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Who cares?

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Summary

This dissertation describes research that provides information about the way informal networks of people with profound intellectual and multiple disabilities (PIMD) can be maintained or expanded. This should contribute to an intervention capable of optimizing the informal social networks of people with PIMD and thus of contributing to a better quality of life.

People with PIMD have profound intellectual as well as severe motor disabilities. In addition to these disabilities, there are sensory problems (for example, vision or hearing), medical problems, and problems with communication. Because of the severity and the combined impact of these problems, people with PIMD are almost completely dependent on others in their daily lives, and, by extension, for maintaining and expanding their social networks.

A social network consists of all those people one has a relationship with; these can be formal (often based on payment, professionals) and informal (based on personal interest, family, friends, etc.) relationships. These relationships can serve multiple purposes that can be roughly divided into practical (providing information, offering goods and services) and emotional (love, trust, care) ones. It is common for people from a formal network to offer mostly practical support, while people from the informal network mainly offer emotional support. Due to the high practical support needs of people with PIMD, a formal network is fairly self-evident. However, little is known about the informal network, even though this is just as important, or even more so, for people with PIMD: informal networks can contribute to participation, inclusion and better health, and can prevent loneliness. In sum, social networks contribute to the quality of life of people with PIMD.

People with only intellectual disabilities have small networks (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, 2016). Research about networks of people with PIMD is lacking. This is remarkable, because it is expected that, due to the severity and combination of the limitations, the networks of people with PIMD are even smaller than for people with only intellectual disabilities. In addition, people with PIMD are heavily dependent on others in their daily lives, meaning that they are not capable of maintaining, let alone expanding their own informal social networks. For that reason, it is important to have a clear impression of the current social networks of people with PIMD. Moreover what is done in order to maintain and expand the social networks should be clear. Finally, it is essential to look into the views and beliefs of professionals with regard to the social networks of people with PIMD.

Chapter One is an introductory chapter that describes the context of the research and the research questions.

Chapter Two provides an overview of the current structure of the social networks of people with PIMD. Professionals directly involved with 205 people with PIMD (90 male, 115 female, average age: 48, SD: 15.8) were questioned about the social networks of these people. They were asked with whom the person with PIMD had had contact in the past year, in what way, and how often. On average, people with PIMD had contact with 5.1 informal contact persons (range: 0–26, SD: 4.2). For 72.7% of the people with PIMD, it turned out that they had contact with one to six informal contact persons in the time span of a year. As for informal social contact persons, 58.2% of them had contact less than once a month and 29.5% had contact only once or twice per year. A total of 18.6% of all the contact persons had contact at least once a week. Of all the contact persons, 79.4% constituted family: Parents had significantly more contact compared to all other contact persons. Visiting was the most frequent form of contact. Based on these results it was concluded that the social networks of people with PIMD are small, and smaller than those of people with only intellectual disabilities. Furthermore, it was concluded that professionals, because of their position, can play an important role in these social networks.

Chapter Three discusses the factors that are related to the structure of the social networks of people with PIMD. These factors are age, communicative abilities (body movement, facial expression/eye movements, vocalizations, and symbolic communication) and their current living arrangements (campus-style setting or small community home). It turned out that only the age of people with PIMD was negatively related to both the size of the network as the frequency of the contacts. The current living arrangement was only related to the frequency of the contacts. Based on these results, it was concluded that the social network of a person with PIMD does not expand once a person comes to live in a facility. With time the networks only become smaller, and the intensity of the contact becomes lower. It seems to be of great importance that, when moving to a facility, attention is especially paid to maintaining and, if necessary, expanding the existing network.

Chapter Four describes explorative research about spontaneous interactions between people with PIMD. This chapter specifically studies the types of interactions that occur in a non-controlled situation and what opportunities people with PIMD are offered in order to interact with group members. A total of 14 people with PIMD were observed, all having an average age of 30.6 years (range: 4–53, SD: 17.6). They were observed for three consecutive hours, and every five minutes it was noted whether interaction occurred, with whom, and what type of interaction it was. In addition, a map was drawn of the group, showing all positions

and relocations. On average, a total of 15.2 interactions per participant were observed (range: 3–33, SD: 8.9): 5.1% of these were with a group member, 73.4% with a direct support person, 14.9% with the observer, and 6.5% with others (for example, a therapist). Of the 14 people with PIMD we observed, five interacted with a group member. It was almost never possible for participants with PIMD to touch a group member. In 61.3% of the observation periods, it was impossible to touch a group member without effort, or to see a group member without effort. We observed ten interactions between a person with PIMD and a group member. In three of these it was impossible for the participant to touch or see the interaction partner: These interactions consisted exclusively of vocalizations. Based on these results, it was concluded that, despite the situation not being facilitating, people with PIMD still need and seek interactions with their group members. Direct support persons are capable of optimizing the conditions, for example by placing group members nearer to each other in order to facilitate interactions between people with PIMD and their group members.

Chapter Five describes the ways professionals try to maintain, strengthen, and expand informal social networks. For that purpose, the content of 60 individual support plans was analyzed. These individual support plans were inductively coded and illustrated with quotes. The final coding scheme contained three main categories, 12 subcategories, and a total of 45 codes. Social contacts were mentioned in all individual support plans. A total of 1340 quotes about social contacts were found, with an average of 22.3 quotes per individual support plan. The three main categories are: history, current situation, and the future. A total of 22.6% of the quotes were about the history of the social contacts and were described in 93.3% of the individual support plans. The current situation was described in all individual support plans and covered 71.2% of the quotes. Of all quotes, only 6.2% were about the future and were described in 68.3% of the plans. Mention of social contacts in the future pertained mainly to what was hoped for; the strategy most often described was simply to maintain the current situation. Less than 1% of the quotes involved goals in the area of social contacts. Based on the results, our conclusion is that more attention needs to be paid to the social contacts of people with PIMD. In addition, it is important for professionals to realize why social contacts for people with PIMD are important.

Chapter Six is a description of the attitudes of professionals vis-à-vis the personal networks of people with PIMD. The personal network contains the long-term and loving relationships that are part of the larger social network. This study specifically examines the importance of personal networks for people with PIMD from the point of view of professionals, and what steps they are taking in order to maintain or expand networks, as well as the facilitating and impeding factors they have experienced in this regard. This chapter provides an analysis

of interviews that were held with 24 professionals about the topic of personal networks for people with PIMD. These professionals had an average age of 38.9 years (range: 23-63, SD: 10.6) and an average working experience of 12.3 years (range: 1-37, SD: 8.9). A total of 12 direct support persons from the living unit, five support persons from the day services setting, and six healthcare psychologists were interviewed. All interviews were individually conducted by the researcher and were voice-recorded. These recordings were transcribed and coded based on the literature and inductive coding. The final coding scheme consisted of five main categories and a total of 45 codes. A total of 808 quotes were coded; sometimes it was possible to assign more than one code to a quotation, therefore a total of 871 codes were assigned. It turned out that all professionals thought the personal networks of people with PIMD were important, especially for a sense of belonging and participation. Maintaining or strengthening the personal network did not occur or only barely occurred in 37.5% of the interviews. The relationship between the person with PIMD and the personal network was maintained or strengthened in direct and indirect ways, for instance by organizing activities, inviting people, sending postcards to or calling people in the personal network to give them information about the person with PIMD. According to 58.3% of the interviewees, consciously expanding the personal network never or hardly ever happened. Putting a person with PIMD on a waiting list for a volunteer did take place. Professionals indicated twice as many impeding factors as facilitating factors. The characteristics of the people with PIMD were experienced as impeding their working with personal networks by 95.8% of the participants. In addition, the personal network itself and society at large were experienced as limiting by a lot of the participants. At the same time, the characteristics of the target group were also experienced as facilitating, because what was involved was a group that evoked a sense of caring, and small things could be perceived as big. The policy for volunteers and the central location of the facility were also perceived as facilitating. The chapter concludes with the statement that close collaboration between the formal and informal network is necessary in order to optimize the informal personal networks of people with PIMD.

This dissertation concludes with *Chapter Seven*, the discussion. Despite the fact that the importance of informal social networks is widely acknowledged, little is being done to improve the current situation. By placing networks in a broader context, opportunities might arise to do so. Networks can be perceived as circles, with the inner circle representing the personal network (the most important relationships), with the circle outside that circle standing for the nominal network (people you know and meet) and the outer circle as the extensive network (people you know only by face). It is important to realize that the goal is to try and get people one circle closer to the inner one, or just into the outer circle and, from there, try to move them inwards.

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