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Efforts to increase social contact in persons with profound intellectual and multiple disabilities: Analysing individual support plans in the Netherlands



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Abstract

Most people with profound intellectual and multiple disabilities (PIMD) have limited social contact and it is unclear what is done to maintain or increase these contacts. Individual support planning (ISP) can be used in the systematic enhancement of social contacts. This study analyses the content of ISPs with respect to the social contacts of people with PIMD. ISPs for 60 persons with PIMD in the Netherlands were inductively coded and illustrated with quotations. It turned out that every ISP contained information about social contacts. Of all the quotations extracted, 71.2% were about current conditions, 6.2% were about the future and less than 1% concerned actual goals. The social contacts of people with PIMD are mentioned in their ISPs, but this is rarely translated into goals. The results of the current study suggest that attention should be paid to ensuring that professionals understand the importance of social contacts and their application in practice.

Keywords

individual support plan, professional support, profound intellectual disabilities, social contacts, social network

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Introduction

‘Social inclusion’, ‘participation’, ‘social interaction’ and ‘social networks’ are only a few of the many terms used in the range of research into the social domain of people with disabilities. The social domain contributes to the quality of life of people with disabilities (Buntinx and Schalock, 2010; Schalock and Verdugo, 2002) and according to the UN Convention on the Rights of People with Disabilities (United Nations, 2006), people with disabilities have the right to participate fully and to be included in society and community life. The social domain is also believed to be of great importance for people with profound intellectual and multiple disabilities (PIMD) (Petry et al., 2005).

In general, people are looking for affectively positive interactions within the context of long-term, caring relationships (Baumeister and Leary, 1995). People with PIMD are also in need of positive social relationships with others (Hostyn and Daelman, 2011; Petry et al., 2005). Social relationships are important for several reasons: In addition to facilitating social inclusion (Abbott and McConkey, 2006; Bigby et al., 2009; Johnson et al., 2010; McConkey, 2007), social relationships are known to prevent loneliness and negative health effects (Baumeister and Leary, 1995; Cohen, 2004). Furthermore, social relationships enable participation – physical participation by bringing the person with PIMD into society and mental participation by providing the person with PIMD with a sense of belonging. This makes having social relationships an important aspect of the quality of life of people with PIMD (Hostyn and Maes, 2009; Nakken and Vlaskamp, 2007; Petry et al., 2005). However, given the severity of their disabilities, having social relationships is not self-evident for people with PIMD, as they are highly dependent on other people. People with PIMD have a profound intellectual disability with a developmental age of under 2 years, combined with a severe or profound motor disability which often means they require a wheelchair to assist with mobility. In addition, sensory disabilities – with visual disabilities as the most prominent kind (Nakken and Vlaskamp, 2007) – are often present. Long-term caring social relationships are formed through repeated successful social interactions (Beauchamp and Anderson, 2010) which can be seen as activities between two people that are rewarding for both parties (Beauchamp and Anderson, 2010; Olsson, 2004, 2005). Such activities, in the broadest sense, can be characterized as social contact. However, due to the severity of the needs of people with PIMD, it is difficult to have successful interactions. Communication is mostly pre- or proto-symbolic for these people (Daelman, 2003). This means that most communicative cues are very subtle, for instance through change in muscle tone, facial expressions, body movement or other cues which are personal or context related. As a consequence, they experience limitations in communicating and signalling their emotional responses and needs (Petry et al., 2005; Schuengel et al., 2010). In order to establish successful interactions, it is important that the social contact person knows the person with PIMD and is able to successfully interpret and respond to the communicative signals. This can only be achieved if there is repeated social contact between the person with PIMD and the social contact person. When successful interactions occur, it is possible that a social relationship is formed. Establishing (new) social relationships is already challenging for people with PIMD, but because of the severity of the disabilities maintaining these relationships is as big a challenge. People with PIMD need other people to provide personal assistance in establishing and maintaining social relationships.

Social contact with others can be seen as the foundation to satisfy their needs in the social domain for people with PIMD. Social contact in this case is every contact between a person with PIMD and another person, varying from enjoying music together to going out for a walk. Despite

the importance of having social contacts, recent research has shown that people with PIMD living in a facility on average have contact with only five social (non-professional) contact persons per year (Kamstra et al, 2015a). The same study also demonstrated that 80% of the social contact persons are family members, predominantly parents. As people with PIMD become older, they have fewer social contact persons and less frequent contact (Kamstra et al., 2015b). After moving to a care facility, people with PIMD gradually lose contact with their former social contact persons and do not acquire new social contact persons (Kamstra et al., 2015b). In contrast with people without profound disabilities, who are able to maintain and extend their network naturally, people with PIMD cannot maintain or extend their network by themselves. In addition, because of advanced medical care, people with PIMD have a longer life expectancy than previously, which means that they have come to outlive their parents more frequently. When the passing of a parent occurs, a person with PIMD loses one of the most valuable social relationships. It is understandable that parents frequently worry about this moment: ‘what will happen to my child when I am no longer around?’ (Luijkx and Vlaskamp, 2012). Despite parental concerns, it is not yet clear how the gap that arises with parental loss can be filled.

In the Netherlands, people with PIMD fall under the ‘long-term care act’. Within this law, one of the options is to receive ‘care and residence’, which entails the combination of receiving care and living in a care facility. In the Netherlands today, when reaching adulthood most people with PIMD move to a care facility (usually near their parents’ residence) where care is available 24 h per day. As persons with PIMD are not able to speak for themselves, they need others to do this for them, with parents usually acting as their spokespersons (Jansen et al., 2013). Ideally parents or other legal representatives and professionals determine in close collaboration the support needs of the person with PIMD, specify agreements and goals to determine what, where, when and by whom support will be delivered, they monitor implementation and evaluate the agreements and goals. This is usually referred to as individual support planning (Herps et al., 2013) and is initiated by the care facilities by means of an individual support plan (ISP). The use of ISPs is required by law in the Netherlands and usually written by direct support persons (DSPs) under supervision of a behavioural scientist. An ISP is a written document which identifies what a person is able to do in his or her daily life and what support he or she needs to do so (Matousova-Done and Gates, 2006), furthermore it contains specific goals and objectives for the person (Herps et al., 2016). It is stated that the person with PIMD has the right to at least two evaluation moments per year. However, it is common that the caretaker and caregiver together make agreements about the frequency. As mentioned previously, contact with social contact persons is one of the factors contributing to quality of life (Hostyn and Maes, 2009; Nakken and Vlaskamp, 2007; Petry et al., 2005). By extension, an ISP should contain information about maintaining and expanding social contacts.

According to several authors, the use of an ISP has multiple benefits (Clark and Gates, 2006; Collins et al., 1999; Giangreco et al., 1994; Herps et al., 2016; Poppes et al., 2002, 2011; Van Gemert and Vlaskamp, 1997): By identifying the wishes and needs of the person with PIMD and considering how these needs or desires should be fulfilled, professionals take a better and closer look at the person with PIMD which leads to a more adequate interpretation of their support needs. ISPs can be viewed as a way of systematically documenting and planning interventions to meet the desires and needs of persons with PIMD in all aspects of their lives. An ISP also makes the care process easier to follow and manage and can be used as a guiding instrument for professionals. Using an ISP contributes to better collaboration among professionals from different fields in attaining common goals. Finally, while there is always some staff turnover in the life of a person

with PIMD's, an ISP is essential to provide information for 'new' professionals and thus provide some continuity for the person with PIMD. Including social contacts in ISPs seems an obvious and relatively easy way to maintain or expand social contacts.

In sum, it is evident that people with PIMD are in need of social contacts; however, these turn out to be limited. It is unclear how social contacts should be maintained or expanded and by whom. Where ISP provides for the determination of support needs, specifying agreements, implementation and evaluation (Herps et al., 2013), it is usually unclear if or how the task of maintaining or expanding social contacts should be included. Therefore, it is important to know what is provided in the ISPs of persons with PIMD with respect to social contacts. We may discover what happens in the ISP process and if and how support needs are translated into agreements and thereby form a basis for implementation and evaluation. Analysing ISPs is also a potentially effective way to collect best practice and to be able to exchange useful information. The question addressed in this study is: what do ISPs for people with PIMD currently contain with respect to social contacts?

Method

Participants and setting

In the Netherlands, especially in the case of a non-invasive study like this study, ethical approval is obtained from the local committee of the facility where the study takes place. At the same time, the research proposal was presented for approval to the legal representatives of the people with PIMD. In the Netherlands, when a person is not able to make independent decisions, a cantonal judge can assign a legal representative. In many cases, this concerns the parents of this person. In the Netherlands, a legal representative stands up for the best interests of the person with PIMD and is by law allowed to make decisions on behalf of the person with PIMD.

All the participants lived at residential facilities in the Netherlands, in 13 locations throughout the Netherlands. A total of 376 people were characterized as having PIMD at these facilities. A random sample of 100 persons was recruited. Legal representatives were asked for their informed consent, which ultimately yielded (after information and reminders) 49 permissions, 2 non-permissions and 49 non-responses. The goal was to analyse at least 60 ISPs, so another random sample of 30 persons was drawn. This time, 15 permissions were received. Written informed consent was ultimately provided by 64 parents or legal representatives. Two ISPs appeared to be empty and it turned out that the person with PIMD did not meet the inclusion criteria for two ISPs. Therefore, a total of 60 participants were included meeting the Nakken and Vlaskamp (2007) criteria: an estimated developmental age of below 24 months with a profound or severe motor disability. Care was available 24 h per day for all participants, 18 (30%) were living in small group homes and 42 participants (70%) were living in a campus environment (Mansell, 2006). The mean age of the participants was 47.2 (range: 10–75, SD = 15.5). Thirty-three (55%) participants were female and 27 (45%) were male. Table 1 provides an overview of the participant characteristics. All the characteristics data were drawn from the ISPs: Because some of the terminology used was inconsistent, more generalized terms have been used here to provide a better overall view of the participants.

Data collection

The ISPs were collected digitally by the first researcher, who was granted access to the participants' files. These files were only accessible from a secure working environment, using a personal username and password.

Table 1. Participant characteristics ($N = 60$).

	N (%)
Cause of disability	
Prenatal	17 (28.3)
Perinatal	13 (21.7)
Postnatal	12 (20.0)
Unknown	18 (30.0)
Visual problems	
Severe to blind	36 (60.0)
Mild to moderate	5 (8.3)
None	15 (25.0)
Unknown	4 (6.7)
Auditory problems	
Severe to deaf	9 (15.0)
Mild to moderate	10 (16.7)
None	30 (50.0)
Unknown	11 (18.3)
Other	
Epilepsy	38 (63.3)

All the text concerning social contacts – understood as contacts with people other than professional support staff – was marked in all the ISPs. To calculate the reliability of the text selection process, both researchers individually selected the text on social contacts from five ISPs. The selected texts were discussed and preliminary guidelines were established to distinguish the passages about social contacts from the rest. Both researchers then again selected text from a further five ISPs. To estimate the agreement between the two researchers on the social contact text, Cohen's κ was calculated by counting the number of words on which the two researchers agreed and on those they did not. For the five ISPs, κ varied from 0.70 up to 1.00, with an overall agreement of 0.79, which is nearly perfect (Landis and Koch, 1977). The preliminary guidelines for selecting the passages on social contacts were substantial, and slight adjustments were made to the final guidelines to improve inter-rater agreement. The final guidelines can be found in Table 2. Only the text on social contacts was coded.

Analysis

Atlas.ti version 7.1.8 was used in the coding process. The first researcher coded the sentences about social contacts and categorized these in several categories (codes) using inductive coding. Inductive coding was done by generating codes through directly examining the data (Christensen and Johnson, 2012). During the coding process, the codes were monitored, new codes were added and codes were merged. Related codes were then grouped in subcategories, and related subcategories were grouped in main categories. This process was carried out in careful collaboration between all three authors of this article. The final coding scheme consists of three main categories, 12 subcategories and 45 codes. Table 3 provides a description of all the main categories, subcategories, the codes and their meanings setting them out using descriptive statistics and, if necessary, illustrating them with quotations.

Table 2. Guidelines for selecting text concerning social contacts.

-
- Only full sentences referring to contacts with non-professionals or group members, including everything that was done and what the response to that was.
 - Sentences about contacts with professionals should not be included.
 - Volunteers are not regarded as professionals, nor are former professionals.
 - Professionals should only be included if they acted as an ‘instrument’: for example, the professional calls the parents to make an appointment to visit them.
 - Activities including the opportunity to meet other people are included, for instance going to church or shopping. This enhances activities which can be assumed to include other people, without knowing in advance whether people will be there. This is about opportunities, not whether they are used.
 - The conditions for the realization of contacts are only included if this relationship is explicit in the text (yes: person x is sensitive of experiencing many stimuli, the professional should warn the contact persons if this is likely to happen, or: in order to visit his parents, person x uses a local taxi. No: person x is sensitive of experiencing many stimuli, or: person x uses a local taxi).
 - Text concerning social contacts and history is included, as are previous living groups and day-care groups.
 - Day care is regarded as a possibility to meet others and is therefore included.
 - If the text literally states how a person comes into contact with someone else, this is included.
 - Contacts between professionals and non-professionals concerning issues other than social contacts are not included, for instance contact about medical issues.
 - Text about the conditions for social contacts or individual opportunities for making contact is included, for instance: he loves to have people around, or to perform activities where others are needed.
-

Results

Table 4 provides an overview of the content of the main categories, subcategories and codes. It shows in how many ISPs a certain code is found and the percentage of the total. Furthermore, it shows how many quotations received a certain code, with the percentage of the total number of quotations. A total of 1340 quotations about social contacts were drawn from the 60 ISPs. The mean number of quotations about social contacts per ISP was 22.3 (SD = 11.0, range = 3–49). Only one code was assigned for 922 quotations (68.8% of the total 1340), 217 quotations (16.2%) received two codes, 145 quotations (10.8%) were given three codes, 47 quotations (3.5%) received four codes, 8 quotations (0.6%) were given five codes and 1 quotation (0.1%) received six codes. This results in a total of 2025 assigned codes, a mean of 33.7 codes per ISP (SD = 17.9, range = 4–69). As shown in Table 4, most of the quotations (71.2%) were about the current social contact situation and the fewest (6.2%) were about the future.

Main category: history

No information about social contacts in the past could be found in four ISPs (6.7%). Quotes about the changes in the social network over the years were mainly about the decease of parents or other family members or about taking over the role of parents:

Johnny’s brother and sister-in-law are taking over this task from his mother and come over every 14 days to walk with Johnny. (codes: 1.1.b., 1.1.e., 2.1.a., 2.1.b., 2.1.c.)

Table 3. Overview of the main categories, subcategories, codes and their meanings.

Category/code	Meaning
I. History	Social contacts in the past
1.1. Informal contact persons	About unpaid contact persons who were involved in the past
1.1.a. Family composition	Composition of the family, for instance parents, brothers and sisters
1.1.b. Persons	Specific mentioning of who was involved
1.1.c. Frequency	The frequency a specific informal contact person was involved
1.1.d. Activities	The activities that were undertaken with an informal contact person
1.1.e. Course	Changes in the social network over the years, for instance the passing of a parent
1.2. Facts/environment	Facts about the physical environment of the person with PIMD
1.2.a. Living group	The name(s) of the living group(s) a person lived in the past
1.2.b. Day care	The name(s) of the group(s) a person received day care in the past
1.2.c. Visiting site	The description of a place the person with PIMD visited, usually places they stayed at for a night or a weekend while living at home
1.3. Peers	Description of contacts with peers in the past
1.3.a. Persons	Name(s) of the peer(s)
1.3.b. Frequency	Frequency of contact with a specific peer
2. Current situation	Social contacts in the present
2.1. Informal contact persons	Unpaid contact persons involved currently
2.1.a. Content of contact	How contact between the contact person and the person with PIMD is shaped, for instance by telephoning or visiting
2.1.b. Persons	Specific mention of the contact persons involved
2.1.c. Frequency	The frequency of the contacts between the contact person and the person with PIMD
2.2. Peers	Contacts with fellow residents, not just group members but also other persons with an intellectual disability
2.2.a. Content of contact	How contact between the peer and the person with PIMD is shaped, for instance by touching or making noises
2.2.b. Frequency of contact	The frequency of the contacts between the peer and the person with PIMD
2.2.c. Environmental influence	The influence of the environment on these contacts or things the environment does to establish contact between peers
2.2.d. No contact, however actions are observed	Statements that there is no contact with peers, along with descriptions of specific actions between peers
2.3. Person with PIMD	Information concerning the person with PIMD
2.3.a. Behaviour in contact	The behaviour a person with PIMD displays when in contact with others
2.3.b. Opportunities	The opportunities a person has for making contact with others
2.3.c. Obstacles	Description of the obstacles a person with PIMD has in establishing social contacts, and/or the limitations in the environment in establishing such contacts because of the person with PIMD disabilities
2.3.d. Need for social contact	Statements that the person with PIMD needs social contact or finds it important
2.3.e. Need for social contact not there/unknown	Statements that the person with PIMD has little or no need for social contact or that this is unknown

(continued)

Table 3 (continued)

Category/code	Meaning
2.3.f. Dependence	Description of the person with PIMD dependence, explicitly in relation to social contacts and the role of the professionals in maintaining these contacts
2.3.g. No social contacts	Statements that this person does not have or barely has any social contacts
2.4. Facts/environment	Facts and opportunities within the environment
2.4.a. Living group	Composition of the living group, its name and the moment the person with PIMD started living in that particular group
2.4.b. Day care	Composition of the day-care group, its name and the moment the person with PIMD started participating in that group
2.4.c. Requirements	Description of situations which enable necessary contacts or requirements, for instance the use of a taxi or the health of the person with PIMD
2.5. Activities	Activities that provide opportunities for contact with others besides professionals
2.5.a. Activities with opportunities for contact	Activities where it is possible to get in touch with others. These are activities where other people are present, for instance church or a coffee house
2.5.b. Activities in day care	Activities carried out during day care
2.5.c. Limitation of activities	Description of activities that are not offered (or no longer offered), but which do offer opportunities for contacts
3. Future	Social contacts in the future
3.1. Desires	Desires stakeholders have for the specific person with PIMD concerning social contacts or opportunities to have them
3.1.a. Activities/participation	Desires for more activities or more participation
3.1.b. Volunteer	Desires for a volunteer for a specific person with PIMD
3.1.c. More contact persons	Desires for more contact persons to expand the social network
3.1.d. Higher frequency of contact	Desires for a greater frequency of contact between the person with PIMD and an existing contact person
3.1.e. Contact with peers	Desires for contacts with peers, or more contacts with peers
3.1.f. Maintain the status quo	Desires to maintain the current social contact situation
3.1.g. Mutual interaction	Desires for more mutual interaction between the person with PIMD and an informal contact person or peer
3.2. Opportunities	Opportunities a person with PIMD has for social contact
3.2.a. Role of professional	The role of the professional in creating opportunities
3.2.b. Within current network	Opportunities to satisfy desires using the current network
3.3. Goals	Goals aimed at social contacts
3.3.a. Activities	Goals aimed at undertaking more activities
3.3.b. Higher frequency of contact	Goals aimed at achieving a higher frequency of contact between the person with PIMD and a contact person or a peer
3.3.c. Participation	Goals aimed at more participation
3.3.d. Expanding social contacts	Goals aimed at expanding the person with PIMD social contacts
3.3.e. More attention	Goals for the person with PIMD to receive more attention
3.3.f. Operationalization of goals	Elaboration of the goals, how to reach them, when, by whom and so on

PIMD: profound intellectual and multiple disabilities.

Table 4. Overview of the distribution of the main categories, subcategories and codes.

Categories and codes	Number of ISPs (%)	Number of quotations (%) [*]
1. History	56 (93.3)	459 (22.6)
1.1. Informal contact persons	48 (80)	246 (12.1)
1.1.a. Family composition	45 (75)	63 (3.1)
1.1.b. Persons	23 (38.3)	54 (2.7)
1.1.c. Frequency	14 (23.3)	14 (0.7)
1.1.d. Activities	10 (16.7)	16 (0.8)
1.1.e. Course	28 (46.7)	99 (4.9)
1.2. Facts/environment	55 (91.7)	197 (9.7)
1.2.a. Living group	49 (81.7)	101 (5.0)
1.2.b. Day care	40 (66.7)	89 (4.4)
1.2.c. Visiting site	6 (10)	7 (0.3)
1.3. Peers	9 (15)	16 (0.8)
1.3.a. Persons	8 (13.3)	14 (0.7)
1.3.b. Frequency	2 (3.3)	2 (0.1)
2. Current situation	60 (100)	1441 (71.2)
2.1. Informal contact persons	60 (100)	661 (32.6)
2.1.a. Content of contact	57 (95)	222 (11.0)
2.1.b. Persons	59 (98.3)	306 (15.1)
2.1.c. Frequency	45 (75)	133 (6.6)
2.2. Peers	45 (75)	131 (6.5)
2.2.a. Content of contact	31 (51.7)	63 (3.1)
2.2.b. Frequency of contact	26 (43.3)	38 (1.9)
2.2.c. Environmental influence	5 (8.3)	5 (0.2)
2.2.d. No contact, however actions are observed	19 (31.7)	25 (1.2)
2.3. Person with PIMD	54 (90)	251 (12.4)
2.3.a. Behaviour in contact	25 (41.7)	43 (2.1)
2.3.b. Opportunities	28 (46.7)	50 (2.5)
2.3.c. Obstacles	25 (41.7)	49 (2.4)
2.3.d. Need for social contacts	30 (50)	61 (3.0)
2.3.e. Need for social contacts not there/unknown	5 (8.3)	5 (0.2)
2.3.f. Dependence	21 (35)	30 (1.5)
2.3.g. No social contacts	12 (20)	13 (0.6)
2.4. Facts/environment	54 (90)	168 (8.3)
2.4.a. Living group	46 (76.7)	67 (3.3)
2.4.b. Day care	42 (70)	89 (4.4)
2.4.c. Requirements	9 (15)	12 (0.6)
2.5. Activities	53 (88.3)	230 (11.4)
2.5.a. Activities with opportunities for contact	50 (83.3)	172 (8.5)
2.5.b. Activities in day care	33 (55)	47 (2.3)
2.5.c. Limitation of activities	10 (16.7)	11 (0.5)
3. Future	41 (68.3)	125 (6.2)
3.1. Desires	40 (66.7)	111 (5.5)
3.1.a. Activities/participation	21 (35)	34 (1.7)
3.1.b. Volunteer	11 (18.3)	18 (0.9)

(continued)

Table 4 (continued)

Categories and codes	Number of ISPs (%)	Number of quotations (%)*
3.1.c. More contact persons	4 (6.7)	4 (0.2)
3.1.d. Higher frequency of contact	5 (8.3)	7 (0.3)
3.1.e. Contact with peers	4 (6.7)	5 (0.2)
3.1.f. Maintain the status quo	29 (48.3)	41 (2.0)
3.1.g. Mutual interaction	2 (3.3)	2 (0.1)
3.2. Possibilities	2 (3.3)	2 (0.1)
3.2.a. Role of professional	1 (1.7)	1 (0.05)
3.2.b. Within current network	1 (1.7)	1 (0.05)
3.3. Goals	7 (11.7)	12 (0.6)
3.3.a. Activities	3 (5)	4 (0.2)
3.3.b. Higher frequency of contact	1 (1.7)	2 (0.1)
3.3.c. Participation	1 (1.7)	1 (0.05)
3.3.d. Expanding social contacts	2 (3.3)	3 (0.1)
3.3.e. More attention	1 (1.7)	1 (0.05)
3.3.f. Operationalization of goals	1 (1.7)	1 (0.05)
Total	60 (100)	2025 (100)

PIMD: profound intellectual and multiple disabilities; ISP: individual support plans.

*The sum of the percentages does not always equal 100 because of rounding.

Other examples from the person's changes in the social network over the years were about moving or broken contacts:

She had contacts with her half-brother for a while, but he has not tried to contact her in the last five years. In 2010 he received an invitation for her fiftieth birthday, but he never responded. (codes: 1.1.b., 1.1.e.)

Main category: current situation

All ISPs ($n = 60$; 100%) described the current social contact situation. Of the 2025 codes assigned, a total of 1441 (71.2%) were about the current situation. All ISPs mentioned something about informal contact persons. The following quote contains information about the content of the contact, who is involved and how often:

His stepfather comes to visit once a month, he takes Peter for a walk and sits with him. (codes: 2.1.a., 2.1.b., 2.1.c.)

Contacts or the lack of contacts with peers (not just group members, but also other persons with an intellectual disability) were described in 75% of the ISPs (45 ISPs). An example of a contact situation between a person with PIMD and her peers, and the role of the professional, is Anne:

She prefers some peers. She likes to sit with other female group members at certain times. When you point this out, she smiles. It is our job to make sure Anne has these contacts. Sometimes, a peer makes contact with Anne by touching her, most of the time Anne likes this and shows that by smiling. (codes: 2.2.a., 2.2.c., 2.3.a.)

The following quotes are about statements that there is no contact with peers, along with descriptions of specific interactions between peers. This code is assigned to a total of 25 quotations (1.2%), within 19 ISPs (31.7%). Of the 25 quotations thus coded, 18 received this code exclusively:

Lana has no friends; she doesn't make contact with other clients. At daycare, a peer often holds her hand. (code: 2.2.d.)

The remaining seven quotations received two or three codes, for example Tom, where environmental influence is acknowledged, examples of contact are mentioned, but at the same time, it is stated that Tom has no contact with peers:

Tom does not really have contact with his peers. It is the professional's job to encourage contact with his peers. He does hear and/or see other people; you can see a reaction in him. He turns his head and eyes towards the person and makes noises. (codes: 2.2.c., 2.2.d.)

Then there is Ally, for whom the content of the contact with Jack is described. For both, these contact moments seem rewarding at times. But when physical contact occurs and the situation may become dangerous, they are separated as soon as possible. The contact is described as pure physical contact with no mentioning of the social component.

She has physical contact with one peer on a regular basis. Sometimes Ally takes the initiative in this contact. Most contact comes from Jack. These contacts between Ally and Jack are accidental, they do not have a bond and they do not try to find each other personally. He regularly sits with her on her seat, he doesn't then look around to find another place to sit and sometimes he almost sits in her lap. He then puts his arm around her, to stroke her, or he takes her socks off to play with them. If she does not enjoy this she pushes him away, but most of the time she laughs and just accepts it. As soon as the professionals notice this, they are immediately separated and each put on an individual seat. It does happen that Jack pulls on Ally's helmet; this could lead to dangerous situations. (codes: 2.2.a., 2.2.d.)

The influence of the environment on the peer contacts or actions by the environment to establish contact between peers was described in five ISPs (8.3%), for example:

We use a sling to get him in and out of his bed box. Jamie likes this a lot because he is then at the same eye height as his peers. We let him swing for a while because he also enjoys the enthusiastic reactions of his peers. (codes: 2.2.c., 2.3.b.)

A little less than half of the ISPs mention the opportunities the person with PIMD has for social contacts, for example Mandy who is able to use a Big Mack and in that way is able to engage in social contacts:

She uses a 'Big Mack': device on which Mandy's direct support personnel or other contact persons can leave messages about a fun experience Mandy had. Mandy is able to push the button, in that way she is able to 'talk' about the recorded experience. (code: 2.3.b.)

However, besides opportunities, obstacles were mentioned in 25 ISPs (41.7%), where the limitations of the person with PIMD were mentioned as an obstacle for social contact:

Because of his severe intellectual disability, he is unable to recognise people. (code: 2.3.c.)

Twenty (33.3%) out of the total of 60 ISPs said nothing about opportunities and obstacles confronting the persons with PIMD with respect to social contacts. Exclusively, obstacles were noted in 12 ISPs (20%) and exclusively opportunities were noted in 15 ISPs (25%). A total of 13 ISPs (21.7%) noted both. An example is Elsa, for whom it is described what limits her in social contact, but also what she is able to do:

Because of Elsa's physical limitations she has few opportunities to actively make contact with others. She does watch and follows peers and professionals. (codes: 2.2.d., 2.3.b., 2.3.c.)

Over one-third of the ISPs mentioned dependence on others in making social contact:

Oscar is unable to establish or maintain contact. Visiting family requires professional help. (codes: 2.3.c., 2.3.f.)

The need for social contacts was expressed for half the persons with PIMD:

If he stayed at home this would cause so much stress that Luke would become agitated or lonely because he missed social contact with others. (code: 2.3.d.)

Twelve ISPs (20%) mentioned that the person had no social contacts. Most of these quotes stated that the person did not have friends or that the person did not have social contacts except for family. Fifty ISPs (83.3%) noted something about activities which provided opportunities for contacts with other people, for instance visiting church, vacations, clubs for people with PIMD, swimming, shopping, going to the theatre or going for a walk.

Future

A total of 125 code assignments (6.2%; in 41 files) were about future social contacts; 19 ISPs (31.7%) did not mention future social contacts at all.

Forty ISPs (66.7%) expressed desires concerning future social contacts and seven ISPs (11.7%) formulated goals for social contacts. The most common statements about the future (for almost half of the persons with PIMD) were about maintaining the status quo. No goals were formulated for this desire. The second most common desire was for the person with PIMD to be involved in more activities in society. This was mentioned in 21 ISPs (35.0%) and these desires were translated into goals in three of these ISPs (5%). The desire for more contact persons was observed in four ISPs (6.7%), and a goal was formulated about establishing new contacts in two ISPs (3.3%). However, no desires concerning this topic were expressed in the ISPs where goals were formulated about it. Furthermore, only one ISP (0.05%) operationalized a goal:

Goal: within six months we will have found a volunteer from the church for Ellen. (code: 3.3.d.)

Operationalization: an email will be sent to the person responsible for volunteers and our community will be consulted. A person from the pastoral service will be consulted, perhaps he or she can help us. (code: 3.3.f.)

Opportunities for social contacts were noted in two ISPs:

It also turns out that there is a niece who wants to come by during the week and go with Julie to the restaurant. (code: 3.2.b.)

In the future Chris would like to have a watching relationship with a peer. The professionals could help try this. (codes: 3.1.e., 3.2.a.)

Discussion

The question addressed in this study was: what do ISPs currently contain about the social contacts of people with PIMD? It turned out that every single ISP had some information related to social contacts. Most of the information about social contacts in the ISPs analysed was about current social contacts, such as who these informal contact persons are, or what contacts or activities with peers were undertaken. Information on past social contacts was far less common. The least information was obtained about future social contacts. For the future, most information concerned the desires DSPs had for the person with PIMD, though less than 1% of the information contained actual goals in this respect.

Before interpreting the results, some study limitations should be noted. After carefully establishing reliable guidelines for extracting quotes on social contacts, only the first author carried out the coding process. This risks information being processed according to a personal frame of reference. Therefore, to prevent biased coding, these codes and the associated statements were frequently discussed with the other authors of this article throughout the coding process. Moreover, ISPs are written plans and do not necessarily reflect the actions actually undertaken by DSPs. There may be a discrepancy between what is written in the ISPs and the real life of the person, and the written plans are possibly seen as a paper exercise (Mansell and Beadle-Brown, 2004). It is possible that more or even less is done to maintain or expand the social contacts of people with PIMD in daily practice. Research into the effectiveness of ISPs is scarce (Herps, Buntinx and Curfs, 2011) and procedural requirements seem more important than the outcomes of care (IGZ, 2007; Buntinx and Herps, 2013). Thus, our results can be regarded as a starting point for future research in this subject and provides us with insights into the ISP process for people with PIMD.

In general, the ISP process starts by determining support needs (Herps et al., 2013). When determining support needs, only 21 ISPs (35%) contained information about dependence on professionals for expanding or maintaining social contacts. Regarding contacts with peers, only five ISPs noted something about the influence of the environment in establishing these contacts. This indicates that the support needs for expanding or maintaining social contacts were clear for fewer than half of the participants. This is not in line with the belief that persons with PIMD need support in maintaining or expanding social contacts. In addition to determining support needs, specifying agreements and goals are part of the ISP process. However, only seven files and 12 quotations (0.6%) mentioned social contact goals, and only one goal was operationalized. This leads us to conclude that implementation is not achieved in any of the ISPs as regards social contacts. In addition, no aspect of evaluation was noted in any of the ISPs. It seems that a fixed method for maintaining or expanding social contacts for people with PIMD is required to help them fully benefit from the advantages of using an ISP.

People with PIMD have limited social contacts, even though these are of great importance for their quality of life (Kamstra et al., 2015a), and these already few contacts only seem to diminish over time (Kamstra et al., 2015b). This makes it even more striking that only seven of the ISPs included goals concerning social contacts and only two ISPs set goals to expand social contacts. Goals are known to provide direction for support and show what is desirable for the person and how this will be achieved (Van der Putten et al., 2009). Goal setting also appears to be a suitable

means to promote social inclusion and can clearly be tailored to individual needs and aspirations (McConkey and Collins, 2010). As for aspirations, merely maintaining the status quo was the expressed desire in almost half the ISPs, though there was no mention in the ISPs how this should be achieved. Other, but less common, desires concerning expanding the social network were about acquiring a volunteer (in 11 ISPs), more social contact persons (in four ISPs) or contact with peers (in four ISPs). The nature of these desires could indicate that the current situation is acceptable for a large group of people with PIMD. Nothing was said about the future at all for another group of people with PIMD (19 ISPs). For these people, it would appear that social contacts are not a key priority in future planning. The direction of their current support barely seems to consider expanding social contacts, which validates the result of Kamstra et al. (2015b) that no new members appear to be being added to the social networks of people with PIMD. If barely any goals or even aspirations are formulated, it is likely that this will receive little to no attention in daily practice.

No goals were formulated concerning contacts with peers, and having contact with peers was mentioned as a desire in only four ISPs. This looks like a missed opportunity for expanding social contacts, because all the participants from this study had access to care 24 h per day at a living unit with peers. They share the same space on a daily basis, and thus form an accessible source of social contacts. The results show that communicative signals between peers are only seldom recognized as such. No contact was observed between the person with PIMD and a peer in 31.7% of the ISPs, but at the same time, peer interactions were described. Apparently, such actions are not viewed as ways of making contact despite the fact that, according to Hostyn and Maes (2009), most of these actions should be interpreted as communicative behaviour. Peer-directed behaviours, such as looking at a peer, touching a peer or the object he or she is holding, body movements towards a peer, vocalizing, gestures or using facial expressions are pre- and proto-symbolic communicative behaviours (Nijs et al., 2015).

Today, it is generally accepted that people with PIMD are capable of building and maintaining meaningful relationships and are able to exert influence on their environment within these relationships (Vlaskamp et al., 2005). This contradicts some of the results found in the current study, where 41.7% of the ISPs mentioned difficulties and obstacles to establishing social contacts. These difficulties were described alongside a person's abilities in 21.7% of the ISPs. However, 20% of the files only mentioned difficulties or inability. Assuming that a person with PIMD is completely unable to make contact with others will influence how the professional interprets communicative signals and responds to them (Vlaskamp et al., 2005). The views and beliefs of staff are of great importance in determining their actions (Bigby et al., 2009). It would appear that the views and beliefs of some of the professionals in the current research also stand in the way of actively working on social contacts. Follow-up research should analyse whether this assumption accords with actual opinions held by professionals. In line with Bigby et al. (2009), the results of the current study suggest that attention must be paid to the understanding in professionals of the importance of social contacts and their application in practice.

For daily practice, it seems important that a more fixed method for maintaining or expanding social contacts for people with PIMD is designed and implemented. Part of this method should, on the one hand, pay attention to the views and beliefs of professionals in this matter. On the other hand, it should provide knowledge about the importance of social contacts and what peer contacts look like. Social contacts need to become an important and permanent topic within the care for people with PIMD in general and thereby within the ISPs.

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