communicate and found that successful participation outside of school was dependent on aspects of the child, environment and occupation. In this study, participation was described as having fun, feeling successful, doing things oneself as well as doing things and being with others. McWilliam et al. [19] found that when children were addressed individually their engagement increased more compared to being addressed as a group. Also, Whaley and Bennett [27] found that opportunities to make choices increased the engagement of children with special needs.

Bedell et al. [28] explored parent’s use of strategies to promote social participation of school aged children with acquired brain injuries and found that the parents used indirect means to create

opportunities, teach skills, and regulate cognitive and behavioral functions. The strategies used were learnt from their own experiences and their understanding of their child, family and their daily life situations.

It is not known whether the strategies identified in the studies described above apply to children with PIMD. Consequently, it is imperative to identify how participation in family activities is enhanced for children with PIMD to ensure they reach optimal functioning, development and well-being.

Aim

The aim of this study was to describe the strategies used by parents and personal assistants to facilitate participation in family activities of children with PIMD. This study is part of a larger research project with the overall aim of investigating how child participation in family activities can be facilitated for children with PIMD.

Methods

Design

The study design was qualitative and explorative, based on semi-structured interviews with 11 parents and 9 personal assistants of children with PIMD. The project was approved by the regional ethics committee, Linköping, Dnr 2010/324-31.

Participants and procedure

Participants were selected from those taking part in the larger research project which included 60 children aged 5–20 years. Parents had completed a questionnaire called Child Participation in Family Activities (Child-PFA) which mainly included questions about frequency of occurrence of family activities, child presence and child engagement in 56 listed family activities, such as joking and fooling around, having dinner together, visiting relatives [17,18]. About 30 of 60 parents of children with PIMD indicated their willingness to be contacted for an interview about strategies related to improving participation in family activities. The questionnaires of these 30 participants were re-analyzed to assist purposeful selection. The aim was to achieve a selection of participants that included children with severe impairments in mobility, cognition and communication and a high level of participation. A second requirement was that the children should have external personal assistance. As a result, 11 parents were contacted, all of whom provided informed consent for this study. Participating parents were then asked to select one of their child's personal assistants that the researcher could contact in order to obtain his or her perspective as well. Interviews with the personal assistants were, in turn, performed after researcher obtained verbal consent from the personal assistants. One personal assistant declined to participate, and, in one interview, there were repeated technical problems. As a result, 11 interviews with parents and nine with personal assistants provided data for this study. Information about the children, their families and the personal assistants are summarized in Table 1.

Each parent chose the place for the interview, and most interviews were performed within the families' homes. Personal assistants were interviewed via telephone. The interviews were performed in accordance with an interview guide, which included open ended questions about the child, how participation in family activities could be facilitated, and about personal assistance.

Sample questions about strategies to facilitate participation are provided below:

- What do you do to have the child be together with everyone else in the family?

- What do you do to make sure your child/the child is as involved/engaged as possible?
- What makes it easier for the child to be engaged?
- How can you tell that your child/the child is engaged?

All interviews were performed by the first author and recorded. The interviews with the parents lasted between 50 and 110 min, and the interviews with the personal assistants lasted between 20 and 55 min.

Data analysis

Each interview was transcribed and carefully read through several times. Qualitative inductive manifest content analysis was carried out; while keeping the research question in mind meaning units were searched for and labeled with a code [29,30]. Examples of meaning units and codes are shown in Table 2. The various codes were compared to identify differences and similarities and then sorted into sub-categories. Following this, different subcategories were combined into categories that comprised groups of content that shared a commonality [29]. Statements from the parents and personal assistants were analyzed together because initial review as well as later analysis of transcripts found few nuances in topics discussed related to type of informant. In the coding process, the Atlas.ti software program [31] was used to support data management.

Trustworthiness

To support the credibility of the study only people in the children's micro environments were interviewed. The group of informants showed a good variation in being parents and personal assistants, respectively, and by caring for boys or girls of different ages. The interviews were individualized through exploratory questions and applicable follow-up questions to elicit each parent's and personal assistant's ways for facilitating participation in the daily life of the child. Agreement in the interpretation throughout the analysis process was reached through dialogue within the author group. Discussions were also held in seminars with other researchers who had a deep knowledge in content analysis. Dependability was supported by the same researcher conducting all the interviews, and the interviews were conducted over as short an interval as possible (4.5 months).

Findings

In the interviews, all informants described ways in which the child showed engagement and how they acted to elicit and support engagement. The informants described engagement as being evident in the child through certain expressions in the eyes and face, vocalizations, increased tonus and/or concentration.

When he is engaged, you can see it in his eyes that he is with you and by the sounds that he makes and his body language, he responds very clearly when spoken to, with sounds when you talk to him. If he isn't engaged you cannot connect with him in that way. (Personal assistant 9)

In total, 17 subcategories were developed which were clustered into seven categories to differentiate what was important for facilitating participation in family activities. These categories were grouped and are presented as "Facilitating strategies related to the child's proximal environment" and "Facilitating strategies related to the child" as seen in Table 3.

Table 1. The children/adolescent, their families and the personal assistants.

Child/ parent	Age (years)	Sex	Examples of difficulties	Examples of child's positive characteris- tics as described by the informants	Interviewed parent/interviewed parent's employments	Time that the personal assistant had worked with the child
1	19	Girl	Walking with aid, severe limitations in communicating ^a on her own, severe intellectual disabilities ^b , chronic health problems under control	Positive, joy of living, joyful, extrovert	Mother/personal assistant for the child with disabilities	12 years
2	11	Boy	Dependent on a wheelchair, severe limitations in communicating ^a on his own, mild intellectual disabilities ^b , chronic health problems under control	Active, determined, want to do things on his own	Mother/personal assistant for the child with disabilities and works part-time outside home	3 years
3	8	Girl	Transported in wheelchair, very severe difficulties in communicating ^a on her own, very severe intellectual disabilities ^b , chronic health problems hard to control	Patient, joyful, social, physically strong	Mother/personal assistant for the child with disabilities and studying	Withdrew from study
4	6	Boy	Walking with aid, severe limitations in communicating ^a on his own, severe intellectual disabilities ^b , chronic health problems under control	Social, physically strong, persistent	Mother/personal assistant for the child with disabilities and works part-time outside home	3 months
5	15	Boy	Transported in wheelchair, very severe limitations in communicating ^a on his own, very severe intellectual disabilities ^b , chronic health problems hard to control.	Loved by everyone, charming, joyful	Mother/personal assistant for the child with disabilities	Withdrew from study
6	16	Boy	Transported in wheelchair, very severe limitations in communicating ^a on his own, moderate intellectual disabilities ^b , chronic health problems under control	Enjoys a lot of everyday life, has sense of humor, radiates joy	Father/personal assistant for the child with disabilities and works part-time outside home	4 years
7	11	Boy	Transported in wheelchair, very severe limitations in communicating ^a on his own, severe intellectual disabilities ^b , chronic health problems under control	Good hearing ability, clear about what he wants	Mother/personal assistant for the child with disabilities and works part-time outside home (now on maternity leave)	8 years
8	12	Boy	Walking with aid/transported in the wheelchair, severe limitations in communicating ^a on his own, severe intellectual disabilities ^b , chronic health problems under control	Joy of living, energetic, likes to explore	Father/personal assistant for the child with disabilities and works part-time outside home	3 years
9	17	Boy	Transported in wheelchair, very severe limitations in communicating ^a on his own, severe intellectual disabilities ^b , chronic health problems under control	Positive, social, wakes up with a twinkle in his eye	Mother/personal assistant for the child with disabilities and works part-time outside home	7 years
10	20	Boy	Transported in wheelchair, very severe limitations in communicating ^a on his own, severe intellectual disabilities ^b , chronic health problems under control	Good hearing, being social, enjoys being a part of a context, has a humor, word comprehension, can answer yes or no	Mother/personal assistant for the child with disabilities and works part-time outside home	3.5 years
11	11	Girl	Transported in wheelchair, very severe limitations in communicating ^a on her own, very severe intellectual disabilities ^b , chronic health problems under control	Joyful, positive, strong, persistent, has the spark of life, shows what she wants and what she doesn't want	Mother/personal assistant for the child with disabilities and works part-time outside home	8 years

^aCommunication ability was rated by the parents on a six-point rating scale; normal to very severe limitations. Overall the described level of communication also included the ability to communicate with sign language, body language, pictures and speech devices.

^bCognitive ability was rated by the parents on a six-point rating scale: Normal to Very severe intellectual disabilities.

Table 2. Examples of the process of content analysis.

Meaning unit	Code	Sub category	Category
You can try stuff to find out what he enjoys and what he thinks is his thing to do.	Find what is enjoyable	Knowing the child/adolescent	Good knowledge about the child/adolescent (Category related to the child's/adolescent's proximal environment)
But I ask him when are we are going to do that (brushing the teeth) later or now.	Provide choices	Being asked	Opportunities to influence (Category related to the child/adolescent)

Table 3. Facilitating strategies for improved participation/engagement in family activities.

Facilitating strategies related to the child's/adolescent's proximal environment			Facilitating strategies related to the child/adolescent			
<i>Categories</i>						
Availability and acceptability of the activity	Good knowledge about the child/adolescent	A positive attitude of people close to the child/adolescent	A sense of belonging	Possible for the child to understand	Opportunities to influence	A feeling of being needed
<i>Subcategories</i>						
- The activity is physically adapted	- Knowing the child/adolescent	- Own engagement	- Spirit of community	- Preparation	- Being asked	- Having a task
- The activity is attractive	- Interpreting the child/adolescent	- Seeing possibilities	- Being in focus	- Recognition	- Having a chance to tell	- Succeeding
		- Having an encouraging attitude		- Getting an explanation	- Being allowed to decide	

Facilitating strategies related to the child's/adolescent's proximal environment

Availability and acceptability of the activity

An activity's availability and acceptability refer to two basic prerequisites for the child's participation and engagement in an activity. This category is illustrated through a physical adaptation and attractiveness of the activity.

The activity is physically adapted. For a child to take part in family activities, the child must, of course, be physically present while the activity occurred. The child also needed to be thoughtfully placed, according to his or her needs, e.g. at the dinner table or concert.

He has got the best place (at the table) so he does not need to be concerned. (Parent 9)

Furthermore the child's comfort in sitting was taken into account. When adapting the environment, consideration was also given to the child's strengths in the activity, particularly in terms of sensory functions, to provide the child with opportunities to listen, touch and taste. These adaptations may create conditions for successful participation.

The activity is attractive. Engagement was increased when the child found the activity enjoyable and interesting. Often, the parent or personal assistant knew what the child liked to do, or alternatively, knew how to make the activity fun for the child through joking or fooling around or by making the activity into a game.

This morning for example he had to take his medicine and he refused and tried to wheel away. He has a plush octopus and then the octopus had to help to give the medicine, and then it was OK, so I guess it is, like, to make it a joke...to find something that makes it more fun for him and meaningful. (Parent 2)

Good knowledge about the child/adolescent

The informants reported that it was important to know the child well and to possess the ability to interpret the child's wants, needs and behavior. Knowledge was also required about the child's relatives, friends and other people in his/her network.

Knowing the child/adolescent. The parents knew their child well, and the interviewed personal assistants had often worked with the child for a long time (see Table 1). Both groups of participants reported that depth of knowledge of the child facilitated their ability to enable the child's participation. Consequently, it was important to take time to introduce new personal assistants to the child.

It is important that one knows about his life and what he has done and what his family situation is... that is if you are going to get him involved in a conversation with other people then I have to know about what he likes to do or what kind of life he has. (Personal assistant 9)

Interpreting the child/adolescent. By knowing the child well the parents and personal assistants described that they had learned to interpret the child's signals and needs, even when quite vague.

I think it has to do with perceptiveness and that we don't really... that you don't just keep going on [...] and I guess this is kind of what I'm talking about that we've learnt to interpret 'Sarah', because that's what we do all the time. (Parent 3)

A positive attitude of people close to the child/adolescent

Having a positive attitude oneself contributed to the child's understanding that the activity was fun and that there was "no problem" in engaging in the activity.

Own engagement. Every informant emphasized the importance of being engaged alongside the child and to clearly show their own engagement. This could include guiding the child toward what one thought was interesting, e.g. or simply acting as though the activity at hand was fun and engaging.

So she probably sensed this engagement, that we were engaged in something. Then she also became very engaged. (Parent 1)

See possibilities. The ability to see opportunities or situations in which it might be possible for the child to engage was stressed by the informants.

But to see that there are opportunities and that it is solvable, maybe not always in the best way but in some way. It is very important for the assistants as well as for the parents to make “Mark” feel that too. (Parent 4)

Having an encouraging attitude. Having an encouraging attitude towards the child, e.g. by motivating and encouraging, was also described as a strategy for improving the child’s participation.

I don’t get any response if I say “if you do that you will get that”. But if I encourage him “I know that you can”. . . (Personal assistant 7)

Facilitating strategies related to the child/adolescent him/herself

A sense of belonging

The child’s participation was increased when he/she directly connected with people in the environment.

Spirit of community. All children were reported to enjoy time together with other family members, especially when siblings were present. This meant being together with the significant people in the child’s life.

Same thing when “John” goes to bed and they come in to him, you can feel that he needs it, I think it gets him engaged, it is his family, that is very important, isn’t it? (Personal assistant 8)

Being in focus. Many of the children enjoyed being the center of attention.

Or if someone sits down next to him and says “Us guys can sit here, right? Did you have a good day? Did you go to school today?” It really doesn’t take much, but the person has to feel warmth towards him and want to talk. (Parent 10)

Possible for the child/adolescent to understand

Because many children with PIMD found external events difficult to understand, the informants described strategies to help the children understand.

Preparation. Engagement was facilitated when the child had been prepared for impending events. The preparation could be verbal or rely upon other sensory inputs, such as smell or touch.

When I say that we are going to go outside he whines at first, but when I say that we’re going outside to swing, and that we are going to swing fast, and you have to show him how fast we’re going to swing by swinging him in your arms, and then he kicks with all of his body and then he is happy, then it is something he wants to do. (Personal assistant 4)

However, the timing of the preparation had to be carefully considered.

He just loves when the [older] brothers are at home, that is just splendid and sometimes one hesitates to tell him the night before that one of them will come the day after, because it is so exciting that he can barely sleep at night. (Parent 6)

Recognition. Recognizing situations, people or activities enhanced children’s understanding. Parents and personal assistants described routines as helpful for providing a sense of security, maintaining routines also fostered children’s understanding that one had to do things.

And it is also . . . so that when she lies down in bed, classical music is put on and then she also knows . . . [that it is time to sleep]. (Parent 3)

Getting an explanation. Explanations and comments about events as they happened were used to help the child understand throughout the activity itself.

All the time she is told what we are going to do. You try to think about what you are doing and show what you offer and tell what you are going to do. (Parent 11)

Opportunities to influence

Engagement was also associated with choice, particularly children’s opportunities to choose between objects or activities, although sometimes such choice was described as a ‘sham democracy’.

Being asked. Asking the child what he or she wanted also engaged the children. Usually, alternative choices were given. Sometimes, pretending not to know answers to specific questions could help engage the child.

Then I need to get him involved in it. He needs to find his cup and where do you usually keep it [I ask]?, I can’t find it in the cupboard. Connect it to him; it is your cup that we are putting away. I don’t know where it is supposed to be, I forgot. Then he thinks; she’s crazy who doesn’t know where the cup goes. (Personal assistant 9)

Having a chance to tell. The informants talked about how important it was that the children were given opportunities to show or tell about what they had experienced on their own. This could be facilitated through use of a ‘contact book’ often used in preschool or school. When using the contact book, it was necessary to wait for the children’s attempts to communicate and also to guide the children in the narrative.

. . . but maybe it is more about that you have to be persistent towards him to get him engaged, if we’re talking about something, the other kids are chattering, but he might have a

harder time to get started, he has to pay a lot of attention to eating, so maybe you have to ask him more directly and one kid says we got hot dogs for lunch and “Sara” says we had fish and then you have to ask “what did YOU have for lunch “Mark”?” It doesn’t go automatically. (Parent 2)

Being allowed to decide. The children not only needed to be asked questions and given opportunities to communicate; parents and personal assistants also stressed the importance of respecting the children’s will. This could occur through making the children feel that they had actually made decisions themselves.

If she communicates ‘no’ we leave and do something else. It is easier for her to say no but it is also obvious when she is happy. If she likes something we continue to do it of course. (Personal assistant 11)

A feeling of being needed

The importance of the children being active, doing as much as possible and providing an opportunity for success, were described as significant. Sometimes, the parent or personal assistant pretended to need help that the child could provide.

Having a task. The informants described the importance of giving the children different tasks, although the personal assistant might need to assist the child to help within these tasks. The child’s contribution to doing the laundry, e.g. could consist of putting the folded laundry in the child’s lap; the child was then expected to keep an eye on the pile and then received credit for completing the chore. Another example involved the child tasting the food before the meal and then telling others that he/she approved of the taste.

It is so wonderful, the little girl, the two-year old, very often asks for help: “Can you help me tie my shoes”?’ And then he becomes happy and does it with the help of the assistant. (Parent 2).

Succeeding. The need for the child to feel skilled and successful was also described by the informants.

He really likes praise and to feel skilled . . . and to feel that he manages to sit on the stool by himself without any help and by that he grows as a person, to get credit, and then he becomes very happy. (Parent 2).

Discussion

The parents and personal assistants in this study improved the participation of children and adolescents with PIMD using a range of particular strategies. The interviews revealed strategies that were related to the child’s/adolescent’s proximal environment such as “Availability and acceptability of the activity”, “Good knowledge about the child/adolescent” and “A positive attitude of people close to the child/adolescent”. There were also strategies directly relating to the child/adolescent him/herself: the child’s “Sense of belonging”, “Possible for the child/adolescent to understand”, “Opportunities to influence” and “Feeling of being needed”. In different ways, these facilitating strategies collectively indicated the need for the people in the proximal environment of a child or adolescent with PIMD to act

as “scene-setters”, that is, people who arrange opportunities for participation.

Although the overall results of this study are supported by other studies, prior research has not focused specifically on children or adolescents with PIMD and their engagement in family activities. Our findings are for example consistent with those reported by parents of school aged children with acquired brain injuries in a study of Bedell et al. [28]. The parents described that they used strategies such as creating opportunities, and regulating the child’s behavior to promote social participation. The severity of these children’s disabilities was not as profound as in children with PIMD. Nevertheless, the strategies are in line with the results of this study – although with less pronounced emphasis on the caregiver’s own attitude. In particular, Bedell et al. also stress that the parent’s evolving knowledge about the child is imperative.

Facilitating strategies related to the child’s/adolescent’s proximal environment

The informants of this study described that in order to facilitate child participation *the activities had to be available and acceptable*. Maxwell and Granlund [32] suggested that availability and acceptability are two of five dimensions that operationalize prerequisites of participation. Availability, as a construct, relates to the opportunity to be in the activity and is thus associated with the frequency of attending. Axelsson and Wilder’s study [17] of children with PIMD, found that the children had fewer opportunities for participation in family activities and were also less often present in the activities when compared to children with TD. In line with the findings of the current study also Hammel et al. [33] found access to opportunities, unrestricted by bodily impairments or disabling physical, social and political environments, to be prerequisites for participation. The results also highlight that activities have to be acceptable, i.e. fun and interesting and, thus, attractive for the child. This aspect relates to the child’s intensity of involvement while being in the activity as also discussed by Heah et al. [26] and Axelsson et al. [18].

The importance of *good knowledge about the child/adolescent* was stressed by the informants of this study as a prerequisite for making the activities available and motivating for the child. Successful participation seemed to be dependent on understanding and interpreting the child’s emotions and wishes as also described in a qualitative meta-synthesis, including children with less severe disabilities, by Kramer et al. [34]. However, expressions of a child with PIMD are not always perceived as easily interpreted. Given this difficulty, successful communication requires high degrees of knowledge and experience [7]. Therefore one important strategy for these children and their families is to minimize turnover of hired external personal assistants, keeping their numbers as low as possible. In our interviews, the importance of *people close to the child having a positive attitude* in the interaction with the child was also stressed. The attitudes of others around persons with disabilities are known to be an influential environmental factor in relation to the participation of individuals with disabilities [35].

Facilitating strategies related to the child/adolescent him/herself

The informants described using their knowledge of the child’s personal interest and characteristics as facilitating strategies to promote participation. The child/adolescent needed *a sense of belonging*, by having a sense that he or she was noticed and a part of a larger context. This result is in line with what was found in a study by McWilliam et al. [19] where their study of children below school age showed that individual targeted interactions

produced more engagement than did group targeted interactions. In addition, Heah et al. [26] and Hammel et al. [33] have reported that “being with others” or “being a part of” as important aspects of participation. For individuals with PIMD, a basic assumption is that close social interaction is especially worthwhile because of their limited cognition and difficulties in engaging in activities on their own [15].

An interaction between the parent/personal assistant and the child is probably more motivating when it generates mutual joy [36]. In our study, strategies for making activities and their related components *possible for the child/adolescent to understand* were stressed as important in facilitating participation; the child needed to understand the activities for the activities to be meaningful. This facilitating strategy included anticipation and a feeling of recognition and is especially important for persons with low contingency awareness [15] (low contingency awareness means having difficulty understanding that the environment can be influenced). The importance of providing opportunities for the children to practice influencing their environment was emphasized in the informants’ descriptions. This finding is consistent with Dunst et al. [37] report that eliciting behaviors in persons with PIMD in a non-contingent manner results in lower, rather than higher, levels of responding. The child’s *opportunities to influence* were reported as yet another important strategy to facilitate participation, similar to what was found by Hammel et al. [33]. Ensuring the child or adolescent has a *feeling of being needed* was also found to be a facilitating strategy and entailed descriptions of the children being given tasks in which they could succeed. This is consistent with the desire to be productive, as described by adults with less severe disabilities [33].

A complex relationship exists between the described facilitating strategies related to the child’s proximal environment and the described facilitating strategies related to the child him/herself. The aforementioned facilitating strategies related to the child are entwined in the child’s dependency on the environment. The facilitating strategies found in this study clearly illustrate the specificity inherent to the transactional processes between the child and his or her proximal environment [38]. As such, the parents’ and personal assistants’ narratives gave explicit examples describing the responsibility of the people close to the child in enhancing the child’s participation.

Limitations

Individual’s participation experiences are, to a large extent, personal experiences and questions about participation should therefore primarily be answered by the children themselves [24]. However, it is difficult to obtain the perspectives of a person with PIMD. In this study, as in other studies of children with more severe disabilities, proxy estimations of the children’s engagement were used, with the researchers relying on the parents’ and personal assistants’ views for qualitative analysis [39,40].

The interviews were not performed in the same way. Parents were met “face to face” while personal assistants were interviewed on the phone. Conducting the interviews by meeting parents “face to face” was important as it facilitated the ability to ask follow up questions based on what the parent was saying. However, this sensitivity was considered less necessary in the interviews with the personal assistants who maintained a different emotional tie to the child; thus, these interviews were conducted on the phone. Despite the pursuit of trustworthiness, the ability to transfer the results to other children and families must be considered carefully. Although the results of this study are supported by their congruity with the results from other studies, consideration must be given the uniqueness of each child, family and personal assistant.

Future research

The presented strategies, individually adapted through awareness and knowledge by the parents and the personal assistants of particular children and adolescents, provide evidence of type of strategies that support engagement of children and adolescents with PIMD. Nevertheless, a deeper understanding of *how* to engage children and adolescents with PIMD is desirable and future studies should investigate the strategies further using video observations and test the effect of interventions on engagement.

Conclusion

Participation in one’s life situation is known to be of great importance for children’s development and emotional well-being. In children and adolescents with PIMD, the child/adolescent is dependent on support to gain participation. This can be obtained through adjustments to the context as well as the presence, knowledge and engagement of others. In turn, the child’s participation in the routines, rituals and other family activities needs to be facilitated by reaching the *needs* of the child/adolescent having a PIMD. This may not be surprising. However, such scene setting strategies are often employed implicitly: that is, without conscious awareness, as they are developed and implemented incrementally over time. Identifying and making these strategies explicit may assist in enhancing the participation of children and adolescents with PIMD in family activities.

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