

## University of Groningen

### Shared responsibility: a load off your mind

Jansen, Suzanne

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# Shared responsibility: a load off your mind

**Collaboration with parents in the support of children with Profound  
Intellectual and Multiple Disabilities**

Suzanne Jansen

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**Shared responsibility: a load off your mind**

Collaboration with parents in the support of children with Profound  
Intellectual and Multiple Disabilities

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Suzanne Jansen

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**Promotor**

Prof. dr. C. Vlaskamp

**Copromotor**

Dr. A.A.J. van der Putten

**Beoordelingscommissie**

Prof. dr. B. Maes

Prof. dr. M.J. Jongmans

Prof. dr. E.J. Knorth

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# Chapter 1

## Introduction

Over the last few decades, opinions about the role of parents in the professional support of persons with disabilities have fundamentally changed. Whereas parents were previously regarded as laymen and the professionals as experts, today the parents' knowledge and their wishes for their children now and in the future are considered to be essential contributions to the professional support of their children. Parents know their children the best in terms of their abilities, disabilities, needs and desires, but above all they are generally the only constant factor in their children's lives. They possess a wealth of information about their children, which is of utmost importance for professionals, and which differs from the knowledge of professionals. When a child has profound intellectual and multiple disabilities (PIMD), the parents' knowledge is even more important due to the complexity of these children's disabilities. Persons with PIMD are characterized by profound intellectual and profound or severe motor disabilities (Nakken & Vlaskamp, 2007). They possess little or no ability to support themselves. Many are confined to a wheelchair, frequently with little or no use of their hands or arms, along with difficulties in maintaining posture balance. Another characteristic of persons with PIMD is their extensive 'additional' impairments, such as sensory disabilities, seizure disorders, chronic pulmonary infections and skeletal deformations (Dunn, 1991; Evenhuis, Theunissen, Denkers, Verschuure & Kemme, 2001; Hogg, 1992; Janicki & Dalton, 1998; Nakken & Vlaskamp, 2002; Oberlander, O'Donnel & Montgomery, 1999; Zijlstra & Vlaskamp, 2005).

In the Netherlands, the parents of children with PIMD have access to an extensive system of professional services, such as different types of schools for special education, with or without therapy services, daycare centres, and various large- and small-scale housing projects. In many cases, parents participate in the practical side of the professional support, such as doing the laundry, going to specialists or contributing to leisure activities, but are less involved in the content of support. In a study by Nijhuis et al. (2007) of rehabilitation, a considerable number of parents indicated that their children did not, in their opinion, receive the support they found important. The differences in opinion between parents and professionals about what is important in the support of a child is a threat to perceptions of satisfaction with the support, experienced by both parents and professionals. Moreover, satisfaction with the support provided could be an important element in collaboration between parents and professionals.

When a child with PIMD moves away from his parental home, professionals take over the daily support of the child. Ideally, the expertise of both parents and professionals should converge to come to a better understanding of who the person with PIMD is and what he or she needs. This will in turn lead to opportunities for joint goal-setting and mutual decision-making (Vlaskamp, 1999). Collaboration in this way can be seen as a way of improving the quality of life of children and their families, working with an idea of shared ownership and responsibility (Bishop, Woll & Arango, 1993).

There appears to be no dispute over the benefits of collaboration with parents to ensure the quality of the support provided and hence the quality of life of the child with special needs, developmental problems or intellectual or other disabilities (Bishop et al., 1993; Epse-Sherwindt, 2008; MacKean, Thurston & Scott, 2005; Petry, Maes & Vlaskamp, 2007). Collaboration with the family of a child with special needs is one of the key elements of family-centred care and includes, for example, an emphasis on the strengths of the family and supportive and respectful treatment (Dunst, 1995; Epse-Sherwindt, 2008; King, Rosenbaum & King, 1996; MacKean et al., 2005; Shelton & Stepanak, 1994). Following this approach, families work in partnership with professionals to determine the content of their child's support. As far as we know, there is very little data on collaboration with parents in the support of children with PIMD. Therefore, we started this research project.

This thesis focuses on parents of children with PIMD who live in small- or large-scale housing projects. A clear definition and operationalization of collaboration and the factors that play a major role in the collaboration between professionals and parents in the support of persons with intellectual disabilities is indispensable; knowledge of what exactly is meant by collaboration in the professional support of persons with PIMD is therefore needed first. How parents of children with PIMD view and experience the collaboration with professionals is as yet unknown.

Moreover, we do not know if they are satisfied with the support provided. Knowledge about what parents find important in the support of their children is therefore needed too. Furthermore, do parents and professionals agree on what is important in the support for persons with PIMD? Finally, knowledge of parental experiences of collaboration with the professionals who support their child is important. When do parents experience collaboration with professionals? How is collaboration expressed in the communication between parents and professionals? All this knowledge helps substantiate good collaboration between parents and professionals, which is of great importance to the quality of the support of persons with PIMD.

The overall aim of the research project was to acquire knowledge about how to optimize collaboration between parents and professionals in the support of persons with PIMD. Therefore, answers to the following research questions were needed:

1. What is known in the literature about the collaboration between parents and professionals in the support of persons with PIMD?
2. What do parents find important in their collaboration with the professionals who support their children with PIMD?
3. Do parents and professionals agree on what is important in the support of a child with PIMD?
4. How do parents with a child with PIMD experience the collaboration with the professionals who support their child over a longer period of time?

### 1.1 Outline of the thesis

After this introductory first chapter, Chapter 2 reports on a literature review about the meaning of collaboration and related factors. Using four databases, relevant literature was selected from an eighteen year period using inclusion criteria. The descriptive analysis reveals seven studies which differ in their aims, the methods they used, samples and setting.

Chapter 3 presents an instrument which maps the family-centredness of the support provided. This instrument, the Dutch Measure of Processes of Care (MPOC), has been adjusted to the target group of persons with PIMD and has been validated (MPOC-PIMD).

Chapter 4 reports on the research into the validity and reliability of an instrument, the Measure of Processes of Care for Service Providers (MPOC-SP), which had already been translated into Dutch and validated by Van Schie, Siebes, Ketelaar & Vermeer (2004), and was adjusted by us to the target group (persons with PIMD). An item response analysis (Mokken scale analysis) was conducted to determine whether the instrument satisfied the assumptions of both monotone homogeneity and double monotonicity.

Chapter 5 describes the agreement (in terms of differences) between parents and professionals in their experiences of the family-centredness of the support provided. Factors which relate to agreements are also outlined. The agreement between parents and professionals in terms of the differences in their opinions about the occurrence and the importance of the family-centredness of the professionals' support was analysed using multilevel analyses.

Chapter 6 describes a multiple case-study (n=4), with repeated measurements over a twelve month period. Frequencies were described for the regularity and the means of contact, and for the professional with whom the parents had contact. The contacts were analysed according to function and subject using a categorization system and the parents' experiences were labelled and described in a narrative. This dissertation ends with Chapter 7, which reflects on the findings of the five studies. The shortcomings of the research and the implications for practice and further research are discussed.

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# Chapter 2

What makes a difference?

Collaboration between parents and professionals in the support of persons with profound intellectual and multiple disabilities: a literature review

Jansen, S.L.G., Putten, A.A.J, van der & Vlaskamp, C. What makes a difference? Collaboration between parents and professionals in the support of persons with profound intellectual and multiple disabilities: a literature review.  
*Manuscript submitted for publication.*

## Abstract

- Background* Collaboration between parents and professionals in the support of persons with profound intellectual and multiple disabilities (PIMD) is of great importance in meeting the needs of persons with PIMD, their parents and service providers. However, collaboration is a broad concept with different meanings for different people. Detailed knowledge of what collaboration comprises and what makes collaboration successful in the support of people with PIMD is still lacking.
- Aim* The purpose of this study is to explore the meaning of the concept of collaboration and related factors.
- Method* A literature study was conducted using four databases for search terms related to parent involvement, collaboration and intellectual disability. The inclusion criteria were that the studies were peer reviewed, full text in English with a focus on collaboration with parents of children in a specific setting, from 1994 to 2013. The studies were subjected to narrative analysis.
- Results* The literature analysis revealed seven studies with different aims, methods, sample sizes and settings. There is no common operationalization of the concept of collaboration in the seven studies. The factors related to collaboration mentioned are communication, mutual decision-making, evaluation, trust and respect.
- Conclusion* There is no unequivocal definition of collaboration, nor are there clear descriptions of the factors indicative of collaboration. Such definitions are indispensable in both scientific research and in practice, since they make results more general and comparable, and provide parents and professionals with a framework in which collaboration can take shape, and can be evaluated and adjusted to the wishes and needs of parents with children with PIMD and the professionals who support them.

What makes a difference?

### 2.1 Introduction

The role of parents in the professional support of children with intellectual disabilities has changed over the past few decades due to social, economic and political developments (Beltman, 2001). Support is defined as 'resources and strategies that aim to promote development, education, interests, and personal well-being of a person and enhance individual functioning' (American Association on Intellectual and Developmental Disabilities 2010, p. 224). Whereas parents were previously considered to be ignorant bystanders and doctors and staff seen as experts, today the parents' knowledge and experience are acknowledged to be essential in providing professional support to persons with intellectual disabilities, special health needs or developmental problems (Dale, 1996; De Geeter, Poppes & Vlaskamp, 2002). Due to their changing role, parents today are partners in the planning of the professional support for their children. This development seems to be in line with the shift from client-centred care to family-centred care in last thirty years, in which the needs and wishes of a child with disabilities are placed in the context of their family and community, at the heart of support (King, Teplicky, King & Rosenbaum, 2004). Collaboration between professionals and parents forms one of the key elements to this approach (Epse-Sherwindt, 2008; MacKean, Thurstone & Scott, 2005).

The benefits of collaboration between parents and professionals in the support of children with special health needs, developmental disorders and intellectual disabilities are well documented. When parents experience effective collaboration with the professionals who support their child, they are more satisfied with the support provided and think their child's quality of life is better than when effective collaboration is absent (Denboba, McPherson, Kenney, Strickland & Newacheck, 2006; Dunst, Trivette & Hamby, 2007; S. King, Rosenbaum & King, 1996; Law, King, Kertoy & Rosenbaum, 2004; MacKean et al, 2005; Trivette, Dunst, Boyd & Hamby, 1995). This is especially true of persons with Profound Intellectual and Multiple Disabilities (PIMD). These persons are characterized by profound intellectual disabilities and profound or severe motor disabilities (Nakken & Vlaskamp, 2007). They have little or no apparent understanding of verbal language and symbolic interaction with objects. Individuals with PIMD also possess little or no ability to support themselves. Many of them are confined to a wheelchair, frequently with little or no use of their hands or arms and difficulties in maintaining posture balance. Another characteristic of persons with PIMD is their extensive 'additional' impairments, such as sensory disabilities, seizure disorders, chronic pulmonary infections and skeletal deformations (Dunn, 1991; Evenhuis, Theunissen, Denkers, Verschuure & Kemme, 2001; Hogg, 1992; Janicki & Dalton, 1998; Oberlander, O'Donnel & Montgomery, 1999; Zijlstra & Vlaskamp, 2005).

The parents of children with PIMD are, given the severity of the disabilities of their children, often spokespersons for their children, as their children literally cannot

speak for themselves. They have – more than parents of children without disabilities – frequent and early contact with child support professionals due to the complex needs of their children (Petry, Maes & Vlaskamp, 2007). These parents have to deal with various professionals (direct support persons, physical therapists, speech therapists, medical doctors, psychologists etc.) and are generally confronted with changes in support staff, which is a threat to the continuity of support (Zijlstra, Vlaskamp & Buntinx, 2001). The parents of children with PIMD possess a wealth of information about their children which is of utmost importance to the professionals working with their children. Collaboration between parents and professionals in the support of persons with PIMD is thus indispensable.

However, establishing collaboration between parents and professionals is often unsuccessful and there appears to be a gap between what is known from research and actual practice (Blue-Banning, Summers, Frankland, Lord Nelson & Beegle, 2004; Epse-Sherwindt, 2008; Kratz, Uding, Trahms, Villareale & Kieckhefer, 2009; MacKean et al., 2005; Pretis, 2011). For instance, MacKean et al. (2005) found in their study that parents wanted more help from healthcare providers, as they felt that they had complete responsibility in managing the support of their children. Blue-Banning et al. (2004) mentioned that partnerships are often a source of stress and concern for both parents and professionals. In another study, parents explained that they felt discounted, ignored or judged by professionals (Kratz et al., 2009). In various studies with a focus on family-centred care, results show that a substantial number of parents indicated not having received support characterized as family-centred or the support they found important (Dyke, Buttigieg, Blackmore & Ghose, 2006; Jansen, Van der Putten & Vlaskamp, 2013; Jansen, Van der Putten, Post & Vlaskamp, 2014; Jeglinsky, Autti-Rämö & Brogren Carlberg, 2011). It would appear that – despite ample research on this topic and the best intentions of both parents and professionals – collaboration in the support of persons with intellectual disabilities is not automatically established. Although collaboration at first sight seems an obvious concept, it is not clearly stated what exactly is meant by the concept, nor what makes collaboration successful. A clear definition and operationalization of collaboration and the factors that play a major role in the collaboration between professionals and parents in the support of persons with intellectual disabilities is still lacking. Moreover, to date, little is known about collaboration with parents when it comes to the professional support of persons with PIMD. For the purposes of this study, collaboration is defined as a process of joint decision-making based on equality, in which there is consensus regarding the contents of support (Bishop et al., 1993; Vlaskamp, Maes & Penne, 2011).

This study focuses on a systematic review of studies of collaboration between parents and professionals in the support of persons with PIMD, to explore the meaning of the concept of collaboration and related factors. Obtaining insight into

what makes collaboration successful provides an opportunity to positively influence identifying factors and hence to establish or improve the collaboration between parents and professionals.

## 2.2 Method

### 2.2.1 Literature search

A systematic search within the period 1994 to 2013 was conducted in four databases: Educational Resource Information Clearinghouse (ERIC), American Psychological Association (PsycINFO), Academic Search Premier (ASP) and Index Medicus (MedLINE). The following search terms were used: parent# OR parental involvement AND collaboration OR cooperation OR Family Cent#red Care AND intellectual disability OR mental retardation OR profound intellectual disability OR severe intellectual disability OR multiple disabilities.

Publications were included if they met the following criteria:

- original scientific publications in full text in English
- peer-reviewed
- primarily focused on collaboration between parents and professionals in the support of persons with intellectual disabilities
- restricted to day care, large or small group homes or respite care for persons with intellectual disabilities

An initial selection based on titles was performed by the first two authors independently, using the criteria mentioned above. When the title of an article raised any doubt, its abstract was read to judge if the article should be included. The second selection was based on the abstracts using the above-mentioned criteria. The results of this screening were compared and any discrepancies or ambiguities were discussed until consensus was reached. If disagreement persisted, the final inclusion decision was based on the full article. The third selection of the articles was performed using the full articles. If there was disagreement between the first two authors, the third author decided. Finally, the references found in all relevant hits were also checked for inclusion.

### 2.2.2 Analysis

As the study designs and result types showed large differences, it was not possible to conduct a meta-analysis. Therefore, the studies were subjected to narrative analysis by identifying the study aims; the sample and setting; the measurements used; and the main conclusions related to the operationalization of collaboration and factors related to collaboration between parents and professionals.

## 2.3 Results

### 2.3.1 Literature selection process

Based on the search terms, 4267 publications were initially found (see Figure 1). Since not all the databases provide searches restricted to results fulfilling all inclusion criteria, many hits did not meet the inclusion criteria. Accordingly, duplicates, conference abstracts, publications in other languages, posters and books were filtered out manually first, which resulted in 497 publications. Next, the independent evaluations by the first two authors based on the titles of the publications yielded 182 publications. The abstracts of these 182 publications were examined, yielding 11 publications. After having read the full articles, another four articles were excluded as they did not meet the inclusion criteria. No additional papers were found in the reference lists of the remaining seven hits. There was no disagreement between the first two authors of the inclusion of the articles, so no final decision was required of the third author. An overview of the selection process and the results is depicted in Figure 1.

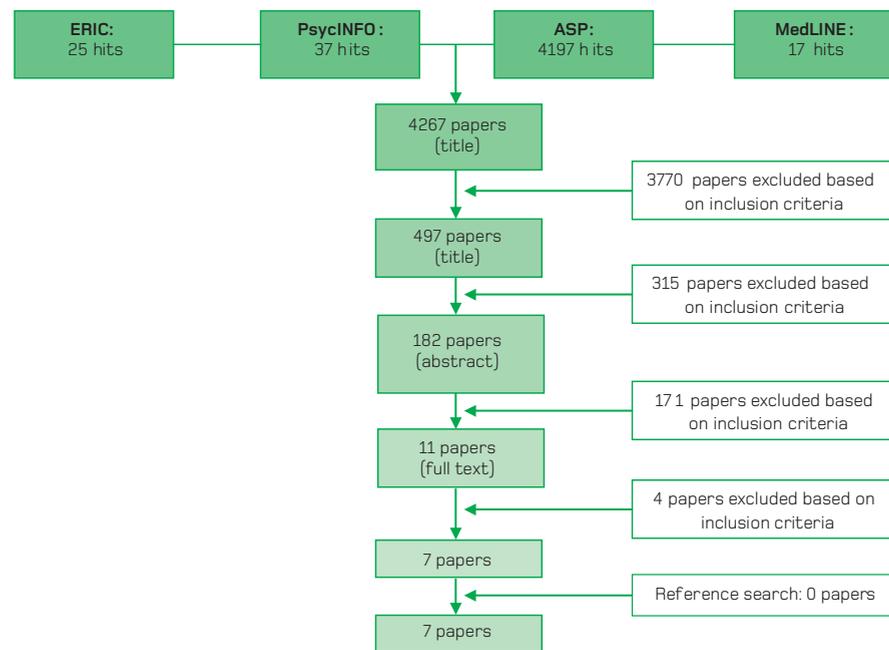


Figure 1 Selection process and results

### 2.3.2 Overview of the descriptive characteristics of the studies included

Seven studies were identified that met all the inclusion criteria. Table 1 provides an overview of the selected studies, the main aim of the study, sample, setting, measurement and major conclusions. Since not all studies contained specific information on these aspects, some information is missing from this overview.

### 2.3.3 Study aims

Although the focus of the studies was collaboration with parents, the specific aims and starting points for these seven studies were different. Five studies explicitly described the experiences and perceptions of parents and their relationships with the professionals who support their children and them as a family (Bleu-Banning et al., 2004; Ferguson, 2008; De Geeter et al., 2002; Schwartz, 2005; Shapiro, Monzó, Rueda, Gomez & Blacher, 2004). One study (Barelds, Van de Goor, Van Heck & Schols, 2011) aimed to develop and validate an instrument focused on the quality of care and service paths. Another study (Fonteine, Zijlstra & Vlaskamp, 2008) considered communication between parents and professionals, in the form of communication logs.

### 2.3.4 Participants

The participants in three studies were parents or other relatives. The other four studies included parents and professionals, mothers and their children, parents and their children and children as participants, respectively. Two studies provided information about the ethnicity of the participants. In the study of Blue Banning et al. (2004), 64 African American, 41 White, 23 Latino and six families of other ethnicity participated. In the study of Shapiro et al. (2004), 16 Latino mothers participated.

The number of participants on the studies varied considerably, from 12 (Fonteine et al., 2008) up to 723 (De Geeter et al., 2002) participants. Information on the gender of the participants was provided in five studies, and showed that most participants were mothers. The mean age of the participating children in three studies was 9.6, 10 and 31.2 years respectively, and varied in another study from 14 to 31 years. The level of disability of the children participating in the studies was profound in two studies, a combination of different levels of disability (mild, moderate, severe and/or profound) in three studies and unknown in one study. The mean age of the participating parents in two studies was 47 and 60.2 years and varied in another study from 35 to 68 years. One study mentioned that 18 percent of the participating parents were aged below 20 and 67 percent were aged between 30 and 60. Professionals participated in one study. Of these professionals, 91 percent were female, 70 percent were white and 32 percent were African Americans.

### 2.3.5 Settings

The studies were conducted in the Netherlands (n=3), the United States (n=3) and Israel (n=1). The settings of four studies were day care facilities (special educational centres, offering day activities and employment). Two studies focused on residential settings (small or large-scale group homes, and independent and semi-independent apartments), and one study considered a combination of residential and day care settings.

**Table 1**  
**Overview of the characteristics of the studies included**

Author(s)	Aim	Sample				Level of disability	Setting	Measurement	Major conclusions
		N	Age (years)	Gender	Ethnicity				
<b>Barelds et al. (2011)</b> <b>(The Netherlands)</b>	To develop and validate an instrument (QUALITRA-ID-P) to assess the quality of care and service trajectories for relatives of people with ID.	38 (pilot study) parents and/or relatives.  182 (preliminary validation) parents and/or relatives.	Mean = 47	28% male 72% female	-	-	R DC	QUALITRA-ID-P <sup>a</sup>	The questionnaire with good psychometric properties consists of 49 items with 3 factors: mutual exchange of information; material and bureaucratic aspects; procedural outcome.
<b>Blue-Banning et al. (2004)</b> <b>(USA)</b>	To examine what specific indicators of professional behaviour parents and professionals identify as indicative of collaborative partnerships.	137 family members  53 professionals	< 20 (18%) 30-60 (67%)  -	- 72% female  91% female	41% African American 17% Latino 30% White 4% Other  70% White 32% African American	Mi: 42% Mo: 45% S+P: 4%	DC	Focus groups and individual interviews	Six themes of professional behaviour facilitative of collaborative partnerships: 1. Communication 2. Commitment 3. Equality 4. Skills 5. Trust 6. Respect
<b>Ferguson (2008)</b> <b>(USA)</b>	This study focus on the relationship of families and professionals in the early twentieth century.	100 parents	-	-	-	-	R	Thematic analysis	The relationship between parents and professionals then, as now, was often a troubled and troubling, characterized by suspicion on both sides.
<b>Fontaine et al. (2008)</b> <b>(The Netherlands)</b>	To explore the nature, topics and form of the information that is transferred between parents and teachers.	12 children	Mean = 9.6 Range 3-18	6 male 6 female	-	P	DC	Communication logs	Exchanging experiences and providing information are the main function of the communication logs.  The most important categories parents and teachers write about are activities, health, ADL, practical matters and mood/emotion.  Teachers write significantly more than parents.

Note. Mi=Mild; Mo=Moderate; S=Severe; P=Profound; R=Residential care; DC=Day care.

<sup>a</sup> The authors did not provide a clarification of the name of the instrument.

(Table continues)

Table 1 (continued)

Author(s)	Aim	Sample				Level of disability	Setting	Measurement	Major conclusions
		N	Age (years)	Gender	Ethnicity				
<b>De Geeter et al. (2002) (The Netherlands)</b>	To describe how parents of children with PMD experience collaboration with professionals and to describe the efficacy of methods that achieve a kind of formalized collaboration.	723 parents (pretest) 337 (of the 723 ) parents (post-test)	M=10 Range 1-23	-	-	P	DC	Questionnaire about supervision and transfer of information Parents are satisfied with their collaboration with the staff of the school.	The supposition that the relationship between parents and the school improves when a method is used that provides parents with an explicit and formalized professional role could not be confirmed by the study.
<b>Schwartz (2005) (Israel)</b>	1. To examine the relationship between parental involvement during and after the process of relocating offspring with ID, and parental perceptions of their offspring's satisfaction with life. 2. How those perceptions are affected by the characteristics of the residents, parents and facility.	71 parents and their children.	Parents: M= 60.2 Range 54-79  Children: M=31.2 Range 20-54	Parents: 54 male 17 female  Children: 39 male 32 female	-	Mi: 48% Mo: 52%		1. Inventory of Client and Agency Planning (ICAP) 2. Parents' demographic questionnaire 3. Parental involvement in residential care questionnaire 4. Pre-placement parental involvement questionnaire 5. Lifestyle Satisfaction Scale (LSS)	1. Parental involvement Post-placement; Most parents expressed a high degree of satisfaction with the extent of contact with staff members, but most parents rated the partnership between staff and parents as low: only 20 percent of parents perceived themselves as full partners in residential care. Thirty-one percent of parents had never met a staff member, 38 percent only once or twice. A majority of the parents did not participate in decisions concerning their offspring. Pre-placement; Half the parents perceived themselves as full partners in the relocation process. There is a positive relationship between the number of meetings with staff members and the degree of perceived partnership. Parents perceive themselves as partners in the relocation process more than in post-placement residential care. 2. Characteristics that correlated with the perception of offspring's life satisfaction Post-placement; Parents' perceptions of being partners in the residential care. Pre-placement; Participation in admissions committee meetings.

Note. Mi=Mild; Mo=Moderate; S=Severe; P=Profound; R=Residential care; DC=Day care.

\* The authors did not provide a clarification of the name of the instrument.

Table 1 (continued)

Author(s)	Aim	Sample				Level of disability	Setting	Measurement	Major conclusions
		N	Age (years)	Gender	Ethnicity				
Shapiro et al. (2004) (USA)	To examine the beliefs and perceptions of Latino parents of young adults with severe developmental disabilities about their relationships with the educational and service delivery system around transition.	16 mothers and their children	Parents: Range 35-68 Children: Range 14-31	Parents: 100% Female Children: -	Parents: Latino Children: -	Mo S	DC	Focus groups	The most important concerns of the mothers were: <ul style="list-style-type: none"> <li>• poor communication</li> <li>• low effort in providing services</li> <li>• negative professional attitudes toward the client-children</li> <li>• negative treatment of parents by professionals</li> <li>• mother's role in relation to the educational and service systems.</li> </ul>

Note. Mi=Mild; Mo=Moderate; S=Severe; P=Profound; R=Residential care; DC=Day care.

\* The authors did not provide a clarification of the name of the instrument.

### 2.3.6 Collaboration and related factors

First, the operationalizations of the concept of collaboration and the factors related to collaboration are discussed for each study. Then, the recurrent factors mentioned in relation to collaboration in the seven studies are described.

Barelds et al. (2011) conducted a study in which they developed an instrument (QUALITRA-ID-P) to help support providers gain insight into the experiences of parents and relatives. To construct the instrument, a document analysis and semi-structured interviews were used to conceptualize 'care and service trajectories'. Next, quality of care and service paths were operationalized using a literature review and focus group discussions with parents and relatives. They considered collaboration to be a necessity in the care and service paths of persons with intellectual disabilities. These paths follow a 'model route' with five distinct phases: the parents' becoming aware that support is needed; working with professionals to clarify the request for help and determining which support is needed; obtaining funding for the support needed; establishing a waiting period when support is not immediately available; and the delivery of the support needed. Regarding collaboration, Barelds et al. (2011) did not define the concept. However, they distinguished three factors when developing the instrument: 'mutual exchange of information', 'material and bureaucratic aspects' and 'procedural outcome'. Aspects of collaboration fall under all three factors mentioned, but not all the items in the questionnaire were

related to collaboration with parents (e.g. collaboration between care facilities). Of the 49 items in the questionnaire, 25 items were related to collaboration. The 'Mutual exchange of information' factor for example contains items on information provision about many aspects of support, taking part in decisions about suitable support and the involvement of client and parent in the care path. Support in completing forms is an example of an item belonging to the 'Material and bureaucratic aspects' factor. The 'Procedural outcome' factor contains items including agreements about the current and temporary situations.

Blue-Banning et al. (2004) explored what specific indicators of professional behaviour parents and professionals identify as indicative of collaborative partnerships. They used focus groups, in-depth interviews with families with limited English proficiency and with the professionals who support them to obtain an understanding of the components of positive partnerships. They mentioned the lack of an operational definition of partnership between parents and professionals, but do not provide a definition of collaboration themselves. In their study, however, indicators of professional behaviour conducive to collaborative partnerships were identified and organized into six broad themes: 'communication', 'commitment', 'equality', 'skills', 'trust' and 'respect'. The specific meaning of and indicators for each theme were described, including similarities and differences between professionals and family members. The indicators for the 'communication' theme are sharing resources;

being clear, honest, tactful and open; communicating frequently and positively; listening; and coordinating information. Demonstrating commitment; being flexible, consistent, sensitive to emotions and accessible to the child and family; regarding work as 'more than a job'; regarding the child and family as 'more than a case'; and encouraging the child and family are all indicative of 'commitment'. 'Equality' is indicated by empowering partners, validating others, being willing to explore all options, acting as an 'equal', fostering harmony among all partners and allowing reciprocity among members. 'Skills' are indicated by taking action, having expectations of the child's progress, meeting individual special needs, considering the whole family of the child and being willing to learn. 'Trust' is indicated by being reliable and discreet and keeping the child safe. Finally, 'respect' is indicated by valuing the child, being nonjudgmental and courteous, exercising non-discrimination and avoiding intrusion. It is remarkable that the themes are strongly interrelated and that communication underlies equality, trust and respect according to the authors (Blue-Banning et al., 2004).

Ferguson (2008) explored the history of family-professional relationships by thematic analysis of correspondence between parents and professionals at an institute for people with intellectual disabilities from the early twentieth century. This study viewed family-professional relationships as mutual exchanges of information, planning and support on behalf of the child involved. Although no factors related to collaboration were mentioned explicitly, there are two themes that can be derived from this study that had negative impact on the collaboration between parents and professionals. Firstly, the lack of equality between parents and professionals, since parents were entirely subordinated to the professionals, who decided what was best for their children. Secondly, the lack of trust in each other's capacity, characterized by suspicion on both sides.

Fontaine et al. (2008) studied the nature of the information transferred between parents and teachers, how it is transferred and the topics that parents and teachers discuss. They analyzed communication logs at special educational centres. Collaboration is not explicitly mentioned in this study, but the underlying assumption is that children with PIMD are dependent on the knowledge and perspectives of both their parents and the professionals involved and, therefore, on the transfer of information between them. Exchanging information and providing information are factors related to collaboration according to Fontaine et al. (2008) and the authors suggested that professionals and parents discuss the content of their communication in advance.

De Geeter et al. (2002) examined whether the collaboration between parents and professionals must meet certain criteria to offer parents a chance to use their knowledge and at the same time acquire new knowledge and develop new skills. They used a questionnaire to conduct comparative research using a pre-test/post-test design with a control group, and introduced a method in which parents had a

formal role as equal partners. This study had no clear definition of collaboration with parents but collaboration was divided into three categories, namely 'providing information', 'mutual decision-making' and 'being kept up-to-date'. By 'providing information' they meant that parents have the chance to share their knowledge with the professionals, who, in turn, should be clear that they value this knowledge. 'Mutual decision-making' implies that a final decision on the content of the support provided should only be arrived at when parents and professionals have reached consensus on this matter. Finally, parents should 'be kept up-to-date' by staff by providing them with detailed information of the progress made towards the mutually chosen goals, and any other agreement.

Schwartz (2005) examined the impact of parental involvement during and after the relocation of their child to a residential facility on their perception of their adult child's life satisfaction. The characteristics of the children, parents and residential facilities were taken into account as possible variables affecting the parents' perceptions. Schwartz (2005) used five different questionnaires to achieve this. Collaboration was not exactly defined in this study, but can be deduced from the descriptions of the concept of involvement and partnership. Parental involvement is interpreted in this study as a partnership between parents and professionals which benefits the person with disability. Parents were seen as active agents who collaborate with professionals in making decisions, obtain and share information, help plan the rehabilitation process and participate in evaluating the outcomes of services. The parents' perception of their partnership in the relocation process was related to two factors of parental involvement: meetings with staff members and participation in activities and events planned for parents. Parents who perceived themselves more as partners also reported more meetings and more participation in activities.

The study of Shapiro, Monzó, Rueda, Gomez and Blacher (2004) examined the beliefs and perceptions of Latino parents about their relationship with the educational and service delivery system around the issue of transition using three focus groups. The study lacked a clear definition of collaboration, but parental participation or involvement was considered as a key component of collaborative partnerships in which the parents are enabled to function as full and equal partners. The factors with a negative impact on a participatory, collaborative partnership were poor communication with professionals and lack of information, a lack of effort by professionals, negative attitudes of the professional toward the children, and negative treatment of parents by professionals. A final factor mentioned was the mother's role in relationship with the educational and service systems. If, due to shortcomings in the service delivery system, mothers dedicated themselves to their children's education and development, this could lead to alienated and adversarial interactions with professionals.

Although there was no common operationalization of the concept of collaboration in the seven studies, there are some recurrent factors related to collaboration. All the studies mentioned the mutual exchange of information or communication, mostly in terms of the information exchanged and the frequency with which it is exchanged. Blue-Banning et al. (2004) added the importance of a clear, open, honest and tactful communication. Another factor mentioned in five studies is mutual decision-making, consensus or equality, which in these five studies boils down to the opportunity for parents to influence the outcome of decisions regarding their children (Barelds et al., 2011; Blue-Banning et al., 2004; Ferguson, 2008; De Geeter et al., 2002; Schwartz, 2005). Evaluation is mentioned in three studies, though under slightly different names (De Geeter et al., 2002; Schwartz, 2005; Shapiro et al., 2004). Evaluation in these studies is explained respectively as supplying parents with details of the progress made towards goals, monitoring the outcomes of services, and coordination and follow-through of programmes. Trust and respect are factors mentioned in three studies (Blue-Banning et al., 2004; Ferguson, 2008; Shapiro et al., 2004). These factors comprise a positive attitude towards child and parents, recognizing their unique strengths and abilities, being reliable and discrete, keeping the child safe, relying on each other's capacities, and showing common courtesy. Commitment and skills, mentioned in the Blue-Banning et al. (2004) study, were not found in the six other studies.

## 2.4 Conclusion and Discussion

The current study focused on a systematic review of studies of collaboration between parents and professionals in the support of persons with PIMD to explore the meaning and operationalization of the concept of collaboration and related factors. The results showed that in an eighteen-year period, only seven studies were found which focused on the collaboration between parents and professionals in the support of persons with ID in residential or day care. The seven studies varied in the number of participants, in their aims and in the method they used, which makes comparisons difficult. Consequently, it was difficult to draw general conclusions. Nevertheless, the results of this review showed one factor related to collaboration which was mentioned in all studies, namely communication. Other factors mentioned in three or more studies were mutual decision-making, evaluation, and trust and respect. The commitment and skills of professionals (e.g. being willing to learn or to take action) were mentioned in one study.

As the studies included in this review mainly focused on white participants, some caution is required when generalizing results to other ethnic groups. Different studies have shown that the risk of miscommunication is high when professionals' cultural backgrounds differ from those of the families they serve (Harry, 2008; Kalyanpur, 1998; Lustig, 1999; Shapiro et al. 2004). Since communication is an important and substantial part of collaboration, further research into collaboration with

parents who are not native speakers of the professionals' languages and/or have different cultural backgrounds from them would be valuable.

Furthermore, most of the parents who participated in the studies included in this review were mothers, which makes it difficult to generalize the results to fathers. In a study by Jansen et al. (2014), differences were found between fathers and mothers in rating the importance of family-centred behaviour in professionals, in which collaboration plays an important role. G. King, King and Rosenbaum (1996) conducted a study into parental views of professional care-giving in a pediatric setting for children with disabilities. They also found that mothers gave significantly higher importance ratings for family-centred aspects of care-giving than did their spouses, although the differences were small. Therefore, further research with fathers as participants would be desirable, to see if fathers have different ideas or experiences of collaboration with professionals than mothers do.

Of the seven studies included in this review, only one included parents and professionals. To establish collaboration between parents and professionals, insight into what parents and professionals find important in this collaboration is required. Only then do agreements and differences become apparent and capable of forming a starting point for further development of collaboration. Jansen et al. (2014) found significant differences between parents and professionals and between the professionals themselves in the ratings of the importance of certain family-centred behaviour, of which collaboration is a key element. The possible differences between parents and professionals in their views on collaboration should therefore be kept in mind. The inclusion of professionals is recommended for further research on this topic.

Although collaboration has been the subject of much research, little research has been done into the collaboration between parents and professionals in the specific context we were looking for, namely related to the services provided to a child with PIMD. The fact that this study only unearthed seven papers which fulfilled the inclusion criteria is remarkable given the importance of collaboration between parents and professionals in precisely this support (Jansen et al., 2013; Jansen et al., 2014). Children with PIMD, regardless of age, are greatly dependent on others for all aspects of their daily lives. Parents are, in most cases, the only constant figures in the lives of these children, as professionals tend to change jobs, leave services, etc. Much research in other fields (e.g. pediatric services, mental health services and schools) has addressed the importance of collaboration and showed that good collaboration leads to more satisfied parents and professionals, but an unequivocal definition of collaboration remains elusive, just as consensus on and clear descriptions of the factors that are indicative of collaboration does. Such definitions and clear descriptions are indispensable in both scientific research and in practice.

In research, they would make results more general and comparable and in practice, they could provide parents and professionals with a framework in which collaboration can take shape, and can be evaluated and adjusted to the wishes and needs of parents with children with PIMD and the professionals who support them. Future studies should focus on parents with children with PIMD who live in residential facilities for longer periods to further explore the meaning of collaboration for these parents and the process of establishing such a collaboration over time.

## 2.5 Acknowledgements

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# Chapter 3

What parents find important in the support of a child with profound intellectual and multiple disabilities

Jansen, S.L.G., Putten, A.A.J., van der & Vlaskamp, C. (2013). What parents find important in the support of a child with profound intellectual and multiple disabilities. *Child: Care, Health and Development*, 39(3), 432-441.

## Abstract

- Background* The importance of a partnership between parents and professionals in the support of children with disabilities is widely acknowledged and one of the key elements of 'family-centred care'. To what extent family-centred principles are also applied to the support of persons with profound intellectual and multiple disabilities (PIMD) is not yet known.
- Aim* The purpose of this exploratory study was to examine what parents with a child with PIMD find important in the support of their child. In addition, we examined which child or parent characteristics influence these parental opinions.
- Method* In total, 100 parents completed an adapted version of the Measure of Processes of Care. Mean unweighted and weighted scale scores were computed. Non-parametric tests were used to examine differences in ratings due to child (gender, age, type and number of additional disabilities, type of services used, and duration of service use) and parent characteristics (gender, involvement with support and educational level).
- Results* Parents rated situations related to 'Respectful and Supportive Care' and 'Enabling and Partnership' with averages of 7.07 and 6.87 respectively on a scale from 1 to 10. They were generally satisfied with the services provided, expressed in a mean score of 6.88 overall. The age of the child significantly affected the scores for 'Providing Specific Information about the Child'. Parents of children in the '6-12 years' age group gave significantly higher scores on this scale than did parents of children in the '> 17 years' age group ( $U = 288, r = -.34$ ).
- Conclusion* This study shows that parents with children with PIMD find family-centred principles in the professional support of their children important. Although the majority of parents are satisfied with the support provided for their children, a substantial minority of the parents indicated that they did not receive the support they find important.

### 3.1 Introduction

In the support of persons with chronic illnesses and/or disabilities, the concept of family-centred care or family-centred services (FCC) has gained increasing interest over the last 20 years (Dunst, Trivette, Davis & Cornwell, 1988; Epse-Sherwindt, 2008; King, Rosenbaum & King, 1996b; King, Teplicky, King & Rosenbaum, 2004). In this context support is defined as "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and enhance individual functioning" (American Association on Intellectual and Developmental Disabilities [AAIDD], 2010, p.224). Whereas chronic health problems were initially approached using the medical model, with its focus on professionals as experts, over the past few decades a shift has taken place to a model in which the needs of the child with chronic illnesses and/or disabilities are placed at the centre of care, in the context of the family and community (MacKean, Thurston & Scott, 2005). FCC recognizes that each family is unique and a constant factor in a child's life (King et al., 2004). In cooperation with service providers the family can make informed decisions about the support needed, corresponding with their child's needs and wishes. This collaborative relationship or partnership between professionals and parents is one of the key elements of FCC (MacKean et al., 2005; Epse-Sherwindt, 2008).

With regard to the support of persons with profound intellectual and multiple disabilities (PIMD), there are no data on the family-centredness of services, as far as we know. Persons with PIMD are characterized by profound intellectual and profound or severe motor disabilities (Nakken & Vlaskamp, 2007). Communication of persons with PIMD is mainly preverbal and they are totally dependent on others in their daily lives. Many of them are confined to a wheelchair, frequently with little or no use of their hands or arms, along with difficulties in maintaining posture balance. Another characteristic of persons with PIMD is their extensive 'additional' impairments: sensory disabilities, seizure disorders, chronic pulmonary infections and skeletal deformations (Dunn, 1991; Evenhuis, Theunissen, Denkers, Verschuure & Kemme, 2001; Hogg, 1992; Janicki & Dalton, 1998; Oberlander, O'Donnell & Montgomery, 1999; Zijlstra & Vlaskamp, 2005). It goes without saying that this is a chronic, life-long condition, starting from birth or early childhood, as is the case with many children in pediatric rehabilitation. However, there are also many differences between the two groups in terms of models of service delivery, specific aims and length of 'treatment'. Persons with PIMD need high levels of support if they are to engage meaningfully socially or educationally. Beside it, they will continue to require high levels of personal care. Because of this the role that parents play is a very important one. Given the severity and complexity of their disabilities, parents of children with PIMD are often spokespersons for their children, as their children cannot speak for themselves. Accordingly, parents are essential in formulating the needs and wishes of their children. Due to their detailed knowledge of their children, parents of children with PIMD should be considered as experts in their care (De Geeter, Poppes & Vlaskamp, 2002).

However, parents can only play this role if the facilities which deliver services to the children and parents are equipped with a kind of framework in which this parental expertise can be embedded. For example, before parents can contribute their expertise and make decisions about the best kind of support for their children, they must be informed about all the available options in terms of therapy, living environment, daily activities, etc. (De Geeter et al., 2002).

As mentioned above, partnership is one of the key elements of FCC. In order to deliver FCC and cooperate with parents, it is important for organizations to know what parents with children with PIMD think about what is done by service providers and about how often it is done. However, in addition to being aware of these views about the support provided, it is even more crucial to know what parents find important in the support of their children. If parents find certain aspects of the services provided important, and these aspects are indeed provided, a logical assumption is that parents will then be satisfied with the support their child receives. Likewise, service providers may have opinions about the support they provide in terms of its importance and frequency. The results of a study conducted by Neece, Kraemer & Blacher (2009) suggest that there is a relationship between what service providers do and how satisfied parents feel. Therefore, when the opinions of parents about what is done and how often it is done by service providers correspond with the opinions of service providers, it is reasonable to conclude that a foundation for cooperation has been laid.

The opinion of parents about what is important for their child may depend on the specific characteristics of the child, such as age or type and number of additional disabilities. The characteristics of the parents may also influence their opinion about or satisfaction with the care their child receives. Various studies in other fields (e.g. pediatric neuropsychology, mental health care, or care for persons with mental or physical disabilities) in other countries (Sweden, U.K. and the U.S.A.) however, have examined the relationship between parental satisfaction with child care and a variety of demographic variables. The variables that have been studied include sex and age of parent, age of child, maternal education, ethnic group, and disability severity (King, King & Rosenbaum, 1996a; Godley, Fiedler & Funk, 1998; Granat, Lagander & Börjesson, 2002; McConachie & Logan, 2003; Bjerre et al., 2004; Bodin et al., 2007). The results of these studies, however, are not unambiguous. Some studies show a negative correlation between the age of the child and parental satisfaction, suggesting that the parents of younger children view their services more positively (Granat et al., 2002; McConachie & Logan, 2003; Bjerre et al., 2004), while other studies have not found such a relationship (Godley et al., 1998; Bodin et al., 2007). Furthermore, significant differences were found in parental satisfaction in relation to disability type by Granat et al. (2002), while McConachie & Logan (2003) and Bodin et al. (2007) did not find differences. Another significant difference that has been

found in parental satisfaction relates to maternal education (Bodin et al., 2007). The abovementioned studies also found no significant relationships between parental satisfaction and the number of disabilities, parental age, ethnicity, family income, or the child's gender. As far as we know, no data are available on the relationship between these characteristics and parental satisfaction for children with PIMD.

The purpose of this study was to examine what parents find important in the support of their children with PIMD and to examine whether this opinion is related to the children's characteristics (gender, age, type and number of additional disabilities, type of services used (e.g. residential facility, school, daycare centre, etc.), or the duration of service use) and the characteristics of the parents (gender, involvement with support and educational level).

## 3.2 Method

### 3.2.1 Participants

The participants were parents with a child with PIMD. Inclusion criteria were:

- The child has a developmental age of up to 24 months and motor disabilities that prevent independent mobility (Nakken & Vlaskamp, 2007).
- The child receives care from professional service providers, such as a residential facility or a daycare centre<sup>1</sup>.

### 3.2.2 Measurements

The opinion of parents about the support of their child was measured with an adapted version of the Dutch version of the Canadian Measure of Processes of Care (MPOC) (Van Schie, Siebes, Ketelaar & Vermeer, 2004). The MPOC was developed in the field of pediatric rehabilitation and is a 56-item self-administered parent questionnaire that was developed to measure parental experiences and perceptions of the care provided by healthcare professionals (King et al., 1996b).

The items from the original Canadian MPOC and the Dutch MPOC (MPOC-NL) cover five scales: (1) *Enabling & Partnership* (16 items); (2) *Providing General Information* (9 items); (3) *Providing Specific Information about the Child* (5 items); (4) *Coordinated & Comprehensive Care for Child and Family* (17 items); and (5) *Respectful & Supportive Care* (9 items) (King et al., 1996b). Each item can be scored on a 7-point scale ranging from 'not at all' (1) to 'to a very great extent' (7), with an additional 'not applicable' category. The values of the response options (2) through (6) are, respectively, 'to a very small extent', 'to a small extent', 'to a moderate extent', 'to a fairly great extent' and 'to a great extent' (King, King & Rosenbaum, 2004). Each of the items asked the parents to what extent a certain 'behaviour' was exhibited by the care providers at the centre working with their child. Each item was presented as a question, 'To what extent did the people who worked with your child in the last year...' followed by

<sup>1</sup> In The Netherlands parents with a child with PIMD can choose from an extensive system of professional services, such as different types of schools for special education, with or without therapy services, daycare centres or residential facilities.

an item describing a specific action or behaviour of the care provider, for example '...accept you and your family without judging?'

The instrument has become a widely used measure, translated into five languages and distributed to 23 countries around the world (King et al., 2004). Both the original Canadian MPOC and the MPOC-NL have sound psychometric properties with Cronbach's  $\alpha$  ranging from 0.80 to 0.96 and ICCs (intraclass correlation coefficient) ranging from 0.78 to 0.94 (King et al., 1996a; Van Schie et al., 2004). The MPOC-NL was supplemented with importance ratings. In addition to the original item scales, participants are asked to rate concurrently the importance of a behaviour (item) in family-centred care provision on a 5-point scale ranging from (0) 'not at all important' to (4) 'very important'. The values of the response options (1) through (3) are 'not very important', 'neutral' and 'important' respectively (Siebes et al., 2007b).

In the current study, minor adjustments were made to the MPOC-NL to adapt it to a different target group. These adjustments concerned terminology and questions not suitable for the target group. Hence, some concepts and questions were formulated differently (e.g. the term 'patient' was replaced by 'client' and 'therapy' by 'support'). Finally, the 'Providing General Information' scale was omitted. This scale contains questions about, for example, information gathering and contact with other parents. The reason for its omission is that there is an important difference in the information requirement for parents with children with PIMD and parents with a chronically ill child admitted to a rehabilitation clinic. It is obvious that those parents need different information about the methods and procedures in their new situation. The adjusted questionnaire (MPOC-NL-PIMD) consists of four scales covering 39 items: (1) *Enabling & Partnership* (14 items); (2) *Providing Specific Information about the Child* (3 items); (3) *Coordinated & Comprehensive Care for Child and Family* (16); and (4) *Respectful & Supportive Care* (6 items) (see Table 1).

**Table 1**  
**Items and scaling of the MPOC-NL-PIMD**

#### Item description<sup>a</sup>

##### **Enabling & Partnership (EP) (14 items)**

- Fully explain the individualized support programme choices to you?
- Tell you about the options for support or services for your child (e.g., equipment, day-activities, school or support)?
- Trust you as the 'expert' on your child?
- Anticipate your concerns by offering information even before you ask?
- Make sure you had a chance during visits to the service provider (e.g., residential facility, special educational centre, daycare centre) to say what is important to you?
- Let you choose when to receive information and the type of information you want?
- Tell you about the reason for support or equipment?
- Provide opportunities for you to make decisions about certain methods or treatment?
- Recognize that your family has the final say regarding the individualized support programme for your child?
- Consult with you when discussing equipment or the implementation of specific interventions or support?
- Tell you about details about your child's services, such as the reasons for the support, the type of support and its duration?
- Make sure you had opportunities to explain what you think are important treatment goals?
- Make you feel like a partner in your child's support?
- Listen to what you have to say about your child's needs for equipment or specialized services for persons with profound intellectual and multiple disabilities?

##### **Providing Specific Information about the Child (PSI) (3 items)**

- Tell you about the results from therapeutic (e.g. physical/occupational therapist, speech therapist, dietician) or psychological assessments?
- Provide you with written information about your child's activity during the provided support?
- Provide you with written information about your child's progress?

<sup>a</sup> Each item begins with, 'To what extent did the people who worked with your child in the last year...'. (Table continues)

**Table 1** (continued)**Coordinated and Comprehensive Care for Child and Family (CCC) (16 items)**

- Suggest proposals that fit with your family's needs and lifestyle?
- Take the time to establish rapport with you when changes occur regarding the support of your child?
- Discuss with you everyone's expectations for your child, so that all are agreed on what is best?
- Make sure that your child's needs and wishes are known to all persons working with your child, so that your needs and wishes are communicated between service providers?
- Provide ideas to help you work with the healthcare system?
- Recognize the demands of caring for a child with special needs?
- Look at the needs and wishes of your 'whole' child (e.g., at mental, emotional and social needs) instead of just at the physical needs?
- Show sensitivity for your family's feelings about having a child with special needs (e.g., your worries about your child's health or function)?
- Follow up at the next appointment on any concerns you discussed at the previous one?
- Make sure that the direct support professional of your child is involved with your child for at least six months in a row?
- Develop both short-term and long-term goals for your child?
- Plan cooperatively so that they all work towards the same goals?
- Make sure you are informed ahead of time about any changes in your child's care (e.g., support, service providers, programmes or equipment)?
- Seem to be aware of your child's changing needs as he/she grows?
- Make themselves available to you as a resource (e.g., emotional support, advocacy, information)?
- Give you information about your child that is consistent from person to person?

**Respectful & Supportive Care (RS) (6 items)**

- Accept you and your family in a nonjudgmental way?
- Give you the impression that they are well informed about the personal circumstances of your child and your family?
- Provide a caring atmosphere rather than just give you information?
- Help you to feel competent as a parent?
- Provide enough time to talk to you so you do not feel rushed?
- Treat you and your family as people rather than as a 'case' (e.g., by not referring to you or your child by diagnosis)?

Additionally, questions were asked about the gender and date of birth of the child, and the gender, country of birth and the educational level of the parents. Next, parents were asked about their children's additional disabilities, such as sensory

limitations, general health problems, service type (e.g. residential facility, school, daycare centre etc.) and the duration of service use.

To assess validity, a principal component analysis with varimax rotation was conducted using data from 100 participants. An a priori interest test for four factors was conducted to confirm the four-factor structure of the MPOC-NL-PIMD. Four factors with eigenvalues of at least 1.0 were identified, accounting for 64.2% of the variance, with factor 1 accounting for 18.6% of the variance, factor 2 accounting for 15.7%, factor 3 accounting for 14.0% and factor 4 accounting for 12.0%. The internal consistency of the four subscales was analyzed by calculating Cronbach's  $\alpha$ . They were 0.84 (Respectful & Supportive Care), 0.93 (Coordinated and Comprehensive Care for Child and Family), 0.90 (Enabling & Partnership) and 0.63 (Providing Specific Information about the Child) respectively. Pearson's product-moment correlation coefficient ( $r$ ) was used to analyze the correlation between the scales. All the scales correlated significantly with the other scales ( $p < 0.01$ ). With  $r$  ranging from 0.55 to 0.92, the Pearson correlations were good. Overall, the psychometric quality of the MPOC-NL-PIMD seemed adequate.

**3.2.3 Procedure**

Using BOSK, a Dutch organization for parents with children with disability, 600 parents were invited by mail to fill in the MPOC-NL-PIMD. For this pilot, only the 600 BOSK members who chose 'Multiply Disabled' as their area of attention were sent an invitation to take part in this study. The questionnaire was accompanied by a letter concerning the purpose of this study and the conditions for participation. All the participants were also assured of anonymity and confidentiality. If a child did not belong to the target group or the parents did not wish to participate, the parents were asked to declare this on the return form and send it back within two weeks in a prepaid envelope.

**3.2.4 Analysis**

An MPOC scale score was calculated as the mean of the ratings for the items in the scale. As the items were not weighted, a scale score could range from 1.00 to 7.00. To get an overall view of the parents' satisfaction with the care provided, the mean unweighted MPOC scale scores were computed. Since not all items were equally important to all parents, scale scores were corrected by calculating weighted scale scores, using the respondent's ratings of each item's importance (on a scale from 1 to 7). To improve the interpretability of these weighted scale scores, weighted grades on a scale from 1 to 10 (like the Dutch school grades) were calculated (Siebes et al., 2007) (see Table 2 for formulas).

**Table 2**  
**Formulas for converting MPOC scale scores or MPOC item scores into weighted scores and grades**

$s_w = \frac{1}{8} (b(-7 + m) + 4(7 + m))$ $g_w = 3/2s_w - 1/2$
<p>m unweighted MPOC scale score or item score (scale: 1–7); <math>s_w</math> weighted MPOC scale score or item score (scale 1–7);                  b score for the importance of a scale or individual items according to the respondents, with 0 = not at all important,                  1 = not very important, 2 = neutral, 3 = important and 4 = very important; <math>g_w</math> weighted MPOC grade for scale or item                  (scale: 1–10).</p>

Scores produced by the MPOC were ordinal because of the seven-point response option (varying from ‘never’ to ‘to a great extent’). Following Streiner and Norman (1995), ordinal data can be analyzed with parametric statistics unless severely skewed. Therefore, the distributions of MPOC scale scores were examined. These scores appeared not to be normally distributed. As a consequence, non-parametric tests were used to examine the differences in ratings related to the gender of the parents, their country of birth, the gender of the children and the type of additional disabilities (Mann-Whitney), and to examine differences in ratings related to involvement with support, educational level, service type, service use duration and the child’s age (Kruskal-Wallis). Spearman’s correlation coefficient was used to analyse associations between scale scores and the number of additional disabilities (Field, 2009).

### 3.3 Results

#### 3.3.1 Characteristics of the participating parents and their children

A total of 152 parents (25.3%) returned the questionnaire. Of these parents, 41 (27%) pointed out that their child did not belong to the target group and 11 parents (7.2%) did not wish to participate in the study. Therefore, 100 (65.8%) of the 152 questionnaires returned could be used in this study. The characteristics of the parents are displayed in Table 3, those of the children in Table 4.

**Table 3**  
**Characteristics of the participating parents**

N=100	%
<b>Identity of respondent</b>	
Mother	78
Father	18
Other	1
Missing	3
<b>Extent of involvement</b>	
Least involved	2
Most involved	64
As much	29
Missing	5
<b>Country of birth</b>	
Netherlands	96
Other	4
<b>Educational level</b>	
University degree	18
Secondary vocational training	48
Intermediate vocational training	17
Higher general secondary education	7
Lower general secondary education	5
Missing	5

**Table 4**  
**Characteristics of the children**

N=100	%
<b>Gender</b>	
Male	54
Female	46
<b>Age</b>	
2-5	14
6-12	26
13-16	21
≥ 17	37
Missing	2
<b>Additional disabilities</b>	
Visual impairments	64
Hearing problems	19
Epilepsy	68
Reflux	21
Chronic lung infections	19
Problems with swallowing and chewing	58
Chronic obstipation	41
Behavioural problems	21
Sleeping disorders	22
<b>Number of additional disabilities</b>	
1	6
2	22
3	22
4	24
5	9
6	10
≥ 7	6
Missing	1

(Table continues)

**Table 4** (continued)

N=100	%
<b>Types of services used</b>	
Daycare centre for children	31
Residential facility	7
School	7
Combination residential facility + school	4
Combination residential facility + daycare centre for children	6
Other (1 setting)	12
Other combination	30
Missing	3
<b>Length of time using services</b>	
0-2 years	13
3-5 years	25
≥ 6 years	51
Missing	11

### 3.3.2 MPOC-NL-PIMD

Table 5 shows the mean unweighted MPOC-NL-PIMD scale scores, divided into two scales: the extent to which specific situations occurred and the extent to which these situations were felt to be important.

**Table 5**  
**Characteristics of the children**

Scale	Extent to which situations occur		Extent to which situations are felt to be important					
	m <sup>a</sup>	sd	m <sup>b</sup>	sd	m <sup>c</sup>	sd	m <sup>d</sup>	sd
Enabling and Partnership	4.71	1.15	3.31	0.45	4.91	1.05	6.87	1.58
Providing Specific Information about the Child	4.64	1.39	3.32	0.59	4.86	1.29	6.79	1.94
Coordinated and Comprehensive Care for Child and Family	4.62	1.15	3.27	0.48	4.85	1.04	6.77	1.57
Respectful and Supportive Care	4.79	1.25	3.12	0.59	5.05	1.10	7.07	1.65
Mean	4.69	1.24	3.26	0.53	4.92	1.12	6.88	1.69

<sup>a</sup> unweighted MPOC scale scores on a scale from 1 to 7; <sup>b</sup> unweighted MPOC scale scores on a scale from 0 to 4; <sup>c</sup> weighted MPOC scale scores on a scale from 1 to 7; <sup>d</sup> weighted MPOC grades on a scale from 1 to 10; n number of respondents; m mean; s<sup>d</sup> standard deviation.

As scale scores regarding the extent to which situations occurred varied from 1 ('not at all') to 7 ('to a very great extent'), the results show that the situations belonging to the four scales occur from 'to a moderate extent' to 'to a fairly great extent', with a tendency for 'to a fairly great extent', according to the parents. When looking at the importance scores, varying from 0 ('not at all important') to 4 ('very important'), on average parents found the situations relating to the four scales 'important' to 'very important', with a tendency towards 'important'.

Table 5 also shows the weighted scores and grades by scale. Parents were on average satisfied with the support provided for their child, given a mean grade of 6.88 over the four scales. The situations within the scale 'Respectful and Supportive Care' were rated the most positively (m=7.07), whereas the situations concerning the scale 'Coordinated and Comprehensive Care for Child and Family' (m=6.77) were rated the least positively, but positively nonetheless.

Although parents were generally quite satisfied with the services provided, a closer look at the data reveals that a substantial proportion of the parents were not satisfied with the services provided for their children. Figure 1 shows the number of parents (%) who provided a negative score (<5.5) on the four MPOC-NL-PIMD scales compared with the number of parents who rated the scales from ≥5.5 - ≤ 8.0 and those who submitted scores > 8.0. Of the 100 parents who completed the MPOC-NL-PIMD, 17, 22, 17 and 18 parents (respectively for 'Enabling and Partnership' (EP), 'Providing Specific Information about the Child' (PSI), 'Coordinated and Comprehensive Care for Child and Family' (CCC) and 'Respectful and Supportive Care' (RS) were not sufficiently satisfied with the support provided by the various facilities.

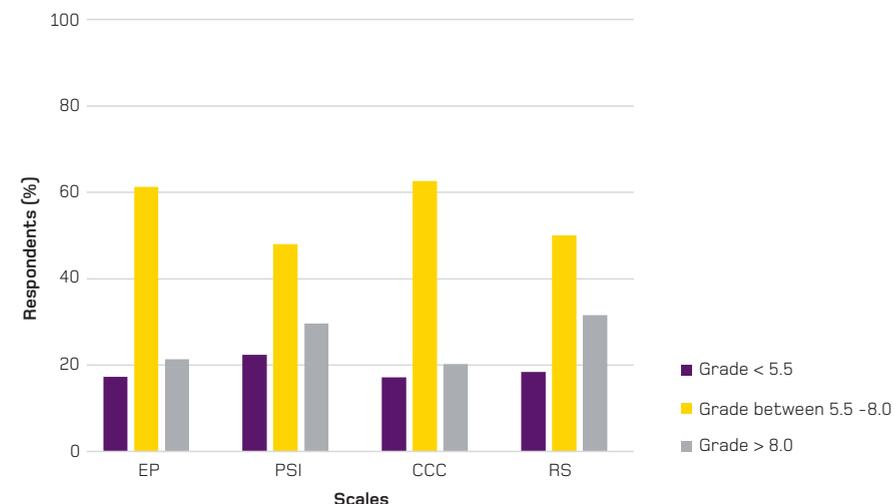


Figure 1 Grade distribution respondents by scale

### 3.3.3 Relationship with sample characteristics

No significant relationships or differences were found between the grades on the four scales and the characteristics of the parents or children, except for the characteristic 'age of child'. The grades on the 'Providing Specific Information about the Child' scale differed significantly between the four age groups,  $H(3) = 8.57, p < .05$ . Mann-Whitney tests were used to follow up this finding. A Bonferroni correction was applied meaning that all effects were reported at a .01 level of significance. It appeared that parents with a child in the '6-12 years' age group submitted significantly higher scores on the 'Providing Specific Information about the Child' scale than did parents with a child in the '≥ 17 years' age group ( $U = 288, r = -.34$ ). Although the grades on the scales 'Providing Specific Information about the Child' and 'Coordinated and Comprehensive Care for Child and Family' seemed to differ significantly between the type of services, Bonferroni corrections do not support these findings. See Table 6.

**Table 6**

Mean weighted MPOC–NL–PIMD scores and standard deviations by scale and

characteristics of the parents and the children

Scale		EP		PSI		CCC		RS	
		m <sup>a</sup>	sd						
Identity of parent	Mother (n=76)	6.96	1.51	6.85	1.97	6.90	1.47	7.21	1.57
	Father (n=18)	6.71	1.73	6.91	1.87	6.57	1.76	6.89	1.75
	Other (n=1)	4.05	-	4.50	-	3.20	-	4.52	-
	p	.501		1.000		.436		.555	
Extent of involvement	Least (n=2)	8.61	0.71	7.47	1.72	8.71	0.71	9.09	1.29
	Most (n=62)	6.90	1.55	6.83	2.02	6.83	1.58	7.02	1.76
	As much (n=29)	6.54	1.63	6.67	1.91	6.42	1.57	6.84	1.38
	p	.095		.831		.083		.139	
Country of birth	Netherlands (n=94)	6.91	1.53	6.83	1.89	6.80	1.55	7.09	1.64
	Other (n=4)	5.92	2.65	5.75	3.08	6.71	2.04	6.64	1.89
	p	.788		.495		.619		.654	
Educational level	University degree (n=18)	6.82	1.62	6.63	2.03	6.82	1.55	7.51	1.34
	Secondary vocational training (n=46)	7.08	1.60	7.26	1.81	6.94	1.69	7.16	1.79
	Intermediate vocational training (n=17)	6.41	1.30	5.90	2.14	6.44	1.08	6.78	1.41
	Higher general secondary education (n=7)	6.41	2.12	6.94	1.62	6.75	2.10	6.87	2.12
	Lower general secondary education (n=5)	7.50	1.11	5.70	2.47	6.72	1.53	6.69	2.00
	p	.258		.167		.597		.578	
Gender child	Male (n=53)	7.01	1.55	6.65	2.10	6.90	1.57	7.14	1.63
	Female (n=45)	6.70	1.61	6.95	1.73	6.62	1.56	6.99	1.68
	p	.285		.394		.452		.598	
Age child	2-5 years (n=14)	7.56	1.30	6.87	2.20	7.65	1.17	7.70	1.42
	6-12 years (n=26)	7.19	0.94	7.76	1.30	7.10	1.01	7.36	1.07
	13-16 years (n=20)	6.77	1.69	1.54	1.65	6.63	1.68	7.00	2.03
	≥ 17 years (n=37)	6.51	1.83	6.34	2.19	6.38	1.73	6.74	1.76
	p	.192		.036*		.303		.056	
Additional disabilities	Visual impairments (n=62)	7.07	1.50	7.05	1.89	6.90	1.60	7.20	1.71
	p	.103		.067		.220		.136	
	Hearing impairments (n=19)	6.66	1.47	6.53	1.55	6.45	1.49	6.76	1.86
	p	.437		.293		.267		.411	
	Epilepsy (n=67)	6.83	1.57	6.62	1.85	6.71	1.62	7.12	1.6.8
	p	.792		.142		.613		.487	
	Reflux (n=21)	6.71	1.44	6.43	1.86	6.62	1.54	6.88	1.69

<sup>a</sup> weighted MPOC grades on a scale from 1 to 10

n number of respondents; m mean; sd standard deviation ; EP Enabling and Partnership; PSI Providing Specific Information about the Child; CCC Co-ordinated and Comprehensive Care for Child and Family; RS Respectful and Supportive Care

\* p < .05

(Table continues)

**Table 6** (continued)

Scale		EP		PSI		CCC		RS	
		m <sup>a</sup>	sd						
<b>Additional disabilities</b>	p	.277		.336		.451		.491	
	Chronic lung infections (n=19)	6.65	1.72	6.93	1.72	6.68	1.79	6.89	1.55
	p	.637		.719		.943		.424	
	Problems with swallowing and chewing (n=56)	6.95	1.49	7.08	1.79	6.85	1.56	7.05	1.62
	p	.914		.081		.742		.855	
	Chronic obstipation (n=41)	6.64	1.67	6.57	1.99	6.53	1.64	6.77	1.73
	p	.249		.439		.282		.139	
	Behavioural problems (n=20)	6.35	1.99	6.11	2.69	6.35	1.96	6.76	1.86
	p	.284		.282		.393		.405	
Sleeping disorders (n=22)	7.00	1.69	7.15	2.33	6.87	1.75	6.97	1.62	
p	.861		.197		.820		.655		
<b>Number of additional disabilities</b>	1 (n=6)	6.62	1.60	6.98	1.70	6.92	1.46	7.06	1.37
	2 (n=22)	6.70	1.80	6.23	2.19	6.66	1.70	7.13	1.75
	3 (n=22)	7.31	1.45	7.30	1.95	7.12	1.23	7.51	1.56
	4 (n=24)	6.99	1.20	7.30	1.54	6.77	1.15	7.11	1.36
	5 (n=9)	6.78	1.89	6.22	1.79	6.44	2.11	6.72	1.91
	6 (n=10)	6.15	2.10	6.62	1.68	6.42	2.37	6.34	2.23
	7 (n=4)	7.43	1.25	6.72	2.34	7.34	1.97	7.58	1.59
	8 (n=1)	5.48	-	1.50	-	6.12	-	4.97	-
	9 (n=1)	5.93	-	6.65	-	5.54	-	5.19	-
	p	.560		.885		.579		.311	
<b>Type of services</b>	Daycare centre for children (n=30)	7.30	1.54	7.35	1.83	7.32	1.57	7.41	1.67
	Residential facility (n=7)	6.26	2.09	5.22	2.41	5.59	1.90	5.85	1.47
	School (n=7)	6.19	1.07	5.92	2.44	6.19	1.07	6.24	1.23
	Combination residential facility + school (n=4)	5.38	1.72	5.15	2.15	5.45	1.34	6.36	1.69
	Combination residential facility + daycare centre for children (n=6)	7.14	0.82	6.24	1.04	7.09	0.66	7.40	0.86
	Other (1 setting) (n=12)	7.38	1.04	7.64	2.01	7.29	1.11	7.65	0.96
	Other combination (n=30)	6.78	1.72	6.76	1.60	6.62	1.65	7.14	1.91
	p	.120		.027*		.039*		.135	
<b>Length of time using services</b>	0-2 years (n=13)	7.50	1.42	6.86	2.67	7.52	1.39	7.56	1.64
	3-5 years (n=25)	6.80	1.58	7.23	1.66	6.76	1.76	7.10	1.70
	≥ 6 years (n=51)	6.96	1.51	6.82	1.74	6.71	1.43	7.05	1.63
	p	.248		.687		.182		.574	

<sup>a</sup> weighted MPOC grades on a scale from 1 to 10

n number of respondents; m mean; sd standard deviation ; EP Enabling and Partnership; PSI Providing Specific Information about the Child; CCC Co-ordinated and Comprehensive Care for Child and Family; RS Respectful and Supportive Care

\* p < .05

### 3.4 Discussion

The purpose of this exploratory study was to establish what parents with children with PIMD find important in the support they and their children receive and to examine whether these opinions are related to the children's characteristics (gender, age, kind and number of additional disabilities, service type used and duration of service use) and the parents' characteristics (gender, involvement with support and educational level). The results show that parents on average rated the items covered by the four scales *'Enabling and Partnership'*, *'Providing Specific Information about the Child'*, *'Coordinated and Comprehensive Care for Child and Family'* and *'Respectful and Supportive Care'*, as important in the care of their children. The assumption that parents were satisfied with the support provided if they found certain situations important and found that the frequency of these situations is high seems to be supported by the grades provided, with a mean of 6.88 (on a scale from 1 to 10).

Although the mean grades were positive (varying from 6.77 to 7.07), further analysis showed that an average of 18.8% of the parents gave the facility concerned a grade of 5.5 or less on the four scales, which indicates dissatisfaction with the support provided. Similar results were found by Nijhuis et al. (2007) in the field of rehabilitation, with a considerable number of parents (19–38%) pointing out that their child did not, in their opinion, receive the care they found important. It is worth mentioning on the other hand that an average of 24.9% of the parents gave a grade of more than 8.0 on the four scales, which implies greater than average satisfaction with the services provided.

When related to specific child and parent characteristics, the results show just one significant relationship, namely that between the age of the child and the scores the parents submitted on the scale *'Providing Specific Information about the Child'*. However, this relationship only applies to the '6 to 12 years' and '17 years and older' age groups. A possible explanation may be that parents with younger children have less experience of services because their children are younger and therefore perhaps have fewer negative experiences with the services provided. Although these findings correspond to findings in other research (Granat et al., 2002; McConachie & Logan, 2003; Bjerre et al., 2004), it is not clear why this does not apply to the two other age groups, '2 to 5 years' and '13 to 16 years'. The fact that no other significant differences in the parental ratings and the particular child and parent characteristics were found corresponds to findings in other studies (King et al., 1996a; Godley et al., 1998; Granat et al., 2002; McConachie & Logan, 2003; Bjerre et al., 2004; Bodin et al., 2007). Nonetheless, it should be noted here that due to different models of service delivery in different countries, comparison of these findings requires some caution. The response rate of 152 parents out of 600 was low in this study. General factors that influence response rate are the respondents not being reachable, their refusal to participate or stopping their participation early (Landsheer, 't Hart,

De Goede & Van Dijk, 2003). Due to the procedure chosen, it was not possible to send a reminder letter after a specific amount of time to the parents who did not return the questionnaire. Another explanation for the low response rate could be the differences in the definition of the target group. For this pilot, BOSK members who chose 'Multiply Disabled' as their area of attention were sent an invitation to participate in the study. However, a substantial number (27%) of the returned questionnaires reported that the child did not belong to the target group. Apparently the term 'Multiply Disabled' is not suitable because it covers every person with more than one disability, a much broader category than this pilot's target. Nakken and Vlaskamp (2007) have already noted this problem and have argued for a taxonomy for PIMD. Although BOSK members come from all levels of the Dutch society, the sample might be biased given the high percentage of highly educated parents in the sample.

Although the response rate was low, gathering the opinions of 100 parents on what they find important in the support of their children with PIMD can be regarded as an important first step towards defining a partnership between parents and professionals in the support of persons with PIMD. Parents of children with PIMD have – more than parents of children without disabilities – frequent and early contact with child support service providers due to the complex needs of their children. Partnership between parents and service providers therefore seems essential in providing the care a child with PIMD needs. This partnership can best be described as mutual cooperation consisting of shared expertise, shared information and shared decision-making (De Geeter et al., 2002). A important next step to arriving at a partnership between parents and service providers is to examine how service providers judge their own support of persons with PIMD in terms of family-centredness, so that differences and agreements in how parents and service providers value the support provided become apparent.

### 3.5 Key messages

- The adapted version of the MPOC is a valid and reliable measurement on how parents value the support provided.
- Parents with a child with PIMD find family-centred principles in professional support important.
- A substantial minority of parents did not receive the support they find important.
- Partnership between parents and service providers seems essential in providing the support a child with PIMD needs.
- An important next step to establish a partnership between parents and service providers is to examine how service providers judge their own support.

### 3.6 Acknowledgements

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# Chapter 4

Family-centredness of professionals who support people with profound intellectual and multiple disabilities: validation of the Dutch 'Measure of Processes of Care for Service Providers' (MPOC-SP-PIMD)

Jansen, S.L.G., Putten, A.A.J. van der, Post, W.J. & Vlaskamp, C. (2014). Family-centredness of professionals who support people with profound intellectual and multiple disabilities: validation of the Dutch 'Measure of Processes of Care for Service Providers' (MPOC-SP-PIMD). *Research in Developmental Disabilities*, 35, 1623-1630.

## Abstract

A Dutch version of the 'Measure of Processes of Care for Service Providers' (MPOC-SP) was developed to determine the extent to which professionals apply the principles of family-centred care in the rehabilitation of children with physical disabilities. However, no data were available on the reliability and construct validity of this instrument when it comes to supporting people with profound intellectual and multiple disabilities (PIMD).

This study aimed to validate an adapted version of the Dutch MPOC-SP for assessing the family-centred behaviours of professionals who support this group (MPOC-SP-PIMD). A total of 105 professionals took part in the study. A Mokken scale analysis was conducted to determine whether the instrument satisfied the assumptions of both monotone homogeneity and double monotonicity. Loevinger's scalability coefficient (H) was used for the scalability of the entire scale and of each item separately. Rho was calculated as a measure of the internal consistency of the scales.

The analyses resulted in two scales: a nine-item scale interpreted as 'Showing Interpersonal Sensitivity', with  $H = .39$  and  $\rho = .76$ , and a seven-item scale interpreted as 'Treating People Respectfully', with  $H = .49$  and  $\rho = .78$ . A validated version of the MPOC-SP-PIMD, suitable for supporting people with PIMD, consists of a subset of two scales from the original Dutch MPOC-SP. This instrument can be used to compare the family-centredness of professionals with parent's expectations and views. This information can be used in practice to match the support to the needs of the parents and family of the child with PIMD.

## 4.1 Introduction

The role of parents in the professional support of children with disabilities has changed considerably in recent decades, moving towards a full partnership with professionals (Dale, 1996; De Geeter, Poppes & Vlaskamp, 2002; Espe-Scherwindt, 2008; MacKean, Thurston & Scott, 2005). In this close collaboration, parents and professionals jointly formulate the aims of the support provided for the child and family, with responsibility for the support process being shared by all those involved. Further characteristics of this partnership are a supportive and respectful attitude towards parents and the exchange of information between parents and professionals. This allows the support to be adjusted to the needs and wishes of both the child and the family. In the present literature, this conceptual shift in service delivery is described as family-centred services or family-centred care (FCC). FCC has been shown to affect not only the child itself, through increased development and improved skill acquisition (Caro & Derevensky, 1991), but also the parents. Research shows, for example, that FCC is associated with an increase in parental wellbeing and in parental satisfaction with services (Dunst, Trivette & Hamby, 2007). If parents are more satisfied, this can in turn facilitate their full partnership with professionals.

The concept of FCC has attracted increasing attention over the past 20 years in the delivery of care to children and adults with chronic illnesses and/or physical disabilities (Dunst, Trivette, Davis & Cornwell, 1988; Espe-Scherwindt, 2008; King, Rosenbaum & King, 1996; King, Teplicky, King & Rosenbaum, 2004b). Today, this concept is also applied to the care of people with intellectual disabilities. The role of parents is particularly important in the support of children with severe or profound intellectual disabilities, who usually have additional motor and general health problems (Vlaskamp, Maes & Penne, 2011). This is because the communicative difficulties experienced by these children make them fully dependent on their environment (Nakken & Vlaskamp, 2007). Parents' experiences and the knowledge they have gathered throughout their child's life are vital for adapting the support to the wishes and needs of the child (De Geeter et al., 2002).

Since the shift towards FCC, several measurements have been developed to evaluate the family-centredness of support to children with disabilities from the perspective of both parents and professionals. These include the 'Measure of Beliefs about Participation in Family-Centered Service' (MBP-FCS), the 'Family-Centered Program Rating Scale' (FamPRS) and the 'Measure of Processes of Care' (MPOC) (King et al., 1996). Of these instruments, the MPOC is the most frequently used. It is implemented in many different countries and settings and with different target groups (Dyke, Buttigieg, Blackmore & Ghose, 2006; King et al., 1996; King, King & Rosenbaum, 2004; Raghavendra, Murchland, Bentley, Wake-Dyster & Lyons, 2007). In 2004 the MPOC was translated into Dutch and was validated for use in the Netherlands (Van Schie, Siebes, Ketelaar & Vermeer, 2004). In terms of quality,

both the original Canadian MPOC and the Dutch version have good psychometric properties (King et al., 1996; Van Schie et al., 2004). The Measure of Processes of Care for Service Providers (MPOC-SP) was developed to assess FCC from the perspective of professionals (Woodside, Rosenbaum, King & King, 2001). The MPOC-SP has also been used in many different studies with different populations (Dyke et al., 2006; Law et al., 2003; O'Neill, Palisano & Westcott, 2001; Siebes et al., 2006; Siebes et al., 2008; Woodside et al., 2001). Studies of the construct, content, face validity and reliability of the Dutch version of the MPOC-SP yielded positive results (Siebes et al., 2006; Siebes et al., 2008). The Dutch MPOC-SP has proved a reliable and valid instrument for measuring the family-centredness of service delivery in paediatric rehabilitation.

Jansen, Van der Putten and Vlaskamp (2013) conducted a study to identify the extent to which family-centred principles are applied in the support of people with PIMD. More specifically, they examined the extent to which parents were satisfied or dissatisfied with the care provision in terms of aspects of FCC (providing information, showing interpersonal sensitivity and treating parents respectfully). Jansen et al. (2013) used an adapted version of the Dutch version of the MPOC. This modified questionnaire (Dutch MPOC-PIMD) showed adequate psychometric quality. The study found that although the majority of the 100 parents approached were satisfied with the support provided, a substantial proportion (almost 20% on average) indicated that they were not (Jansen et al., 2013). The study focused on the views of parents and did not compare the results with those of professionals. Only when the needs and wishes of parents coincide with the views and behaviour of professionals can there be increased collaboration between the two groups and an increase in parental satisfaction with the support offered. Nijhuis et al. (2007) analysed differences in ratings between parents and professionals with respect to the importance of family-centred behaviours in the field of rehabilitation and found that 19-38% of parents did not receive the support they considered important. Knowing about these differences in general and for each family in particular provides opportunities for optimizing collaboration between parents and professionals and therefore for improving the quality of support.

In order to boost this quality, a follow-up step to Jansen et al.'s study (2013) is to assess the family-centred behaviours of professionals and compare them with parent ratings. To date, however, the psychometric properties of the MPOC-SP when used to support individuals with PIMD are still unknown. We therefore need to establish these properties if we wish to use the instrument in a different setting and with a different target group from those of the original MPOC-SP (Yun & Ulrich, 2002). The purpose of the present study is to construct and validate the adapted version of the Dutch MPOC-SP (MPOC-SP-PIMD) for supporting people with PIMD. This should lead to an instrument that assesses the FCC of professionals working

with this group. We can then use the instrument, together with the Dutch MPOC-PIMD, to evaluate the level of FCC from the perspective of professionals and parents and to identify areas where support can be improved.

## 4.2 Material and methods

### 4.2.1 Participants

A convenience sample of 105 professionals working with people with PIMD was recruited from seven different facilities across the Netherlands providing support to this group. These facilities were of different sizes and were located in different parts of the country, in both rural and urban areas. At each facility, professionals working with people characterized by a combination of profound intellectual disabilities (IQ below 20 or a developmental level of up to 24 months and profound or severe motor disabilities; Nakken & Vlaskamp, 2007) were asked to participate on a voluntary basis. The MPOC-SP-PIMD questionnaires were distributed, accompanied by a letter outlining the purpose of the study. All participants were also assured of anonymity and confidentiality. They were asked to return the questionnaire in a prepaid envelope within two weeks.

Ultimately, a total of 105 professionals from seven different facilities gave their informed consent to take part in the study. They worked in different disciplines as direct support staff<sup>1</sup> (n = 67; 63.8%), therapists, for example physical, occupational and speech therapists (n = 17; 16.2%), physicians (n = 5; 4.8%) and healthcare psychologists (n = 8; 7.6%). Other disciplines included physician assistant or nurse (n = 7; 6.7%). The discipline of one participant (n = 1; 1.0%) was not stated. Their mean total experience came to 13.7 years (range: 43 years, SD 8.8 years).

### 4.2.2 Instrument

The MPOC-SP-PIMD, an adapted version of the Dutch MPOC-SP, was used to assess the FCC of professionals working with people with PIMD (Siebes et al., 2006). The original MPOC-SP (Woodside et al., 2001) is based on the MPOC for parents and consists of 27 items categorized into four scales: 1. Showing Interpersonal Sensitivity (SIS), comprising ten items that describe support actively involving parents supporting their child, 2. Providing General Information (PGI), five items dealing with parents' general information needs, 3. Communicating Specific Information about the Child (CSI), three items that reflect behaviours whereby parents obtain information about their child, and 4. Treating People Respectfully (TPR), nine items that reflect support in which all family members are treated with respect (Woodside et al., 2001).

For the present study, a few adaptations were made to the Dutch version of the MPOC-SP. Questions were omitted that did not apply to the target group. Thus the 5-item PGI scale was omitted, together with other items about providing general

<sup>1</sup> Direct support staff are responsible for the daily support of an individual with PIMD. Senior direct support staff have additional tasks such as coordinating the planning of multidisciplinary meetings, contact with parents, and partial responsibility for the content of individual support plans, etc.

information (items 17 and 18 on the TPR scale) because parents of children with PIMD have very different information requirements than parents of a chronically ill child admitted to a rehabilitation clinic. Clearly, the latter group need different information about the methods and procedures in their new situation than parents of a child who is already involved in the care process (such as children with PIMD). A second adaptation involved modifying the terminology to bring it more into line with the terms used for individuals with PIMD (e.g. 'patient' was replaced by 'client' and 'therapy' by 'support') (Jansen et al., 2013). The result was a final version, still to be validated, of the Dutch MPOC-SP adapted for use with people with PIMD (MPOC-SP-PIMD). The instrument consists of 20 items divided into three different scales (see Table 1).

Each item was presented as a question starting with 'During the past year to what extent did you ...' followed by an item describing an event or situation performed by the professional. Each item could be scored on a 7-point scale, ranging from 'never' (1) to 'to a great extent' (7), with an additional 'not applicable' category.

Previous studies show that the psychometric properties of both the Dutch and the original MPOC-SP are sufficient in terms of validity and reliability (Siebes et al., 2006; Woodside et al., 2001). Siebes et al. (2006) found that all items correlated best and significantly with their own scale score (rs 0.48-0.82,  $P < 0.001$ ). They (Siebes et al., 2006) also found sufficient internal consistency; Cronbach's alphas, as a measure of the internal consistency of the four scales, ranged from .65 to .84 and there were statistically positive significant correlations between the different scales (with Pearson correlation coefficients ranging from .18 to .60) and the ICC as a measure of test-retest reliability (from .83 to .89). The content and face validity of the Dutch MPOC-SP are also good according to Siebes et al. (2006). Siebes et al. (2008) also analysed the validity of the Dutch MPOC-SP when used in a family-specific way (i.e. filled out for a particular child and his or her family rather than in relation to services provided to children and their families) by pairing family-specific and general scores. The analysis of construct validity confirmed the scale structure: 21 items (77.8%) loaded highest in the original MPOC-SP factors, and all items correlated best and significantly with their own scale score ( $r = 0.565$  to  $0.897$ ;  $P < 0.001$ ). Inter-correlations between the scales ranged from  $r = 0.159$  to  $r = 0.522$ . In total, 94.4% of the mean absolute difference scores between general and family-specific scale scores were larger than the expected difference. The family-specific Dutch MPOC-SP is therefore a valid measure that can be used for the individual evaluation of family-centred services (Siebes et al., 2008).

**Table 1**  
**Items and scaling of the Dutch MPOC-SP-PIMD, based on Siebes et al. (2006) and Jansen et al. (2013)**

Scale	Items <sup>a</sup>
<b>Showing Interpersonal Sensitivity (SIS) (10 items)</b>	1 Suggest treatment/management activities that fit with each family's needs and lifestyle. 2 Offer parents and children positive feedback or encouragement. 3 Take the time to establish rapport with parents and children. 4 Discuss expectations for each child with other service providers, to ensure consistency of thought and action. 5 Tell parents about options for services or treatments for their child. 8 Discuss/explore each family's feelings about having a child with special needs. 9 Anticipate parents' concerns by offering information even before they ask. 11 Let parents choose when to receive information and the type of information they want. 12 Help each family to secure a stable relationship with at least one service provider who works with the child and parents over a long period of time. 21 Help parents to feel competent in their roles as parents.
<b>Treating People Respectfully (TPR) (7 items)</b>	6 Accept parents and their family in a non-judgemental way. 7 Trust parents as the 'experts' on their child. 10 Make sure parents have a chance to say what is important to them. 13 Answer parents' questions completely. 19 Make sure parents have opportunities to explain their treatment goals and needs. 20 Help parents feel like a partner in their child's care. 22 Treat children and their families as people rather than as 'cases'.
<b>Communicating Specific Information about the Child (CSI) (3 items)</b>	14 Tell parents about the results of tests and/or assessments. 15 Provide parents with written information about their child's condition, progress, or treatment. 16 Tell parents details about their child's services, such as the types, reasons for, and durations of treatment/management.

<sup>a</sup>The numbers of the items correspond to the sequence in the Dutch MPOC-SP (Siebes et al., 2006)

### 4.2.3 Analysis of the validity and reliability of the MPOC-SP-PIMD

Frequency scores were calculated for each item and the distribution of these scores was explored to determine whether or not they were normally distributed. Since the distributions of some items were extremely skewed to the left, the Mokken model, a nonparametric item-response theory (IRT) model (Molenaar & Sijtsma, 2000), was used to analyse the data for the three scales of the MPOC-SP-PIMD. In an IRT model, the relationship between the latent trait (in the current study, the degree of FCC by professionals supporting those with PIMD) and the responses (1 to 7) to the items (the questions about statements describing an event or situation performed by the professional) reflected in the item response function must satisfy certain measurement properties. Mokken scale analysis, named after its developer Robert Mokken, is a non-parametric Item Response Theory model, where the probability of response on a certain item, reflected in its item response function, must satisfy several measurement assumptions. The Mokken model takes idiosyncratic behaviour into account, and can be regarded as a probabilistic version of the deterministic Guttman method, where no randomness is allowed. It is widely applied in social sciences as well as in medicine and nursing (Doyle, McGee & Delaney, 2010; Luinge, Post, Wit & Goorhuis-Brouwer, 2006; Stewart, Watson, Clark, Ebmeier & Deary, 2010; Watson, van der Ark, Lin, Fieo, Deary & Meijer, 2011,). The Mokken model consists of two types of nonparametric models (Molenaar & Sijtsma, 2000). In the homogeneous monotonicity model, the measurement assumption is that the item response function of each item is a monotone non-decreasing function of the latent trait. This corresponds with the statement of Watson and colleagues (2011).

In the more restrictive double monotonicity model, the item response functions of different items do not intersect. To carry out all the analyses, the item scores were dichotomized into 0 or 1, with scores from 1 to 4 (not at all – to a moderate extent) dichotomized into ‘0’ and scores from 5 to 7 (to a fairly great extent – to a very great extent) into ‘1’. The ‘non-applicable’ scores were also scored as ‘0’.

The Mokken scale analyses were conducted by means of the MSP5 program (Mokken scale analysis for polytomous items) (Molenaar & Sijtsma, 2000) using the search default option. The main statistic in this search procedure is Loevinger’s scalability coefficient (H), indicating the strength of the scale. The H-coefficient can be calculated for a pair of items, for each item and for the entire scale. Mokken (1971, p. 185) considered a set of items to constitute a weak scale if  $0.3 \leq H < 0.4$ . Medium scalability is obtained if  $0.4 \leq H < 0.5$ , and a scale is considered strong if  $0.5 \leq H \leq 1.0$  (Molenaar & Sijtsma, 2000). If the coefficient for both the items and the scale was satisfactory, crit statistics were used to determine whether each item satisfied the assumptions of homogeneous and double monotonicity within the scales. The crit value should be below 40: crit values exceeding 80 are a strong indication that an item violates the described assumptions. Crit values between 40 and 80 are ‘questionable’. Finally, reliability was calculated in MSP (rho) as a measure of internal consistency. This measure is only a good estimator of reliability in cases of double

monotonicity. The scales obtained by the default research option were thereafter adapted by excluding items with high crit values and including other items based on interpretational reasons.

### 4.3 Results

Table 2 presents the frequency scores of the items within the SIS, TPR and CSI subscales.

**Table 2**  
**Frequency scores of items in the SIS, TPR and CSI subscales**

Scale	Item	n	Scores							N <sup>a</sup>
			To a..... extent							
			Not at all (score 1)	Very small (score 2)	Small (score 3)	Moderate (score 4)	Fairly reat (score 5)	Great (score 6)	Very great (score 7)	
SIS	1	103	10	9	11	17	26	11	4	15
	2	104	2	8	11	22	33	14	9	5
	3	101	2	4	3	16	44	19	12	1
	4	105	0	2	0	7	43	37	15	1
	5	103	4	10	7	24	28	20	9	1
	8	104	3	8	15	20	30	15	9	4
	9	105	9	14	16	27	19	11	3	6
	11	104	6	8	13	18	35	15	5	4
	12	103	17	10	10	9	14	18	8	17
	21	102	4	10	12	14	24	15	12	11
	TPR	6	105	3	2	6	13	30	32	17
7		104	1	5	3	13	24	32	25	1
10		104	3	0	4	10	36	34	16	1
13		104	0	2	4	12	27	36	23	0
19		102	3	5	8	24	26	19	10	7
20		104	4	3	5	13	31	31	15	2
22		102	2	0	3	4	15	29	49	0
CSI	14	105	7	4	5	12	25	26	21	5
	15	102	11	9	9	12	22	17	13	9
	16	103	7	4	6	18	28	23	13	4
<b>Total</b>			<b>98</b>	<b>117</b>	<b>151</b>	<b>305</b>	<b>560</b>	<b>454</b>	<b>288</b>	<b>91</b>

N<sup>a</sup>: not applicable

### 4.3.1 SIS scale

For the SIS scale, the analysis was conducted with a sample of 92 participants, with 13 participants excluded because of missing values for one or more items. All items fulfilled the criterion of a scalability score above .30 (ranging from .30 to .55), apart from three (items 1, 8 and 11). These scalability scores were .25, .28 and .27 respectively. Removing item 1 resulted in an adequate H-coefficient for item 8 (.32) and an H-coefficient for the entire scale of .36 and rho = .76. However, the H-coefficient for item 11 was still below .30 (.25). Removing this resulted in H-coefficients for the remaining items from .31 to .59 and for the entire scale of .40. The crit values for all items were lower than 40, except for items 2 and 8, where the crit values were 64 and 42 respectively and therefore 'questionable'. The reliability of the scale, rho, was .75. In conclusion, Mokken analyses resulted in an SIS scale consisting of a total of eight items (2, 3, 4, 5, 8, 9, 12 and 19) with adequate H-coefficients, a medium scalability and good internal consistency.

### 4.3.2 TPR scale

Analysis of the TRP scale was conducted with a sample of 98 participants, with seven participants excluded because values for one or more items were missing. Results show that the H-coefficient for three items (6, 13 and 22) on the TRP scale were below .30 (.11, .27 and .15 respectively) and for the remaining items ranged from .30 to .47. The scalability score (H) for the entire scale was .30. Omitting item 6 resulted in an increase in the H-coefficient for the whole scale to .39 as well as in the fit of item 13 in the scale (item H = .31). Because the H-coefficient of item 22 was still below .30 (namely .15), this item was removed, which resulted in a scalability score of .45 for the TRP scale. Coefficient scores for the separate items ranged from .35 to .59. The crit values of the items were all lower than 40, and rho was 0.72. Based on these results, the TRP scale consists of five items (7, 10, 13, 19 and 20) with a medium scalability and a good internal consistency.

### 4.3.3 CSI scale

One hundred and two participants were included in the analysis of the CSI scale. Three respondents were excluded due to missing values. The first analysis resulted in H-coefficients for the three items (14 - 16) of .17, .38 and .41 respectively and a scale coefficient (H) of .33. Omitting item 14 resulted in a scalability coefficient (H) for the CSI scale of .60. The H-coefficient scores were .60 for items 15 and 16. Crit values for both items were 0 and therefore below 40. Rho was .66. Based on these results, the CSI scale consists of two items with a strong scalability and an adequate internal consistency.

Since only two items remained in the CSI scale, we reanalysed the scale structure of the MPOC-SP-PIMD, adding the three items (14 - 16) from the original CSI scale to the original SIS and TRP scales. Ninety-two and 98 participants respectively were included in these analyses due to missing values. The results of this stepwise

analysis, removing items 15, 1, 11 and 16 from the SIS scale and 6, 22 and 14 from the TRP scale, are presented in Tables 3 (SIS scale) and 4 (TRP scale).

Item 16 of the original CSI scale fits into both the final SIS scale and the final TPR scale (see Tables 3 and 4). However, the scalability of this item is stronger in the TPR scale (Item H = .56) than in the SIS scale (item H = .36). Fitting item 16 into the final TPR scale therefore seems to be more appropriate. The scaling of the items thus follows the original scaling, since items 15 and 16 were grouped together in the original scale.

This resulted in a final SIS scale of nine items and a final TPR scale of seven items, with a scalability of .39 (almost medium scalability), adequate crit values (all smaller than 40) and a rho of .76 for the SIS scale, and a scalability of .49 (almost strong scalability) and an internal consistency (rho) of .78 for the TPR scale. Table 5 shows the final version of the MPOC-SP-PIMD, based on the results presented.

**Table 3**  
**Results of the stepwise Mokken analysis of Items in the SIS scale and CSI scale**

Item	Adding items 14 - 16		Removing item 15		Removing item 1		Removing item 11		Removing item 16	
	Mean	Item H	Mean	Item H	Mean	Item H	Mean	Item H	Mean	Item H
1	.38	.25*	.38	.26*	-	-	-	-	-	-
2	.55	.32	.55	.31	.55	.30	.54	.32	.54	.32
3	.74	.51	.74	.51	.73	.51	.73	.53	.73	.53
4	.92	.35	.92	.37	.92	.37	.93	.36	.93	.40
5	.55	.33	.55	.35	.56	.34	.56	.35	.56	.36
8	.55	.26*	.55	.27*	.55	.30	.55	.33	.55	.35
9	.30	.48	.30	.50	.31	.49	.32	.49	.32	.50
11	.53	.25*	.53	.28*	.54	.26*	-	-	-	-
12	.40	.34	.40	.34	.40	.39	.40	.40	.40	.36
21	.51	.35	.51	.38	.51	.39	.50	.40	.50	.42
14 (CSI)	.71	.34	.71	.37	.70	.37	.70	.35	.70	.36
15 (CSI)	.53	.24*	-	-	-	-	-	-	-	-
16 (CSI)	.63	.34	.63	.32	.62	.32	.63	.36	-	-
Scale H	.33		.35		.36		.38		.39	
Rho	.78		.78		.78		.78		.76	

\* Items H below .30 do not fulfil the criterion of scalability and are removed subsequently

**Table 4**  
Results of the stepwise Mokken analysis of the TRP scale and items in the CSI scale

N = 98	Adding items 14 – 16		Removing item 6		Removing item 22		Removing item 14	
Item	Mean	Item H	Mean	Item H	Mean	Item H	Mean	Item H
6	.76	.16*	-	-	-	-	-	-
7	.77	.35	.77	.39	.77	.42	.77	.48
10	.83	.51	.83	.56	.83	.59	.83	.57
13	.82	.29*	.82	.32	.82	.34	.82	.38
19	.53	.44	.53	.47	.53	.48	.53	.51
20	.73	.35	.73	.40	.74	.41	.74	.44
22	.91	.22*	.91	.23*	-	-	-	-
14 (CSI)	.69	.27	.69	.27*	.70	.26*	-	-
15 (CSI)	.51	.44	.51	.45	.52	.45	.52	.50
16 (CSI)	.62	.46	.62	.50	.63	.51	.63	.56
Scale H	.35		.41		.43		.49	
Rho	.77		.78		.78		.78	

\*Items H below .30 do not fulfil the criterion of scalability and are removed subsequently

**Table 5**  
Final version of the MPOC-SP-PIMD based on the Mokken scale analysis

Scale	Items
<b>Showing Inter-personal Sensitivity (SIS) (9 items)</b>	2 Offer parents and children positive feedback or encouragement. 3 Take the time to establish rapport with parents and children. 4 Discuss expectations for each child with other service providers, to ensure consistency of thought and action. 5 Tell parents about options for services or treatments for their child. 8 Discuss/explore each family's feelings about having a child with special needs. 9 Anticipate parents' concerns by offering information even before they ask. 12 Help each family to secure a stable relationship with at least one service provider who works with the child and parents over a long period of time. 14 Tell parents about the results of tests and/or assessments. 21 Help parents to feel competent in their roles as parents.
<b>Treating People Respectfully (TPR) (7 items)</b>	7 Trust parents as the 'experts' on their child. 10 Make sure parents have a chance to say what is important to them. 13 Answer parents' questions completely. 15 Provide parents with written information about their child's condition, progress, or treatment. 16 Tell parents details about their child's services, such as the types, reasons for, and durations of treatment/management. 19 Make sure parents have opportunities to explain their treatment goals and needs. 20 Help parents feel like a partner in their child's care.

#### 4.4 Discussion

The main objective of the current study was to validate the MPOC-SP-PIMD as an instrument to support people with PIMD. More specifically, we analyzed the instrument's reliability and construct validity. This resulted in two scales: a nine-item scale representing the concept 'Showing Interpersonal Sensitivity' with almost medium scalability and good internal consistency, and a seven-item scale covering the concept of 'Treating People Respectfully' with almost strong scalability and good internal consistency.

The following methodological issues should be considered when interpreting the results. First, analyses were conducted based on a relatively small convenience sample, which may limit the generalizability of the results. The direction of this bias can be twofold. On the one hand, we can assume that professionals who are more motivated or who are familiar with the principles of FCC would be more inclined to respond. On the other hand, it may largely have been professionals with a negative attitude towards FCC who volunteered for the study and took the opportunity to express their dissatisfaction. This might have influenced the results of our analysis. Second, although both scales showed satisfactory results for the entire sample, further analysis is needed to determine whether the Mokken scales also hold for other subgroups, such as professionals directly involved in the daily support of people with PIMD (e.g. direct support staff in the residential group or day activity group) and professionals involved in support but not on a regular daily basis (e.g. physical and occupational therapists, healthcare psychologists, physicians). The analyses of the 'sample independency' of the MPOC-SP-PIMD could not be conducted in the current study because the groups were too small once the sample was divided into these two subgroups (67 and 37 participants respectively; the profession of seven individuals was unknown). Preliminary analysis, however, showed that the TPR scale satisfied roughly the property of sample independence, but this was not the case for the SIS scale. Further studies involving larger, randomly selected samples are therefore needed in order to confirm the results of the current study. Third, although only a small amount of data was missing from the questionnaires (a non-response rate of between 3% and 12%), we did not ask the professionals why they did not answer a particular item. One explanation could be that they questioned the applicability of that item to their profession. In future, we should also take the rationale behind the missing data into account. Fourth, to run the Mokken scale analyses, we dichotomized the scores of all items based on arguments relating to the content. Scores between 5 and 7 (indicating 'to a fairly great extent – to a very great extent') were assumed to be family-centred behaviour that had 'occurred'. Items scored between 1 and 4 (reflecting 'not at all – to a moderate extent') were recoded into a score indicating that this particular family-centred behaviour 'did not occur'. We also included the 'not applicable' score in the 'family-centred behaviour did not occur' category. Although professionals could argue that certain behaviour was not applicable to their profession, partly due to their role in the support process, we did not distinguish between 'did not occur' and 'not

applicable' because of our views on the shift towards full collaboration between parents and all professionals, regardless of their background. This decision may also have biased the results. Finally, the results do not explain the extent to which the professionals' answers reflect their actual behaviour or simply the socially desired behaviours of professionals. This could also have influenced the scores. Observational studies could provide more information about actual FCC behaviour (Siebes et al., 2008).

Notwithstanding these methodological shortcomings, the MPOC-SP-PIMD seems to have adequate psychometric properties that are generally consistent with earlier studies (Dyke et al., 2006; Law et al., 2003; O'Neill et al., 2001; Siebes et al., 2006; Woodside et al., 2001). The current study focused on the construct validity of the MPOC-SP-PIMD. Future studies of construct validity, however, should also focus on the extent to which the MPOC-SP-PIMD has sound psychometric properties when used in a 'family-specific' way – in other words, when used for a particular child and his or her family, rather than in relation to care provision for children and their families in general. Siebes et al. (2008) have already shown that the Dutch MPOC-SP has sound psychometric properties when used in this family-specific way in a rehabilitation setting. If this family-specific validation also yields positive results, the MPOC-SP-PIMD can be used to compare the ratings of parents and professionals in general and for dyad-specific as well as individual evaluations of family-centred services provided by different professionals. Detecting differences in parents' perception of aspects of FCC and the behaviours of professionals working with people with PIMD will lead to a better mutual understanding of the content of support and perhaps to better quality support. In addition to further studies of construct validity, the criterion-oriented validity of the MPOC-SP-PIMD also needs to be analysed, for example, by correlating parental satisfaction with the support offered with the 'amount' of FCC offered by professionals, measured by means of the MPOC-SP-PIMD. Criterion-oriented validity can also be analysed by determining the sensitivity over time of the MPOC-SP-PIMD when it comes to measuring changes in FCC in response to the implementation of organizational or policy changes towards FCC.

To conclude, the MPOC-SP-PIMD has been validated and is potentially useful for measuring the extent of family-centredness among professionals supporting people with PIMD. It can be used to compare the extent of professionals' FCC with the perceptions and expectations of parents. It can also be used to evaluate differences between facilities in terms of their family-centredness. However, further studies with larger, randomly selected samples are needed to confirm that the MPOC-SP-PIMD can be used by professionals from different disciplinary backgrounds. In addition, more studies should be carried out on the MPOC-SP-PIMD's sensitivity to change over time. This will enable it to be used to evaluate organizational change that is intended to create a more FCC-oriented facility.

#### 4.5 Acknowledgements

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# Chapter 5

Do they agree? How parents and professionals value the support provided to persons with profound intellectual and multiple disabilities

Jansen, S.L.G., Putten, A.A.J., van der, Post, W.J. & Vlaskamp, C. Do they agree? How parents and professionals value the support provided to persons with profound intellectual and multiple disabilities. *Manuscript under revision.*

## Abstract

- Background* The aim of this study is to explore agreements in the way parents of a child with profound intellectual and multiple disabilities and professionals value the support in terms of its family-centredness.
- Method* An adapted version of the Dutch Measure of Processes of Care was completed by 109 parents and an adapted version of the Dutch Measure of Processes of Care for service providers was completed by 144 professionals. Agreement between parents and professionals were analysed using multilevel analysis.
- Results* Sensory problems of the child, the role of parents, the type of professional and years of experience of the professional were related to the agreements between parents and professionals.
- Conclusion* In order to deliver family-centred support, service providers should take note of the wishes of parents and should be aware that there are differences in these wishes depending on the role of the parents and the type of professional.

Do they agree?

## 5.1 Introduction

Over the past few decades ample research has addressed the role of parents in the support of children with special health needs, developmental problems or intellectual or other disabilities (e.g. De Geeter, Poppes, & Vlaskamp, 2002; Hubert, 2010; Pretis, 2011). More specifically, collaboration or partnership between parents and professionals has received a great deal of attention (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Dale, 1996; Dunst, Trivette, Davis, & Cornwell, 1988). There seems to be no dispute about the benefits of collaboration with parents to ensure the quality of the support provided and hence the quality of life of the child with special needs, developmental problems or intellectual or other disabilities (Bishop, Woll, & Arango, 1993; Epse-Sherwindt, 2008; MacKean, Thurston, & Scott, 2005; Petry, Maes, & Vlaskamp, 2007). Collaboration with the family of a child with special needs is one of the key elements of Family-Centred Care, and includes, for example, an emphasis on the strengths of the family and supportive and respectful treatment (Dunst, 1995; Epse-Sherwindt, 2008; King, Rosenbaum, King, 1996; MacKean et al., 2005; Shelton & Stepanak, 1994). In this approach, families work in partnership with professionals to determine the content of their child's support.

Concerning the support of children with profound intellectual and multiple disabilities (PIMD), collaboration with parents is even more important due to the complex needs of the children. Persons with PIMD are characterised by profound intellectual and profound or severe motor disabilities (Nakken & Vlaskamp, 2007). They have little or no apparent understanding of verbal language and symbolic interaction with objects. Individuals with PIMD also possess little or no ability to support themselves. Many of them are confined to a wheelchair, frequently with little or no use of their hands or arms, along with difficulties in maintaining posture balance. Another characteristic of persons with PIMD is their extensive 'additional' impairments, such as sensory disabilities, seizure disorders, chronic pulmonary infections and skeletal deformations (Dunn, 1991; Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Hogg, 1992; Janicki & Dalton, 1998; Oberlander, O'Donnel & Montgomery, 1999; Zijlstra & Vlaskamp, 2005). As with all parents, parents of children with PIMD know their child the best in terms of their disabilities, needs and wishes, but above all, they are the only constant factor in the life of their child. They possess a wealth of information about their child which is of utmost importance for professionals, and which differs from the knowledge of the latter. Parents know, for example, how their child communicates, when he or she is at ease and with whom. In other words, parents are specialists regarding their own child (Vlaskamp, Maes, & Penne, 2011). Professionals, on the other hand, have specific knowledge about persons with PIMD due to their clinical experience in supporting them. Ideally, the expertise of both parents and professionals should thus converge to come to a better understanding of who the person with PIMD is and what he or she needs. This will in turn lead to opportunities for joint goal-setting and mutual decision-making (Vlaskamp,

1999). Collaboration in this manner can be seen as a way to improve the quality of life of children and their families, working with a notion of shared ownership and responsibility (Bishop et al., 1993). Collaboration is defined as a process of joint decision-making based on equality, in which there is consensus regarding the content of support (Bishop et al., 1993; Vlaskamp et al., 2011). Collaboration between parents and professionals is therefore indispensable and efforts need to be made to establish this collaboration.

With regard to collaboration with parents in the support of children with PIMD, there is, as far as we know, very little data. Although terms such as 'work together as equal partners', 'honest and open communication', 'full partnership', 'mutual understanding', 'respect', 'trust', 'providing information', 'mutual decision-making' and 'keeping parents up to date' are mentioned in the literature as important aspects concerning working with parents who have a child with PIMD (De Geeter et al., 2002; Petry et al., 2007), it is not yet known precisely how collaboration with parents takes shape or how it can be established. Studies on collaboration with parents in the field of paediatric rehabilitation show that differences in the ideas of parents and professionals about what is important in the support of children with cerebral palsy are a threat to the levels of satisfaction of both parents and professionals with the support provided (Nijhuis et al., 2007).

In a previous study, we therefore examined what parents found important in the professional support of their child with PIMD in terms of its family-centredness (reference removed for blind review). Although the parents were generally satisfied with the support provided, a substantial minority indicated some dissatisfaction. These parents indicated, for example, that they were not actively engaged by professionals in terms of decision-making or providing input, such as pointing out their concerns and presenting their opinions. They also reported that they had not obtained information about their child, were not viewed as individuals and equals, had not been treated with respect and had not experienced behaviours by professionals that encompassed the holistic needs of their child and their family. While these results demonstrate the weaknesses in the support provided, they do not provide us with any insight into the opinions of professionals about their own family-centred behaviours, and thus no insight into the points of agreement and disagreement between parents and professionals on this topic. Professionals can, for example, show family-centred behaviour, but when parents do not find this specific behaviour to be important, there is no agreement on what is needed. The next step, therefore, is to examine how professionals judge their own support of persons with PIMD, so that agreements and disagreements between parents and professionals in terms of how they value the support provided become apparent (reference removed for blind review). Indeed, by comparing these two views of the same process, areas in need of development will be localised, and ultimately this

will lead to a better understanding of how good collaboration with parents can be established.

The present paper will analyse agreements (measured in terms of differences in rating scores) between parents (and/or legal representatives) and professionals in relation to how they value the occurrence and importance of the support provided to the person with PIMD. Below, the term 'parent(s)' and 'child(ren)' will be used to make the text more readable. Furthermore, the assumption that child characteristics (type and number of additional disabilities, duration of service use), parent characteristics (role and educational level) and professional characteristics (type of professional, years of experience working with the target group) are related to the ratings of both parents and professionals will also be examined.

The overall aim of our research project is to optimise collaboration between parents and professionals in the support of persons with PIMD. The goal of this particular study is to explore agreements between parents and professionals in relation to how they value the support provided with respect to its family-centredness and to determine which factors are related to these agreements. 'Problem areas', that is, when parents do not receive the support they rate as important or receive support they rate as not important, are also described.

## 5.2 Method

### 5.2.1 Participants

The participants were parents or other legal representatives of a child with PIMD and the professionals working with these children. Inclusion criteria were:

- The child has a developmental age of up to 24 months and motor disabilities that prevent independent mobility (Nakken & Vlaskamp, 2007)
- The child receives support from professional service providers, such as a residential facility or special educational services<sup>1</sup>
- The professional has worked with the child for at least the past 12 months
- The professional has been actively involved with the child for a period of time in the past 12 months; that is, the professional has treated the child and/or has given advice concerning the child

<sup>1</sup> In the Netherlands, parents of a child with PIMD have access to an extensive system of professional services, such as different types of schools for special education, with or without therapy services, daycare centres or various small or large-scale housing projects.

### 5.2.2 Measurements

#### Parents

The opinion of parents about the support of their child was measured using an adapted version of the Dutch version of the Canadian Measure of Processes of Care (MPOC) (Van Schie, Siebes, Ketelaar, & Vermeer, 2004). Our adapted questionnaire (Dutch MPOC-PIMD) consists of four scales covering 39 items: (1) Enabling & Partnership (14 items); (2) Providing Specific Information about the Child (3 items); (3) Coordinated & Comprehensive Care for Child and Family (16 items); and (4) Respectful & Supportive Care (6 items). The internal consistency of the four subscales was analysed by calculating Cronbach's  $\alpha$ . They were 0.84 (Respectful & Supportive Care), 0.93 (Coordinated and Comprehensive Care for Child and Family), 0.90 (Enabling & Partnership) and 0.63 (Providing Specific Information about the Child) respectively. Pearson's product-moment correlation coefficient ( $r$ ) indicated that all scales correlated significantly with each other ( $p < 0.01$ ). With  $r$  ranging from 0.55 to 0.92, the Pearson correlations were good. Overall, the psychometric quality of the Dutch MPOC-PIMD seems adequate (reference removed for blind review).

Each item can be scored on a 7-point scale ranging from 'not at all' (1) to 'to a very great extent' (7), with an additional 'not applicable' category. The values of the response options (2) through (6) are, respectively, 'to a very small extent', 'to a small extent', 'to a moderate extent', 'to a fairly great extent' and 'to a great extent' (King, King, & Rosenbaum, 2004). Each of the items asked the parents to what extent a certain 'behaviour' was exhibited by the care providers at the centre working with their child. Each item was presented as a question (e.g. 'To what extent did the people who worked with your child in the last year...?') about a specific action or behaviour of the care provider (e.g. '...accept you and your family without judging?').

The instrument has become a widely used measure, translated into five languages and distributed across 23 countries (King et al., 2004). Both the original Canadian MPOC and the Dutch MPOC have sound psychometric properties, with Cronbach's  $\alpha$  ranging from 0.80 to 0.96 and ICCs (intraclass correlation coefficient) ranging from 0.78 to 0.94 (King, King, & Rosenbaum, 1996; Van Schie et al., 2004). The Dutch MPOC was also supplemented with importance ratings. In addition to the original item scales, participants are also asked to rate the importance of a behaviour (item) used in family-centred care provision on a 5-point scale ranging from (0) 'not at all important' to (4) 'very important'. The values of the response options (1) through (3) are 'not very important', 'neutral' and 'important', respectively (Siebes et al., 2007).

#### Professionals

The opinions of professionals about the support given to a child with PIMD was measured with an adapted version of the Dutch version of the Canadian

Measure of Processes of Care for Service Providers (MPOC-SP) (Siebes et al., 2006). Our adapted questionnaire (Dutch MPOC-SP-PIMD) consists of two scales covering 16 items: (1) Showing Interpersonal Sensitivity (9 items); and (2) Treating People Respectfully (7 items). The Dutch MPOC-SP-PIMD has been validated and results show medium to strong scalability and good internal consistency (reference removed for blind review). Loevinger's scalability coefficient,  $H$ , was used for the scalability of the entire scale and of each item, separately.  $\rho$  was calculated as measure for the internal consistency of the scales. They were  $H = .39$  and  $\rho = .76$  (Showing Interpersonal Sensitivity) and  $H = .49$ , and  $\rho = .78$  (Treating People Respectfully).

The scoring of the items is the same as with the MPOC for parents mentioned above, including the additional importance ratings (Siebes et al., 2007). Each of the items asked the service provider to rate 'the extent to which' they had engaged in the various behaviours included in the MPOC 'in the past year'.

Woodside et al. (2001) pointed out that the MPOC can be used in conjunction with the MPOC-SP to compare parental and professional perceptions of service delivery, which has been done in various international studies (Dyke, Buttigieg, Blackmore, & Ghose, 2006; Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007; Whitton, Williams, Wright, Jardine, & Hunt, 2008; Dickens, Matthews, & Thompson, 2010; Jeglinsky, Autti-Rämö, & Brogren Carlberg, 2011). Nijhuis et al. (2007) created an analogy between the Dutch MPOC and Dutch MPOC-SP domains to compare scores of parents and professionals and used the questionnaires in a family-specific way. For the Dutch MPOC-PIMD and Dutch MPOC-SP-PIMD, scores on the Enabling & Partnership and Respectful & Supportive Care scales for parents will be compared with scores on the respective scales used for professionals: Showing Interpersonal Sensitivity and Treating People Respectfully. Note that the Dutch MPOC-PIMD scales of Providing Specific Information about the Child and Coordinated & Comprehensive Care for Child and Family are not measured in the Dutch MPOC-SP-PIMD and therefore are not used here.

### 5.2.3 Procedure

In the Netherlands, especially in the case of a non-invasive study like this, ethical approval is obtained via the facility where the study takes place. An independent ethics committee is consulted when a study has high personal impact for the participants. Before the study started, a research proposal was presented for approval to parents and professionals. Informed consent was obtained from both groups of participants. Using an organization in the Netherlands that gives support to people with intellectual disabilities, 392 parents were invited by mail to fill in the Dutch MPOC-PIMD. The organization mentioned is one of the largest organizations in the Netherlands that gives all kinds of support to persons with intellectual

disabilities. It not only delivers services throughout the whole of the Netherlands, but also delivers a broad spectrum of support services such as day-care services, small or large-scale housing services, community housing services and ambulatory services. The questionnaire was accompanied by a letter explaining the purpose of the study and the conditions for participation. Parents were also given the opportunity to fill in the questionnaire digitally. All of the participants were also assured of anonymity and confidentiality. If a child did not belong to the target group or the parents did not wish to participate, the parents were asked to declare this on the return form and send it back within two weeks in a prepaid envelope. After two weeks, a reminder letter was sent.

Professionals, such as direct support persons, psychologists, physicians and therapists (speech therapists, occupational therapists, physical therapists, dieticians) involved with a child whose parents had filled in the Dutch MPOC-PIMD (N = 746) were then invited by mail to complete the Dutch MPOC-SP-PIMD. The questionnaire was accompanied by a letter explaining the purpose of the study and the conditions for participation. All of the participants were also assured of anonymity and confidentiality. After two months, a reminder letter was sent to those who had not yet responded.

#### 5.2.4 Analysis

Descriptive statistics were calculated for the Dutch MPOC-PIMD and Dutch MPOC-SP-PIMD domains separately. An MPOC scale score was calculated as the mean of the ratings for the items in the scale. As the items were not weighted, a scale score could range from 1 to 7. In addition to the occurrence scores, importance scores were also calculated. An importance score could range from 0 to 4 (Siebes et al., 2007). Following Nijhuis et al. (2007), both occurrence and importance scores were dichotomised to examine whether parents had received the support they considered important. Mean scores  $\geq 5$  on occurrence reflect that parents had received support in this domain and mean scores  $< 5$  reflect that they had not. For the mean importance scores, scores  $\geq 3$  were defined as important and mean scores  $< 3$  as not important. When parents had not received the support that they had rated as important and when they had received support that they did not find important, this was defined as a 'problem'.

Bland-Altman plots were performed for exploratory reasons, where the mean scores of professionals for one child were compared with the scores of the parents of that particular child. Following this, agreement between parents and professionals – in terms of differences in ratings of the occurrence and importance of the family-centredness of the support provided – was investigated using multilevel analysis, with the child as the highest level and professionals as the lowest level, to take into account the dependencies between scores of differ-

ent professionals for one child. Child characteristics such as age, type (challenging behaviour, sensory problems) and number of additional disabilities, duration of service use and whether or not the child lived in a residential setting, parent characteristics such as role (father, mother or other legal representative) and educational level, and professional characteristics such as specific profession (directly versus not directly involved)<sup>2</sup> and years of experience working with the target group, were included in the model as explanatory variables. Fixed as well as random effects were considered. A p-value smaller than 5% was considered to be statistically significant.

## 5.3 Results

### 5.3.1 Characteristics of the parents and their children

A total of 257 parents (65.6%) returned the questionnaire. Of these, nine respondents (3.5%) pointed out that their child did not belong to the target group and 57 respondents with a child that belonged to the target group (22.2%) did not wish to participate in the study. Another seven respondents (2.7%) did not wish to participate, but it was not clear whether their child belonged to the target group or not. Nine respondents (2.3%) pointed out that they knew too little about the support provided to participate. The validity criterion for the questionnaire was completion of at least half of the items (King, Rosenbaum, & King, 1995). Consequently, of the 175 remaining questionnaires, 151 questionnaires could be used in this study. However, the professionals (see Section 3.2.) only provided valid questionnaires for 109 children, therefore the results are only based on those 109 parents and children.

The parents' mean age was 59.3 years (SD 10.9), ranging from 34 to 84 years. Of the children, 48.6% were female and 45.0% were male. The children's mean age was 38.7 years (SD 16.3), ranging from 5 to 75 years. The mean number of years of use of services was 28.4 (SD 16.7). Three children lived with their parents and eight children were under 19 years old. 105 Parents were born in the Netherlands and four parents were not. Other characteristics of parents and children are shown in Table 1.

<sup>2</sup> Directly involved professionals are professionals that are involved in the support of persons with PIMD on a daily basis. In the Dutch context, these are professionals with either a medical or educational background. Indirectly involved professionals are professionals that are involved in the support of persons with PIMD, but not on a daily basis, such as psychologists, physicians and therapists (speech therapists, occupational therapists, physical therapists, dieticians).

**Table 1**  
**Characteristics of parents, children and professionals**

N = 109 (parents and children)	%		%
<b>Educational level of parents</b>		<b>Additional disabilities</b>	
MAVO, HAVO, MBO <sup>a</sup>	63.3	Challenging behaviour	19.3
VWO, HBO, WO	25.7	Sensory problems	42.2
		Number of additional health problems:	
<b>Role of parent</b>		1	11.9
Father	22.0	2	19.3
Mother	33.9	3	19.3
Other	36.7	4	14.7
		5	18.3
<b>Type of professional (N = 122, 22 missing values)</b>			
Directly involved	31.8		
Not directly involved	68.2		

<sup>a</sup> MAVO = junior general secondary education; HAVO = senior general secondary education; MBO = senior secondary vocational education; VWO = pre university education; HBO = higher professional education or university of applied sciences; WO = university education.

### 5.3.2 Characteristics of the professionals

A total of 494 questionnaires (66.2%) were returned. Of these, 15 questionnaires were not filled in (3.0%), 105 questionnaires were completed by professionals who had not been actively involved with the child in the past year (21.3%), and 11 questionnaires could not be used for various reasons, such as filling out the questionnaire with direct support staff in mind instead of the parents of the child (2.2%).

The validity criterion for the questionnaire was completion of at least half of the items (King et al., 1995). Consequently, of the 363 remaining questionnaires, 299 questionnaires could be used in this study. These 299 questionnaires were completed for 109 children by 144 professionals. Most professionals completed a questionnaire for only one child (62%) and 27% of the professionals completed a questionnaire for two to four children. The number of professionals that filled out a questionnaire per child ranged from one to six professionals, whereas two professionals (30%) per child occurred the most, followed by three professionals (24%), four professionals (20%) and one professional (17%). The mean age of the professionals was 39.7 years (SD 11.8) and the mean years of experience working with persons with PIMD was 18.1 years (SD 11). Other characteristics of the professionals are shown in Table 1.

### 5.3.3 Comparisons between parents and professionals

For each child, mean scores on the Enabling and Partnership and Respectful and Supportive Care scales for the parents (N = 109) and mean scores on the Showing Interpersonal Sensitivity and Treating People with Respect scales for the professionals (N = 144) were calculated. These mean scores for the parents and the professionals are listed under the titles 'Enabling and Partnership' and 'Respectful and Supportive Care' (see Section 2.2.2.) in Table 2. The group means indicate that the parents rated the occurrence of behaviours higher than the professionals. The group means of the importance scores show that parents and professionals rated the importance of the first scale (Enabling and Partnership) almost identically, but parents rated the level of the second scale (Respectful and Supportive Care) lower than the professionals. The results of the Bland Altman plots showed that there was no lack of agreement in the scores between parents and professionals, but a linear relationship was found on the importance scale for both the Enabling and Partnership and Respectful and Supportive Care scales: the higher the mean scores of both parents and professionals, the greater the differences between the scores of the parents and professionals.

**Table 2**  
**Means and standard deviations of the Dutch MPOC-PIMD and the Dutch MPOC-SP-PIMD occurrence and importance scores for the parents and the professionals**

Respondents	Enabling and Partnership		Respectful and Supportive Care	
	Occurrence scores <sup>a*</sup>	Importance scores <sup>b</sup>	Occurrence scores <sup>*</sup>	Importance scores <sup>*</sup>
<b>Parents</b>	4.83 (SD 1.10)	3.15 (SD .54)	4.46 (SD 1.34)	2.95 (SD .69)
<b>Professionals</b>	2.69 (SD 1.00)	3.08 (SD .41)	3.42 (SD 1.29)	3.27 (SD .37)

<sup>a</sup> mean occurrence score on a scale from 1 to 7;

<sup>b</sup> mean importance score on a scale from 0 to 4;

sd standard deviation.

\* significant difference between parents and professionals based on multilevel models without predictors

A 'problem area' was identified when parents did not receive the support they rated as important, or received support that they rated as not important. In all domains, a considerable number of parents (29.8%-36.4%) indicated not having received the support they found important. These 'problem areas' are presented in Table 3. The highest percentages were found on items concerning the provision of written information about the child (progress, treatment, changes in support), anticipating and following up concerns, providing help in working with the system of support, being aware of changing needs and being a resource for parents. In all domains, a few parents (3.3%-6.0%) indicated having received support they rated as not important.

**Table 3**  
Percentages of parents reporting ‘problems’ with the family-centredness of the support provided

Item	N	%
<b>Enabling and Partnership (EP)</b>	45	29.8
Fully explained the individualized educational programme/individualized support programme choices to you?	28	18.5
Gave information about options for support or services for your child (e.g., assistive devices, day activities, school or support)?	35	23.2
Trusted you as the ‘expert’ on your child?	22	14.6
Anticipated your concerns by offering information even before you asked?	44	29.1
Made sure you had a chance during visits to the care facility to say what was important to you?	17	11.3
Let you choose when to receive information and the type of information you want?	24	15.9
Explained the reason for support or assistive devices?	31	20.5
Provided opportunities for you to make decisions about certain methods or treatment?	37	24.5
Recognized that your family has the final say regarding the individualized educational programme/individualized support programme for your child?	23	15.2
Consulted with you when discussing assistive devices or the implementation of specific interventions or support?	34	22.5
Gave you detailed information about your child’s services, such as reasons for the support, the type of support and length of time?	33	21.9
Made sure you had opportunities to explain what you thought were important treatment goals?	29	19.2
Made you feel like a partner in your child’s support?	20	13.2
Listened to what you had to say about your child’s needs regarding assistive devices or specific support for persons with profound intellectual and multiple disabilities?	27	17.9
<b>Providing Specific Information about the Child (PSI)</b>	55	36.4
Told you about the results of therapeutic (e.g. physical/occupation therapist, speech therapist, dietician) or psychological assessments?	22	14.6
Provided you with written information about what your child does while receiving a certain kind of support provided?	47	31.1
Provided you with written information about your child’s progress?	43	28.5
<b>Coordinated and Comprehensive Care for Child and Family (CCC)</b>	53	35.1
Suggested proposals that fit with your family’s needs and lifestyle?	31	20.5

(Table continues)

**Table 3** (continued)

Item	N	%
<b>Enabling and Partnership (EP)</b>	45	29.8
Took the time to establish rapport with you when changes occurred regarding the support of your child?	28	18.5
Discussed with you everyone’s expectations for your child, so that all agreed on what is best?	32	21.2
Made sure that your child’s needs and wishes were known to all persons working with your child, so these needs and wishes were known across service providers?	36	23.8
Provided ideas to help you work with the system of support provided?	56	37.1
Recognized the demands of caring for a child with special needs?	29	19.2
Looked at the needs and wishes of your ‘whole’ child (e.g., at mental, emotional and social needs) instead of just at the physical needs?	20	13.2
Showed sensitivity to your family’s feelings about having a child with special needs (e.g., your worries about your child’s health or function)?	25	16.6
Followed up at the next appointment on any concerns you discussed at the previous one?	42	27.8
Made sure that the direct support professional working with your child was involved with your child for at least six months in a row?	27	17.9
Developed both short-term and long-term goals for your child?	30	19.9
Planned together to ensure everyone was working in the same direction?	35	23.2
Made sure you were informed ahead of time about any changes in your child’s care (e.g., support, care professionals, programmes or assistive devices)?	38	25.2
Seemed aware of your child’s changing needs as he/she grows?	38	25.2
Made themselves available to you as a resource (e.g., emotional support, advocacy, information)?	38	25.2
Gave you information about your child that is consistent from person to person?	26	17.2
<b>Respectful and Supportive Care (RS)</b>	45	29.8
Accepted you and your family in a nonjudgmental way?	7	4.6
Gave you the idea that they were well informed about the personal circumstances of your child and your family?	21	13.9
Provided a caring atmosphere rather than just giving you information?	28	18.5
Helped you to feel competent as a parent?	26	17.2
Provided enough time to talk to you so you did not feel rushed?	28	18.5
Treated you and your family as people rather than as a ‘case’ (e.g., by not referring to you or your child by diagnosis)?	12	7.9

### 5.3.4 Relationship with sample characteristics

The results of the multilevel analysis showed that the type of professional was a significant explanatory variable in all models, except for the Respectful and Supportive Care importance model. The role of the parent was significant in the Respectful and Supportive Care importance model. Additionally, the presence of sensory problems turned out to be significant in the Enabling and Partnership occurrence model, and years of experience of the professional was significant in the Respectful and Supportive Care importance model. To determine which groups of parents, children and professionals agree with each other and which groups do not, we calculated the estimated agreement for the different groups (see Table 4). The estimated agreement in the Respectful and Supportive Care importance model is given for the professional with mean years of experience. Six additional groups are distinguished in the Enabling and Partnership occurrence model due to the significance of the presence of sensory problems in this model.

**Table 4**  
Estimated agreement between professionals and parents for different groups of parents and professionals with respect to importance and occurrence in the Enabling and Partnership and Respectful and Supportive Care models

Factors	Model diff occurrence EP <sup>a</sup>	Model diff importance EP	Model diff occurrence RS <sup>a</sup>	Model diff importance RS <sup>b</sup>
Indirect/other	-3.087 (0.295)* <sup>c</sup>	-0.011 (0.109)	-1.433 (0.269)*	0.430 (0.121)*
Indirect/father	-2.55 (0.320)* <sup>c</sup>	-0.158 (0.139)	-1.357 (0.344)*	0.427 (0.152)*
Indirect/mother	-2.648 (0.307)* <sup>c</sup>	-0.273 (0.113)*	-1.26 (0.277)*	0.054 (0.124)
Direct/other	-1.621 (0.317)* <sup>c</sup>	0.283 (0.117)*	-0.058 (0.299)	0.532 (0.127)*
Direct/father	-1.084 (0.334)* <sup>c</sup>	0.136 (0.143)	0.018 (0.364)	0.529 (0.155)*
Direct/mother	-1.182 (0.325)* <sup>c</sup>	0.02 (0.120)	0.115 (0.306)	0.156 (0.130)
Indirect/other	-2.467 (0.244)* <sup>d</sup>	-	-	-
Indirect/father	-1.93 (0.310)* <sup>d</sup>	-	-	-
Indirect/mother	-2.028 (0.258)* <sup>d</sup>	-	-	-
Direct/other	-1.001 (0.269)* <sup>d</sup>	-	-	-
Direct/father	-0.464 (0.325) <sup>d</sup>	-	-	-
Direct/mother	-0.562 (0.279)* <sup>d</sup>	-	-	-

<sup>a</sup> EP Enabling and Partnership; RS = Respectful and Supportive Care

<sup>b</sup> For mean professional experience in years

<sup>c</sup> No sensory problems

<sup>d</sup> With sensory problems

\* significant

The results presented in Table 4 show that in the Enabling and Partnership importance model, mothers and indirectly involved professionals significantly disagree (mothers gave higher ratings), and other legal representatives disagree significantly with directly involved professionals (other legal representatives gave lower ratings). In the Enabling and Partnership occurrence model, all groupings of parents, professionals, and children with and without sensory problems, disagree significantly (all gave higher ratings than the professionals), with the exception of one group: fathers and directly involved professionals agree when the child has sensory problems. In the Respectful and Supportive Care importance model, fathers and other legal representatives disagree significantly with both indirectly involved and directly involved professionals: they gave lower ratings than the professionals. Finally, in the Respectful and Supportive Care occurrence model, fathers, mothers and other legal representatives all disagree significantly with indirectly involved professionals: they gave higher ratings than the indirectly involved professionals. No significant disagreement was found between any type of parent and directly involved professionals. Age of the child, amount of additional disabilities, the presence of challenging behaviour and whether the child lived in residential setting or with family carers were not significant explanatory for the found differences in agreement between parents and professionals.

### 5.4 Discussion

In this study, we analysed agreements between parents and professionals in relation to how they valued the support provided to a child with PIMD. The relationship between these agreements and child characteristics, the characteristics of the parents and the characteristics of the professionals were also examined. Multilevel analyses showed that sensory problems, the role of the parent (father, mother or other legal representative), the type of professional (directly versus indirectly involved) and years of experience of the professional explained the agreements in scale scores between parents and professionals for the different models. Furthermore, in all domains a considerable number of parents (29.8%-36.4%) indicated not having received the support they found important. Only a few parents (3.3%-6.0%), however, indicated that they had received support they did not find important.

As far as we know, there are no other studies on the level of agreement between parents and professionals concerning the family-centredness of the support given to persons with PIMD using the Dutch MPOC-PIMD in combination with the Dutch MPOC-SP-PIMD, therefore, some remarks are appropriate.

Firstly, the fact that this was the first time the instruments were used in this way is a limitation of the study, as no reference data are available. Secondly, our multi-level analysis did not take into account that a third (37%) of the professionals gave scores for more than one child, implying additional dependencies between children.

However, as nearly two third of the professionals scored only one child, and as both child and professional characteristics were included in the model, we expect that these additional dependencies will have little effect on the results. A model taking these dependencies into account would require a lot more data. Thirdly, parents had to judge the behaviours of professionals in general and this raises difficulties when there are a number of professionals involved, as is the case in the support of persons with PIMD (Mencap, 2001). Nijhuis et al. (2007) suggest that if the Dutch MPOC and MPOC-SP are to be used in a family-specific way, ideally, parents should rate each professional involved separately. The reason we decided not to ask parents to fill out a questionnaire for each professional involved related to the supposed burden upon the parents, given the number of professionals involved with their child. This may have influenced the ratings of the parents due to mediating scores over the different professionals involved. When interpreting the results, these considerations should be kept in mind.

In order to determine whether the 109 children were a representative sample of the 151 children, t-tests were performed and results showed that the 42 parents whose questionnaires were not included in this study had significantly lower ratings on the two scales concerning occurrence. Also, the number of years living in a facility differed significantly, with the children of the 42 parents who were not included, spending more years living in a facility than the 109 children included in the study. A possible explanation for these findings may be that the professionals were not actively involved with these 42 children, perhaps due to the number of years the child had lived in a facility, and therefore did not fill out the questionnaire. Since the 42 parents not included only differed on these two aspects, we assume that the 109 children included in this study are representative of the 151 children. In this study, the parents were (with the exception of four persons) born in the Netherlands. Their children were adults and in residential provision. Analyses without children under 19 years old or children living at home did not reveal other results. Further research should focus on parents who were not born in the Netherlands and on parents with children under 19 years old, living with them at home, as we presume that collaboration with professionals might differ in these situations.

Noteworthy is that the agreement between parents and professionals on the two respective scales for Enabling and Partnership and Respectful and Supportive Care regarding occurrence and importance is not consistently explained by the same characteristics of the children, parents or professionals. Apparently, based on the results above, perceptions of the occurrence and importance of family-centred behaviour differ across themes such as 'Enabling and Partnership' and 'Respectful and Supportive Care', although a clear trend is lacking.

The organization of the support within the facility that took part in this study might have influenced the scores of both parents and professionals. In order to be

family-centred, there has to be contact between the parent and the professional, either face to face, verbally (by telephone) or in writing (by email or mail). In practice, according to the comments of the professionals on the questionnaire, most of the communication between professionals and parents and between professionals themselves takes place via a senior direct support person.

The dissatisfaction of a substantial number of the parents with the support provided, as shown in this study, is similar to the findings of Nijhuis et al. (2007). In the international literature on the MPOC, various studies have found similar results, but only on the occurrence of family-centred behaviour by professionals (Dyke et al., 2006; Jeglinsky et al., 2011). While these studies did not look at importance ratings by parents, at least one-third of the parents identified family-centred situations or behaviours as occurring only sometimes, or even less frequently. By focusing on the care that parents identified as not having received but which they valued as very important, areas of improvement become clear. In this study, providing written information about the child's progress and activity during the support provided, providing ideas to help working with the system of support, anticipating concerns by offering information, following up on any concerns, informing parents ahead of time about any changes in the child's support, being aware of changing needs as the child grows, and being available as a resource are all issues that deserve attention. Although parents indicated dissatisfaction with other issues, these are the issues that 25% or more parents identified as 'problematic'. While Nijhuis et al. (2007) labelled the combination of not-important/received as 'non-problematical', we included this combination as a 'problem' since it obviously exposes differences in the opinions of parents and professionals about what needs to be done. In this study, only a few parents (3.3%-6.0%) indicated having received support they did not find important. Although these percentages are not striking, they show that further fine-tuning of the specific content of the support may be considered.

The differences in scores between parents and professionals and within professionals are also mentioned in a study by Nijhuis et al. (2007), in which parents had higher scores on occurrence and importance on the Enabling and Partnership and Respectful and Supportive Care models compared to different kinds of professionals, and professionals rated the importance of Enabling and Partnership and Respectful and Supportive Care themes differently from each other. Although this study took place in a different context, with a different target group, collaboration with parents apparently has a different content or is shaped differently depending on which parent we are dealing with, who the professional is, how many years of experience the professional has and the presence of additional problems.

The results of this study advocate the importance of an inventory of the needs and wishes of each family with respect to collaboration, and the attitude of professionals with respect to collaboration with parents. The Dutch MPOC-PIMD

and MPOC-SP-PIMD are suitable instruments to explore this. In practice, when parents and the facility that provides support to a child with PIMD sit down to determine the content of the support, the points of view of all involved should be taken into account to ensure the desired and required support is adequately stipulated. In this way, the support provided can be evaluated and adapted to the changing needs of both the child with PIMD and their family.

In a next study, we have followed a couple of parents for a longer period of time to acquire more qualitative data on collaboration. We used both interviews and log-books for this data collection.

### 5.5 Acknowledgements

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# Chapter 6

Parents' experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: a multiple case study

Jansen, S.L.G., Putten, A.A.J., van der & Vlaskamp, C. Parents' experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: a multiple case study. *Manuscript submitted for publication.*

## Abstract

- Background* There is little data on the collaboration between parents and professionals in the support of persons with profound intellectual and multiple disabilities (PIMD), particularly when the person lives in a group home. Since communication is essential to collaboration, further exploration of this topic is needed.
- Aim* To acquire knowledge on the frequency, means and personal experiences of communication between parents and professionals.
- Method* A multiple case-study (n=4) was conducted, in which mothers logged observations every time they had contact with the professionals supporting their children during an uninterrupted twelve-month period. The frequency and the means of contact were logged, along with the professional with whom the parents had contact. The contacts were analysed according to function and subject using a categorization system and the parents' experiences were labelled and described in a narrative.
- Results* The mean number of contacts a month ranged from 1.9 to 16.7 across the four cases. Most of the contacts were with the child's direct support persons (DSPs) or senior DSPs (85.2%) and exchanging information (35.5%) was the most common function of communication. Issues concerning health/physical functioning (28.4%) were the most common subjects discussed. The majority of the mothers' experiences were positive and were related to being listened to, having concerns acknowledged, and with professionals thinking problems through with the parents. Negative experiences related to not being listened to, not receiving replies to emails, appointments not being kept, and not being kept informed.
- Conclusion* There are great differences in the number of contacts with parents. The DSPs play a crucial role in all cases. DSPs need to be aware of this role and need training and support from management to fulfil their role, in order effectively to acknowledge parents as partners in the support of children with PIMD.

## 6.1 Introduction

The benefits of collaboration between parents and professionals in the support of children with special health needs, developmental disorders and intellectual disabilities are well documented. If parents experience effective collaboration with the professionals who support their children, they are more satisfied with the support provided and feel that their children's quality of life is better than when effective collaboration is absent (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Denboba, McPherson, Kenney, Strickland & Newacheck, 2006; Dunst, Trivette & Hamby, 2007; King, Rosenbaum & King, 1996; Law, King, Kertoy & Rosenbaum, 2004; MacKean, Thurston & Scott, 2005; Trivette, Dunst, Boyd & Hamby, 1995). Collaboration between parents and professionals is essential in the support of persons with profound intellectual and multiple disabilities (PIMD) because these children literally cannot speak for themselves: their parents are their spokespersons. Children with PIMD are characterized by a combination of profound intellectual and profound or severe motor disabilities and are often faced with additional disabilities such as sensory impairments and various health problems (Nakken & Vlaskamp, 2007). The parents of a child with PIMD possess a wealth of information about their child and should be regarded as experts in their own child and his or her needs, desires and opportunities (De Geeter, Poppes & Vlaskamp, 2002; Vlaskamp, Maes & Penne, 2011).

Previous studies have argued that in order to establish effective collaboration between parents and professionals in the support of persons with PIMD, insight into what parents and professionals find important regarding the support provided is necessary (Jansen, Van der Putten & Vlaskamp, 2013; Jansen, Van der Putten, Post & Vlaskamp, manuscript submitted). Jansen et al. (manuscript submitted) found that although most parents of children with PIMD supported by a large organization<sup>1</sup> were satisfied with the support provided in terms of family-centredness, a substantial proportion of the parents indicated that they did not always receive the support they found important (34.4%), or received support that they did not find important (4.8%). Topics such as the provision of written information about the child (progress, treatment and changes in support), anticipating and following up concerns, providing help in working with the support system, being aware of changing needs and being a resource for parents were the most commonly mentioned items reported by parents as important but not received. Furthermore, parents and professionals often disagree about whether they perceive professional behaviour as family-centred. Professionals and parents can also disagree on the importance of certain family-centred behaviour, e.g. trusting parents to be the 'experts' on their child or helping parents feel competent. Jansen et al. (manuscript submitted) found disagreements on all these points between parents and professionals and, moreover, their study revealed that certain variables had significant effects on this disagreement. It appeared that the presence of sensory problems in the child, the role of the parent (father, mother or other legal representative), the type of pro-

<sup>1</sup> In the Netherlands, parents of a child with PIMD have access to an extensive system of professional services, such as various types of schools for special education, with or without therapy services, daycare centres or various small- or large-scale housing projects.

professional (direct or indirect involvement)<sup>2</sup> and the number of years of experience working with the child were related to disagreements. Parents encounter many professionals in supporting their child with PIMD (Mencap, 2001) and therefore, building collaboration with parents is an important challenge.

In a literature review on the collaboration between parents and professionals in the support of persons with intellectual disabilities who receive support from professional service providers such as residential facilities, daycare centres or respite care, Jansen, Van der Putten, and Vlaskamp (2014) found that there is a lack of an unequivocal definition of the concept of collaboration, as well as clear definitions of related factors. Despite that, some recurrent factors related to or underlying collaboration were found. These factors are 1. communication, 2. mutual decision-making or equality, 3. evaluation, 4. trust and 5. respect. We define collaboration in the support of persons with PIMD as a process of joint decision-making based on equality in which there is consensus regarding the content of support (Bishop et al., 1993; Vlaskamp et al., 2011). Communication plays an important role in collaboration, first as a factor in its own right, but secondly also in relation to mutual decision-making and evaluation. Thirdly, communication is a means to experience trust and respect and can therefore be considered to be a connecting factor (Blue-Banning et al., 2004). Communication is thus essential in collaboration between parents and professionals, and even more crucial in collaboration with parents of children with PIMD, as these children cannot speak for themselves.

Communication is the exchange of information between at least two persons and has various aspects. These include how the communication is achieved, and the relationship between the persons communicating and the actual information exchanged. Therefore, how information is exchanged can impact on parents' experience of respect and feeling equal partners as much as the information itself, creating trust in the professionals supporting their children. Graungaard and Skov's (2006) study of parents' reactions to learning that their child is severely disabled notes the parents' desires and needs as regards communication. These are equality in collaboration between parents and physicians, an individual and specifically designed information strategy, an empathic and personal approach, treating the child as a child and not as a case, and consideration of the child's opportunities despite its disabilities. Galil et al., (2006) evaluated the communication between physician and parent in child development centres, where they distinguished three different dimensions of communication: care, interest and collaboration. Communication was therefore respectively focused on aspects which showed care for parents, which showed interest in parents or which showed the intention to collaborate with parents in terms of joint decision-making. In a study by Pruitt, Wandry and Hollums (1998) on parents' experiences about their interactions with special educators, almost a quarter of the parents responded that the quantity and the quality of the

<sup>2</sup> Directly involved professionals are professionals who are involved in the support of persons with PIMD on a daily basis. In the Dutch context, these are professionals with either a medical or educational background. Indirectly involved professionals are professionals who are involved in the support of persons with PIMD, but not on a daily basis, such as psychologists, physicians and therapists (speech therapists, occupational therapists, physical therapists or dieticians).

communication should be improved and indicated that communication with professionals should occur on a more frequent and consistent basis. The abovementioned studies show that communication is not only about the specific information being exchanged between parents and professionals. The frequency, specific content and quality of the communication (being personal and showing equality and respect) seem to be of crucial importance if parents are to experience a sense of collaboration with professionals, which in turn leads to satisfaction with the support provided.

There is little data on the collaboration between parents and professionals in the support of persons with PIMD, particularly when the person with PIMD lives in a group home. Jansen et al. (2013, manuscript submitted) gathered quantitative data about the satisfaction of parents with the support of children with PIMD and the opinions of parents and professionals about the occurrence and importance of family-centred behaviour. Given the complexity of the concept of collaboration and related factors (e.g. communication) due to the lack of unequivocal definitions and the interdependency of factors indicative of collaboration, qualitative data on collaboration is also needed.

The overall aim of our research is to optimize collaboration between parents and professionals in the support of persons with PIMD. Since communication seems to be an essential factor in collaboration, knowledge about how parents and professionals communicate and how parents perceive the communication with professionals in the support of their child with PIMD is necessary. Knowledge of how often communication occurs, with whom and by which means parents communicate, and of parents' experiences with the communication with professionals is needed to arrive at a better understanding of how effective collaboration can be shaped.

## 6.2 Method

### 6.2.1 Participants and procedure

Parents of children with PIMD were asked to participate in this study. The inclusion criteria were:

- The child has a profound intellectual and multiple disability: a combination of profound intellectual and profound or severe motor disabilities, and is often faced with additional disabilities such as sensory impairments and various health problems (Nakken & Vlaskamp, 2007).
- The child has recently (<24 months) moved from home.

The last criterion was chosen to gain knowledge of the possible changes in collaboration over time. Various facilities in the Netherlands which provide small- or large-scale housing projects to persons with intellectual disabilities were approached by email or telephone for respondents willing to participate in this study. The parents could indicate their willingness to participate on a return form which was provided with a prepaid envelope. Thirteen parents who met the inclusion criteria were informed about the study and invited to participate. Of these thirteen parents, five indicated that they did not want to participate without providing any reasons for their decision. One parent initially expressed her commitment but was eventually unable to participate due to personal circumstances. Of the seven parents who had expressed their commitment and took part in the study, three parents did not consequently complete the logbooks, despite several reminders, indicating that this method was too time-consuming for them.

This left data on four parents, all mothers. Before the study began, the mothers were assured of anonymity and confidentiality. Ethical approval was obtained in the Netherlands through the facility where the study was conducted. The mothers lived in different parts (North, East and West) of the Netherlands and their children lived in small or large group homes run by the three different organizations which provide support to persons with intellectual disabilities. The mothers were all married and had other children in addition to their child with PIMD. At the start of the study the children had lived for 14, 23, 23 and 20 months in the residential facility. All the children used daycare services. The distance from the parental homes to the homes where the children lived were comparable, namely between 22 and 35 kilometres. The parents agreed to the publication of the results of the study in a manuscript. The names of the parents and children presented here are fictional.

#### Mother 1

Marleen has a daughter, Janine, aged 23 years at the time the study started. At that time, Janine had been in residential care for 14 months. Janine has a profound intellectual disability and cannot walk but instead, she crawls. She has a visual impairment and chronic constipation. Janine has an older brother who moved from home at around the same time as Janine. Janine was in a respite care home from the age of 14.

#### Mother 2

Paula has a 23-year old son with PIMD, Bob, who had lived in a residential facility for 23 months when the study started. Bob has severe intellectual and motor disabilities. He is confined to a wheelchair but loves to play on the ground. He moves by pushing himself around on his bottom. Bob cannot speak but makes all kind of sounds. He has epilepsy. Bob used respite care before going to live in the residential facility where he now lives. Bob has an older brother and sister.

#### Mother 3

Sandra has a son, Thomas. He was 15 years old when the study started and had lived in residential care home for 23 months. Thomas has profound intellectual and motor disabilities, is confined to a wheelchair and has epilepsy. He can move around in his wheelchair by using his arms. Thomas has an older brother and sister (twins).

#### Mother 4

Linda's son Koen was 25 years old when the study started and had lived in a residential facility for 20 months. Koen has profound intellectual and motor disabilities and is confined to a wheelchair. Koen has epilepsy. Before Koen lived in a residential home, he used respite care. He has two older sisters.

See Table 1 for an overview of the characteristics of the mothers and their children.

**Table 1**  
Characteristics of participating mothers and their children

Case	Age mother	Education	Profession	Other children	Age child	Distance to facility (km)
1	51	HBO	Domestic worker/volunteer	Older brother	23	22
2	51	HBO	Volunteer	Older brother and sister	23	35
3	52	MBO	Nurse	Older brother and sister (twins)	15	28
4	54	HBO	Farmer	Two older sisters	25	33

Note. HBO = Higher Professional Education or university of applied sciences; MBO = senior secondary vocational education.

### 6.2.2 Design

A multiple case-study was performed, with repeated measurements over a twelve-month period, meaning that each time the mothers had contact with a professional within the residential facility, data on this contact were entered into a logbook.

### 6.2.3 Data collection

The data was gathered using a logbook. Over an uninterrupted period of twelve months, the mothers made entries into their logbooks each time they had contact with the professionals who supported their children. The mothers were asked to complete their logbooks for twelve months, partly to get more representative information and partly because of the assumption that the collaboration would change over time due to the growth in trust between the parents and the professionals as they got to know each other better and as the professionals got to know the children better. The mothers were told at the start of the study that because of the burden this study would place on them, they were free to decide how often they made entries into the logbooks. The professionals the mothers had contact with could be professionals involved with the child on a daily basis, such as DSPs, or professionals who provide ad hoc support (e.g. speech therapists, physicians, psychologists, occupational therapists etc.). The logbooks were semi-structured: the mothers had to enter with whom they had had contact, what the duration of the contact was (in minutes), how the contact was made (visit to the child, support plan meetings<sup>3</sup>, formal meetings about the child<sup>4</sup>, contact by telephone, letter or email etc.), what the content of the contact was and how they experienced the contact in terms of communication.

The logbooks came with a short manual and an illustration of communication. This manual explained when the mothers should write in their logbooks (every time they had contact with a professional from the facility where their child lives), what they should write about (their experiences with and feelings about the contact they had) and an explanation about how the data could be stored (digitally or on paper). Additional data on the children's and the mothers' characteristics were collected, including gender, age, education, profession, family structure and distance to the children's homes. The researcher maintained email contact with the parents every two months to check whether they had any problems in completing the logbooks or to remind them to complete the logbooks.

### 6.2.4 Analysis

The total number of contacts per case was counted. Frequencies were calculated for the means of contact per type of professional. The contacts were analysed according to function and subject using a categorization system and the parents' experiences were labelled and described in a narrative. To analyse the content of the logbooks, a categorization system was used to classify the function and

<sup>3</sup> A support plan meeting is an interdisciplinary meeting in which the support plan of the child is discussed and determined.

<sup>4</sup> A formal meeting about the child is an interdisciplinary meeting in which issues other than the discussion and determination of the support plan are discussed.

the subject of the communication described in the logbooks (Fonteine, Zijlstra & Vlaskamp, 2008; Vlaskamp, 1997). The classification system we used distinguished five categories (instead of the six categories of Fonteine et al., 2008): 1. exchanging information, 2. requesting, 3. expressing pleasure or displeasure, 4. complying with/denying requests and 5. other. The subject classification system had ten categories; 1. sensomotor, 2. mood/emotions, 3. communication, 4. self-reliance, 5. health/physical functioning, 6. activity/relaxation, 7. activities of daily living, 8. practical matters, 9. private life and 10. other. The mothers' experiences were first labelled as positive, negative, not clear or missing. Cohen's Kappa was calculated for the function, the subject and the mothers' experiences as a measure of inter-rater reliability, with scores of 23.3% for the entries made by the first two authors. The results showed adequate inter-rater reliability: 0.80 for the function of the contact, 0.68 for the subject covered and 0.86 for the mothers' experiences with the contact. The content of the mother's experiences were then described in a narrative.

## 6.3 Results

### 6.3.1 Contact characteristics

The period the mothers filled in the logbooks differed: 9, 16, 12 and 13 months respectively. Mother 1 did not manage to complete the log after 9 months, due to personal circumstances. Table 2 shows the frequency, means of contact and with whom the mother had contact per case. The total frequency of contacts per mother varied from 25 to 200 within the data collection period. The mean number of contacts per month ranged from 1.9 to 16.7. There were a total of 480 contacts between the mothers and the professionals, the majority of which were with the children's DSP or senior DSP (85.2%). The most common means of contact varied by mother. Whereas mothers 1 and 2 had the most contact by email (39.8% and 57.7% respectively), mother 3 and 4 mainly had contact with professionals visiting their children (59.5% and 24% respectively). Mothers 2 and 4 had no contact with a physician or therapist. Except mother 4, none of the mothers had contact with a psychologist.

**Table 2**  
**Characteristics of contact**

Case	N of months in facility	N of months filling in logbooks	Total N of contacts (mean per month)	Means of contact	N of contacts per professional (%)				
					DSP	Psychologist	Physician	Therapist	Manager
1	14	9	113 (12.6)	Visit	20 (17.7)	0	0	0	0
				Support Plan Meeting	0	0	0	0	0
				Formal meeting	6 (5.3)	0	1 (.9)	2 (1.8)	0
				Telephone	3 (2.7)	0	1 (.9)	1 (.9)	0
				Written	45 (39.8)	0	6 (5.3)	1 (.9)	2 (1.8)
				Other	22 (19.5)	0	2 (1.8)	1 (.9)	2 (1.8)
				Total	96 (85.0)	0	10 (8.8)	5 (4.4)	4 (3.5)
2	23	16	142 (8.9)	Visit	7 (4.9)	0	0	0	0
				Support Plan Meeting	0	0	0	0	0
				Formal meeting	0	0	0	0	0
				Telephone	36 (25.4)	0	0	0	0
				Written	82 (57.7)	0	0	0	4 (2.8)
				Other	1 (0.7)	0	0	0	1 (.7)
				Total	126 (88.7)	0	0	0	5 (3.5)
3	23	12	200 (16.7)	Visit	119 (59.5)	0	2 (1.0)	7 (3.5)	1 (.5)
				Support Plan Meeting	1 (.5)	0	0	0	0
				Formal meeting	2 (1.0)	0	1 (.5)	2 (1.0)	0
				Telephone	20 (10.0)	0	1 (.5)	1 (.5)	2 (1.0)
				Written	24 (12.0)	0	0	6 (3.0)	0
				Other	2 (1.0)	0	1 (.5)	1 (.5)	0
				Total	168 (.84)	0	5 (2.5)	17 (8.5)	3 (1.5)
4	20	13	25 (1.9)	Visit	6 (24.0)	0	0	0	2 (8.0)
				Support Plan Meeting	1 (4.0)	0	0	0	1 (4.0)
				Formal meeting	0	0	0	0	0
				Telephone	5 (20.0)	1 (4.0)	0	0	1 (4.0)
				Written	4 (16.0)	0	0	0	1 (4.0)
				Other	3 (12.0)	0	0	0	1 (4.0)
				Total	19 (76.0)	1 (4.0)	0	0	6 (24.0)
<b>Total</b>			<b>480</b>		<b>409 (85.2)</b>	<b>1 (.2)</b>	<b>15 (3.1)</b>	<b>22 (4.6)</b>	<b>18 (3.8)</b>

Note. The numbers may not sum to the total number of contacts per professional or to the total number of professionals due to missing data on means of contact or type of professional. Since the mothers were free to indicate several professionals per contact in their logbook, the number of professionals they had contact with does not necessarily correspond to the total number of contacts they had. DSP = Direct Support Person.

### 6.3.2 The function and the subject of communication

Figure 1 shows the function of the communication between the mothers and the professionals. 'Exchanging information' was the most common function of communication between the mothers and the professionals. This was the function on average in 39.2% of the contacts that mothers had with professionals. Exchanging information means updating each other about the child and the family. Exchanging information included, for example, the evaluation of a new intervention, keeping parents up-to-date about the child's wellbeing, discussing options for day-services and making appointments to visit specialists. Some examples of exchanging information are:

*Everything is going well with Bob: he is enjoying the lovely weather, he plays on the mat and now and then we have a water fight. Bob is always laughing: very nice to see him like this! (Bob's DSP).*

*When we brought Janine back to her group home, we told them how thrilled she was to see all her family at her grandparents' wedding anniversary. (Marleen, Janine's mother).*

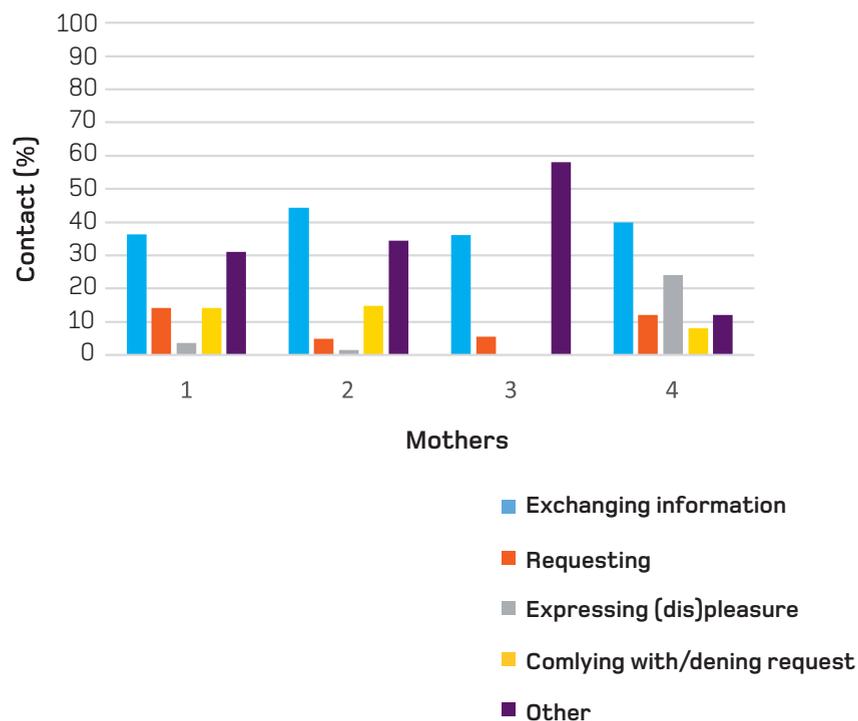


Figure 1 Function of communication per mother

Issues concerning 'health/physical functioning' were the most common subjects covered in the contacts the mothers had with the professionals (see Table 3). On average, 28.4% of the content of the contacts dealt with the health and/or physical functioning of the child. The side-effects of medication, the occurrence of epileptic seizures and their treatment, constipation, fever and surgeries were all subjects about which the mothers had contact, as can be seen from the following comments:

*The physician got a question about the orthosis from the physical therapist, because she could not find information about the reason for the orthosis from Janine's file. She wants a new opinion from the physician treating Janine and new photos of her hips. (Marleen, Janine's mother).*

*Bob did not go to the day activity centre today because he was not feeling well after the epileptic fit he had last week. (Bob's DSP).*

The 'other' category was common for both contact function and subject. This category comprised for example the bringing and picking up of the child, visiting the child, general meetings for all parents, meetings to discuss future housing or day activities, a mother cooking for all the children at the home and a check-up at the dentist. The following fragments are illustrative of the 'other' category:

*This home project was initially meant for children and young adults. Later on, they said it would be decided if the children could stay or whether they should move to another home. Today, we got a letter that the age limit is 25 years. Our son is 25 years old now, so we have to find another home for him. This decision has made me feel very anxious now. (Linda, Koen's mother).*

*We picked up Thomas to go to horse riding and to have lunch at our home. When we came back, we treated everyone to French fries for Thomas' birthday. (Sandra, Thomas's mother).*

Subjects falling under the 'other' category included the introduction of a new manager or senior DSP, painting the home's living room and issues concerning staffing. When several subjects were mentioned in a single contact or where nothing was noted about the contact, these were also categorized under 'other'.

**Table 3**  
**Content of contact per mother**

Case	1		2		3		4	
	n	%	n	%	n	%	n	%
Sensomotor	7	6.2	3	2.1	15	7.5	-	-
Mood/emotion	2	1.8	1	0.7	-	-	-	-
Communication	-	-	1	0.7	-	-	-	-
Self-reliance	1	0.9	-	-	1	0.5	0	0
Health/physical functioning	27	23.9	49	34.5	38	19.0	9	36.0
Activity/relaxation	20	17.7	4	2.8	1	0.5	3	12.0
Activities of Daily Living (ADL)	3	2.7	-	-	-	-	1	4.0
Practical matters	4	3.5	24	16.9	6	3.0	3	12.0
Private life	11	9.7	5	3.5	1	0.5	-	-
Other	31	27.4	53	37.3	24	12.0	8	32.0

Note. Percentages may not add up to 100% due to missing entries.

### 6.3.3 Mothers' experiences with communication

Of the 480 entries in the logbooks from the four mothers, 317 entries were related to the mothers' experiences. The mothers did not mention their experiences with the contact they had with a professional (missing data) in 163 instances. Mothers 2 and 3 left the most gaps on their experiences, 25.4% and 62.5% of their contacts respectively. The reason for this is unclear. Of the 317 experiences mentioned, 239 were positive, 33 were negative, and in 45 cases it was unclear whether the mothers' experiences were positive or negative or both. This is illustrated by the mother's remark below, on getting an email about the home's unstable staffing situation and forthcoming changes:

*Finally, something is going to happen. It was about time!! (Marleen, Janine's mother)*

The mothers' experiences with the contacts could be positive despite what was being communicated being negative, as in the following remark:

*A DSP would appreciate my advice on what to do after forgetting to give Koen his medication. I appreciated her honesty, though I did regret that it happened. (Linda, Koen's mother).*

Negative experiences accounted for a range from 0% (mother 3) to 28% (mother 4) of all the mothers' experiences. The mothers indicated that being kept well up-to-date about their children is important to them – even if the news is bad – which is illustrated by the following comments:

*As far as we are concerned, it is good and important to be kept up-to-date about everything that concerns your child, even if it concerns warts. (Marleen, Janine's mother).*

*It's nice that we are being well kept up-to-date about Bob's ups and downs (Paula, Bob's mother).*

*This week, I had several telephone calls about spots on his legs. Eventually, the physician came over, which seemed necessary because Koen got ill. I appreciated it a lot that I was informed immediately when something appeared to be wrong. (Linda, Koen's mother).*

Not being kept up-to-date can lead to worries and tension as these mothers mentioned:

*This week, Koen went on vacation for the first time with his group. I was quite excited about it and had expected an email or a call with information beforehand, but no. Also, during the week not a bit of news. I felt that a call on my part was not appropriate, so I did nothing. Fortunately, everything went well that week. (Linda, Koen's mother).*

*At least we got some information from the day services people. Out of sight, out of mind? (Paula, Bob's mother).*

The negative experiences that the mothers had in their contacts with professionals concerned getting no, too little or vague information, or getting it too late. As this mother stated after a serious situation where her son had fallen out of a hoist:

*They day services people called in the morning while I was exercising, but it was afternoon before I heard about it from Bob's senior DSP of at the home. What happened and how? How is Bob? (Paula, Bob's mother).*

No communication can cause sorrow, worries, indifference and a loss of trust, which can be seen from the following comment:

*For quite some time I had a feeling that things were not going well within Koen's team. There was not much left of the enthusiastic team I met at the start of the group, full of determination to make things work well. The DSP's illness, commitments not being*

*honoured etc. And no communication at all! It made me sad and I worried about my son, and eventually it gave me a feeling of indifference. An unexpected conversation with the manager, who acknowledged my concerns, showed understanding and told me of the upcoming improvements in the team, restored my confidence that things will improve. (Linda, Koen's mother).*

Other negative experiences were related to not keeping promises, poor internal communication and not being listened to, which are illustrated by the following comments:

*I should have been introduced to Koen's new senior DSP three months ago, but I have still not heard anything. It's inconvenient. I feel as though I'm being overlooked and that communication is breaking down as a result. When I ask about things, I feel a bit brushed aside. (Linda, Koen's mother).*

*We had already explained that Bob had a few days off and that he was about to be vaccinated against influenza. Why do they [the DSPs] keep asking again? (Paula, Bob's mother).*

*We are tired of waiting for an appointment with the manager to discuss the situation at the day services. It takes too long. (Paula, Bob's mother).*

Communication by the professionals which demonstrates interest in and care for the child and family is important to the mothers, as is shown in the following remarks:

*When I pick Janine up for a weekend at home, it is usually very busy at the group. However, the DSPs always find time to tell us what happened during the week, and how Janine felt. We appreciate that a lot. (Marleen, Janine's mother).*

*Before a support plan meeting, we always receive a report about our son. Always exciting! What do they think of our child? We are so anxious to hear good news... I was touched by the fact that so many people do their best for my child... It makes me feel good! (Linda, Koen's mother).*

*It is nice when other people think Janine's day activities through with us. Especially because they understand why this is so important for us and Janine. In these conversations we can see that they care about our child and that is very nice. (Marleen, Janine's mother).*

*They have time to listen to our weekend experiences. Also, they explain about the orthosis. I appreciate their concern, it shows they care about our child. (Marleen, Janine's mother).*

Some communication or experiences are examples of the ideas and feelings that professionals and parents have about collaboration and the specific role the partners in this collaboration play:

*I would like to hear your opinion and arguments so we are on the same page. Your opinion is naturally the most important. (Bob's senior DSP).*

*... But she [the senior DSP] is Bob's third parent! (Paula, Bob's mother).*

*She [the senior DSP] has a huge heart, two even: one with love for her own family and one with love for another person. (Paula, Bob's mother).*

These comments show that the professional sees the mother as a serious partner in the professional support of her son, and gives her the final say in decisions. In the mother's comments, she compares the senior DSP to her husband and herself, referring to her as 'the third parent'.

#### 6.3.4 Differences between the mothers' experiences

Although the mothers had many similar experiences in their communications with the professionals who support their children, there were some differences. Mother 3 had no negative experiences in her contact with professionals. She experienced being kept well up-to-date, being consulted and having her views taken into account, dedication to her son and her family, and felt the warmth in the home that her son lives in. Of the three mothers who had negative experiences, mother 2 mainly had these with the professionals who support her son at the day services centre. She experienced too little communication in the sense of not being kept well up-to-date and she mentioned the lack of a personal relationship with these professionals. Mother 1 also mentioned negative experiences with the professionals at her daughter's day services centre. These experiences concerned not being listened to on what is best for her daughter and a lack of attention during the day. Mother 4's negative experiences concerned promises not being kept and not being kept up-to-date.

#### 6.3.5 Changes over time

The results show that the mothers' experiences did change over time: they became more positive or negative over the twelve month period. Mother 1's experiences got worse towards the end, with five of the total of eight negative experiences occurring in the last two months. Mother 2 had most of the negative experiences at the beginning of the study period, with seventeen of the eighteen negative experiences occurring in the first half. Mother 4 also had most of her negative experiences (six out of seven) in the first half of the study period. Contact between the mothers and the professionals did increase periodically, for example due to accidents, an increase in epileptic seizures, surgery or changes to the aids used.

#### 6.4 Conclusion and discussion

The aim of this study was to acquire knowledge of the frequency and the means of communication and the personal experiences of mothers with their communication with the professionals supporting their children with PIMD. The total frequency of contact per mother varied. Most of the contacts the mothers had were with the child's DSP or senior DSP. The most common means of contact varied per mother, but visiting the child, written contact and telephone were more common than support plan meetings and formal meetings. Exchanging information was the most common function of communication between the mothers and the professionals and communication mainly concerned issues of health/physical functioning. Furthermore, the 'other' category was common for both the function and the subject of contact. Most of the mothers' experiences were positive. Being kept up-to-date about their children, being listened to by professionals, having their concerns acknowledged, thinking matters through with them, showing initiative, keeping promises and showing care for the children are all related to the mothers' positive experiences. These aspects result in a sense of trust that their children are in good hands. Negative experiences were related to not being listened to, not receiving replies to emails, appointments not being kept and not being kept up-to-date.

This case study has some limitations. First, it is impossible to generalize the findings from four cases to the whole population of mothers with children with PIMD. However, the results of this study offer detailed and valuable information about the parents' contacts with the professionals supporting their children with PIMD and about how the parents experienced these contacts. These findings could be representative of all parents with children with PIMD and could provide useful information for future research and practice. For example, it is important for professionals to know that the DSP plays an important and crucial role in the contact with parents and that experiences are generally positive, regardless the frequency of the contact that parents have with the professionals supporting their children. In this study the four mothers were much alike concerning age, education, ethnic background, family structure, age of child, severity of the child's disabilities and the period that the child lived away from home. Future research should also focus on other populations of parents with children with PIMD, such as younger parents, parents belonging to ethnic minority groups and parents whose children are about to move away from home or have lived away from home longer than the children in this study had. Collaboration with professionals for these parental groups could have other features or be experienced differently. Furthermore, there were major differences between the mothers in terms of the number of contacts they reported on and in the manner of reporting, since the mothers were more or less free in what they wrote down in their logbooks. Whereas three mothers filled in their logbooks each time they had contact with professionals, one mother did not fill in her

logbook when the contacts were practical in nature or announcements. This impacted on the results in all aspects of the contacts (frequency, means, the function, the subject and this mother's experiences with the contact). Indeed, mother 4 reported the fewest contacts and the highest percentage of negative experiences with the contacts she had with professionals, which might have been different if she had reported on all the contacts she had. It is also likely that the parents' experiences do not depend on the frequency of the contacts but on the quality of the contacts they have.

Despite these shortcomings, this study offers much detailed information over a longer period about the contacts between mothers and professionals, enabling more in-depth analysis. By following the mothers for a longer period, more precise information on what is important in the collaboration with parents in the professional support of persons with PIMD is gathered. The findings of this study correspond with other, more quantitative studies of collaboration with parents. In a study by Jansen et al. (manuscript submitted), in which the 'problem areas' in the collaboration between parents and professionals were described as instances where support indicated as important was not received, the highest percentages of dissatisfied parents were found on items including the provision of written information about the child (progress, treatment, changes in support) and anticipating and following up concerns.

The DSPs and senior DSPs of the children in this study played a very important and substantial role in the communication with parents, since much of the communication is with them. DSPs might not be sufficiently well equipped for this role and they might not receive enough support from their managers in fulfilling this important role. Furthermore, given the complexity of the support given to persons with PIMD, a more multidisciplinary approach seems appropriate. Such an approach would involve all disciplines, including the parents to reach consensus about the content of the support. This argues for more formal meetings with the parents and all the professionals involved to arrive at joint goal-setting.

At the start of this study, the children of the mothers who participated had lived away from home for a year or more. In this time, the communication between the mothers and the professionals had already begun, relationships were established and the mothers may or may not have had negative experiences in their communication with the professionals. This could have influenced their opinions about the communication. Future studies should focus on the beginning of the collaboration between parents and professionals in the support of persons with PIMD, preferably from the moment the decision is taken that a child should live at a facility. Involving the fathers in more qualitative studies is also recommended, to examine whether fathers have different wishes, needs and experiences as regards communication

with professionals than mothers do. In their study on the agreement between parents and professionals on what is important in the support of persons with PIMD related to the family-centeredness of support, Jansen et al. (manuscript submitted) found significant differences between fathers and mothers in their ratings of importance compared to the professionals' ratings.

Although guidelines for communication between parents and professionals can be formulated and are useful, the relationship being built between parents and professionals is of crucial importance and starts with the communication between parents and professionals. Acknowledgement of the fact that each family is unique, with its own family structure, cultural background, standards and needs and wishes is required. It is up to the professionals who work with families of children with PIMD to be sincerely interested in the parents and to respect them as equal partners. Ultimately, parents are and will be the only constant people in their children's lives, the people who know their children the best, even though their children no longer live at home.

### 6.5 Acknowledgements

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# Chapter 7

General discussion

## General Discussion

The prevailing approach to the support of children with PIMD has shifted from a medical to a family-centred model over the last few decades. Such a model places the needs and wishes of both the child with disabilities and its family at the centre of the support. Collaboration between parents and professionals is essential in order to deliver good quality, family-centred support. Until recently, research into collaboration with parents has mostly focused on paediatric rehabilitation, early intervention and special education (Dyke, Buttigieg, Blackmore, & Ghose, 2006; Nijhuis et al., 2007; Pretis, 2011; Summers et al., 2005). Little was known about collaboration with the parents of children with intellectual disabilities, let alone children with PIMD living in residential facilities. These parents' knowledge is of particular importance, given their children's complex condition. Therefore, the overall aim of this research project was to acquire knowledge about the specific content of collaboration between parents and professionals in the support of children with PIMD to optimize this collaboration. To accomplish this aim, a literature review was carried out to analyse the operationalization of collaboration between parents and professionals in the support of children with PIMD. Knowledge of what the parents and professionals find important in their collaboration in the support of children with PIMD was also needed. Only then could agreements and differences on what is important in the support relationship between parents and professionals come to light. As having profound intellectual and multiple disabilities is a lifelong condition, knowledge of how parents with children with PIMD experience collaboration with the professionals who support their children over longer periods was needed.

### 7.1 Summary of the main findings

Communication emerged from the systematic literature review in Chapter 2 as the recurring factor related to collaboration in all seven studies included. Other factors mentioned in three or more studies were mutual decision-making, evaluation, and trust and respect. These factors were explored further in the studies we conducted.

In the explorative study presented in Chapter 3, we found that the majority of the parents were satisfied with the support provided to their children, but also that almost a fifth of parents indicated that they had not received the support that they found important. These parents indicated, for example, that they were not actively engaged by professionals in terms of decision-making or providing input, for example by pointing out their concerns and presenting their opinions. They also reported that they were not provided with information about their children, that they were not viewed as individuals and equals, that they had not been treated with respect, and that they had not experienced behaviours from the professionals which embraced the holistic needs of their children and their families. In other words, these parents indicated dissatisfaction with the support provided. The dissatisfaction with the support provided by professionals reported in this study corresponds with

similar findings in other studies in other countries in the field of paediatric rehabilitation and early childhood intervention in which the importance of family-centred care was emphasized (Dickens, Matthews, & Thompson, 2010; Dyke et al., 2006; King, Rosenbaum, & King, 1997; Petris, 2011; Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007; Whitton, Williams, Wright, Jardine, & Hunt, 2008).

The results of the abovementioned study led us to believe that we needed to know what the professionals involved in the support find important in their professional behaviour concerning their collaboration with parents. The adjusted Measure of Processes of Care for Service Providers (Dutch MPOC-SP-PIMD) was therefore validated as an instrument to measure the family-centredness of support for children with PIMD (see Chapter 4). More specifically, we analysed the instrument's reliability and construct validity. This resulted in two scales: a nine-item scale representing the concept 'Showing Interpersonal Sensitivity' with almost medium scalability and good internal consistency, and a seven-item scale covering the concept of 'Treating People Respectfully' with almost strong scalability and good internal consistency.

The extent to which parents and professionals agree on what is important in the support provided was examined using this validated Dutch MPOC-SP-PIMD (see Chapter 5). The group means indicated that the parents rated the occurrence of behaviours covered by 'Enabling and Partnership' and 'Respectful and Supportive Care' more highly than the professionals. The group means of the importance scores showed that parents and professionals rated the importance of the first scale ('Enabling and Partnership') almost identically, but parents rated the second scale ('Respectful and Supportive Care') less highly than the professionals. Furthermore, we saw that the presence of sensory problems, the role of the parent (father, mother or other legal representative), the type of professional (directly versus indirectly involved) and the professional's years of experience explained the agreements in scale scores between parents and professionals for the different models on occurrence and importance ('Enabling and Partnership' and 'Respectful and Supportive Care'). The dissatisfaction percentages among the parents in this study correspond to those in the study presented in Chapter 3 and confirm that a substantial minority of the parents do not receive the support they find important.

Since communication emerged as an important aspect of the collaboration between parents and professionals (see Chapter 2), this aspect was examined in greater detail in Chapter 6. In this multiple case-study (n=4) with repeated measurements over a twelve month period, frequencies were described for the regularity and the means of contact, and for the professional with whom the parents had contact. The purpose and subject of the contacts were analysed using a categorization system and the parents' experiences were labelled and described in a narrative. It appeared

that how the communication was done was more important than its frequency, and even more important than the specific content of communication between the parents and professionals. Professionals keeping parents up to date about their children, listening to them, acknowledging concerns, thinking issues through with them, showing initiative, keeping promises and showing that they care for the children were all aspects related to the positive experiences for the parents involved in the study and resulted in a sense of trust that the children were in good hands.

### 7.2 Methodological reflections and future research

The findings of the various studies provided important knowledge on what parents and professionals find important in the support of children with PIMD in terms of the family-centredness of the support, despite the sufficient but small sample of parents used (Chapter 3). Moreover, specific knowledge of what could and should be improved in the collaboration between parents and professionals was obtained. The problem of relatively small samples in studies of persons with PIMD can be explained by the overall size of this target group. In a recent report on the prevalence and characteristics of persons with PIMD, the size of this population in the Netherlands ranges between 7,800 and 20,600 persons, with 9,639 adults being considered the most accurate estimate (Vugteveen, Van der Putten, & Vlaskamp, 2014). Another explanation for the small sample size is that the burden of having a child with PIMD places upon the parents can cause them not to have the time or energy to participate in research. To increase the response rate, sending reminder letters, offering different ways of completing questionnaires (digital or written) and finding ways of reducing the time needed to participate in research could help future research.

Since we examined collaboration with parents of children with PIMD in the specific setting of residential facilities, further research could focus on collaboration with parents of children with PIMD at schools or day services centres to gain further knowledge on this collaboration. Research could focus on the collaboration with those parents whose children are about to move away from the parental home, to acquire information on the parents' needs and wishes as regards collaboration at this particular stage of their lives and during these transitional phases.

This study yielded two valid questionnaires, the MPOC-PIMD for parents and the MPOC-SP-PIMD for professionals, which are useful in measuring the family-centredness of the support for persons with PIMD, and to enable comparisons between the opinions of parents and those of professionals on the family-centredness of the support (Chapter 3 and 4). As this was the first time that these questionnaires were used in the specific context of support of children with PIMD, some suggestions for further research are called for. Since there are differences in the extent of involvement of professionals (more or less on a regular basis) in the support of an individual child with PIMD, further analysis is needed to determine whether the

structure of the items and scales for measuring the underlying trait of family-centredness also holds for different subgroups of professionals. This would create opportunities to adjust the collaboration with parents, depending on the type of professionals collaborated with. Furthermore, attention should be paid to determining which professionals completed the questionnaire, since a condition for providing appropriate answers to the questions is contact with the parents. Finally, to obtain knowledge on the collaboration between an individual parent and an individual professional, the questionnaires can be used in a family-specific way, with parents completing in questionnaire for each professional supporting their child and these professionals in turn completing a questionnaire for each child (Nijhuis et al., 2007).

Despite the methodological limitations, the strength of our research is its combination of different results, both quantitative as qualitative, which sustained each other and created knowledge of the collaboration with parents, an important aspect in the support of children with PIMD.

### 7.3 Implications for practice

Although the majority of parents were satisfied with the support provided for their children, a substantial minority of the parents indicated that they did not receive the support they find important. Organizations should focus on the subjects with which parents are dissatisfied and improve aspects such as the provision of written information about the child (progress, treatment and changes in support), anticipating and following up concerns, providing help in working with the system of support, being aware of changing needs and being a resource for parents. Furthermore, in order to deliver truly family-centred support, service providers should note carefully the desires and needs of parents in this regard and should be aware that they differ depending on the role of the parents (father, mother or other legal representative) and the type of professional. Using the validated versions of the MPOC-PIMD for parents and the MPOC-SP-PIMD for professionals in a family-specific way, these desires and needs concerning the family-centredness of support become clear. Agreements or differences between parents and professionals on the importance of family-centred support are also exposed. This information can then be used in practice to match the support to the needs of the parents and family of the child with PIMD. The use of the abovementioned instruments in the support of children with PIMD is therefore recommended. Moreover, ideally at the early stages of professional collaboration with parents, the parents' needs and desires concerning collaboration should be inventoried in detail: the extent of involvement in the professional support, the professionals with whom the parents wish to communicate, and the way, the frequency and the content of the communication. Organizations which support persons with PIMD should attend to the communication with parents as an important aspect of collaboration and train or coach their

professionals in effectively communicating with them. Organizations can also make a difference in the way the support is organized by using programmes specially developed to support children with PIMD, in which the role of parents is more or less formalised and communication between parents and professionals goes without question (Vlaskamp, 1999). By involving parents in developing the support plan for their children and setting goals for the children's future, support becomes transparent. In addition, parents should be involved in determining the content of the support because of their extensive knowledge of their children. Indeed, the study in Chapter 6 showed that parents provide a great deal of information about their children and are being asked to give advice. By collaborating with parents in this way, the number of parents who express dissatisfaction with the support provided to their children can decrease easily. Furthermore, parents should be involved in the professional support of their children right from the start. We can thus give parents the opportunity to choose a method of collaboration which fits their needs, wishes and opportunities, which does justice to the uniqueness of each family.

#### 7.4 References

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## Summary

Children and adults with profound intellectual and multiple disabilities (PIMD) are characterized by a combination of profound intellectual and severe or profound motor disabilities and additional disabilities such as sensory impairments and various health problems. As with all parents, parents of children with PIMD know their child the best in terms of their abilities, disabilities, needs and desires, but above all, they are the only constant factor in their children's lives. They possess a wealth of information about their child which is of utmost importance for professionals, and which differs from the knowledge of the latter. Parents know, for example, how their child communicates, when he or she is at ease and with whom. In other words, parents are specialists regarding their own child. Professionals, on the other hand, have specific knowledge about persons with PIMD due to their education and clinical experience in supporting them. In the professional support of children and adults with PIMD, collaboration with parents is indispensable. Ideally, the expertise of both parents and professionals should thus converge to come to a better understanding of who the person with PIMD is and what he or she needs.

The above-mentioned is in line with the development the last decades of client-centred support to family-centred support, in which the needs and desires of the child with disabilities are placed at the context of the family and community. In this family-centred support collaboration plays an very important role. In the support of persons with PIMD, little is known about the precise content of collaboration, what is important in the collaboration with parents, which factors influence this collaboration and how parents perceive the collaboration with the professionals who support their child. In this dissertation, research is described that aims to obtain knowledge about the collaboration between parents and professionals in the support of persons with PIMD. This, to eventually achieve an optimal collaboration in which parents and professionals, abreast, contribute to a good quality of life for children and adults who are, in many ways, very vulnerable.

Chapter 1 is an introductory chapter in which the context of the research is described.

Chapter 2 reports on a literature review about the meaning of the concept of collaboration and related factors. Using four databases, relevant literature in an eighteen year period based on inclusion criteria was selected. The descriptive analysis reveals seven studies which differ in their aims, the methods they used, samples and setting. A common operationalization of the concept of collaboration is lacking in the seven studies. Recurrent factors related to collaboration in the studies are 'communication', 'mutual decision-making', 'evaluation', 'trust' and 'respect'.

In conclusion, an unequivocal definition of collaboration remains elusive, just as consensus on and clear descriptions of the factors that are indicative of collaboration does.

In Chapter 3, an instrument that maps the family-centredness of the support provided is presented. This instrument, the Dutch Measure of Processes of Care (MPOC), has been adjusted to the target group of persons with PIMD and has been validated (MPOC-PIMD). A total of 100 parents of a child with PIMD completed the MPOC-PIMD. Parents indicate the importance and occurrence of certain behaviour of professionals. Parents' satisfaction with the support provided can be derived from a combination of the occurrence of certain family-centred behaviour and the importance given by parents to that behaviour. Results show that parents are in average satisfied with the support provided (mean grade is 6.88 on a scale from 1 to 10). However, a substantial minority of the parents (on average 18.8%) indicate that they do not receive the support they deem important.

Chapter 4 reports on the research into the validity and reliability of an instrument, the Measure of Processes of Care for Service Providers (MPOC-SP-PIMD), that already had been translated in Dutch and validated, and is adjusted by us to the target group of persons with PIMD. An item response analysis (Mokken scale analysis) was conducted to determine whether the instrument satisfied the assumptions of both monotone homogeneity and double monotonicity. Loevinger's scalability coefficient ( $H$ ) was used for the scalability of the entire scale and of each item separately.  $\rho$  was calculated as a measure of the internal consistency of the scales. The analyses resulted in two scales: a nine-item scale interpreted as 'Showing Interpersonal Sensitivity', with  $H = .39$  and  $\rho = .76$ , and a seven-item scale interpreted as 'Treating People Respectfully', with  $H = .49$  and  $\rho = .78$ . The conclusion of this study is that the validated version of the instrument, suitable for supporting persons with PIMD, can be used to measure the family-centredness of professionals to compare this with parents' expectations and views.

Chapter 5 describes the agreements (in terms of differences) between parents and professionals in their experiences of the family-centredness of the support provided. Also, factors that relate to agreements are outlined. In total, 109 parents and 144 professionals completed the adjusted versions of the Dutch MPOC for parents and professionals respectively. Agreements between parents and professionals in terms of differences in their judgements about the occurrence and the importance of the family-centredness of the professionals support were analysed with use of multilevel analyses. Results show that parents rate the occurrence of family-centred behaviour on average higher than the professionals do on both scales of the MPOC. The importance of the scale 'Enabling and Partnership'

('Showing Interpersonal Sensitivity' in the MPOC-SP-PIMD) is rated almost identically, but parents rate the importance of the scale 'Respectful and Supportive Care' ('Treating People Respectfully' in the MPOC-SP-PIMD) less high than the professionals. Results also show that sensory problems of the child, the role of the parents (father, mother, or other legal representative), the type of professionals (directly versus indirectly involved in the support), and the amount of years of experience with persons with PIMD of the professionals relate to the agreements in scale scores for the different models. Furthermore, a considerable number of parents (29.8%-35.4%) indicate not receiving the support they find important, or receive support they do not find important. In conclusion, to provide real family-centred support, professionals should take into account parents' needs and desires in this regard, and they should be aware of the dependency of those needs and desires on the role of the parent and the type of the professional.

Chapter 6 describes a longitudinal study, in which four parents filled out logbooks in a twelve month period, every time they had contact with the professionals that give support to their child in a residential facility. The aim of this study was to acquire knowledge of the frequency and the means of communication and the personal experiences of mothers with their communication with the professionals supporting their children with PIMD. The total frequency of contact per mother varied. The results show that most of the contacts the mothers have are with the child's DSP or senior DSP. The most common means of contact varies per mother, but visiting the child, written contact and telephone are more common than support plan meetings and formal meetings. Exchanging information is the most common purpose for communication between the mothers and the professionals and communication mainly concerned issues of health/physical functioning. Most of the mothers' experiences are positive. Being kept up-to-date about their children, being listened to by professionals, having their concerns acknowledged, thinking matters through with them, showing initiative, keeping promises and showing care for the children are all related to the mothers' positive experiences. These aspects result in a sense of trust that their children are in good hands. Negative experiences are related to not being listened to, not receiving replies to emails, appointments not being kept and not being kept up-to-date.

This dissertation ends with chapter 7, in which is reflected upon the findings of the five studies. The shortcomings of the research and the implications for practice and further research are being discussed.

## Samenvatting (Summary in Dutch)

Kinderen en volwassenen met (zeer) ernstige verstandelijke en meervoudige beperkingen (zevmb) worden gekenmerkt door een combinatie van zeer ernstige verstandelijke en (zeer) ernstige motorische beperkingen en hebben bovendien vaak bijkomende zintuigelijke stoornissen en diverse gezondheidsproblemen. Net als iedere ouder kennen ouders van een kind met zevmb hun kind het best in de zin van (on)mogelijkheden, behoeftes en wensen en bovenal zijn zij de enige constante factor in het leven van hun kind. Ouders van deze kinderen bezitten een schat aan informatie over hun kind, die van belang is voor professionals en welke verschilt van de kennis van professionals. Ouders weten bijvoorbeeld hoe hun kind communiceert, wanneer hij op zijn gemak is en bij wie. Ouders zijn als ware de specialist van hun eigen kind. Professionals, aan de andere kant, hebben specifieke kennis van personen met zevmb door zowel hun opleiding als door hun praktische ervaringen in de ondersteuning aan hen. In de professionele ondersteuning aan kinderen en volwassenen met zevmb is samenwerking tussen ouders en professionals onontbeerlijk. De expertise van zowel ouders als van professionals zou moeten samenkomen om tot een beter begrip te komen van wie de persoon met zevmb is en wat hij nodig heeft.

Bovenstaande is in lijn met de ontwikkeling die de laatste decennia heeft plaatsgevonden van cliënt gerichte ondersteuning naar gezinsgerichte ondersteuning, waarbij de behoeftes en wensen van het kind met beperkingen geplaast worden in de context van het gezin en de gemeenschap. In deze gezinsgerichte ondersteuning vormt samenwerking tussen ouders en professionals een cruciale rol. Binnen de ondersteuning aan personen met zevmb is echter weinig bekend over wat deze samenwerking precies inhoudt, wat van belang is in de samenwerking met ouders, welke factoren van invloed zijn op deze samenwerking en hoe ouders de samenwerking met de professionals die hun kind ondersteunen ervaren. In dit proefschrift wordt onderzoek beschreven dat tot doel had inzicht te krijgen in de samenwerking tussen ouders en professionals in de ondersteuning aan personen met zevmb. Dit om uiteindelijk te komen tot een optimale samenwerking waarbij ouders en professionals, zij aan zij, bijdragen aan een goede kwaliteit van bestaan voor kinderen en volwassenen die in vele opzichten zeer kwetsbaar zijn.

Hoofdstuk 1 is een inleidend hoofdstuk waarin de context van het onderzoek wordt beschreven.

In hoofdstuk 2 wordt verslag gedaan van een literatuuronderzoek naar de betekenis van het begrip samenwerking en aan deze samenwerking gerelateerde factoren. In vier datasystemen is op basis van inclusiecriteria in een periode van 18 jaar

relevante literatuur geselecteerd. Uit de beschrijvende analyse komen zeven onderzoeken naar voren met allen verschillende doelen, methodes, steekproefgroottes en context. Een gemeenschappelijke operationalisering van het begrip samenwerking ontbreekt in de zeven studies. Overlappende factoren gerelateerd aan samenwerking in de onderzoeken zijn 'communicatie', 'gezamenlijke besluitvorming', 'evaluatie', 'vertrouwen' en 'respect'. Geconcludeerd wordt dat een eenduidige definitie van samenwerking ontbreekt, evenals eenduidige beschrijvingen van de factoren die bijdragen aan samenwerking.

In Hoofdstuk 3 wordt een instrument dat de gezinsgerichtheid van de geboden ondersteuning in kaart brengt, geïntroduceerd. Dit instrument, de Nederlandse Measure of Processes of Care (MPOC, ook wel Vragenlijst Ervaringen van Ouders met het Zorgproces), is aangepast aan de doelgroep van personen met zevmb en vervolgens gevalideerd (MPOC-PIMD). Totaal hebben 100 ouders met een kind met zevmb de MPOC-PIMD ingevuld. Ouders geven aan hoe belangrijk zij bepaald gedrag van professionals vinden en hoe vaak het voorkomt. De tevredenheid van ouders over de geboden ondersteuning kan worden afgeleid uit een combinatie van het voorkomen van bepaald gezinsgericht gedrag en het belang dat ouders daaraan hechten. De resultaten laten zien dat ouders over het algemeen tevreden zijn over de geboden ondersteuning (gemiddelde cijfer is 6.88 op een schaal van 1 tot 10). Echter, een substantiële minderheid van de ouders (gemiddeld 18.8%) geeft aan dat zij niet de ondersteuning krijgen die zij belangrijk vinden.

Hoofdstuk 4 doet verslag van een onderzoek naar de validiteit en betrouwbaarheid van het instrument, de Measure of Processes of Care for Service Providers (MPOC-SP-PIMD), dat al in het Nederlands vertaald en gevalideerd was (Vragenlijst Ervaringen van Zorgverleners met het Zorgproces), en door ons aangepast aan de doelgroep van personen met zevmb. Een item respons analyse (Mokken schaal analyse) is uitgevoerd om te bepalen of het instrument voldoet aan de aannames van zowel monotone homogeniteit als dubbele monotoniciteit. Loevingers schaal coefficient (H) is gebruikt voor de schaalbaarheid van de hele schaal en voor ieder item afzonderlijk. Rho is berekend als maat voor interne consistentie voor de schalen. De analyses resulteerden in twee schalen: een negen-item schaal, aangeduid als 'Interpersoonlijke Sensitiviteit Tonen', met  $H = .39$  en  $\rho = .76$ , en een zeven-item schaal, aangeduid als 'Mensen Respectvol Behandelen', met  $H = .49$  en  $\rho = .78$ . De conclusie van dit onderzoek is dat de gevalideerde versie van het instrument, geschikt voor de ondersteuning aan personen met zevmb, gebruikt kan worden om de gezinsgerichtheid van professionals te meten zodat dit vergeleken kan worden met de verwachtingen en oordelen van ouders.

Hoofdstuk 5 beschrijft de overeenkomsten (in termen van verschillen) tussen ouders en professionals in hoe gezinsgericht zij de geboden ondersteuning beoordelen.

Tevens is geanalyseerd welke factoren samenhangen met de overeenkomsten. In totaal vulden 109 ouders en 144 professionals de aangepaste versies van de Nederlandse MPOC voor respectievelijk ouders en professionals in. Overeenkomsten tussen ouders en professionals in termen van verschillen in het oordeel over het voorkomen en het belang van de gezinsgerichtheid van de professionele ondersteuning werden geanalyseerd met behulp van multilevel analyses. De resultaten laten zien dat ouders het voorkomen van gezinsgericht gedrag gemiddeld hoger scoren dan de professionals op beide schalen van de MPOC-PIMD. Het belang van de schaal 'In staat stellen en partnerschap' ('Interpersoonlijke sensitiviteit tonen' in de MPOC-SP-PIMD) wordt door ouders en professionals gemiddeld even hoog geacht, maar ouders scoren het belang van de schaal 'Respectvolle en ondersteunende zorg' ('Mensen respectvol behandelen' in de MPOC-SP-PIMD) gemiddeld minder hoog dan de professionals. Uit de resultaten komt tevens naar voren dat zintuiglijke problemen bij het kind, de rol van de ouders (vader, moeder of andere wettelijke vertegenwoordiger), soort professional (direct versus indirect betrokken bij de ondersteuning) en aantal jaren werkervaring met de doelgroep van personen met zevmb, samenhangen met de overeenkomsten in schaalscores voor de verschillende modellen. Verder gaf een aanzienlijk deel van de ouders (29.8%-35.4%) aan dat zij niet de ondersteuning ontvangen die zij belangrijk vinden, of juist ondersteuning krijgen die zij niet zozeer belangrijk vinden. Conclusie is dat, om echte gezinsgerichte ondersteuning te bieden, professionals rekening moeten houden met de wensen en behoeftes van ouders op dit gebied én dat zij zich ervan bewust moeten zijn dat deze wensen en behoeftes onder andere afhangen van de rol van de ouder en het soort professional waarmee samengewerkt wordt.

Hoofdstuk 6 beschrijft een longitudinaal onderzoek waarbij vier ouders voor een aaneensluitende periode van 12 maanden logboeken hebben ingevuld iedere keer dat zij contact hadden met de professionals die ondersteuning aan hun kind bieden in een residentiële instelling. Het doel hiervan was het vergaren van kennis over de frequentie en de manier van communiceren en de persoonlijke ervaringen van ouders over hun communicatie met professionals die hun kind ondersteunen. Beschrijvende statistiek werd uitgevoerd voor het totale aantal contactmomenten, het soort contact en met wie het contact plaatsvond. Met behulp van een categorisatiesysteem werden de functie en het onderwerp van de communicatie geclassificeerd. De resultaten laten zien dat het totaal aantal contacten per ouder (allen moeders) verschilt. De meeste contacten zijn met de begeleider of persoonlijk begeleider van het kind. De meest gebruikelijke manier van contact verschilt per moeder, maar hun kind bezoeken, schriftelijk contact (ook email) en telefoneren komen meer voor dan contact door middel van aanwezigheid bij planbesprekingen en multidisciplinaire overleggen. Het uitwisselen van informatie is de meest voorkomende functie van de communicatie tussen de moeders en de professionals en de communicatie gaat meestal over gezondheidskwesties.

Het merendeel van de ervaringen van de moeders is positief. Op de hoogte gehouden worden over hun kind, gehoord worden, erkend worden in hun zorgen, meedenken door professionals, initiatief door professionals, afspraken nakomen en zorg en warmte tonen voor het kind, zijn aspecten die gerelateerd zijn aan de positieve ervaringen van de moeders. Bovenstaande aspecten zorgen voor een gevoel van vertrouwen bij de moeders, het gevoel dat hun kind in goede handen is bij de professionals binnen de voorziening. Negatieve ervaringen houden verband met niet gehoord worden, geen antwoord op mails krijgen, afspraken die niet worden nagekomen en niet op de hoogte gehouden worden.

Dit proefschrift sluit af met Hoofdstuk 7, waarin wordt gereflecteerd op de bevindingen van de vijf onderzoeken. De beperkingen van het onderzoek en de implicaties voor de praktijk en vervolgonderzoek worden beschreven.

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Zonder de medewerking van de ouders was dit onderzoek niet mogelijk geweest. Ik ben de vele ouders die hebben bijgedragen onmetelijk dankbaar voor het invullen van vragenlijsten. Daarnaast wil ik in het bijzonder de ouders bedanken die mee hebben gewerkt aan het longitudinale deel van mijn onderzoek, waarin ik een persoonlijke inkijk kreeg in hun leven als partner in de samenwerking met de professionals die zorg dragen voor hun kind: niet altijd een even makkelijke positie. Nog meer in het bijzonder gaat mijn dank uit naar de vier moeders die een jaar lang hun ervaringen

met samenwerking en communicatie hebben bijgehouden in logboekjes: wat een karwei en wat een prachtige, soms verdrietige, inzichten heeft dit opgeleverd!

Ook de professionals die hebben meegewerkt aan dit onderzoek wil ik bedanken. Ik weet als geen ander dat een werkdag van een professionals in de zorg tjokvol zit en er eerder tijd tekort dan tijd over is, dus dat jullie ruimte hebben willen maken voor het uitzetten en invullen van vragenlijsten waardeer ik zeer.

Gedurende dit traject ben ik weer teruggekeerd naar een voor mij bekende plek (alleen de afdeling verschilde), de Rijksuniversiteit Groningen, waar ik begeleid ben en nieuwe collega's heb mogen ontmoeten. 'The totally awesome women' moet ik bedanken voor de gedeelde smart, maar vooral voor de vele lol die we hebben gehad tijdens congressen waarbij de communicatie via speciale groupapps bij tijd en wijlen interessanter en in ieder geval veel grappiger was dan de meeste presentaties (sorry). Annet ten Brug, mijn privé statistiek/SPSS juf, jou wil ik in het bijzonder bedanken voor je bijdrage aan de inventarisatie van de cliënten met ZEVMB binnen 's Heeren Loo Zorggroep, factoranalyse en je eindeloze geduld met zo'n nitwit als ik. Anouk van Es, bedankt voor je hulp bij die immense klus van literatuur screenen (buiten heel veel andere zaken in het leven, zijn vooral databases ondoorgrondelijk) en de factoranalyse die je voor me hebt uitgevoerd. Cynthia de Jong ben ik dank verschuldigd voor het uitwerken van vele uren interviews met veel uh's en eh's en haperende systemen. Wendy Post, dankzij jouw hulp ben ik erachter komen dat de mogelijkheden in het doen van analyses schier onuitputtelijk zijn wat mij bij vlagen tot wanhoop dreef, maar uiteindelijk ook twee prachtige, goed gefundeerde artikelen heeft opgeleverd. Knap hoe je opkomende paniek feilloos wist aan te voelen en iedere keer wist om te buigen naar een minder wanhopig 'ik ga deze berekeningen gewoon nog een keer doen'.

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dan wel twee andere paranimfen, maar jij bent mijn enige wandelnimf!

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## About the author

Suzanne Jansen was born in Utrecht, the Netherlands, on November 27, 1970. In 1989, the author received her Atheneum diploma from the Gemeentelijke Scholengemeenschap in Emmen. After one year living in Geneva, Switzerland, as an au-pair, she moved to The Hague to study at the Hogere Economische Beroepen Opleiding (HEBO). In 1991 the author switched to the University of Leiden to begin her study Psychology at the Faculty of Social Sciences. After one year, she moved to Groningen to continue and finish her study Psychology at the University of Groningen. In 1996, the author concluded her studies with a thesis on the effects of 'De Speelklas', a programme to stimulate the early childhood development.

After her study and some administrative jobs, the author went working at the Immigratie- en Naturalisatiedienst in Arnhem in 1998, where she did various activities, such as the treatment of requests for asylum, coaching of colleagues and providing different kinds of training. In January 2009, the author started working as a psychologist for persons with intellectual disabilities at 's Heeren Loo Zorggroep. In October that year, she entered the PhD programme for two days a week, at the University of Groningen, Department of Special Needs Education and Youth Care. From 2009 to 2014, she worked on her dissertation, studying the collaboration between parents and professionals in the support of persons with profound intellectual and multiple disabilities. The results of this study are summarized in this thesis. During her PhD study the author had the opportunity to visit various interesting conferences in both the Netherlands as abroad, with Rome, Halifax (Canada) and Vienna as high points.