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Who cares?

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Chapter 1

Introduction

In research on people with intellectual disabilities (ID), the topic of social networks features in both scientific discussions and practical initiatives. This is not surprising, considering that the social domain is an important aspect of the quality of life of people with ID (Schalock & Verdugo, 2002). Furthermore, the social networks of people with ID are believed to contribute to social inclusion (Abbott & McConkey, 2006; Bigby, Clement, Mansell, & Beadle Brown, 2009; McConkey, 2007), leading to more personal freedom and autonomy (Forrester-Jones et al., 2006), and contributing to mental health (Scott & Haverkamp, 2014). Social networks can be described in terms of two categories: how they are structured and what function(s) they serve (Buysse, 1997; Heaney & Israel, 2008; Lippold & Burns, 2009, Lunsy, 2006). Lunsy (2006) considers the structure of a social network as “a layout of a group of persons who give to and receive support from one another.” The characteristics of a social network are: size of the network, density, homogeneity, multiplicity (the variety of functions a relationship serves), and frequency of interactions (Lunsy, 2006). In addition to its structure, a social network can serve multiple functions, which generally can be divided into emotional (expressions of love, empathy, caring, and trust) or practical (goods, services, advice, information) support (Heaney & Israel, 2008; Lunsy, 2006). What function a relationship serves is often derived from the type of contact there is between two persons. The type of people in a social network can be divided into formal (paid) contacts and informal (unpaid) contacts (Bigby, 2008; Forrester-Jones et al., 2006; Heaney & Israel, 2008). For people with ID living in a residential facility, formal contacts are uppermost in their lives (Lunsy, 2006). It is likely that those contacts mainly provide practical support. Providing emotional support usually springs from personal motives rather than employment (Bigby, 2008) and is thus more likely to be provided mainly by informal contacts.

Multiple research projects have been carried out, which study the structure and function of informal social networks of people with ID (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, 2016). These studies have shown that these informal social networks are limited in size, become smaller with aging, and mainly consist of family members and peers. Recommendations include the involvement of persons with ID when determining satisfaction with the existing informal social network and their wishes. Furthermore, teaching social skills to persons with ID and supporting them in leisure activities is recommended. It is remarkable that these research projects mainly focus on people with mild intellectual disabilities and seldom on people with severe or profound intellectual disabilities (Verdonschot et al., 2009). Even more striking is that the socially most vulnerable group of people within the group of people with ID is the one least likely to be included: people with profound intellectual and multiple disabilities (PIMD).

People with PIMD have a profound intellectual disability, with a developmental age of less than two years, combined with a severe or profound motor disability that often leaves them wheelchair-bound (Nakken & Vlaskamp, 2007). People with PIMD almost always experience sensory disabilities, mainly visual and auditory, in addition to physical health problems such as problems with eating and drinking, and hence growth problems, gastro-intestinal problems, problems with oral hygiene and dental care, sleeping problems, over or underweight, epilepsy, orthopedic problems or osteoporosis (De Cock, 2011; Maes, Lambrechts, Hostyn, & Petry, 2007; Nakken & Vlaskamp, 2007, Van Timmeren et al., 2016). These physical health problems can lead to pain (De Cock, 2011) or excessive use of medicines (polypharmacy) (Van der Heide, Van der Putten, Van den Berg, Taxis, & Vlaskamp, 2009), which, in turn, can affect, among other things, the level of alertness of people with PIMD. Furthermore, physical health problems, such as sleep and auditory problems, can be related to the exhibition of challenging behaviour (Poppes, Van der Putten, Post, & Vlaskamp, 2016). Due to the variety and severity of the disabilities seen in people with PIMD, they form a highly heterogeneous group (Zijlstra & Vlaskamp, 2005). However, people with PIMD do have one thing in common: They are highly dependent on other people in all aspects of their daily lives (Maes et al., 2007; Nakken & Vlaskamp, 2007; Vlaskamp, Poppes, & Zijlstra, 2005).

Because of the severity of their disabilities, people with PIMD experience limitations in communicating; they are almost incapable of expressing themselves verbally. People with PIMD interact on a pre- or protosymbolic level (Petry & Maes, 2006). Communication therefore mainly occurs through body movement, posture, muscle tension, facial expressions, sounds, or other cues that are personal or context-related (Hostyn & Maes, 2009; Vlaskamp et al., 2005). By deploying these communicative signals, they try to express their wishes, needs, and feelings (Vos, Cock, Petry, Van den Noortgate, & Maes, 2010). The communicative signals can be so subtle that they often go unnoticed. Given the severity of their disabilities, especially their limited and idiosyncratic abilities in terms of communication, it is questionable whether the results from studies into the informal social networks of people with ID, as mentioned earlier, can be plainly generalized to include the specific group of people with PIMD. Moreover, the implications for practice, such as how to teach them social skills, are not suitable for people with PIMD due to their disabilities.

Due to the high support and care needs of people with PIMD, the formal network is often well represented, for instance, care practitioners, therapists, or direct support persons (DSPs). It is assumed that this formal network's primary goal is to provide practical support, since a DSP has a clear job description. Furthermore, the relationship with a person with PIMD is characterized by inequality. This does

not mean that DSPs do not provide emotional support as well. However, it takes time to build a positive relationship, and this time is most often spent on the high physical care needs of the persons with PIMD. Furthermore, DSPs do not necessarily work with the same persons with PIMD for a prolonged period of time, as they change jobs or the person with PIMD moves. The emotional support provided by DSPs is usually not unconditional. Unconditional emotional support is generally provided by an informal, unpaid, network. Their involvement is based on personal motives and is not dependent on working schedules or payment. In order to be able to provide emotional support, it is important to know a person, meaning that a person with PIMD needs people in his/her life who are able to correctly interpret the communicative signals and respond accordingly, and are willing to establish a long-term caring relationship (Hostyn & Maes, 2009; Maes et al., 2007; Vlaskamp et al., 2005). These long-term caring social relationships are formed through repeated successful social interactions (Beauchamp & Anderson, 2010), which, in turn, can be seen as activities between two people, which are rewarding for both parties (Beauchamp & Anderson, 2010; Olsson, 2004; Olsson, 2005).

In general, such relationships are important for everyone; most people are looking for affectively positive interactions within the context of long-term, caring relationships (Baumeister & Leary, 1995), or positive informal relationships. People with PIMD are also in need of positive informal relationships with others (Hostyn & Daelman, 2011; Petry, Maes, & Vlaskamp, 2005). Positive informal relationships are important for several other reasons: They prevent loneliness and negative health effects (Baumeister & Leary, 1995; Cohen, 2004) and facilitate social inclusion (Abbott & McConkey, 2006; Bigby et al., 2009; Johnson, Douglas, Bigby, & Iacono, 2010; McConkey, 2007). Finally, positive informal relationships enable participation by bringing the person with PIMD into society and providing the person with PIMD with a sense of belonging (Petry et al., 2005). This makes having positive informal relationships an important aspect of the quality of life of people with PIMD (Hostyn & Maes, 2009; Nakken & Vlaskamp, 2007; Petry et al., 2005).

Despite the importance of an informal network for people with PIMD, little information is available. First of all, it remains unclear what the characteristics of their social networks are. For one thing, the size and composition are unknown, although they are expected to be small for a lot of the people with PIMD. As mentioned earlier, research into the social networks of people with ID have shown that those networks are indeed small, and mainly consist of family members and peers (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, 2016). Due to the severity of their disabilities, it is expected that the structure of the informal networks of people with PIMD is not the identical and probably smaller. If this turns out to be the case, it is worrisome, especially because people with PIMD are dependent on other people

in all aspects of their daily lives and rely on people who know them in order to be understood. Having limited social networks can thus lead to an impoverished lifestyle for people with PIMD. Furthermore, this would confirm the assumption that the informal networks of people with PIMD need more attention. Studies on the informal networks of people with ID have shown that age and type of living arrangement are related to the size of the network (Bigby, 2008; Emerson et al., 2000); this is likely also to be true for people with PIMD. If this is the case, attention should be paid to informal social networks at an early stage, and careful choices in terms of housing (for instance, when moving out of the parental home) should be made.

If a person with PIMD lives at home with his or her parents and siblings, they are usually the ones that make sure this informal network is formed and maintained; moreover, they constitute the network. When persons with PIMD move out of their homes and into a residential facility, this can cause disruption in the maintenance of relationships (Abbott, Bettger, Hampton, & Kohler, 2012). So far, it is not clear how these existing relationships can best be maintained. Even though a move can cause relationships to vanish, it may also create new possibilities. People with PIMD living in residential facilities have contact with other people with disabilities on a daily basis (Lancioni, O'Reilly, & Oliva, 2002). Group members (peers) from the living unit or day-services setting can therefore create opportunities to establish informal relationships (Abbott et al., 2012). Where the relationship with a DSP, a formal network member, is characterized by inequality, this is not the case for a relationship with a group member. Such a relationship is ideally based on choice and equality, where they are not dependent on each other for practical support. Compared to individual activities, people with PIMD spend a large amount of their time in group activities with peers (Vlaskamp, Hiemstra, Wiestra, & Zijlstra, 2007). Such group activities enable people with PIMD and their peers to undertake or experience activities together and, in that way, create long-term caring relationships (Beauchamp & Anderson, 2010). Yet, research has shown that direct support persons (DSPs), even when explicitly requested, rarely stimulate people with PIMD and their peers to interact (Nijs, Penne, Vlaskamp, & Maes, 2015). Even though the people with PIMD in this study showed interest in their peers and showed peer-directed behaviours, DSPs did not recognize such an interest nor did they facilitate these peer interactions (Nijs et al., 2015).

Looking at the benefits that informal social networks provide, it seems only logical that this should be part of the support provided by the formal network. It is known that professionals, when it comes to facilitating social inclusion, are important in terms of mapping social networks, and offering support in maintaining and expanding these (Abbott & McConkey, 2006; Van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014); however, their attitudes for a large part

are the determining factor in the extent to which this happens (Clement & Bigby, 2009). Yet, research shows that, although professionals involved with people with PIMD do support principles like social integration and participation, generally speaking, they do not think these are applicable for people with PIMD (Bigby et al., 2009; Venema, Otten, & Vlaskamp, 2015). It is likely that such attitudes keep professionals from offering support in terms of maintaining and expanding informal social networks for people with PIMD.

The present thesis aims to arrive at a better understanding of the informal social networks of people with PIMD. Not only will the current characteristics of the informal social networks be investigated but also the active steps undertaken by professionals in this regard, as well as their attitudes concerning informal social networks. This information is needed in order to be able to intervene in an appropriate and fitting manner, and, in the long-term, to succeed in creating informal networks that can contribute to the quality of life of people with PIMD.

The main research question of the present study is:

How can the informal social networks of people be maintained and, if necessary, expanded, and what role do professionals play in this matter?

To answer this main question, three sub-questions have been formulated:

- What are the characteristics of the current social networks of people with PIMD?
- What active steps are undertaken by professionals in order to maintain, enhance, or expand these informal social networks?
- What are the attitudes of professionals concerning the topic of informal social networks in persons with PIMD?

1.1. Outline of the thesis

Following on the present introductory chapter, Chapter 2 reports on the structure of informal social networks of 205 people with PIMD. Data was collected by proxy, meaning that, per person with PIMD, two direct support persons were questioned. The results indicated the size of the informal social network, the composition of the network, and the frequency of the contacts. Finally and from this, the type of informal contact person, who most frequently has contact with the person with PIMD, is ascertained.

Chapter 3 analyses how age, communicative abilities, and current living arrangements are related to the number and frequency of the informal contacts, concluding with a discussion of the role of the professional in this regard.

Chapter 4 explores spontaneous interactions between people with PIMD and member of their group in the course of their daily lives. Observational data was obtained from 14 people with PIMD for three consecutive hours. The results describe the type of interactions seen, and with whom, how often, and in what way DSPs enable the interactions between group members. Interactions with group members and the role of the DSP in this regard will be described in more detail. The results show if and how interactions between group members are made possible or hindered by DSPs.

Chapter 5 reports on the content of the individual support plans (ISPs) of 60 people with PIMD, with respect to their informal contacts. The ISPs were inductively coded and, in the results, these codes are illustrated with quotes. Additionally, the results provide information about the content of the ISPs with respect to their history, current situation, and the future they entail, and conclude with the importance of including informal contacts in the ISPs.

Chapter 6 describes the attitudes and active steps on the part of professionals to enhance the informal networks of people with PIMD. Semi-structured interviews were held with DSPs, professionals from daycare, and psychologists, all working with people with PIMD. After transcription of the interviews, these were inductively coded. An overview of the coding scheme and descriptive statistics is provided, illustrated with quotes from the interviews. This serves to clarify whether professionals do find social networks for people important and, if so, why. Further results show what professionals do in order to maintain, strengthen, or expand the networks of people with PIMD, and what they feel are impeding and facilitating factors in this regard.

This thesis concludes with Chapter 7, which reflects on the main findings of all the studies, and answers the main question and sub-questions addressed in this thesis. In conclusion, the limitations of the research are discussed, and implications for practice and research are presented.

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