

## Exploring spontaneous interactions between people with profound intellectual and multiple disabilities and their peers

A. Kamstra, A. A. J. van der Putten, B. Maes & C. Vlaskamp

**To cite this article:** A. Kamstra, A. A. J. van der Putten, B. Maes & C. Vlaskamp (2019) Exploring spontaneous interactions between people with profound intellectual and multiple disabilities and their peers, *Journal of Intellectual & Developmental Disability*, 44:3, 282-291, DOI: [10.3109/13668250.2017.1415428](https://doi.org/10.3109/13668250.2017.1415428)

**To link to this article:** <https://doi.org/10.3109/13668250.2017.1415428>



© 2018 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 15 Feb 2018.



Submit your article to this journal [↗](#)



Article views: 2464



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 6 View citing articles [↗](#)

ORIGINAL ARTICLE



## Exploring spontaneous interactions between people with profound intellectual and multiple disabilities and their peers

A. Kamstra<sup>a,b</sup>, A. A. J. van der Putten<sup>a,b</sup>, B. Maes<sup>c</sup> and C. Vlaskamp<sup>a</sup>

<sup>a</sup>Department of Special Needs Education and Youth Care, University of Groningen, Groningen, Netherlands; <sup>b</sup>s Heeren Loo, Amersfoort, Netherlands; <sup>c</sup>Faculty of Psychology and Educational Sciences, Parenting and Special Education Research Unit, University of Leuven, Leuven, Belgium

### ABSTRACT

**Background:** Peers living in the same group form important interaction partners for people with profound intellectual and multiple disabilities (PIMD). Given the severity of their disabilities, direct support persons (DSPs) play a significant role in facilitating interactions between these peers. This study explores the spontaneous interactions between persons with PIMD and the possibilities provided by DSPs related to physical positioning.

**Method:** Observational data were obtained from 14 people with PIMD for three consecutive hours in a non-controlled situation.

**Results:** Of all 213 observed interactions, 5.1% were with peers, 73.4% with DSPs, 14.9% with the observer, and 6.5% with others. In 61.3% of the observed timeframes, the participants with PIMD were positioned in a way that made it impossible to touch or/and to look at a peer.

**Conclusion:** Generally, the observed positioning of the participants made contacts between peers nearly impossible. DSPs should create optimal conditions for interaction between peers.

### KEYWORDS

Profound intellectual and multiple disabilities; interaction; positioning; context; direct support person; peers

Social relationships are an important dimension in quality of life of people with intellectual disabilities (IDs) (Schalock & Verdugo, 2002). Also when the ID is more severe or accompanied with motor and/or sensory disabilities, having social relations can be beneficial. Such relationships are believed to prevent negative health effects and loneliness (Cohen, 2004; Scott & Havercamp, 2014), enable social inclusion (Abbott & McConkey, 2006; Bigby, Clement, Mansell, & Beadle-Brown, 2009; Johnson, Douglas, Bigby & Iacono, 2010; McConkey, 2007), and facilitate participation (Petty, Maes, & Vlaskamp, 2005). Notwithstanding these benefits, forming social relationships is challenging as well.

Long-term supportive social relationships are formed through repeated successful social interactions (Beauchamp & Anderson, 2010). Interactions are defined as two partners exchanging information and/or mutually influencing each other (Olsson, 2004, 2005). People with the most severe disabilities such as people with profound intellectual and multiple disabilities (PIMD) too are in need of affective and reciprocal interactions with others in order to establish long-term relationships (Hostyn, Petty, Lambrechts, & Maes, 2011; Petty et al., 2005).

People with PIMD are characterised by a combination of profound intellectual and severe or profound motor disabilities (Nakken & Vlaskamp, 2007) and a developmental age of up to 24 months. In addition, most are non-ambulant and the majority also have sensory impairments (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006) which further impede successful interactions with others (Hostyn et al., 2011; Vlaskamp, 2011). Their communicative abilities are generally at a preverbal level, and while some people with PIMD may develop limited spoken or signed expressive language, comprehensive communication will always be minimal. These communicative limitations affect the way people with PIMD interact with others.

In this article, we refer to other service users in the day activities centre or in the group homes as peers. Peers can be important in the day to day lives of people with PIMD, as they spend a large amount of time together (Johnson, Douglas, Bigby, & Iacono, 2012). Social interactions with peers would therefore be expected in such situations. In several studies, including people with severe and profound ID, it was found that interactions with people without disabilities were seen more often

**CONTACT** A. A. J. van der Putten  [a.a.j.van.der.putten@rug.nl](mailto:a.a.j.van.der.putten@rug.nl)

© 2018 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

compared to interactions with peers with disabilities (Foreman, Arthur-Kelly, Pascoe, & King, 2004; Johnson et al., 2012; Nijs, Penne, Vlaskamp, & Maes, 2015). When the interaction partners are both persons with disabilities, it can be expected that their communicative and interactive strategies will differ from non-disabled interaction partners. As shown by a study of Johnson et al. (2012), positive social interactions between people with severe ID and their peers mainly consisted of touching, body language and facial expressions instead of spoken language.

Besides characteristics of the person with PIMD and his or her interaction partner, also contextual factors are related to peer interactions. Hostyn and Maes (2009) describe the context as the setting and the circumstances in which the interaction takes place. The setting is not directly related to the individual, but refers to the physical environment of a person, such as the living environment or the day services setting. The circumstances include the contextual factors directly related to the person with PIMD or the interaction partner, for example, the physical location of the person with PIMD (Hostyn & Maes, 2009) or the physical closeness between the person with PIMD and the interaction partner (Gleason, 1989). Due to the motor limitations, most people with PIMD are unable to move independently, and they are therefore dependent on other actors in their environment, such as direct support persons (DSPs), to be positioned in such a way that it is possible to make contact. Antelius (2009) argued that positioning is related to what an individual is allowed or able to do: sitting within reach of somebody enables the individual with PIMD to touch the other person and make contact, whereas sitting alone in a room or being further away from others limits all forms of contact for most of these people. Nijs et al. (2015) found a relationship between the positioning of children with PIMD and peer-related behaviour. The most peer-directed behaviour was observed in children who were given the opportunity to see or to touch a peer. Results also showed that despite the request to maximise the opportunity for interaction, DSPs positioned the children in such a way that opportunities for peer interaction were limited (Nijs et al., 2015). As the circumstantial factor “position” can easily be adjusted by DSPs, a logical first step is to observe the position of a person with PIMD in relation to interactions with peers. As Arthur-Kelly, Bochner, Center, and Mok (2007) pointed out, the position of people with PIMD in relation to others, or the social proximity, should be part of future research.

While Nijs et al. (2015) investigated interactions among children with PIMD in a controlled situation, it remains unclear whether spontaneous interactions with

peers occur in uncontrolled settings in the daily lives of people with PIMD. Furthermore, if such interactions are indeed observed, we do not know which communicative behaviours these people do show. Finally, it is unclear what is needed in order to create optimal conditions to facilitate interactions between peers.

The questions addressed in this explorative study are: How much spontaneous interactions between persons with PIMD are observed in a non-controlled situation and what are the opportunities, provided by DSPs, for interactions between peers?

## Method

### Participants

In the Netherlands, especially in a non-invasive study such as the current study, ethical approval must be obtained from the local committee of the organisation where the study takes place. The research proposal was presented for approval to the committees of each participating organisation. After the approval of the local committees, a convenience sample of persons with PIMD from three different settings (special education centres, day services settings, and group homes) was used. The choice was made to include different types of settings and organisations in order to cover the typical situations in which people with PIMD live. Three groups were randomly selected for each setting and only individuals with PIMD who met the criteria of Nakken and Vlaskamp (2007) – diagnosed with a developmental age of less than 24 months and having severe or profound motor disabilities – were included. Being non-ambulant was also used as a selection criterion. This yielded a sample of 21 individuals with PIMD.

The legal representatives of these 21 individuals with PIMD were informed about the study and asked for their written informed consent. This was given by 18 legal representatives. In the pilot, it became clear that it was impossible to observe more than two participants during one observation period; therefore, only two participants were selected per group. This yielded a total sample size of 14 participants with PIMD in seven groups in three types of settings. The mean age of these persons was 30.6 years ( $SD = 17.6$ ). Six participants (42.9%) were observed at a special education centre, four (28.6%) at their day services setting, and four (28.6%) were observed in their group home. The groups in which the observations took place were heterogeneous in number and severity of disabilities. Group size varied from 5 to 10 people, and the number of DSPs per group varied from 1 to 3. On average, there was one DSP for 4.2

**Table 1.** Participant characteristics.

Participant	Sex (f = female, m = male)	Chronological age (in years)	Visual	Able to reach	Observed at
A	F	8	No reported problems	Yes	Special Education Centre 1
B	F	6	Partially sighted	Yes	Special Education Centre 1
C	M	4	Partially sighted	Yes	Special Education Centre 2
D	M	18	No reported problems	Yes	Special Education Centre 2
E	F	16	No reported problems	Yes	Special Education Centre 3
F	F	14	No reported problems	No	Special Education Centre 3
G	F	57	No reported problems	Yes	Day-care Adults 1
H	M	47	No reported problems	Yes	Day-care Adults 1
I	M	33	Blind	No	Group Home 2
J	F	30	No reported problems	Yes	Day-care Adults 2
K	F	53	No reported problems	Yes	Day-care Adults 3
L	M	26	Blind	No	Group Home 1
M	M	46	Partially sighted	No	Group Home 3
N	M	41	No reported problems	No	Group Home 3

peers (range: 2.5–8, SD = 1.7). [Table 1](#) shows more details about the participants.

The peers of the participating persons with PIMD had various disabilities: some were persons with PIMD as well, while others had less severe disabilities. There were differences in the way these peers communicated, the severity of their ID and their abilities related to mobility. For privacy reasons, it was only noted if these peers were also diagnosed as having PIMD, or not. Moreover, this was only noted if a certain peer interacted with the person with PIMD (see results).

## Design

This study is an explorative observational study in which descriptive statistics were used. Two researchers conducted participatory observations independently. To ensure objective observations, these were structured within an observation scheme and the observers tried not to be involved in conversations or activities. The sample size is small in order to be able to collect detailed information.

## Instrument

Peer-directed behaviour was assessed with an observation scheme that was applied in the study by Nijs et al. (2015) and that has been adapted for this study. The scheme included codes for the characteristics of the interaction partners, the interactive behaviours of the interaction partners, and the add-on of position changes. This adjusted scheme was tested in a pilot study in two group homes where two persons with PIMD were observed (not included in the current study) by two independent observers. Interrater reliability was calculated, revealing agreements of 0.46 for “Interactive expressions”; 0.74 for “Was there interaction?”; 0.61 for “Who was the interaction partner?”; and 1.00 for “Was there a change in position?” With

the exception of “Interactive expressions,” the agreement was 0.61 or higher and therefore sufficient or good (Sim & Wright, 2005). While an agreement of 0.46 is reasonable (Sim & Wright, 2005), the following adjustments were made to the observation scheme: the division of “interactive expressions” into expressions by the person with PIMD and expressions by the interaction partner; the additional category of “details”; and the inclusion of the observer as a possible interaction partner. The category “details” contained information for instance about observed activities, if participants had a meal or received medication. The inclusion of the observer as an interaction partner was added because the observers noticed that the individuals with PIMD attempted to make contact with them during the pilot, which could not always be ignored. See [Table 2](#) for the final coding scheme used in the current study.

As shown in [Table 2](#), the interactive expressions were divided into eight subcategories (based on Nijs et al., 2015): (1) Vocalisation: making sounds, singing, laughing out loud, crying, screaming, whining, or talking. (2) Gestures: waving, pointing, nodding, or shaking one’s head. (3) Touching: hugging, giving hand, stroking the other person, hugging, short touching. (4) Facial expressions: smiling, scowling, or pursing lips. (5) Making sounds: hitting the table (of the wheelchair), stamping feet, or any other sounds with materials that attract the attention of the interaction partner. (6) Looking at the interaction partner. (7) Movement: moving the body towards the interaction partner, moving the upper body back and forth or bouncing in the wheelchair. (8) Object related: touching objects, taking objects away from the interaction partner, offering own object to interaction partner, looking at the object of the interaction partner. Object-related behaviour will not be scored if the interaction partner puts the object in the hands of the person with PIMD, but only if the person then manipulates the object. It was only possible to score for interaction if the person with PIMD was

**Table 2.** Coding scheme.

Timeframe	Was there a change in position for this person?	Was there interaction?	Who was the interaction partner?	Interactive expressions of the interaction partner	Interactive expressions of the person with PIMD	Details
	0. No	0. No	1. Peer with PIMD	1. Vocalisation	1. Vocalisation	
	1. Yes (see map)	1. Yes	2. Direct support person	2. Gestures	2. Gestures	
		2. Not in room	3. Peer without PIMD	3. Touching	3. Touching	
			4. Observer	4. Facial expressions	4. Facial expressions	
			5. Other	5. Making sounds	5. Making sounds	
				6. Looking at the interaction partner	6. Looking at the interaction partner	
				7. Moving	7. Moving	
				8. Object related	8. Object related	

alert, visible to the observer and if one of the interaction partners responded to the interactive expressions of the other. If the person with PIMD or the interaction partner attempted to initiate interaction but the other person did not respond, this was scored as “no interaction.” Reciprocity was a precondition for interaction, regardless of who acted as initiator.

In addition to scoring interactions, the position of the person with PIMD was reported. At the start of the overall observation period, the position of the individual and the position of all other people in the room were drawn on a map. In accordance with Nijs et al. (2015), these maps allowed us to determine whether the participant was in a position to be able to touch a peer (not able, able with effort, able from a resting position) and whether the participant could look at a peer (not able, able with head movement, able without head movement). Subsequent observations were made in timeframes of five minutes. If the participant with PIMD was repositioned within a timeframe, this was noted as “a change of position”; if a person was repositioned twice within a timeframe, this was noted as a second change of position. A map was drawn up for every situation in which changes in position were noted, where applicable. If an individual had moved – for example, from the living room to somewhere outside – this was scored as “not in the room.” This decision was made because in most observation periods two or three individuals with PIMD were observed simultaneously, making it impossible to observe spaces other than the living room. Furthermore, for privacy reasons, no observations were made if an individual was asleep in his or her bedroom, or if someone was being changed or refreshed. These observations were all scored as “not in the room.”

### Procedure

The researchers made an appointment with the DSPs of the units participating in the current study. Overall observation periods lasted for three consecutive hours, with the observation form filled in at the end of every five minutes (one timeframe). In five observation

periods, two persons with PIMD were observed and in four observation periods one person with PIMD was observed, yielding to a total of nine observation periods and a total of 27 observational hours. In the special education centres and the day services setting, these observation periods took place between 11.30 a.m. and 2.30 p.m. The observation periods in the group home occurred between 4.30 p.m. and 7.30 p.m. These times differed because the participants were not in the group home between 10.00 a.m. and 4:00 p.m. Nevertheless, both observation times included the activity of eating (lunch or dinner) in order to create optimal similarity in the observation periods. No names were noted, instead the participants were assigned an alphabetic character.

Upon arrival in the group home, day service setting, or special education centre, the observer introduced herself to the DSPs and shortly explained the purpose: observing one or two specific persons with PIMD. Next, the observer asked the DSP the following questions about the participants: What are the visual abilities of this person? What are the physical abilities of this person? Does this person interact with others? What behaviours are noticeable prior to these interactions? What behaviours are noticeable during the interaction? What do you see or hear if this person likes something? What do you see or hear if this person does not like something? Then, in consultation with the DSP, the observer was seated in the common room. This had to be a place where the observer was able to see the participants at all time. During the observations the observer did not talk. If a resident tried to make contact this was not rejected, but it was also not initiated or stimulated. If necessary, the observer could change position in order to create a better view. Using a stopwatch, the observer made notes about the past events every five minutes. The timeframes were numbered during the observation in order to recollect at what specific time a certain event or interaction occurred. The observer filled in the observation scheme and wrote down details if needed (for instance if there was a music-therapist working on the group). Per interaction sequence, a row was



filled out and the interactive expressions that were used within that particular interaction were noted. If there were more interactions within this five minute timeframe, more rows were filled out. When the interaction partner was a peer, it was noted if this persons had PIMD or not. After three hours, the observer talked to the DSP again, now explaining the specific purpose of the observation.

## Analysis

For each participant, the observation period included 36 timeframes, leading to a dataset of 504 observational timeframes. The timeframes were analysed to determine the percentage of the timeframes in which an individual was actually observed. It was found that in 47 timeframes (9.3%), the individual was not in the room. Excluding these timeframes left a total of 457 timeframes to be included in the subsequent analyses. In 10 timeframes (2.2%) out of this total of 457, the individual was moved out of the room, but it was still possible to score for interaction prior to this and, therefore, these timeframes were included.

All of the interactions and interactive behaviours observed are presented using descriptive statistics. Following this, the interactions with peers will be described more in detail and then presented in an overview which reveals the opportunities for peer interaction.

## Results

### Interactions

In 188 (41.1%) of the 457 timeframes, interaction was scored as present. As it was possible to interact with more than one person within an observation period, a total of 213 interactions took place with an average of 15.2 interactions per person (range: 3–33, SD = 8.9). Of these 213 interactions, 5.1% (10) were with a peer, 73.4% (157) with a DSP, 14.9% (32) with the observer,

and 6.5% (14) with others (a physical therapist, a music therapist, and a volunteer).

These 213 interactions, seen in 188 timeframes, included a total of 895 interactive expressions in both directions. The participants with PIMD exhibited a total of 364 (40.7%) interactive expressions, and the interaction partners a total of 531 (59.3%). Of all the 531 (100%) interactive expressions of the interaction partners, the DSPs expressed 411 (77.4%), the peers showed a total of 16 (3.0%) interactive expressions, the observer 42 (7.9%), and the other people 62 (11.7%) expressions (see Table 3). Compared to the participants with PIMD, the interaction partners used more vocalisations. Furthermore, touching was used more often by the interaction partners than by the people with PIMD. The participants with PIMD used movement in their interacting more than the interaction partners

### Interactions with peers

Interaction between the participant with PIMD ( $n = 5$ ) and a peer was observed in 10 timeframes (see Table 4 for an overview of these timeframes).

Of the 14 participants, 5 (36%) exhibited one or more interactions with a peer; the others ( $n = 9$ ) did not. Three of these interacting participants were allocated to the special education group and two at the group homes.

The participants with PIMD did not use gestures, touch, or object-related expressions in their interactions with a peer. The peers also did not use gestures; however, they did use touch (three times) and object-related expressions (one time). The interactions between peers were with a peer with PIMD (five times) and with a peer without PIMD (five times). When both interaction partners were persons with PIMD, the only interactive expressions observed were vocalisations. The context of the observed interactions with peers is presented more in detail as case descriptions in Table 5.

**Table 3.** Number of interactive expressions of people with PIMD and their interaction partners.

	Interaction partners											
	People with PIMD		DSPs		Peer		Observer		Other		Total interaction partners	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Vocalising	55	15.1	136	33.1	6	37.5	0	0.0	14	22.6	156	29.6
Gestures	2	0.5	10	2.4	0	0.0	0	0.0	4	6.5	14	2.8
Touching	11	3.0	85	20.7	3	18.7	0	0.0	8	12.9	96	18.0
Facial expressions	85	23.4	36	8.8	2	12.5	4	9.5	5	8.1	47	8.8
Sounds	8	2.2	4	1.0	1	6.3	1	2.4	3	4.8	9	1.7
Looking at	97	26.6	75	18.2	1	6.3	32	76.2	14	22.6	122	22.8
Movement	75	20.6	27	6.6	2	12.5	4	9.5	8	12.9	41	7.7
Object related	31	8.5	38	9.2	1	6.3	1	2.4	6	9.7	46	8.6
Total	364	100.0	411	100.0	16	100.0	42	100.0	62	100.0	531	100.0

Note: The sum of the percentages does not always equal 100 due to rounding off.

**Table 4.** Interactions between peers and contextual factors.

Participant	Sex	Age	Setting	Total interactions with peers	Peer	Timeframe	Interaction PIMD	Interaction peer
B	F	6.8	Special education centre 1	1	PIMD	15	Vocalising	Vocalising
D	M	18.5	Special education centre 2	3	Peer without PIMD	1	Looking Movement	Movement Facial expression Touching
					Peer without PIMD	2	Movement	Movement Touching
					Peer without PIMD	3	Movement Facial expression	Touching
E	F	16.5	Special education centre 3	2	Peer without PIMD	22	Looking Vocalising Sounds	Vocalising Sounds Object related
					Peer without PIMD	24	Looking	Looking Facial expression
M <sup>a</sup>	M	41.1	Group home 3	2	PIMD	15	Vocalising	Vocalising
					PIMD	34	Vocalising	Vocalising
N <sup>a</sup>	M	46.9	Group home 3	2	PIMD	15	Vocalising	Vocalising
					PIMD	34	Vocalising	Vocalising

<sup>a</sup>Participant M and participant N were interacting with each other.

### *Positions and interactions between a person with PIMD and a peer*

The mean number of changes in positioning for all participants was 4.9 times (SD = 2.2, range: 1–9 times) within a time span of three hours. Table 6 provides an overview of the opportunities for peer interaction. For

the participants with PIMD, 61.3% of the time it was not possible to touch a peer nor to look at a peer. In 37.4%, it was possible to look but not to touch a peer. In six timeframes (1.3%), it was possible for the person with PIMD to touch a peer with some effort. For the remainder of the time (98.7%), it was not possible to touch a peer.

**Table 5.** Case descriptions: context of interactions with peers.

**Participant B** is a girl of 6 years old and observed in a Special Education Centre, she was partially sighted and able to reach. According to the DSP, participant B was able to make contact with somebody if that person was within reach of one meter, she used throat sounds, smiled, reached towards people or pulled people's hair or clothes. If she was unhappy or not willing to do something she used her arms to push things away or turned her head away. The observation started when there was a music therapist at the group. All persons were positioned in a circle. Participant B was positioned between the bed box and the waterbed (both beds were occupied) facing away from both beds, having a playing rack on her wheelchair desk. She sat there since timeframe 5. Two persons were outside with one DSP. Another occupied bed box was approximately three meters away. One more child (her brother, the interaction partner) sat in the room, about two meters away, turned half away from the table. When they turned their heads they were able to see each other. There was one DSP in the room. Before starting the interaction with the peer (her brother), the observer noticed an increase in sounds by participant B, a DSP responded to one of the sounds in timeframe 14 by vocalizing. The amount of sounds made by participant B increased. Interaction with brother by both making sounds.

**Participant D** is a young man of 18 years old and observed in a Special Education Centre. He has no reported problems with seeing or reaching. According to the DSP participant D is able to make contact with others. If he tries to make contact he is smiling and makes cooing sounds. In contact his whole face smiles and he makes laughing sounds. When he really enjoys something his face lights up and he stretches out his whole body. When he does not like something his face looks scared and he cries, his body starts to cramp. There were three interactions with a peer, all right at the beginning of the observation during a group session with a music therapist. The group was set up in a circle and participant D sat in between two peers, almost wheelchair to wheelchair. This was the position when the interactions occurred. All interactions were with one peer without PIMD. The peer always used touching as an interactive expression, with participant D responding with movement. Participant D also looked at his peer, resulting in a facial expression.

**Participant E** is a girl of 16 years old, observed in a Special Education Centre, with no reported problems with seeing or reaching. According to the DSP she is able to make contact with other people, she does so by making sounds, facial expressions and eye contact. If she likes something she smiles and raises up her body. If she dislikes something she makes unhappy sounds, as crying or moping, she also uses her arms to bang on her wheelchair table or scratches her ears. She had three interactions with a peer. The first one happened two timeframes after she was positioned at the table for lunch. A peer, who was able to walk, pushed her wheelchair, in reaction she looked at this peer. After a while this peer started talking and making sounds. In reaction participant E also made sounds and vocalisations and started banging on her wheelchair table with her hand (indicating that she did not enjoy this). Two timeframes later the same peer looked at her, participant E responded by vocalizing. After another timeframe the DSP started interacting with her. After this, no more interactions with peers occurred.

**Participant M and participant N** are both male and living in the same group home. They were observed at the same time. Participant M is a man of 46 years, who is partially sighted and not able to reach. Participant N is 41 years old, with no reported visual problems and not able to reach. According to the DSP participant M makes contact through action – reaction, if a person makes a sound, he responds to that. If he likes something, his body will relax and he smiles. If he does not like something, his body cramps and his feet will go up in the air. Participant N makes contact by facial expressions and moaning sounds, if he likes something, he smiles and makes “happy” sounds. If he does not like something his lip starts to purl, he moans or looks away. The first interaction occurred when they were sitting at the table, participant M in a wheelchair with table and participant N in a wheelchair without table. They sat opposite each other at the table. Participant M was sitting at the table for over an hour and the last interaction was with a DSP while he was tube fed over 15 minutes ago. Participant N was sitting the same amount of time at the table and interacted almost every timeframe with the DSP or the observer. Both interactions between participant M and N consisted of vocalisations back and forth. After the first interaction, participant M fell asleep. The second interaction occurred in front of the TV where they were positioned next to each other. This was only seen once for the whole period they were sitting in front of the TV and it happened after over an hour after they have been positioned in front of the TV.

**Table 6.** Opportunities in relation to positioning and interaction with peers.

	Group general		Interaction with peer		Type of interaction with peer
	<i>n</i>	%	<i>n</i>	%	
Touching not possible and looking not possible	280	61.3	3	30.0	Vocalising (3)
Touching not possible and looking possible with head movement	122	26.7	2	20.0	Vocalising (2)
Touching not possible and looking possible without head movement	49	10.7	2	20.0	Vocalising (1) Sounds (1) Looking (2)
Touching with effort and looking possible without head movement	4	0.9	3	30.0	Facial expression (1) Looking (1) Movement (3)
Touching with effort and looking with head movement	2	0.4	0	0.0	–
Total	457	100.0	10	100.0	14

## Discussion

The questions addressed in this study were: How much and what types of spontaneous interactions of persons with PIMD are observed in a non-controlled situation and what are the possibilities, provided by DSPs, for interactions with peers? Results show that only 5.1% of all the interactions observed were with a peer, the remaining interactions were predominantly with DSPs (73.4%). The participants with PIMD most often used “looking at” and used “facial expressions” and “movement” in their interactions.

In only five of the participants (35.7%), interactions with peers were observed, varying from one to three times during a period of three hours. Vocalisations were observed most often in these interactions; none of the participants with PIMD used gestures, touching, or objects as a means to interact with a peer. In general, for 61.3% of the observed time, the participants were positioned in such a way that they were not able to touch or look at a peer. In only four timeframes (0.9% of the time), it was possible for a participant to touch a peer – with some effort – or to look at a peer without effort.

In the current study, only 5.1% of all the observed interactions were with peers, while almost 75% of all the interactions observed were with a DSP. The study by Nijs et al. (2015) had similar outcomes, namely that the children with PIMD were focused on the DSP for 67.7% of the observed time, and on their peers for only 8.1% of the time. Due to the limitations of people with PIMD, they are dependent on others in all aspects of

their daily life. For DSPs, it is their job to support people with PIMD and help them to facilitate interactions with peers. Nijs et al. (2015) found that for almost 95% of the time the DSPs were not focused on facilitating such interactions, even though they had been asked to set up an activity that facilitates mutual interacting. Looking at the results of the current study, as well as the study of Nijs et al. (2015), people with PIMD do not even seem to get this opportunity. They are not positioned in such a way that interaction is possible and consequently most interaction is with the DSPs, leaving less room for interaction with others, such as peers. The combined findings of both studies strengthen the belief that interactions with peers are not believed to be an essential part of the support required by people with PIMD. This raises questions about the scaffolding behaviour of DSPs and related perceptions and beliefs of professionals concerning the importance and feasibility of interactions between peers.

The most observed interactive expressions of the participants with PIMD in the current study were (1) looking at, (2) facial expressions, and (3) movement. In interaction with peers, the persons with PIMD showed mostly vocalisations as an interactive expression. This is not consistent with Johnson et al. (2012) who analysed communicative behaviour in people with severe ID and found that social communication in these individuals mainly consists of touching or being physically close to someone else. This deviating result may be ascribed to the observation that in only 1.3% of the timeframes it was possible to touch a peer. For instance, sitting in a wheelchair a few metres apart from each other clearly limits the options for interaction. This may also explain why gestures, touching, or object-related interactions were not observed in the interactions with peers in the current study. For 61.3% of the time, the participants were not able to touch and not able to look at a peer. This is striking because the participants included in this research were fully dependent on others to put them in a certain position and create a positive environment.

The participants in this study had a mean change of position of five times, including the changes needed for lunch/dinner and for hygienic reasons. This appears to be representative for the support to people with PIMD in general, with Van der Putten, Bossink, Frans, Houwen, and Vlaskamp (2017) also finding that the number of transfers and relocations were minimal. Nijs et al. (2015) found that during group activities, the children were not moved at all. Optimal body positioning has been shown to be important for the use of technical aids such as a speech generating device (Costigan & Light, 2010), while also noted for improving functional



activities (Bergen, Presperin, & Tallman, 1990), for instance, by training the arm function in such a way that the individual is able to use a technical aid that helps communication or increases mobility (Van der Putten, Vlaskamp, Reynders, & Nakken, 2005). Furthermore, it enables people with PIMD from experiencing the world from different points of view and making contact with others. Positioning can therefore be assumed to be an important precondition for enabling interaction between individuals with PIMD and their peers.

It is necessary to discuss some methodological limitations of this study. Firstly, only 14 individuals with PIMD were observed for a continuous period of three hours. In these three hours, timeframes of five minutes were used. This yielded information about a lot of timeframes; however, it did not provide information about for instance the sequence of the interactions, the length of an interaction, or the content of the interactions. By conducting a small and exploratory study, it was possible to take all interactions that occurred into account in order to better map what is needed in terms of follow-up research and directions for recommendations. Secondly, as a first exploratory study of spontaneous social interactions by people with PIMD, several factors that might have influenced the results may not have been adequately taken into account; for example, the DSPs working at the time, their knowledge of the individual with PIMD and their expertise in PIMD in general, or the activities undertaken on a certain day in the group. We attempted to address the latter by requesting that the observations be made on a typical day. Thirdly, with respect to the individuals with PIMD who were observed, we did not include their additional limitations and/or abilities or their physical well-being as factors that could be related to the variables measured. For example, a participant who is blind will never be able to look at a peer, regardless of the position he or she is in. Nevertheless, knowing about such limitations, DSPs should make the effort to enable social interaction that does not rely on sight. Fourthly, because of the limited observed number of interactions between peers, in combination with the design of the study, the results cannot be considered representative for all people with PIMD, nor for every daily living condition. The results can thus only be understood as a starting point for future research.

Considering the limitations listed above, for any repetition of such a study, it would be recommended to observe a participant more than once, in different situations. This way the elements of the model of Hostyn and Maes (2009): the person with PIMD, the interaction partner, and the context can be better mapped and related to the amount and types of interactions. The

observation should be an ongoing process, without using the timeframes and noting more detailed information about the observed interactions. Using such observation techniques gathers data that allow for sequential analysis. The advantage of sequential analysis is that it shows if there are sequences in behaviour and if there is a relationship with the context. It is possible to collect this data if solely interactions with peers are to be observed.

## Conclusion

Of the 10 observed interactions with peers, in 3 of them (30%) the participants were not able to touch or see a peer, and the interaction observed in such positions only consisted of vocalisations. This can be seen as a sign that people with PIMD do attempt to interact with their peers, even if conditions are far from optimal. For a DSP, this means that he or she needs to play an active role in mediating. If optimal conditions for interaction are created by positioning peers in such a way that interaction is possible and if this interaction is further stimulated, we assume that the number of interactions would increase. In a study of the content of support plans for people with PIMD (Kamstra, van der Putten, & Vlaskamp, 2016), it was shown that goals related to creating or increasing interaction with peers are lacking. Furthermore, while DSPs could describe interactive behaviours, they also stated that interactive behaviour between peers was non-existent. It seems that it is not clear to DSPs what interaction between peers actually entails, which may lead to a lack of interest in interactions between peers or even a belief that interactions between peers are not feasible for people with PIMD (Bigby et al., 2009) or that is not part of their job (Prain, Mcvilly, & Ramcharan, 2012). The views and beliefs of DSPs may be one possible reason for the small number of interactions observed in this study, as well as for the limited conditions they created for interaction between peers. Future research should thus focus on the views and beliefs of DSPs and their related social and physical scaffolding behaviour with respect to interactions between peers and their facilitation in practice.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## References

- Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual

- disabilities. *Journal of Intellectual Disabilities*, 10, 275–287. doi:10.1177/1744629506067618
- Antelius, E. (2009). Whose body is it anyway? Verbalization, embodiment, and the creation of narratives. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 13, 361–379. doi:10.1177/1363459308018080
- Arthur-Kelly, M., Bochner, S., Center, Y., & Mok, M. (2007). Socio-communicative perspectives on research and evidence-based practice in the education of students with profound and multiple disabilities. *Journal of Developmental and Physical Disabilities*, 19(3), 161–176. doi:10.1007/s10882-007-9045-9
- Beauchamp, M. H., & Anderson, V. (2010). Social: An integrative framework for the development of social skills. *Psychological Bulletin*, 136(1), 39–64. doi:10.1037/a0017768
- Bergen, A. F., Presperin, J., & Tallman, T. (1990). *Positioning for function: Wheelchairs and other assistive technologies*. Valhalla, NY: Valhalla Rehabilitation.
- Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, 53, 363–376. doi:10.1111/j.1365-2788.2009.01154.x
- Cohen, S. (2004). Social relationships and health. *American Psychologist*, 59(8), 676–684.
- Costigan, F. A., & Light, J. (2010). Effect of seated position on upper-extremity access to augmentative communication for children with cerebral palsy: Preliminary investigation. *American Journal of Occupational Therapy*, 64, 596–604. doi:10.5014/ajot.2010.09013
- Evenhuis, H. M., Theunissen, M., Denkers, I., Verschuure, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, 45, 457–464. doi:10.1046/j.1365-2788.2001.00350.x
- Foreman, P., Arthur-Kelly, M., Pascoe, S., & King, B. S. (2004). Evaluating the educational experiences of students with profound and multiple disabilities in inclusive and segregated classroom settings: An Australian perspective. *Research and Practice for Persons with Severe Disabilities*, 29(3), 183–193.
- Gleason, J. J. (1989). *Special education in context: An ethnographic study of persons with developmental disabilities*. New York: Cambridge University Press.
- Hostyn, I., & Maes, B. (2009). Interaction between persons with profound intellectual and multiple disabilities and their partners: A literature review. *Journal of Intellectual & Developmental Disability*, 34, 296–312. doi:10.3109/13668250903285648
- Hostyn, I., Petry, K., Lambrechts, G., & Maes, B. (2011). Evaluating the quality of the interaction between persons with profound intellectual and multiple disabilities and direct support staff: A preliminary application of three observation scales from parent–infant research. *Journal of Applied Research in Intellectual Disabilities*, 24(5), 407–420.
- Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2010). The pearl in the middle: A case study of social interactions in an individual with a severe intellectual disability. *Journal of Intellectual and Developmental Disability*, 35(3), 175–186.
- Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2012). Social interaction with adults with severe intellectual disability: Having fun and hanging out. *Journal of Applied Research in Intellectual Disabilities*, 25, 329–341. doi:10.1111/j.1468-3148.2011.00669.x
- Kamstra, A., van der Putten, A. A., & Vlaskamp, C. (2016). Efforts to increase social contact in persons with profound intellectual and multiple disabilities analysing individual support plans in the Netherlands. *Journal of Intellectual Disabilities*, 21. doi:10.1177/1744629516653037
- McConkey, R. (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research*, 51(3), 207–217.
- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 83–87. doi:10.1111/j.1741-1130.2007.00104.x
- Nijs, S., Penne, A., Vlaskamp, C., & Maes, B. (2015). Peer interactions among children with profound intellectual and multiple disabilities during group activities. *Journal of Applied Research in Intellectual Disabilities*. doi:10.1111/jar.12185
- Olsson, C. (2004). Dyadic interaction with a child with multiple disabilities: A system theory perspective on communication. *Augmentative and Alternative Communication*, 20, 228–242.
- Olsson, C. (2005). The use of communicative functions among pre-school children with multiple disabilities in two different setting conditions: Group versus individual patterns. *Augmentative and Alternative Communication*, 21, 3–18.
- Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 18, 35–46. doi:10.1111/j.1468-3148.2004.00209.x
- Prain, M., Mcvilly, K. R., & Ramcharan, P. (2012). Interacting with adults with congenital deafblindness: The experiences of disability support workers. *Journal of Intellectual And Developmental Disability*, 37(1), 27–34. doi:10.3109/13668250.2012.647808
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.
- Scott, H. M., & Haverkamp, S. M. (2014). Mental health for people with intellectual disability: The impact of stress and social support. *American Journal on Intellectual and Developmental Disabilities*, 119(6), 552–564. doi:10.1352/1944-7558-119.6.552
- Sim, J., & Wright, C. C. (2005). The kappa statistic in reliability studies: Use, interpretation, and sample size requirements. *Physical Therapy*, 85, 257–268.
- Van der Putten, A. A., Bossink, L. W., Frans, N., Houwen, S., & Vlaskamp, C. (2017). Motor activation in people with profound intellectual and multiple disabilities in daily practice. *Journal of Intellectual and Developmental Disability*, 42, 1–11. doi:10.3109/13668250.2016.1181259

- Van der Putten, A., Vlaskamp, C., Reynders, K., & Nakken, H. (2005). Children with profound intellectual and multiple disabilities: The effects of functional movement activities. *Clinical Rehabilitation*, 19, 613–620. doi:10.1191/0269215505cr899oa
- Van Splunder, J., Stilma, J. S., Bernsen, R. M. D., & Evenhuis, H. M. (2006). Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: Cross-sectional study. *Eye*, 20, 1004–1010. doi:10.1038/sj.eye.6702059
- Vlaskamp, C. (2011). Kijken naar ontwikkeling. In B. Maes, C. Vlaskamp, & A. Penne (Eds.), *Ondersteuning van mensen met ernstige meervoudige beperkingen. Handvatten voor een kwaliteitsvol leven* (pp. 179–198). Leuven/The Hague: Acco.