Chapter 7
General discussion
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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, & Ghoe, 2006; Njehuis et al., 2007; Pretis, 2013; 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; Pretis, 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
Dickens, K., Matthews, L.R., & Thompson, J. (2010). Parent and service providers' perceptions regarding the delivery of family-centered paediatric rehabilitation services in a children's hospital. Child: Care, Health & Development, 37(1), 64-73.