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ORIGINAL ARTICLE

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

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ABSTRACT

Background: The aim of this study was to explore agreements in the way parents of a person with profound intellectual and multiple disabilities and professionals perceive the support in terms of its family-centredness in order to gain a better understanding of their collaboration.

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. Agreements between parents and professionals were analysed using multilevel analysis.

Results: In general, the parents and the professionals disagreed on occurrence and importance of both the Enabling and Partnership scale and the Respectful and Supportive Care scale.

Conclusion: In order to deliver family-centred support, service providers should be aware that there are disagreements between the parents' perception of what is important in the support provided and the perception of the professional.

KEYWORDS

multiple disabilities;
profound intellectual
disability; parents;
professionals; collaboration;
Measure of Processes of Care;
family-centredness

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, 2011; 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; Espe-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; Espe-Sherwindt, 2008; King, Rosenbaum, & King, 1996; MacKean et al., 2005; Shelton & Stepanek, 1994). In this approach, families work in partnership with professionals to determine the content of their child's support.

Concerning the support of children and adults with profound intellectual and multiple disabilities (PIMD), collaboration with parents is even more important due to the complex needs of these persons. Persons with PIMD are characterised by profound intellectual and profound or severe motor disabilities (Nakken & Vlaskamp, 2007). They may have little or no apparent understanding of verbal language and symbolic engagement with objects. Individuals with PIMD also possess little or no ability to support themselves in all aspects of daily living. Many of them are not independently mobile, frequently have little or no functional 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'Donnell, & Montgomery, 1999; Zijlstra & Vlaskamp, 2005).

As with all parents, parents of children with PIMD know their child in terms of their abilities, disabilities, needs and wishes, but above all, they may be 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 these professionals. Parents often 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 (in this context, physicians, healthcare psychologists, therapists, [senior] direct support persons), on the other hand, have specific knowledge about persons with PIMD due to their study and practical 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 and might want. This will in turn lead to opportunities for joint goal-setting and shared 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 extremely valuable, and efforts need to be made to establish this collaboration.

With regard to collaboration with parents in the support of persons 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. In several studies in other fields evaluating family-centred services, the perceptions of families and/or professionals were examined by using the Measure of Processes of Care for families and/or service providers (MPOC and MPOC-SP; Dickens, Matthews, & Thompson, 2011; Dyke, Buttigieg, Blackmore, & Ghose, 2006; Jeglinsky, Autti-Rämö, & Brogren Carlberg, 2012; King, King, & Rosenbaum, 1996; O’Neil, Palisano, & Westcott, 2001; Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007; Whitton, Williams, Wright, Jardine, & Hunt, 2008). Woodside, Rosenbaum, King, and King (2001) pointed out that the MPOC can be used in conjunction with the MPOC-SP to compare parental and professional perceptions of service delivery. Results of studies into this comparison show that comparing the perceptions of both families and professionals is helpful in identifying areas

of improvement in family-centred care (Dickens et al., 2011; Dyke et al., 2006; Jeglinsky et al., 2012; O’Neil et al., 2001; Raghavendra et al., 2007; Whitton et al., 2008). Furthermore Nijhuis et al. (2007) stated in their study on collaboration with parents in the field of paediatric rehabilitation 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.

In a previous study, we therefore examined what parents of children and adults with PIMD found important in the professional support in terms of its family-centredness (Jansen, van der Putten, & Vlaskamp, 2013). 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. Although these results suggest 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 perceive the support provided become apparent (Jansen et al., 2013). 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.

In the present paper, we will analyse agreements (measured in terms of differences in rating scores) between parents (and/or legal representatives) and professionals in relation to how they perceive the *occurrence* and *importance* of the support provided to the person with PIMD. The term “parent(s)” and “persons with PIMD” will be used to make the text more readable. Furthermore, the assumption that characteristics of the person with PIMD (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 perceive 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.

Method

Participants

The participants were parents or other legal representatives of a person with PIMD and the professionals working with these persons. Inclusion criteria were as follows:

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

Measurements

Parents

The perceptions of parents about the support of their child were 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 (three items), (3) Coordinated & Comprehensive Care for Child and Family (16 items), and (4) Respectful & Supportive Care (six items). The internal consistency of the four subscales was analysed by calculating Cronbach's α and found to

be sufficient to very good (0.84, Respectful & Supportive Care; 0.93, Coordinated & Comprehensive Care for Child and Family; 0.90, Enabling & Partnership; and 0.63, Providing Specific Information about the Child). Pearson's product-moment correlation coefficient (r) indicated that all scales correlated significantly with each other ($p < .01$). Pearson correlations were good (r ranging from 0.55 to 0.92). Overall, the psychometric quality of the Dutch MPOC-PIMD seems adequate (Jansen et al., 2013).

Each item is 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 being 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 MPOC 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 α ranging from 0.80 to 0.96 and ICCs (intraclass correlation coefficient) ranging from 0.78 to 0.94 (King et al., 1996; van Schie et al., 2004). The Dutch MPOC and the Dutch MPOC-PIMD were 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 person with PIMD were 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 (nine items), and (2) Treating People Respectfully (seven items). The Dutch MPOC-SP-PIMD has been validated and results show medium to strong scalability and

good internal consistency (Jansen, van der Putten, Post, & Vlaskamp, 2014). 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 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 previously, 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."

Nijhuis et al. (2007) took the analogy between the Dutch MPOC and Dutch MPOC-SP domains as a starting point to compare scores of parents and professionals and used the questionnaires in a family-specific way: the items of the scales remained the same, but instead of examining the professionals' behaviour in general, it now evaluates the professionals' behaviour towards a particular child and its family. 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.

Procedure

Approval for conducting this study was given by the organisation's ('s Heeren Loo Zorggroep) independent ethics committee. Information about the study was presented to parents and professionals from the organisation's administrative personnel, who did not know the parents, and informed consent was requested from both groups. The names of parents and/or legal representatives were gathered by administrative personnel who had no contact with the parents. Parents were not informed about which professionals completed the questionnaires, nor were the professionals informed of the ratings of the parents.

Using an organisation in the Netherlands that gives support to people with intellectual disability, 392 parents were invited by mail to fill in the Dutch MPOC-PIMD. Additionally, information was gathered about their son or daughter's age, type, and number of additional disabilities (e.g., sensory disabilities, epilepsy, chronic

constipation, dysphagia, chronic pulmonary infections, sleeping problems, challenging behaviour), duration of service use, and whether or not the person lived in a residential setting. The organisation mentioned is one of the largest organisations in the Netherlands. 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 services at the parents' home. 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 confidentiality: they provided identifying data but were assured that they would not be individually identified in any report of the study.

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 2 weeks in a prepaid envelope. After 2 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 person whose parents had filled in the Dutch MPOC-PIMD ($n = 746$) were then invited by mail to complete the Dutch MPOC-SP-PIMD. Next, the professionals were asked about the number of years working with the target group and whether or not they were directly involved in the support of the person with 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 confidentiality in the sense that their identity and responses were not revealed to the organisation they work for and the data were processed anonymously and confidentially. After 2 months, a reminder letter was sent to those who had not yet responded. Response rates will be reported in the Results.

Research design

This study was a cross-sectional study, in which data concerning the family-centredness of support were gathered from two groups of participants (parents and professionals) at one time. For each child, one type of parent (mother, father, or other legal representative) filled out a questionnaire, whereas more than one professional filled out a questionnaire for that particular child. Agreement between parents and professionals was defined in terms of differences in ratings of the occurrence and importance of the family-centredness

of the support provided. As a consequence, there were several scores of agreement for each child.

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 ≥ 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 ≥ 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 person with PIMD were compared with the scores of the parents of that particular person. 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 person with PIMD as the highest level and professionals as the lowest level, to take into account the dependencies between scores of different professionals for one person with PIMD. The person with PIMD’s characteristics, such as age, type (challenging behaviour, sensory problems), and number of additional disabilities, duration of service use and whether or not the person 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 vs. not directly involved)² 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. Effect sizes and confidence intervals were added in order to understand the practical importance of the results. Effect size estimates between .00 and .19 are considered as insignificant, between .20 and .49 as small, between .50 and .70 as medium, and .80+ as large (Dempsey & Balandin, 2012;

Dunst & Hamby, 2012). We regard an estimated agreement of more than 0.5 in the importance scales as practically relevant, as they have a range of 0 to 4. Confidence intervals including a more than 0.5 category difference (-0.5 or 0.5) indicate, therefore, not practically relevant agreement for these importance scales. We regard an estimated agreement of more than one point in the occurrence scales as practically relevant, as they have a range of 1 to 7. Confidence intervals including more than one category difference (-1 or 1) indicate, therefore, not practically relevant agreement for these occurrence scales.

Results

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 son or daughter did not belong to the target group and 57 respondents with a son or daughter 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 son or daughter belonged to the target group or not. Nine respondents (3.5%) 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 Characteristics of the professionals section) only provided valid questionnaires for 109 persons; therefore, the results are only based on those 109 parents and their children. In order to determine whether the 109 persons were a representative sample of the 151 persons with PIMD, *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 persons with PIMD included in the study.

The parents’ mean age was 59.3 years ($SD = 10.9$), ranging from 34 to 84 years. Of the persons with PIMD, 48.6% were female and 45.0% were male (6.4% were missing data). The persons with PIMD’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 people lived with their parents and eight were under 19 years old. One hundred and

five parents were born in the Netherlands and four parents were not. Other characteristics of the parents and their son or daughter are shown in Table 1.

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 person with PIMD 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 persons with PIMD by 144 professionals. Most professionals completed a questionnaire for only one person with PIMD (62%) and 27% of the professionals completed a questionnaire for two to four persons with PIMD. The number of professionals that filled out a questionnaire per person with PIMD ranged from one to six professionals, whereas two professionals (30%) per person with PIMD 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 ($SD = 11$). The percentages of the type of professionals are shown in Table 1.

Comparisons between parents and professionals

For each person with PIMD, mean scores on the Enabling & Partnership and Respectful & Supportive

Care scales for the parents ($n = 109$) and mean scores on the Showing Interpersonal Sensitivity and Treating People Respectfully scales for the professionals ($n = 144$) were calculated. These mean scores for the parents and the professionals are listed under the titles “Enabling & Partnership” and “Respectful & Supportive Care” in Table 2. The group means indicate that the parents rated the occurrence of behaviours significantly higher than the professionals. There was no significant difference in means of the importance scores of the first scale (Enabling & Partnership) between parents and professionals. Parents rated the importance of the second scale (Respectful & Supportive Care) significantly lower than the professionals. Effect size estimates were added in Table 2 and show a negative practically insignificant effect size on the Enabling & Partnership importance scale ($d = -.11$), a negative large effect size on the Enabling & Partnership occurrence scale ($d = -1.42$), a positive small effect size on the Respectful & Supportive Care importance scale ($d = .37$), and a negative medium effect size on the Respectful & Supportive Care occurrence scale ($d = -.58$). This means that the statistically significant disagreements between parents and professionals on the Enabling & Partnership and Respectful & Supportive Care occurrence scales and the Respectful & Supportive Care importance scale are also practically relevant.

The results of the Bland–Altman plots showed that there was on average 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 & Partnership and Respectful & 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.

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,

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

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

Note. 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.

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 & Partnership		Respectful & Supportive Care	
	Occurrence scores ^{a*}	Importance scores ^b	Occurrence scores*	Importance scores*
Parents	4.83 ($SD = 1.10$)	3.15 ($SD = .54$)	4.46 ($SD = 1.34$)	2.95 ($SD = .69$)
Professionals	2.69 ($SD = 1.00$)	3.08 ($SD = .41$)	3.42 ($SD = 1.29$)	3.27 ($SD = .37$)
<i>d</i>	–1.42	–.11	–.58	.37

Note. *d* = effect size agreement.

^aMean occurrence score on a scale from 1 to 7.

^bMean importance score on a scale from 0 to 4.

*Significant difference between parents and professionals based on multilevel models without predictors.

Table 3. Percentages of parents reporting “problems” with the family-centredness of the support.

Item	n	%
Enabling & Partnership (EP)	45	29.8
Fully explained the individualised educational program/individualised support program 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
Recognised that your family has the final say regarding the individualised educational program/individualised support program 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
Providing Specific Information about the Child (PSI)	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
Coordinated & Comprehensive Care for Child and Family (CCC)	53	35.1
Suggested proposals that fit with your family’s needs and lifestyle?	31	20.5
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 that 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
Recognised 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., 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, programs, 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
Respectful & Supportive Care (RS)	45	29.8
Accepted you and your family in a non-judgemental 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

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.

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 &

Supportive Care importance model. The role of the parent was significant in the Respectful & Supportive Care importance model. Additionally, the presence of sensory problems turned out to be significant in the Enabling & Partnership occurrence model, and years of experience of the professional was significant in the Respectful & Supportive Care importance model. To determine which groups of parents, persons with PIMD, and professionals agree with each other and which groups do not, we calculated the estimated agreement for the different groups (see Tables 4 and 5). The estimated agreement in the Respectful & Supportive Care importance model is given for the professional with mean years of experience. Six additional groups are distinguished in the Enabling & Partnership occurrence model due to the significance of the presence of sensory problems in this model.

Table 4. Estimated agreement (diff) between professionals and parents for different groups of parents and professionals with respect to occurrence and importance in the Enabling & Partnership model.

Factors	Occurrence EP Estimated agreement 95% CI	Importance EP Estimated agreement 95% CI
Indirect/other	-3.087* [-3.68, -2.50] ^a	-0.011 [-.23, .21]
Indirect/father	-2.550* [-3.19, -1.91] ^a	-0.158 [-.44, .12]
Indirect/mother	-2.648* [-3.26, -2.03] ^a	-0.273* [-.50, -.05]
Direct/other	-1.621* [-2.26, -.99] ^a	0.283* [.05, .52]
Direct/father	-1.084* [-1.75, -.42] ^a	0.136 [-.15, .42]
Direct/mother	-1.182* [-1.83, -.53] ^a	0.020 [-.22, .26]
Indirect/other	-2.467* [-2.96, -1.98] ^b	
Indirect/father	-1.930* [-2.55, -1.31] ^b	
Indirect/mother	-2.028* [-2.54, -1.51] ^b	
Direct/other	-1.001* [-1.54, -.46] ^b	
Direct/father	-0.464 [-1.11, .19] ^b	
Direct/mother	-0.562* [-1.12, .00] ^b	

Note. EP = Enabling & Partnership.

^aNo sensory problems.

^bWith sensory problems.

* $p < .05$.

The results presented in Table 4 show that in the Enabling & Partnership occurrence model, all groupings of parents, professionals, and persons with PIMD with and without sensory problems disagreed significantly (all gave higher ratings than the professionals), with the exception of one group: fathers and directly involved professionals agree when the persons with PIMD have sensory problems. Although this agreement is not statistically significant (zero is in the interval), the confidence interval also includes minus one, indicating that more than one response category difference is also compatible with the data. This means that the estimated agreement can be regarded as practically relevant. In the Enabling & Partnership importance model, mothers and indirectly involved professionals significantly disagreed (mothers gave higher ratings), and other legal representatives disagreed significantly with directly involved professionals (other legal representatives gave lower ratings). The confidence intervals all include relevant differences, showing that all statistically significant

Table 5. Estimated agreement (diff) between professionals and parents for different groups of parents and professionals with respect to occurrence and importance in the Respectful & Supportive Care model.

Factors	Occurrence RS Estimated agreement 95% CI	Importance RS ^a Estimated agreement 95% CI
Indirect/other	-1.433* [-1.97, -.89]	0.430* [.19, .67]
Indirect/father	-1.357* [-2.05, -.67]	0.427* [.12, .73]
Indirect/mother	-1.260* [-1.81, -.71]	0.054 [-.19, .30]
Direct/other	-0.058 [-.66, .54]	0.532* [.28, .79]
Direct/father	0.018 [-.71, .75]	0.529* [.22, .84]
Direct/mother	0.115 [-.50, .73]	0.156 [-.10, .42]

Note. RS = Respectful & Supportive Care.

^aFor mean professional experience in years.

* $p < .05$.

disagreements are also practically relevant. Table 5 shows that in the Respectful & Supportive Care occurrence model, fathers, mothers, and other legal representatives all disagreed significantly with indirectly involved professionals: they gave higher ratings than the indirectly involved professionals. Finally, in the Respectful & Supportive Care importance model, fathers and other legal representatives disagreed significantly with both indirectly involved and directly involved professionals: they gave lower ratings than the professionals. No significant disagreement was found between any type of parent and directly involved professionals. The confidence intervals show that all statistically significant disagreements were also practically relevant, and all not statistically significant disagreements were also not practically relevant. Age of the person with PIMD, amount of additional disabilities, the presence of challenging behaviour, and whether the person with PIMD lived in a residential setting or with family carers were not significantly explanatory for the found differences in agreement between parents and professionals.

Discussion

In this study, we analysed agreements between parents and professionals in relation to how they perceived the support provided to the person with PIMD. The relationship between these agreements and person with PIMD's characteristics, the characteristics of the parents, and the characteristics of the professionals were also examined. Multilevel analyses showed that, in general, the parents and the professionals disagreed on occurrence and importance of both the Enabling & Partnership scale and the Respectful & Supportive Care scale. Sensory problems, the role of the parent (father, mother, or other legal representative), the type of professional (directly vs. indirectly involved), and years of experience of the professional explained the agreements in scale scores between parents and professionals for the different models. The effect size estimates and confidence intervals show that all statistically significant disagreements also have practical relevance and that the not statistically significant disagreements, with one exception, do not have any practical relevance. In the Enabling & Partnership occurrence scale, the agreement between fathers and directly involved professionals when the person has sensory problems is practically relevant. An explanation for this finding may be that in this study the number of fathers is relatively small. In such cases there is insufficient information to get significant results in case of relevant results. 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 support given to persons with PIMD. However, research in the field of paediatric disability and early intervention has focused on comparisons between parents' and professionals' perceptions of the family-centredness of services (Dickens et al., 2011; Dyke et al., 2006; Jeglinsky et al., 2012; O'Neil et al., 2001; Raghavendra et al., 2007; Whitton et al., 2008). In these studies, mean ratings of parents and professionals on the different scales of the MPOC are presented separately. The dissatisfaction of a substantial number of the parents with the support provided, as shown in our study, is similar to the findings of Nijhuis et al. (2007), showing that 19–38% of the parents indicated that they did not receive the support they deemed important. In the international literature on the MPOC, various studies have found similar results, but only on the occurrence of family-centred behaviour by professionals, as no important ratings were added (Dyke et al., 2006; Jeglinsky et al., 2012). Although 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 support that parents identified as not having received but which they valued as very important, areas of improvement become clear. In our 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." Although Nijhuis et al. (2007) labelled the combination of not-important/received as "non-problematical," we included this combination as a "problem" as it suggests 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. These percentages are not striking, but they show that further fine-tuning of the specific content of the support may be considered.

In this study, the parents were (with the exception of four persons) born in the Netherlands. Their children

were adults and in residential provision. 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.

This study has some limitations. First, 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. Second, we used the Dutch MPOC-SP-PIMD for adults with PIMD, whereas the original instrument was developed for children. Only recently, the MPOC for service providers working with adult clients (MPOC-SP(A)) in the field of rehabilitation was developed and validated by Bamm, Rosenbaum, Wilkins, and Stratford (2015). The MPOC-SP(A) is an adaptation of the original MPOC. As our target group of persons with PIMD is characterised by, among others, a developmental age up to 24 months, and persons with PIMD are totally dependent on others in every aspect of their daily lives, we feel it is justifiable to have used the MPOC-SP-PIMD for an adult population. Notwithstanding, we should accept that there may be significant differences in perceptions of occurrence and importance of different supports as the person with PIMD ages and sometimes lives a life more independent of their parental direct care. Third, our multilevel analysis did not take into account that a third (37%) of the professionals gave scores for more than one person with PIMD, implying additional dependencies between persons. However, as nearly two-thirds of the professionals scored only one person with PIMD, and as both person with PIMD and professional characteristics were included in the model, we expect that these additional dependencies will have had little effect on the results. A model taking these dependencies into account would require a lot more data. Fourth, 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. The study of Nijhuis et al. (2007) is, as far as we know, the only other study that made use of the MPOC and MPOC-SP in a family-specific way. Also in this study, the parents rated the behaviours of professionals in general, whereas the professionals rated their own behaviour towards a specific family. 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. Fifth, in this study, we regarded an estimated agreement of more than 0.5 in the importance scales as practically relevant, as they have a range of 0 to 4. We regarded an estimated agreement of more than one point in the occurrence scales as practically relevant, as they have a range of 1 to 7. For instance, a difference of at least one point in the occurrence scales means that the disagreement makes sense only if there is a difference of more than one response category (e.g., *to a small extent* vs. *to a moderate extent*). For the importance scale, a difference of more than 0.5 point means that the disagreement is not larger than the half of a response category (e.g., *halfway neutral* vs. *important*). These cut-off scores seem to be rather arbitrary but do make sense regarding the practical relevance of the results. Sixth, participants were not aware of the fact that if they did not complete the questionnaire fully, the questionnaire may not be valid and therefore their responses would not be analysed. This is a point of attention for further use of the MPOC in general. Finally, the response of 42 parents could not be used in the analysis, due to the fact that professionals did not return valid questionnaires for the children of these 42 parents. A possible explanation for the finding that these 42 parents who were not included in this study had significantly lower ratings on the two scales concerning occurrence may be that the professionals were not actively involved with these persons, perhaps due to the number of years the persons had lived in a facility, and therefore did not fill out the questionnaire completely. As the 42 parents not included only differed on these two aspects, we assume that the 109 persons with PIMD included in this study are representative of the 151 persons with PIMD.

The results of this study show 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. The importance of collaboration and shared decision-making might even increase as people with PIMD get older. As they are more likely to experience significant health issues and may have increasing physical deformities, significant medical intervention may be needed.

In practice, when parents and the facility that provides support to a person 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 person with PIMD and his or her family.

Notes

1. In the Netherlands, parents of a person 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, day care centres, or various small- or large-scale housing projects.
2. 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 a social or educational background. Indirectly involved professionals are professionals that are involved in the support of persons with PIMD, but not on a structural daily basis, such as psychologists, physicians and therapists (speech therapists, occupational therapists, physical therapists, dieticians).

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