Shared responsibility: a load off your mind
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Chapter 1

Introduction

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

In the Netherlands, the parents of children with PIMD have access to an extensive system of professional services, such as different types of schools for special education, with or without therapy services, daycare centres, and various large- and small-scale housing projects. In many cases, parents participate in the practical side of the professional support, such as doing the laundry, going to specialists or contributing to leisure activities, but are less involved in the content of support. In a study by Nijhuis et al. (2007) of rehabilitation, a considerable number of parents indicated that their children did not, in their opinion, receive the support they found important. The differences in opinion between parents and professionals about what is important in the support of a child is a threat to perceptions of satisfaction with the support, experienced by both parents and professionals. Moreover, satisfaction with the support provided could be an important element in collaboration between parents and professionals.
When a child with PIMD moves away from his parental home, professionals take over the daily support of the child. Ideally, the expertise of both parents and professionals should converge to come to a better understanding of who the person with PIMD is and what he or she needs. This will in turn lead to opportunities for joint goal-setting and mutual decision-making (Vlaskamp, 1999). Collaboration in this way can be seen as a way of improving the quality of life of children and their families, working with an idea of shared ownership and responsibility (Bishop, Woll & Arango, 1993).

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

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

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

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

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

1.1 Outline of the thesis

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

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

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

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

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