

## University of Groningen

### Family matters

Luijkx, Jorien

**IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.**

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2016

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Luijkx, J. (2016). *Family matters: The experiences and opinions of family members of persons with (severe) or profound intellectual disabilities*. [Thesis fully internal (DIV), University of Groningen]. Rijksuniversiteit Groningen.

#### Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

#### Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

# 7

---

## General discussion

The aim of this study was to acquire knowledge concerning the views and experiences of parents and family members raising a child with ID in order to improve support for families. First, we wanted to acquire knowledge about the views of parents and/or legal guardians concerning the quality of the support provided to their relative with ID in residential care. Second, we focused on a specific category of parents, namely those with a child with severe or profound intellectual and multiple disabilities (PIMD). In this part we wanted to acquire knowledge about the experiences and views of family members (parents and siblings) of children with PIMD living at home. Both objective time use as well as the perceived quality of life were studied.

### **7.1 Main findings**

In the first part of this thesis the focus was on the parents and/ or legal guardians of persons with ID living in a residential facility. In the study presented in chapter two, we found that the majority of parents and/or legal guardians are satisfied with the quality of support (score: 7.3 out of 10). However, some of parents and/or legal guardians are not satisfied with the quality of support (rate below 6; 10%) or only marginally satisfied (rate: 6 to 7; 25%). In a previous study by Jansen, Van der Putten and Vlaskamp (2013), we saw similar results indicating that a substantial proportion of parents of children with PIMD were not completely satisfied, especially with regard to mutual cooperation. Parents pointed out that they were neither actively engaged in decision-making, nor asked to present their concerns and opinions. Residential facilities need to focus on improving support by aiming to deliver family-centred support and listen to what parents find important in the support for their relative. This is especially important for those parents and/or legal guardians who are not or only marginally satisfied. The study in chapter two also showed that the highest percentage of unsatisfactory scores by parents and/or legal guardians were in the leisure activities domain.

The results of the abovementioned study suggest that other factors explain the differences in satisfaction of parents and/or legal guardians. Literature shows an association between the number and severity of disabilities in a person with ID and the intensity of support needed (Harries et al, 2006); the severity of the ID is related to support outcomes (Felce & Emerson, 2001). Thus, a follow-up analysis was conducted. This is reported in Chapter Three. Parents and/or legal guardians were divided into two groups (and two subgroups) depending on the severity of the ID (and additional disabilities) of their relative. Results showed that only on the leisure activities domain did parents and/or legal guardians of people with a severe or profound ID rate the quality of leisure activities significantly lower than parents and/or legal guardians of people with less severe ID did. In all other domains, no differences were found between the groups of parents. Also, no significant differences were found between the opinions of parents and/or legal guardians of people with and those without severe additional disabilities. We concluded that differences in the opinion of parents seems to be less dependent on the severity of the ID and additional disabilities than was expected. It still remains to be seen what aspects do relate to the differences in the opinion of parents. The results concerning leisure activities correspond with those of a previous study, in which concerns were raised about the quality and quantity of leisure activities for persons with PIMD (Zijlstra & Vlaskamp, 2005). Zijlstra and Vlaskamp (2005) showed that the majority of persons with PIMD were only offered 2 to 5 leisure activities per weekend, including passive activities such as watching television (Zijlstra & Vlaskamp, 2005). Also, the number of activities offered decreases with increasing age of the person with PIMD (Zijlstra & Vlaskamp, 2005). Daily leisure programmes for people with severe to profound intellectual disabilities in residential facilities have shown promising results (Fox, Burke, & Fung, 2013). A stronger focus on the high-

quality leisure activities which are adapted to the needs and wishes of people with PIMD is therefore of great importance to enhance the quality of support to people with PIMD in a residential facility.

In the second part of the current thesis, we focused on families with children with PIMD living at home. Raising a child with PIMD is expected to be extremely demanding. However, we know little about the daily time use of parents raising a child with PIMD. Getting a better understanding of the time use of parents can help to improve support for families raising a child with PIMD. In this study, the daily time use of parents was examined and compared to the daily time use of parents of typically developing children under 12 (chapter four). Despite the similarities in the average time spent by parents raising children with PIMD and the average time spent by parents of typically developing children on contracted activities (paid work and educational activities) and necessary activities (personal care, eating and drinking, sleeping), some important differences were found. Mothers and fathers of children with PIMD spend a substantial amount of time on activities concerning the care and supervision of their child with PIMD (on average 2.1-2.6 hours per day), especially when compared to parents of typically developing children (on average 0.2 hours per day). Thus, mothers of children with PIMD spend significantly less time on domestic work compared to mothers of typically developing children. Also, both mothers and fathers have significantly less free time compared to parents of typically developing children. The most important conclusion is that notwithstanding the substantial hours of professional support (on average 41 hours per week), the daily time use of parents raising a child with PIMD is still substantially different and more burdensome compared to the time use of parents of typically developing children.

We also examined parents' positive and negative appraisals of the impact of raising a child with PIMD on family life in chapter five, to get a better understanding of the subjective impact on parents raising a child with PIMD. An important finding in this study was that mothers and fathers appraise the impact of raising a child with PIMD on family life both positively and negatively to a substantial degree. This corresponds with previous research (Trute, Hiebert-Murphy, & Levine, 2007). A more striking result was that parents raising a child with PIMD appraise the impact of raising a child with PIMD on their family significantly more positively and more negatively than parents of children with less severe disabilities. Apparently, parents of children with PIMD should be seen as a group with their own perspective, who experience a more pronounced impact both positively and negatively. Negatively appraised items mainly concerned problems in time use, such as extraordinary demands, reduction of time with friends and disruption of habits. It also concerned a worsening of the financial situation of parents, which corresponds with the study described in chapter four. The aspects valued positively by the majority of parents were mainly non-material, such as the awareness of family members of the needs and struggles of other people with family members with persons with disabilities.

Children with PIMD not only have a substantial impact on their parents, but most likely also on their siblings. Therefore, we studied the positive and negative experiences of young siblings of children with PIMD in chapter six. Siblings of children with PIMD experience both a positive and negative impact of having a sibling with PIMD, which indicates it influences the siblings in multiple ways. The combination of positive and negative aspects of having a sibling with PIMD corresponds with a previous meta-analysis study by Rossiter and Sharpe (2001), which showed that there is at most a minor negative impact of having a sibling with ID. The topic most

often mentioned by the siblings of children with PIMD, and therefore an important topic, was 'joint activities'. The siblings described how they enjoyed shared activities, but many activities were not possible with their brother or sister with PIMD. Another important outcome is the siblings' need for private time. Support and opportunities to share experiences were not or rarely mentioned in the interviews with the siblings of children with PIMD. It is possible that the method used did not encourage siblings to talk about getting (professional) support, or whether the siblings did not mention this topic because support was unavailable or not considered necessary.

The overall conclusion of this thesis is that a large proportion of parents and legal guardians are satisfied overall with the quality of support offered to their child with ID in residential support. However, a considerable proportion is not, or only marginally, satisfied, especially in the domain of leisure activities. Nonetheless, the results of the study do not explain why this group of parents and/or legal guardians is less satisfied. Raising a child with PIMD at home has objective and subjective consequences for the family members. Parents spent substantially more of their time on child care activities compared to parents of typically developing children, and they experience these extraordinary time demands as a burden, in particular with regard to their (the parents') social activities. On the other hand, parents also experience positive consequences of raising a child with PIMD. Similarly, young siblings of children with PIMD experience some difficulties, but their overall view is rather positive. The results underline the importance of awareness of the experiences and views of parents and siblings in order to better understand the lives of families of people with ID/PIMD.

## **7.2 Theoretical reflections**

Although much remains unknown with regard to the importance of family-centred services for families and the quality of family life, evidence suggests

that a family-centred approach enhances the well-being of families (King et al., 1999). The emphasis on systems theory and family-centred services has broadened the focus from the individual with ID to the individual and his or her family. It is important to know more about the views of family members and the impact of a person with ID/PIMD on family members. Every member of the family is affected by the child with PIMD in his or her own way, and has his or her own views. This research increases our understanding of the views of family members of a person with ID/PIMD by asking all family members for their views. This is important when we want to support the whole family instead of just the person with ID/PIMD. The results of the research provide insight into the views of parents and/or legal guardians on the quality of support for their relative with ID in residential care. This is an important perspective in addition to the views of the person with ID himself or herself. Our research also added to the knowledge base concerning a specific group of family members, namely family members of people with PIMD who are growing up at home. We now know in more detail about the unusual ways in which mothers and fathers in our study use their time. We also know more about the positive and negative parental appraisals of the impact of raising a child with PIMD. Also, we let siblings explain how a brother or sister with PIMD has an impact on their lives. Broadening the focus to include the individual with ID/PIMD and his or her family suggests that a broader range of support for families is necessary. The distinctly negative appraisals of parents of the impact of children with PIMD on family life indicate that not only the individual with PIMD should be professionally supported, but family members too. However, the different family roles and experiences related to the impact a child with PIMD has on the family result in a complex situation when it comes to professional support in families. In a study of Davis and Gavidia-Payne (2009) professional support was found to



be one of the greatest predictors in promoting positive family outcomes. In supporting families with children with PIMD, professionals, policymakers and other people involved should take into account the conclusions of this study concerning time use patterns of families raising a child with PIMD, the parental appraisal of the impact of a child with PIMD on family life, and the impact on the lives of siblings of children with PIMD. Support should be tailored to the needs and wishes of all family members, according to the principles of family systems theory, especially since previous research has shown that families of children with disabilities seem to have smaller networks of informal support than families of typically developing children (Herman & Thompson, 1995). In addition, professionals and policymakers should be aware of the extra time and energy that home-based programmes and additional therapy activities demand of families (Crowe & Florez, 2006). This is particularly relevant when parents are expected to provide therapeutic care, or are expected to play roles which they do not want (Leiter, 2004). While interventions and therapy are important to help children reach their full potential, the roles and tasks parents take upon themselves need to be taken in account when supporting families. Support such as services which enable parents to take a short break should be made available. In the Netherlands, government policy encouraging the provision of informal care makes this type of support to families even more necessary (De Klerk, De Boer, Plaisier, Schyns, & Kooiker, 2015).

The growing emphasis on the impact of children with ID on the family as a whole has generated studies on not only negative but also on positive aspects. Positive and negative emotions can coexist during times of distress and provide protective functions (Blacher, Baker, & Berdovits, 2013). Although this research identified important negative aspects of raising a child with PIMD, it also generated insight into the positive aspects of

having a family member with PIMD. Both parents and siblings described positive aspects of having a child with PIMD in the family. It is important to understand not only the the negative experiences, but also the positive ones because these can be seen as a form and outcome of coping for parents. Further, several studies showed that positive experiences can be seen as a buffer for stressful experiences (Folkman, 2008, Folkman & Moskowitz, 2000).

### **7.3 Methodological reflection and future research**

Although the studies presented in this thesis provide important knowledge on the views and experiences of family members of people living in a residential facility and at home, some general methodological limitations should be recognized.

The parents and/or legal guardians in this thesis gave their views on the quality of support provided to their relatives in one large care organization. This limits the generalizability of the results of this part of the study. Also, in the studies on families of children with PIMD (chapters four, five and six), the participants were not randomly selected but part of a convenience sample. In order to engage as many parents as possible, various strategies were used. The estimated number of people with PIMD in the Netherlands is nearly 10,000 (Vugteveen, Van der Putten, & Vlaskamp 2014). The population size of children with PIMD cannot be determined, which makes it difficult to know how representative our sample is (Vugteveen, Van der Putten, & Vlaskamp 2014). Vlaskamp estimates that there are between 3000 and 4000 children with PIMD living in the Netherlands (Vlaskamp, 2015). Our sample consisted of only Caucasian, two-parent families of children with PIMD living at home, so the results cannot be generalized to single parents, or families with different ethnic backgrounds, or to families of children with PIMD not or only partly living at

home. It would be interesting to study the relationship between family and child characteristics and the impact of a person with PIMD on family members in future research. For example, families from different ethnic backgrounds might have different experiences of raising a child with PIMD at home (Harry, 2008; Seligman & Darling, 2009). In a multicultural society like the Netherlands, such information is of great importance for professionals supporting these families. Further, the results of our study do not give us insight into changes in impact over time. Transition periods, marked by transitions to school or daycare, for example, or the transition from childhood to adolescence and later to adulthood, can be challenging and stressful for parents of children with severe disabilities (Minnes, Perry, & Weiss; Neece, Kreamer, & Blacher, 2009). The impact of children with PIMD on the quality of family life can fluctuate over time. Future research should therefore focus on the impact a child with PIMD has on family life before, during and after specific transition periods, and on the support families need during these periods.

Rather short and straightforward questionnaires were used in the studies described in chapters two, three and five. This data provided insight into the views of parents about the quality of support for their relative in professional support, and insight into the appraisals of parents of the impact a child with PIMD has on the family, but these insights are merely a starting point. The questionnaire method does not provide parents with an opportunity to explain why they answered as they did. In future research, but also in practice, in-depth interviews should help us to understand which aspects of professional support should be improved and give us insight in the experiences of families raising a child with PIMD at home

In the study on the experiences of siblings of children with PIMD, relatively young siblings participated. The research aimed to describe rather

than quantify the experiences of siblings. The extent to which these experiences also apply to older siblings, such as teenagers, cannot be estimated. It is quite possible that the impact on siblings evolves over time. Therefore it would be interesting to focus on the experiences of older siblings in future research and follow siblings longitudinally. Also, siblings could, for example, be given the opportunity to recall their childhood experiences. Letting siblings look back with more distance and greater maturity on their childhood with a brother or sister with PIMD might give us an interesting insider's perspective. Knowing more about the experiences of siblings over time could lay a framework for the needs and supports of siblings. Future research should look into the support needs of siblings. It is unknown whether siblings of children receive support, what form this support takes, and how siblings experience this support.

A final recommendation for future research would be to conduct studies in close cooperation and partnership with families, for example in participatory research (Carpenter, 1997; Jagosh et al., 2012). The research agenda should be composed of topics families themselves consider important, and designed and conducted in collaboration with families (Knox, 2000).

#### **7.4 Implications for practice**

Although this thesis showed that the majority of parents were satisfied with the quality of support in residential care, professionals should keep asking for the perspective of family members on the quality of support and work in close collaboration with families. Organizations should focus in particular on family members who are dissatisfied, and should work in partnership with these families to improve the quality of support. This corresponds with the emphasis on family-centred services (King et al., 1999). The questionnaire used in this study is recommended as a tool or starting point to discuss the quality of support offered to a person with ID with family members. But

attention should also be paid to the wellbeing of all family members in families raising a child with PIMD at home. The focus should not only be on supporting the child with ID/PIMD, but on supporting the family as whole and meeting the needs of all individual family members.

The results of this study showed that extraordinary demands are made on the time of parents raising children with PIMD at home. Parents reported that a substantial number of hours were spent on care responsibilities, and that they had fewer hours of free time per week than parents of typically developing children. Research showed that having more time for leisure activities improves well-being and mental and physical health (Iwasaki, 2006). Tailor-made professional support for parents of children with PIMD, such as short-break services in or outside the family home, can be a key solution to temporarily relieve parents of their care responsibilities (Robertson et al., 2011). A review study suggests that short-break services have a potentially positive impact on the well-being of parents, their children with ID and the family as a whole (Robertson et al., 2011). Short-break services also show promising effects on the well-being of siblings of children with ID (Welch et al., 2012) and might enable siblings to enjoy private time with their parents. Short-break service providers and families together should consider how the services can be combined with other professional support. The current study showed that siblings of children with PIMD enjoyed shared activities with their brother or sister with PIMD, but also report barriers to performing such activities. Since shared experiences are the basis for long-term sibling relationships (Campbell, Connidis, & Davies, 1999), it is important for professionals to look for opportunities to facilitate shared activities for brothers and sisters with and without PIMD.

It is important to know what families raising a child with PIMD experience in daily life. We should also listen carefully to the support needs

of parents and siblings, in addition to the support needs of the person with PIMD. A more interpretive approach which recognizes all family members as experts on their own experiences is critical (Knox, 2000). All family members have their own perspectives on the quality of support and the impact on family life if a child is still living at home. Only by listening to and integrating the perspectives of all family members will it be possible to offer support that is adapted to the needs and wellbeing of families raising a person with ID/PIMD.

## References