

The Structure of Informal Social Networks of Persons with Profound Intellectual and Multiple Disabilities

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Background Persons with less severe disabilities are able to express their needs and show initiatives in social contacts, persons with profound intellectual and multiple disabilities (PIMD), however, depend on others for this. This study analysed the structure of informal networks of persons with PIMD.

Materials and Methods Data concerning the number, type and frequency of contacts were collected in 205 persons with PIMD.

Results The mean number of contact persons was 5.1 (range: 0–26, SD: 4.2) per year. 79.4% of the contact persons are family, with an average of 72.3 contacts per

year. Parents had significantly more contact compared to the other informal contact persons. In 2.2% of the sample contacts with peers were seen.

Conclusions The informal networks of persons with PIMD consist mainly of family. The question arises how informal networks can be expanded and which role professionals have in this process.

Keywords: informal networks, parents, profound intellectual and multiple disabilities, residential facility, social contacts

Introduction

Having social contacts is an important aspect of the quality of life of persons with intellectual disabilities (Schalock & Verdugo 2002), not only for persons with intellectual disabilities in general, but also for persons with profound intellectual and multiple disabilities (PIMD) (Petry *et al.* 2005). The social contacts of a person can be with many different people and can vary in terms of number and function; taken all together they form a social network. The characteristics of a social network can be distinguished by the structure and function of these contacts (Buisse 1997; Lippold & Burns 2009). Structure encompasses the number of different contact persons, the relation between the contact persons and the other person, the frequency of the contacts and the type of contacts. Function encompasses mainly the purpose of the relation, which can be derived from both informal (unpaid) and formal (paid) sources (Forrester-Jones *et al.* 2006; Bigby 2008).

Buisse (1997) divides the function of the contacts into social–emotional support and practical–instrumental support. Social–emotional support focuses on emotional adaption by means of listening, discussing and advising. This type of support is based on personal ties, rather than employment (Bigby 2008). Practical–instrumental support has a more problem-solving nature and includes material and concrete help in the form of goods and services.

Studies about the structure and function of the social networks of persons with intellectual disabilities have shown that in general three contact groups are most common: staff, family members and other persons with an intellectual disability. Thus, the social contacts least reported have been those with informal contact persons without disabilities who are not family (Robertson *et al.* 2001; Forrester-Jones *et al.* 2006; Bigby 2008; Lippold & Burns 2009). It is striking that in the numerous studies, discussions and practical initiatives about the structure of social contacts, barely any attention is paid to the

social contacts of people who are the most severely disabled; persons with PIMD. Persons with PIMD have a profound intellectual disability in combination with a severe or profound motor disability and, in many cases, a sensory disability with visual disabilities as most prominent (Nakken & Vlaskamp 2007). As a result, persons with PIMD are completely dependent on others in almost all aspects of their daily lives. In addition, difficulties in communication reinforce this high level of dependency (Petry *et al.* 2005). Persons with PIMD experience limitations in signalling and communicating their emotional responses and needs, such as difficulties in communication concerning when and how support should be given (Petry *et al.* 2005; Schuengel *et al.* 2010). In addition, persons with PIMD are totally dependent on others in the maintenance of social contacts with relatives, friends, acquaintances, peers or staff. With the intensive care needs of persons with PIMD living in a residential facility, it is obvious that they have formal contact persons in their network whose primary goal usually is to provide practical-instrumental support. To what extent formal contact persons provide social-emotional support during contact moments is unclear. The type of relation often determines the type of support given. Bigby (2008) for instance writes about 'special occasion family' and 'engaged family. The 'special occasion family members' mainly have contact on special occasions, such as at Christmas or on a birthday, and then provide social-emotional support. 'Engaged family' provide both social-emotional support and practical-instrumental support, such as actively monitoring the well-being of the person with PIMD and the support provided to them, and they have contact on a regular basis. The main difference between formal and informal contact persons is the fact that formal contact persons are paid and have a clear job description. Informal contact persons all have their own motives for providing either social-emotional support or practical-instrumental support to a person with PIMD.

Until now no data are available about the structure and function of the social networks of persons with PIMD in general. This study focuses on the structure of informal social networks of persons with PIMD. Specifically, it aims at providing detailed information about the number of informal contact persons, the relation between the informal contact person and the person with PIMD, frequency and type of the informal contacts of persons with PIMD. Formal contact persons have been excluded and are considered in a separate analysis about the structure and function of the formal network.

Materials and Methods

Participants and setting

Because persons with PIMD experience major limitations in communication, information needs to be gathered by proxy. In order to get the best information possible, the choice was made to use the direct support persons (DSP) as the source of information. In the Netherlands, especially in the case of a non-invasive study like our study, ethical approval is obtained from the facility where the study takes place. The research proposal was presented for approval to the participating organization that informed parents and legal guardians and asked to give their informed consent.

The DSPs were the participants in this research, who served as proxies for the persons with PIMD. Inclusion criterion for the DSPs was that they had known the person with PIMD for at least 6 months. All persons with PIMD were selected according to the main characteristics described by Nakken & Vlaskamp (2007). Hence, every person has both a profound intellectual disability and a severe or profound motor disability, leading to being wheelchair bound or leading to little or no use of their hands or arms. The guidelines for a profound intellectual disability are an intelligence quotient of below 20–25 points or an estimated developmental age of up to 24 months (Nakken & Vlaskamp 2007). Furthermore, only persons were included who are not living at home with parents or family.

The persons with PIMD were recruited from 13 facilities for persons with an intellectual disability across the Netherlands. All persons with PIMD living in these facilities were included, in total 375 persons. All parents and legal representatives of these 375 persons with PIMD were informed and from 205 (54.7%) written informed consent was obtained. The persons with PIMD had a mean age of 48.0 years (range: 13–79, SD = 15.8), 90 were male and 115 were female. Next to diversity in regions, there is variation in the living scheme; 58 participants were recruited from small group homes and 147 persons with PIMD were living in campus settings (Mansell 2006). 69.8% (143) had visual problems, 26.4% (54) had auditory problems, 31.7% had behavioural problems and 64.9% (133) had epilepsy.

Data and instruments

Data were collected concerning the structure of the social network and investigated as follows: (i) Number

of informal contact persons: the total number of different people a person with PIMD had contact with within the 12 months. (ii) The relation between the informal contact persons and the person with PIMD, for instance 'mother' or 'father', 'other person of the living group' (Robertson *et al.* 2001; Forrester-Jones *et al.* 2006; Lippold & Burns 2009). (iii) Frequency of the informal contact; the estimated amount of contact between the informal contact person and the person with PIMD, regardless of the duration of one particular contact. (iv) Type of contact between the person with PIMD and the informal contact person such as calling, visiting, taking the person away from the facility etc. (Baker *et al.* 1993). Data were gathered through interviews with the DSPs. The interviews were held face-to face by the same researcher with two DSPs about one specific person with PIMD. A semi-structured questionnaire was designed and used in the interviews with the DSPs (see for details Table 1). All of the questions answered concerned the last 12 months.

The aim of the interview was to keep it short and unambiguous through the use of the questionnaire. A pilot version of the questionnaire was therefore tested on intelligibility, user-friendliness and completeness by professionals who worked in a nursing home for the elderly ($n = 10$). The education level of these professionals was similar to the education level of the professionals dealing with persons with PIMD. The choice was made to use a different target group to test the questionnaire because in this way the group of persons with PIMD was kept as large as possible. Based

on the feedback, the questionnaire was adjusted, questions or the response options were adjusted or changed completely, for example adding the options 'per week' and 'per month' in questioning how often someone visited or called, instead of only 'per year'.

The first author conducted all the interviews with the two DSPs per participant and therefore visited all the facilities. Appointments with the DSPs were made in advance over the phone with the DSPs themselves or with their team manager.

The questionnaire was retrospective. As the structure of the social network was not stated in detail within the daily reports, the present authors had to rely on the information provided by the DSP. To increase the reliability, two DSPs were asked to answer the same questions and, in case of disagreement, were asked to discuss their answers and achieve consensus. The questionnaire was repeated for each of the informal contact persons in the social network of a person with PIMD.

Analysis

Descriptive statistics have been used to describe the structure of the social networks. First, the number of social contacts with informal contact persons was calculated for each person and the mean, SD and ranges were calculated. Second, the relation between the informal contact persons and the person with PIMD was displayed in percentages of the different kinds of informal contact persons. Third, the frequency of the contacts was calculated in amount per year. Then, the types of informal contact persons were divided into four groups: (i) parents; (ii) brothers and sisters; (iii) other family members; and (iv) other informal contact persons. For every group, the percentages per frequency category were calculated and displayed. Then the mean frequencies of the contacts, per group, were calculated and an analysis of variance (ANOVA) was used to check whether the mean frequency of contact between the four groups was different. If the P -value was smaller than 0.05 ($P < 0.05$), the differences between the groups were considered to be statistically significant. In that case, a post hoc test was used to find out which groups differed from each other. Finally, the types of contacts with the informal contact persons were calculated. Per category of type of contact, percentages were calculated. After this, percentages of the types of contact were given for each of the subcategories; parents, brothers and sisters, other family members and other informal contact persons. Also, descriptive statistics were used

Table 1 Categories used in the questionnaire

Relation between person with PIMD and informal contact person				
<input type="radio"/>	Father			
<input type="radio"/>	Mother			
<input type="radio"/>	Brother			
<input type="radio"/>	Sister			
<input type="radio"/>	Other family member			
<input type="radio"/>	Person with disabilities (not a group member)			
<input type="radio"/>	Neighbour			
<input type="radio"/>	Volunteer			
<input type="radio"/>	Other (not family, not a person with disabilities)			
How often has there been contact, per type of contact?				
	Times	Per week	Per month	Per year
Calling	—	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visiting	—	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Away from facility	—	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	—	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

to calculate the amount of contacts per year, per type of contact and per type of informal contact person. ANOVA was used to check whether the averages were equal and whether these differed significantly post hoc tests were used to determine which averages were significant.

Results

Number of informal contact persons

Of all 205 persons involved, 198 (96.6%) had contact with one or more informal contact persons that year. Seven participants (3.4%) did not have contact with any informal contact persons in the last year. In total, 1051 different informal contact persons were involved with an average of 5.1 different informal contact persons (range: 0–26; SD = 4.2) per person with PIMD over the period of 1 year. Almost three-quarters (72.7%, $n = 149$) of the participants with PIMD had contact with one to six informal contact persons in the recent year, 23.9% ($n = 49$) had seven or more informal contact persons as contacts and 3.4% ($n = 7$) had no informal contact persons at all.

Relation between the informal contact person and the person with PIMD

Out of all 205 persons with PIMD included in this study, 45 (22%) had contact with only one parent, 73 (35.6%) had contact with both parents. One hundred and forty-nine persons with PIMD (70.7%) had contact with a brother and/or a sister varying from one up to eight siblings. One hundred and fifteen persons with PIMD (56.1%) had contact with a family member, with a broad range from just one up to 20 other family members. Finally, 104 persons with PIMD (50.7%) had contact with other informal contact persons, varying from one up to 15 other informal contact persons, such as neighbours, volunteers or friends of family members.

Concerning the relation between the informal contact persons and the persons with PIMD, 834 (79.4%) of the informal contact persons were family members. Of all the family members, 'other family members' (such as uncles, aunts, grandparents, nieces or nephews) cover the largest part of the social network (34.3%), followed by siblings (26.9%) and finally parents (18.2%). Only 2.2% of the social network consisted of persons with an intellectual disability. The category 'other' contains, for example, friends without disabilities or friends of other members of the social network. Table 2 provides an

overview of the relation between the informal contact persons and the person with PIMD.

Frequency of the informal contacts of persons with PIMD

On average, a person with PIMD had contact 24.4 times that year (range: 1–832; SD = 54.8) with the non-professional within their network. All the informal contact persons taken together ($n = 1051$), 58.2% had contact less than once a month and over a quarter (29.5%) only had contact once or twice a year. 18.6% of all the informal contact persons had contact at least once a week or more.

The mean frequency of contact per category of informal contact persons is shown in Figure 1. Parents had an average of 72.32 contacts, siblings 13.65, other family member 8.35 and other informal contact persons 23.77. The differences in mean frequency between the four groups of informal contact persons are statistically significant ($F = 75.51$, d.f. = 1050, $P < 0.001$).

A Bonferroni post hoc analysis shows that the frequency of contact with parents is significantly higher compared with that of the other groups and that the group 'other informal contact persons' has more contact than the group of 'other family members'.

Type of the informal contacts of persons with PIMD

As for the type of contacts, 84.8% of the informal contact persons visited the person with PIMD in the facility where they lived. Taking a person away from the facility for a stroll, for a stay in the paternal home or

Table 2 The relation between the informal contact persons and the person with PIMD: number and percentage per category

Type of informal contact person	<i>n</i>	%
Parents	191	18.2
Father	84	8.0
Mother	107	10.2
Siblings	283	26.9
Brother	124	11.8
Sister	159	15.1
Other family members	360	34.3
Other informal contact persons	217	20.6
Person with disabilities	23	2.2
Volunteer	100	9.5
Other	94	8.9
Total	1051	100

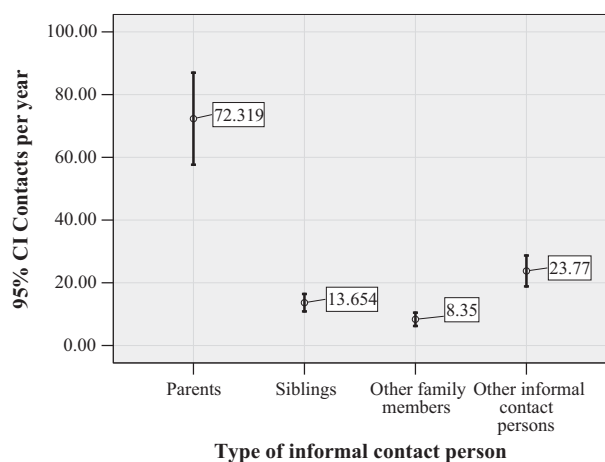


Figure 1 95% confidence interval of frequency of contacts per year, per category informal contact persons.

for an outing, was performed by 27.3% of the informal contact persons. These two categories, visiting or taking away from the facility, combined, were performed by 96.4% of the informal contact persons. Of all the informal contact persons, 4.6% used phone calls to contact the person with PIMD. Other types of contact, like sending a postcard, were used by 7% of the informal contact persons.

16.6% (34) persons with PIMD received one or more phone calls per year, 92.2% (189) were visited once or more, 48.3% (99) were taken away from the facility at least once and 13.7% (28) had one or more other contacts, such as receiving a postcard or an email.

As for the frequency of the contacts, per type of informal contact person, differences have been found within the two most used types of contact: visiting and taking a person away from the facility. An ANOVA shows that there were significant differences between the groups of informal contact persons and the frequency of visiting ($F = 78.24$, $d.f. = 1050$, $P < 0.001$). A Bonferroni post hoc analysis shows that parents visited significantly more often (mean of 41.9 visits per year) than all the other groups of informal contact persons (siblings; 6.77, other family members; 6.65 and other informal contact persons; 11.40 visits per year). When a person was taken away from the facility, there were significant differences between the categories of informal contact persons and the frequency of these outings ($F = 27.14$, $d.f. = 1050$, $P < 0.001$). Parents took their child away significantly more often (mean 18.25 times per year) compared with the other categories (siblings; 4.75, other family members; 0.97, other informal contact persons; 9.25).

The group 'other informal contact persons' took a person with PIMD away significantly more often than the category of 'other family members' (9.25 versus 0.97). As for contacts in general, and for visiting and for taking a person away from the facility, parents did this significantly more frequently than all the other categories of informal contact persons.

Discussion

The aim of this study was to explore the structure of the informal social networks of persons with PIMD. We can assume that the data collected over this period of twelve months are representative for all periods of twelve months. This allows us to state that the results show that on average, persons with PIMD have contact with five informal contact persons a year of which 80% is a family member. Only 2.2% of the social network consisted of persons with an intellectual disability. The mean frequency of contact with informal contact persons is low, namely 24.4 per year, where parents have significantly more contact with their child than all other informal contact persons. Even though parents are most frequently involved, only 57.6% of all the persons with PIMD have contact with one or both parents. This means that 42.4% of the persons with PIMD depend on the remaining informal contact persons for social contacts. But this remaining group has significant less frequent contact than parents. Visiting and taking a person away from the facility are the most used forms of contact.

When interpreting the results, the following methodological issues of this study need to be considered. First, because persons with PIMD experience limitations in communication and have severe intellectual disabilities, they are not able to provide information about their informal network. Therefore, gathering information by proxy is the alternative. A disadvantage of this method is that data might be incorrect or incomplete. However, to enhance the reliability of the given information, the interviews were held with two DSPs who had to reach consensus about the number of informal contact persons involved. A more reliable and valid way to get information can be to 'follow' the persons with PIMD in daily life and actually count the number and frequency of (informal) contacts. For practical reasons, this is not feasible, given the group size of 205 persons with PIMD. The information that was collected by the DSP can also be biased as they have no information about the nature and frequency of informal contacts of the person with

PIMD outside the facility. For these cases, the number of informal contacts may be higher than reported in this study. Second, concerning the frequency of the contacts, the length of a particular contact is not taken into account. This means that both (very) short and (quite) long contacts are counted as one contact. Third, this study focused on the contacts with informal contact persons. All the participants live in a facility and therefore also have contact with professionals, but it remains unclear in what way these contacts can also be seen as part of the social contacts and network. Although the results of the current study cannot be generalized to cover the social networks of persons with PIMD in general, the number of persons with PIMD included (205) is very high, especially when the sample size is related to the estimated number of persons with PIMD living in the Netherlands. These figures range between 8.000 and 20.000 (Vlaskamp 2003; Maes *et al.* 2008, 2009; Schuurman 2010; SCP 2010). That means that in the current study, 1–3% of the whole population was included. It should be taken into account that all the persons involved in this research lived in a residential facility. It is still unclear in what way these results can be applied to, for instance, persons with PIMD still living at home, or with another family member.

Bigby (2008) studied trends in the informal social networks of middle-aged and older people (mean age: 51.5 years) with intellectual disabilities after moving into the community. The size of each person's informal network ranged from 0 to 6 people, with an average of 1.92. This number was based on the number of people that had contact with the person with an intellectual disability and consisted of family and friends. Robertson *et al.* (2001) found that the median size of a social network, excluding staff members, was two people, with a range of 0–13 different contact persons. The general picture from the current results seems to be much more positive (mean number of five informal contact persons a year) although Robertson *et al.* (2001) only included people in the network who were considered to be important in someone's individual life. Our research included all contact persons without rating the relationship. Even though Bigby (2008) and Robertson *et al.* (2001) studied different target groups and used other conditions in order for a person to be considered a network member, their studies provides a general overview of the small network sizes of persons with an intellectual disability. The current research shows similar outcomes which emphasize that besides being small in number, the networks of persons with PIMD also consist mainly of family members.

This is consistent with the findings in the field of persons with intellectual disabilities in general (Robertson *et al.* 2001; Forrester-Jones *et al.* 2006; Lippold & Burns 2009). More specifically, Chou *et al.* (2011) found that the majority of the primary family carers of adults with PIMD not living in a residential facility were their parents. However, in this research the involvement of other persons with disabilities in the social networks differs between persons with intellectual disabilities in general and persons with PIMD. Persons with an intellectual disability tend to have significantly more friends with intellectual disabilities than friends without such disabilities (Emerson & McVilly 2004). This can also be expected to be the case when it comes to persons with PIMD. The current study, however, shows that the networks of persons with PIMD barely contain peers; only 2.2% of all the informal contact persons are persons who also have intellectual disabilities. It is unclear whether these relations do not exist or whether the DSPs interviewed are simply unaware of these contacts or even do not consider such contacts possible. Further studies in which these relationships will be observed in daily practice and compared with social networks diagrams derived from DSPs are recommended.

Concerning the results of the current study, the relation with age is also an interesting topic that needs to be studied. Research shows that as time progresses, in the course of the years, family visits to the facility become less frequent (Blacher *et al.* 1999). Baker *et al.* (1993) also found that age is related to the degree of involvement of the network; where younger persons with PIMD are concerned the involvement of the network is more intense.

Robertson *et al.* (2001) and Bigby (2008) found that age was negatively related to the size of social networks of persons with an intellectual disability. Elderly persons with disabilities generally do not have children or a spouse on whom they can depend for support (Bigby 1997). The same is true for elderly persons with PIMD. On the basis of these findings and the results of the current study, one can assume that the ageing of a person with PIMD probably relates to a smaller number of people in a social network, a less varied network and a lower frequency of contacts. More research on the relationship between age and the structure of the informal contacts of persons with PIMD is needed.

Other research shows that the size and type of the living scheme is strongly related to the size and composition of the social network, and the type of activities undertaken (Emerson & McVilly 2004;

McConkey 2007). In addition, the previous living scheme seemed to relate to the size of the network; participants who came from their home to the facility had larger social networks than participants who came from somewhere else (Robertson *et al.* 2001). Further analysis is required to clarify whether the same can be seen in persons with PIMD. This research only included persons with PIMD living in a residential facility and measures were only taken once. It would be interesting to take multiple measures across the lifespan of a person with PIMD concerning social contacts, where the living schemes are taken into account. In particular, comparing the social network of the group of persons with PIMD living with their family to those living in a residential facility, will yield important information. Although the social networks of individuals living within a family might be assumed to be richer, this might not necessarily be the case considering the fact that living in a residential facility means living with peers.

Research also shows that networks for persons with intellectual disabilities mainly consist of staff (Robertson *et al.* 2001; Forrester-Jones *et al.* 2006; Lippold & Burns 2009) and are also related to the type of living scheme. Considering the living scheme of the participants in the current study and their limitations, it can be assumed that their networks also consist generally of professionals. Further research is required to elaborate on this and also to study the function of these contacts with professionals. Buysse (1997) divides the function of the contacts into social-emotional support and practical-instrumental support. Because of their limitations, persons with PIMD receive a lot of practical-instrumental support, especially from professionals. It remains unclear how much social-emotional support persons with PIMD receive from the professionals. Petry *et al.* (2005) found that parents and DSPs thought that the well-being of a person with PIMD was affected by the degree to which a DSP felt committed and could express attention, warmth and affection (social-emotional support). At the moment, it is unclear if the contacts with professionals can be seen as social contacts and consequently contribute to a person's well-being. A follow-up study should provide more details on the role of professionals in the contact networks of persons with PIMD.

To summarize, follow-up research should focus on the existence of peer relations of persons with PIMD and on the role of professionals in that matter. Furthermore attention should be paid to the relations between the informal social network, age and living

scheme. On the other hand, it should also focus on the formal social network of persons with PIMD.

The current study shows that the social networks of persons with PIMD are small. This is worrisome because having a large social network will facilitate social inclusion (Abbott & McConkey 2006; McConkey 2007; Bigby *et al.* 2009). It can also be argued that small networks can be seen as more supportive than large networks (Bigby *et al.* 2009). Forrester-Jones *et al.* (2006) state that a wide social network puts less pressure on the professionals and can lead to greater personal freedom and autonomy. The question that arises is in what ways social contacts with people other than parents and professionals can be meaningful for persons with PIMD? In what way, can they benefit from having an extensive social network outside of their direct living environment? Until now, it remains unclear who is responsible for organizing the network, professionals or informal contact persons, and how it can be organized that existing contacts are maintained or even expand throughout the years? Considering the fact that persons with PIMD mainly depend on professionals and have contact with them on a daily basis, professionals are probably in a good position to be coordinators of a social network. In order to make this work, a protocol is needed to optimize the social networks of persons with PIMD. The results of the current research are a first step in achieving these goals. More knowledge about the structure and function of social contacts in persons with PIMD and other related factors is needed in order to arrange the best support possible for persons with PIMD and to enhance their quality of life.

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