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

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; 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...
What makes a difference?

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-Centred 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 publications 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.

![Selection process and results](image)

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 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>
<thead>
<tr>
<th>Author(s)</th>
<th>Aim</th>
<th>Sample</th>
<th>Level of disability</th>
<th>Setting</th>
<th>Measurement</th>
<th>Major conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barelds et al. (2011)</td>
<td>To develop and validate an instrument (QUALITRA-ID-P) to assess the quality of care and service trajectories for relatives of people with ID.</td>
<td>38 (pilot study) parents and/or relatives. Mean = 47 28% male 72% female</td>
<td>-</td>
<td>R DC</td>
<td>QUALITRA-ID-P*</td>
<td>The questionnaire with good psychometric properties consists of 49 items with 3 factors: mutual exchange of information, material and bureaucratic aspects, procedural outcome.</td>
</tr>
<tr>
<td>Blue-Banning et al. (2004)</td>
<td>To examine what specific indicators of professional behaviour parents and professionals identify as indicative of collaborative partnerships.</td>
<td>137 family members &lt; 20 (18%) 30-60 (67%) - 72% female 91% female</td>
<td>41% African American 17% Latino 30% White 4% Other 70% White 32% African American</td>
<td>Mi: 42% Mo: 45% S+P: 4%</td>
<td>DC</td>
<td>Focus groups and individual interviews</td>
</tr>
<tr>
<td>Ferguson (2008)</td>
<td>This study focus on the relationship of families and professionals in the early twentieth century.</td>
<td>100 parents - - - -</td>
<td>-</td>
<td>R</td>
<td>Thematic analysis</td>
<td>The relationship between parents and professionals then, as now, was often a troubled and troubling, characterized by suspicion on both sides.</td>
</tr>
<tr>
<td>Fonteine et al. (2008)</td>
<td>To explore the nature, topics and form of the information that is transferred between parents and teachers.</td>
<td>12 children Mean = 9.6 Range 3-18 6 male 6 female</td>
<td>-</td>
<td>P</td>
<td>DC</td>
<td>Communication logs</td>
</tr>
</tbody>
</table>

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.
### Shared responsibility: a load off your mind

What makes a difference?

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Aim</th>
<th>Sample</th>
<th>Setting</th>
<th>Measurement</th>
<th>Major conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>De Geeter et al. (2002) (The Netherlands)</td>
<td>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.</td>
<td>723 parents (pretest) 337 (of the 723 ) parents (post-test)</td>
<td>P</td>
<td>Questionnaire about supervision and transfer of information</td>
<td>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.</td>
</tr>
<tr>
<td>Schwartz (2005) (Israel)</td>
<td>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.</td>
<td>71 parents and their children.</td>
<td>Mo: 52%</td>
<td>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)</td>
<td>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.</td>
</tr>
</tbody>
</table>

Note: M=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)
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.

Fonteine 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 Fonteine 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.

Shared responsibility: a load off your mind

What makes a difference?
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
We wish to thank Anouk van Es for assisting with the literature search.

2.6 References


Shared responsibility: a load off your mind

What makes a difference?


