Who cares?
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Chapter 7

General discussion
This dissertation presents and analyses data on how to maintain, strengthen, and expand the informal social networks of people with profound intellectual and multiple disabilities (PIMD) in order to be able to intervene in the long term, and to achieve satisfactory informal social networks attuned to the needs and wishes of the individual.

A social network can be considered as “the layout of a group of persons who give to and receive support from one another” (Lunksy, 2006). These people can be divided into two categories: (i) formal network members, people who are part of the network based on payment; and (ii) informal network members, people who are part of the network based on personal reasons (Bigby, 2008; Forrester-Jones et al., 2006; Heaney & Israel, 2008). Within the social network, roughly two different types of support can be received from and provided to its members: practical and emotional support (Buysse, 1997; Heaney & Israel, 2008; Lunsky, 2006). Practical support is about providing goods, services, information, and advice. It is believed that formal network members mostly provide practical support. Emotional support includes expressions of love, empathy, and care, and arises from personal motives rather than employment (Bigby, 2008); it is therefore believed to be provided mainly by informal network members.

Every person is in need of long-term caring relationships that provide emotional support, and this is also true for people with PIMD. By extension, people with PIMD are therefore in need of satisfying informal social networks, including long-term caring relationships. Where multiple research projects have been carried out, which deal with the structure and function of the informal social networks of people with intellectual disabilities, the most vulnerable persons within this group, those with PIMD, rarely seem to be included. The research described in this thesis has been conducted into: (i) the characteristics of the current informal social networks of people with PIMD, (ii) the active steps that are undertaken by professionals in order to maintain, strengthen, or expand these informal social networks, and (iii) the attitudes of professionals vis-à-vis the topic of the informal social networks of persons with PIMD.

7.1. Summary of main findings
The results show that the informal social networks of people with PIMD contain little variety in terms of composition, and are also limited in size. A negative relationship vis-à-vis age is also found: When a person with PIMD becomes older, the size of the informal social network decreases, as does the frequency of contacts (see Chapters 2 and 3). Where the second and third chapters explicitly study informal social contact persons outside the living unit, the fourth chapter observes the interactions with group members and the role that the professional plays in facilitating such contacts. It turns out that interactions...
(interactive expressions back and forth) with group members were observed incidentally, especially when compared to the number of interactions with direct support persons. Persons with PIMD barely had any chance to interact with another group member: their physical position relative to other group members made it nearly impossible to interact. In order to explore the active steps that professionals undertake to maintain, strengthen, or expand the current informal social networks, individual support plans (n=60) were analyzed. It turned out that, in general terms, hardly any goals involving social contacts were found at all. In only 8.3% of the plans analyzed, was there any description of the influence of the environment on establishing contacts with other people with disabilities (see Chapter 5). It seems that no steps were undertaken to try to maintain the existing informal social contacts, nor were there any measures taken to expand the informal social networks so as to forestall the expected impoverishment of the networks. In order to understand why there was so little systematic and goal-oriented support for maintaining or improving the social networks of people with PIMD, professionals were interviewed about their attitudes towards the informal social contacts of people with PIMD. The results confirmed that there was hardly any action undertaken to improve the informal social networks of people with PIMD, either within or outside the living unit. Even though professionals believe that social networks are important (see Chapter 6), they also believe that the characteristics of the target group, people with PIMD, are impeding factors. Consequently, the professionals stated that they felt that environmental factors were not supporting them sufficiently to be able to improve informal social networks. This may explain why steps for maintaining, enhancing, and expanding informal social networks are not included in their daily support program. Little effort was made to maintain the informal social networks (see Chapter 6). Visiting was the method most often used by informal contact persons to maintain contact (see Chapter 2). Professionals stated that they worked to maintain these informal social networks by making their members feel welcome (see Chapter 6). It seems that the steps taken by professionals to maintain the informal social networks of people with PIMD are often the result of action taken by the social network members themselves. Therefore, in general it appears that a network member has to take the first step, and then the professionals follow that lead. This way, maintaining informal social networks takes place in a reactive manner, causing professionals to depend on the initiative of the informal social contact persons instead of the professionals themselves being proactive and supportive of informal social contacts through their own initiative. This may also explain why the expansion of informal social networks rarely occurs, if initiatives on the part of the professionals are what are required.
7.2. Methodological reflection

The aim of this research was to collect information on how to maintain, strengthen, and expand the informal social networks of people with PIMD. Although people with PIMD were the target group within this research, the severity of their disabilities prevents them from providing research data themselves. Therefore, professionals were involved in the collection of data throughout the project (see Chapters 2 and 3). This may have resulted in a bias in the results, especially regarding the structure of the informal social network. On the one hand, professionals may have given socially desirable answers so that the informal social networks probably appear to be more extensive than they really are. On the other, professionals may not know all the details about the structure of the informal networks of people with PIMD so that the networks may in fact be larger than stated. Therefore, for more detailed information about the structure of the informal social networks, further studies should focus on monitoring the development of the networks of people with PIMD for a prolonged period of time. A less time consuming alternative would be to involve members of the personal network, and parents in particular, in the data collection. Parents form not only an important and extensive source of knowledge about the person with PIMD, and his or her history (De Geeter, Poppes, & Vlaskamp, 2002; Jansen, Van der Putten, & Vlaskamp, 2013) but also know about the current structure of the informal social network. Nevertheless, our study does provide an important insight into the current situation, in which the size of the informal social network seems to be rather small and strategies for expansion are limited.

A total of 205 people with PIMD participated in these studies: mainly adults from the Netherlands, all living in residential facilities (see Chapters 2 and 3). This sample size is substantial compared to the total number of people with PIMD in the Netherlands. The most recent estimate of the size of the population of people with PIMD is a number of 9639 people with PIMD, of whom 97% were adults (Vugteveen, Van der Putten, & Vlaskamp, 2014). According to Krejcie and Morgan (1970), a representative sample size of a population size of roughly 10,000 would be 370. Of the 375 potential participants for this study, 205 eventually could be included in our research (see Chapters 2 and 3). Furthermore, the average age of the people in the population of the Netherlands (49.23 years, SD: 15.75) and the average age of the people with PIMD in our studies (48.7 years, SD: 15.84) are quite similar. Finally, the people included in our research resided throughout the Netherlands. Therefore, we are confident that the current research provides a good overview of the situation of informal social networks of people with PIMD living in residential facilities in the Netherlands.
This study used multiple techniques for data collection: interviews (see Chapters 2, 3, and 6), observations (see Chapter 4), and analysis of support plans currently in use (see Chapter 5). This provided us with qualitative as well as quantitative data. The quantitative data have become more meaningful in the light of the qualitative data. Furthermore, we were able to compare results from the different studies within this dissertation. This has provided us with a more in-depth understanding of the current situation of informal social networks of people with PIMD.

7.3. Theoretical reflections and future research

Our research has provided information about the structure of the informal social network of people with PIMD. These networks are small in size and not very diverse. It was also found that age was negatively related to the size of the informal social network of people with PIMD, an outcome which is also found in studies on people with intellectual disabilities in general (Bigby, 2008; Dagnan & Ruddick, 1997; Robertson et al., 2001). The main difference between the informal social networks of people with PIMD and those of people with intellectual disabilities in general is that, for people with PIMD, the network is even smaller and even less diverse. Furthermore, the current study showed that, even though professionals unanimously stated that they thought informal social networks were important for people with PIMD, only limited steps were taken to maintain or expand these networks. This is worrisome, since people with PIMD are dependent on others in all aspects of their daily lives (Nakken & Vlaskamp, 2007), including maintaining, strengthening, or expanding their informal social networks. If professionals do not take active steps, the informal social network is left to do so on its own, yet these informal social networks have very few members. This tends to create a vicious circle that needs to be broken in order to achieve satisfactory informal social networks for people with PIMD.

Despite their disabilities, people with PIMD are assumed to be capable of building meaningful relationships. These relationships play an important role for people with PIMD in terms of being able to have control over their own lives (Vlaskamp, Poppes, & Van der Putten, 2015). When other people recognize the communicative signals of a person with PIMD and respond accordingly, the person with PIMD experiences that he or she is being “heard” and in that way is able to influence his or her own life (Vlaskamp, Poppes & Zijlstra, 2005). These communicative interactions will then become successful and perhaps enjoyable, rewarding for both parties, and can form the basis for a social relationship (Beauchamp & Anderson, 2010; Johnson, Douglas, Bigby, & Iacono, 2012; Olsson, 2004, 2005). The hypothesis that people with PIMD are able to establish such relationships is widely acknowledged (Forster & Iacono, 2008; Gleason, 1989; Hughes, Redley, & Ring, 2011). This assumption is crucial when it comes to maintaining, strengthening, and expanding the informal social networks of people with PIMD. Future research
should focus on how these relationships are established, and under what circumstances, in order for professionals to be able to support the development of new relationships and thereby expand the informal social networks.

Despite the general consensus that relationships (and thereby informal social networks) of people with PIMD are possible and important, professionals rarely take active steps in this regard. It is quite possible that professionals simply do not know where or how to begin. Using a model to understand informal social networks may be helpful. The model developed by Baars, Uffing, and Dekkers (1990) divides an informal social network into different layers. The outer layer is the extensive network and contains all the people a person knows by face but not name. The middle layer is the nominal network and includes people a person knows (indirectly) and meets. The inner layer is the personal social network that comprises the direct, sustainable, and meaningful relationships in daily life. Usually, people move from the extensive network into the nominal network and finally into the personal network, which means that a relationship is formed. It seems that people with PIMD have a rather small inner layer, comprised mostly of family, and scarcely any other members (see Chapters 2 and 4). Furthermore, the majority of the group members (from day-services setting or the living unit) of people with PIMD appear to be found within the extensive network, where hardly any interactions were observed (see Chapter 5). According to the professionals, the extensive network scarcely contains any people from outside the living unit, because people with PIMD do not get out of their homes much (see Chapter 6). Considering that professionals mainly try to expand the informal social network of people with PIMD by including volunteers, meaning people who are not even part of the extensive network, there is little chance of success. It would be desirable for every layer to consist of at least a few people. This means that being present in society is already a way of working on expanding the informal social network: “Knowing someone’s face” can be seen as a first step towards forming informal social relationships. This works in two directions, as other people get to know the “face” of the person with PIMD as well. A subsequent step might be to try moving a person from the extensive network to the nominal network. Finally, a person from the nominal network could then become part of the personal network. Future research should first focus on the personal network itself. What do they consider to be the impeding factors preventing them from maintaining the relationship with the person with PIMD and what are the facilitating factors? In line with this reasoning, people from the nominal network and extensive network should also be included in future research.

The principle of extensive, nominal, and personal networks can also be applied to contacts with group members. Since all group members naturally form a part of the extensive network, becoming a part of the nominal network should be a
first step towards achieving a relationship between a person with PIMD and a group member. Providing opportunities for interaction paves the way towards moving to a more inner layer of the network. Future research into relationships between people with PIMD and their group members should take into account the opportunities provided for people with PIMD to interact.

7.4. Practical implications

The current study shows that support is needed to enhance the informal social networks of people with PIMD. However, interventions designed to support this for people with PIMD are scarcely available. For people with intellectual disabilities, there are multiple interventions for enhancing informal social networks available. These interventions cannot, however, simply be applied in support of people with PIMD because of their specific characteristics. Therefore, the interventions available need to be adapted. In the Netherlands, several interventions for enhancing the informal social networks of people with intellectual disabilities are available (see Kruiswijk et al., 2014, for a compilation). Roughly speaking, all these interventions follow similar steps: (1) mapping the network, (2) discussing the network, (3) taking active steps, and (4) evaluation. This routine can be intertwined with an Individualized Support Program for people with PIMD (Vlaskamp et al., 2015). As the name already suggests, this program is tailored to individual wishes and needs. In this program, the following steps are taken: (1) setting up a personal profile, (2) defining a multi-disciplinary long-term goal for two years by all people involved (family and professionals), (3) defining the main goals for a period of one year in order to reach the long-term goal and to execute monodisciplinary short-term goals for a period of 4-6 weeks, and (4) evaluation of the outcomes (Vlaskamp et al., 2015).

Whereas the Individualized Support Program begins with setting up a personal profile, network interventions begin with mapping the networks. When mapping the social network of people without disabilities, or of people with intellectual disabilities, the person him/herself is the informant. Due to the severity of the disabilities of people with PIMD, they are not able to function as informants in a direct way. They need other people to do this for them. This needs to be done in close collaboration with parents, or other people from the personal network, and professionals, since both parties play an important role in the lives of people with PIMD (Jansen et al., 2013, Wibaut, Calis, & Van Gennep, 2006). Mapping the network is an important part of identifying problems and requires specific instruments. Commonly used instruments in general network mapping are a genogram (family tree), an ecogram (mapping friends, acquaintances, and formal support), or network circles (number of people in a network and their positions relative to the individual) (Smit & Van Gennep, 1999). Specifically for people with intellectual disabilities, the MSNA-ID (Maastricht Social Network Analysis for...
People with Intellectual Disabilities, Van Asselt-Goverts et al., 2012) has been designed. Drawing up genograms (e.g., McGoldrick, Gerson, & Petry, 2008) and ecograms (e.g., Herman, 2012) can be a convenient method for professionals to get to know the background of the personal network and to work indirectly on strengthening the relationship between these two. Furthermore, genograms as well as ecograms are useful for revealing sources that might enhance the informal networks. In the support of people with PIMD, network mapping should be part of the personal profile (Vlaskamp et al., 2015).

In the Individualized Support Program, the personal profile forms the basis for determining the perspective for an individual with PIMD, and indicates the desired situation or advisable change (Vlaskamp & Van der Putten, 2009). When working with social networks, the map of the network always constitutes the starting point for further action. Discussing the network is an important second step, especially for people with PIMD. Since people with PIMD are not able to express their own wishes and needs concerning their social networks, others are needed to do so for them. For future action it is important that the personal network and the professionals reach some sort of consensus. In the discussion about the current network, different aspects should be discussed. In line with Van Asselt-Goverts et al. (2012), we would recommend discussing the size and composition of the network, the variety of its members, the accessibility of the members, and the structure of the relationships (frequency, initiative, length, basis, activities, and function). Per topic, the personal network and the professionals should discuss whether they find the current situation satisfactory and, if so, why. If the personal network and the professionals feel that the current network is unsatisfactory, two general needs can be distinguished: strengthening the existing network or expanding the network (Heaney & Israel, 2008; Smit & Van Gennep, 1999). The chosen direction should be tailored to the (assumed) wishes and needs of the individual with PIMD. The discussion should conclude with what the desirable situation is, according to all the people involved. Within the Individualized Support Program (Vlaskamp et al., 2015), this can be seen as a part of setting up the perspective, that is, what is believed to be important for this individual with PIMD.

When the desirable situation has been formulated, active steps can be taken. If the direction of strengthening the current network is chosen, it is possible to do this in different ways (Smit & Van Gennep, 1999): reanimating (refreshing faded contacts or giving predictable relationships a boost), activating (more effectively using the qualities of a network member or increasing the involvement between the two), unblocking (resolving disturbances in the network or resolving practical issues), intensifying (higher frequency of contact, contact in another situation, eliminating shallow contacts), and maintaining (keeping the network as
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Smit and Van Gennep (1999) provide multiple examples for when expansion of the network is desired. However, with regard to these examples it is important to keep some considerations in mind. First, all the people involved need to realize that it takes time to form a relationship and small steps are required, and so thinking in terms of inner and outer circles can be helpful. Second, it is important to make sure that the personal network and the professionals collaborate: The network is already small and therefore often under pressure; making members responsible for expanding the networks without the support of the professionals will increase the pressure and damage the network (Van Lanen & Claassens, 2012). Third, it is important to understand why expansion is desired: Is it for closer relationships, or is it to enable the person with PIMD to perform more activities? According to Wibaut et al., (2006) it is important for a (new) network member never to be assigned the tasks of a professional.

As well network interventions as the Individualized Support Program conclude by evaluating the steps taken and ascertaining in the end whether the desirable situation has been achieved. Wibaut et al. (2006) studied those effective factors found in network interventions with positive outcomes. These factors, among others, included individualized planning, working methodically with a clear goal and small steps, and structural integration into the organization. These factors, in turn, form the basis of the Individualized Support Program (Vlaskamp et al., 2015; Zijlstra, Vlaskamp, & Poppes, 2005). For future research it would be interesting to focus on the applicability and results of network interventions within the Individualized Support Program.

In sum, for people with PIMD it is definitely important to map the current social network in close collaboration between the personal network and the professional. Subsequently, this current network needs to be discussed and, based on the wishes and needs of the individual with PIMD, a desired situation should then be formulated. In order to achieve this desirable situation, it is important to set clear goals. These goals should then be translated into small steps leading to concrete action. This form of network intervention can be seamlessly integrated into the Individualized Support Program and thereby become a part of the daily support.
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References


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