Who cares?
Kamstra, Aafke

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Chapter 6

Attitudes of professionals to enhancing the informal personal networks of people with profound intellectual and multiple disabilities.

This chapter is submitted as:

Kamstra, A., Van der Putten, A.A.J., Kiezebrink, A., Maes, B. & Vlaskamp, C. Attitudes of professionals to enhancing the informal personal networks of people with profound intellectual and multiple disabilities.
Abstract

Background: Personal networks are an important aspect of the quality of life of people with profound intellectual and multiple disabilities (PIMD). To support professionals in enhancing the personal networks of people with PIMD, the attitudes of professionals towards these networks need to be explored.

Method: Semi-structured interviews were conducted with 24 professionals. After transcription and coding, a total of 45 codes were created and 808 quotations were extracted.

Results: All the professionals felt personal networks were important for people with PIMD, especially for inclusion. Personal networks were maintained by focusing on the relationship between the personal network and the person with PIMD or the professional. A total of 58.3% of the professionals stated that networks barely expanded. Professionals indicated twice as many impeding factors as facilitating ones.

Discussion: Professionals experience difficulties in working with networks of people with PIMD, mainly due to the limitations of the target group, other priorities and lack of time.
6.1. Introduction
Having a social network has positive effects on mental, social and physical health (Heaney & Israel, 2008) and is therefore of great importance to everyone. A social network generally consists of all the people a person has contact with (Heaney & Israel, 2008). All these people can be characterized by a degree of closeness and be placed within three dimensions (Baard, Uffing, & Dekkers, 1990): the extensive network, the nominal network and the personal network. The extensive network is composed of all accidental and incidental contacts (knowing a person’s face but not necessarily their name), the nominal network consists of people a person indirectly knows and meets. The personal network consists of personal relationships: the long-term and caring relationships characterized by repeated successful or enjoyable social interactions, also regarded as contacts which are rewarding for both parties (Beauchamp & Anderson, 2010; Johnson, Douglas, Bigby, & Iacono, 2012; Olsson, 2004; Olsson, 2005). Furthermore, a personal network can be divided into informal (unpaid) personal networks and formal (paid) personal networks (Bigby, 2008; Forrester-Jones et al., 2006; Van Asselt-Goverts, Embregts, & Hendriks, 2013). The degree of closeness of the people within social networks is subject to constant change, related to age, time and environmental factors. People move between the personal network to the nominal network or even to the extensive network. New people are also added to the social networks from society and people move from the extensive network, through the nominal network, into the personal network (Baars et al., 1990).

For people with profound intellectual and multiple disabilities (PIMD), having relationships is an important aspect of quality of life (Hostyn & Maes, 2009; Nakken & Vlaskamp, 2007; Petry, Maes, & Vlaskamp, 2005). Where a personal network consists of personal relationships, a satisfactory personal network by extension contributes to the quality of life of people with PIMD. People with PIMD are characterized by a profound intellectual disability which can be compared to a developmental age of less than 24 months. Furthermore, they have severe or profound motor disabilities (Nakken & Vlaskamp, 2007). Often these disabilities are accompanied by sensory disabilities and health problems which are more prevalent in comparison to typically developing people (De Cock, 2011; Van Timmeren et al., 2016). Because of the severity of their limitations, people with PIMD experience difficulties in communication (Batshaw, Pellegrino, & Roizen, 2007; Evenhuis, Sjoukes, Koot, & Kooijman, 2009; Petry & Maes, 2006). Most people with PIMD communicate at a preverbal level (Hostyn & Maes, 2009; Petry & Maes, 2006), for example through body language and facial expressions (Vlaskamp, Poppes, & Zijlstra., 2005). Not only is it hard for people with PIMD to express their feelings and needs, the person interacting with the person with PIMD needs to know that person to interpret the communicative expressions correctly and respond to them appropriately (Forster & Iacono, 2008; Hostyn
& Maes, 2009; Vlaskamp et al., 2005). The limitations of people with PIMD make it difficult to have successful interactions with others (Vlaskamp, 2011), while interactions are a precondition for establishing informal personal relationships. Informal personal relationships for people with PIMD are important for several reasons: they can facilitate social inclusion (Abbott & McConkey, 2006; Bigby, Clement, Mansell, & Beadle-Brown, 2009; Johnson, Douglas, Bigby, & Iacono, 2010; McConkey, 2007), prevent loneliness and negative health effects (Cohen, 2004; Scott & Havercamp, 2014), enable participation by bringing the person with PIMD into society and provide the person with PIMD with a sense of belonging (Petry et al., 2005).

Having close personal relationships also makes a person vulnerable: the passing or severance of a personal relationship is associated with greater risks of sickness and death (Stroebe, Schut, & Stroebe, 2007). According to Baumeister and Leary (1995), a person is less vulnerable if there is someone who can fill the void left behind. Having multiple informal personal relationships is therefore of great importance. However, people with PIMD have informal personal contacts with an average of only five people in the course of a year. Furthermore, 80% of these contacts are with family, with the parents being the most prominent contact (Kamstra, Van der Putten, & Vlaskamp, 2015a). As people with PIMD get older, it appears that no new informal personal contacts are added; in fact, older people with PIMD have fewer informal personal contacts (Kamstra, Van der Putten, Post, & Vlaskamp, 2015b). The personal networks of people with PIMD are fragile because there are hardly any substitutes for the parents if they, for whatever reason, are no longer available as a personal relationship. This is worrying given the importance of informal personal networks to people with PIMD.

Because of the high levels of support people with PIMD need, it would appear obvious that people with PIMD should have an extended formal network. However, formal networks are sensitive to change and are often not able to provide social support for longer periods (Heaney & Israel, 2008). Furthermore, if an informal network is small, the formal network plays an important role in maintaining or expanding that network (Abbott & McConkey, 2006) and this should therefore be part of the support provided by the formal network, for instance by describing the current network in individual support plans and defining what is desired concerning its development and how this should be achieved. However, this does not seem to be the case: the individual support plans of people with PIMD rarely contain goals topic ‘social contacts’ in general (Kamstra, van der Putten, & Vlaskamp, 2016). It seems that no systematical actions being undertaken to enhance the personal networks of people with PIMD. However, it is unknown whether this is in fact the case as it is possible that interventions are being carried out but not written down. Furthermore, it is unknown what the impeding
Factors are for maintaining or expanding the personal networks of people with PIMD, for instance the attitudes of professionals.

According to Pickens (2005), an attitude consists of three components: a belief or a thought (cognition), a feeling (affection) and behaviour (an action). Beliefs, thoughts and feelings combined result in behaviour. An attitude is described as the effect of modelling others, learning and direct experiences with people and situations. An attitude influences decisions and guides behaviour (Pickens, 2005). Research shows that professionals interacting with people with PIMD agree on the importance of principles such as social integration and participation, but they do not consider them practicable for people with PIMD (Bigby et al., 2009; Venema, Otten, & Vlaskamp, 2015), which therefore influences their actions. It is possible that their attitudes, how they think about the importance of having informal personal networks and what they feel are impeding and facilitating factors in this matter, affect how they support people with PIMD.

So far it remains unclear what should be done in the formal support of these persons to facilitate their personal relationships. To be able to maintain, strengthen and expand the informal personal networks of people with PIMD, it is necessary to understand the attitudes of professionals towards the personal networks of people with PIMD. Such knowledge can help understand what is currently being done and could clarify where potential problems will arise. To be able to support professionals in maintaining, strengthening and expanding the personal networks of people with PIMD, it is important to explore the thoughts, beliefs, feelings and actions of professionals towards the informal personal networks of people with PIMD. Therefore the questions addressed in this study are:

• What, according to professionals, is the importance of having a personal network for people with PIMD?

• What is being done to maintain, strengthen or expand the personal networks of people with PIMD?

• What, according to professionals, are the limiting and facilitating factors concerning the personal networks of people with PIMD?

6.2. Method

6.2.1. Participants and setting

The research was carried out at eight different locations distributed throughout the Netherlands, all of which belonged to a national organisation providing support to people with intellectual disabilities. A total of eight regions were
identified within this organisation, which together housed a total 376 people with PIMD (understood to mean that they had an estimated developmental age of less than 24 months in combination with a profound or severe motor disability (Nakken & Vlaskamp, 2007)). Of these 376 people with PIMD, a total of 205 were included in previous studies (e.g. Kamstra et al., 2015a; Kamstra et al., 2015b). One of these studies (Kamstra et al., 2016) found that the living unit was related to the structure of the social network. Therefore, stratified random sampling was used based on the location. The participants in the current study were the professionals working with these people with PIMD. The aim was to interview the direct support professionals (DSPs) from the living units of 10% of the people with PIMD of who participated in the previous study. This yielded a goal total of 20 DSPs working at the living units of people with PIMD. In addition to the DSPs from the living units, the aim was to interview one DSP from the day services of every location and one healthcare psychologist per location. The goal total for professionals was therefore 36 (20 DSPs from the living unit, eight DSPs from day services and eight healthcare psychologists). This was needed in order to collect information from different points of view. All the professionals had at least one year work experience in the field of people with PIMD and were currently working with at least one person with PIMD. Because saturation point was reached, a total of 24 professionals were included, the average age of all the professionals combined (12 DSPs living unit, five DSPs day services and seven healthcare psychologists) being 38.9 (range: 23–63, SD: 10.6). The group comprised 23 women (95.8%) and one man (4.2%) working as DSPs at a living unit. The average age of the living unit DSPs was 40.2 (range: 23–63, SD: 12.1), 37.4 for the day services DSPs (range: 27–45, SD: 7.1) and 37.9 for the healthcare psychologists (range: 24–49, SD: 10.8). The average years' work experience of the professionals combined was 12.3 (range: 1–37, SD: 8.9): specifically, 14.5 for the living unit DSPs (range: 2.5–37, SD: 10.7), 11.7 for the day services DSPs (range: 5.5–17, SD: 4.5) and 8.9 for the healthcare psychologists (range: 1–12, SD: 7.5). No significant differences were found between the groups for age or years of work experience.

6.2.2 Data collection
Semi-structured interviews were conducted using a standardized interview protocol with open questions. The interview outline was based on the interview protocol of Van Asselt-Goverts, Embregts, Hendriks and Frielink (2010), who studied the experiences of support staff with strengthening and expanding the social networks of people with mild disabilities. The participants were asked if they felt personal networks were important for people with PIMD and why, what they did to maintain, strengthen and expand the personal networks of people with PIMD, why this was done, by whom, how, when, how often, if there were differences per individual, and what they thought were the impeding and facilitating factors. These topics were also discussed in the study by Van Asselt-
Goverts et al. (2010). The interviewer ensured that all topics were discussed by raising them in conversation.

6.2.3. Procedure
The healthcare psychologist who specialized in the target group of people with PIMD was the researcher’s contact person for each location. The healthcare psychologist decided which living unit DSPs and which day services DSPs should be interviewed, specifically those who were actively working with people with PIMD. Not all the locations were able to gather the desired number of DSPs, meaning that sometimes other locations stepped in to collect as much data as possible. Appointments were made in advance with all participants. The researcher visited all the participants and interviews were conducted face to face. A saturation point was reached after 24 interviews: new interviews did not yield new information. All interviews were voice recorded; these recordings were transcribed and guidelines were set on how to transcribe silences, intonations and difficult to understand speech. The transcribed interview was sent to the participant to be checked and, if necessary, corrected. Six participants responded, this concerned additions or corrections to utterances which were difficult to understand. These transcribed interviews were used in the analysis.

6.2.4. Analysis
Atlas.ti version 7.1.8 was used. The following steps were taken to ensure sufficient reliability in the coding process:

1. Two researchers read five of the 24 transcripts and coded the interviews based on the coding categories in Van Asselt-Goverts, Embregts and Hendriks (2014): 1. interventions to maintain and strengthen social networks, 2. interventions to expand social networks, 3. impeding factors and 4. facilitating factors. The researchers added the category ‘importance’ for all text where professionals expressed if and why they thought personal networks were important, and added codes based on reasons from the literature: inclusion or a sense of belonging, participation, preventing loneliness and negative health impacts, development (Abbott & McConkey, 2006; Baumeister & Leary, 1995; Bigby et al., 2009; Cohen, 2004; Johnson et al., 2010; McConkey, 2007), advocacy, and more general reasons which could not be placed in any of the previous categories. The coding process used the categories as presented by Baars et al. (1990): the personal, nominal and extensive networks were each taken into account, as well as society. Furthermore, the formal and informal networks were coded separately (Bigby, 2008; Forrester-Jones et al., 2006; Van Asselt-Goverts et al., 2013).
2. Another five transcripts were coded using the categories as described in the first step. During this coding process, inductive coding was performed by one of the two researchers who generated subcategories by directly examining the data (Christensen & Johnson, 2012). These subcategories were discussed by all the authors of this study and merged where possible. This yielded the model presented in Figure 1 and provides a framework for the social networks of people with PIMD as perceived in this study, where the arrows represent relationships between different types of networks.

3. Based on the framework for the social networks of people with PIMD, two researchers coded five transcripts and discussed the codes assigned, then finalized the codes for those transcripts.

4. Next, one researcher used the framework as presented in Figure 1 and coded all the transcripts.

5. The second researcher coded one interview individually to estimate the agreement between the two researchers. Cohen’s Kappa was calculated by counting the quotes the researchers agreed upon. Cohen’s Kappa was 0.65, which is substantial (Landis & Koch, 1977).

6. Finally, the second researcher checked all the codes assigned by the first researcher and made some slight adjustments and final decisions where the first researcher was unsure.

7. Considering the high number of quotations per category (every professional mentioned items categorized under ‘impeding factors – professional’), it turned out that the specific quotations differed. This category was therefore inductively coded separately by one researcher and checked by the other. This lead to a final coding scheme with a total of 45 codes. These codes were categorized into five main categories: the importance of social networks for people with PIMD, interventions to maintain or strengthen the social network, interventions to expand the social network (with the subcategories how and with who), and impeding and facilitating factors.
Attitudes of professionals to enhancing the informal personal networks of people with profound intellectual and multiple disabilities.

6.3. Results

6.3.1. Number of quotations, codes and coding categories
The 24 interviews lasted an average of 29 minutes and 59 seconds each (range: 18:17-44:43, SD: 7:41). The transcripts of the interviews were divided into 808 quotations concerning the social networks of people with PIMD. A total of 45 codes were created and applied to the quotations. Some of the quotations received more than one code, meaning that a total of 871 codes were assigned. An interview yielded an average of 36.3 codes (range: 19–63, SD: 12.5). Table 1 presents the number of codes and the frequencies for the five main categories.

Table 1: Number of codes and frequencies for the five main categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of subcodes</th>
<th>Number of quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Importance</td>
<td>6</td>
<td>55</td>
</tr>
<tr>
<td>2. Interventions to maintain or strengthen the personal network</td>
<td>5</td>
<td>161</td>
</tr>
<tr>
<td>3. Interventions to expand the personal network</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- How</td>
<td>8</td>
<td>76</td>
</tr>
<tr>
<td>- With whom</td>
<td>3</td>
<td>40</td>
</tr>
<tr>
<td>4. Impeding factors</td>
<td>14</td>
<td>391</td>
</tr>
<tr>
<td>5. Facilitating factors</td>
<td>9</td>
<td>148</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
<td>871</td>
</tr>
</tbody>
</table>
6.3.2 Importance
Every professional (n=24; 100%) stated that personal networks were important for persons with PIMD. Six categories of reasons for why personal networks are important could be distinguished: for general development, for inclusion or a sense of belonging, for preventing loneliness and negative health effects, for advocacy, for participation and more general reasons. Table 2 provides an overview of all the codes, examples and frequencies.

The most commonly mentioned reason why personal networks are important for people with PIMD were inclusion or a sense of belonging, followed by participation and general reasons. The following quote is an example of the importance of personal networks for inclusion reasons or a sense of belonging, and a general comment:

*So yes, I do think it is very important. Just to feel loved. That somebody loves you. And that somebody thinks you are worth the effort. And that it is possible to feel safe with someone. Yes, it is as important for them as it is for us.* (Healthcare psychologist)

Table 2: Overview of codes, examples and frequencies

<table>
<thead>
<tr>
<th>Codes</th>
<th>Examples</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Importance</strong></td>
<td>Text about why professionals felt personal networks were important for people with PIMD</td>
<td>24 (100)</td>
</tr>
<tr>
<td>Inclusion or a sense of belonging</td>
<td>Being part of something, being yourself, self-esteem</td>
<td>18 (75)</td>
</tr>
<tr>
<td>Participation</td>
<td>Activities, widening your horizon</td>
<td>11 (45.8)</td>
</tr>
<tr>
<td>General reasons</td>
<td>Because it is important for everyone, it is something you want for everyone</td>
<td>10 (41.7)</td>
</tr>
<tr>
<td>Advocacy</td>
<td>Someone who stands up for your rights, someone who knows your history</td>
<td>6 (25)</td>
</tr>
<tr>
<td>Preventing loneliness and negative health effects</td>
<td>Network as a stable factor in a person's life, provides energy</td>
<td>5 (20.8)</td>
</tr>
<tr>
<td>Development</td>
<td>Important for development, for instance learning new skills</td>
<td>3 (12.5)</td>
</tr>
<tr>
<td><strong>2. Maintaining and strengthening</strong></td>
<td>Actions about maintaining or strengthening the personal networks of people with PIMD, all concerning the existing network</td>
<td>23 (95.8)</td>
</tr>
<tr>
<td>None</td>
<td>Statements that maintaining or strengthening the social networks of people with PIMD did not occur</td>
<td>9 (37.5)</td>
</tr>
</tbody>
</table>
Attitudes of professionals to enhancing the informal personal networks of people with profound intellectual and multiple disabilities.

**Table 2: continued**

<table>
<thead>
<tr>
<th>Codes</th>
<th>Examples</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship between person with PIMD and personal network, directly</td>
<td>Organising activities, actively inviting people to come and join in (e.g. a barbeque or party), asking them to do activities (swimming, a day out or other daily activities), Skype</td>
<td>19 (79.2)</td>
</tr>
<tr>
<td>Relationship between person with PIMD and personal network, indirectly</td>
<td>Attendance at support plan meetings, sending postcards, calls (a professional calls someone from the personal network to talk about the person with PIMD), sending emails, reports or newsletters, taking photos or making videos to show to the personal network</td>
<td>19 (79.2)</td>
</tr>
<tr>
<td>Relationship between personal network and formal network</td>
<td>Taking the initiative in calling and trying to be as accessible as possible for the personal network</td>
<td>18 (75)</td>
</tr>
<tr>
<td>Personal network</td>
<td>Making the personal network responsible for maintaining or strengthening itself</td>
<td>2 (8.3)</td>
</tr>
</tbody>
</table>

### 3. Expanding

**Descriptions of efforts to expand the personal network to include people not already in the personal network**

<table>
<thead>
<tr>
<th>How</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Statements that expanding the personal networks of people with PIMD did not occur</td>
</tr>
<tr>
<td>Formal network</td>
<td>Bringing the subject up in the yearly support plan meetings, assigning it as a task to an intern, placing a person with PIMD on a waiting list at a 'volunteer bank' (an organisation which assigns volunteers to clients)</td>
</tr>
<tr>
<td>Relationship between person with PIMD and society, directly</td>
<td>Going to church, assigning them to clubs, walking around the neighbourhood</td>
</tr>
<tr>
<td>Relationship between personal network and formal network</td>
<td>Talking about visiting hours, inviting more people to family activities</td>
</tr>
<tr>
<td>Personal network</td>
<td>Facilitating the exchange of ideas among family members, asking them if they know anyone who is willing to be a volunteer for a person with PIMD</td>
</tr>
</tbody>
</table>
Table 2: continued

<table>
<thead>
<tr>
<th>Codes</th>
<th>Examples</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship between person with PIMD and society, indirectly</td>
<td>Placing notices (contact advertising) in the supermarket</td>
<td>2 (8.3)</td>
</tr>
<tr>
<td>Extensive network</td>
<td>Looking for other service users who are less disabled</td>
<td>2 (8.3)</td>
</tr>
<tr>
<td>Relationship between society and formal network</td>
<td>The professional asks around in his or her own network</td>
<td>1 (4.2)</td>
</tr>
<tr>
<td>With whom</td>
<td></td>
<td>20 (93.3)</td>
</tr>
<tr>
<td>Nominal network</td>
<td>Family (aunts and uncles), group members, former DSPs or the families of group members</td>
<td>8 (33.3)</td>
</tr>
<tr>
<td>Extensive network</td>
<td>Other service users who are less disabled</td>
<td>5 (20.8)</td>
</tr>
<tr>
<td>Society</td>
<td>Volunteers</td>
<td>18 (75)</td>
</tr>
</tbody>
</table>

4. Impeding factors | Statements on factors which impede working with the personal networks of people with PIMD | 24 (100) |
| Characteristics of person with PIMD | Severity of disability (intellectual and motor), age (older = smaller network), it takes time to get to know someone with PIMD/build a relationship, dependence on others | 23 (95.8) |
| Personal network | Is already small, acceptance, distance, time | 22 (91.7) |
| Society | People with PIMD are invisible to society, society does not know this target group or what they need (they often think ‘too big’), society is scared | 19 (79.2) |
| Relationship personal network and formal network | Parents and professionals have different views about the person with PIMD, maintaining the relationship with a personal network takes time | 13 (54.2) |
| History | Hospitalization, placed out of their homes at a very young age, back then ‘professionals’ knew everything and parents ‘nothing’, atmosphere and rules in the facilities | 7 (29.2) |
| Relationship between formal network and society | Investing in new network members (from society) takes a lot of time for the professional | 3 (12.5) |
| Relationship between person with PIMD and nominal network | Family members (uncle/aunt) hardly know the person with PIMD | 1 (4.2) |
Facilitating factors

<table>
<thead>
<tr>
<th>Relationship between formal network and nominal network</th>
<th>No direct contact between professionals and nominal network</th>
<th>1 [4.2]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formal network</td>
<td></td>
<td>24 [100]</td>
</tr>
<tr>
<td>- Environmental factors</td>
<td>Not enough time/money/staff, no clear policy, remote location of the facility</td>
<td>23 [95.8]</td>
</tr>
<tr>
<td>- No priority</td>
<td>Other things are more important, not a part of the daily care</td>
<td>14 [58.3]</td>
</tr>
<tr>
<td>- Personal opinion</td>
<td>Harder to do your job with network member around, fear; what does an individual need?</td>
<td>9 [37.5]</td>
</tr>
<tr>
<td>- Lack of knowledge</td>
<td>Lack of knowledge, no [known] interventions.</td>
<td>7 [29.2]</td>
</tr>
<tr>
<td>- Relationship between professionals</td>
<td>Position of daycare services with respect to living unit</td>
<td>4 [16.7]</td>
</tr>
</tbody>
</table>

5. Facilitating factors Statements about factors which facilitate working with the social networks of people with PIMD

| Formal network                                         | Volunteer policy, having guidelines, central location of the facility | 18 [75] |
| Person with PIMD                                       | They evoke caring, young age, making sounds, reactions in contact, small things are perceived as big | 17 [70.8] |
| Personal network                                       | Involved and active personal network, acceptance, views of the personal network about networks | 16 [66.7] |
| Relationship between person with PIMD and personal network | People with PIMD going to their network instead of them coming to the facility, encouraging activities between person with PIMD and the personal network | 11 [45.8] |
| Relationship between personal network and formal network | Investing in relationships, making people feel welcome | 9 [37.5] |
| Relationship between person with PIMD and society directly | Being present in society, explaining the behaviour of person with PIMD to society | 7 [29.2] |
| Relationship between person with PIMD and society indirectly | Looking for people with a common interest, making some sort of profile of the person with PIMD | 2 [8.3] |
| Relationship between person with PIMD and nominal network | Being a part of regular clubs or groups | 1 [4.2] |
| Nominal network                                         | Having fun group members | 1 [4.2] |
6.3.3 Maintaining and strengthening the social network

The professionals stated in nine interviews (37.5%) that they did not or rarely acted to maintain or strengthen personal networks:

*We all think that having social contacts is very important, but we currently rarely pay attention to this.* [Living unit DSP]

The professionals stated in 19 interviews (79.2%) that they maintained or strengthened personal networks by focusing directly on the relationship between the person with PIMD and his or her personal network. Maintaining or strengthening the personal network by indirectly focusing on the relationship between the person with PIMD and his or her personal network was also mentioned in 19 interviews (79.2%). The most importance difference with directly focusing on the relationship is that in indirectly focusing, there is no contact between the person with PIMD and his or her personal network, whereas there is in directly focusing. An example of focusing on a direct relation is using Skype:

*She used Skype once or twice to contact her mother. She did this on our initiative.* [Living unit DSP]

Taking photos or videos to show to the personal network of the person with PIMD are examples of indirectly focusing on the relationship with his or her personal network:

*One thing we started at one point was that at every multidisciplinary meeting I attend, I bring photos. At the meeting they [personal network] would receive a folder with photos of their brother or sister from the previous year, especially photos about things the parents, brothers or sisters would not know about the things he or she [the person with PIMD] is able to do, or enjoys.* [Daycare services DSP]

Another way professionals try to maintain or strengthen the personal networks of people with PIMD is through the relationship between the professional and the personal network. This was mentioned in 18 interviews (75%) and was done by taking the initiative in calling and trying to be as accessible as possible to the personal network:

*We try to invite people in more often if they come to pick someone [the person with PIMD] up. We try to offer them something, to talk to them and make contact. I think that before – of course I cannot be completely sure about how things were before – but, I am under the impression that people [DSPs] were mainly focused on their daily tasks and did not pay much attention to the people with PIMD and their*
networks. And they did not take the initiative in this matter, you could say. (Living unit DSP)

Finally, it was stated in two interviews (8.3%) that they tried to maintain or strengthen the personal networks through the personal network:

And we do say that to other parents as well, if there are brothers and sisters who do not come by regularly. We tell these parents that it would be fun if they [the brothers and sisters] would come by more often or […] well, then the ball is in their court. (Living unit DSP)

6.3.4. Expanding the social network

A total of 14 professionals (58.3%) stated that they did not pay attention to expanding the personal networks of people with PIMD:

No, no. I know that we did discuss it once, like: ‘how can we expand the network?’ But we never really put those ideas into action. Even though this remains a wish. (Living unit DSP)

Efforts to expand a personal network are usually made by the professionals, most often by putting a person with PIMD on a waiting list at a ‘volunteer bank’ (a place which assigns volunteers to clients):

Well, when the person [with PIMD] needs to be able to go outside more often, or another activity, then we ask the coordinator of the volunteers. (Living unit DSP)

Another way to expand personal networks is by focusing on the relationships between the person with PIMD and wider society. Consciously bringing a person with PIMD into contact with wider society permits contact with other people:

We try to go out and walk, and if someone walks along with a dog, then we make small talk and try to involve the person with PIMD. But that is just, yes, very minimal. Yes, you try to do it by walking to the town centre or going somewhere. (Living unit DSP)

6.3.5. Impeding factors

The majority of the quotes (44.9%) were about impeding factors. All professionals (n=24; 100%) mentioned factors which impede working with personal networks. Each professional mentioned on average 6.2 impeding factors [range: 2–9, SD: 1.8] All professionals but one (n=23; 95.8%) mentioned the characteristics of the person with PIMD as an impeding factor when working with personal networks:
They are not cute. It is hard, if you do not come over enough you cannot understand them, some talk with their eyes, some with their hands and some only with their posture. They are older, they are not as fun as people with Down syndrome are, who rush to you with a big smile and start chatting and being all enthusiastic. No, they are not always enthusiastic. (Daycare services DSP)

The personal network itself was experienced as a limiting factor in 22 interviews (91.7%):

And P. had a brother who is also her legal representative. And we barely see him here. And I have to call him like, eh, and if he does drop by, I feel like he barely pays any attention to her. (Living unit DSP)

And often family members also age and it [keeping in touch] becomes too hard for them. Obviously we cannot expect them to do it then (Healthcare psychologist)

The society in general is also perceived as a limiting factor:

I think that the target group [people with PIMD] are not in the picture for society and that people within society often do not even know what a PIMD is. (Living unit DSP)

The be unknown is to be unloved. (Living unit DSP)

All 24 professionals (100%) also perceived the formal network as a limiting factor. Environmental factors were mentioned particularly often:

Well, it is very hard. We would really love to see our clients go out. Somewhere in the neighbourhood to go to. There is just no staff to go with them. (Living unit DSP)

But otherwise it is, well look, they [society] do not come inside, so it is pretty isolated here. (Daycare services DSP)

Fourteen professionals (58.3%) mentioned that working with personal networks is not a priority:

I think that other priorities are set. Basic care takes a lot of time, that is being cut. So yes, you have to work very hard. Therefore social contacts have less priority. (Daycare services DSP)
There is little attention paid to expanding social contacts, I think. At least, in the past I did not pay attention to that. It was never really a topic for these people [with PIMD]. (Healthcare psychologist)

The code ‘personal opinion’ mainly brought together the questions professionals had concerning personal networks for people with PIMD:

What are we doing, what can we do? It is always very subjective. It is my perception when if I say ‘I think someone wants five acquaintances in his life’. To really know what someone wants… I find that very difficult. (Healthcare psychologist)

6.3.6. Facilitating factors
Each participant mentioned on average 3.4 facilitating factors for working with personal networks (range: 2–5, SD: 1.2). The formal network itself was the most frequently mentioned as facilitating:

Well, our manager is very engaged, she wants to set things up. Because of her we initiated the ‘evening for relatives’. (Living unit DSP)

Openness, something that was lacking in the past. Now we can say, ‘you can come over whenever you want to, not a problem’. (Daycare services DSP)

In addition to being perceived as an impeding factor, the person with PIMD was also viewed as a facilitating factor:

Looking after this group, you get a lot of appreciation in return. You can see why you are doing this [going out with a person with PIMD], you can see how happy they are after a walk or a short bike ride. Even that makes them happy, let alone if you take them out all day. I think that those things help us keep doing them. (Living unit DSP)

The personal network itself was also believed to be helpful for working with social networks:

Parents who are still able to think about and help build a network around their son or daughter. Like, there is this one couple who are really focused on creating a network around their son. People to do activities with him: a sister, two volunteers, uncles, aunts who come by regularly. So if his parents are not available, there are plenty others who are. (Living unit DSP)
6.4. Discussion
The first question addressed in this study concerned the opinion of professionals about the importance of having a personal network for people with PIMD. All professionals stated that a personal network was important for people with PIMD, especially with respect to social inclusion or a sense of belonging. The second question concerned the actions professionals undertake to maintain, strengthen or expand the personal networks of people with PIMD. A total of 37.5% stated that they did not consciously maintain or strengthen these personal networks, and another 58.3% indicated that expanding personal networks was not even on their agenda. If maintaining or strengthening personal networks occurred, professionals generally focused on the relationship between the person with PIMD and the personal network, the personal network itself or the relationship between the personal network and the formal network. Interventions for expanding the personal network were mentioned far less often compared to actions related to maintaining or strengthening the network. It was notable that actions are typically expected from the informal network when expanding the networks. For instance, putting a person with PIMD on a waiting list for a volunteer requires at the very least that people become volunteers and thus that someone or some organisation will mediate between the person with PIMD and the volunteer. The responsibility for expanding networks appeared to shift to another party. The third question concerned the limiting and facilitating factors for cooperation with the personal networks of people with PIMD. Professionals mentioned twice as many impeding factors than facilitating factors, which suggests that professionals find working with personal networks for people with PIMD difficult and experience obstacles in cooperation. Not only is the severity and complexity of the disability of the people with PIMD experienced as a limiting factor, professionals also felt that it had no priority in their daily support.

Before interpreting the results, some methodological limitations should be mentioned. First, only the perspective of the professional is taken into account in the present study. Due to the severity of the disabilities of people with PIMD, it is not possible to ask them about their perspectives. To interview members of their personal network would have been an alternative for this lack of self-report. The experiences of members of this personal network could provide interesting and supplementary information on maintaining, strengthening and expanding the social networks of people with PIMD. Second, all the professionals were interviewed individually. To conduct the interviews in groups was considered, because group interviews tend to be more interactive, help participants to explore their views more comprehensively, and encourage the generalization of new ideas (Coenen, Stamm, Stucki, & Cieza, 2012; Van Asselt-Goverts et al., 2014). On the other hand, close attention should be paid to the composition of such groups and the development of trust within a group in order for everyone.
to feel comfortable with expressing their own individual thoughts and opinions (Rabiee, 2004). Therefore, we chose to conduct interviews individually. Thirdly, as the current study used qualitative research, there is always a chance of biased coding. We tried to overcome this by establishing clear guidelines developed in careful collaboration between the researchers, checking for sufficient inter-rater reliability, and by one of the researchers performing a final check of the assigned codes. Finally, the participants all worked for the same organisation. This organisation is, however, the largest in the country, covering all regions in the Netherlands and providing support in many different locations, both large and small scale. The results can therefore be regarded as general recommendations for improving the cooperation with the social networks of people with PIMD.

The current study is to our knowledge the first which aimed specifically at strengthening and expanding the social networks of people with PIMD. Van Asselt-Goverts et al. (2014) explored the experiences of professionals concerning strengthening and expanding the social networks of people with an intellectual disability. The results of that study showed that interventions were aimed at the people with intellectual disabilities, for example by psycho-education or by encouraging them to be involved in leisure activities. However, because the study by Van Asselt-Goverts et al. (2014) was of people with less severe intellectual disabilities and no multiple disabilities, those results cannot apply to people with PIMD. This is mainly due to the dependency of people with PIMD on others for maintaining and expanding their networks. This is also reflected by the results in the current study, where actions or interventions are never aimed at the person with PIMD them self. This requires professionals to implement other strategies to maintain, strengthen or expand social networks for people with PIMD.

Van Asselt-Goverts et al. (2014) also found that professionals generally listed a large number of impeding factors. This is in line with the results from the current study, where professionals listed twice as many impeding factors as facilitating factors for maintaining and expanding social networks. Focusing on the obstacles to working with social networks will not motivate actions in this direction as attitudes seem important to determining actions (Bigby et al., 2009). The characteristics of the people with PIMD were mentioned most often as impeding expanding personal networks. Due to the limitations of this target group, professionals state that it takes time to really get to know a person with PIMD and to build a relationship; by extension it takes time to become a part of the personal network. Some professionals noted that explaining the behaviour of the person with PIMD helped in such situations, but that this also takes a lot of time. The current study shows that time is one of the things that professionals feel is lacking. Organisations should help by looking at creative ways to provide professionals with more time. The personal network itself can possibly also be
used to explain or interpret behaviours and thus to facilitate the relationship between the person with PIMD and other network members. If the personal network can explain the meaning of behaviours, less time is needed for another network member to understand the person with PIMD and relationships can then be established more quickly.

Even though all the participants agree on the importance of an informal social network for people with PIMD, they all find it difficult to provide this part of the support. Given the actions actually undertaken, maintaining and strengthening an informal network seems to emerge more naturally through daily practice, instead of as a consciously undertaken activity targeted at maintaining or strengthening the informal network. Making people from the networks of people with PIMD feel welcome in their living unit is not necessarily an action which specifically aims at maintaining or strengthening networks, it appears to be more like a bonus. Yet it remains unclear whether the actions undertaken – such as organising activities for personal network members, making calls to the personal network about the person with PIMD or sending postcards – had the desired effect. Do the people from the personal network experience such actions as supporting their relationship with the person with PIMD? This needs to be understood so that professionals can provide support which actually benefits the relationship.

Even where participants were able to explain how they tried to maintain or strengthen an existing personal network, concrete actions appeared to be lacking when it came to expanding the network. Yet expanding the networks is of great importance where the personal networks are small and vulnerable. Results show that if expansion happens, professionals predominantly try to expand with people from society at large. If a network is categorized by its degree of closeness (Baars et al., 1990), people from society in general are the furthest away, with the extensive network a bit closer, followed by the nominal network and the personal network the closest. Therefore, if the goal is to expand the personal network, it seems contradictory to expand it with people from society at large, the most distant network. It would be more obvious to try and get people from the nominal network into the personal network. Furthermore, professionals stated that society does not know the target group of people with PIMD and is therefore not interested in them, and is sometimes even scared of them. Expanding the personal network with people from wider society seems a strategy which is unlikely to succeed. However, when it comes to expanding the extensive network, doing this with people from society seems achievable. Following this line of reasoning, interventions for expanding networks should aim at ‘one network closer at a time’, meaning that a personal network is ideally expanded with people from the nominal network, the nominal network should be expanded with people from the extended network and the extended network should be expanded with
people from society. This means that the network of people with PIMD needs to be mapped carefully and in close collaboration with people from the personal network, because they know the person with PIMD and his or her networks the best. After mapping the network of the person with PIMD, professionals and the personal network should determine whether they feel that the network is sufficient, and if not, what is needed for the network to become sufficient. Concrete actions should be discussed, taking the abilities and the personality of an individual with PIMD into account, and it should become clear who does what and when. To get this process started, ‘the social networks of people with PIMD’ needs to be a part of the daily support, with organisations supporting and facilitating this, for instance by training their staff.

The current research confirms that extra attention to the networks of people with PIMD is needed and hoped for. Professionals need practical initiatives to maintain, strengthen and expand the personal networks of people with PIMD consciously. The involvement of personal networks in this matter is of great importance to yield the best possible outcome: a sufficient personal network of people with PIMD with high quality relationships. Follow-up research should thus aim to discover the views, beliefs and wishes concerning the networks of people with PIMD of the people in the personal networks themselves.
References


Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). ‘It’s pretty hard with our ones, they can’t talk, the more able bodied can participate’: Staff attitudes about the applicability of disability policies to persons with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, 53, 363–376.


