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Published in:
Journal of Intellectual Disabilities

DOI:
[10.1177/1744629516641843](https://doi.org/10.1177/1744629516641843)

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:
2017

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

Citation for published version (APA):

Jansen, S. L. G., van der Putten, A. A. J., & Vlaskamp, C. (2017). Parents' experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: A multiple case study . *Journal of Intellectual Disabilities*, 21(1), 53-67. <https://doi.org/10.1177/1744629516641843>

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Parents' experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: A multiple case study

Journal of Intellectual Disabilities
2017, Vol. 21(1) 53–67
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DOI: 10.1177/1744629516641843
journals.sagepub.com/home/jid

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Date accepted: 6 March 2016

Abstract

Background: There is little data on the collaboration between parents and professionals in the support of persons with profound intellectual and multiple disabilities. Since communication is essential to collaboration, this study analysed the frequency, means, and personal experiences of communication between parents and professionals. **Method:** A multiple case study ($n = 4$) was conducted. Observations were logged for every contact between professionals and parents during 12 months. **Results:** The mean number of contacts a month ranged from 1.9 to 16.7 across the cases. Most of the contacts were with the child's direct support persons (85.2%) and exchanging information (35.5%) was the most common function. Issues concerning health (28.4%) were the most common subjects discussed. The majority of the mothers' experiences were positive. **Conclusion:** Direct support persons play a crucial role; they need to be aware of this role and to be trained to fulfill their role to acknowledge parents as partners.

Keywords

collaboration, communication, case study, profound intellectual and multiple disabilities, professionals

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Introduction

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. If parents experience effective collaboration with the professionals who support their children, they are more satisfied with the support provided and feel that their children's quality of life is better than when effective collaboration is absent (Blue-Banning et al., 2004; Denboba et al., 2006; Dunst et al., 2007; King et al., 1996; Law et al., 2003; MacKean et al., 2005; Trivette et al., 1995). Collaboration between parents and professionals is essential in the support of persons with profound intellectual and multiple disabilities (PIMDs) because these children literally cannot speak for themselves: their parents are their spokespersons. Children with PIMDs are characterized by a combination of profound intellectual and profound or severe motor disabilities and are often faced with additional disabilities such as sensory impairments and various health problems (Nakken and Vlaskamp, 2007). The parents of a child with PIMDs possess a wealth of information about their child and should be regarded as experts of their own child and his or her needs, desires and opportunities (De Geeter et al., 2002; Vlaskamp et al., 2011).

Previous studies have argued that in order to establish effective collaboration between parents and professionals in the support of persons with PIMDs, insight into what parents and professionals find important regarding the support provided is necessary (Jansen et al., 2013). Jansen et al. (2014) found that although most parents of children with PIMDs supported by a large organization¹ were satisfied with the support provided in terms of family centredness, a substantial proportion of the 109 parents indicated that they did not always receive the support they found important (mean 34.4%), or received support that they did not find important (mean 4.8%). Topics 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 support system, being aware of changing needs and being a resource for parents were the most commonly mentioned items reported by parents as important but not received. Furthermore, parents and professionals often disagree about whether they perceive professional behaviour as family centred. Professionals and parents can also disagree on the importance of certain family-centred behaviour, for example, trusting parents to be the "experts" of their child or helping parents feel competent. Jansen et al. (2014) found disagreements on all these points between parents and professionals and, moreover, their study revealed that certain variables had significant effects on this disagreement. It appeared that the presence of sensory problems in the child, the role of the parent (father, mother or other legal representative), the type of professional (direct or indirect involvement)² and the number of years of experience working with the child were related to disagreements. Parents encounter many professionals in supporting their child with PIMDs (Mencap, 2001) and, therefore, building collaboration with parents is an important challenge.

In a literature review on the collaboration between parents and professionals in the support of persons with intellectual disabilities who receive support from professional service providers such as residential facilities, day-care centres or respite care, Jansen et al. (2015) found that there is a lack of an unequivocal definition of the concept of collaboration as well as clear definitions of related factors. Despite that, some recurrent factors related to or underlying collaboration were found. These factors are (1) communication, (2) mutual decision-making or equality, (3) evaluation, (4) trust and (5) respect. We define collaboration in the support of persons with PIMDs 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). Communication plays an important role in collaboration, first as a factor in its own right, but secondly also in relation to mutual decision-making and

evaluation. Thirdly, communication is a means to experience trust and respect and can therefore be considered to be a connecting factor (Blue-Banning et al., 2004). Communication is thus essential in collaboration between parents and professionals, and even more crucial in collaboration with parents of children with PIMDs, as these children cannot speak for themselves.

Communication is the exchange of information between at least two persons and has various aspects. These include how the communication is achieved, and the relationship between the persons communicating and the actual information exchanged. Therefore, how information is exchanged can impact on parents' experience of respect and feeling equal partners as much as the information itself, creating trust in the professionals supporting their children. Graungaard and Skov's (2006) study of parents' reactions to learning that their child is severely disabled notes the parents' desires and needs as regards communication. These are equality in collaboration between parents and physicians, an individual and specifically designed information strategy, an empathic and personal approach, treating the child as a child and not as a case and consideration of the child's opportunities despite his/her disabilities. Galil et al. (2006) evaluated the communication between physician and parent in child development centres, where they distinguished three different dimensions of communication: care, interest and collaboration. Communication was therefore, respectively, focused on aspects that showed care for parents, that showed interest in parents or that showed the intention to collaborate with parents in terms of joint decision-making. In a study by Pruitt et al. (1998) on parents' experiences about their interactions with special educators, almost a quarter of the parents responded that the quantity and the quality of the communication should be improved and indicated that communication with professionals should occur on a more frequent and consistent basis. The above-mentioned studies show that communication is not only about the specific information being exchanged between parents and professionals. The frequency, specific content and quality of the communication (being personal and showing equality and respect) seem to be of crucial importance if parents are to experience a sense of collaboration with professionals, which in turn leads to satisfaction with the support provided.

There is little data on the collaboration between parents and professionals in the support of persons with PIMDs, particularly when the person with PIMDs lives in a group home. Jansen et al. (2013, 2014) gathered quantitative data about the satisfaction of parents with the support of children with PIMDs and the opinions of parents and professionals about the occurrence and importance of family-centred behaviour. Given the complexity of the concept of collaboration and related factors (e.g. communication) due to the lack of unequivocal definitions and the interdependency of factors indicative of collaboration, qualitative data on collaboration are also needed.

The overall aim of our research is to optimize collaboration between parents and professionals in the support of persons with PIMDs. Since communication seems to be an essential factor in collaboration, knowledge about how parents and professionals communicate and how parents perceive the communication with professionals in the support of their child with PIMDs is necessary. Knowledge of how often communication occurs, with whom and by which means parents communicate, and of parents' experiences in communicating with professionals are needed to arrive at a better understanding of how effective collaboration can be shaped.

Method

Participants and procedure

Parents of children with PIMDs were asked to participate in this study. The inclusion criteria were:

- The child has a profound intellectual and multiple disability: a combination of profound intellectual and profound or severe motor disabilities and is often faced with additional disabilities such as sensory impairments and various health problems (Nakken and Vlas-kamp, 2007).
- The child has recently (<24 months) moved from home.

The last criterion was chosen to gain knowledge of the possible changes in collaboration over time. Various facilities in the Netherlands that provide small- or large-scale housing projects to persons with intellectual disabilities were approached by email or telephone for respondents willing to participate in this study. The parents could indicate their willingness to participate on a return form that was provided with a prepaid envelope. Thirteen parents who met the inclusion criteria were informed about the study and invited to participate. Of these 13 parents, 5 indicated that they did not want to participate without providing any reasons for their decision. One parent initially expressed her commitment but was eventually unable to participate due to personal circumstances. Of the seven parents who had expressed their commitment and took part in the study, three parents did not consequently complete the logbooks, despite several reminders, indicating that this method was too time-consuming for them.

This left data on four parents, all mothers. Before the study began, the mothers were assured of anonymity and confidentiality. Ethical approval was obtained in the Netherlands through the facility where the study was conducted. The mothers lived in different parts (north, east and west) of the Netherlands and their children lived in small or large group homes run by the three different organizations that provide support to persons with intellectual disabilities. The mothers were all married and had other children in addition to their child with PIMDs. At the start of the study, the children had lived for 14, 23, 23 and 20 months in the residential facility. All the children used day-care services. The distance from the parental homes to the homes where the children lived were comparable, namely, between 22 and 35 km. The parents agreed to the publication of the results of the study in a manuscript. The names of the parents and children presented here are fictional.

Mother 1

Marleen has a daughter, Janine, aged 23 years at the time the study started. At that time, Janine had been in residential care for 14 months. Janine has a profound intellectual disability and cannot walk, but instead she crawls. She has a visual impairment and chronic constipation. Janine has an older brother who moved from home at around the same time as Janine. Janine was in a respite care home from the age of 14.

Mother 2

Paula has a 23-year-old son, Bob, with PIMDs and who had lived in a residential facility for 23 months when the study started. Bob has severe intellectual and motor disabilities. He uses a wheelchair but loves to play on the ground. He moves by pushing himself around on his bottom. Bob cannot speak but makes all kinds of sounds. He has epilepsy. Bob used respite care before going to live in the residential facility where he now lives. Bob has an older brother and sister.

Mother 3

Sandra has a son, Thomas. He was 15 years old when the study started and had lived in residential care home for 23 months. Thomas has profound intellectual and motor disabilities, uses a

Table 1. Characteristics of participating mothers and their children.

Case	Age mother	Education	Profession	Other children	Age of child	Distance to facility (km)
1	51	HBO	Domestic worker/volunteer	Older brother	23	22
2	51	HBO	Volunteer	Older brother and sister	23	35
3	52	MBO	Nurse	Older brother and sister (twins)	15	28
4	54	HBO	Farmer	Two older sisters	25	33

Note. HBO: higher professional education or university of applied sciences; MBO: senior secondary vocational education.

wheelchair and has epilepsy. He can move around in his wheelchair using his arms. Thomas has an older brother and sister (twins).

Mother 4

Linda's son Koen was 25 years old when the study started and had lived in a residential facility for 20 months. Koen has profound intellectual and motor disabilities and uses a wheelchair. Koen has epilepsy. Before Koen lived in a residential home, he used respite care. He has two older sisters.

See Table 1 for an overview of the characteristics of the mothers and their children.

Design

A multiple case study was performed, with repeated measurements over a 12-month period, meaning that each time the mothers had contact with a professional within the residential facility, data on this contact were entered into a logbook.

Data collection

The data were gathered using a logbook. Over an uninterrupted period of 12 months, the mothers made entries into their logbooks each time they had contact with the professionals who supported their children. The mothers were asked to complete their logbooks for 12 months, partly to get more representative information and partly because of the assumption that the collaboration would change over time due to the growth in trust between the parents and the professionals as they got to know each other better and as the professionals got to know the children better. The mothers were told at the start of the study that because of the burden this study would place on them, they were free to decide how often they made entries into the logbooks. The professionals the mothers had contact with could be the professionals involved with the child on a daily basis, such as direct support persons (DSPs) or professionals who provide ad hoc support (e.g. speech therapists, physicians, psychologists, occupational therapists, etc.). The logbooks were semi-structured: the mothers had to enter with whom they had had contact, what the duration of the contact was (in minutes), how the contact was made (visiting the child, support plan meetings,³ formal meetings with the child,⁴ contact by telephone, letter or email, etc.), what the content of the contact was and how they experienced the contact in terms of communication.

The logbooks came with a short manual and an illustration of communication. This manual explained when the mothers should write in their logbooks (every time they had contact with a professional from the facility where their child lives), what they should write about (their

experiences with and feelings about the contact they had) and an explanation about how the data could be stored (digitally or on paper). Additional data on the children's and the mothers' characteristics were collected, including gender, age, education, profession, family structure and distance to the children's homes. The researcher maintained email contact with the parents every 2 months to check whether they had any problems in completing the logbooks or to remind them to complete the logbooks.

Analysis

The total number of contacts per case was counted. Frequencies were calculated for the means of contact per type of professional. The contacts were analysed according to function and subject using a categorization system and the parents' experiences were labelled and described in a narrative. To analyse the content of the logbooks, a categorization system was used to classify the function and the subject of the communication described in the logbooks (Fonteine et al., 2008). The classification system we used distinguished five categories (instead of the six categories of Fonteine et al., 2008): (1) exchanging information, (2) requesting, (3) expressing pleasure or displeasure, (4) complying with/denying requests and (5) other. The subject classification system had 10 categories: (1) sensomotor, (2) mood/emotions, (3) communication, (4) self-reliance, (5) health/physical functioning, (6) activity/relaxation, (7) activities of daily living, (8) practical matters, (9) private life and (10) other. The mothers' experiences were first labelled as positive, negative, not clear or missing. Cohen's κ was calculated for the function, the subject and the mothers' experiences as a measure of inter-rater reliability, with scores of 23.3% for the entries made by the first two authors. The results showed adequate inter-rater reliability: 0.80 for the function of the contact, 0.68 for the subject covered and 0.86 for the mothers' experiences with the contact. The content of the mother's experiences were then described in a narrative.

Results

Contact characteristics

The period the mothers filled in the logbooks differed: 9, 16, 12 and 13 months, respectively. Mother 1 did not manage to complete the log after 9 months, due to personal circumstances. Table 2 shows the frequency, means of contact and with whom the mother had contact per case. The total frequency of contacts per mother varied from 25 to 200 within the data collection period. The mean number of contacts per month ranged from 1.9 to 16.7. There were a total of 480 contacts between the mothers and the professionals, the majority of which were with the children's DSP or senior DSP (85.2%). The most common means of contact varied by mother. Whereas mothers 1 and 2 had the most contact by email (39.8% and 57.7%, respectively), mothers 3 and 4 mainly had contact with professionals visiting their children (59.5% and 24%, respectively). Mothers 2 and 4 had no contact with a physician or therapist. Except mother 4, none of the mothers had contact with a psychologist.

The function and the subject of communication

Figure 1 shows the function of the communication between the mothers and the professionals. 'Exchanging information' was the most common function of communication between the mothers and the professionals. This was the function on average in 39.2% of the contacts that mothers had

Table 2. Characteristics of contact.

Case	Number of months in facility	Number of months filling in logbooks	Total number of contacts (mean per month)	Means of contact	Number of contacts per professional (%)				
					DSP	Psychologist	Physician	Therapist	Manager
1	14	9	113 (12.6)	Visit	20 (17.7)	0	0	0	0
				Support plan meeting	0	0	0	0	0
				Formal meeting	6 (5.3)	0	1 (0.9)	2 (1.8)	0
				Telephone	3 (2.7)	0	1 (0.9)	1 (0.9)	0
				Written	45 (39.8)	0	6 (5.3)	1 (0.9)	2 (1.8)
				Other	22 (19.5)	0	2 (1.8)	1 (0.9)	2 (1.8)
				Total	96 (85.0)	0	10 (8.8)	5 (4.4)	4 (3.5)
2	23	16	142 (8.9)	Visit	7 (4.9)	0	0	0	0
				Support plan meeting	0	0	0	0	0
				Formal meeting	0	0	0	0	0
				Telephone	36 (25.4)	0	0	0	0
				Written	82 (57.7)	0	0	0	4 (2.8)
				Other	1 (0.7)	0	0	0	1 (0.7)
				Total	126 (88.7)	0	0	0	5 (3.5)
3	23	12	200 (16.7)	Visit	119 (59.5)	0	2 (1.0)	7 (3.5)	1 (0.5)
				Support plan meeting	1 (0.5)	0	0	0	0
				Formal meeting	2 (1.0)	0	1 (0.5)	2 (1.0)	0
				Telephone	20 (10.0)	0	1 (0.5)	1 (0.5)	2 (1.0)
				Written	24 (12.0)	0	0	6 (3.0)	0
				Other	2 (1.0)	0	1 (0.5)	1 (0.5)	0
				Total	168 (84.0)	0	5 (2.5)	17 (8.5)	3 (1.5)
4	20	13	25 (1.9)	Visit	6 (24.0)	0	0	0	2 (8.0)
				Support plan meeting	1 (4.0)	0	0	0	1 (4.0)
				Formal meeting	0	0	0	0	0
				Telephone	5 (20.0)	1 (4.0)	0	0	1 (4.0)
				Written	4 (16.0)	0	0	0	1 (4.0)
				Other	3 (12.0)	0	0	0	1 (4.0)
				Total	19 (76.0)	1 (4.0)	0	0	6 (24.0)
Total				409 (85.2)	1 (0.2)	15 (3.1)	22 (4.6)	18 (3.8)	

Note. The numbers may not sum to the total number of contacts per professional or to the total number of professionals due to missing data on means of contact or type of professional. Since the mothers were free to indicate several professionals per contact in their logbook, the number of professionals they had contact with does not necessarily correspond to the total number of contacts they had. DSP: direct support person.

Figure 1. Function of communication per mother.

with professionals. Exchanging information means updating each other about the child and the family. Exchanging information included, for example, the evaluation of a new intervention, keeping parents up to date about the child’s well-being, discussing options for day services and making appointments to visit specialists. Some examples of exchanging information are:

Everything is going well with Bob: he is enjoying the lovely weather, he plays on the mat and now and then we have a water fight. Bob is always laughing: very nice to see him like this! (Bob’s DSP)

When we brought Janine back to her group home, we told them how thrilled she was to see all her family at her grandparents’ wedding anniversary. (Mother 1).

Issues concerning ‘health/physical functioning’ were the most common subjects covered in the contacts the mothers had with the professionals (see Table 3). On average, 28.4% of the content of the contacts dealt with the health and/or physical functioning of the child. The side effects of medication, the occurrence of epileptic seizures and their treatment, constipation, fever and surgeries were all subjects about which the mothers had contact, as can be seen from the following comments:

The physician got a question about the orthosis from the physical therapist, because she could not find information about the reason for the orthosis from Janine’s file. She wants a new opinion from the physician treating Janine and new photos of her hips. (Mother 1)

Bob did not go to the day activity centre today because he was not feeling well after the epileptic fit he had last week. (Bob’s DSP)

The ‘other’ category was common for both contact function and subject. This category comprised, for example, the bringing and picking up of the child, visiting the child, general meetings for all parents, meetings to discuss future housing or day activities, a mother cooking for all the

Table 3. Content of contact per mother.

Case	1		2		3		4	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Sensomotor	7	6.2	3	2.1	15	7.5	–	–
Mood/emotion	2	1.8	1	0.7	–	–	–	–
Communication	–	–	1	0.7	–	–	–	–
Self-reliance	1	0.9	–	–	1	0.5	–	–
Health/physical functioning	27	23.9	49	34.5	38	19.0	9	36.0
Activity/relaxation	20	17.7	4	2.8	1	0.5	3	12.0
ADLs	3	2.7	–	–	–	–	1	4.0
Practical matters	4	3.5	24	16.9	6	3.0	3	12.0
Private life	11	9.7	5	3.5	1	0.5	–	–
Other	31	27.4	53	37.3	24	12.0	8	32.0

Note. Percentages may not add up to 100% due to missing entries. ADLs: activities of daily living.

children at the home and a check-up at the dentist. The following fragments are illustrative of the other category:

This home project was initially meant for children and young adults. Later on, they said it would be decided if the children could stay or whether they should move to another home. Today, we got a letter that the age limit is 25 years. Our son is 25 years old now, so we have to find another home for him. This decision has made me feel very anxious now. (Mother 4)

We picked up Thomas to go to horse riding and to have lunch at our home. When we came back, we treated everyone to French fries for Thomas' birthday. (Mother 3)

Subjects falling under the other category included the introduction of a new manager or senior DSP, painting the home's living room and issues concerning staffing. When several subjects were mentioned in a single contact or where nothing was noted about the contact, these were also categorized under other.

Mothers' experiences with communication

Of the 480 entries in the logbooks from the four mothers, 317 entries were related to the mothers' experiences. The mothers did not mention their experiences with the contact they had with a professional (missing data) in 163 instances. Mothers 2 and 3 left the most gaps on their experiences, 25.4% and 62.5% of their contacts, respectively. The reason for this is unclear. Of the 317 experiences mentioned, 239 were positive, 33 were negative, and in 45 cases it was unclear whether the mothers' experiences were positive or negative or both. This is illustrated by the mother's remark below, on getting an email about the home's unstable staffing situation and forthcoming changes:

Finally, something is going to happen. It was about time!! (Mother 1)

The mothers' experiences with the contacts could be positive despite what was being communicated being negative, as in the following remark:

A DSP would appreciate my advice on what to do after forgetting to give Koen his medication. I appreciated her honesty, though I did regret that it happened. (Mother 4)

Negative experiences accounted for a range from 0% (mother 3) to 28% (mother 4) of all the mothers' experiences. The mothers indicated that being kept up to date about their children is important to them – even if the news is bad – which is illustrated by the following comments:

As far as we are concerned, it is good and important to be kept up to date about everything that concerns your child, even if it concerns warts. (Mother 1)

It's nice that we are being well kept up to date about Bob's ups and downs. (Mother 2)

This week, I had several telephone calls about spots on his legs. Eventually, the physician came over, which seemed necessary because Koen got ill. I appreciated it a lot that I was informed immediately when something appeared to be wrong. (Mother 4)

Not being kept up to date can lead to worries and tension as these mothers mentioned:

This week, Koen went on vacation for the first time with his group. I was quite excited about it and had expected an email or a call with information beforehand, but no. Also, during the week not a bit of news. I felt that a call on my part was not appropriate, so I did nothing. Fortunately, everything went well that week. (Mother 4)

At least we got some information from the day services people. Out of sight, out of mind? (Mother 2)

The negative experiences that the mothers had in their contacts with professionals concerned getting no, too little or vague information, or getting it too late. As this mother stated after a serious situation where her son had fallen out of a hoist:

They day services people called in the morning while I was exercising, but it was afternoon before I heard about it from Bob's senior DSP at the home. What happened and how? How is Bob? (Mother 2)

No communication can cause sorrow, worries, indifference and a loss of trust, which can be seen from the following comment:

For quite some time I had a feeling that things were not going well within Koen's team. There was not much left of the enthusiastic team I met at the start of the group, full of determination to make things work well. The DSP's illness, commitments not being honoured, etc. And no communication at all! It made me sad and I worried about my son, and eventually it gave me a feeling of indifference. An unexpected conversation with the manager, who acknowledged my concerns, showed understanding and told me of the upcoming improvements in the team, restored my confidence that things will improve. (Mother 4)

Other negative experiences were related to not keeping promises, poor internal communication and not being listened to, which are illustrated by the following comments:

I should have been introduced to Koen's new senior DSP 3 months ago, but I have still not heard anything. It's inconvenient. I feel as though I'm being overlooked and that communication is breaking down as a result. When I ask about things, I feel a bit brushed aside. (Mother 4)

We had already explained that Bob had a few days off and that he was about to be vaccinated against influenza. Why do they [the DSPs] keep asking again? (Mother 2)

We are tired of waiting for an appointment with the manager to discuss the situation at the day services. It takes too long. (Mother 2)

Communication by the professionals, which demonstrates interest in and care for the child and family is important to the mothers, as is shown in the following remarks:

When I pick Janine up for a weekend at home, it is usually very busy at the group. However, the DSPs always find time to tell us what happened during the week, and how Janine felt. We appreciate that a lot. (Mother 1)

Before a support plan meeting, we always receive a report about our son. Always exciting! What do they think of our child? We are so anxious to hear good news . . . I was touched by the fact that so many people do their best for my child . . . It makes me feel good! (Mother 4)

It is nice when other people think Janine's day activities through with us. Especially because they understand why this is so important for us and Janine. In these conversations we can see that they care about our child and that is very nice. (Mother 1)

They have time to listen to our weekend experiences. Also, they explain about the orthosis. I appreciate their concern, it shows they care about our child. (Mother 1)

Some communication or experiences are examples of the ideas and feelings that professionals and parents have about collaboration and the specific role the partners in this collaboration play:

I would like to hear your opinion and arguments so we are on the same page. Your opinion is naturally the most important. (Bob's senior DSP)

. . . But she [the senior DSP] is Bob's third parent! (Mother 2)

She [the senior DSP] has a huge heart, two even: one with love for her own family and one with love for another person. (Mother 2)

These comments show that the professional sees the mother as a serious partner in the professional support of her son and gives her the final say in decisions. In the mother's comments, she compares the senior DSP to her husband and herself, referring to her as 'the third parent'.

Differences between the mothers' experiences

Although the mothers had many similar experiences in their communications with the professionals who support their children, there were some differences. Mother 3 had no negative experiences in her contact with professionals. She experienced being kept well up to date, being consulted and having her views taken into account, dedication to her son and her family and felt the warmth in the home that her son lives in. Of the three mothers who had negative experiences, mother 2 mainly had these with the professionals who support her son at the day services centre. She experienced too little communication in the sense of not being kept well up to date and she mentioned the lack of a personal relationship with these professionals. Mother 1 also mentioned negative experiences with the professionals at her daughter's day services centre. These experiences concerned not being listened to on what is best for her daughter and a lack of attention during

the day. The negative experiences of mother 4 concerned promises not being kept and not being kept up to date.

Changes over time

The results show that the mothers' experiences did change over time: they became more positive or negative over the 12-month period. The experiences of mother 1 got worse towards the end, with five of the total of eight negative experiences occurring in the last 2 months. Mother 2 had most of the negative experiences at the beginning of the study period, with 17 of the 18 negative experiences occurring in the first half. Mother 4 also had most of her negative experiences (six of seven) in the first half of the study period. Contact between the mothers and the professionals did increase periodically, for example, due to accidents, an increase in epileptic seizures, surgery or changes to the aids used.

Discussion

This case study has some limitations. First, it is impossible to generalize the findings from four cases to the whole population of mothers with children with PIMDs. However, the results of this study offer detailed and valuable information about the parents' contacts with the professionals supporting their children with PIMDs and about how the parents experienced these contacts. These findings could be representative of all parents with children with PIMDs and could provide useful information for future research and practice. For example, it is important for professionals to know that the DSP plays an important and crucial role in the contact with parents and that experiences are generally positive, regardless of the frequency of the contact that parents have with the professionals supporting their children. In this study, the four mothers were much alike concerning age, education, ethnic background, family structure, age of child, severity of the child's disabilities and the period that the child lived away from home. Future research should also focus on other populations of parents with children with PIMDs, such as younger parents, parents belonging to ethnic minority groups and parents whose children are about to move away from home or have lived away from home longer than the children in this study had. Collaboration with professionals for these parental groups could have other features or be experienced differently. Furthermore, there were major differences between the mothers in terms of the number of contacts they reported on and in the manner of reporting, since the mothers were more or less free in what they wrote down in their logbooks. Whereas three mothers filled in their logbooks each time they had contact with professionals, one mother did not fill in her logbook when the contacts were practical in nature or announcements. This impacted the results in all aspects of the contacts (frequency, means, the function, the subject and this mother's experiences with the contact). Indeed, mother 4 reported the fewest contacts and the highest percentage of negative experiences with the contacts she had with professionals, which might have been different if she had reported on all the contacts she had. It is also likely that the parents' experiences do not depend on the frequency of the contacts but on the quality of the contacts they have.

Despite these shortcomings, this study offers much detailed information over a longer period about the contacts between mothers and professionals, enabling more in-depth analysis. By following the mothers for a longer period, more precise information on what is important in the collaboration with parents in the professional support of persons with PIMDs is gathered. The findings of this study correspond with other studies of collaboration with parents. In a study by

Jansen et al. (2014), in which the ‘problem areas’ in the collaboration between parents of a child with PIMDs and professionals were described as instances where support indicated as important was not received, the highest percentages of dissatisfied parents were found on items including the provision of written information about the child (progress, treatment and changes in support) and anticipating and following up concerns. Results of studies with other participants than parents with a child with PIMDs show similar needs and desires of parents as in our study when it comes to collaboration and communication with professionals: equality, empathic and personal approach, care, interest and joint decision-making (Galil et al., 2006; Graungaard et al., 2006).

The DSPs and senior DSPs of the children in this study played a very important and substantial role in the communication with parents, since much of the communication is with them. DSPs might not be sufficiently well equipped for this role and they might not receive enough support from their managers in fulfilling this important role. Furthermore, given the complexity of the support given to persons with PIMDs, a more multidisciplinary approach seems appropriate. Such an approach would involve all disciplines, including the parents to reach consensus about the content of the support. This argues for more formal meetings with the parents and all the professionals involved to arrive at joint goal setting.

At the start of this study, the children of the mothers who participated had lived away from home for a year or more. In this time, the communication between the mothers and the professionals had already begun, relationships were established and the mothers may or may not have had negative experiences in their communication with the professionals. This could have influenced their opinions about the communication. Future studies should focus on the beginning of the collaboration between parents and professionals in the support of persons with PIMDs, preferably from the moment the decision is taken that a child should live at a facility. Involving the fathers in more qualitative studies is also recommended, to examine whether fathers have different wishes, needs and experiences as regards communication with professionals than mothers do. In their study on the agreement between parents and professionals on what is important in the support of persons with PIMDs related to the family-centeredness support, Jansen et al. (2014) found significant differences between fathers and mothers in their ratings of importance compared to the professionals’ ratings.

Although guidelines for communication between parents and professionals can be formulated and are useful, the relationship being built between parents and professionals is of crucial importance and starts with the communication between parents and professionals. Acknowledgement of the fact that each family is unique, with its own family structure, cultural background, standards and needs and wishes is required. It is up to the professionals who work with families of children with PIMDs to be sincerely interested in the parents and to respect them as equal partners. Ultimately, parents are and will be the only constant people in their children’s lives, the people who know their children the best, even though their children no longer live at home.

Conclusion

The aim of this study was to acquire knowledge of the frequency and the means of communication and the personal experiences of mothers with their communication with the professionals supporting their children with PIMDs. The total frequency of contact per mother varied. Most of the contacts the mothers had were with the child’s DSP or senior DSP. The most common means of contact varied per mother, but visiting the child, written contact and telephone were more common than support plan meetings and formal meetings. Exchanging information was the most common

function of communication between the mothers and the professionals and communication mainly concerned issues of health/physical functioning. Furthermore, the other category was common for both the function and the subject of contact. Most of the mothers' experiences were positive. Being kept up to date about their children, being listened to by professionals, having their concerns acknowledged, thinking matters through with them, showing initiative, keeping promises and showing care for the children are all related to the mothers' positive experiences. These aspects result in a sense of trust that their children are in good hands. Negative experiences were related to not being listened to, not receiving replies to emails, appointments not being kept and not being kept up to date.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Notes

1. In the Netherlands, parents of a child with with profound intellectual and multiple disabilities (PIMDs) have access to an extensive system of professional services, such as various 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 those who are involved in the support of persons with PIMDs on a daily basis. In the Dutch context, these are professionals with either a medical or educational background. Indirectly involved professionals are those who are involved in the support of persons with PIMDs, but not on a daily basis, such as psychologists, physicians and therapists (speech therapists, occupational therapists, physical therapists or dieticians).
3. A support plan meeting is an interdisciplinary meeting in which the support plan of the child is discussed and determined.
4. A formal meeting about the child is an interdisciplinary meeting in which issues other than the discussion and determination of the support plan are discussed.

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