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Onderzoeksgroep Gezins- en Orthopedagogiek

# INTERACTIONS BETWEEN PEOPLE WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES AND THEIR DIRECT SUPPORT STAFF

Proefschrift aangeboden tot het verkrijgen van de graad van Doctor in de Pedagogische Wetenschappen door **Ine Hostyn** 

Promotor: Prof. Dr. Bea Maes



### Ine Hostyn, Interactions between people with profound intellectual and multiple disabilities and their direct support staff.

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Positive relationships with others are important in the life of every human being. Especially for people with profound intellectual and multiple disabilities (PIMD), high quality interactions are indispensable for a good quality of life. Because of their complex support needs, they need others to explore the world, to show their abilities, and to feel comfortable. However, the development of high quality interaction with people with PIMD is subject to considerable challenges and empirical research has demonstrated that the interactions between people with PIMD and their proxies are not always optimal. Besides, there is no comprehensive understanding of the key characteristics of interaction within this group and methods to describe the quality of the interaction from an interpersonal view have been lacking. Therefore, the aim of this doctoral dissertation was threefold. First, we wanted to get a thorough understanding of the key elements determining the quality of the interactions with people with PIMD. Second, we wanted to find justified methods to describe the quality of reciprocal interaction processes between people with PIMD and their direct support staff. Third, we wanted to examine how an inclusive understanding and integrated description of the mutual interaction between people with PIMD and their support staff may offer directions to support their interaction. Five manuscripts, published or submitted in interactional peer-reviewed journals, addressed these research objectives.

The first part of this project consisted of a review of the current research literature on the interaction between people with PIMD and their interaction partners (**manuscript 1**). Next to a methodological characterization of the research on this topic, important interaction elements were overviewed in an explanatory interaction model. Influencing factors on the level of the persons with PIMD, the interaction partners, and the context were revealed. Constituting components of the interaction were sensitive responsiveness, joint attention, co-regulation, and an emotional component (e.g., mutual feelings of warmth or closeness).

In continuation of this manuscript, the second part of this doctoral research explored the usefulness of several observation methods to describe relevant components of the reciprocal staff-client interaction by a combination of quantitative and qualitative data. In a first observation study (manuscript 2) three rating scales from parent-infant research were found to be appropriately describing both interaction partners' behaviours that build up positive and mutual interaction. A second observation study demonstrated the value of an observation instrument based on the dialogical theory to describe dyadic variables in the interaction between people with PIMD and their direct support staff (manuscript 3). In a third observation study, the frequency and the nature of attention-directing behaviours of the persons with PIMD, attention-directing behaviours of the staff members, and the attention episodes in the dyad were successfully described (manuscript 4).

Using the obtained knowledge and justified methods from the first and the second part of this thesis, the third part of this project consisted of a qualitative single-case study combining direct observation with a staff-researcher dialogue (**manuscript 5**). The results were convincing in how strengths and difficulties in an interaction between a boy with PIMD and his direct support staff member could be identified by means of an integrative theoretical framework and methodology, and by involving the experiential knowledge of the staff member as a complementary source of information in the observation analysis.

The empirical findings as well as the methodological and theoretical reflections derived from this doctoral study provide essential knowledge to guide future research on interactions between people with PIMD and their direct support staff. With regard to practice, the obtained understandings and the observation tools can be considered a vehicle for practitioners to gain insight into their interaction patterns, to be confirmed in the available qualities in their interactions, and to discover new perspectives.

### Ine Hostyn, Interacties tussen mensen met ernstige meervoudige beperkingen en hun directe begeleiders.

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Promotor: Prof. Dr. Bea Maes

Kwaliteitsvolle en positieve relaties met anderen zijn belangrijk in het leven van iedereen. Zeker voor personen met ernstige meervoudige beperkingen (EMB) zijn wederzijds afgestemde interacties van cruciaal belang omdat ze, omwille van hun complexe ondersteuningsnoden, voor nagenoeg alle aspecten van hun dagelijks leven afhankelijk zijn van anderen. Doorheen ondersteunende interacties kunnen ze hun mogelijkheden en persoonlijkheid ontplooien. De ontwikkeling van kwaliteitsvolle interacties met personen met EMB blijkt echter een ware uitdaging te zijn en empirisch onderzoek toont aan dat de kwaliteit van de interacties tussen personen met EMB en hun interactiepartners vaak ontoereikend is. Daarnaast is er geen duidelijk inzicht in de componenten die een rol spelen in het opbouwen van warme en wederzijdse interacties in deze doelgroep. In hedendaags onderzoek zijn wederkerige interactieprocessen ook onderbelicht gebleven, waardoor het niet mogelijk is om met de bestaande methoden het interactief gedrag en de onderlinge emoties van beide interactiepartners te beschrijven. De centrale doelstelling van het voorliggend doctoraatsproefschrift was dan ook drieledig. In eerste instantie wilden we een grondig inzicht ontwikkelen in de kernelementen van interacties met personen met EMB. In tweede instantie wilden we observatiemethoden vinden om de kwaliteit van de wederkerige interacties tussen personen met EMB en hun directe begeleiders op een wetenschappelijk verantwoorde manier in kaart te brengen. In laatste instantie wilden we nagaan op welke manier een beter begrip en een omvattende interactiebeschrijving een aanzet kunnen vormen om de interactie tussen personen met EMB en hun directe begeleiders te ondersteunen. Vijf manuscripten die gepubliceerd zijn of ingediend zijn bij internationale tijdschriften, zijn aan deze onderzoeksdoelstellingen tegemoet gekomen.

In het eerste deel van dit onderzoeksproject werd de recente onderzoeksliteratuur aangaande de interactie tussen personen met EMB en hun interactiepartners geanalyseerd (**manuscript 1**). De methodologische kenmerken van de bestaande studies werden eveneens in kaart gebracht. De resultaten werden samengevat in een beschrijvend interactiemodel. Vier kerncomponenten maken deel uit van het interactieproces zelf: sensitieve responsiviteit, co-regulatie, gedeelde aandacht, en een emotionele component (zoals het ervaren van wederzijdse warmte en nabijheid). De kwaliteit van de interactie wordt beïnvloed door factoren in de persoon met EMB, de interactiepartner en de context.

Voortbouwend op de inzichten van het literatuuronderzoek, werden in het tweede deel van dit doctoraatsproject drie studies uitgevoerd om de belangrijke componenten in de interactie tussen personen met EMB en hun directe begeleiders vanuit verschillende theoretische perspectieven en met verschillende observatiemethoden in kaart te brengen. In een eerste observatiestudie (manuscript 2) werden drie instrumenten uit ouder-kind onderzoek toegepast om het gedrag van beide interactiepartners ten opzichte van elkaar in kaart te brengen. Voor een tweede observatiestudie (manuscript 3) werd een instrument ontwikkeld om dyadische variabelen in de interactie te beschrijven. In een derde observatiestudie op basis van de dialogische theorie (manuscript 4) werden drie codeerschema's ontwikkeld om een beeld te krijgen van de frequentie en de aard van de aandachtsrichtende gedragingen van de personen met EMB en van hun begeleiders, en van de mate van gedeelde aandacht in hun interactie. Zowel de kwantitatieve scores als de kwalitatieve beschrijvingen die resulteerden uit deze observatiestudies toonden aan dat de instrumenten voldoende wetenschappelijke waarde hebben om de interactie tussen personen met EMB en hun directe begeleiders in kaart te brengen.

In het derde en laatste deel van dit doctoraatsproject werden de verkregen inzichten vertaald in een kwalitatieve gevalsstudie waarin gebruik werd gemaakt van zowel directe gedragsobservatie als een dialogisch gesprek tussen de onderzoeker en de deelnemende begeleider (**manuscript 5**). Op een overtuigende manier toonde deze studie aan hoe de aanwezige kwaliteiten en moeilijkheden in de interactie tussen een jongen met EMB en zijn begeleidster konden worden vastgesteld. Het geïntegreerd theoretisch kader en de combinatie van methoden, samen met het gebruik van de ervaringskennis van de begeleidster waren hiertoe bijdragende factoren.

Niet alleen de empirische bevindingen van dit project maar ook de methodologische en theoretische reflecties vormen een essentieel uitgangspunt voor vervolgonderzoek. Voor mensen uit de praktijk kunnen de opgedane inzichten en de onderzochte observatie-instrumenten een aanzet en inspiratiebron zijn om inzicht te verwerven in hun eigen interactiepatronen, om bevestigd te worden in hun sterktes en mogelijkheden, en om nieuwe perspectieven op de interactie met personen met EMB te verkennen.

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### **CHAPTER 1**

#### GENERAL INTRODUCTION

# Equal and exceptional<sup>1</sup>: A relational perspective on people with profound intellectual and multiple disabilities

The fundamental law of human beings is inter-dependence.

A person is a person through other persons.

~ Desmond Tutu

Positive relationships with others are an important aspect of people's lives. The essence of human being is the interconnectedness between people, which is reflected in the notion of relational autonomy (Nedelsky, 1989). Although contradictory at first sight because of our inclination to think of autonomy in terms of individuals separated and isolated from one another, interpersonal relationships are constitutive for people's autonomy. As Tronto clearly describes (1992), human beings should not be conceived as fully autonomous and independent but in a condition of interdependence. 'Persons are socially embedded and agents' identities are formed within the context of social relationships', as Mackenzie and Stoljar (2000, p.4) point out.

All people are equal with regard to this condition of interdependence. Human beings are born totally dependent on others, and gradually develop towards a condition of autonomy in interdependence in which they relate to each other in a mutually dependent way. But for some people, the dependency on others is striking and remains a core issue throughout their entire life. This is, amongst others, the case for people with profound intellectual and multiple disabilities (PIMD).

People with PIMD have profound intellectual disabilities in combination with serious neuromotor and/or sensory impairments (Nakken & Vlaskamp, 2002; Nakken & Vlaskamp, 2007; Petry, Maes, & Vlaskamp, 2005). They also often suffer from medical problems such as feeding problems or respiratory problems. These multiple and complex disabilities result in high support needs. People with PIMD must rely on others for support in all aspects of their daily functioning. Like other people but more explicitly and during their entire life, they are totally dependent on supporting relationships to develop their competencies and personalities. High quality interaction is therefore particularly important and constitutive for the personal identity and relational autonomy of people with PIMD.

<sup>1</sup> In reference to the title of the third European conference of the International Association for the Education of Deafblind People (IAEDB), Potsdam, Germany, July 31- August 5, 1993.

As a result, it is generally recognized that the quality of the relationships between people with PIMD and their proxies (peers, parents, and direct support staff) is highly decisive for their life quality (Maes, Lambrechts, Hostyn, & Petry, 2007; Vlaskamp, 2000). Interactions can stimulate the further development and the optimal functioning of the person with PIMD (Fogel, 1993). As Lubinski (1981) reflects, high-quality interaction can make the difference between isolation and social connectedness, dependence and independence, withdrawal and fulfilment for persons with communicative impairments. Likewise, Bradshaw (2001) stresses the importance of developing communication partnerships with people with PIMD. Moreover, empirical research results point to the importance of high quality interaction for this target group. In the study of Petry et al. (2005), social wellbeing, mainly referring to personal relationships, was found to be the only domain that was spontaneously named by all participating parents and direct support staff as crucial for the quality of life of persons with PIMD. Also, almost all long-term goals for people with PIMD formulated in the individual support programs within the study of Vlaskamp and van der Putten (2009) were related to interaction and social roles. Social interaction was found to contribute to the alertness and engagement of persons with PIMD (Arthur, 2004) and to their happiness and well-being (Davis, Young, Cherry, Dahman, & Rehfeldt, 2004; Favell, Realong, & Sutton, 1996; Realon, Bligen, La Force, Helsel, & Goldman, 2002). Also, respectful and mutual exchanges in everyday interactions between partners are a matter of inclusion (Finlay, Antaki, Walton, & Stribling, 2008) and enable people with PIMD to have active influence on their path of life (Vlaskamp, 2000).

As Arthur-Kelly, Foreman, Bennett, and Pascoe (2008), Petry and Maes (2007), and Vlaskamp (2000) rightly argue, a relational support perspective, interpersonal variables, and high quality interaction are therefore most important to improve the support for persons with PIMD. The quality of the interactive togetherness between people with PIMD and their partners must be the core focus of good professional practice and, consequently, also of good scientific research of this target group.

# Problem statement: The shortcomings and challenges in developing high quality interaction with people with PIMD

Despite the general acknowledgement of the importance of interpersonal relationships, there is evidence that the development of high quality interaction with people with PIMD is not self-evident and subject to considerable challenges.

Empirical research has demonstrated that the interactions between people with PIMD and their proxies, in particular direct support staff, are not always successful. Both the quantity (Hile & Walbran, 1991) and the quality (e.g., McConkey, Morris, & Purcell, 1999) of the interactions between direct support staff and persons with intellectual disabilities are, in general, insufficient. Specific shortcomings of the interactions with persons with a high support need are the high proportions of time without communicative interaction or partner response (Arthur, 2003), the preponderance of instructions and neutral affects (Seys, Duker, Salemink, & Franken-Wijnhoven, 1998), and an overall

lack of connectedness and responsivity to the clients' capacities and needs (De Waele & Van Hove, 2005). Campo, Sharpton, Thompson, and Sexton (1997) also report that the quality of life of persons with PIMD is threatened by limited supportive interactions with support staff.

The reported lacks in interaction quality might partially be explained, next to all kinds of organizational and other matters, by the fact that the development of rewarding interactions with people with PIMD is hampered by the difficulty to understand their feelings, needs, and thoughts. They seldom use verbal language and mostly communicate in a pre- or protosymbolic way using idiosyncratic utterances such as vocalisations, changes in muscle tone, bodily movements, facial expressions, and other subtle cues that are context- and person-bound (Daelman, 2003; Stillman & Siegel-Causey, 1989). Because of this use of unconventional communication, leading to ambiguity of meaning, it is no coincidence that their communicative signals are difficult to interpret and are often misunderstood or ignored by people who are used to verbal communication and conventional language (Grove, Bunning, Porter, & Olsson, 1999; Porter, Ouvry, Morgan, & Downs, 2001). Self-evident communicative principles get lost in interaction with people whose communication is difficult to understand. This is the reason why sensitive partners who are willing to understand people with PIMD and create meaning with them in real partnership are indispensable.

In sum, the high dependency and idiosyncratic communication of people with PIMD imply that their interaction partners need particular skills to understand persons with PIMD and to create an optimal interactional environment. It is obvious that people with PIMD and their support partners are at risk for experiencing non-optimal and non-mutually rewarding interactions, which threatens their life quality. Supported by theoretical and empirical research outcomes, we can conclude that it is a true challenge to develop mutual and positive interactions with people with PIMD. There is need to improve the interaction between people with PIMD and their interaction partners.

#### State of the art and lacks in current research

In the current empirical research literature, as stated above, several quantitative and qualitative studies have been directed at the interaction with persons with PIMD. Descriptive small sample size studies, mainly based on video observation or interviews and performed in various settings, have explored the interaction between children and adults with PIMD and their interaction partners (Hostyn & Maes, 2009). Besides, improving the quality of the interpersonal interaction and communication between persons with PIMD and significant others has been a central focus of some recent intervention studies (Bloomberg, West, & Iacono, 2003; Chen, Klein, & Haney, 2007; Dobson, Upadhyaya, & Stanley, 2002; Golden & Reese, 1996; Maes, Lambrechts, Hostyn, & Petry, 2007). For example, the intensive interaction program (Nind, 1996; Nind & Hewett, 1994), taking the quality of the interaction as a fundamental and central starting point, has been used successfully within the target group of people with PIMD (Kellett, 2000; 2003; Leaning & Watson, 2006; Nind, 2009). These

studies all highlight the importance of focussing on the quality of the interaction between persons with PIMD and their interaction partners.

Notwithstanding the relevance of these available studies, to date our insight into this specific interaction phenomenon remains limited, incomplete, and vague. First, there is no comprehensive understanding of the key characteristics of quality interaction within this group. With regard to the available descriptive studies, most of them have addressed only one specific component of the interaction, such as the initiatives of the person with PIMD, the strategies used by the interaction partner, or the influence of using a communication aid, without putting this into an overarching interaction framework. With regard to existing intervention studies, they fragmentary focussed on one specific element of the staff-client interaction and do not provide clear information on the interaction components addressed. As a result, up to now it is not clear how interactions with people with PIMD are shaped in all their aspects, and what high quality interactions must generally imply to promote wellbeing and a good life quality in people with PIMD.

Second, in addition to this conceptual indistinctness, in present research the interactions were mostly evaluated by investigating strategies or knowledge of the interaction partner (e.g., Dobson et al., 2002; Healy & Noonan Walsh, 2007) or individual communicative utterances from the person with PIMD (e.g., Arthur, 2004; Kellett, 2000; Olsson, 2005) but less by evaluating both partners' behaviours and emotions towards each other or how they mutually influence each other. Although, particularly for the target group of people with PIMD interactions need to be fine-tuned to the abilities, needs, and wishes of both interaction partners to establish a positive emotional climate (Petry et al., 2005; Wilder & Granlund, 2003). One qualitative case study (Olsson, 2004) and some interview studies (e.g., Wilder & Granlund, 2003) have addressed this, but no generalizing observation studies were performed. Also, existing intervention studies did not offer comprising directions to improve and evaluate the mutual interaction between people with PIMD and their proxies. Accordingly, the methodologies used in the available studies did not provide insight into nor enabled to describe the unique characteristics of the interpersonal interaction.

In sum, existing research lacks rich and detailed understanding of the reciprocal interaction between persons with PIMD and their interaction partners and how it can be improved. The available studies do not enable to understand or describe the interaction with people with PIMD from an integrated and true interpersonal point of view. There is vagueness on the conceptual level together with indistinctness on the methodical level, i.e. how to describe the interaction quality. However, if we want to know how we might support reciprocal interactions with people with PIMD and the skills of their proxies, it is required to develop an overarching comprehension of relevant and essential elements of the interaction process with persons with high support needs. Specifically, to be able to profoundly understand and evaluate research and intervention outcomes, there is considerable need for knowledge about the nature of interaction with people with PIMD and for methods to describe and

assess its quality. In view of their quality of life, it is of great importance to particularly gain a grasp of the affective and reciprocal interactions between people with PIMD and their interaction partners.

#### Aims and central research questions

To meet the reported challenges in practice and the gaps in current scientific research, this doctoral research project intends to gain more in depth knowledge about the interaction by investigating interpersonal processes between people with PIMD and their interaction partners. In particular, following the determined research needs, the aims of the project are threefold. First, we want to get a thorough understanding and comprehensive overview of the key elements determining interactions with people with PIMD. Second, we want to find justified methods to describe the interactional processes and relevant aspects in the mutual interaction between people with PIMD and their interaction partners. Third, we want to suggest directions to support the interaction between people with PIMD and their proxies based on a better understanding and integrated description of the occurring interactional processes. We believe that these three objectives are essential to facilitate and guide future research and practice in this field.

The reciprocity between persons with PIMD and their interaction partners is central to this doctoral research project. Referring to the first paragraphs of this general introduction, we aim to examine the interdependency between the two interaction partners rather than how one of them is dependent from the other or how they function independently from each other. We want to understand how both interaction partners relate to each other in a mutually dependent way. That is why this doctoral thesis is dedicated to the interaction between people with PIMD and their proxies, which we conceive as the process 'by which two individuals mutually influence each other' (Bjerkan, 1996; Janssen, Riksen-Walraven, & Van Dijk, 2003b, p. 198). This is in line with other definitions. Interaction is a "self-organizing process which is shaped by the iterative interplay between the participants" (Steenbeek & van Geert, 2007, p. 3). It refers to how participants alter their behaviour to adapt to each other and through which a coherent sequence of activities is shaped (Messer, 1994). For interaction to occur "the separate activities of the participants must be co-ordinated in such a way as to form a unitary sequence" (Schaffer, 1984, p 5). It is about two independent entities that enter into mutual dependence (Markova & Linell, 1996). Interaction is a continuous process where partners coregulate their actions depending on the interpretations of the others ongoing and anticipated actions (Fogel, 1993). This corresponds to a transactional view (Sameroff, 1975), stressing how both interaction partners modulate their behaviour and unfold themselves in close contact with each other. Interaction is a turn taking process consisting of bodily contact, eye contact, facial expressions, pointing, reaching, nodding, etc. (Blokhuis & van Kooten, 2003). It is about reciprocal engagement and mutually influencing each other, and less about the message. As Granlund and Wilder (2006) define, interaction is "a process of turn-taking between persons independent of the form used by the interaction partners for conveying the message" (p. 177). This last element, referring to the transfer of information by non-verbal or verbal means, is exactly the core aspect of most communication definitions (Messer, 1994). Thus, although the concept of *communication* is regularly used as a synonym for the concept of interaction and the distinction between both concepts is subtle, we do not explicitly focus on the communicative messages or the communicative utterances of people with PIMD (as were investigated for example in the doctoral dissertation of Daelman, 2003). It is clear that quality interaction is considered a vehicle for more complex communication (Bjerkan, 1996; Janssen, 2003a; Snell, 2002) and processes of interaction and communication are often melting gradually (Blokhuis & van Kooten, 2003). In this dissertation, however, we mainly want to focus on the very basic processes of searching and making contact in intense, meaningful, and mutual interaction. Other concepts found in the research literature are *rapport* (McLaughlin, & Carr, 2005), *proximal processes* (Olsson, 2005; Wilder, 2008a) and *partnership* (Bradshaw, 2001) but are not used in this dissertation. Also, we will not focus on the *relationship* built up on the long term between the interaction partners.

Furthermore, we principally focus on the interaction between **people with PIMD** and their **direct support staff** because many people with PIMD in Flanders rely on professional support in day care settings or residential services (Maes, Penne, de Maeyer, & Vandevorst, 2008a; 2008b). Even though we are convinced that the interactions with family members and also between people with PIMD certainly provide opportunities to experience mutuality too (Arthur-Kelly, Foreman, Bennett, & Pascoe, 2008), it is a fact that paid direct support workers are the primary contact people and communication partners for many persons with high support needs living in supported accommodation (Forster, 2005; Golden & Reese, 1996). Next, although group interactions are an integral part of the daily routine in these professional settings, we will particularly investigate **one on one interactions** between a person with PIMD and their interaction partner without disabilities as we believe that there lies a fundamental basis for individualised, attuned, and high quality interaction.

Lastly, the phenomenon of interest in this doctoral thesis is particularly the **quality of the interaction**. The intense moments of qualitative one on one interaction with familiar persons, even if limited in quantity, are especially valuable with regard to a person's well being, feeling of worthiness, and overall life quality. The moments in which a person with PIMD gets one hundred percent of the attention of the interaction partner, offer the most ideal conditions for meaningful interaction in which a true partnership can be developed (e.g., Forster, 2008). We also suppose that shortcomings in the quantity of the interactions with people with PIMD are mainly determined by organizational and/or policy measures (e.g., staff shortage) which cannot be solved in the close and immediate contact between interaction partners. However, better insight into high quality interactions and its importance for people with PIMD might also stimulate staff to more frequently engage in these interactions.

As a result, the three main research questions that we want to deal with in this doctoral study are:

- What are key elements of high quality interaction facilitating the understanding of the interaction processes between people with PIMD and their interaction partners?
- Which methods enable to describe the quality of the reciprocal interaction between people with PIMD and direct support staff?
- How can an inclusive understanding and description of the interactional processes between a person with PIMD and his support worker offer directions to support their interaction quality?

#### Design and outline of the doctoral research project

The structure of this doctoral thesis is based on the threefold aim of the research project. Particularly, the dissertation consists of five manuscripts submitted in international peer-reviewed journals, of which four are published. The finishing chapter comprises a concluding discussion on the research project.

## Part 1: Understanding key elements of the interaction between people with PIMD and their interaction partners

In the first part of the project, aiming to gain further understanding of the interaction phenomenon, the current research literature on the interaction between people with PIMD and their interaction partners was analysed and synthesized. In first instance, the methodological qualities of the available studies addressing this topic were investigated. Next to this, the fifteen articles, resulting from a computerized literature search with a predefined set of inclusion and exclusion criteria, were examined with regard to the information provided on key elements of the interaction process. In particular, the narrative synthesis of the papers yielded information on relevant interpersonal constituting components of the interaction between persons with PIMD and their partners. Also, several influencing factors on the level of the persons with PIMD, their interaction partners, and the context were examined. The findings of the literature analysis enabled to construct an explanatory interaction model. This literature review resulted in a **first manuscript** (second chapter of this thesis).

#### Part 2: Describing the quality of the interaction between people with PIMD and direct support staff

The second part of the doctoral research project consisted of an exploration of different methods to describe relevant components of the reciprocal staff-client interaction. In particular, we investigated the usefulness of several observation scales to unfold interpersonal processes between persons with PIMD and their support partners. We adjusted existing observation tools from other research contexts and developed new supplementary tools where lacunas were established.

The general design of the studies performed in this part of the thesis was similar. First, all studies were performed in accordance with the ethical guidelines of the university. The participants or their representatives were informed on the purpose and the design of the studies, and the data were treated confidentially and anonymously.

Second, we chose to apply video observation as a method to describe the interactional processes between persons with PIMD and their direct support staff. It is not possible to work with self-report or questionnaires in the target group of people with PIMD and, generally, it is difficult for all people to have insight into their own interaction patterns. Video observations make it possible to describe complex interaction patterns and processes by a coding system, as is for example recommended in family observational research to reduce training for observers and to be able to make a careful judgment (Lindhal, 2001). The findings of our literature review (Hostyn & Maes, 2009) confirm that video observation is the most frequently used method to examine interactions with the target group of persons with PIMD. In addition, this is also relevant in view of developing guidelines for video analyses, an often used tool in staff intervention programs to improve the interaction quality (e.g., Bloomberg, West, & Iacono, 2003; Dobson, Upadhyaya, & Stanley, 2002).

Third, the participants for the studies were selected through convenience sampling. The people with PIMD were selected according to the widely accepted definition of the target group of Nakken and Vlaskamp (2002), and the direct support staff members in the participating services had to work directly with the client for at least six months.

Fourth, the observation contexts of the one-on-one interactions were a natural but quiet context, i.e. a familiar room in the facility where they were alone. Specific objects were introduced or not, in line with the research aims. Staff was asked to behave as they would normally do in similar situations. The staff-client interaction was videotaped with two cameras, one providing an overview of the dyad in its context and the other zooming in on the person with PIMD to be able to register his or her subtle expressions.

Fifth, all observations were preceded by an in-depth training of the raters. Along with becoming acquainted with the underlying theoretical concepts and target behaviours of the different coding tools, these trainings consisted of exercises in coding videotapes which were not part of the actual study. During the consensus-based observer trainings emphasis was laid on resolving disagreements between the raters through conversation and on doing observation trials again until consensus was reached.

Sixth, the definite observations were based on client information forms to enhance the raters' understanding of the communicative utterances of the people with PIMD included. These forms, filled in by staff members, consisted of profiles of affective communication and engagement (Petry & Maes, 2006) summarizing clients' characteristic utterances to show (non-)wellbeing and (dis-)engagement with persons and objects. In addition, scoring sheets were developed to stimulate raters to justify their scores with concrete behavioural, verbal as well as non-verbal, indicators.

Lastly, the studies mainly enabled to quantify different aspects of the interaction between people with PIMD and their interaction partners and to trace strengths and weaknesses in the observed interactions. However, in the margin, some rich qualitative descriptions were also resulting from these studies.

To fulfil the objective of the second part of this doctoral research project, different observation studies were performed complementary to each other. We explored various methods that tap into different facets of the interaction phenomenon (Greene, 2007). We experimented with different theoretical frameworks, observation tools and procedures to describe the interaction between people with PIMD and their direct support staff as completely and differentiated as possible. In each observation study, we chose to focus on a specific aspect of the interaction between people with PIMD and their direct support staff, referring to one or more constituting components of the interaction concluded from our literature review. In line with this, we ended up with different theoretical frameworks and research traditions. On its turn, the observation focus and theoretical backgrounds determined in each study our further decisions regarding the coding level, recording duration, observation context and materials, and reliability calculation. The characteristics and specific accents of the resulting three studies are reviewed in the first three columns of Table 1.

**Table 1** Characteristics of the observation studies

	Manuscript 2	Manuscript 3	Manuscript 4	Manuscript 5
Background elements				
Observation focus	Persons' interactive behaviour towards each other	The dyad in interaction	Persons' attention directing behaviour towards each other + attention episodes in the dyad	The interaction in total
Theoretical background and research tradition	Parent-infant and attachment research	Dialogical approach	Joint attention (developmental psychology)	Integrative framework
Methodological element	ts			
Coding level	Global coding	Global coding	10-s partial interval coding	Combination of global and interval coding
Recording duration	20 minutes	10 minutes	10 minutes	Natural duration of the interaction sequence
Observation context and materials	Semi-structured situation with new objects	Semi-structured situation without objects	Semi-structured situation with objects of preference	Daily life context
Reliability	Interrater agreement	Consensus rating	Interrater agreement	Triangulation of data + dialogue with staff

Note. This table emphasizes the differences between the observation studies. The similarities in the research designs are discussed in the text.

In a first observation study, resulting in a **second manuscript** (third chapter of this thesis), we focused on how the interaction partners perceive and respond to each other's signals and how they use strategies that build up a reciprocal and positive emotional interaction. As people with PIMD have a low developmental age, we started from existing observation tools that demonstrated their merit in parent-infant or attachment research. The theoretical backgrounds of this research tradition were considered a rich basis to investigate the affective and reciprocal interaction with people with PIMD by giving insight into the interactional needs and capacities of persons with PIMD, and, at the same time, by giving an indication about the role of partners to stimulate further development. In particular, we examined the value and usefulness of three instruments to evaluate the quality of interactions between people with PIMD and their direct support staff: the Emotional Availability Scales (Biringen, Robinson, & Emde, 1998), the Maternal/Child Behavior Rating Scales (Mahoney, 1992; 1998), and the Revised Erickson Scales (Egeland, Erickson, Clemenhagen-Moon, Hiester, & Korfmacher, 1990). Through the use of these dyadic interaction scales the interactive behaviours of one interaction partner towards the other person were focussed on. To be able to examine the mutual dependent behaviour of both interaction partners as much as possible and to observe for example instructive behaviour, the eighteen staff-client interactions were videotaped in a problem-solving task situation, which we conceived as a situation in which the participants were confronted with new objects for which the person with PIMD needed a scaffold from his partner to discover them. The interaction quality was described in a global way, applying one overall judgement to the whole interaction of twenty minutes. In accordance with the guidelines of these traditional instruments, the study's reliability was determined by calculating interrater agreement on one third of the video records that were double coded. Correlational analyses enabled to pass a judgement about the construct and convergent validity of the instruments. Furthermore, descriptive analyses and analyses of the qualitative score descriptions were done to examine whether the instruments yield useful and significant information about the quality of interactions with persons with PIMD. Lastly, the applicability of the scales to the target group of people with PIMD as well as the added value of simultaneously using different instruments from parent-infant research were determined during the training and scoring process.

Since the first observation study did not enable to describe the co-regulative processes in the interacting dyad, though this was established as an important constituting interaction component in our literature review, a second observation study was carried out. This study, of which the results are summarized in a **third manuscript** (fourth chapter of this thesis), explicitly started from a dialogical perspective on communication and human interaction. This theoretical background, which had never been used in research within the target group of this dissertation, was translated in the self-developed Scale for Dialogical Meaning Making (Hostyn, Janssen, Daelman, & Maes, 2009). In line with the emphasis on how persons co-create meaning together through an open-ended negotiation process, not the individuals' separate interactive behaviour but the interaction dyad and different relationship variables were focused on. Accordingly, a global coding was again a logical choice as this enabled to

take into account the flow of the dialogue, essentially consisting of a dynamic variation between moments of synchrony and asynchrony. As the mutual creation of a joint context is one of the aspects of dialogue and we consequently did not want to influence the context by ourselves, the eighteen dyads of persons with PIMD and their direct support staff were observed for ten minutes in a situation without objects. Following the theoretical basis of this study, a consensus rating procedure was applied to preserve the richness of dialogue as much as possible. This is a dialogical process in which the raters discuss their scores and observations after which a shared score can be agreed upon. Reliability analysis together with an analysis of the range in scores and correlations between the subscales were determined to investigate the scale's reliability and versatility. We explored whether the Scale for Dialogical Meaning Making provides a significant description of the dialogue between persons with PIMD and their communication partners through descriptive analyses of the obtained scores and their qualitative descriptions. Lastly, to decide whether this observation method based on the dialogical theory can form a break with traditional approaches on communication, the dialogical character of the descriptions on the scoring sheets was evaluated.

In the **fourth manuscript** (fifth chapter of this thesis), a third observation study is described. As from the previous studies no detailed conclusions could be drawn on joint attention though being an important aspect of high-quality interaction, the attention between people with PIMD and their direct support staff was central in this study. Besides, joint attention is generally assumed to be related to the emotional relations and social interactions between interaction partners (Eilan, Hoerlh, McCormack, & Roessler, 2005), which made describing joint attention suiting well our overall research aim. Following the establishment of a dual usage problem in the general developmental psychology literature on this topic, the attention directing behaviours from both partners towards each other as well as the occurrence of attention episodes within the dyad were focused on. Therefore, three coding schemes were developed (Hostyn, Neerinckx, & Maes, 2011): attention-directing behaviour of the client, attention-directing behaviour of the staff, and attention episodes in the dyad. Taking into account that the global measures in the previous studies were ideal to describe general interactive behaviours and processes but not allowed to get an accurate view on the occurrence of joint attention, we applied in this study a 10-s partial interval coding system on the 10-minute observations of seventeen staff-client dyads. Since we wanted to observe how triadic communicative interactions could occur, the participants interacted with objects of preference stimulating the interest and attention of the person with PIMD as much as possible. Given the large amount of data, it was most appropriate to determine the interobserver agreement on the double coded video records. Descriptive statistics were calculated to portray the occurrence of the different categories of the target behaviours, across the group as well as for each observation separately. Preliminary correlational analyses were computed to offer a beginning understanding of how the episodes of attention were associated and how the individual attention directing behaviours and the attention episodes in the dyad related to each other.

Part 3: A start towards supporting the quality of the interaction by a better understanding and more profound description of the interactional processes between people with PIMD and their direct support staff

The first and second part of this doctoral research project facilitated our understanding of the interaction between people with PIMD and their direct support staff and made it possible to describe the interactional processes from a variety of perspectives and through diverse methods. However, the relevance of the obtained knowledge remained questionable because it was not easily transferable to practice. The findings of the observation studies mainly offered conclusions on a methodological level, i.e. about the usefulness of the instruments to describe interactions with people with PIMD. As group results preponderated in these studies, directions to improve the interaction quality could only be drawn indirectly and certainly no individualized suggestions for action could be deducted. In addition, the obtained results were originating from scientific deliberation only and not directly from consultation of experienced practitioners. Also, the descriptive results remained fragmented and did not suit the reality of and the need for a holistic view on the staff-client interaction within a daily life context.

Therefore, the third part of this project consisted of a qualitative case study, reported in the **fifth manuscript** (sixth chapter of this thesis) of which the characteristics are summarized in the last column of Table 1. A person with PIMD and his staff member were observed in interaction within a daily life context. In order to heighten the appropriateness and the usefulness of the interaction descriptions, the experiential knowledge of the staff member was examined through staff-researcher dialogue and valued as a complementary viewpoint to the direct observation results. Furthermore, an in-depth holistic description of the interactional processes was strived for by using an integrative theoretical framework and a combination of different methodologies that were used complementary to each other. Strengths and difficulties in the staff-client interaction were described by focusing on the person with PIMD, the direct support staff member as well as the interacting dyad.

Obviously, the aim of the concluding part of this dissertation was not to organize formal training to change participants' interaction as such but to give staff members insight into their interaction. On the one hand, descriptions to confirm and consolidate positive aspects of the staff-client interaction were strived for. On the other hand, starting points *to do it differently* and to improve the negative or difficult aspects of their interaction were pursued. As we are convinced that being able to comprehensively describe interaction processes is a basis for understanding, and having a profound understanding is a basis for improving, this last part of the thesis can be considered to form a first and modest start towards the improvement of the interaction quality with people with PIMD.

### **CHAPTER 2**

# INTERACTION BETWEEN PERSONS WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES AND THEIR PARTNERS: A LITERATURE REVIEW <sup>2</sup>

#### **Abstract**

High quality interactions are of crucial importance for quality of life of persons with profound intellectual and multiple disabilities (PIMD). This literature review describes and synthesises studies addressing the interaction between persons with PIMD and their partners. A computerised literature search using defined inclusion criteria yielded 15 articles. The literature analysis revealed four components important in interactions: sensitive responsiveness, joint attention, co-regulation, and an emotional component. The abilities and disabilities, interactive behaviours, and personality of persons with PIMD influence these interactions. Additional influences are the partners' interactive strategies, knowledge, and perceptions and the context of the interaction. An overview model integrates the results and forms a vehicle to facilitate our understanding of interactions with persons with high support needs. Methodological analyses of the studies show lacunae in current research. This review offers a starting point to guide future research and intervention.

<sup>&</sup>lt;sup>2</sup> 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*(4), 296-312.

#### Introduction

Positive relationships with significant others are important in the life of every human being. From a philosophical perspective, this statement is supported by the notion of relational autonomy (Nedelsky, 1989). According to this approach, which Tronto (1993) clearly described, human beings are not conceived as fully autonomous but in a condition of interdependence. Mackenzie and Stoljar (2000, p. 4) pointed out that "persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants". As such, human relationships are a core aspect of people's lives.

Schalock (2004) consolidated this idea for persons with intellectual disability. In a recent literature analysis of quality of life studies, he found that interpersonal relations are the most frequently referenced quality of life indicator. Additionally, people with intellectual disability report that relationships with staff and family members are an important source of practical, informational, and emotional support (Robertson et al., 2001).

Positive relationships are essential for the personal autonomy and identity of persons with profound intellectual and multiple disabilities (PIMD)(Nakken & Vlaskamp, 2002; Petry, Maes, & Vlaskamp, 2005). Their multiple and complex support needs make them dependent on others for almost all daily life activities. In addition, persons with PIMD mostly use pre- or protosymbolic communication such as idiosyncratic utterances, bodily movements, changes in muscle tone, and other subtle cues that are context- and person-bound (Daelman, 2003). Consequently, their needs, thoughts, and emotions are difficult to interpret and are often misunderstood or ignored (Grove, Bunning, Porter, & Olsson, 1999). Therefore, researchers (e.g., Lyons, 2005) have noted that familiar communication partners who are willing to understand and create meaning are indispensable in the life of persons with PIMD.

This dependency on others is one of the main reasons why the relationship between persons with PIMD and their proxies is of crucial importance for a good quality of life (Maes, Lambrechts, Hostyn, & Petry, 2007). People with PIMD need supportive relationships to demonstrate their competencies and personalities, and to flourish as active partners all their life. As Lubinski (1981) correctly reflected, high-quality interaction and communication can make the difference between isolation and social connectedness, dependence and independence, withdrawal and fulfilment for persons with communicative impairments. Social interaction contributes to the alertness and engagement of persons with PIMD (Arthur, 2004) and to their happiness and well-being (e.g., Davis, Young, Cherry, Dahman, & Rehfeldt, 2004; Favell, Realon, & Sutton, 1996). Furthermore, respectful exchanges in everyday interactions with important partners contribute to inclusion for persons with PIMD (Finlay, Antaki, Walton, & Stribling, 2008). Therefore, Arthur-Kelly, Foreman, Bennett, and Pascoe (2008) and Petry and Maes (2007) argued that a relational support perspective, interpersonal variables, and quality interaction are critical to improve the support of persons with PIMD.

Nevertheless, research has demonstrated that the interactions between people with PIMD and their partners, in particular direct support staff, are not always successful. Both the quantity (Hile & Walbran, 1991) and the quality (e.g., McConkey, Morris, & Purcell, 1999) of the interactions between direct support staff and persons with intellectual disabilities are, in general, insufficient. Specific limitations of the interactions with persons with a high support need are the high proportions of time without communicative interaction or partner response (Arthur, 2003), the preponderance of instructions and neutral affects (Seys, Duker, Salemink, & Franken-Wijnhoven, 1998), and an overall lack of connectedness and responsivity to the clients' capacities and needs (De Waele & Van Hove, 2005). It is clear that people with PIMD and their support partners are at risk for experiencing non-optimal and non-mutually rewarding interactions.

If we want to know how we might improve the interactions between persons with PIMD and their partners, we need to develop knowledge about relevant elements of the interaction process. In the empirical research literature, several studies and interventions directed at interaction with persons with PIMD are available. However, to date there is no clear understanding of the key elements of interaction within this group. There is need for a better understanding of the interaction process with persons with high support needs to facilitate and guide future research and practice in this field. Therefore, the aim of this review is to provide an overview of recent empirical studies that have addressed the interaction between persons with PIMD and their partners, and to summarise the findings by constructing an explanatory model. The questions addressed in this study are

- What are the methodological characteristics of studies that focus on the interaction between persons with PIMD and their partners?
- What are the key elements in interactions with persons with PIMD apparent from studies that have investigated interaction quality?

#### Method

#### Literature Search

We conducted a computerised literature search with multiple data sources: Social Sciences Citation Index, PsychINFO, and ERIC. These are considered to be the largest and most respected subscription databases in the social sciences (Gardner & Eng, 2005). We used the following sets of search terms: (a) multiple disabilities, multiple impairments, profound intellectual disabilities, profound learning disabilities, and profound mental retardation; and (b) interaction, relation(ship), and communication. Although the interaction phenomenon forms the central focus of our review, we expanded the second set of keywords with the related terms *relationship* and *communication* because of the conceptual confusion on this point. We combined all keywords with each other in their singular, plural, and, if indicated, their verbal form. Next, we used a snowballing technique, examining the reference lists of the found articles in order to trace other relevant studies. We conducted an author

search of the first authors retrieved from the computerised literature search. Neither method revealed extra articles that met the inclusion criteria.

#### **Inclusion Criteria**

In this study, we included peer-reviewed studies, published between January 1990 and October 2008, investigating the interaction between persons with PIMD and their partners. Further inclusion criteria were:

- (1) Empirical studies, with a quantitative or qualitative design.
- (2) Studies investigating the target group of persons with PIMD or with profound intellectual disability across the life span. We assumed that characteristics of positive interaction would not differ greatly according to chronological age.
- (3) Publications with a clear focus on the interaction between persons with PIMD and their partners. For that criterion, we started from a working definition of interaction based on the work of Janssen, Riksen-Walraven, and Van Dijk (2003, p. 198): "the process by which two individuals mutually influence each other's behavior." In line with this, we searched for studies that emphasized the interpersonal and interdependent process between two partners rather than the content or message they transfer to each other.
- (4) Articles focusing on adult interaction partners without disability. There was no restriction on the relationship between partners (e.g., parents, teachers, staff). Studies addressing interactions with peers with and without disability were excluded because we wished to focus on asymmetrical relationships where one partner is directed towards the well-being and development of the other.
- (5) Studies yielding information about key elements of the interaction process between persons with PIMD and their partners.

#### Literature Selection Process

Our search of studies published in peer-reviewed journals within the determined time period yielded 320 different articles. This high number of publications may have been because relation and interaction are used also as methodological terms (e.g., relation between variables). All titles and abstracts of the retrieved articles were screened using the predefined criteria. An overview of this analysis process, with the number of publications excluded by each exclusion criterion, is provided in Table 1.

**Table 1**Overview of the literature selection process.

	Exc	clusion criteria	Number of publications excluded
1.	No e	empirical studies	42
2.	Not	persons with PIMD	
	a.	Persons with different degrees of intellectual disability in the study group	48
	b.	Study group not well enough described	42
	c.	Additional psychiatric or medical disorders	19
3.	No i	focus on the interaction	
	a.	Methods, programs unrelated to interaction	66
	b.	Characteristics of persons with PIMD unrelated to interaction	39
	c.	Living circumstances of persons with PIMD	12
4.	No f	focus on adult interaction partners without disability	
	a.	Peer interaction	5
	b.	Partner-partner interaction	3
5.		nformation on essential components in the raction	
	a.	Aim to obtain methodological knowledge	17
	b.	Interaction as explanatory factor for other processes	4
	c.	Undifferentiated, too broad programs	7

Based on the inclusion criterion of empirical studies (criterion 1), book and non-systematic literature reviews, personal comments, or congress abstracts were excluded because they contained too little information and/or empirical evidence (n = 42).

A total of 34.1 % of the articles (n = 109) were excluded because the studies did not focus on the target group of persons with PIMD (criterion 2). In 48 articles, persons with different degrees of intellectual disability were studied, but in 42 articles the description of the target group was too vague to decide if participants had PIMD or not (e.g., individuals with "mental retardation" and severe language delays, people dependent in activities of daily living, people with sensory and intellectual disabilities). Nineteen studies were excluded because participants with profound disability had autism or other psychiatric or medical disorders which have specific consequences for social interaction.

All publications that did not clearly focus on interaction were excluded from this review (criterion 3). Reports describing the contents, methods, or results of programs without reference to interaction components were excluded (n = 66). These articles, for example, focused on the person

with PIMD (e.g., learning communication skills), on someone else (e.g., effect of a program on the professional's competencies), or on the method examined (e.g., the operation of a communication aid). Other studies excluded (n = 39) consisted of an assessment or description of the needs, characteristics, competencies, and difficulties of one partner, usually the person with PIMD, without relating this to interaction with others. We also excluded 12 articles studying the living conditions of persons with PIMD in institutions, educational settings, or in the broader society.

Eight articles were excluded because they did not focus on adult interaction partners without disability (criterion 4). In particular, five manuscripts about peer interaction and three focusing on partner interaction (e.g., between parents and professionals) were excluded.

Finally, 28 articles that did not provide information on the essential components in the interaction were excluded (criterion 5). Specifically, studies with a clear aim of obtaining methodological knowledge (e.g., testing instruments) (n = 17) were not included. Four studies investigated interaction and communication as an explanatory factor for other client processes, such as the effect of a communicative environment on a person's behaviour state, and were also excluded. Additionally, we excluded seven reports of intervention programs that addressed the interaction between persons with PIMD and their partners but were too broad and undifferentiated for us to identify if the interaction contributed to the result or which elements were essential.

Thus, 16 articles met our inclusion criteria. Since one manuscript (Perry, 2003) was not available within three months of our interlibrary loan request, this literature review is based on 15 articles.

#### Literature Analysis

We analysed the literature qualitatively (Cozby, 2003) according to the principles of narrative synthesis in systematic literature reviews and the three analysis steps proposed by Petticrew and Roberts (2006). We first organised and summarised the selected studies, which resulted in an overview table (Table 2).

We then performed a within-study analysis that contained a narrative description of the findings of each study, which are summarised in Table 2. Finally, we conducted a cross-study synthesis to generate a total picture of the interaction phenomenon addressed in the different studies. In line with our research questions, we examined the studies' thematic content and evaluated the research designs and methods used. The selected articles did not lend themselves to a meta-analysis because the studies were statistically too weak and the sample sizes were too small to opt for a quantitative analysis (Cozby, 2003). In addition, the variables of interest in the different studies varied. Our purpose was not to synthesise the research quantitatively (Cooper, 1998) but to characterise the interaction phenomenon in all its aspects.

 Table 2

 Overview of the studies included in the literature review.

Study	Theoretical background	Design	Aim	Participants	Method	Results	Interaction element(s)
Clegg, Standen, & Cromby, 1991a	Not specified	Quantitative	Evaluating interactions between staff-client pairs while staff employs particular strategies	Study 1. 9 adults with profound intellectual disabilities and additional disabilities, 9 care staff Study 2. 16 adults (11 with an additional disability), 13 care staff	Videotape recordings evaluated with a coding scheme	Staff interactive strategy (talk, choice, instruct, contingent responding, social routine)	Partner strategies
Clegg, Standen, & Cromby, 1991b	Not specified	Quantitative	Investigating the relationship between positive client behaviour and other types of responses. Examining whether interactions showed evidence of responsivity or turn-taking	20 adults with profound intellectual disabilities (15 with additional disabilities), and 16 staff members	Videotape recordings evaluated with a coding scheme	<ul> <li>Staff and client responsivity to each other</li> <li>Turn-taking</li> <li>Client response behaviour (positive, negative, stereotyped, neutral)</li> </ul>	<ul> <li>Sensitive responsiveness</li> <li>Co-regulation</li> <li>Persons' behaviour</li> </ul>
Clegg, Standen, & Jones, 1996	Interaction levels of Doise	Qualitative	Identifying constraints and enablements experienced by direct care staff in their relationship to adults with profound learning disabilities	20 staff members from 4 units for adults with profound learning disabilities	<ul> <li>Filmed interaction sessions</li> <li>Interviews analysed using grounded theory</li> </ul>	<ul> <li>Intra-individual characteristics (chronological and developmental age, type of disabilities)</li> <li>Obtaining a balance of control by staff</li> <li>Staff's account of the relationship</li> <li>Factors in the organisation</li> </ul>	<ul> <li>Persons' abilities and disabilities</li> <li>Partner strategies</li> <li>Partner perception</li> <li>Setting</li> </ul>
Finlay, Antaki, Walton, & Stribling, 2008	Empowerment and inclusion	Qualitative	Describing the interactional practice of staff and how this produces certain identities for the clients	A 36-year-old man with profound learning disabilities and 1 support worker	• Videotaped records, analysed using Conversation Analysis	• Staff's actions in the interaction	Partner strategies
Foreman, Arthur-Kelly, Pascoe, & King, 2004 (part of the study)	Integration and inclusion	Quantitative	Investigating differences between students in special or general classrooms in terms of behaviour states and socio- communicative variables	8 matched pairs of school-aged students with profound and multiple disabilities	<ul><li>Classroom observations</li><li>Behaviour state assessment</li></ul>	Setting (general classroom or inclusive classroom)	• Setting
Forster & Iacono, 2008	Not specified	Qualitative	Exploring the nature of the interaction between disability support workers and persons with profound intellectual disabilities	3 disability support workers of an adult with profound intellectual disabilities	<ul> <li>Interviews analysed using a phenomenological approach</li> </ul>	<ul> <li>Communication style to which the client responds</li> <li>Emotional component and attachment</li> <li>Staff's ascription of meaning, use of touch</li> <li>Knowledge about the clients, spending time with each other</li> <li>Organisational policy</li> </ul>	<ul> <li>Sensitive responsiveness</li> <li>Emotional component</li> <li>Partner strategies</li> <li>Partner knowledge</li> <li>Setting</li> </ul>

Table 2 (Continued)

Study	Theoretical background	Design	Aim	Participants	Method	Results	Interaction element(s)
Healy & Noonan Walsh, 2007	Not specified	Qualitative and quantitative	Exploring what staff nurses find important in communication with their service users and which strategies they adopt in these communications	10 adult service users with severe and profound intellectual disabilities (4 had additional sensory disabilities) and 10 staff nurses	Video recordings     Individual and focus group interviews analysed using thematic content analysis	<ul> <li>Adjusting behaviour to the clients' needs</li> <li>Staff's communication acts (verbal and non-verbal, in specific touch)</li> <li>Staff's approach to the client, and perception</li> <li>Knowing the client, education and training</li> <li>Environmental influences (choice opportunities, physical properties)</li> <li>Communication boards and objects</li> </ul>	<ul> <li>Sensitive responsiveness</li> <li>Partner strategies</li> <li>Partner knowledge</li> <li>Partner perception</li> <li>Setting</li> <li>Circumstances</li> </ul>
McEwen, 1992	Dynamic system perspective	Quantitative	Examining the effect of assistive positioning on the social-communicative interaction between students and staff	10 elementary school students with profound multiple disabilities and their classroom staff	<ul> <li>Video recordings coded using videotaped interactions analysis</li> </ul>	<ul> <li>Assistive position of the student (wheelchair, sidelyer, or a mat on the floor)</li> <li>Context (unstructured/structured situation)</li> </ul>	• Circumstances
Olsson, 2004	System theory	Qualitative	Providing a description, interpretation, and model for communicative interaction between a child and his caregiver	A 6-year-old boy with severe multiple impairments and his caregiver at preschool	<ul> <li>Video recordings analysed using inductive analysis and the conceptual framework of Fogel</li> </ul>	<ul> <li>Shared focus of attention, consensual frames (persons, objects, how to communicate)</li> <li>Co-regulation, matching, and attunement</li> <li>Communicative strategies of the caregiver, negotiation about meaning</li> </ul>	<ul><li> Joint attention</li><li> Co-regulation</li><li> Partner strategies</li></ul>
Olsson, 2005 (first part of the study)	Functions of early communication	Quantitative	Determining the extent to which the use of communicative functions is related to individual-specific characteristics and setting characteristics	9 preschool children with severe multiple disabilities in interaction with a person of the preschool staff	<ul> <li>Interview with staff before data collection</li> <li>Video recordings coded with regard to communicative functions</li> </ul>	<ul> <li>Joint attention</li> <li>Individual-specific characteristics (cognition, vision, mobility, manipulation skills)</li> <li>Environmental condition (mobility, manipulation)</li> </ul>	<ul><li> Joint attention</li><li> Persons' abilities and disabilities</li><li> Circumstances</li></ul>
Schepis & Reid, 1995	Augmentative communication	Quantitative	Investigating the effect of VOCA use (voice output communication aid) on communicative interactions	A young adult with multiple disabilities and 4 staff members (1 teacher aide and 3 residential service personnel)	Observations using a continuous 30-s partial-interval system.	<ul> <li>Staff's understanding of the client, and interaction responses</li> <li>Communication aid</li> </ul>	<ul><li>Sensitive responsiveness</li><li>Circumstances</li></ul>

**Table 2 (Continued)** 

Study	Theoretical background	Design	Aim	Participants	Method	Results	Interaction element(s)
Tucker & Kretschmer, 1999	Interactional sociolinguistics	Qualitative	Describing the interactions between a mother and a physical therapist, and a child with multiple disabilities	A 2-year-old girl with multiple disabilities, her mother and the physical therapist. (Additional interview with an adult from the day care centre and a speech therapist.)	<ul> <li>Interviews</li> <li>Field notes</li> <li>Videotapes</li> <li>Analysed with (micro-) ethnographic techniques</li> </ul>	<ul> <li>Shared repertoire of utterances and affective cues</li> <li>Adult's beliefs, and values about communication and about the child</li> <li>Meaningful context</li> </ul>	<ul><li> Joint attention</li><li> Partner perception</li><li> Setting</li></ul>
Vlaskamp, de Geeter, Huijsmans, & Smit, 2003 (part of the study)	Not specified	Quantitative	Evaluating the effect of multisensory environments on the alertness and interaction of persons with PIMD	19 adults with profound multiple disabilities and their direct support staff	<ul><li>Observations</li><li>Momentary time sampling</li></ul>	<ul> <li>Non-continuous stimuli offered by staff in a multisensory or normal living environment</li> <li>Availability of materials and other participants</li> </ul>	<ul><li>Partner strategies</li><li>Circumstances</li></ul>
Wilder, Axelsson, & Granlund, 2004	International Classification of Functioning, Disability and Health	Quantitative	Investigating parents' perceptions of interpersonal interactions with their child, and their desires for ideal interaction	91 parents in 3 groups. Group 1 (30): children with profound multiple disabilities. Group 2 (31): developmentally matched. Group 3 (30): chronologically matched	<ul> <li>Structured telephone interview</li> <li>3 questionnaires about interaction, behaviour style, and emotions</li> </ul>	<ul> <li>Understanding the child</li> <li>Joint attention, sharing a topic</li> <li>Child's expression of emotions, motor activity level, communicative abilities, and attention span</li> <li>Initiations and responses by the child</li> <li>Child's behaviour style</li> <li>Adults' directing of the child's attention</li> </ul>	<ul> <li>Sensitive responsiveness</li> <li>Joint attention</li> <li>Persons' abilities and disabilities</li> <li>Persons' behaviour</li> <li>Persons' personality</li> <li>Partner strategies</li> </ul>
Wilder & Granlund, 2003	Goodness of fit theory Ecological theory	Qualitative	Exploring caregivers' perception of interaction in relation to the children's behaviour style	7 caregivers of children with multiple disabilities	<ul> <li>Home visits with interviews</li> <li>Hermeneutics and thematic analysis</li> </ul>	<ul> <li>Parental sensitivity, supportive and responsible role</li> <li>Sharing of experience, joint attention</li> <li>Reciprocity, mutual participation and mutual understanding, turn-taking</li> <li>Appreciation, mutual joy, and contentment</li> <li>Child functional (physical) abilities, interaction method (initiations and responses), expressions of inner will, and role</li> <li>Parental interaction methods, and monitoring</li> <li>Environmental context</li> </ul>	<ul> <li>Sensitive responsiveness</li> <li>Joint attention</li> <li>Co-regulation</li> <li>Emotional component</li> <li>Persons' abilities and disabilities</li> <li>Persons' behaviour</li> <li>Persons' personality</li> <li>Partner strategies</li> <li>Setting</li> </ul>

#### Construction of an Explanatory Model

One aim of our study was to construct an explanatory model that integrates the key elements of interaction and reflects the findings in the literature. The selected articles revealed elements of the interaction, indicating core principles in successful interaction processes. These elements are named constituting components. They are interpersonal and dyadic variables, which cannot be evaluated at the individual level and which can only exist when two partners are involved in a joint process. We synthesised the similar findings on sensitive responsiveness, joint attention, co-regulation, and emotions into four constituting subcomponents. This synthetization process is further clarified for each subcomponent in the results section. The selected studies also investigated factors that influence the interaction process. We labelled these *influencing factors*. To guide the categorisation of influencing factors, we used an existing classification: the tri-focus framework of Siegel-Causey and Bashinski (1997). This communication framework encompasses elements on three levels: the person with multiple disabilities, the partner, and the environmental context. Thus, these influencing factors typically refer to the intrapersonal traits of both interaction partners and the quality of the context. Further sub factors for each of the three levels were determined by grouping together similar findings. All subcomponents are indicated in the last column of Table 2 titled "interaction element(s)." Finally, we ordered the different elements according to the frequency of occurrence in the literature in descending order.

#### **Results**

First, we present the research methodologies and second the key elements in the interactions between persons with PIMD and their partners.

#### Research Methodologies

The 15 studies that met our inclusion criteria included eight quantitative and six qualitative studies, and one mixed method study. The participants in 10 studies were interaction dyads, or in four studies the interaction partners, who were interviewed about the interaction with persons with PIMD. In one study persons with PIMD were the focus, although observed in interaction with their partners. Seven studies focused on children, and eight focused on interactions with adults with PIMD. The number of participants was generally low, ranging from 1 to 30. Ten studies included 10 or fewer participants. Two case studies and two studies focusing on one participant with PIMD interacting with different partners were included. Nine studies were conducted in residential or day care settings, five in schools and three in the family context. In two studies, a combination of settings (the residential or day care setting in combination with the school or the family context) was examined.

The most frequently used method to examine interactions with the target group of persons with PIMD was video observation (n = 12). Interviews were also used (n = 7). Only one study utilised questionnaires. Five studies incorporated more than one method. Six of the seven qualitative studies

included a well described conceptual framework and method of analysis. All qualitative reports provided rich illustrations of the data on which the results are based. One study mentioned that the videotapes were viewed and discussed with the participants (Tucker & Kretschmer, 1999). Only two qualitative studies reported on observer agreement (Healy & Noonan Walsh, 2007; Olsson, 2004). Of these, one provided evidence for the validation of the data (Healy & Noonan Walsh, 2007). In contrast, all eight quantitative observation studies described interrater reliability. The questionnaire study utilised Cronbach's alpha as an indication of reliability (Wilder, Axelsson, & Granlund, 2004). One observation study investigated intrarater reliability (Clegg, Standen, & Cromby, 1991b). The effect size was determined in one quantitative study (McEwen, 1992).

Two quantitative investigations made use of matched groups (Foreman, Arthur-Kelly, Pascoe, & King, 2004; Wilder et al., 2004). Three studies made a comparison between conditions (McEwen, 1992; Olsson, 2005; Vlaskamp, de Geeter, Huijsmans, & Smit, 2003), and two studies made a baseline measurement (Clegg, Standen, & Cromby, 1991a; Schepis & Reid, 1995). The theoretical background of five studies was not specified in detail. In these articles, several introductory ideas were mentioned but there was no explicit indication from which theoretical framework the study started. The authors who did describe their theoretical starting point adopted systemic and ecological theories (n = 4), theories about early communication and development (n = 3), or general theories such as the International Classification of Functioning, Disability and Health model (World Health Organization, 2001) (n = 3).

# Key Elements in the Interaction Process

Figure 1 illustrates the model developed in this study which summarises the key elements in the interaction between persons with PIMD and their partners.

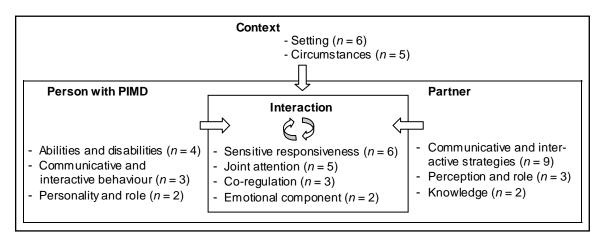


Figure 1. Explanatory model of the interaction between persons with PIMD and their partners. Note. The number of studies that informed each interaction element is indicated.

# Constituting Components of the Interaction

Sensitive responsiveness.

Although this terminology was not always used explicitly, several studies emphasised the importance of sensitivity and responsivity in the interaction. We group these studies under the category of *sensitive responsiveness*, which we consider a dyadic quality of the interaction referring to the way partners perceive each other's signals accurately and correspondingly respond to each other (Ainsworth, Blehar, Waters, & Wall, 1978).

In only one study (Clegg et al., 1991b) has sensitive responsiveness been demonstrated by means of observational findings. Staff were alert to changes in the positive responses of the client, and this was associated with cessation of talking by staff. Individuals with profound intellectual disabilities were also sensitive to changes in staff behaviour, to which they responded negatively. Results, however, indicated less responsiveness from clients than from staff. These findings are contrary to those of Healy and Noonan Walsh (2007) who concluded from their observations that staff nurses used too many verbal strategies and failed to adjust their language to the needs of the service users.

Other studies that addressed sensitive responsiveness examined partners' perspectives about the interaction with persons with PIMD. Staff nurses in Healy and Noonan Walsh's (2007) study explicitly reported that it is important to adjust behaviour to the client's needs. Similarly, staff participants in the interviews by Forster and Iacono (2008) mentioned the importance of using behaviours and objects in response to the clients' preferences. Staff members were not primarily occupied with age-appropriate activities but rather with being playful and responsive to their clients' wishes and needs. Likewise, parents seemed to consider their role, which they called *sensitive responsibility*, as supportive and responsive to what their children need (Wilder & Granlund, 2003). Observation, interpretation, and sensitivity were necessary according to the parents. However, Wilder et al. (2004) indicated that although parents of children with PIMD considered sensitivity important, they often had difficulties in understanding what the child was communicating about. This was significantly more difficult for parents of children with PIMD compared with a group of parents matched according to the developmental or chronological age of their children without a disability (Wilder et al., 2004).

Schepis and Reid (1995) showed that the use of a communication aid increased staff's acknowledgement of communication cues, responsiveness, and interaction.

### Joint attention.

Joint attention was another constituting factor mentioned in the examined studies. This term indicates the sharing of a focus of attention (e.g., object, topic) between two partners. According to parents of children with multiple disabilities, sharing experiences and obtaining joint attention forms an essential part in well functioning interactions (Wilder & Granlund, 2003). Olsson's (2004)

qualitative description of a dyadic interaction revealed the existence of a shared focus between the two partners in the interaction. In accordance with Fogel, Olsson defined this as *consensual frames*; that is, "mutual agreements about what is to be communicated between partners, about when and how interactions take place and for how long" (Fogel, 1993, p. 36). Congruence between the behaviours of the caregiver and the child was indicative of this process. Similarly, Tucker and Kretschmer (1999) described the existence of a shared repertoire of utterances and affective cues in the two interactions they studied.

In a further study, Olsson (2005) examined the nature of the communication and interaction of nine preschool children with severe multiple disabilities. She identified that joint attention was the communicative function used most frequently by the children, 43% of the time in a mobility condition and 65% of the time in a situation that permitted them to manipulate objects. However, Wilder et al. (2004) concluded on the basis of interviews and questionnaires with 91 parents that children with PIMD and their caregivers had difficulties in maintaining joint attention. These dyads directed each other's attention towards a shared topic less frequently compared to two other groups, matched according to chronological and developmental age.

# Co-regulation.

In analysing the different manuscripts we sought a concept to bring together different ideas about mutuality, reciprocity, and turn-taking. In line with Olsson's (2004) suggestion, we defined this concept as *co-regulation* (Fogel, 1993). This refers to the relationship between the behaviours of two partners, the interaction synchrony, the mutual coordination, and the moulding of the communication in flexible ways.

Olsson's (2004) analysis of a play interaction between a boy with severe multiple disabilities and his caregiver demonstrated evidence of co-regulation. Both partners in the dyad sometimes immediately matched their behaviours and continuously altered them according to what the other partner was doing. Olsson also identified attunement in the interaction, which is a form of co-regulation with regard to the feeling state of the partner. Whereas Olsson explicitly studied co-regulation in her analysis, Wilder and Granlund (2003) concluded that mutuality was a formative element in the interaction. They found that successful interaction for parents contains mutual participation and mutual understanding.

Two studies emphasised turn-taking (Clegg et al., 1991a; Wilder & Granlund, 2003). According to the parents interviewed by Wilder and Granlund (2003), interaction is practised as turn-taking. In the turn-taking the children's focus of interaction gradually forms the content of the interaction. Clegg et al. (1991b) mentioned that the mutual exchanges in turn-taking give people a sense of interdependence or connection. However, although the sequential analysis of transitions between the responses of the partners indicates responsiveness, no empirical evidence of turn-taking was shown (Clegg et al., 1991b).

## Emotional component.

The last interaction component in the studies examined relates to emotions. Results from two interview studies (Forster & Iacono, 2008; Wilder & Granlund, 2003) clearly demonstrated that emotions are demonstrated in the interaction. Firstly, parents declared that successful interaction is characterised by mutual feelings of contentment, appreciation, and joy resulting from the participation of both partners in the dyad (Wilder & Granlund, 2003). Secondly, three professionals supporting an adult with profound intellectual disability described many emotions generated in their interactions including sympathy, warmth, and closeness (Forster & Iacono, 2008). They ascribed an attachment or an emotional bond to the interaction. Importantly, they noted that this emotional relationship was contrary to expectations from their employers.

Characteristics of the Person with PIMD as Influencing Factors

### Abilities and disabilities.

The influence of the abilities and disabilities of persons with PIMD on the interaction has also been studied. According to parents, children with PIMD have more difficulties in expressing complex emotions like curiosity and interest compared with typically developing children (Wilder et al., 2004). Besides, their cognitive disabilities (e.g., short attention span) and the ability to change the focus from one situation to another influences the interaction and differs significantly from that of typically developing children (Wilder et al., 2004). Parents also mentioned that children with multiple disabilities decide the topic of the interaction less frequently than children of similar developmental and chronological age. In addition, parents perceived their children's physical disability as one of the main and non-changeable obstacles in interaction (Wilder & Granlund, 2003).

However, these parental perceptions were not supported in other studies. Olsson (2005) offered empirical evidence that the motor skills of children with PIMD were not significantly related to the use of communicative functions in the interaction. Children's cognitive abilities, on the other hand, were significantly related to the communicative functions of joint attention and behaviour regulation. Similarly, visual abilities had a significant relationship with the use of joint attention and behaviour regulation. Nevertheless, the influence of these individual-specific characteristics was not strong when compared with the influence of context. Olsson concluded that a child with better cognitive, visual, or motor skills does not necessarily use these skills during interactions. Olsson suggested that the communicative behaviours of individuals with multiple disabilities were more important than the type of disability. Clegg, Standen, and Jones (1996) also minimised the influence of the type of disability of clients with profound intellectual disabilities. Only health-related problems seemed to influence staff-client interaction patterns, albeit slightly.

### Communicative and interactive behaviour.

The communicative and interactive behaviour of persons with PIMD is operationalised in the selected studies as the way persons with PIMD initiate and respond in the interaction. Wilder et al. (2004) reported that parents perceived children with PIMD to initiate and respond in the interaction less frequently than children matched on developmental and chronological age. In addition, according to parents, children with multiple disabilities initiated the interaction less often than they responded in the interaction (Wilder & Granlund, 2003). Clegg et al. (1991b) described the nature of the interactive behaviour for 20 persons with PIMD. Videotape analyses showed that clients displayed neutral responses (e.g., suggesting that the person was alert but not responding actively) most of the time. Positive interactive behaviours were observed for about a third of the time, and there was also a large range of stereotypical behaviour such as involuntary reflexive behaviours. Overall, with the exception of some clients, there was little negative behaviour.

## Personality and role.

The personality and role of the person with PIMD was named as an influencing factor by parents. In particular, they considered the children's behaviour styles as expressions of their inner will, which strongly influence the interaction methods and roles of both partners, as some children are more easygoing than others (Wilder & Granlund, 2003). Considering this influence of the child's personalities on the interaction, parents of children with PIMD did not differ in their opinion from parents of typically developing children (Wilder et al., 2004).

# Influencing Staff Characteristics

# Communicative and interactive strategies.

In the studies reviewed, the interactive and communicative strategies of the interaction partners were the main focus of study. Nine of the 15 studies treated these strategies as decisive factors in the interaction. In general, although co-regulation occurred, interaction partners considered themselves being responsible for leading the interaction using concrete strategies (Olsson, 2004). Specific interactive behaviours identified were offering objects and physical help to discover the objects (Olsson, 2004), talking, showing, confirming, and reinforcing (Wilder & Granlund, 2003), ascribing meaning to a persons' behaviour and negotiating about meaning (Forster & Iacono, 2008; Olsson, 2004). Staff members in the study of Forster and Iacono (2008) described touch as a core interactive strategy. This was also named as the preferred non-verbal strategy by eight of the 10 nurses in Healy and Noonan Walsh's (2007) study. Additionally, interaction partners asked for participation (Olsson, 2004) and monitored the interaction (Wilder & Granlund, 2003). However, parents of children with PIMD experienced more difficulties in maintaining the child's concentration than parents of typically developing children (Wilder et al., 2004).

Vlaskamp et al. (2003) demonstrated by using video analysis that staff behaviour, rather than the nature of the environment, was significant in developing interactions. Interaction in both regular living and multisensory environments occurred almost always in the presence of non-continuous stimuli offered by staff. Healy and Noonan Walsh (2007) demonstrated that there was no significant difference in the overall frequency of verbal and non-verbal acts used by the nurses. However, within staff's verbal behaviours, *questions* and *comments* occurred most frequently, and *opinions* least frequently. Across staff's non-verbal behaviours, *looking* was most frequently observed and shifts in *posture* (e.g., body orientation in relation to the other) the least. In an overview of how partners' strategies were related to different behaviour states of persons with profound intellectual disability, Clegg et al. (1991a) noted that the strategies *talk* and *social routine* were significantly associated with more positive client behaviour and less neutral client behaviour. The strategies *instructing* and *giving choices*, were linked to less positive client behaviour and more neutral client behaviour. *Contingent responding* was not generally successful in facilitating positive client behaviour.

Additionally, Finlay et al. (2008) described staff's responding to clients' ambiguous and non-compliant behaviour by sustaining the interaction, as interactive behaviour related to principles of empowerment and social inclusion in everyday interaction. In line with this, staff in the study of Clegg et al. (1996) also reported their concern to achieve an appropriate balance of control and power in their interactive behaviour towards the clients.

## Perception and role.

Three studies (Clegg et al., 1996; Healy & Noonan Walsh, 2007; Tucker & Kretschmer, 1999) examined the influence of the interaction partner's perception and role. The case study of Tucker and Kretschmer (1999) illustrates the influence of the partner's belief about communication and about the child. The authors described the difference in goals and the subsequent difference in behaviours between a mother and a physical therapist interacting with the same girl with multiple disabilities. The mother wanted to teach her child communication skills according to a general development model, whereas the therapist accepted the child's unique communication attempts and used her existing abilities as a starting point. Similarly, Healy and Noonan Walsh (2007) described how five respondents in their study claimed that they approached their clients in the same way as they would any person. In this study, participants' perception about the communicative environment also played a role in the interaction.

Clegg et al. (1996) illustrated the different roles and perceptions of interaction partners. Staff members who considered their role as *providers* (e.g., providing food but not emotional warmth) engaged in a one-sided instrumental relationship based on the clients' care needs and not based on developing an interpersonal bond. *Meaning makers* considered their role as staff member as understanding the client's moods and gestures and tried to create meaning within the relationship. Support staff that perceived their position as teaching but also sharing experiences and joy, were

adopting a *mutual* role. A final role assumed by staff was that of *companion*, connecting to clients through trust and personal comfort.

# Knowledge.

Lastly, knowledge by staff about the persons with PIMD and their interaction and communication, were found to influence the development of positive, quality interactions. Disability support workers indicated the importance of knowing the client through spending time together (Forster & Iacono, 2008). Similarly, all but one staff nurse participating in the study of Healy and Noonan Walsh (2007) stressed the importance of knowing the service user in order to develop interaction and communication. The participants in both these studies also referred to knowledge as education and training to improve interactive skills. Forster and Iacono (2008) stressed the importance of building on existing staff knowledge and skills.

# Contextual Influencing Factors

## Setting.

The denominator setting refers to organisational variables not necessarily connected to individuals but which surround them and therefore may have an influence on the interaction. Results from four studies (Clegg et al., 1996; Forster & Iacono, 2008; Healy & Noonan Walsh, 2007; Wilder & Granlund, 2003) gave an indication of how partners involved in the interaction with persons with PIMD perceive the influence of the setting. Parents of children with PIMD in Wilder and Granlund's (2003) study reported that being in contact with an existing environment in combination with their children's vulnerability often forms an obstruction in the interaction. Staff nurses reported that some physical properties of the organisational setting (e.g., lack of privacy, and the restricted opportunities for choice) contributed negatively to interaction and communication (Healy & Noonan Walsh, 2007). Clegg et al. (1996) revealed that high staff turnover and the absence of an acceptable staff: client ratio or key worker system (i.e., a staff member being responsible for a certain client), in the residential unit were obstacles to the development of positive staff-client interaction. Staff also reported that they experienced dilemmas because their employing organisation held other opinions and priorities in the support of persons with PIMD. Staff strove for individualised care, whereas the service emphasised teaching and stimulation. Similarly, support workers mentioned conflicts with the organisation's policy (Forster & Iacono, 2008).

One study compared interactions in different setting conditions. Foreman et al. (2004) demonstrated that there was significantly more communicative interaction, conceived as the exchange of meanings between partners, in a general classroom than in a special classroom. Finally, Tucker and Kretschmer (1999) demonstrated the importance of a meaningful context for the person with PIMD; that is, a context that links with the interests and abilities of the person and in which his or her utterances have meaning.

# Circumstances.

The term *circumstances* refers to context factors that are directly related to the individual with PIMD or the communication partner. Firstly, the influence of the position (e.g., in a wheelchair, side lying, on a mat on the floor) of students with PIMD on their interactions with staff was demonstrated in the study of McEwen (1992). Video observations revealed that there was more communication initiation by the classroom staff if the student was positioned in a wheelchair during unstructured interactions. During structured interactions, lower functioning students were more communicative when they were supine on a mat without assistive equipment. Olsson (2005) also demonstrated an influence of the position of the children with multiple disabilities on their interaction patterns. When children were positioned for independent mobility, there was more social interaction than when children were stationary.

Secondly, the availability of communication aids and other communication resources was an important factor in promoting interactions. A voice output communication aid was found to increase interactions (Schepis & Reid, 1995). Augmentative and alternative communication methods (e.g., picture books, objects) were identified by staff nurses as important in the interaction with persons with profound intellectual disability (Healy & Noonan Walsh, 2007).

Lastly, the influence of the availability of materials on interaction was partially demonstrated by Vlaskamp et al. (2003) who showed that this influence was larger when staff offered these materials. Vlaskamp and colleagues (2003) did not find a meaningful association between the presence of other persons in the environment and the level of interaction.

# **Discussion**

The aim of this review was to describe recent studies of interactions between persons with PIMD and their partners and to summarise the reported key interaction elements in an explanatory model.

# Trends and Gaps in the Current Research

Firstly, the methods used in the current research about interaction with persons with PIMD vary and often the sample size is small. Four authors (Olsson, 2004; Olsson, 2005; Vlaskamp et al., 2003; Wilder & Granlund, 2003) explicitly mentioned small sample size as a limitation; others (Foreman et al., 2004; Schepis & Reid, 1995) suggested further research with more participants. Larger studies would enable better generalisation of results; however, in-depth case studies can provide a good picture of the interpersonal dynamics between interaction partners. The most obvious methodological merits in the studies reviewed are the determination of interrater reliabilities in quantitative studies and the establishment of clear conceptual and analytic frameworks in qualitative studies. On the other hand, the lack of effect size indexes in quantitative studies and the lack of reports on interobserver agreement in qualitative studies are an indication of their methodological flaws. Regarding the theoretical frameworks adopted in the studies, two trends are apparent. Some studies start from a more

traditional interactional approach in which two partners are seen as entities exchanging information and mutually influencing each other. Other studies start from the view that both partners are always engaged in a co-creative interaction process. Both approaches are certainly valuable, but it is important that researchers are clear about their theoretical backgrounds.

Four components were identified as important in interactions: sensitive responsiveness, joint attention, co-regulation, and emotions. In many studies (Forster & Iacono, 2008; Healy & Noonan Walsh, 2007; Wilder & Granlund, 2003; Wilder et al., 2004), these components are indicated as core characteristics of interaction by the partners (parents and staff), who stressed that realising this attunement and sharing between partners is not evident at all in interactions with persons with PIMD. Emotions, described by parents and staff as feelings of contentment, joy, and attachment (but also as contrary to the institutions' expectations), received the least attention in the research literature. However, it may be important to approach interaction with people with PIMD in further research from a more emotional viewpoint.

The results of the reviewed studies indicate the importance of the influence of the individual characteristics of the person with PIMD, their initiations and responses in the interaction, and their personality on interactions with others. A frequently recurring theme in the literature is the importance of the partners' interactive and communicative behaviour. Interviews revealed a variety of communication strategies and video analysis confirmed the different frequency and effect of these strategies. The importance of partners' perceptions and knowledge on interaction in general, and on the person with PIMD specifically, was also demonstrated. Regarding the context, empirical studies report equivocal findings with regard to the influence of setting conditions, although all recognised the importance of the setting.

# Reflection on the Model

The descriptive interaction model provides an overview of the key interaction elements that are addressed in the recent literature. Our model does not claim to comprehensively describe interaction, since there are gaps in the current research, but rather aims to integrate current research findings. As the included studies are often based on small sample sizes, have methodological shortcomings, and as each of the factors are derived from only a few articles, there is limited support for the model. However, the model is strengthened by considering both interview studies, reflecting partners' perspectives on key interaction elements, and observational studies. The representation of elements in the model does not reflect the strength of each individual factor in relation to the whole. The order of elements is thus not a reference to their importance in actual interaction.

The division between the model elements is not easy to make. In traditional views, *sensitive responsiveness* is regarded as an intrapersonal trait. However, other authors, for instance Crittenden and Claussen (2000), consider sensitivity and responsivity as characteristics of the interaction itself. Therefore, in conformity with our starting point, sensitive responsiveness is a constituting component

since it is shaped by the particular interaction. In contrast with a person's interactive behaviour, sensitive responsiveness implies an adjustment to each other, which makes it a dyadic construct in nature. Similarly, emotions are also partly a personal condition, but we consider the emotional component as mutually created in the interaction through the participation of both partners. The component of co-regulation covers mutuality, turn-taking, and reciprocity. Whereas mutuality is a general characteristic of successful interaction, turn-taking is a possible means to bring mutual interaction into practice for persons with PIMD. As such, co-regulation is broader than sensitive responsiveness. In comparison to all previous components, joint attention does not only refer to the two partners in the dyad but also to a third element (an object, a topic). As the model results from our analysis and classification of the included studies, the original theoretical backgrounds of all these components need to be further analysed in order to fully understand the content and the relation of the different dimensions in the interaction. All the constituting variables are positively formulated. However, it must be kept in mind that in interactions with this target group there are intermissions, conflicts, or misunderstandings that may need to be repaired. Additionally, the constituting components are considered to be dyadic qualities, but this does not alter the fact that interaction partners still have a responsibility "to enable the less skilled individual ... to fulfil his or her potential to contribute [in the interaction]" (Olsson, 2004, p. 237).

Regarding the influencing variables on the level of the persons with PIMD and the interaction partners, different terminology is used to refer to comparable constructs. The *abilities and disabilities* of persons with PIMD are investigated instead as *knowledge* on the side of the partners. The counterpart of the *behaviours* of persons with PIMD is the partners' *strategies*, and the counterpart of the *personality* of a person with PIMD is the partners' *perception*.

The general terminology used for the elements of our model points to the fundamental human character of interaction. Nevertheless, as Olsson (2004) and Janssen et al. (2003) claimed, we need to study the unique interaction between partners and clients with high support needs to understand its characteristics. Moreover, interaction quality remains important throughout the entire life of persons with PIMD to guarantee personal development and well-being.

A last reflection in this area relates to our separate discussion of the elements of our model throughout the results section. This could be wrongly interpreted as regarding these elements as only isolated entities. In reality, complex combinations and mutual influence between the different elements determines interaction quality. The articles reviewed do not permit conclusions to be drawn about causal relationships between the elements. Clearly, interaction, in its entirety, is more than the sum of its parts.

## Comparison to Other Studies

Our model contains elements similar to those found in comparable studies. Janssen et al. (2003) investigated the topic of interaction for persons with congenital deafblindness. The correspondence

between the core characteristics of harmonious interaction they identified (mutual attention, reciprocal attunement, and adequate emotional regulation) and our model is striking. However, our review did not identify the influence of clients' stereotypical behaviours and high arousability, and staff's lack of skills to engage with persons with complex disabilities. This points to gaps in the current research on interactions with persons with PIMD. Arthur-Kelly, Bochner, Center, and Mok (2007) drafted an integrative model within an educational context, containing dyadic, setting-specific, and individual variables. Our model shows several similarities but is build from a larger body of research. It is also apparent that existing interventions to improve interaction with this target group focus on similar components that we identified (e.g., Bloomberg, West, & Iacono, 2003; Dobson, Upadhyaya, & Stanley, 2002). Lastly, our model components correspond to what parents of children without disability consider important in interaction: joint attention, patterns of shared feelings, and mutual joy (McCollum & McBride, 1997).

#### Limitations

Due to the lack of conceptual clarity, it was sometimes difficult to compare the different studies. Although it is possible that we may have altered the authors' interpretations by imposing our point of interest on their work, we tried to meet this limitation by retaining the study authors' terminology.

In this literature review, we did not formulate specific selection criteria regarding the interaction partners. Persons with PIMD could be children or adults, and interaction partners could be parents, teachers, and direct support staff because we hypothesised that this would not make a difference when tracing important elements in the interaction. However, we are aware that the interactions will be shaped differently according to how partners relate to each other. For example, partners will hold different perceptions, roles, and strategies in interactions with children, and interactions will be different if partners have a familial or professional relationship. We did exclude studies about peer interactions, although we recognise that they offer opportunities to persons with PIMD to experience mutuality (Arthur-Kelly et al., 2008). Therefore, knowledge about peer interactions would be supplementary to our model. Moreover, we did not include studies into the effect of quality interaction on the interaction partners. This could be an interesting addition to our model.

# Implications for Future Research and Practice

This study reveals methodological and conceptual starting points for future research. In addition, because concepts such as interaction, communication, and relationship are often poorly defined in the research, our review demonstrates that it is important for researchers to be conceptually clear and conceptually detailed. We recommend clearly describing intervention programs by explicitly stating which variables are targeted for intervention, and which variables are controlled.

In conclusion, our explanatory model may be considered as a descriptive framework which permits a description of interaction patterns, provides starting points for the development of support and training programs, and suggests hypotheses for future studies.

# **CHAPTER 3**

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 <sup>3</sup>

### **Abstract**

Affective and reciprocal interactions with others are essential for persons with profound intellectual and multiple disabilities (PIMD) but it is a challenge to assess their quality. This study aimed to investigate the usefulness of instruments from parent-infant research to evaluate these interactions. Eighteen videotaped staff-client interactions were coded with the Emotional Availability Scales, the Maternal/Child Behavior Rating Scales, and the Revised Erickson Scales. The scales could generally be applied to persons with PIMD and substantial interobserver agreement was found. The tools' subscales appeared to be distinct but there was also evidence that they measure an overarching construct. Client and staff interactive behaviours were highly related. Convergent validity was demonstrated by strong correlations between theoretically related dimensions. An acceptable range in scores, a ceiling-effect, and relative high mean scores occurred. The instruments' applicability and usefulness was demonstrated in this study, which offers directions for future research and intervention.

<sup>&</sup>lt;sup>3</sup> 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, 407-420.

## Introduction

It is widely acknowledged that persons with profound intellectual and multiple disabilities (PIMD) benefit highly from positive relationships with others. Because of their complex needs, caused by a combination of profound intellectual and serious motor and/or sensory disabilities, they are almost totally dependent on other people to attain an optimal life quality and wellbeing (Nakken & Vlaskamp, 2002; Petry & Maes, 2007). This is illustrated by the study of Petry et al. (2005), in which social wellbeing, mainly referring to personal relationships, was found to be the only domain that was spontaneously named by all participating parents and direct support staff as crucial for the quality of life of persons with PIMD. Similarly, Bradshaw (2001) stresses the importance of developing communication partnerships with persons with PIMD. Improving the quality of interpersonal interactions or rapport between persons with PIMD and significant others is, therefore, necessarily a central focus of many interventions and empirical research studies (Chen et al., 2007; Leaning & Watson, 2006; Maes et al., 2007; McLaughlin, & Carr, 2005). To be able to evaluate intervention and research outcomes, there is considerable need for knowledge about the nature of interactions with persons with PIMD and for methods to assess their quality.

In current research, these interactions are mostly evaluated by investigating strategies or knowledge of the interaction partner (e.g., Dobson et al., 2002; Healy & Noonan Walsh, 2007) or individual communicative utterances from the person with PIMD (e.g., Arthur, 2004; Olsson, 2005) but less by evaluating both partners' behaviours and emotions in relation to each other. Some qualitative studies (e.g., Olsson, 2004) address this, but no generalizable quantitative studies are available. However, for the target group of persons with PIMD in particular, it is important to get insight in to the unique characteristics of interpersonal relationships that need to be fine-tuned to the abilities, needs, and wishes of both interaction partners and establish a positive emotional climate (Petry et al., 2005; Wilder & Granlund, 2003).

Parents and direct support staff, for example, explicitly mention attachment as a central aspect of interactions with persons with PIMD (Forster & Iacono, 2008; Petry et al., 2005). They refer to the importance of meeting a person's need for basic security and to develop positive affective relationships. Additionally, in a recent review of the empirical research literature (Hostyn & Maes, 2009) four core components have been found to constitute the interaction process with persons with PIMD: sensitive responsiveness, joint attention, co-regulation, and an emotional component (e.g., mutual feelings of warmth, joy, closeness, or appreciation). These components are considered by the authors to be dyadic variables that are formed through the contribution of both partners and determine the interaction quality and successfulness. In this respect, the question arises how to evaluate the affective and reciprocal relationship between persons with PIMD and their interaction partners.

Affective and reciprocal interpersonal relationships have been profoundly investigated within parent-infant research. Social interactions and joint experiences between children and their caregivers

in the very beginning of life are described and examined, and their impact on further development is reported. Numerous studies provide evidence for the importance of sensitivity, responsivity, and an adequate emotional attunement within interpersonal relationships (e.g., Ainsworth et al., 1978; Emde, 1980). Also, the attachment position, for example, emphasizes that both interaction partners have a shared part in achieving and maintaining a positive rewarding relationship (Bowlby, 1988). In that way, methods from parent-infant research possibly form a fruitful basis for investigating the quality of the interaction between persons with PIMD and their partners.

At first sight, it may seem inappropriate to make use of methods developed within parent-infant research to evaluate interactions with persons with complex disabilities, children as well as adults. In that regard, we must be aware of the fact that there is a tension between normalization and developmental paradigms, or between age and developmental appropriateness, in research and practice with persons with PIMD (Goldbart, 2002; Nind & Hewett, 1996). Some authors defend the use of age-appropriate methods (e.g., Light et al., 2002). However, since the developmental age of persons with PIMD is low (below 24 months), it may be helpful to use knowledge from infant or attachment research to get an idea of the interactional needs and capacities of persons with PIMD, and, at the same time, to give an indication about the role of others to stimulate further development. As several authors suggest, descriptions of interactions between caregivers and children with normal development are an important source of knowledge about interaction processes with persons with disabilities (Hodapp, Burack, & Zigler, 1990; McCollum & Hemmeter, 1997). The Intensive Interaction approach (Nind & Hewett, 1994), for example, explicitly starts from a model of infant-caregiver interaction, combining intuitive processes and reflection, to promote high quality interaction (e.g., Kellett, 2003; Nind, 1996).

In sum, it is of great importance to examine affective and reciprocal interactions with persons with PIMD, as this is an important issue for their quality of life. Since no specific instruments for this target group are available, the aim of this study is to investigate the value and usefulness of instruments that showed their merit in parent-infant or attachment research to evaluate the quality of interactions between persons with PIMD and their partners. The following research questions are put forward:

- Are instruments from parent-infant research applicable to interactions with persons with PIMD?
- Are instruments from parent-infant research reliable and valid when applied to interactions with persons with PIMD?
- Does the use of instruments from parent-infant research yield useful and significant information about the quality of interactions with persons with PIMD?
- What is the added value of using different instruments from parent-infant research to describe interactions with persons with PIMD?

## Method

# **Participants**

For this study, we collaborated with four residential support services in Flanders. Eighteen persons with PIMD and their direct support staff participated. In accordance with the ethical standards of our university, all staff members and the clients' representatives were informed about the nature of the study and the confidentiality of the obtained data, and gave their written consent.

The persons with PIMD in our sample were mainly female (n = 12; 66.7 %) and all had a developmental age below 24 months in combination with severe motor and/or sensory disabilities. At the time of our study, these clients were aged between three and 59 years (M = 24.3; SD = 16.7). Two persons had auditory impairments (11.1 %) and ten had visual impairments (55.6 %) but only one person was blind. Four persons (22.2 %) were reported by staff to show aggressive or destructive behaviour. For each person with PIMD, a staff member knowing the person for at least six months and having contact with the particular client for more than once a week was selected. The average staff age was 40.1 years (Range = 27 - 55; SD = 9.0) and the majority of them was female (n = 15; 83.3 %). The group of staff participants consisted of 1 therapist (5.6 %), 10 direct support staff members (55.6 %), and 7 staff members that combined direct support in the living unit with team support (38.9 %). Twelve persons (66.7 %) had a bachelor's or higher education degree, and one third (n = 6) of the staff members had a degree below the bachelor level (secondary education, or adult education between secondary and higher education). Regarding the staff's educational background, most of them completed education in the pedagogical field (n = 12; 66.7%). Three people had teacher training (16.7) %) and three had a paramedical background (16.7 %). The mean experience with persons with PIMD was 15.8 years (Range = 3.5 - 28.0; SD = 8.3) and 4.9 years with the particular client of the study (Range = 1.0 - 15.5; SD = 3.9).

#### Measures

The instruments from parent-infant research were selected according to several criteria. Firstly, we searched for instruments that explicitly address the quality of the interaction between two partners. In particular, we opted for dyadic interaction scales, by which we mean that they 'rate each focal's behavior toward one specific other person in the interaction' (Melby & Conger, 2001, p. 39). Thus, it was necessary that they considered two partners mutually influencing each other and, therefore, did not only evaluate staff dimensions but also client variables. Secondly, we required that the instruments could be used to analyse video recordings. Video observations make it possible to evaluate complex interaction processes by a coding system. This is a recommended method in family observational research to reduce observers' training and to be able to make a careful judgment (Lindahl, 2001). In addition, this is also relevant in view of developing guidelines for video analyses in intervention programs to improve the interaction. Thirdly, we chose tools that synthesized the interaction and

applied an overall judgement (Lindahl, 2001) because we aimed to globally evaluate the interaction quality with a quantitative measure, guaranteeing the possibility to examine interactive processes that are built up over time. Fourthly, we wanted to use scales that proved their psychometric qualities in previous research and that were already applied to young children or persons with disabilities. Lastly, although all sharing a background of parent-infant interaction, we strived for instruments with different theoretical inspirations to get diversity in our measurements. On the basis of these criteria, three instruments were selected.

The *Emotional Availability Scales* (EAS; Biringen et al., 1998) are built around the concept of emotional availability, which is an elaboration of the traditional attachment conception of sensitive responsiveness with an emotional ground. The EAS have been widely used to examine the quality of adult-child interactions but have also been applied to interactions with persons with disabilities (e.g., Biringen et al., 2005). The scales evaluate the quality of attunement in dyadic interactions. Four dimensions on the adult level (sensitivity, structuring, non-intrusiveness, and non-hostility) and two child dimensions (responsivity and involvement of the partner) are distinguished. Each aspect is relational in nature, conceived as a quality of the particular relationship rather than as a trait of an individual (Easterbrooks & Biringen, 2005). All adult scales are evaluated on a 5-point scale, except for the 9-point sensitivity scale. The child scales range from 1 to 7. It is allowed and even encouraged to use midpoints on all scales. For this study, we used the infancy to early childhood version in combination with the adaptation for younger infants. The first author of this paper has obtained a certificate of reliability from the EA scales' author.

The Maternal Behavior Rating Scales (MBRS; Mahoney, revised 1992) and the Child Behavior Rating Scales (CBRS; Mahoney, revised 1998) evaluate aspects of maternal and child interactive behaviour that are related to child development. The scales were initially developed to evaluate the effects of early intervention programs that promoted the interaction between mothers and their children with severe disabilities (Mahoney et al., 1985; Mahoney et al., 1986). The M/CBRS have been used in diverse samples and especially in groups of young children with developmental and intellectual disabilities. The 12 maternal behavioural scales, ranging from 1 to 5, assess four interactive style factors (Boyce et al., 1996). The factor responsive/child oriented consists of sensitivity to the child's interest, responsivity, and effectiveness/reciprocity. The factor affect/animation is built up of acceptance, enjoyment, expressiveness, inventiveness, and warmth. Achievement and praise belong to the factor achievement orientation, and directiveness and pace to the factor directive. Child interactive behaviour, again evaluated on 5-point Likert scales, is split up in two components: attention (attention to activity, persistence, involvement. compliance/cooperation) and initiation (activities, adult, and affect). Some scales are conceived as intra-individual qualities, but the majority of them are evaluating the persons' behaviours towards their interaction partners.

The Rating Scales for Structured Tasks or Erickson Scales (Erickson et al., 1985) were originally developed within the Mother Child Interaction Research Project at the University of Minnesota. For this study, we used the 1990 revision of the Forty-two Month Tools Coding, and, in line with other authors, we refer to it as the *Revised Erickson Scales* (RES; Egeland et al., 1990). The RES, developed from an attachment background, evaluate maternal and child interactive behaviour in a task situation on twelve 7-point rating scales. Subscales on the level of the adult are: supportive presence, hostility, clarity of instruction, sensitivity and timing in instruction, confidence, and intrusiveness. Child dimensions are: dependency, enthusiasm and persistence, noncompliance, negative affect, experience of the session, and affection to the partner. Again, interpersonal scales preponderate but are alternated with a few intra-individual and task oriented scales. The observation tool has demonstrated its potential to evaluate parent-child interactions in the STEEP project (Egeland & Erickson, 2004) but also in a variety of other research contexts addressing the relationship quality between adults and (young) children.

All scales' manuals explicitly refer to the use of video observations to evaluate the interpersonal relationship and offer guidelines to attach one total score on each subscale dimension of the interaction. All instruments' subscales are simply rated and do not form a combination of sub-items. The three selected instruments underwent one or more revisions, indicating that previous research experiences had resulted in improved scoring guidelines.

### **Procedure**

# Client Profiles

At the start of the study, staff members were asked to fill in a *client information form*, consisting of an affective communication profile and a profile of engagement. These standardized profiles respectively summarize a client's utterances to show (dis-)satisfaction or (non-)wellbeing, and (dis-)engagement with a person and with objects. Utterances can be described on the following levels: gaze direction, facial expression, mouth activity, sounds, head position or movements, body position or movements, physiological reactions, and conventional gestures.

# Observations

We observed each staff-client interaction in a one to one contact for 20 minutes, which is recommended as the observation duration in the EAS manual and which is necessary to observe moments of conflict and repair. These observations were done in a natural but quiet context and, in accordance with the prerequisite of the RES, in a problem-solving task situation. We conceived this for our target group as a situation in which the participants were working together with *challenging* objects, for which the person with PIMD needs a scaffold from his partner to handle them. We selected objects in vivid colours and different materials (soft, hard, or making noise). Although it was allowed to simply play together too, it was briefly explained to the direct support staff what the aim of

the objects was: taking toy ducks in and out of a water tray, putting blocks in a box, building a ring tower, and opening a wrapped present with a puppet inside. They were asked to deal with all four objects during the session together with the client and to behave as they would normally do in similar situations. All sessions were videotaped with two cameras, one providing an overview of the dyad in its context and the other zooming in on the person with PIMD to be able to register his or her subtle signs.

## Observer Training and Rating Process

In this study, seven observers participated: the first author, two colleague researchers, and four masters students. For each instrument, a preceding and in-depth training process was set up. The separate trainings were given to the raters that would afterwards use the tool, but were always guided by the first author. The training firstly consisted of an acquaintance with the instrument and underlying concepts by going through the scale's manuals and accompanying materials, such as the training DVD's of the EAS. In addition, the general trends and the different codes were discussed in group and relevant literature discussing the tool was read. Since the selected observation scales were, to our best knowledge, never applied to interactions with persons with PIMD, the first training step was followed by making agreements about how to apply the subscales to persons with PIMD. This was not only discussed and written down in a theoretical way but also talked over in a concrete way with examples (e.g., how can we observe responsivity in persons with PIMD?). In that regard, the emphasis was laid on observing non-verbal and physical utterances. The scales' application to persons with PIMD was guided by three core questions (i.e. What do we know about the individual behaviours of persons with PIMD? What do we know about interactions with persons with PIMD? What can we predict about the dimensions of the observation scales?), as proposed by Biringen et al. (2005) to apply the EAS to persons with disabilities. Afterwards, we exercised this by viewing different videotapes. Disagreements were resolved through conversation and by doing observation trials again until consensus was reached. Throughout this process, we decided to formulate all RES subscales positively to make the scoring process more uniform. Then, a high rating on all RES subscales represented a high and positive occurrence of each dimension being scored. Also, we decided to leave out the staff hostility scale, because during all exercises only two scores were observed. Due to a difficult application to the target group and not sufficient agreement as a consequence, client dependency was not used either too. Lastly, a variety of video records of persons who did not take part in this study, were coded independently until sufficient interobserver agreement ( $\kappa > .61$ ) was reached.

After the training, videotapes were coded using each observation scale. One third of the video records (33%), randomly selected for each instrument, were double coded by a different team of two independent researchers. During this coding process, the client information forms were used as a means to better understand the behaviours of the persons with PIMD. The actual scoring was done on the basis

of the original subscale and score descriptions of each instrument. Scoring sheets were developed to argue on the scores and to make transfer to practice easier at a later stage.

As every video record was rated three times with a different instrument, the possibility of a halo effect across the measures occurred. Especially because some of the scales' dimensions have similar names or are clearly informed by related underlying concepts, it was possible that the scoring with one instrument would be influenced by a previous scoring with another instrument. To avoid this, as indicated, we worked with different rater teams for each scale. Only the first author was part of each observer team, because of her experience with each instrument. In addition, we left minimally three weeks between the scoring processes with the different instruments. To prevent a halo effect within our measures, i.e. the tendency to rate an interaction highly or lowly on all instrument's subscales that are seen as similar dimensions, we explicitly rehearsed during the training the different accents and focus in these subscales. We also asked the observers to argue on each subscale score on the scoring sheets on the basis of concrete observable behaviour.

# Data Analysis

Firstly, during the observer training, we explored the possibilities to translate and apply the different codes and scoring descriptions to the particular interactions with persons with PIMD. Secondly, for each instrument in total, the level of interobserver agreement was calculated using Cohen's kappa as an indication of reliability. The degree of agreement was interpreted in accordance with the widely accepted benchmarks of Landis and Koch (1977) (i.e. .21-.40: fair agreement; .41-.60: moderate agreement; .61-.80: substantial agreement; > .81: almost perfect agreement). Repeated measures with the scales to determine the test-retest reliability, could not be performed within the scope of this study. To report on the construct validity, the correlations between the subscales of one observation tool were computed to examine the interconnection between the parts composing each instrument. Furthermore, correlations between all subscales of the instruments were calculated to make conclusions about the interrelationship between the EAS, M/CBRS, and RES. These correlations were determined as a measure of convergent validity, a variant of construct validity, assuming that subscales theoretically evaluating similar qualities would correlate..Since a normality test showed that not all subscales adequately fitted the normal distribution but also in light of our small sample size, we calculated Spearman rank order correlations. The correlation strengths were judged according to the criteria of Cohen (1988), indicating small correlations from .10 to .30, medium correlations from .30 to .50, and strong correlations higher than .50. Thirdly, to examine whether the instruments yield significant information, we generated some descriptive statistics summarizing the results obtained with each instrument. Mean scores and standard deviations were calculated for all subscale dimensions. We also evaluated the range of the observational data by comparing the actual with the theoretical range, which also gives an indication of the usefulness of the scales. Additionally, we examined the qualitative descriptions on the scoring sheets. Fourthly and lastly, conclusions about the instruments' added value to each other were also drawn during the training and scoring process.

All analyses were performed using SAS software (SAS Institute Inc.).

## **Results**

# Applicability of the Scales

The three observation scales appeared to be applicable to the interaction between persons with PIMD and their support staff. It was possible to translate and apply the score descriptions in line with the original content of the scales, but only if based on sufficient understanding of the specific characteristics of interactions with this target group. For example, persons with PIMD will generally not ask for the attention of their interaction partner verbally but can do this through hand reaching or looking towards the other, or other nonverbal utterances. The translation process made the observers' training with each instrument interesting but also time-consuming. In particular, the client subscales were difficult to score because persons with PIMD communicate by subtle and idiosyncratic utterances that are context- and person bound (e.g., teeth gnashing, body tension). The client information forms, which were only used during the actual scoring process (to better target the utterances for which to be attentive), were most useful in that context. The training and rating process also made clear that identical subscale scores could refer to other qualities (e.g., active refusal versus passive distraction), which illustrates the importance of combining scores with qualitative arguments.

, It appeared important to keep in mind that the scales only evaluate the interaction process at a specific moment and, therefore, do not imply a value judgement about the capacities or professional competences of the persons in general. It likely reduced stress for staff when the raters explained during the training that the scoring did not intend to make judgements about the participants but to describe their interactive behaviours at that particular moment.

# Reliability and Validity

### Interobserver Agreement

For all instruments, a sufficient interobserver agreement was found. For the EAS scores, a substantial Kappa coefficient of .72 was obtained. Cohen's Kappa, calculated on the 19 subscales of the M/CBRS, appeared to be substantial too ( $\kappa$  = .75). But, to avoid redundancy, we will only report on the M/CBRS scores at the factor level in this paper (detailed M/CBRS results are available from the authors). Since these six factor scores were non-categorical and a Kappa coefficient could not be determined, we calculated the correlation between the observers' factor results as an indication of interobserver agreement. This correlation was almost perfect ( $\rho$  = .94; p < .001). Lastly, substantial interobserver agreement ( $\kappa$  = .78) was established for the RES.

# Construct Validity

The correlations between the EAS subscales, the M/CBRS subscales, and the RES subscales, are respectively summarized in Table 1, Table 2, and Table 3.

Table 1
Intercorrelations between subscales Emotional Evailability Scales.

Subscale	1	2	3	4	5	6
1. Sensitivity	_	.67**	.71***	.59**	.73***	.49*
2. Structuring		_	.30	.52*	.61**	.37
3. Non-intrusiveness			_	.63**	.52*	.30
4. Non-hostility				_	.78***	.41
5. Responsivity					_	.69**
6. Involvement partner						_

<sup>\*</sup>p < .05; \*\*p < .01; \*\*\*p < .001

 Table 2

 Intercorrelations between factors Maternal/Child Behavior Rating Scales.

Factor	1	2	3	4	5	6
1. Responsive / child oriented	_	.41	03	43	.60**	.44
2. Affect / animation			.09	.01	.33	.15
3. Achievement orientation				14	.38	31
4. Directive				_	41	40
5. Attention					_	.42
6. Initiation						_

<sup>\*</sup>p < .05; \*\*p < .01; \*\*\*p < .001

Most correlations between the EAS subscales were significantly positive and strong, between .49 and .78. This suggests that, although evaluating separate dimensions, they also represent aspects of a global EA evaluation. The four staff subscales, as well as the two client subscales, were associated. However, the highest correlations were found between the client responsivity and all four staff dimensions, signifying that client and staff behaviour are connected to each other. The least significant correlations were found with the client subscale *involvement of the partner*, indicating that this forms a fairly distinct aspect of the scale.

There were no significant intercorrelations between the staff MBRS factors, or between the client CBRS factors, which confirms that the scores at factor level measure separate constructs. But, there appeared to be a rather strong association between staff responsiveness and client attention ( $\rho$  = .60; p < .01), which shows the only mutual connection between staff and client behaviour. Furthermore, a trend towards a negative correlation between staff's achievement orientation and directiveness, and the other factors was noticeable.

The significant correlations ranging from .48 to .91 between many subscales of the RES indicate that the RES dimensions were highly related to each other. The correlations between the staff subscales varying from .53 to .74 were not as high as the correlations between the client subscales. Particularly the client subscales *enthusiasm*, *compliance*, and *experience of the session* were almost coinciding ( $\rho \ge .85$ ; p < .001). These three client subscales also correlated rather strongly to the five staff subscales, again showing the mutual dependency between staff and client behaviours. There were few significant correlations between the RES subscales and the client subscales *affect* and *affection toward the partner*, which, thus, represent distinct measures.

 Table 3

 Intercorrelations between subscales Revised Erickson Scales.

Subscale	1	2	3	4	5	6	7	8	9	10
1. Supportive presence		.44	.58*	.53*	.73***	.63**	.66**	.28	.74***	.42
2. Clarity instruction		—	.70**	.74***	.32	.59**	.65**	.29	.62**	.10
3. Sensitivity of instruction				.45	.58*	.59**	.59**	.28	.75***	.19
4. Confidence					.30	.56*	.59**	.21	.52*	.30
5. Non-intrusiveness						.50*	.48*	.30	$.54^*$	.19
6. Enthusiasm, persistence							.85***	.64**	.91***	.59**
7. Compliance								.70**	.89***	.39
8. Affect									.59*	.29
9. Experience session									_	.43
10. Affection to partner										

<sup>\*</sup>p < .05; \*\*p < .01; \*\*\*p < .001

 Table 4

 Intercorrelations between client subscales of the three instruments.

Subscale	EAS Responsivity	EAS Involvement	RES Enthusiasm	RES Compliance	RES Affect	RES Experience	RES Affection
EAS Responsivity	_	_	.81***	.87***	.59**	.80***	.59**
EAS Involvement	_	_	.57*	.49*	.39	.44	.86***
<b>CBRS</b> Attention	.82***	.54*	.78***	.86***	.63**	.86***	.31
CBRS Initiation	.51*	.88***	.41	.24	.33	.27	.77***

<sup>\*</sup>p < .05; \*\*p < .01; \*\*\*p < .001

**Table 5**Intercorrelations between staff subscales of the three instruments.

Subscale	EAS Sensitivity	EAS Structuring	EAS Non-intr.	EAS Non- host.	MBRS Respons.	MBRS Affect	MBRS Achievem.	MBRS Directive
RES Supportive presence	.89***	.55*	.67**	.73***	.70**	.57*	.20	52 <sup>*</sup>
<b>RES</b> Clarity instruction	.38	.69**	.25	.50*	.36	.36	.48*	35
<b>RES Sensitivity instruction</b>	.66**	.71***	.60**	.64**	.62**	.39	.17	47
RES Confidence	.47*	.56*	.17	.52*	.28	.50*	.21	23
<b>RES Non-intrusiveness</b>	.68**	.31	.93***	.68**	.68**	.13	.11	75***
EAS Sensitivity	_	_			.68**	.66**	.03	54*
EAS Structuring		_		_	.59*	.60**	.18	19
EAS Non-intrusiveness	_	_		_	.65**	.16	.06	78***
EAS Non-hostility		_	_	_	.77***	.38	.21	32

<sup>\*</sup>p < .05; \*\*p < .01; \*\*\*p < .001

# Convergent Construct Validity

Although all scales aspire to explore the interaction quality, the training and scoring process provided, as already mentioned in the foregoing, preliminary evidence of some subscale dimensions being more related than others. This is also reflected in the obtained interscale correlations between the instruments, which will be separately discussed for the client subscales (Table 4) and the staff subscales (Table 5).

The client subscales, theoretically referring to similar constructs, were significantly positive and strongly associated with each other, which points to the scales' convergent construct validity. Subscales evaluating response and attention behaviours were strongly correlated ( $\rho \ge .78$ ; p < .001): EAS responsivity, CBRS attention, RES enthusiasm, RES compliance, and RES experience. Likewise, the dimensions referring to the clients initiatives and affection towards the partner, were strongly connected ( $\rho \ge .77$ ; p < .001): EAS involvement, CBRS initiation, and RES affection. The RES subscale affect, which is theoretically referring to the affective state of the persons with PIMD on their own and not towards the interaction partner, was rather distinct and, logically, only significantly correlating with the responsivity dimensions and not with the dimensions addressing the initiatives of involvement towards the interaction partner.

On the staff level, convergent construct validity was supported by the fact that, although there is also some overlap, the subscales based on equal theoretical constructs were most strongly correlated with each other. Firstly, the subscales EAS sensitivity, EAS non-hostility, MBRS responsiveness, MBRS affect, and RES supportive presence, purporting to measure constructs referring in theory to the affective, sensitive, and adaptive attitude of staff, also appeared to be highly correlated in the actual results. Most remarkable was the strong correlation between EAS sensitivity and RES supportive presence ( $\rho = .89$ ; p < .001). Secondly, the two subscales that theoretically examine the instructive quality (EAS structuring and RES clarity instruction) were also strongly associated ( $\rho =$ .69; p < .01). Lastly, the correlations between EAS non-intrusiveness, MBRS directiveness, and RES non-intrusiveness, three subscales evaluating the (non)directiveness of the staff, were strong. Particularly, the correlation between the two non-intrusiveness subscales (EAS and RES) was high (ρ = .93; p < .001). With regard to the RES sensitivity and timing in instruction subscale, there were significant correlations between .60 and .71 with all dimensions, which is also theoretically relevant since this scale integrates an evaluation of the instruction quality with the responsivity to the client's needs. Furthermore, RES confidence and particularly MBRS achievement orientation seemed to be distinct qualities, with almost no or, in comparison to the other correlations, rather small significant associations with other subscales.

# Scoring Results

The statistics summarizing the results obtained with the three instruments are reviewed in Table 6.

Table 6
Scoring Results

Subscale	Theoretical range	Observed min.	Observed max.	Mean	Standard deviation
Emotional Availability Scales					
Staff					
Sensitivity	1 - 9	5.0	8.5	6.39	1.17
Structuring	1 - 5	2.5	4.5	3.75	0.62
Non-intrusiveness	1 - 5	2.0	5.0	3.64	0.87
Non-hostility	1 - 5	2.5	5.0	4.53	0.72
Client					
Responsivity	1 - 7	2.5	6.5	5.00	1.01
Involvement partner	1 - 7	3.0	6.0	4.61	0.95
Maternal / Child Behavior Rating Scale					
Staff					
Responsive / child oriented	1 - 5	2.3	4.7	3.74	0.65
Affect / animation	1 - 5	2.2	4.0	3.11	0.52
Achievement orientation	1 - 5	2.0	4.0	3.22	0.57
Directive	1 - 5	2.0	4.5	3.39	0.63
Client					
Attention	1 - 5	1.8	4.8	3.34	0.79
Initiation	1 - 5	1.3	3.7	2.73	0.64
Revised Erickson Scales					
Staff					
Supportive presence	1 - 7	3.0	7.0	5.39	1.24
Clarity instruction	1 - 7	3.0	7.0	5.00	1.14
Sensitivity instruction	1 - 7	3.0	6.0	5.06	1.11
Confidence	1 - 7	2.0	7.0	5.06	1.30
Non-intrusiveness	1 - 7	2.0	7.0	4.89	1.71
Client					
Enthusiasm, persistence	1 - 7	2.0	6.0	4.11	1.37
Compliance	1 - 7	1.0	7.0	4.94	1.86
Affect	1 - 7	2.0	7.0	6.22	1.26
Experience session	1 - 7	2.0	7.0	5.17	1.34
Affection to partner	1 - 7	1.0	7.0	4.06	1.83

The data analysis with the EAS showed that all subscales had an acceptable range in scores although the lowest scores were not observed. Even, on the 9-point staff sensitivity scale, only scores higher or equal to 5 were attached to the recordings. Mean scores, all above the theoretical mean, also indicated the medium to high EA qualities of the interactions. The factor scores on the M/CBRS were differentiated although the range in scores was rather limited. This could be due to the fact that extreme scores on the separate subscales are likely to move to the average by calculating condensed factor scores and are therefore not visible in our table. Relatively high mean scores were established. For the client, especially on the factor *initiation*, lower scores were observed. With the RES, a considerable range in scores was obtained, generally higher on client subscales. On two client subscales, *compliance* and *affection to partner*, even the total range in scores was used. Again, mean scores were relatively high and above the theoretical mean of the subscales. The mean scores on the RES client subscales were more varied.

In general, all instruments' standard deviations, taking the different theoretical ranges into account, were not remarkably high or low but indicate a good spreading in the data.

With regard to the qualitative descriptions of the observed interactions, we provide here some short and abbreviated examples of justifications from the scoring sheets to illustrate the information obtained by using the instruments.

- EAS, staff non-intrusiveness (score 4): She explains to the client what has to be done but leaves enough openness for contribution of the client. For example, she takes the hand of the client to feel the water together but not in a forcing way as she does not exercise pressure and lets loose the hands several times too (while keeping her hands available for further contact). She gives the client the opportunity to initiate something by pausing frequently, and also leaves enough time between the introductions of several objects, by which becomes clear that there is no overstimulation. She gives the client a lot of time to discover each object in her own pace. She follows the lead of the client by observing where the client is looking and smiling at, and engages in her interests. On scarce moments, she slightly overpowers the interaction (e.g. by taking the hands of the client in a too fixed way when exploring the ring tower or by sometimes taking away an object when the client is still looking at it). Nevertheless, the interaction is mainly spacious.
- CBRS, client initiation towards the adult (score 2): The client almost never initiates interaction with his caregiver. He mostly avoids eye contact or he does not turn his body towards the caregiver. Sometimes, he even squeezes his eyes. He frequently makes vocalisations but they are directed towards himself (e.g., because they are not combined with looking at the caregiver). After 9 minutes, for the first time, he looks at the caregiver after she makes noise with the blocks and smiles to the caregiver, as if he wants to ask for more. Similarly, when the caregiver sings a song he likes, he shares his happiness with her through eye contact, reaching with his hands, and laughing. So, only occasionally he attempts to share experiences with the caregiver.

RES, client compliance (score 6): He never clearly refuses or rejects suggestions of his caregiver, and stays on task for the majority of the time. For example, if the caregiver asks to put a ring on the tower, he tries to do that with her help or if the caregiver asks to look at the puppet or a block, he smiles when looking towards it. He also frequently follows the caregiver's hands or makes eye contact when the caregiver shows what she wants him to do. Nevertheless, at one moment he shows a brief period of frustration by screaming and becoming restless, when the caregiver opens a metal box and asks him to play with it. This does not really reflect autonomy but is a clear utterance of noncompliance, as he also turns away his eyes from the caregiver. This episode is recovered soon when the caregiver pauses for a while and re-introduces the object in a quiet manner. So, the client complies with virtually all major directions of the caregiver.

In sum, the quantitative and qualitative scoring results demonstrate that the instruments lead to meaningful information about the quality of interaction within and between persons on several distinct interactional dimensions.

# Added Value of the Scales

In the first instance, the training and rating process resulted in the experience of all (sub)scales having their own accent, rather focusing on personal, emotional, or task related behaviours. In addition, it became clear that the score descriptions of equal dimensions in the different scales (e.g., sensitivity, intrusiveness, persistence, etc.) are subtly different. For example, adult sensitivity is conceived as the monitoring and awareness of the child's interests in the MBRS while it combines recognition of the child's signals with aspects as authentic positive affect and timing in the EAS. The scales' manuals must necessarily and attentively be gone through to understand that. Still, it was also obvious that all scales aim to evaluate the interaction quality, with some dimensions being more coherent than others.

Some other training and scoring experiences clarify the instruments' values against each other. Regarding the scoring guidelines, the EAS manual and training DVD's are very illustrative, while the limited background information and score descriptions in the M/CBRS and RES form a threat for the scales' usefulness. On the other hand, the EAS requires more information since the evaluation of staff sensitivity and client responsivity integrates different aspects (e.g., affective and behavioural dimensions). In that context, the M/CBRS consist of more separate subscales, belonging to several overarching factors, which does not necessarily make the scoring more time-consuming but, on the contrary, makes the theoretical constructs clearer. For example, the separation between the clients' initiation of activities and initiation towards the partner or between staff's sensitivity, responsivity, and effectiveness are valuable, although it requires some exercise to distinguish this on video records. Lastly, it is noteworthy that the possibility to use midpoints and the fact that repair of inevitable conflict states (that is, moving from mismatched to synchronous states) are taken into account in the EAS, makes the scoring realistic. Within the RES, it is significant for the target group of persons with

PIMD that it is explicitly mentioned that stereotyped behaviour must not be included in the evaluation of client behaviour, such as persistence.

## **Discussion**

Instruments from parent-infant research are theoretically assumed to form a rich source to understand the dynamics in interpersonal relationships with people with low developmental ages. Therefore, the aim of this study was to investigate whether it is valuable to apply these instruments to evaluate interactions with people with PIMD. The results of the study demonstrate the applicability and usefulness of the EAS, the M/CBRS, and the RES to evaluate interactions between people with PIMD and their direct support staff on the basis of sufficient training and knowledge of the interaction with people with PIMD.

Firstly, an intensive translation process showed that the subscales, except for two RES dimensions, are applicable to interactions with people with PIMD on the basis of adequate knowledge about this target group. Secondly, the instruments proved to be reliable by substantial interobserver reliabilities, which could only be obtained because the coding process was preceded by a repeated and intensive training. With regard to the correlations between the subscales of each instruments, the intrascale correlations within the EAS and RES were rather strong, indicating that they measure the same underlying concept within the overall instrument but, at the same time, there is quite some overlap. Still, some EAS and RES subscales formed clearly distinct dimensions. Also, the M/CBRS factors seemed to form distinct measures. In general, client and staff behaviours appeared to be related to each other. The significant strong and positive correlations between the scores on theoretically related constructs within the different observation tools, with a few exceptions, provided supportive evidence for the convergent construct validity of the instruments. Thirdly, a substantial range in the scores was obtained but a ceiling-effect occurred, and rather high mean scores were obtained. This might be due to the effect of the video camera but also shows the competencies of the observed dyads. This is possibly related to the fact that all staff participants had a lot of experience in working with people with PIMD or with the specific client. Besides, the dyads were selected by the residences themselves, which probably choose well functioning interactions to generate a positive image. It is also important to keep in mind that the lower scores on the caregiver scales, such as the EAS (Biringen et al., 1998), refer to pathology, which is normally not observed in professionals. However, despite the fact that no extreme low scores were observed, it remained possible to differentiate between dyads scoring higher and dyads scoring rather moderate by the different subscales, indicative of higher or less quality interaction. Besides, and maybe most important, the instruments appeared to be suitable to make significant qualitative observations, as appeared from the justifications on the scoring sheets. Lastly, with regard to the interrelationship between the instruments, the training and scoring process showed that they all seemed to have their own benefits. More specifically, the high correlations between all client subscales, referring to two general trends (response and initiation), showed that instruments

were having almost no additional value to each other on the client level. However, on the level of direct support staff, the instruments were partially overlapping but also had supplementary value on some dimensions.

In addition to these findings in favour of instruments from parent-infant research to approach interactions with people with PIMD, it is important to note that one must be aware of their underlying philosophical and ethical assumptions (Goldbart, 2002; Kellett & Nind, 2001). The instruments described and, in general, the developmental approach implicitly assume a striving to facilitate development and progression. In that regard, it would be valuable to suggest to researchers and practitioners the idea that a developmental approach can be complementary with an ordinary life approach, valuing relationships and persons as they are (Burton & Sanderson, 1998).

### Limitations

There are some limitations to our study. To begin with, the staff-client observations were made, in line with the RES, in a task situation with the instruction to use the four objects. This possibly evoked some stress, an inclination to take away objects when time passes, or an urge to demonstrate the clients' capabilities. Still, there was variation between the dyads and the nature of the situation also makes some behaviour, such as staff's way of instructing and client's responsivity, better observable. Additionally, even in a task situation, a lot of time was spent on merely playing simple games in line with the clients' interests (e.g., the towel on which the water tray was positioned). Similarly, it should be noted that the presence of a video camera might have an influence on the support staff, who may try to show their best, which is not necessarily a problem because it is a good sign if staff members know what this best implies. This may also explain the fact that the lower scores of the scales were not observed in these video recorded conditions. Ideally, but not possible within the scope of this study, some test recordings should be conducted before the actual recording to obtain habituation. At this point, however, the generation of some stress by the task instruction, can form a good condition to assess natural occurring interaction processes and to prevent socially desirable behaviour. Furthermore, the 20 minute duration of the observations, which is certainly long for interactions with people with PIMD, also reduces the chance that people behave unnaturally during the whole observation. This observation length is, as already referred to, also necessary to be able to observe repair of conflict moments.

Secondly, although we took measures to reduce the likelihood of a halo effect, we must still be aware of its possible occurrence in our data, since, halo errors reflect a variety of influences which can not be fully avoided even under optimal rating conditions (Murphy & Anhalt, 1992). The danger of a halo effect within each of our instrument measures remained difficult to control.

Another limitation of the study bears upon the difficult and risky process of ascribing meaning to the behaviour of staff and especially people with PIMD (Grove et al., 1999). The *client information* forms partially avoid this pitfall of interpretation. Still, it would be interesting to code the video

records with the staff themselves or with other people who know the people with PIMD, such as their parents. However, even in that case, a subjective element remains because these people are maybe too closely involved. In this context, a plea for a consensus model, in which different observers discuss all records until consensus is reached, as an alternative to obtain interobserver reliability, may be indicated.

A last and obvious limitation of our study is the small sample size. This makes it difficult to draw generalizable conclusions, to calculate kappa scores on each subscale, or conduct factor analysis for example. Still, it allowed a view of the applicability and usefulness of the scales and offers some first conclusions with regard to the quality of the interaction between people with PIMD and their support staff.

## **Implications**

The limitations illustrate the preliminary and explorative character of the study, which offers directions for further research. Mainly, our study results provide information to make better methodological choices in future research projects. Depending on the focus of interest (e.g. emotional or more task related behaviours), one of the instruments described could be chosen to evaluate the quality of interactions with people with PIMD. Also, it would be possible to make a new integrated instrument specifically targeted at people with PIMD in which the different subscales having a unique contribution in evaluating the interaction quality would be combined. This all contributes to the continuous search for appropriate instruments in research on interactions with people with PIMD.

In addition, since our preliminary results mostly lead to hypotheses that should be the object of further investigation, it would be valuable to apply the instruments to more dyads to make further conclusions about their usefulness to evaluate interactions with people with PIMD. It would be useful to make more in depth conclusions about the interaction behaviours and processes too. For example, to examine whether the initiation of people with PIMD is less than their response behaviour, as suggests our data. Also, it would be particularly interesting to compare the interaction quality in dyads with different interaction partners (parents, teachers, direct support staff, etc.) or in different situations (structured, free play, etc.).

Furthermore, the instruments that were used in this study all implied global evaluations of the observed interactions. This has the consequence that detailed information gets lost in the analyses in favour of a condensed score. Therefore, it would be significant to further qualitatively analyse the observations and arguments on the scoring sheets to do justice to the richness of the interaction. In that regard, another possibility is to combine the global evaluations with direct behavioural observation techniques in the future. Connected to this, it would be significant to compare the data obtained with data retrieved by other methods, such as interviews with the direct support staff.

With regard to practice, this study and the observation tools used create a framework to inform parents, direct support staff, and other interaction partners of people with PIMD about crucial elements in well functioning interaction. The scales can form an excellent basis for video analysis, an often used technique in staff interventions. This complements the ongoing development of best practice interventions to support interaction partners and contributes to the challenge of better understanding the relational needs of people with PIMD.

# **CHAPTER 4**

DESCRIBING DIALOGUE BETWEEN PERSONS WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES AND DIRECT SUPPORT STAFF USING THE SCALE FOR DIALOGICAL MEANING MAKING <sup>4</sup>

## **Abstract**

The dialogical approach of meaning making forms a rich and renewing theoretical perspective to study communication between presymbolic communicators and their interaction partners. The aim of this study is to investigate whether an observation scale based on the dialogical theory, the Scale for Dialogical Meaning Making (S-DMM), has potential to describe these communicative interactions. Eighteen videotaped observations of persons with PIMD and their support staff were coded using the S-DMM and a consensus rating procedure. Sufficient interrater agreement and an acceptable range in scores confirm the usefulness of the S-DMM. Strong subscale intercorrelations were identified. The quantitative scores and the qualitative arguments supporting the ratings, demonstrate how the S-DMM aids to significantly describe staff-client dialogue. Using the S-DMM to describe dialogue with persons with PIMD appears to be promising. The value of the S-DMM and its consensus rating procedure are reflected upon and discussed with regard to implications for research and practice.

<sup>&</sup>lt;sup>4</sup> Hostyn, I., Daelman, M., Janssen, M. J., & Maes, B. (2010). Describing dialogue between persons with profound intellectual and multiple disabilities and direct support staff using the Scale for Dialogical Meaning Making. *Journal of Intellectual Disability Research*, *54*, 679-690.

# Introduction

Communication is an important and central issue in working with persons with profound intellectual and multiple disabilities (PIMD). Persons with PIMD mostly communicate in a presymbolic way using idiosyncratic and subtle utterances that are person- and context-bound, such as vocalizations, facial expressions, or changes in muscle tone (Daelman, 2003; Stillman & Siegel-Causey, 1989). This use of unconventional communicative behaviour, leading to ambiguity of meaning, poses a real challenge to understanding the needs, thoughts, and feelings of persons with PIMD and to develop shared understanding with them (Grove et al., 1999; Porter et al., 2001). Consequently, many studies have been directed at assessing the communicative abilities of persons with PIMD (e.g., Iacono et al., 2009; Snell, 2002) and at evaluating (e.g., Healy & Noonan Walsh, 2007; Wilder, 2008b) or improving (e.g., Bloomberg et al., 2003; Granlund & Olsson, 1999; Snell et al., 2006) the communication between persons with PIMD and their interaction partners.

Up to now, research on communication has been dominated by a traditional information processing approach (e.g. Schramm, 1954; Shannon & Weaver, 1949). In this approach, the focus is on the transfer of information by non-verbal or verbal means (Messer, 1994). The communicating persons are seen as entities that transmit meanings by sending and receiving information. More recently, communication and human interaction have been approached from a dialogical perspective, embracing different research traditions such as conversational analysis (Sacks et al., 1974) and the transactional view (e.g. Barnlund, 1970; Sameroff, 1975). From the dialogical approach, communication partners simultaneously engage in a process of meaning making. They mutually influence each other and there is a continuous interaction and mutual adaptation, as is elaborated on in Fogel's (1993) continuous process model and concept of co-regulation. Rather than a transmission of information, communication is a dynamic and creative process. The involved persons jointly construct new meanings that were not available before they participated in an ongoing and open-ended process of negotiation (Bakhtin, 1986). In dialogue, therefore, meaning is discovered between persons rather than owned by each individual (Arnett, 1986). Through negotiation, a fundamental process in human meaning making, the involved partners can co-create mutual understanding (Markova et al., 1995). Though the close relationship and reciprocity between communication partners are essential to the dialogical perspective, the existence of asymmetries is inevitable. This pertains to various kinds of inequalities that, while maybe incompatible with dialogue at first sight, do not exclude the development of mutual understanding in and through interaction (Linell, 1998). Communication even presupposes asymmetry (Linell & Luckmann, 1991), as, if there were no differences in position and knowledge between persons, there would be little reason to negotiate (Linell, 1998).

In sum, communication is no longer seen as monologue, a 'from-to process' (Linell, 1998, p. 24), but is considered to be dialogue or a 'between process' (Linell, 1998, p.24). As a theoretical approach,

the dialogical framework is therefore in tune with our postmodern times in which meaning is not fixed but dynamic and constructed through relationships.

The application of the dialogical perspective to communication with persons with PIMD yields relevant insights. The recognition of asymmetry as intrinsic property of dialogue corresponds to a great extent to the reality of engaging with persons communicating at a pre-symbolic level. The particular characteristics of their communication, as described above, indicate why meaning creation with persons with PIMD is dynamic and influenced by the context (Grove et al., 1999; Olsson, 2004), and the chance for misunderstandings and breakdowns are higher (Snell, 2002; Wilder, 2008a). Significantly, the dialogical theory stresses that the process of meaning creation is rewarding and meaningful in itself, whether a final understanding is obtained or not. Therefore, as Olsson (2004) states, thinking about meaning as something that must be created between partners can overcome concerns about communicating with persons with PIMD. That dialogue can arise with persons with low developmental ages and despite substantial asymmetry, is shown by Papousek's (1995) description of mutuality and shared understanding in preverbal parent-child communication. Similarly, Nafstad and Rødbroe (1999) demonstrated how the dialogical perspective applies to the development of meaningful relationships with persons with congenital deafblindness and/or complex multiple disabilities. A dialogical viewpoint, emphasizing the general existence of asymmetry between communication partners, makes communication with persons with PIMD less deviant from all human interaction.

Although the dialogical viewpoint appears to be highly advantageous for approaching communication with persons with PIMD, it has seldom been adopted as an explicit starting point for research. In the few papers using the viewpoint, Olsson (2004) provided a detailed qualitative description of the co-regulation between a child with PIMD and his caregiver, and Wilder (2008b) studied the dynamics of turn taking in interactions with children with PIMD. However, no specific studies reporting on dialogue between persons with PIMD and their communication partners are available. Additionally, up to now, it is quite unclear how theoretical approaches focussing on the co-construction of meaning can provide methodological starting points for the systematic study of communication (Messer, 1994). While it is obvious that the dialogical perspective forms a conceptual and theoretical break with traditional approaches on communication, it is not clear whether it is also possible to capture this shift in concrete observational methods.

Therefore, an observation rating scale, the Scale for Dialogical Meaning Making (S-DMM; Hostyn et al., 2009a)<sup>5</sup>, was developed to describe the dialogue in a two-person contact. As every relationship is considered to involve a greater or lesser degree of dialogic attitude (Buber, 1966), the S-DMM intends to place an interpersonal communication on the continuum between monologue and dialogue. In accordance with the dialogical theory, the interacting dyad and not the two individuals

<sup>&</sup>lt;sup>5</sup> The manual of the Scale for Dialogical Meaning Making is available from the author.

forms the core focus (Markova et al., 1995). The different components of the S-DMM are not considered to be personal traits or individual acts but relationship variables or dialogical contributions (Markova & Linell, 1996). This makes the S-DMM a dyadic relationship scale, rating 'process characteristics of each dyad's relationship that cannot be scored at the individual level' (Melby & Conger, 2001, p. 39). The S-DMM aims to give a global picture of the meaning making, which means that it uses 'large coding units that require coders to synthesize the interaction and apply a global judgement' (Lindahl, 2001, p. 24). Hence, the S-DMM considers the dynamic flow of interaction (Linell, 1998) as much as possible, and its scores provide an overall measure of the common dialogue.

The aim of this study is to investigate whether the S-DMM can be used to describe dialogue between persons with PIMD and their communication partners. The research questions are:

- Is the S-DMM a reliable and versatile instrument to map the process of dialogue between persons with PIMD and their communication partners?
- Does the S-DMM yield a significant description of the dialogue between persons with PIMD and their communication partners?
- Does the S-DMM generate descriptions of communicative interactions between persons with PIMD and their communication partners in real dialogic terms?

### Method

### **Participants**

This observational study was performed in coherence with the standards of the university ethical committee. Four residential support services in Flanders (Belgium) agreed to participate. They were asked to identify residents with PIMD (Nakken & Vlaskamp, 2002 definition), and support staff who had worked directly with the person for at least six months. The organisations gave explanatory statements about the study's design and confidentiality together with consent forms to client representatives (as degree of intellectual disability precluded the person providing consent on their own behalf) and direct support staff, resulting in 18 dyads being recruited for the study. Demographic characteristics are presented in Table 1.

**Table 1**Participants' demographic characteristics.

Demographic variable	Descriptives
<i>Clients (N = 18)</i>	
Age	Range = $3 - 59$ years ( $M = 23.1$ ; $SD = 17.0$ )
Gender	
Female	n = 13 (72.2 %)
Male	n = 5 (27.8 %)
Sensory impairments	
Visual impairments	n = 10 (55.6 %)
Auditory impairments	n = 1 (5.6 %)
Challenging behaviour	<i>n</i> = 14 (77.8 %)
Staff Members $(N=18)$	
Age	Range = $22 - 55$ years ( $M = 39.1$ ; $SD = 10.0$ )
Gender	
Female	n = 15 (83.3 %)
Male	<i>n</i> = 3 (16.7 %)
Experience in working with	
Persons with PIMD	Range = $3.5 - 28$ years ( $M = 15.1$ ; $SD = 8.8$ )
Client of the study	Range = $0.6 - 15.5$ years ( $M = 4.8$ ; $SD = 4.0$ )
Function	
Direct support staff	<i>n</i> = 11 (61.1 %)
Direct support staff and team support	n = 6 (33.3 %)
Therapist	n = 1 (5.6 %)
Level of education	
Bachelor's degree	<i>n</i> = 11 (61.1 %)
< Bachelor's degree	n = 7 (38.9 %)
Education	
Special education	<i>n</i> = 13 (72.2 %)
(Para-)medical education	<i>n</i> = 3 (16.7 %)
Teacher training	<i>n</i> = 2 (11.1 %)

The persons with PIMD, of which 72.2 % were female, were aged between three and 59 years but all had a developmental age below 24 months and severe motor disabilities. Ten of them had visual impairments but only one person was blind, and one person had auditory impairments. Staff identified the majority of the clients (77.8 %) as showing challenging behaviour. The staff members, of which the majority was also female (83.3 %) were aged between 22 and 55 years. Their general length of time working with persons with PIMD was high (M = 15.1), and the mean period of experience with the client of the study was 4.8 years. The participating staff members were mainly direct support staff (94.4 %), of which 6 persons combined the direct support in the living unit with team support, and 1 therapist also joined our study. With regard to their educational level, 61.1 % of the staff members had a bachelor's degree. 72.2 % of the staff had a special educational background, whereas the others had a paramedical (16.7%) or teacher (11.1%) education.

# Scale for Dialogical Meaning Making

The S-DMM comprises five subscales inspired by the ideas of Per Linell (1998; Markova & Linell, 1996) and Martin Buber (Buber, 1966; Johannesen, 1971; Thomlison, 2004). Each subscale refers to a dimension of dialogical meaning making. Verbal and non-verbal behavioural indications are provided for each subscale in order to be able to observe more focussed. A few examples are described after each subscale's explanation.

- (1) *Mutual openness* concerns the mutual openness for and noticing of each other's utterances and experiences. It is about turning toward and becoming totally aware of each other. E.g., mutual eye-contact, body position directed towards each other, making comments on (nonconventional) utterances, feelings, etc. they notice in each other.
- (2) *Joint embedding context* refers to the joint creation of a context that embeds what is happening and makes the sequence between separate activities meaningful. To be able to construct meaning together, the joint development of a common frame for the dialogue is necessary. E.g., joint attention for a shared object or theme, creating repetition, sharing comments on the context, using utterances of each other.
- (3) *Non-manipulative negotiating* considers the way both partners negotiate about possible meanings without manipulating each other. As persons can never read someone's experiences or thoughts, it is necessary to engage in a process of reciprocal consultation. This negotiation is a continuous process in which both partners take part and which happens in a pace and form that is adjusted to both persons. E.g., pausing and respecting each other's reaction time, balance between initiatives and responses, checking what the other means or whether the other is understood, suggestive tone instead of decisive tone.
- (4) *Joint confirmation* does not only mean a confirmation of each other's utterances and the shared created meanings but also a mutual confirmation of each other as worthy partners. E.g., imitating each other, confirming the understanding of the other or the noticing of an utterance.

(5) *Non-evaluativeness* pertains to a general attitude of empathy for the perspective of each other. This also refers to a willingness to see the world from the other's point of view, and to accept each other's strengths and weaknesses. E.g., being patient, sharing happiness, expressing excitement for each other's interests.

Each of the subscales is measured on a Likert scale, spread across 5 units with midpoints allowed (1, 1.5, 2, ...). For each score, a detailed description is provided in the manual. The differentiation between the scores was first made theoretically (guided by the question how a higher or lower subscale score would manifest according to theory), and then described in behavioural terms by two researchers discussing several video recordings. Refinements were made afterwards on the basis of a preliminary test of the S-DMM on eight observations with presymbolic persons (Hostyn, 2008). To support the S-DMM content validity, seven experts in interaction with presymbolic communicators, from the field of research as well as from practice, were consulted to provide comments and suggestions on the basis of which the S-DMM was further improved.

#### **Procedure**

#### **Observations**

The 18 dyads of persons with PIMD and their staff members were observed in a familiar room where they were alone. Their interactions were filmed without objects because we did not want to influence the context by ourselves, as one of the S-DMM dimensions intends to evaluate how interaction partners create an embedding context together. Staff were asked to interact with the client as they would usually do in a similar situation.

The observations lasted for ten minutes, which is already quite long for this target group. This was sufficient to observe the building of a process of dialogue, including moments of asynchrony and repair. All interactions were videotaped with two cameras, one providing an impression of the whole situation and the other zooming in on the person with PIMD in order to notice subtle expressions.

### Scoring Process

The video observations were coded with the S-DMM by two persons: an academic researcher experienced in observing interactions with persons with PIMD and a special educationalist with doctoral degree, qualified in working with presymbolic communicators. The scoring process started with a review of the theoretical background of the S-DMM. This was followed by coding videotapes, not part of this study. During this coding the scores and accompanying observations were discussed. Disagreements were resolved through conversation and by doing observation trials again until consensus was reached. Then, during the actual scoring, the 18 video records were presented randomly. Before coding, the raters were given information about the clients' abilities and disabilities and typical way of uttering (dis-)satisfaction and (dis-)engagement.

The unique feature of the S-DMM is that the scoring process is considered a dialogical process in itself. As a start, the two raters code each video independently. They are asked to note down their scores but also their qualitative observations, which function as score argumentations. This makes the coding process repeatable to a certain extent and, therefore, ensures a kind of argumentative reliability (Van Ijzendoorn, & Miedema, 1986). Scoring sheets were developed to stimulate raters to justify their scores with verbal and non-verbal behaviour. After the individual scoring, the two observers discuss their scores and observations. Discussion is had over both differing and similar scores to check whether not only scores but also observations agree. Finally, as a result of the dialogue, a shared score for each S-DMM subscale can be agreed upon.

Rather than emphasizing interrater reliability, this dialogical scoring process corresponds to a consensus rating procedure which has been shown to lead to high rating accuracy (Roch, 2006). The combination of individual observation and discussion, which is the major benefit of this consensus rating procedure, is certainly valuable to evaluate something as complex as a dialogue. Because, we can wonder whether the 'very process and technique of empirical research and objective observation destroy the dialogue atmosphere and relation' (Johannesen, 1971, p. 378). Although it is partially true that we can not totally represent the dialogue in a research context and the quantitative and qualitative scores are inevitably decontextualizing in a way (Markova & Linell, 1996), we believe that the focus on joint discourse has a surplus value to preserve the richness of the dialogue in all its aspects. As suggested by Wittenbaum et al. (1996) and elaborated on by Roch (2006), persons who anticipate group discussion and the obtainment of consensus may be more attentive for unique information because they are trying to make their argumentations more convincing for the upcoming discussion. In this study, it was especially interesting that the two raters shared theoretical knowledge to a certain extent but also partially had a different background, guaranteeing in-depth discussion, and the inclusion of diverse perspectives. This follows the conclusion of Nemeth et al. (2004) that debate and possible competing views stimulate divergent and creative thinking, and contribute to an atmosphere of idea generation.

In this study, all discussions between the raters were audio taped to enable reviewing of the scoring process afterwards.

#### Data Analysis

To answer the first research question, we examined the reliability of the S-DMM. Although consensus scores were decided, interrater reliability could still be calculated on the scores obtained by each rater before the negotiation phase. We computed the percentage agreement within 0.5 scale point for each subscale as well as for the S-DMM in total, using the formula agreements divided by disagreements plus agreements multiplied by 100. Additionally, the versatility of the S-DMM was determined by the range in scores and the multidimensionality. We examined the observed minimum and maximum scores for each subscale, and the score variation. Correlations between the subscales

were calculated to pass a judgement about the interconnection of the S-DMM sub-dimensions. As not all subscale scores were normally distributed and because of our small sample size, we calculated Spearman rank order correlations. The degree of association was interpreted according to the criteria of Cohen (1988) (i.e., .10 - .30: small correlations; .30 - .50: medium correlations; >.50: strong correlations). Medium correlations would support the instrument's multidimensionality.

To investigate whether the S-DMM provides a significant description of the dialogue between persons with PIMD and their communication partners, we analysed the obtained quantitative and qualitative data across the group as well as for each separate case. We calculated mean scores, standard deviations, and median scores for all subscales to determine how they describe dialogue across the group. Furthermore, the qualitative descriptions on the scoring sheets together with the audiotaped discussions, were examined to establish their meaningfulness and to trace general trends.

To answer the last research question, we evaluated the dialogical character of the descriptions on the scoring sheets. We considered the way the raters put into words what happened between the two interaction partners, i.e. whether and to what extent they used dialogical terms referring to interpersonal processes and not to individual contributions.

## **Results**

# Observer Agreement

For the S-DMM in total, the agreement within 0.5 scale point between the initial scores of the two raters was 78%. The lowest observer agreement was obtained for the subscale *mutual openness* (61%). High interrater agreement was reached for the subscales *joint embedding context* (89%), *non-manipulative negotiating* (83%), and *joint confirmation* (83%). The last subscale, *non-evaluativeness*, resulted in 72% agreement.

#### Range and Variation in Scores

All S-DMM subscales obtained an acceptable and wide range in scores (Table 2). All subscale (mid-)scores were assigned minimally once, except for the *non-manipulative negotiating* score of 4.5 and the *non-evaluativeness* scores of 1.5 and 2.5.

**Table 2**Subscale results.

Subscale	Observed	Observed	Mean	Standard	Median
_	min.	max.		deviation	
Mutual openness	1.5	5.0	3.28	1.03	3.00
Joint embedding context	1.0	4.5	2.58	1.22	2.25
Non-manipulative negotiating	1.0	5.0	2.33	1.20	2.00
Joint confirmation	1.5	4.5	2.69	1.03	2.75
Non-evaluativeness	1.0	5.0	3.00	1.25	2.50

#### Subscale Correlations

The correlations between the S-DMM subscales are presented in Table 3.

**Table 3**Subscale intercorrelations.

Subscale	1	2	3	4	5
1. Mutual openness	_	.80***	.87***	.93***	.67**
2. Joint embedding context		_	.86***	.79***	.74***
3. Non-manipulative negotiating			_	.90***	.82***
4. Joint confirmation				_	.67**
5. Non-evaluativeness					

<sup>\*\*</sup>p < .01; \*\*\*p < .001

All correlations between the subscales were significantly positive and strong. This indicates that, although theoretically distinguished from each other, the S-DMM dimensions also represent interconnected aspects of a global and overarching process. The results demonstrate that *non-evaluativeness* was the least strongly associated with the others.

## Quantitative Scoring Results

The quantitative scoring results for each subscale can be found in Table 2. Except for *non-manipulative negotiating*, which had the lowest mean (M = 2.33), all mean scores were above the theoretical mean. The mean score for *mutual openness* (M = 3.28) is the highest. Correspondingly, the median score for *mutual openness* indicates that half of the obtained scores were above 3.00. Likewise, half of the *non-manipulative negotiating* scores were below 2.00. Standard deviations of all subscales are not prominently high or low, pointing out that scores generally deviated about 1 point from the mean.

#### Qualitative Scoring Results

The individual observations of both raters were mainly analogous and complementary instead of conflicting. By considering them both throughout the negotiation phase a rich image of the observed dialogues could be generated. To illustrate how the S-DMM yields significant descriptions, we provide one case example of the communicative interaction between a 28-old woman with PIMD (P.) and her caregiver (C.). This case yields varying subscale scores, which shows how the S-DMM provides a tool to describe positive as well as negative aspects in the communication. The summarized descriptions provided here combine the argumentations of both raters and the elements raised during their discussion.

- Mutual openness (score 4.5). The bodily contact is steadily built up, and both partners show comfort in the distance between them (not too close, not too far). Both partners are not directed towards the surrounding or themselves, but are constantly attending for each other. This appears from C. who is making eye contact with P. (sometimes she is literally searching for the eyes of P. or she joins in when P. lets her head hanging) and the simultaneous alertness of P. for C (e.g. gaze following or turning her body towards C.).
- Joint embedding context (score 4): After a short introductory phase in which C. takes the lead, both partners build up a shared context of bodily games. The themes to which they are both attending are mainly their hands, giving kisses, and two songs. Initiatives of P. are also used as starting points (e.g. caressing each other). The different themes of attention constantly return, and are made accessible for both (e.g. bringing hands in P.'s visual field). However, sometimes there is a sudden switch to another theme by C. (e.g. from caressing to talking about mom who came on visit yesterday), not immediately clear to P.
- Non-manipulative negotiating (score 3): There are clear moments of negotiation (e.g. P. starts caressing, C. imitates, P. again confirms this, and so on). C. often asks "And now?" "Again?", and waits for a reaction. Pauses make it possible for P. to respond or initiate communication. On the other hand, C. is sometimes manipulative (e.g. "Give a kiss" "Do this, do that"), or keeps stuck in a system of questions and answers. Similarly, some initiations of P. are ignored (e.g. vocalizations or hand reaching).
- Joint confirmation (score 3.5): C. often nods or verbally acknowledges an utterance from P. (e.g. "A smile, yes", while laughing herself), while P. is smiling or lifting her head then to confirm C. However, several conversations remain unfinished because C. is switching to a next topic forgetting to re-confirm an utterance of P (e.g. C. starts to sing although P. is still reaching with her hand).
- Non-evaluativeness (score 2): *P. is regularly smiling towards C. She does not refuse the bodily contact of C. and also makes bodily contact with C. herself in a relaxed way. C. tolerates the sometimes abrupt physical contact of P. (e.g. messing up her hair or suddenly touching her face). On the other hand, short verbal sentences demonstrate some annoyance in how P. behaves (e.g. when P. is slobbering, C. gives a negative comment "yes, spittle, there is enough"). She sometimes literally controls P. (e.g. her hands), through which it is possible that P. feels herself the less worthy partner. It is not clear whether C. sees P.'s intentions for contact (e.g. interpreting hand reaching as slapping). There is no clearly observed shared pleasure.*

In general across the group, a notable trend in the qualitative descriptions was that there was more reference to basic bodily processes (such as bodily contact or the utterance of simple sounds) when interactions were highly scored. For lower scored videos, verbal conversations not adapted to the communication level of persons with PIMD, were more frequently mentioned. Remarkably in this regard, when young children with PIMD were involved, the themes around which meaning was

successfully built up often concerned bodily contact, frequently in combination with playful games (e.g. taking the child on the lap, rocking and singing together). In interactions with adults with PIMD, however, this playful bodily element was less observed and a verbal component (e.g., talking about) seemed to be more present.

# Dialogical Character of the Scoring Descriptions

With regard to the perspective from which the descriptions were built up, it was remarkable that the observations accompanying the lower scores were often described in monologic terms, predominantly emphasizing the separate communicative behaviours of (one of) both partners towards each other (e.g., in terms of 'he/she', 'I and it'). For example, score 1 on non-manipulative negotiating: The caregiver is constantly talking and dropping out ideas. She decides which topics are addressed (horses, daddy, etc.) She is not suggestive, as she also does not wait for a reaction of the child. She is trying to animate the girl as much as possible without taking account of her interests. The girl with PIMD does not get a chance to initiate. She only sometimes smiles in response to the funny sounds the caregiver produces. Only when dyads obtained higher scores, the qualitative descriptions were drafted in dialogic terms, accentuating the co-creative processes between both communication partners (e.g., in terms of 'they', 'me and you and it'). For example, score 4.5 on joint embedding context: In the beginning the caregiver introduces several songs to get the attention of the woman with PIMD. But after a short while, the context is formed on the basis of the initiatives of both, as they are constantly searching together for themes in the communication. They are rhythmically knocking on their bodies and build up songs together. Utterances from both partners give rise to a shared context of 'knocking and singing'. They are communicating in the 'here and now', through which it is clear for both of them to what they are attending to. The jointly created context embeds what is happening between them.

# **Discussion**

Given the theoretical value of the dialogical perspective to approach communication with persons communicating at a presymbolic level, the overarching aim of this study was to explore whether the S-DMM, an observation scale based on the dialogical approach, can be used to describe dialogue between persons with PIMD and their communication partners. The application of the S-DMM on eighteen videotaped staff-client interactions supports this.

Firstly, the S-DMM appeared to be a reliable and versatile instrument to map the dialogue between persons with PIMD and their support staff. Sufficient interobserver agreement was established on the individual scores obtained before the consensus rating procedure. For each S-DMM subscale, almost the full range in scores was observed. This shows that the S-DMM leads to score variation and makes it possible to differentiate between higher and lower functioning dyads on the five dimensions of dialogue. The subscales showed strong positive intercorrelations, which does not

support the scale's multidimensionality but rather indicates that the subscales are interconnected dimensions. The high correlations can also be explained by the occurrence of a halo effect, i.e. the raters' inclination to score an observation highly or lowly on all subscales because they consider them as similar dimensions. However, the fact that each score needed to be argued on the scoring sheets based on observable behaviours, could be seen as a control measure for this effect. In any case, future practice with the S-DMM should be attentive to this and try to further refine the different subscale accents in relation to the overarching concept of dialogue.

Secondly, this study demonstrated that the S-DMM aids in the description of dialogue between persons with PIMD and their support staff. The quantitative scoring results made it possible to depict some tendencies across the group. Considering the low mean and median score, *non-manipulative negotiating* seems to be the most difficult aspect to establish in the communication. The scores obtained for the other subscales indicate the general successfulness of the dyads on these dimensions, with *mutual openness* achieving the highest scores. The S-DMM yields qualitative descriptions that are referring to several behavioural aspects of dialogue, making a balance between positive and negative observations. This reveals that the S-DMM yields substantial information to provide a comprehensive picture of each staff-client communicative interaction. Additionally, a general trend was the importance of non-verbal and bodily processes to establish co-regulated communication, which is in line with other authors (Nafstad & Rødbroe, 1999; Olsson, 2004; Papousek, 1995).

Thirdly, in comparison to traditional instruments focussing on the separate behaviours of interaction partners (e.g., Hostyn et al., 2009b; Markova & Linell, 1996), the S-DMM enabled raters to describe co-creative communication and interaction processes in dialogical terms. A possible reflection on the dialogical approach is that persons with PIMD are considered to perform behaviours which are difficult according to their developmental age (e.g., empathy, joint attention). However, it is characteristic for high quality interaction that communication partners use over-interpretation while constantly checking the potential meaning of a person's behaviour (Daelman, 2003; Grove et al., 1999). In that way, persons with PIMD are approached as equal partners, and their communicative development can be promoted through dialogue.

### Limitations

Firstly, due to the intense and time consuming consensus rating process, the study's sample size remained rather small. Because of this, it was not possible to compute advanced statistical analyses, for example, to consider the influence of participants' characteristics on the dialogue. Although the in depth analysis of 18 observations by two raters delivered quantitative insights across the group and, mainly, significant qualitative knowledge, only preliminary conclusions can be drawn from this small-scale study. The convenience sample also does not make it possible to generalize our results. Therefore, it is recommended to further use the S-DMM to get a more profound evaluation of its value to describe dialogue with persons with PIMD.

Secondly, within the scope of this study, we could not do test recordings before the actual observations were done. Therefore, there is a risk that the video recording might have influenced the participants' behaviours. In addition, as it is known that persons communicating at a presymbolic level fluctuate in their interaction skills over time, context and persons (Wilder, 2008a), it must be concluded that this study's observations are only momentary snap shots. Hence, it is a good suggestion for future research to use the S-DMM for observations of persons with PIMD in different situations.

## Suggestions for Future Research

This study started from the idea that the equal low developmental age of our participants and their use of presymbolic communication are most influential and challenging in developing dialogue. Therefore, the large age range (3-59 years) of the participants was not considered as problematic. However, it is possible that staff holds other attitudes towards children and adults. The integration of video records of children and adults in this study made us conscious about the trends that playful bodily themes were easier established as a source of meaning making in interactions with children. The search for appropriate topics to develop an equal bodily based dialogue with adults seemed to be more taxing. This would be worthy of future research.

The S-DMM provides a global evaluation of the meaning making process, resulting in a synthesized quantitative score as well as general qualitative argumentation. Though this has the advantage that the interaction dynamics can be considered, detailed information gets lost in a way. Therefore, a combination with micro analytic systems, such as behavioural registrations, the three-step analysis (Markova & Foppa, 1991) or the initiative-response analysis (Linell, 1998), would be significant to get a thorough picture of the meaning making.

Lastly, the validity of the S-DMM should be further investigated.

## **Implications**

Although this study demonstrates the innovative value of the dialogical viewpoint and the S-DMM observation tool, it can be questioned whether they also offer new understandings when adopted in an intervention context. Certainly, as the dialogical theory is often unknown by practitioners, the S-DMM can be inspiring to clarify how high quality and co-creative communication can be built up. The S-DMM demonstrates that persons with complex disabilities, despite their idiosyncratic communication, also can and must have a valuable contribution in the search for shared meaning. Even their most simple utterances can be used as a starting point in developing dialogue. However, this does not exclude that the responsible and more skilled person (i.e. the staff member) has a task in stimulating the contribution of the person with PIMD (Olsson, 2004) and creating the conditions for dialogue to occur. In that way, being a staff member inspired by a dialogical viewpoint is: having an influence on and supporting the development of clients, through mutual consultation and negotiation, and by taking into account their interests and (dis)abilities. Therefore, the S-DMM can be introduced to practitioners as an encouragement to build on the strengths and initiatives of

presymbolic communicators when developing dialogue, in face of the asynchronies present in interactions between professionals and clients, and between persons with and without disabilities. However, it is an important future task to unravel how this can be translated for staff and/or family in intervention. The qualitative descriptions on the S-DMM scoring sheets may be a first step to indicate points of improvement but also, and of equal importance, to confirm the participants' dialogical behaviours. These can be starting points to enhance developmentally promotive communication.

In sum, the S-DMM makes it possible, through its quantitative and qualitative aspects, to give a reliable and significant description of the communicative interactions between persons with PIMD and their support staff from a dialogical viewpoint.

# **CHAPTER 5**

ATTENTIONAL PROCESSES IN INTERACTIONS BETWEEN PEOPLE WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES AND DIRECT SUPPORT STAFF  $^6$ 

### **Abstract**

Few studies have examined joint attention in interactions with persons with profound intellectual and multiple disabilities (PIMD), despite its important role in high-quality interaction. The purpose of this study is to describe the attention-directing behaviours of persons with PIMD and their direct support staff and the attention episodes resulting from their interactions, and to understand how these variables relate to each other. Video observations of 17 staff-client dyads were coded using partial interval recording. The results showed considerable variation across individuals and dyads. In general, persons with PIMD directed the attention of staff members infrequently. The staff members frequently directed their clients' attention towards a topic of interest but did not often use the tactile modality. Within the staff-client dyad, there was not much joint attention; however, shared attention episodes occurred frequently. Shared attention and joint attention are strongly correlated. A negative correlation was found between clients not using attention-directing behaviours and staff members using tactile methods to direct the attention, and joint attention episodes. This study presents both directions for future research and practical implications.

<sup>&</sup>lt;sup>6</sup> Hostyn, I., Neerinckx, H., & Maes, B. (2011). Attentional processes in interactions between people with profound intellectual and multiple disabilities and direct support staff. *Research in Developmental Disabilities*, *32*, 491-503.

## Introduction

A recent literature review determined that joint attention is an essential component in high-quality interactions with persons with profound intellectual and multiple disabilities (PIMD) (Hostyn & Maes, 2009). Similarly, caregivers mention that sharing experiences and joint attention is a fundamental part of successful interactions with children with PIMD (Wilder & Granlund, 2003). Sharing a joint focus of attention, however, poses a considerable challenge in interactions with persons with PIMD. Persons with PIMD seldom use verbal language, but they communicate pre- or protosymbolically through idiosyncratic and subtle utterances (Daelman, 2003; Stillman & Siegel-Causey, 1989); consequently, it is challenging to track, understand, direct, and share their focus of attention and interest. Parents of children with PIMD confirm that they have difficulty directing their child's attention towards a shared topic and maintain joint attention within the interaction (Wilder, Axelsson & Granlund, 2004). Wilder (2008a) also found that parents' wishes about changing their interactions with their children with PIMD all relate to joint attention.

Though a variety of definitions and perspectives exists (see Tasker & Schmidt (2008) for an overview), joint attention generally refers to an interaction in which two people are simultaneously focussed on the same object, action, or event while also sharing each other's attention and engagement towards that element of mutual interest. Baldwin (1995) states that this is accomplished when interaction partners recognise that they share a mental focus on a certain external element or, as Tomasello (1995, p. 107) indicates, "an understanding that the other participant has a focus of attention to the same entity as the self". Trevarthen and Hubley (1978) use the term secondary intersubjectivity, referring to coordinating and sharing each other's attention, feelings, and intentions toward the same outside object or activity. This state is preceded by primary intersubjectivity (Trevarthen, 1979), in which a person only engages in joint dyadic activities with either objects or persons. It is only when people integrate a third entity into their dyadic social interactions that triadic communicative interactions with people and objects are possible (Carpenter, Nagell, & Tomasello, 1998). Three kinds of behaviour, demonstrated by many observation studies, are indicative of this capacity (Carpenter et al., 1998): sharing attention with others, following their attention and behaviour, and *directing* their attention and behaviour with protodeclaratives and protoimperatives, respectively (Bates, Camaioni, & Volterra, 1975). Within developmental psychology, it is widely accepted that the capacity for joint attention emerges towards the end of a child's first year of life (Tasker & Schmidt, 2008), between 9 and 18 months of age (Eilan, Hoerlh, McCormack, & Roessler, 2005), and is fully established by 15 to 24 months in typically developing children (e.g., Bakeman & Adamson, 1984; Tasker & Schmidt, 2008).

People with PIMD generally function at a development age below 24 months (Ware, 1994); however, because individual functional skills and interactional experiences vary widely, we might assume that joint attention will occur in some interactions with people with PIMD. Therefore, it is

important to find out whether people with PIMD are capable of triadic interactions, which facilitating behaviours their interaction partners demonstrate, and how joint attention is manifested in the interactions between persons with PIMD and their significant others.

Some observation studies have investigated joint attention among people with PIMD, but they are not numerous. Olsson's (2004) case study qualitatively described the building of shared focus between a child with PIMD and his caregiver, defined as the theme upon which they agreed to communicate. In another study, Olsson (2005) revealed that more than half of the communicative behaviours of preschool children with PIMD served the function of joint attention, i.e., they were focused on sharing their experiences of an object or event. Another study (Hostyn, Daelman, Janssen, & Maes, 2010), using an observation scale based on a dialogical framework, described joint attention using the subscale of a joint embedding context. The degree to which a shared frame was jointly created within the interaction appeared to vary across the staff-client dyads. Scores ranged widely but were generally moderate.

An overall analysis of these available studies reveals two trends. Regarding the methods used, it is apparent that two of the three studies (Olsson, 2004; Hostyn et al., 2010) provided a global coding of joint attention. Although this certainly had the advantage of presenting a comprehensive picture of the interaction, it omitted detailed information on the exact occurrence and existence of joint attention. Regarding the underlying view of joint attention, two studies approached joint attention as an interpersonal variable (Olsson, 2004; Hostyn et al., 2010), whereas Olsson (2005) considered joint attention a communicative function of a person's individual behaviour. This discrepancy is acknowledged by Tasker and Schmidt (2008) as the *dual usage problem* (Patterson, 1982) in the study of joint attention. It occurs when behaviours of interest are used interchangeably with the function or purpose they serve. On one hand, the concept of joint attention refers to a co-created outcome of interpersonal interaction; on the other hand, it refers to a set of personal behaviours or skills that allows the individual to initiate or respond to joint attention (Tasker & Schmidt, 2008). Regarding the latter, two sets of joint attention behaviours are acknowledged: attention-directing behaviours, which direct the attention of the interaction partner, and attention-tracking behaviours, which respond to the interaction partner's joint attention acts (Tasker & Schmidt, 2008).

To summarise, detailed, non-global studies of attention in the interactions of people with PIMD remain rare, despite its important role in high-quality interaction. Furthermore, the dual usage problem seems to be endemic to this research area. Therefore, the primary aim of this study is to describe the occurrence of joint attention behaviours in people with PIMD and their interaction partners, along with the occurrence of attention episodes in their interaction, using direct behavioural observation. Of the two types of joint attention behaviours, we specifically focused on attention-directing behaviours because these behaviours represent individuals' own initiatives in the process of developing joint attention. With regard to the attention episodes, we sought to describe how both interaction partners distributed attention towards one other and towards a third element and to examine the degree of joint

attention during their interaction. Like Tasker, Nowakowski, and Schmidt (2010), we combined measures of individual attention-initiating acts with descriptions of the dyads' attention establishment, and we aimed to draw conclusions about the frequency and nature of these variables. A secondary goal of this study was to understand how staff and client attention-directing behaviours and episodes of attention relate to each other. The following research questions were addressed:

- (1) To what extent do people with PIMD use behaviours to direct their interaction partners' attention?
- (2) To what extent do interaction partners use behaviours to direct the attention of the person with PIMD?
- (3) How do both interaction partners distribute attention towards each other and towards a third element in the interaction, and to what extent do the interacting dyads engage in joint attention episodes?
- (4) Are the attention-directing behaviours of persons with PIMD and their interaction partners and the different attention episodes related to each other?

One hypothesis is that people with PIMD do not use attention-directing behaviours to a great extent, as the literature reports that people with multiple disabilities initiate little and communicate mostly in response to partners' cues, in a very subtle way (e.g., Bruce & Vargas, 2007; Rowland & Schweigert, 1993; Wilder, 2008a). The main hypothesis regarding interaction partners' attention-directing behaviours is that they use these behaviours to a great extent because they consider themselves to have a pivotal and responsible role in the interaction (e.g., Olsson, 2004; Wilder & Granlund, 2003), and partners of people with severe disabilities are often rather directive in their interactions (e.g., McCollum & Hemmeter, 1997). Previous studies have shown that they exhibit frequent verbal behaviour, such as asking questions or giving instructions (e.g., Healy & Noonan-Walsh, 2007). Regarding the occurrence of attention episodes, we hypothesised that triadic joint attention episodes do not occur often because of clients' complex disabilities but that dyads engage more frequently in dyadic interactions. This is in line with the parent-reported difficulties in achieving joint attention (e.g., Wilder, 2008a). There are no precise hypotheses regarding the relationship between attention-directing behaviours and attention episodes because this study was, to our best knowledge, a first exploration of this topic in the target group.

## Method

### **Participants**

The participants of this study were 17 dyads of persons with PIMD (Nakken & Vlaskamp, 2002 definition) and their direct support staff, who had worked with the clients for at least half a year. They were recruited using convenience sampling from four residential support services that agreed to participate after being informed of the design and purpose of the study. Staff members and client

representatives (because severe disabilities prohibited the clients from providing permission on their own behalf) were informed about the study, including a guarantee of anonymity and confidentiality in data treatment. Those who agreed to participate gave their written consent. We made the explicit choice to exclude blind and deaf people to avoid distorting the results with regard to the use of visual or auditory attention-directing behaviours by staff. However, we did not exclude people with the visual or auditory impairments that frequently occur in this target group (Evenhuis, Theunissen, Denkens, Verschuure, Kemme, 2001). Though they clearly benefit from the staff's adapted use of visual and auditory stimuli (e.g., showing an object in their visual field or directing sounds to their better hearing side), these sensory cues can still be included. Detailed participant characteristics can be found in Table 1.

### **Coding Instruments**

To answer our research questions, three coding schemes were developed to capture the attention-directing behaviours of the clients (ADB-c), the attention-directing behaviours of the staff (ADB-s), and the attention episodes in the dyad (AE-d). The coding manuals and the decision trees guiding the scoring of the three variables are available from the authors.

# Attention-Directing Behaviour (Client/Staff)

Like Tasker and Schmidt (2008, p. 267), we used the term "attention-directing behaviour" (ADB) to describe acts that are "displayed to elicit the attention of a social partner" or to "direct the attention of the partner to the object or event". We defined three conditions required to code verbal or nonverbal staff or client behaviour as ADB (Nowakowski, Takser, & Schmidt, 2009; Tasker & Schmidt, 2008): (1) active and intentional behaviour (2) clearly directed to the interaction partner (3) aimed at establishing or directing the interaction partner's attention.

Regarding the first criterion, the intentionality of a person's behaviour is difficult to identify; however, some behavioural indicators make it possible to infer intentionality, even in individuals with significant disabilities. A first indication is the goal-directedness of the behaviour, as apparent from the behaviour's persistence or its extended or modified repetition until the goal is reached (e.g., Bruce & Vargas, 2007; Daelman, 2003; Iacono, Carter, & Hook, 1998; Vandereet, Maes, Lembrechts & Zink, 2010; Wetherby & Prizant, 1989). Furthermore, evidence of the intentionality is also demonstrated by the anticipation of a response and/or by showing satisfaction or dissatisfaction with the response (e.g., Iacono et al., 1998; McLean, McLean, Brady, & Etter, 1991; Stephenson & Linfoot, 1996; Wetherby & Prizant, 1989). Lastly, the intentionality of the person's behaviour is also indicated by its directedness towards another person (e.g., Daelman 2003; Ogletree, Fischer & Turowski, 1996; Warren, Yoder, Gazdag, Kim & Jones, 1993), which we formulated as a separate, second ADB criterion.

**Table 1**Participants' demographic characteristics.

Demographic variable	Description
Clients ( $N = 17$ )	
Age	Range = $3-59$ years ( $M = 23.2$ ; $SD = 17.3$ )
Gender	
Female	<i>n</i> = 11 (64.7 %)
Male	n = 6 (35.3 %)
Sensory impairments	
Visual impairments	<i>n</i> = 9 (52.9 %)
Auditory impairments	n = 2 (11.8 %)
Challenging behaviour	<i>n</i> = 13 (76.5 %)
Staff members $(N=17)$	
Age	Range = 22-54 years ( $M = 37.4$ ; $SD = 9.3$ )
Gender	
Female	<i>n</i> = 14 (82.4 %)
Male	<i>n</i> = 3 (17.6 %)
Experience working with	
Persons with PIMD	Range = $3.5$ - 28 years ( $M = 13.8$ ; $SD = 8.6$ )
Client in the study	Range = $0.6-10$ years ( $M = 3.8$ ; $SD = 2.8$ )
Function	
Direct support staff	<i>n</i> = 11 (64.7 %)
Direct support staff and team support	<i>n</i> = 5 (29.4 %)
Therapist	n = 1 (5.9 %)
Level of education	
Bachelor's degree	n = 10 (58.8 %)
< Bachelor's degree	<i>n</i> = 7 (41.2 %)
Educational background	
Special education	<i>n</i> = 12 (70.6 %)
Teacher training	n = 3 (17.6 %)
(Para-)medical education	n = 2 (11.8 %)

A behaviour's directedness towards the partner is apparent in the person's bodily proximity, body or head orientation, eye-gaze direction, hand contact and voice direction (e.g., Daelman, 2003), or by the actor's alternating their gaze or body between the interaction partner and the goal (e.g., Carpenter et al., 1998; Iacono et al., 1998; Wetherby & Prizant, 1989). Behaviours that pertain only to the self or the self in relation to an object without involving a partner by trying to direct his/her attention were not considered. Therefore, no organisational acts (e.g., positioning a wheelchair or taking out the client's gloves) or self-directed behaviours (e.g., exploring an object, putting one's own behaviour into words) were coded as ADB. Particularly for clients with PIMD, stereotyped behaviours, which were frequently observed, were not coded as ADBs.

Regarding the third and final criterion, an ADB aims to establish or direct the interaction partner's attention towards the actor or an object upon which the partner was not focused. The behaviour may or may not be effective (i.e., noticed by or attracting the attention of the other person); however, we did not take this into consideration when coding ADBs and rather took it into account during the AE-d coding. In relation to this, no approval behaviours or other forms of feedback (e.g., hugging or nodding to confirm) and no response behaviours (e.g., performing a requested action, smiling or showing pleasure in what the other person does, following the other's attentional focus) were integrated.

Both staff and client attention-directing behaviours were coded in an analogue manner. First, the main code was determined by the sensory experience that was induced by the attention-directing behaviour; that is, the kind of sensory stimuli used to attract the partner's attention. Only the three sensory modalities that were observable on videotape (visual (1), auditory (2) and tactile (3)) were included; no olfactory or gustatory stimuli were coded. We chose to focus on the sensory stimuli that one partner evoked for the other partner to experience because this stressed the interactional dimension of staff and client behaviour. Since, the sensory experiences individuals evoked with their ADB behaviour were obviously directed towards the interaction partner. For example, talking to attract the client's attention was coded as an auditory ADB instead of a verbal behaviour, making clear that the staff member's speech was intended to be heard by the client. Second, a subcode was added to distinguish whether the ADB was caused by (a) the person him/herself or (b) the available object. For example, a visual ADB could originate from the client's own body (e.g., via pointing or making eye contact to guide the partner toward the object of interest) or from the object itself (e.g., showing the object to the partner). Using the object of interest to direct the interaction partner's attention does involve the participant's body; however, the emphasis here was on the stimulus the object evoked. We wanted to describe this characteristic to observe whether staff members were more likely to use themselves as instruments of the interaction or to use the objects to direct clients' attention.

It is obvious that multiple codes could apply to a single action (i.e., taking a client's hand to touch an object while making noise with it could be considered a tactile and auditory ADB caused by the object). This is why the codes, summarised in a coding scheme described in Table 2, were non-mutually exclusive.

Table 2

Coding scheme for attention-directing behaviour (staff /client).

Attention Directing Behaviour	Code	Examples
No ADB	0	
Visual		
Through person	1a	Pointing, active eye contact
Through object	1b	Showing the object
Auditory		
Through person	2a	Talking, giving instructions
Through object	2b	Making noise with the object
Tactile		
Through person	3a	Touching a person's arm
Through object	3b	Taking a person's hand to feel the object

## Attention Episodes (Dyad)

To code how the staff and clients distributed attention towards each other and towards a third element in the interaction, and the extent to which their attention was shared, a coding scheme addressing the dyad in interaction (AE-d) was developed. In general, the code *having no attention* meant that the participants' attention was self-directed or directed toward something other than the topic of interest of our study. *Having attention*, on the other hand, meant that the participants were not superficially looking or responding but were actively focused on and engaged in the objects of interest or to the interaction partner. Four possible episodes of attention were distinguished, as described in Table 3.

**Table 3**Coding scheme for attention episodes (dyad).

Attention episode	Code
No attention	0
Non-shared attention	
From staff but not from client	1a
From client but not from staff	1b
Divergent	1c
Shared attention	
Object	2a
Person	2b
Joint attention	3

In the first category, both partners paid no attention to the objects of interest or the interaction partner (0). The second category was used to code situations in which the participants were attending to the interaction, but the attention was not shared. This occurred when staff attended to the objects of interest and to the client with PIMD, but the client did not (1a). The reverse, when the client attended to the objects of interest and/or the staff member, but the staff did not, was also coded as nonshared attention (1b). In a third possible example of nonshared attention, both interaction partners attended to the interaction, but focused on something different or in a different way. For example, the client might be attending to the staff member while the staff member attended to the object, or each person was attending to different objects. Code 2 referred to shared attention, meaning that both dyad members shared attention on the same object of interest (2a) or each other (2b). It was possible for one partner to also attend to the other person (2a) or the object (2b), but unless that attention was shared by the partner, the attention remained dyadic rather than triadic. Although the term "shared attention" is sometimes used as a synonym for joint attention, we used it only for situations in which participants shared their attention for the object of interest or for each other with no evidence of a triadic relationship. Only when there was observable evidence of a triadic interaction was Code 3 of joint attention used. As Tasker & Schmidt (2008, p. 275-276) indicate, a triadic interaction is established when both partners "focus on the object or event of shared attention and communicatively and attentionally engage one another and the object through, for example, the exchange of smiles, vocalizations, verbalizations, or eye talk for a minimum of 3 s." Joint attention was coded when there was evidence that both people were attending to the same object and were also aware of the other person's interest. It is clear that the alternation of eye gaze between person and object, traditionally a prerequisite for joint attention, is not the only indication of joint attention; joint attention can also be indicated by gestures, body positions (e.g., leaning toward), touch, or vocalisations (Bruce & Vargas, 2007; Carpenter et al., 1998). The difference between Codes 2a and 3 is similar to Bakeman and Adamson's (1984) difference between passive joint engagement, referring to playing together with the same object without showing awareness of the other's participation or presence, and *coordinated joint* engagement, in which there is an active coordination of attention to both the object and the other person.

#### Procedure

This observation study was performed in accordance with the guidelines of the ethical committee of the author's university.

# Client Information Forms

Before the observations were conducted, staff members were asked to provide information about the client's characteristic utterances indicating (dis-)satisfaction or (non-)wellbeing and (dis-)engagement with persons and objects. This resulted in standardised forms containing each client's profile of affective communication and engagement (Petry & Maes, 2006).

#### Observations

Staff-client dyads were observed in one-on-one interaction in a familiar setting, i.e., a quiet room in the institution. All observations were made by two cameras, one capturing the dyad as a whole in its context and the other focused on the person with PIMD, to pick up on his or her subtle behaviours. The materials available were selected by a combination of standardised and individualised procedures (Petry & Hermans, 2007). First, to partially control the effect of the objects' characteristics on the nature of attention-directing behaviours, a group of eight objects was selected by the researchers. These objects were accessible to the target group of people with PIMD, were easy to handle, and could be used to invoke auditory, visual and tactile stimuli. Second, to guarantee the meaningfulness of the situation for the person with PIMD and to maximally stimulate interest and attention, two objects of preference were determined for each individual client through repeated observation. During those observations, the clients were given the objects nine times with no talking or interaction from the staff, on different days and in a different order each time, whereas their wellbeing, involvement, and duration of interest were scored. For each person, the two objects with the highest combined score were selected for the use in this study.

Our observations lasted for ten minutes, which is a considerable length of time for most persons with complex disabilities. The participants were not informed about the study's purpose, but were told that they could freely interact with the objects together and behave as they normally would in a similar situation in daily life.

### Coding Process

Starting with the description provided above, the frequencies of the target behaviours were calculated based on direct behavioural observation because there is less data reduction when using small coding units rather than global evaluations. All observations were quantified with an interval

coding system to estimate the frequency of occurrence of ADB-s, ADB-c, and AE-d. Partial interval sampling, in which the target behaviours were coded if they occurred at any point within the time interval, was considered the most appropriate and feasible, particularly because AE-d is a process variable that is difficult to code at one specific moment and reliably indicate when exactly a certain episode starts. We applied a 10-s partial interval coding procedure because this appeared to be a suitable compromise between a too-short and a too-long sample interval length in a pilot study in which the variables were continuously coded (Engel, 1996). Codings were performed using Vitessa (Van Puyenbroeck, Maes, & Laeremans, 2005) and The Observer XT 10 (Noldus, 2010).

Consensus-based observer training was organised to allow raters to become familiar with the target behaviours and the coding schemes. After sufficient interrater reliability was reached (Cordes, 1994), the three coding instruments were implemented. To prevent the influence of previous scoring (halo error) (Murphy & Anhalt, 1992), a minimum interval of six weeks was used between coding. Additionally, the three target behaviours were coded using separate scoring guidelines, and the randomly-determined order of the observations was different for the three coding processes.

Before actually coding, the client information forms were consulted to ensure that coders were sensitive to and understood the clients' utterances. They were also advised to first watch the entire fragment to gain a total view of the staff-client interaction. To make the coding more meaningful, raters were asked to take notes supporting their codings on a scoring sheet. Because the ADB-s and ADB-c categories were not mutually exclusive, all ADB behaviours occurring in an interval were coded. Each category could be coded no more than once in each interval, even when the same code could have applied to two separate ADB behaviours. An ADB behaviour that continued in a next interval was coded again. Regarding the mutually exclusive AE-d codes, the highest category best representing what occurred during the interval was coded. Again, each interval was coded separately, and an attention episode could continue in subsequent intervals.

### Interobserver Agreement

The reliability of the three coding schemes was assessed by calculating interobserver agreement between the primary investigator and a second independent rater. For that, six video records (35.3 %), randomly and separately selected for each coding scheme, were double-coded. These records were compared on an interval-by-interval basis for each of the measures. When both raters agreed on the occurrence of the target behaviour, i.e. one or more ADB(s) or a certain AE, an agreement was counted. The percentage agreement, determined by dividing the number of agreements by the sum of agreements and disagreements and multiplying by 100, was as follows: ADB-c (82 %), ADB-s (83 %), and AE-d (83 %). These measures, all above 80%, indicated good reliability (Cordes, 1994). Because the ADB-s was a high-rated behaviour and the ADB-c was a low-rated behaviour occurring in only a few intervals (Hopkins & Hermann, 1977), we also calculated kappa coefficients, which control for

chance agreements. These were, according to Landis and Koch's evaluations (1977), substantial for ADB-s (0.79) and AE-d (0.74) and moderate for ADB-c (0.58).

#### Data Analysis

To answer the first and second research questions, we generated descriptive statistics for the ADB-c and ADB-s data. We quantified the frequency of occurrence of the seven different categories of behaviours used to direct the interaction partner's attention by dividing the number of intervals containing a certain ADB across the whole sample by the total number of intervals observed. Next, we determined the different ADBs' frequency of occurrence for each individual separately, which allowed us to describe standard deviations, medians, and the minimum to maximum frequency of each ADB type. In addition, because the ADB categories were non-mutually exclusive, we examined how many different ADBs occurred during an interval to determine the percentage of intervals containing a certain number of ADB codes.

To describe the distribution of the attention between both interaction partners and the object, which pertains to the third research question, we calculated the occurrence frequencies for each kind of AE across the group and for each individual separately in the same manner, resulting in the same sort of descriptive statistics. Furthermore, the occurrence of joint attention episodes was investigated in-depth by establishing the number of joint attention episodes per dyad, the number of intervals containing joint attention episodes, and the attention episodes occurring before and after the joint attention episodes.

In addition to descriptive analyses, which suited the primary goal of this explorative study, we also wanted to understand the possible association between the individuals' attention-directing behaviours and attention episodes within the dyad. To examine whether interactions with more or fewer episodes of a certain ADB contained more or fewer episodes of a certain AE, and the reverse, we computed correlational analyses. These were conducted for the ADB frequencies per individual and the AE frequencies per dyad. As such, the correlations were not based on the exact association between the two sets of variables during a certain interval but on the individual or the dyad's general use of a certain ADB or engagement in a certain AE. We were uncertain whether attention-directing behaviours and attention episodes occurred simultaneously, as Norimatsu (2006), for example, found in mother-infant interactions that attention-sharing was often observed when neither participant called attention to the partner. Consequently, our correlational analyses to identify general trends suited the explorative nature of this study, the first to investigate attentional processes in the interactions of people with PIMD using direct behaviour observation. To further investigate the attention episodes, part of the third research question, we intercorrelated all AE categories, including the compound categories of nonshared attention (Codes 1a, 1b, and 1c) and shared attention (Codes 2a and 2b), to measure the strength and direction of their association. To answer the fourth research question, correlations between ADB-c and AE-d and between ADB-s and AE-d were assessed. We used nonparametric Spearman's rank order correlation tests because our data were not normally distributed, because of our small sample size, and because this type of correlation is less sensitive for outliers, which were certainly present in our data. The correlations' strength was interpreted according to the standards of Cohen (1988) (i.e., .10 - .30: small correlations; .30 - .50: medium correlations; >.50: strong correlations).

All analyses were completed using SAS software (SAS Institute Inc.).

### **Results**

# Attention-Directing Behaviours of Clients and Staff

A summary of the descriptive results for clients' and staff members' attention-directing behaviour can be found in the first part of Table 4.

The clients with PIMD did not produce behaviours to direct their interaction partners' attention in 88.82% of the observed intervals. Two people used no ADBs, and a total of ten clients showed no ADBs in more than 90% of the intervals, which is also indicated by the high median score (91.67%) for the "No ADB" category. However, three individuals with PIMD showed ADB in 30.00% of the intervals. When the clients did engage in ADB, they mostly directed staff's attention through visual cues and their own actions. When the object was involved in the ADB, which was only observed for three different clients, it was always in a visual way; i.e., showing the object to the staff. Only 9.71% of all observed intervals contained one ADB code for the clients' behaviours. A minority of the intervals were coded with two (1.18%) or three (0.29%) ADB's.

The staff members, on the other hand, displayed no ADBs in only 5.49% of the intervals. These ABD-free intervals occurred mostly when they were organising the environment or were in close contact and actively waiting for initiatives from the client. In two intervals, the same staff member was passively watching what the client was doing, with the object at a distance. Four staff members continually presented ADBs. The most frequently occurring ADBs were auditory, presented through the participant (e.g., talking to the client) (78.14%; *Mdn* = 81.67%) and visual, presented through the object (e.g., showing the object to the client) (66.47%; *Mdn* = 70.00%). Tactile ADBs, through the person (9.41%) as well as through the object (18.04%), were less frequently observed. Three persons never engaged in tactile ADB through their person, whereas one staff member used this sort of ADB during 60.00% of the intervals. In general, the minimum and maximum scores and standard deviations showed that the use of ADB differed considerably among staff members. Thirteen staff members demonstrated all six different kinds of ADB during the 10-minute interaction. Slightly more than 14% of the observed intervals for staff were coded with one ADB. Many intervals contained two (42.94%) or three (29.51%) ADB codes. In some intervals, four (7.06%) or five (0.49%) different ADB were observed.

**Table 4**Descriptive results.

Variable	Mean frequency	Min	Max	Median	Standard deviation	
Attention-directing behaviour						
Client (ADB-c)						
No ADB (0)	88.82 %	70.00 %	100.00 %	91.67 %	10.12 %	
Visual						
Person (1a)	6.57 %	0.00 %	28.33 %	5.00 %	8.22 %	
Object (1b)	1.08 %	0.00 %	15.00 %	0.00 %	3.63 %	
Auditory						
Person (2a)	2.84 %	0.00 %	11.67 %	0.00 %	4.20 %	
Object (2b)	0.00 %	0.00 %	0.00 %	0.00 %	0.00 %	
Tactile						
Person (3a)	2.45 %	0.00 %	18.33 %	0.00 %	4.86 %	
Object (3b)	0.00 %	0.00 %	0.00 %	0.00 %	0.00 %	
Staff(ADB-s)						
No ADB (0)	5.49 %	0.00 %	20.00 %	3.33 %	6.12 %	
Visual						
Person (1a)	27.94 %	1.67 %	66.67 %	23.33 %	18.83 %	
Object (1b)	66.47 %	38.33 %	93.33 %	70.00 %	19.52 %	
Auditory						
Person (2a)	78.14 %	51.67 %	98.33 %	81.67 %	14.81 %	
Object (2b)	20.20 %	0.00 %	56.67 %	16.67 %	16.18 %	
Tactile						
Person (3a)	9.41 %	0.00 %	60.00 %	6.67 %	13.96 %	
Object (3b)	18.04 %	0.00 %	36.67 %	15.00 %	13.10 %	
Attention episodes: Dyad (AE-d)						
No attention (0)	0.29 %	0.00 %	3.33 %	0.00 %	0.88 %	
Non-shared attention						
From staff (1a)	44.51%	3.33 %	100.00 %	43.33 %	26.46 %	
From client (1b)	0.49 %	0.00 %	6.67 %	0.00 %	1.64 %	
Divergent (1c)	7.16 %	0.00 %	35.00 %	3.33 %	9.53 %	
Shared attention						
Object (2a)	37.94 %	0.00 %	83.33 %	35.00 %	21.11 %	
Persons (2b)	6.47 %	0.00 %	25.00 %	3.33 %	7.19 %	
Joint attention (3)	3.14 %	0.00 %	18.33 %	0.00 %	5.13 %	

## Attention Episodes in the Dyad

The descriptive results regarding the attention episodes in the dyad are summarised in the second part of Table 4.

Within the staff-client dyads, there was no attention in 0.29% of the intervals. In almost half of the observed intervals (44.51%), the dyads were involved in nonshared attention, in which staff members were actively attending to the client and/or the object, but the client was not. Variety among the dyads, visible in the wide score range (3.33% - 100.00%) and high standard deviation (26.46%), is notable. One dyad spent their entire interaction in this condition. Episodes in which clients actively attended to the staff member and/or the object but the staff member did not occurred in 0.49% of the observed intervals and in only two different dyads. Divergent nonshared attention, in which the attentional focus of both interaction partners did not meet, was observed in 7.16% of the intervals. Shared attention to objects was observed in 37.94% of the intervals, again with great variety among dyads. Less shared attention towards persons was observed (6.47%), and this condition occurred among about one-third of the dyads (29.41%).

Dyads engaged in joint attention in only 3.14% of the intervals. However, eight of the seventeen dyads (47.06%) engaged in joint attention. In total, Code AE-d 3 was assigned to 32 intervals but only led to 13 different episodes of joint attention. Most dyads were involved in one joint attention episode (n = 5), but two dyads engaged in two joint attention episodes and one dyad engaged in four joint attention episodes. Of these episodes, three consisted of one interval, six of two intervals, three of three intervals and one of eight successive intervals. Before the joint attention episodes, shared attention to the object was most frequently observed (76.92%), with shared attention to a person observed in other cases. After an episode of joint attention, the AE-d codes 1a (23.08%), 1c (7.69%), 2a (53.85%) or 2b (15.38%) occurred. The intercorrelations between the AE categories are presented in Table 5.

**Table 5** Intercorrelations: AE-d.

Category	0	1a	1b	1c	Non- shared	2a	2b	Shared	3
AE-d 0	-	07	13	.48	.18	25	.19	24	13
AE-d 1a		-	21	42	.91***	69**	47	85***	69**
AE-d 1b			-	08	29	.41	12	.41	04
AE-d 1c				-	07	11	.24	02	.26
AE-d non-shared					-	83***	47	98***	69**
AE-d 2a						-	.05	.92***	.25
AE-d 2b							-	.33	.81***
AE-d shared								-	.56*
AE-d 3									-

<sup>\*</sup>*p* < .05; \*\**p* < .01; \*\*\**p* < .001

In general, the dyads that engaged in more in episodes of nonshared attention from staff and nonshared attention in general were less likely to engage in episodes of shared attention to the object, shared attention in general and joint attention, as is apparent from all six strong negative correlations. The correlation between episodes of nonshared attention from staff and compound episodes of nonshared attention was strongly positive ( $\rho$  = .91; p < .001). Shared attention to the object and shared attention in general were positively and strongly associated ( $\rho$  = .92; p < .001). Shared attention to a person and joint attention were strongly correlated ( $\rho$  = .81; p < .001), and shared attention in general and joint attention were significantly and positively correlated ( $\rho$  = .56; p < .05).

# Association between ADB and AE

The correlations between ADB-c, ADB-s, and AE-d are presented in Table 6.

**Table 6**Correlations: ADB and AE-d.

Category	AE-d 0	AE-d 1a	AE-d 1b	AE-d 1c	AE-d Non- shared	AE-d 2a	AE-d 2b	AE-d Shared	AE-d 3
ADB-c 0	.02	.42	04	32	.43	13	58*	32	62**
ADB-c 1a	06	74***	.16	.29	75***	.40	.68**	.64**	.84***
ADB-c 1b	.31	17	17	.65**	.15	16	08	20	06
ADB-c 2a	32	.10	.06	20	07	.13	02	.08	.03
ADB-c 2b	-	-	-	-	-	-	-	-	-
ADB-c 3a	.15	.20	26	.26	.22	37	.21	30	03
ADB-c 3b	-	-	-	-	-	-	-	-	-
ADB-s 0	.28	06	01	.61**	.11	07	08	11	18
ADB-s 1a	18	.16	17	12	.11	30	.21	19	.34
ADB-s 1b	.05	21	.05	28	42	.35	.62**	.42	.42
ADB-s 2a	12	.37	28	38	.31	34	.04	35	01
ADB-s 2b	25	40	.27	01	50*	.42	.04	.51*	.23
ADB-s 3a	13	.31	.14	07	.38	40	16	39	23
ADB-s 3b	.16	.02	.05	.19	.19	.08	67**	12	51*

<sup>\*</sup>p < .05; \*\*p < .01; \*\*\*p < .001

In general, there were significant negative correlations between interactions in which clients did not produce ADB and episodes of shared attention to a person ( $\rho = -.58$ ; p < .05) and joint attention episodes ( $\rho = -.62$ ; p < .01) in the dyad. This indicates that dyads in which clients with PIMD direct their interaction partner's attention less actively, there is a decreased likelihood of shared and joint attention. The reverse was also true: in dyads that less successfully shared a focus of interest, there was less likelihood that clients would pose ADBs. Particularly, when clients performed more visual

ADBs with their own bodies (the most frequently occurring client ADB category), there were fewer nonshared attention episodes and more shared and joint attention episodes. Finally, a positive correlation between client visual ADB through the object and divergent nonshared attention episodes was noticeable ( $\rho = .65$ ; p < .01). In interactions in which clients attempted to direct attention by showing the object, there were more episodes in which the interaction partners did not share an attention focus.

Divergent nonshared attention episodes were also significantly correlated with interactions in which staff did not pose ADBs ( $\rho$  = .61; p < .01). Furthermore, there were no significant correlations between staff ADBs through their own person and attention episodes. When staff ADBs involved the objects, a positive association emerged between visual ADBs through the object and shared attention ( $\rho$  = .62; p < .01). Staff auditory ADBs through the object were negatively associated with compounded nonshared attention episodes ( $\rho$  = -.50; p < .05) and positively associated with the compounded shared attention episodes ( $\rho$  = .51; p < .05). Finally, dyads in which the staff engaged more in tactile ADBs through the object were less associated with episodes of shared attention to the persons and joint attention episodes.

### **Discussion**

#### **Conclusions**

This observation study aimed to examine attentional processes during interactions between people with PIMD and their direct support staff. Our results confirmed that it is possible to use reliable, direct behavioural observation to generate a meaningful and detailed picture of the frequency and nature of both partners' attention-directing behaviours, the attention episodes resulting from their dyadic interaction, and the association between these variables, both for the individual dyads and for the group as a whole.

Clients with PIMD generally appeared to direct the attention of their staff members at low rates, which corresponds with our hypothesis. However, this does not mean that they did not communicate at all during the interactions. Persons with PIMD send numerous communicative signals, such as withdrawal, excitement, or challenging behaviours, to which interaction partners need to be sensitive and responsive and upon which interaction can be built. This study's results, therefore, pertain only to the specific, coded attention-directing behaviours. As hypothesised in the introduction, we observed that people with PIMD mostly respond or react to their interaction partners' behaviours and initiations. Nonetheless, our results demonstrate that some clients were actively directing their staff member's attention about one-third of the time.

Most hypotheses regarding the attention-directing behaviours of staff members were confirmed. The staff members did indeed frequently direct the attention of their clients with PIMD. The fact that staff often used several attention-directing behaviours within a single interval further confirms the staff's directiveness. Staff mainly used the objects in a visual way to direct attention and used their

own person in an auditory way, particularly using verbal attempts to direct the clients' attention to a topic or theme. Contrary to the results of several interview studies, in which staff members reported that touch was an important and preferred strategy in interacting with people with PIMD (Forster & Iacono, 2008; Healy & Noonan-Walsh, 2007), staff members did not frequently direct the client's attention tactilely in our study. An explanation for this may be that staff members, though aware of the importance of touch in interactions with people with PIMD, were uncomfortable with close bodily contact for several reasons, as described by Hewett (2007). During the few intervals in which staff members were not employing attention-directing behaviours, they were organising the environment or passively waiting. Some staff members also appeared to be actively waiting for client initiatives during the 10-s period. This could be regarded positively as nonintrusiveness, which is an important quality when interacting with people with PIMD (e.g., Hostyn, Petry, Lambrechts, & Maes, in press). Further research is necessary to distinguish between these periods with no attention-directing behaviour because they are relevant to interaction quality.

Within the dyad, as hypothesised, joint attention was only minimally observed. However, 13 episodes of joint attention were established, and almost half of the participating dyads appeared to be capable of triadic interactions. Although we did not explicitly code the duration of joint attention episodes, the frequent occurrence of successive joint attention intervals suggests that joint attention episodes are not short but often persist over several intervals. Supporting our hypothesis, shared attention occurred frequently. Shared attention between staff and clients focused mainly on objects. This could be partially because the staff thought that the available objects needed to be handled for the study, though this was never explicitly stated. Shared attention to persons was not often observed, although dyadic attention sharing on the interpersonal level is generally acknowledged as important to presymbolic communication, and triadic interaction is a natural extension of this (Daelman, 2003). The high correlation between shared attention on the personal level and joint attention in our study may demonstrate that this interpersonal dyadic interaction is not only a developmental milestone or precursor to joint attention (e.g., Camaioni, 1993) but is also associated with the occurrence of joint attention within every interpersonal interaction. Also, shared attention generally appeared to have a significant positive correlation with joint attention. These correlations, however, do not necessarily indicate causal relationships. However, we found that every episode of joint attention was preceded by an episode of shared attention, although there was no consistent profile of the attention episodes that followed joint attention.

The presence of a video camera may explain why attention from the client but not from the staff member (Code 1b) was not frequently observed. The same applies to the low number of attention-free episodes within this research context. We did observe many episodes of attention from the staff members towards the client and/or the object in which the clients were focused on themselves or something else in the environment. Divergent nonshared attention occurred minimally but provide

crucial opportunities for improvement. The presence of attention from both partners should be considered an opportunity to initiate joint attention towards a shared focus.

The correlations between ADB and AE highlight some preliminary trends in the association between individual behaviours and attention within the dyad. Our results regarding the negative association between client nonattention directing behaviour and shared/joint attention in interactions in general indicate that clients' initiatives to direct the attention of their interaction partners could provide an important starting point for building shared/joint attention and, on the other hand, that successful shared/joint attention also stimulates attention-directing behaviour from the client.

Only staff attention-directing behaviour through the object was significantly related to certain kinds of shared or joint attention. This could be explained by the fact that shared attention is focused mainly on the object and that joint attention is triadic in nature. However, this only accounts for the staff using the object in a visual and auditory way to direct the clients' attention and not using it for tactile attention-directing behaviour. Inviting the client to discover the object in a tactile way (e.g., by touching and feeling it) as a manner of directing their attention towards it seems not to lead to shared or joint attention; or, it seems to be a strategy used when an interaction is perceived as not functioning on a shared or joint attention level. In any case, tactile ADB and shared/joint attention occurred together infrequently in the interactions. This could be because persons with PIMD suffer from impaired tactile perception, which is often underdiagnosed (Evenhuis et al. 2001; Zijlstra & Vlaskamp 2005), or because staff is not familiar with using tactile behaviours in a non-functional or interpersonal way (Hewett, 2007).

#### Limitations

First, our sample size was small because of the intensive coding procedures required for the three observation schemes. Therefore, our results cannot be generalised and need to be treated with caution. This, along with the small variation in participants' characteristics, did not allow us to investigate the influence of certain client and staff characteristics (i.e., client autism spectrum disorders or staff experience) on the occurrence of attention-directing behaviours and attention episodes. This should be further investigated in larger groups.

Second, we considered using partial interval coding, but that would have prevented us from determining the exact duration of the episodes of shared and joint attention. Also, when coding the intervals in this explorative study, we did not distinguish between the occurrence of two separate successive attention-directing behaviours (e.g., first pointing to the object and then taking one's hand to touch it) and integrated attention-directing behaviour (e.g., pointing to an object while talking about it). The exploration of combined attention-directing behaviours would be interesting for future research. Flom and Pick (2003), for example, found that verbal behaviour was effective when combined with pointing and gestures to obtain longer periods of joint attention in parent-infant interactions.

## Suggestions for Future Research

Our study was the first exploration of the attention-directing behaviour of people with PIMD and their direct support staff and the attention episodes resulting from their interaction using direct behavioural observation. The descriptive results and preliminary trends and conclusions offer a starting point for further hypotheses and research directions, and offers a significant scope for future research.

We chose to make observations in a natural situation, not to inform participants on the study objectives, and to instruct the participants to behave as they would normally do. This allowed us to explore real interaction patterns, although we are aware of the possible influence of the presence of the video camera. However, we cannot conclude that we have accurately portrayed the maximum capacities of the clients with PIMD, the staff members, and the dyad with regard to attention-directing behaviour and shared/joint attention. For example, when staff members were very intrusive in directing the client's attention, the client may not have shown his full potential for initiating attentiondirecting behaviour or engaging in joint attention. Also, the range between minimum and maximum scores showed great differences between clients, staff members, and dyads in the use of attentiondirecting behaviours and the occurrence of attention episodes. It is difficult to know whether these differences relate to the complexity of the disabilities of persons with PIMD (e.g., level of intellectual functioning, autism spectrum disorders, and health status) or to the optimality of environmental characteristics, such as staff behaviour (e.g., having enough opportunities to initiate and direct their interaction partners' attention). To investigate the dyad's and individual's maximum capacities and further explore the differences between clients, staff members and dyads, experimental designs in which influencing variables are controlled or investigated are needed. This could also provide a view of the most optimal environmental conditions to elicit initiation from people with PIMD and joint attention in their dyadic interactions with staff. Relatedly, we used preferred objects but controlled the objects' sensory characteristics and did not work with objects from the clients' daily life, which would be necessary in research that explored clients' maximum capacities to direct their interaction partners' attention and engage in dyadic or triadic interactions.

More particularly, the preliminary correlational analyses used in this study allowed us to trace general trends and examine possible preceding attention-directing behaviours or attention episodes of shared/joint attention, along with the possible effects of shared/joint attention episodes on the partners' attention-directing behaviours or attention episodes in the dyad. However, no causal relationships or events could be determined. Therefore, to continue this exploratory study, in-depth analyses of the relationship between staff and client behaviours and attention episodes must be performed. First, more knowledge should be gathered on the effectiveness of different (combinations of) staff attention-directing behaviours in promoting shared and joint attention. Studies should also examine which behaviours or events negatively impact obtained shared and joint attention (e.g., not noticing a client's

initiative or posing a new attention directing behaviour too soon) because we know from parent-infant research that especially lengthy episodes of joint attention are important for social-emotional development (Tasker & Schmidt, 2008). Sequential analyses are necessary for this, and interviews with the participating staff could help clarify their views of the behaviours and events that do or do not promote shared/joint attention. On the other hand, when no general effective strategies emerge and every interaction needs to be considered individually, case studies would deliver valuable knowledge for future research.

The defining characteristic of this study was its use of direct behavioural coding. Although we are convinced of its merits, we also think it is necessary to integrate this study's findings with other methods in future research. First, we only coded staff behavioural cues, not the emotional and affective qualities of these behaviours. It would be interesting to also examine staff members' sensitivity, warmth, enthusiasm, and other affective qualities (Hostyn, Petry, Lambrechts, & Maes, in press) when they are directing the attention of the client. Affect and emotion could be considered important qualities for motivating people with PIMD to shared/joint attention and could make certain behaviours, such as touch, more or less effective for developing joint attention. Second, the use of qualitative methods is necessary to fully describe the topics on which participants are focusing. More than establishing that people are sharing attention to a certain object, which our direct behavioural coding registered, qualitative methods would allow us to describe in depth on which theme regarding that object they are focused. Additionally, this would make it possible to describe joint attention on the level of feelings and emotions, too, because joint attention does not only occur towards an object, but can be focused on another third element as well. Qualitative case studies, such as that of Olsson (2004), are most valuable for that purpose.

Furthermore, the coding of attention-tracking behaviours (Tasker & Schmidt, 2008) was outside the aim and scope of this study but remains an area of interest for future research.

### *Implications*

Regarding practical implications, our study demonstrates that a descriptive view of attentional processes within an interaction can provide insights and reveal specific characteristic interaction trends. Therefore, before trying to improve joint attention with intervention programs, we should offer staff opportunities to gain insight into their interactions, for example by analysing video records. In that regard, our coding schemes can give staff a theoretical background, a vocabulary, and a framework for these kinds of video analyses. Additionally, the design of our study shows that the focus on individual behaviours as well as dyadic relationship variables not only has a surplus value in research, but also in practice, to offer staff different perspectives for approaching attention in interactions. Awareness of individual attention-directing behaviours increase staff members' knowledge of their own contributions, strengths and weaknesses in directing the attention within interactions, whereas awareness of the types of attention episodes could help them to see the

possibilities and limitations of their interactions with specific clients. Finally, our study results, particularly the high correlation between shared and joint attention, demonstrate that we should not only target joint attention in intervention programs, but also shared attention with staff. Attention sharing on a purely interpersonal level, in particular, could be an interesting starting point for intervention.

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# **CHAPTER 6**

Interaction with a person with profound intellectual and multiple disabilities: A case study in dialogue with an experienced staff member  $^7$ 

### **Abstract**

Current observation studies examining the interaction between people with profound intellectual and multiple disabilities (PIMD) and their interaction partners seldom include practitioners nor provide in depth descriptions of the interactional processes occurring. The aim of this single case study is to develop a profound description of a unique interaction with a person with PIMD in dialogue with an experienced staff member. A videotaped interaction of the staff-client dyad was analyzed guided by a conceptual framework focusing on the client, the staff member, and the interacting dyad. Qualitative descriptions were generated by triangulation of data retrieved from direct observations and a staff-researcher dialogue. Results demonstrate that it is possible and meaningful to thoroughly describe an interaction episode supported by an integrative theoretical framework and valorizing experiential staff knowledge. This study confirms the importance of staff involvement supplemental to research observations, highlights the value of video-analysis, and offers directions for intervention.

<sup>&</sup>lt;sup>7</sup> Hostyn, I., & Maes, B. (2011). *Interaction with a person with profound intellectual and multiple disabilities: A case study in dialogue with an experienced staff member.* Manuscript submitted for publication.

### Introduction

People with profound intellectual and multiple disabilities (PIMD) have profound intellectual and profound motor disabilities often in combination with sensory disabilities and medical problems (Nakken & Vlaskamp, 2002; Vlaskamp, 2005). Their complex and high support needs make them thoroughly dependent on other people for their daily functioning. This is why supportive and well functioning relationships with significant others are a crucial determinant of the wellbeing and life quality of people with PIMD (Nind, 2009; Petry, Maes, & Vlaskamp, 2005; Petry & Maes, 2007).

Following this acknowledgement of the importance of high quality interaction for people with PIMD, the scientific interest and the number of empirical studies in this field have significantly grown during the last decades. Next to some intervention studies (see Maes et al. (2007) for an overview), several descriptive observation studies on interaction between persons with PIMD and their interaction partners have been performed (see Hostyn and Maes (2009) for an overview). These observation studies aim to identify and describe what is happening in the interaction between people with PIMD and their interaction partners from different perspectives. Some studies focused on the individual contributions from the persons with PIMD (e.g., Arthur, 2004; Hostyn, Neerinckx, & Maes, 2011a; Hostyn et al., 2011b; Olsson, 2005) or the interaction partners (e.g., Healy & Noonan-Walsh, 2007; Hostyn et al., 2011a; Hostyn et al., 2011b) while other studies focused on the interpersonal processes in the interaction from a dialogical (Hostyn et al., 2010), system theoretic (Olsson, 2004) or joint attention (Hostyn et al., 2011a) viewpoint.

The instruments that have been used as well as the studies' results have significantly contributed to the knowledge about interaction with people with PIMD and how to describe it. However, the current research has two notable shortcomings. First, the persons who engage with the people with PIMD on a daily basis (family or direct support staff) have not been directly involved in the description or evaluation of the interactional process. Instead, the coding of the observations and the studies' reliability have been determined by interobserver agreement between researchers only. In that case, results are based on intensive training in which researchers develop their own referential interpretative framework through exercise and discussion (Carter & Iacono, 2002). As it is known that the interpretations of presymbolic communication are not always consistent between researchers and professionals (e.g., Carter & Iacono, 2002), the studies' ecological validity together with the appropriateness and usefulness of the resulting descriptions could be better achieved by taking into account the experiential knowledge of persons familiar to the people with PIMD and the context as a complementary viewpoint. Second, except for the study of Olsson (2004), the available studies have focused on group results and only have provided descriptions of individual interactions in the margin. In depth and integrative descriptions of single staff-client interactions in their real-life context have been lacking. However, focusing on an individual staff-client dyad enables to look at the interaction from a dynamic and holistic perspective (Magnusson & Allen, 1983). Moreover, it is known that the target group of people with PIMD is very heterogeneous with large intra-group variability (Nakken & Vlaskamp, 2002; Olsson, 2005; Wachs, 2000). In specific, their communication is very idiosyncratic, and difficult to understand and interpret as a group (Grove et al., 1999; Vlaskamp, 2005). Related to these two shortcomings, the available studies only hold few direct relevance for practice. The studies' results certainly provide useful general insights but do not deliver individualized suggestions for action. Since, participants do not get to see the research videotapes, are not involved in creating a personalized description of the interactional processes occurring, nor get feedback on the strengths and difficulties in interaction with their specific client.

In sum, there is a need for observational research with a person-centered design (Magnusson & Allen, 1983) describing unique interactions in depth and involving the knowledge and experience of interaction partners who know the person with PIMD and his characteristic communication. Therefore, the purpose of this study is twofold. On the one hand, we want to describe a unique interaction with a person with PIMD from a holistic point of view and providing an integrative image of the interaction focusing on the person with PIMD, the direct support staff as well as the interacting dyad. On the other hand, we want to value the knowledge of the interaction partner, i.e. a member of the direct support staff, as an additional and complementary source of information in the observation process of the interaction. A descriptive single case study was set up because this enables to gain a comprehensive understanding of the particularity, complexity, and multifaceted aspects of the interaction in its real-life context (Stake, 1995; Yin, 2003). The research question was: How can we describe the interactional contributions of the person with PIMD and the staff member, and the occurrence of dyadic processes in an interaction episode relying on research observations and staff report?

### Method

#### Procedure

Following our case study protocol, a small-scale day care centre in the Dutch speaking part of Belgium was selected for the study based on their specialization in supporting exclusively individuals with PIMD, their valuable collaboration in a centre of expertise on the target group of people with PIMD, their interest in interaction research, and their willingness to participate. After being informed on the study design, a staff-client dyad yielding maximum opportunity to learn (Stake, 1995) was selected in dialogue with the head of the facility, the special educationalist and the direct support staff. It was requested to select a client who's way of interacting they were interested in and whom they wanted to get to know better by way of video observation. The facility was free to choose for a person whose interactions generally passed smoothly or precisely with difficulties. In addition, it was requested to select a member of the client's direct support staff, working with the client for at least one year, interested in watching video observations, and willing to reflect on interactional processes together with a researcher. Following the ethical standards of our university, both the client's parents

and the staff member were guaranteed confidentiality and gave their written consent for the study. The representatives of the fellow clients gave their written consent for filming in the group.

### **Participants**

The participating dyad consisted of a client with PIMD (C.) and one of his direct support staff members (S.). At the moment of the study, C. is a sixteen-year-old boy cognitively functioning at a developmental level of twelve to fourteen months (IQ below 25). He is capable of head movements but has severe motor dysfunctions: paralysis of the upper and lower limbs, spasms, hypotonia, and deformations. Scores on the Vineland Adaptive Behavior Scale are: communication 6 months, daily living skills 2 months, socialization 7 months, and motor skills 1 month. C. has no limitations in visual or auditory skills, nor does he show problem behaviour or suffer from other mental health problems. He needs intensive specialized medical care on a daily basis and suffers from epilepsy controlled with medication. Because of severe feeding problems, C. is tube fed. He stays in the facility for five days a week since he was one year old. Staff describe him as a sweet, calm, and happy boy, feeling at ease in the group he knows. He was selected for this study by the staff members of his group because he is introvert, easy going, and he disappears more easily into the background in comparison to the fellow clients in his group although he enjoys individual contact. That is why staff considered the case study an ideal opportunity to pay attention to and reflect on his communicative signals and interactive capacities in one-on-one contact. The participating staff member, a woman of 49 years old, knows C. for about four years and has thirty years of experience in working with clients with PIMD. She has a secondary education degree. S. works part-time but sees C. several times a week and assists him with all his daily needs. She was selected for the study because of her experience with the target group as well as with C., and she was willing to participate herself because of her interest to talk and learn about the interaction with C.

## Recordings and Case Description

During three days, the researcher was present in the group with the camera and the staff-client dyad was regularly filmed in his normal living environment. This was an ideal opportunity to get acquainted with the people involved, their context, and to make a quiet entry for the study (Stake, 1995). The number and nature of the naturalistic video observations were defined in consultation with the centre's head and the participating staff member. They were asked to select several moments in which one-on-one interaction between the client and the staff member could be observed during well-known and real-life activities in their natural setting to be as less intervening and intruding as possible, an important feature of qualitative case study research (Stake, 1995). To capture diverse interaction patterns and to have the chance to evaluate the potential occurrence of triadic interaction afterwards, the availability of minimally one object was required, but not necessarily during the full interaction episode. The staff member was instructed to act as she normally would in the particular situation and to perform the activities as usual. Furthermore, the staff member could decide on the observations'

duration (though minimally five minutes and maximally half an hour), i.e. by indicating to stop the filming when she had the feeling that the interaction episode was over and she would normally switch to another activity. To be able to evaluate the possible repair of conflict moments, we explicitly asked to not immediately stop the interaction when a temporary breakdown was noticed. These decisions maximalized the opportunity to record interactions with a natural flow, beginning, and end.

All interactions were videotaped with two cameras, one capturing the dyad as a whole in its context and the other zooming in on the person with PIMD to pick up his subtle expressions. In total, five video records were made. They represented several daily situations meaningful for C.: a morning greeting moment, an activity with coloured bags, a musical activity, a story telling session, and a moment where he lies down on a mattress. Afterwards, these records were shown to S. She was asked to select the record that was to her opinion containing the most interesting and rich information with regard to the interaction with C. A decisive criterion in the selection process was that S. had to choose a record in which she considered the dyad as demonstrating its most full potential and strengths to interact together, as the opportunity to learn and reflect can be considered to be maximized by positive examples (Dekker et al., 2004; Kennedy, Landor, & Todd, 2010). Finally, one video record was chosen as the final case of interest for analysis by S.

The selected observation, lasting for eight minutes and 24 seconds, shows C. and S. interacting together with music instruments. C. is sitting in his wheelchair next to the window and S. is standing close to him. Five other clients and one colleague staff member, well known by S. and C., are also present in environment but are not directly involved in the activity. The musical activity is built around three instruments: hand bells, a recorder, and a frame drum. After introducing the instruments by playing them for C., S. successively disappears with the three instruments from the visual field of C. and makes noise with them. Then she comes back to C. and asks him what he heard while she repeatedly lets the music instruments hear. For example, S. asks "Did you hear the drum?" while beating it. After that, S. goes ringing the bells behind the door and behind the curtains. Before rounding off the activity, C. gets the opportunity to beat the drum himself and to play with the hand bells.

S. was immediately convinced of her choice for this fragment. She generally knows that C. likes music instruments and she enjoyed this interaction much during the activity itself but she is even more convinced of this while watching the record during the video selection process. She noticed that C. was very alert, open, and cheerful. She was astonished by the fact that C. was constantly and enthusiastically following what happened even when she was not directly in his neighborhood. She also saw much communicative signals of C., of which some of them were not noticeable to S. during daily interaction. She was convinced that this video record positively reflects the possibilities of interacting with C. and demonstrates his interactive capacities. At the same time, S. saw some interaction features that she wanted to further examine because they were unclear when first watching the observation during the video selection process (e.g., is he nodding or vocalizing at that moment or

not?). In sum, arguments from the perspective of the client (e.g., he was really enjoying the event and showing his capacities) as well as from S.'s perspective (e.g., I was satisfied by the interaction, I want to watch it in detail) led to the final video selection.

### Conceptual Framework

As a blueprint for the data collection and analysis, and to sharpen the focus of our study, a guiding conceptual structure related to the study topic was developed (Stake, 1995; Yin, 2003). The conceptual framework was based on previously used theoretical backgrounds from interaction studies focusing on people with PIMD and their interaction partners. As sufficient experience is a necessary prerequisite to conduct high quality case study research (Stake, 1995; Yin, 2003), we adopted theoretical approaches familiar to the researcher team involved in this study (see Hostyn et al., 2010; Hostyn et al., 2011a; Hostyn et al., 2011b for detailed information). They served as a coat closet and spotlight for this research (Maxwell, 1996). Key ideas from parent-infant research and attachment theory on affective and reciprocal interpersonal processes were used as one source of inspiration. It concerns interactive behaviours of children and their interaction partners that are promotive in developing emotional availability and mutual interactions (e.g., Ainsworth et al., 1978; Emde 1980). In specific, these theories describe how persons with a low developmental age influence their interaction partners and are having a shared part in the development of positive relationships. These frameworks also give relevant insight into how caregivers promote a positive relational climate by sensitivity, responsivity, and emotional attunement. In addition, understandings from developmental psychology on how children and their caregivers coordinate and direct each other's attention towards a topic of interest were valued (e.g., Carpenter, Nagell, & Tomasello, 1998). Particularly, the knowledge on how intentional communication and directedness towards another person or a third entity in the interaction are developed in presymbolic persons were helpful additions. Besides, notions from the joint attention theory were adopted, outlining how two people can simultaneously focus on the same communication theme (an object, event, or act) while also being aware of each other's attention and engagement towards that element of mutual interest (e.g., Carpenter et al., 1998). Lastly, a dialogical approach was consulted explaining how interaction partners with different thoughts and abilities can jointly create meaning and come to shared understanding through continuous interaction and negotiation (e.g., Linell, 1998; Markova, Graumann, & Foppa, 1995).

We clustered these different theories into an integrative conceptual framework for this case study by tracing several interactional dimensions. These were formed by putting together the concepts from different theories belonging to an overarching component of a person's interactive behaviour or reflecting the same aspect of the dyad's interaction. They are described in the first four columns of Table 1. In line with the above described research questions, the framework was drafted providing an understanding of: (1) the person with PIMD, (2) the direct support staff member, and (3) the interacting dyad. With regard to the interactive contributions of the person with PIMD, three

dimensions were distinguished: (1a) responsiveness and attention (to the activity and to the interaction partner respectively), (1b) initiation (towards the activity and towards the interaction partner respectively), and (1c) emotions. Similarly, dimensions to comprehend staff contributions in the interaction were: (2a) responsiveness, (2b) initiation (structuring, nonintrusiveness, and stimulation respectively), and (2c) emotions. The interaction processes in the dyad were grouped into three dimensions: (3a) mutual openness and respect, (3b) joint context, and (3c) negotiation.

This use of diverse perspectives inspiring our study's data collection methods and enabling to focus on the different facets of the complex interaction phenomenon, is a form of theory triangulation (Patton, 1987). The selected combination of theoretical frameworks can be considered to provide a full range and holistic image regarding our study topic (Yin, 2003) as they reflect on behavioural as well as more emotional components both from the individual interaction partners as well as within the dyad. The interactional dimensions focus on sensitive responsiveness, joint attention, co-regulation as well as emotional aspects of the interaction which are considered to be four constituting components of interaction with people with PIMD in a recent literature review (Hostyn & Maes, 2009).

### Data Collection

Multiple sources of evidence, complementary and convergent to each other, were used to increase the construct validity of this case study (Yin, 2003) and as a form of data-triangulation (Patton, 1987).

# Direct Observation

As a first part of the data collection process, the videotaped staff-client interaction was described and evaluated by direct observation. Several documents, i.e. C.'s individual support plan, his communication passport, and a standardised profile (Petry & Maes, 2006) of his affective communication and engagement filled in by the staff member, were consulted to get to know the client as a person in interaction with his context. In accordance with the conceptual framework, the following observation rating scales were applied to the case of interest by a trained and experienced researcher: the Emotional Availability Scales (EAS; Biringen et al., 1998) (for which the first author obtained a certificate of reliability), the Maternal Behavior Rating Scales (MBRS; Mahoney, revised 1992), the Child Behavior Rating Scales (CBRS; Mahoney, revised 1998), the Revised Erickson Scales (RES; Egeland et al., 1990), and the Scale for Dialogical Meaning Making (S-DMM; Hostyn et al., 2009), which were all global rating scales. Partial interval coding was applied using coding schemes developed by Hostyn et al. (2011a) on attention-directing behaviour of the client (ADB-c), attention-directing behaviour of the staff (ADB-s), and attention episodes in the dyad (AE-d).

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**Table 1** Conceptual framework and data collection dimensions.

Focus	Inspiring theoretical frameworks	Interactional dimension	Sub dimensions	Direct observation subscales	Examples of questions from the interview guide
(1) Person with PIMD	Parent-infant research Developmental psychology	(1a) Responsiveness and attention	Activity	<ul> <li>Attention to activity (CBRS)</li> <li>Persistence (CBRS)</li> <li>Involvement (CBRS)</li> <li>Enthusiasm and persistence (RES)</li> </ul>	<ul> <li>Does C. has attention for the activity?</li> <li>Does C. participates with effort and eagerness?</li> </ul>
			Interaction partner	<ul> <li>Responsivity, part 1 (EAS)</li> <li>Compliance/cooperation (CBRS)</li> <li>Compliance (RES)</li> <li>Experience (RES)</li> </ul>	<ul><li>Does C. complies with your suggestions?</li><li>Does C. cooperates with you?</li></ul>
		(1b) Initiation	Activity	Initiation activities (CBRS)	• Does C. initiates activities himself?
			Interaction partner	<ul> <li>Involvement partner (EAS)</li> <li>Initiation partner (CBRS)</li> <li>Attention-directing behavior (ADB-c)</li> </ul>	<ul> <li>Does C. initiates interaction with you?</li> <li>Does C. directs your attention towards himself, an object, or event?</li> </ul>
		(1c) Emotions		<ul> <li>Responsivity, part 2 (EAS)</li> <li>Affect (CBRS)</li> <li>Affect (RES)</li> <li>Affection (RES)</li> </ul>	<ul> <li>Does C. shows pleasure in the interaction?</li> <li>Does C. shares his feelings with you?</li> </ul>

**Table 1 (Continued)** 

(2) Staff member	Parent-infant research Developmental psychology	(2a) Responsiveness		<ul> <li>Sensitivity, part 1 (EAS)</li> <li>Sensitivity (MBRS)</li> <li>Responsivity (MBRS)</li> <li>Effectiveness (MBRS)</li> <li>Sensitivity and timing (RES)</li> </ul>	• To what extent do you notice and follow the interests of C.?
		(2b) Initiation	Structuring	<ul> <li>Structuring (EAS)</li> <li>Clarity of instruction (RES)</li> <li>Attention-directing behavior (ADB-s)</li> </ul>	<ul><li> How do you structure the interaction?</li><li> How do you focus C.'s attention towards something?</li></ul>
			(Non)intrusiveness	<ul> <li>Non-intrusiveness (EAS)</li> <li>Directiveness (MBRS)</li> <li>Pace (MBRS)</li> <li>Non-intrusiveness (RES)</li> </ul>	• To what extent are you directing C.'s behavior?
			Stimulation	<ul> <li>Inventiveness (MBRS)</li> <li>Achievement (MBRS)</li> <li>Praise (MBRS)</li> <li>Supportive presence (RES)</li> </ul>	• To what extent do you stimulate C.'s sensorimotor or cognitive development?
		(2c) Emotions		<ul> <li>Sensitivity, part 2 (EAS)</li> <li>Non-hostility (EAS)</li> <li>Acceptance (MBRS)</li> <li>Enjoyment (MBRS)</li> <li>Expressiveness (MBRS)</li> <li>Warmth (MBRS)</li> <li>Confidence (RES)</li> </ul>	<ul> <li>To what extent do you enjoy the interaction with C.?</li> <li>How do you demonstrate your emotions and acceptance towards C.?</li> </ul>

**Table 1 (Continued)** 

(3) Dyad	Joint attention (developmental theory) Dialogical theory	(3a) Mutual openness and respect	<ul> <li>Mutual openness (S-DMM)</li> <li>Non-evaluativeness (S-DMM)</li> </ul>	• To what extent are you both directed towards each other?
		(3b) Joint context	<ul><li> Joint embedding context (S-DMM)</li><li> Attention episodes (AE-d)</li></ul>	To what extent do you both have attention for the same topic in your interaction?
		(3c) Negotiation	<ul> <li>Non-manipulative negotiating (S-DMM)</li> <li>Joint confirmation (S-DMM)</li> </ul>	<ul> <li>To what extent is there a balanced and reciprocal exchange of turns?</li> </ul>

The rating scales were used in a quantitative way, delivering scores on different subscales, but mainly in a qualitative way, providing multiple perspectives and comprehensive descriptions of the interaction being studied. The RES subscales were positively formulated and, as in the study of Hostyn et al. (2011b), the staff hostility and the client dependency scale were not preserved. The attention directing behaviours existed from seven non mutually exclusive categories. Based on the theoretical descriptions of the concepts in the scales' manuals and partially on the correlations from the study of Hostyn and colleagues (2011b), the subscales were grouped into the different dimensions of our conceptual framework. An overview of the subscales applied to the interactive behaviour of the person with PIMD and the staff member, and to the dyad in the interaction can be found in the fifth column of Table 1.

The tools have all been successfully and reliably applied in descriptive interaction studies in the target group of people with PIMD. Detailed information on the instruments' content and their use can be found in the manuscripts reporting on these studies (Hostyn et al., 2010; Hostyn, et al., 2011a; Hostyn, et al., 2011b).

# Staff-researcher Dialogue

As the explicit aim of this study was to involve the interaction partner of the client with PIMD during the observation process, an open-ended interview with S. constituted the second part of the data gathering. Multiple observations of the selected staff-client interaction video record were the central basis for the discussions between the researcher and the informant, with the purpose to discover and portray multiple views of the case (Stake, 1995). Therefore, the interview was conceived as a dialogue, starting from the acknowledgement that both parties have an a-symmetry in knowledge on interactions with people with PIMD (Linell & Luckmann, 1991). The role of expert and novice (Wintermantel, 1991) continuously changed between the researcher having theoretical knowledge and the staff member having experiential knowledge from practice. By a dialogical encounter between S. and the researcher and through their discussions, the different forms of knowledge could be valued and exchanged, leading to new insights. This resembles the principles of Video Interaction Guidance in which a supportive atmosphere to develop new thoughts is also created by the intersubjectivity and relationship between guider and parent (Kennedy et al., 2010). As such, the staff-researcher dialogue was not a structured query but a guided conversation (Yin, 2003). The conceptual framework and the described observation rating scales offered direction for the development of the interview guide consisting of issue-oriented questions on the three interaction levels, all dimensions and the different instruments' subscales. In total, four discussions were organized, rapidly after the recordings were made to prevent the loss of information as much as possible. First, the videotaped staff-client interaction was watched for several times and discussed in general (e.g., what are you seeing?, what are crucial moments?). In a second and third meeting, the interactional behaviour of the client and the staff member respectively were focused on. Lastly, the interacting dyad was the central aspect of the fourth conversation. Examples of questions can be found in the last column of Table 1, though only reflecting basic questions. Since, the interaction aspects were explained to S. and she was not only questioned about the facts of a matter, but also about her feelings, thoughts and behaviours, her descriptions of interaction episodes, her opinions about the interaction event, and her own insights and explanations of certain occurrences and linkages (Maxwell, 1996; Stake, 1995; Yin, 2003). Also, for each variable, we asked when and how she observed it, how important this variable was to her, and which elements are influencing the occurrence of the variable. Based on some pilot projects, the researcher was experienced in translating the theoretical concepts into open questions to practitioners. Additionally, the interview guide was reviewed on its completeness and clearness by an independent researcher, who was informed about the study's objectives and procedures through the case study protocol. However, the questions were used in a flexible way during the interview and mainly served as a reminder regarding the information that needed to be collected. From active listening to the informant during the meetings, other questions arose promoting a smooth flow of the discussion and enabling to go along with S.'s interests.

All discussions were tape-recorded with S.'s permission. Within a few hours after the meetings, a written facsimile with a reconstruction of ideas and key episodes captured (Stake, 1995) was drafted by the researcher.

#### Data Analysis

A qualitative approach in which interpretation is central and the multiple realities of the study topic are preserved was most desirable to understand the case in depth and in a holistic way. The principal interest of this study was intrinsically in the case itself. Therefore, thoroughly understanding the case was the primary data analysis goal (Stake, 1995). Following Maxwell's (1996) recommendations, first the observational codings, notes, and interview transcripts were red repeatedly and extensively. The data sources were analyzed with regard to thematic content (Miles and Huberman, 1994; Stake, 1995). Furthermore, data analysis was established by triangulation of the collected data (Thurmond, 2001). An analytic tactic similar to a pattern matching strategy (Yin, 2003) was used. The data were categorized by seeking patterns, i.e. recurring themes across the different sources of information. Through analytic generalization our conceptual framework was used as a template against which our data were compared (Yin, 2003). A gradual process of rearranging and mapping the data into the different categories was expanded spirally and flexibly in interaction with our data being analyzed. Throughout the data analysis process, memos were continually drafted by the researcher facilitating the analytic thinking on the obtained data and leading to analytic insights (Maxwell, 1996).

This application of a systematic analytic tactic to our data set guaranteed the internal validity of our study as much as possible (Yin, 2003). Besides, to reduce the possibility of misunderstandings and in light of the study's construct validity (Yin, 2003), a provisional case study report of about twenty

pages of text and illustrated with snap shots of the video record was examined and reviewed by our key informant within two weeks after the staff-research meetings. There were no disagreements but S. made some additions regarding more detailed clarifications and rewordings of her perspective. Although a member check cannot be the sole source of validation in qualitative research, we used it in this study as a tool for reflection by the participant, to confirm the interpretations of the researcher and to stimulate the researcher to reexamine the analytic process (Morse, Swanson, & Kuzel, 2001).

### **Results**

This results section is organized according to the three interaction levels presented in the conceptual framework: the person with PIMD, the staff member, and the interacting dyad. Results from the direct observations (overviewed in Table 2), and the staff-researcher dialogue are integrated with citation to relevant data sources.

Table 2
Direct observation results

Instrument	Subscales	Results
Emotional	Sensitivity	6
Availability Scales	Structuring	4
	Non-intrusiveness	3.5
	Non-hostility	5
	Responsivity	6
	Involvement partner	4
Maternal Behavior	Sensitivity	4
Rating Scales	Responsivity	3
	Effectiveness	3
	Acceptance	3
	Enjoyment	3
	Expressiveness	4
	Inventiveness	4
	Warmth	3
	Achievement	4
	Praise	2
	Directiveness	4
	Pace	3
Child Behavior	Attention to activity	4
Rating Scales	Persistence	3
	Involvement	4
	Compliance/cooperation	4
	Initiation activities	2
	Initiation partner	2
	Affect	4

**Table 2 (Continued)** 

Instrument	Subscales	Results
Revised Erickson	Supportive presence	5
Scales	Clarity instruction	6
	Sensitivity and timing	5
	Confidence	5
	Non-intrusiveness	4
	Enthusiasm, persistence	6
	Compliance	6
	Affect	7
	Experience session	6
	Affection to partner	5
Scale for Dialogical	Mutual openness	3.5
Meaning Making	Joint embedding context	3
	Non-manipulative negotiating	2
	Joint confirmation	3
	Non-evaluativeness	4
Attention-directing	No ADB-c (0)	90.20%
behaviour client	Visual through person (1a)	9.80 %
	Visual through object (1b)	0.00 %
	Auditory through person (2a)	0.00 %
	Auditory through object (2b)	0.00 %
	Tactile through person (3a)	0.00 %
	Tactile through object (3b)	0.00 %
Attention-directing	No ADB-s (0)	17.65 %
behaviour staff	Visual through person (1a)	15.69 %
	Visual through object (1b)	29.41 %
	Auditory through person (2a)	58.82 %
	Auditory through object (2b)	64.71 %
	Tactile through person (3a)	1.96 %
	Tactile through object (3b)	5.88 %
Attention episodes	No attention (0)	1.96 %
dyad	Non-shared attention staff (1a)	5.88 %
-	Non-shared attention client (1b)	13.73 %
	Divergent non-shared attention (1c)	17.65 %
	Shared attention object (2a)	37.25 %
	Shared attention persons (2b)	5.88 %
	Joint attention (3)	17.65 %

# Interactional Contributions of the Person with PIMD

## Responsiveness and Attention

From the observations as well as from the staff-researcher conversations, C. appears highly attentive to the music activity. Both data sources agree on the fact that in the beginning he is somewhat distracted by the camera but then he is constantly alert to what is happening until the end of the episode. This mainly appears from the way he is following the material with his eyes and by turning his body and head towards the material. Only after the third time of playing a music instrument C. is very shortly directed towards himself, indicated by a brief sigh, but afterwards he is immediately tuning in the activity again. For most of the time, C. is enthusiastically involved in the activity, which appears from regular smiling, vocalizing, and tension in his body posture. This is in line with the tension created in the music activity: each time S. goes away with an instrument, C. is stretching his body and hands, and starts to laugh and vocalize. At other moments, C. is more neutrally following S.'s activity and waits patiently for the next step in the interaction.

"I am surprised by the fact that C. is constantly following because this is not evident for him.. In the middle, he is sighing briefly but this is a signal of taking a brief rest, similar to how we are repositioning ourselves after a bit of interaction with others. Sometimes he is just following too. But he does not show negative signals then, it is more neutral and an awaiting attitude as if he wants to say "what is going to happen next?". He is attentive for one hundred percent and almost never distracted by something else in the environment. The way how he is absorbed into the game I create, is really beautiful." (Staff-researcher dialogue)

"Attention to activity, score 4 CBRS. [...] When S. takes a music instrument from the ground floor, C. follows and accordingly looks to the ground floor." (Direct observation)

"Enthusiasm and persistence, score 6 RES. C. shows eagerness and does not need much encouragement to participate in the activity. He is interested and only sporadically loses concentration. [...] Even in the end, when S. is ending the activity, he is doing effort to ring the bells himself." (Direct observation)

The direct observations with the different subscales agree on the rather high responsiveness of C. towards his interaction partner. When S.'s asks questions, he tries to answer most of them, although it is unclear whether he understands all of them. He obviously complies with the request of S. and follows her suggestions for the majority of the time. During the staff-researcher dialogue, however, this aspect of the interaction was less stressed by S. The most important aspect of C.'s orientation to her, was the way how he followed her by orienting his body and turning his head when going away with the instruments.

"Responsivity, score 6 EAS. C. is never avoidant. Sometimes he is a bit on his own but this is optimally in balance with his responsive behaviours towards S. [...] S. asks which instrument C. has heard. "Did you hear the drum?" and he turns away his head, which means "no" as appears from his

communication passport. "Did you hear the bells?" and he looks at S., smiles and brings forward his head, which apparently means 'yes'. However, on other questions C's answers are much more vague." (Direct observation)

#### Initiation

The amount of C.'s initiatives towards the activity and towards the interaction partner respectively is low, as appears from the scores on the different direct observation subscales. Only five different attention directing behaviours (9.80 %) were visible during the observation through partial interval coding. In particular, these were described as how C. by his own initiative repeatedly looked at a music instrument while alternately also being directed towards S. During the staff-researcher dialogue, S. does not tell anything about C.'s initiatives until the researcher asks for this topic. She never sees him taking initiative during the observed interaction. Though after repeated observation, she describes him looking in the direction of the bells. According to S., this is to share his feelings with her and to say "I like what you have done with the bells", which is a response then. Afterwards, she doubts whether this could be an initiative meaning "I want the bells".

"Initiation activities, score 2 CBRS. A few times, C. looks at the bells not on S.'s demand but by his own initiative. Furthermore, he does not attempt to initiate activities and follows the agenda of S." (Direct observation)

"In general, we present things to C. and he reacts. C. is compliant. He would lie down on a mattress the whole day without complaining and while enjoying to follow what is happening in the group. He would never ask something by himself and he waits until we take initiative. In this video also, I never see him asking for something. C. would not have done anything if I would not have offered the instruments. You don't have to wait for an initiative of C. but you have to offer by yourself. This is his personality: he is a good boy satisfied with what he gets and he will not call for something." (Staffresearcher dialogue)

#### **Emotions**

The absence of negative emotions is agreed on in the results of the direct observations as well as the staff-researcher dialogue. Furthermore, both data sources agree on the fact that C. is displaying signs of pleasure in the interaction mainly through his smiles and body movements but also through vocalizations. He shares his positive feelings with S. by looking at her but also with the other group members, as direct observations as well as the dialogue reveal. At other times, C. is more neutral and less expressive but he is still feeling comfortable as appears from his relaxing attitude. The observation that C. tolerates S. going away and remains enthusiastic is also recognized by S. as a sign of feeling happy and at ease in the situation with her.

"Affection, score 5 RES. C. frequently smiles while looking at S. and being directed towards her with his body. He sustains in this sharing of positive affect during several periods. Sometimes he also

shares his positive feelings, e.g. being proud when ringing the bells himself, with the other youngsters in the group. [...]" (Direct observation)

"For me, it is clear that C. is having pleasure during the whole interaction. He is never angry or frustrated, because then he would bite or spit. I see him smiling, bringing his head to the front, tighten his arms, and so on. The positive emotions are a combination of "I like it" and "I feel at ease". [...] The fact that he likes what is happening is most important for me during an interaction. And I know that C. would not smile to do me a favor but only smiles when he really likes it. [...] Especially when I ring the bells, his face and eyes light up. This is really nice. And in particular, his vocalizations and little cries of contentment and excitement are convincingly showing his positive feelings. This truly makes me happy myself!" (Staff-researcher dialogue)

### Interactional Contributions of the Staff Member

### Responsiveness

The main conclusions from the different observation subscales are that there are no conflict situations and S. succeeds in engaging S. throughout the entire interaction, which might be an indication of her responsiveness. Though, S. mostly takes initiatives in deciding what to happen within the activity. During the staff-researcher dialogue, S. confirms and explains this by claiming that she knows C., indirectly recognizes his preferences, and accordingly adjusts herself to that. For her, reacting on immediate choices of activity is less necessary as he hardly demonstrates such concrete signals. Accordingly, from direct observation, it also appears that S. is not all the time alert to C.'s signals as she is sometimes directed towards something in the larger group context (another client or a colleague).

"Sensitivity, score 4 MBRS. S. is not constantly visually monitoring. She sometimes misses a signal of C., for example when he cursorily looks down to the bells. [...] On different occasions, S. puts into words a signal of C.. For example "yes, that is your favorite sound" and then she rings the bells again." (Direct observation)

"Although I see more signals on the video screen, I did not find it difficult to notice what C. liked during the activity. I used the bells frequently because he clearly showed his enthusiasm for them. Not because he asks for this but because I know him and I see to what he is attracted the most. [...] You can read on his face what he wants and enjoys. As such, though you mainly have to direct as a staff member, it is certainly possible to join in his interests. Of course, you have to stay alert because his signals are brief." (Staff-researcher dialogue)

# Initiation

With regard to the structuring behaviour of S., the observational descriptions indicate how S. first introduces the different instruments and then initiates a constantly repeated game of going away and coming back with the instruments. Her instructions are clear, slow, and frequently repeated.

Frequently she finishes the different parts of the activities, e.g. by clearly saying and showing that the drum will be put away, though in the end she sometimes overlooks this. During the staff-researcher dialogue, S. also stresses how she wants to create a for C. recognizable overall pattern while also trying to bring in novelties such as ringing the bells behind the curtains. However, as is observed by the researcher too, S. notices on the video images that she is temporarily confusing when not knowing anymore which instrument she has been playing.

"Structuring, score 4 EAS. S. provides a framework for the interaction by announcing (e.g. "I am going away again"), repeating the course of the game and clearly saying and showing what she expects from C. ("C. has to listen then" while simultaneously showing the drum). She is successful as C. engages in and never obviously drops out. [...]" (Direct observation)

"I want to give C. a kind of basic security by explaining to him what is going to happen, because this is not evident for him. C. really needs a guide throughout the activity.[...] Therefore, it maybe looks boring, but I constantly repeat. I also call his name so he knows I am directed towards him." (Staffresearcher dialogue)

Furthermore, during the dialogue, S. concretely explains her strategies to create clear expectations, and to get and sustain C.'s attention to the activity as follows: repeating questions and suggestions, doing the same thing over and over again, splitting up the activity in different parts, changing the pace (e.g. slowly playing the flute followed by a fast rhythm), changing the physical distance, and addressing his auditory as well as visual senses. These examples were noticed by the researcher too. The use of humor to engage C. into the activity, on the other hand, was explicitly mentioned by S. but was not recognized as such in the research observations.

"As you see, I use an amusing voice here and earlier on I did some funny body movements. [...] I like humor and acting funny in order to attract C. He understands the humor and he also likes small teasing between the clients and support workers. He really enjoys it. It is something we have built up over the years in our group." (Staff-researcher dialogue)

Both data sources agreed on the fact that S. uses a variety of modalities, which is also confirmed by the high percentages of different attention directing behaviours of S. Observation also demonstrated how S. uses different ADB-s modalities at the same time to intensify her message. She almost never only talks but combines her auditory attention-directing behaviour with showing or letting him feel the objects, which corresponds to S.'s explanations during the dialogue. Contrary to S.'s conviction that it is important to use touch (e.g., caressing his hair) to get his engagement, few tactile attention directing behaviours (7.84 %) were determined.

The non-intrusiveness observations indicate how S. decides on the content and progress of the music activity. She has a scenario I mind in which she goes along with C.'s interests but in which she does not actively offer him opportunities to decide on what is happening. This corresponds to how S. accentuated during the dialogue that C. needs guiding and does not take initiative by himself. The fairly high amount of stimulation was noticed in the research observations as well as in the staff-

researcher dialogue. However, S.'s conviction that confirming C.'s positive behaviour is necessary was contrary to the observations which only identified a small number of verbal praising behaviours.

"During this activity I wanted to stimulate C. to direct himself to the sounds produced by the instruments, and in the end to use the instruments by himself. Of course, personal and medical care are important, and C. needs rest and comfort but I want to keep him stimulating too. That is: offering him experiences of listening, feeling, etc. It's about experiencing his body and not necessarily about expecting concrete realizations. [...]" (Staff-researcher dialogue)

"Praise, score 2 MBRS. A few times S. says "yeah" to confirm C. but most of the time she does this through non-verbal behaviours such as nodding and laughing. She indirectly praises C. by telling to a colleague that he does it well." (Direct observation)

#### **Emotions**

"Yes, I liked this interaction much. I was satisfied because I noticed that C. enjoyed the activity. You see, I was proud that he followed so well, that he ringed the bells himself, that he was smiling and vocalizing. [...] Repeating, acting slow, being patient, ... it is a professional attitude, I am not always like that at home. It is not difficult for me to accept his disabilities, I don't see them anymore. I do not feel compassion for him. Of course, sometimes it is confronting, for example in comparison with my own children. But, in my job, I am happy if I see C. feeling contented." (Staff-researcher dialogue)

The different observation subscales agree on how S. demonstrates enjoyment and warmth towards C. but not exaggerates in that through which her affect can be considered authentic. No signs of impatience, disapproval, or hostility were perceived.

"Warmth, score 3 MBRS. S. is regularly smiling towards C. while talking to him with an enthusiastic and warm voice. She sometimes goes closer towards C. but in general few physical contact is made. [...] Her positive affect towards C. is permanently present but is of low intensity." (Direct observation)

The fact that S. brings in emotions into the interaction is also visible in the research observations describing how she regularly changes her voice volume and intonation (e.g., whispering to create tension or intimacy) and shows animated facial expressions (e.g., when being proud). During the dialogue, S. draws attention to the importance of being emotionally expressive in order to keep C.'s attention and fascination during the activity.

#### The Interacting Dyad

### Mutual Openness and Respect

Direct observations and S.'s contributions during the staff-researcher dialogue correspond in how they first observe C. as being distracted by the camera but then see how they both become open for each other. For S., the mutual openness towards each other is preponderating and a constant element during the interaction. Direct observation, however, tones this down.

"Mutual openness, score 3.5 S-DMM. Mutual eye contact is visible during the game. Furthermore, despite their spatial and physical separation when S. is playing the music instruments behind the door, mutual openness and shared attention is observed in their vocalizations and body direction towards each other. They keep following each other. A few times, especially towards the end, S. is directed towards a colleague or other clients through which she does not always notice his subtle signals. Similarly, C. is sometimes not open for S. but is more directed towards the instruments only (through which S. becomes an employer of the instruments rather than a interaction partner as such), or he is directed towards his fellow group members." (Direct observation).

Although the coding of attention episodes is originally not part of this interaction dimension in Table 1, the coding of about one third of the intervals (39.22%) as the dyad displaying no or non-shared attention, also confirms this medium mutual openness towards each other.

Direct observation results draw attention to the mutual eye contact, the body direction towards each other, and their shared vocalizations. For S., it is difficult to give expression to how she exactly recognizes this mutual openness. It is more a matter of a feeling for her.

"We felt one, a unity, during this interaction. We were totally operating at the same frequency. Especially on an emotional level. See, how we are smiling and vocalizing. We both liked this activity and both felt comfortable with each other during this interaction. We know from each other how we exist." (Staff-researcher dialogue).

Both data sources agree on how they generally both accept each other's being which results in mutual feelings of enjoyment and non-evaluativeness.

# Joint Context

For S., the joint fascination for the music instruments was clear. She is aware of the fact that she decides on the content but, on the other hand, she adjusts herself to the observed preferences of C. S. recognizes that it is difficult for C. to have attention for the materials simultaneously with having attention for her. This is confirmed by the direct observations.

"Joint embedding context, score 3 S-DMM. The common theme to which S. and C. both attend is the sounds of the music instruments "here and now". The game is repeated through which an overarching framework for the activity is created, and they both listen and enjoy it. Towards the end, C. does not seem to understand all questions anymore as his absence of reactions indicate. [...] However, this context is decided on by S. and C. does not have a share part in creating the interaction theme." (Direct observation)

This direct observation of fluctuating joint embedding context, is confirmed by the partial interval coding. About as much of the intervals were coded as existing from no or non-shared attention (39.22%) and dyadic shared attention for the object or each other (43.13%). 17.65 % of the observed intervals were coded as joint attention episodes. It considered only four different episodes in which

triadic interaction on "me and you and the object" was recognized. Then, C. was observed as alternating smiling and looking at the music instrument and the staff member.

### Negotiation

S. is observed as almost constantly deciding and directing the development of the activity. C.'s signals of looking towards the bells are not seen, and S. continues her game scenario. She operates with the instruments and in the end, C. can play with them himself. For certain, it is a fact that S. takes C.'s interests into account (e.g., by more playing his favorite bell sound) but she does not actively negotiate with him.

"Non-manipulative negotiating, score 2 S-DMM. [...] There is a kind of apparent dialogue. S. asks questions to C. which he can answer but the answers are mostly determined in before (e.g. "Did you hear the drum?" "Do you want to hear the bells again?"). S. sometimes tells him what to do "And C. has to listen now". In general, C. must only answer 'yes' or 'no', and S. decides on when and how. But this works for both of them, no frustration is observed."

There is few mutual consultation and there is no balance in initiatives and responses of both partners. S. usually takes initiatives and C. responds and follows, though clearly doing this with pleasure. This corresponds to S.'s view on the necessity of offering the activity to C.

"I think there is a kind of indirect consultation between C. and me but still, I have to decide on the course of things. He needs it to be offered a framework. But I also offer him chances for free exploration, for example in the end, when I give him the opportunity to the ring the bells himself. [...]" (Staff-researcher dialogue)

The joint confirmation score of 3 within the S-DMM indicates that S. not always notices and confirms C.'s utterances, or takes them as a starting point for the interaction. At certain moments, however, it is nice to see how she brings C.'s non-verbal signals into words. For example "yes, you like the bells". Then, they both smile as to confirm the message to each other. Especially towards the end, C. is not always answering the communication started by S. In the end too, it is clear that S. is sometimes switching to a new instrument before clearly finishing the use of the previous one. S. recognizes this.

"I should have offered the flute again so that he could have answered. As I immediately offered another instrument, he could not confirm here. [...]" (Staff-researcher dialogue)

# **Discussion**

### **Conclusions**

The aim of this descriptive single case study was to gain a complete and holistic insight into the processes occurring in an interaction between a person with PIMD and a direct support staff member. Furthermore, this study explicitly intended to include the experience and the view of a staff member

knowing the person with PIMD to understand the interaction in all its aspects. Therefore, conclusions concerning the integrative description of the interaction as well as on the used method will be drawn.

# Integrative Description of the Interaction

The strength of the integrative conceptual framework is determined by the linking of direct observation subscales and guiding questions for the staff-researcher dialogue to some basic interactional dimensions on the level of the person with PIMD, the direct support staff, and the interacting dyad. This study demonstrated that this analytic framework formed a vehicle to generate an integrative description of a staff-client interaction.

The study revealed that spontaneously S. principally made observations on the client, who was most surprising for her to see on the video screen, and less on herself or the dyad, which is possibly more threatening. However, it was remarkable too that after a while she certainly put her descriptions within a larger interaction framework by linking elements of the client's behaviour with her interactive behaviour. For example, "He is attentive but that is because of my voice intonation here.".

Results support the overall conclusion that the recurring pattern within this interaction is the direct support staff member offering C. an activity that she considers a nice and stimulating experience for him, and C. following with pleasure and alertness. This is clear from the staff-researcher dialogue, in which S. mainly raises elements with regard to C's attention to the activity and her variety of strategies to guide C. through the activity, as well as from the direct observations, with high responsiveness scores of C., low initiation scores of C. and high initiation and structuring scores of S. Not accidently, this high degree of alertness and enthusiastically following was exactly the reason why S. chose this video observation as the case of interest for this study. In line with these results on the level of the individuals, it is not surprising that rather low scores resulted from the observation with the dialogical subscales, in which mutual consultation instead of one-sided and individually decided activities is central. For S., the activity and not the persons themselves were central in the interaction. In any case, the fact that mutual pleasure was established and no negative emotions such as anger or frustration were observed in none of the interaction partners, indicates that they are obviously used to this way of interacting and feel comfortable with it.

# Combining Research Observations and Staff Report

Next to the individual description of the S.-C. interaction, this case study also and maybe even more relevant enables to draw conclusions on the used method. In general, the findings of this study are more convincing and accurate because they are based on different sources of information (Yin, 2003). In particular, results demonstrate that combining direct observations with narratives resulting from staff-researcher dialogue was valuable to generate a comprehensive and differentiated description of the unique interaction patterns occurring.

First of all, the inclusion of the staff's view and experiences was valuable in itself. For that, the study demonstrated that it is possible to have a mutual discussion with the staff member guided by some orienting questions. In particular, during the dialogue, it appeared that the staff member often brought in her familiarity with C. For example "He is always laughing when you ring the bells" or "He does not often vocalizes as such, so this is really a peak moment". So, in comparison to the researcher, she had the advantage of being able to relate specific processes occurring on the video to general knowledge of the person with PIMD and the context, by which she was able to pass a judgment on the usualness or exceptionality of certain occurrences. She is more able to interpret the findings by explaining influencing factors. For example "He is open and happy when sitting in the sun in front of the window" "C. is less open for interaction in the morning when he had to stay over for the night and did not saw his mom". Therefore, the staff report certainly enhanced the study's ecological validity because the informant was someone who knew the client well for a long time (Cascella, 2005). Furthermore, S.'s explanations on her interactive behaviour are elucidating her intentions, which make the direct observation results less evaluative. For example, it shows that you can perfectly have good intentions during an interaction rather characterized as a monologue.

Second, the combination of direct observation with staff report together with the member check process was clarifying and enhanced our interpretation of the interaction (Thurmond, 2001). Results from both data sources seemed to be mostly analogous. But still, the integration of both perspectives had a surplus value to interpret the findings more differentiated because they both emphasize different accents or apply different words to describe the events. For example, "They feel comfortable with each other as appears from their relaxed attitude" (research observation) versus "We felt one" (staff member). Some observations, however, only resulted from one of both data sources. For example, the staff member pointed to the use of humor, an element that has never been appointed to in research on people with PIMD and which was also not observed by the researcher. Direct observations, on the other hand, revealed some own initiated attention directing behaviours in C., while S. did not saw client initiations and considers C. as not being interested in taking initiative. So, in line with Daelman (2003), the researcher was found to see more communicative behaviours then the familiar interaction partner. Afterwards, though, the staff member recognized that C. was maybe asking to ring the bells himself earlier. Definite conclusions on this cannot be drawn without further observation but, in any case, the valorization of both data sources helped to see the interaction from different perspectives. The viewpoints of staff and researcher certainly can be concluded to be complementing contributions (Petry & Maes, 2006).

#### Limitations

First, the recording of the staff-researcher dialogue could have restricted the staff member to share all her thoughts. Also, though the dialogue was explicitly presented to the staff member as being not a moment of evaluation, the one-one contact with the researcher from a university setting could

have hampered her. From that point of view, it would be interesting to set up a similar dialogue with a group of staff members.

Second, within this study effort was done to explain all interactional dimensions to the staff member as a start of the staff-researcher dialogue. However, it appeared that it remains a real challenge to clarify the dialogical view and its different subscales. Although the staff member, driven by the researcher, was indirectly referring to their interdependency (e.g., I feel content when I see him happy, he is alert because I am enthusiastic), it remained difficult to think in dialogical terms. This may be caused by the fact that the dialogical dimensions were presented during the last meeting and the video record was then already observed repeatedly through which it was difficult to discover new approaches. In further research, therefore, there is need for more time and effort to concretely explain this dialogical viewpoint and to discuss concrete alternatives to engage in dialogue, for example by illustration with clarifying video fragments.

# Suggestions for Future Research

The principal interest of this study was intrinsically the case itself, i.e. understanding the interaction system in its entirety, through which we mainly achieved an in depth understanding of the particular interaction between S. and C. However, it would be interesting to conduct further research in continuation of the knowledge acquired in this study.

First, within this case study we wanted to understand the interpersonal interaction in itself and not necessarily the influence of contextual variables. Therefore, one case was selected for in depth description and influencing variables were only indirectly inquired during the staff-researcher dialogue. In future research, multiple case studies and cross case analyses of different interactions with a particular client (e.g., comparing smooth with difficult interactions), could enhance the understanding of influencing variables such as mood, context, etcetera. A longitudinal analysis of a staff-client interaction would also help to trace influencing variables.

Second, in line with its primary goal the results of this study are descriptive. Though partially questioned within the staff-research dialogue, no clear-cut causal explanations on the occurring interactional processes could be drawn. But, this case study enables to generate hypotheses for investigation in future research. A concrete example of this is the difficulty to know whether the low amount of initiation by C. is typical of C.'s personality that may be rather passive, or originates from his disabilities and developmental capacities to which S. adapts herself, or evolves from the high degree of directing and structuring by which S. restricts C.'s own initiatives. According to the staff member herself, she is convinced that C. is not able and not interested to initiate, and needs a structuring guidance. However, another hypothesis may be that more initiatives would arise when actively waiting and inviting him to bring in something, and confirming his initiatives even the most small and subtle ones. To be able to draw conclusions on the influence of the client's disabilities and personality in comparison to the influence of the interactive context and staff strategies, more

observations in which the interactive behaviour of the staff member is experimentally controlled are necessary.

Third, the staff member involved in this study regularly made reference to the importance of the group as a context for the one-one interaction. The presence of the colleague staff member as well as from the other clients in the group, in which S. and C. both feel comfortable, was according to her mainly influencing the successfulness of the observed interaction. The way how C. shared his smiles with another client or how he proudly looked towards his peers in the group were indicative of that. But, S. is also convinced that C. liked the feeling of the other group members watching him. Therefore, future research should investigate peer interactions and staff-client interactions within the broader context of the group, certainly because in reality there is limited time for one on one interaction.

Lastly, in comparison to earlier studies, the surplus value of this case study was the involvement of an experienced persons knowing the person with PIMD to obtain information on the interaction. But for future research, it would even be more interesting to also involve a parent during the dialogue to obtain another completing viewpoint.

# **Implications**

The descriptions resulting from this case study do not form a totally new understanding of the staff-client interaction but can be considered as a refined understanding (Stake, 1995) by taking evidence from the two data sources together and by putting evidence from different interaction dimensions into a larger framework. This sharpened understanding does not only lead to scientific conclusions with regard to the interactional processes and the used study method, but also has implications for practice.

During the staff-researcher dialogue, meta reflections on the value of the video analysis were made by the staff member. Pertaining to the client, it was considered a means to notice signals that otherwise gets lost within cursory daily interaction. "I am really pleasantly surprised. It is only by watching the video that I notice how he is following me when I go behind the door. In our daily work, we are busy with the materials and with the group. [...] This helps to see the capacities of C.". Furthermore, the video analysis enabled S. to evaluate her own strategies. "Now I see the effects of my behaviour on C. so clear. The video record makes me again more conscious about my behaviour". The advantage of playing back the video multiple times (e.g., Jordan & Henderson, 1995) was acknowledged. In addition, the orienting questions within the different interaction levels were motivating for S. to think of the interaction in a differentiated way and to pay attention to certain interaction aspects she otherwise overlooks. But maybe most important, for S., it was confirming and enjoyable to see how C. was happy within the interaction. "This is really beautiful. All my colleagues must see this, and the parents too." The video record provoked proud feelings towards C. The staff member concluded that they should do this video analysis exercise for all clients of the group.

The staff-researcher dialogue guaranteed the important and necessary valorization of the skills and experiential knowledge from the staff working with people with PIMD (Daelman, 2003; Forster & Iacono, 2008). This study's method in which researcher-participant collaboration was central, can therefore form a preceding step towards improvement. For, it is our hypothesis that discussing video observations with staff from these interactional points of view and through a dialogical encounter, might already have an effect on their knowledge, attitudes, and interactional competencies. The integrative framework as well as the resulting understandings do not form an evaluation but are a motor to see things differently. It encourages becoming aware of other possibilities and questioning the evidence of their habits.

By getting a view on the strengths and difficulties within an interaction, this case study's method is believed to hold much relevance for practice. On the one hand, suggestions for action can be deducted from the description of less available interaction qualities, which can inspire them to experiment with different interactive behaviours. In this case, possible suggestions that should be further concretized with the staff member, could be: not starting from available knowledge but negotiating with the client, actively waiting on client initiations, immediately confirming client initiations for example by imitating them, creating conditions for triadic joint attention to occur, or using tactile contact. On the other hand, and most important, the dialogue is a way to support the available strengths in the interaction. It is a manner to give them insight into their available skills and how they can build further on them (Kennedy et al., 2010). This was acknowledged by S. in a note she wrote afterwards "A positive aspect of the meetings is that an external person is interested and amazed by our method of working and 'being'. This stimulates to go on." Gaining a more profound understanding of the interaction is, as such, an impulse for improvement and future engagement in high quality interaction.

To conclude, not only the staff member was inspired by the meetings but the researcher also gained more relevant knowledge on the possibilities to interact with people with PIMD and to discuss this with staff. Therefore, the dialogical encounter between staff member and the researcher was mutually clarifying and rewarding.

# CHAPTER 7

# **GENERAL CONCLUSION**

This doctoral research project comprised five manuscripts consisting of a literature review, three group observation studies, and a single case study. By this design, we have combined several methods to reach the aim of this dissertation, which was to better understand and describe the quality of the interaction between people with PIMD and their direct support staff on the basis of which starting points for improvement could be deducted.

To start, a literature review was performed to gain an understanding of the interaction with people with PIMD by detecting key elements of high-quality interaction (chapter 2). By building on previous research, an explanatory model of interaction was constructed. Next, three observation studies were accomplished in order to describe the interaction between people with PIMD and their direct support staff (chapter 3, 4, and 5). Inspired by the review results and the explanatory model, different perspectives and methodological approaches were used. Lastly, a case study was completed as an example to support the quality of the interaction with people with PIMD by a comprehensive understanding and description of the interactional processes occurring (chapter 6).

Considering this research project, it can be concluded that an oscillating movement was made from an inclusive interaction framework to specific interaction components and back. The literature review provided a broad view on the interaction with people with PIMD by highlighting constituting components as well as influencing factors. The three observation studies, then, were each narrowed down to a certain specific aspect of the interaction. To conclude, the case study again put all different perspectives into one comprehensive and integrative framework.

Another pattern that came forward in reflection on this doctoral study, was that of a continuous refinement towards practical relevant knowledge. The first part of this thesis consisted of an exclusively theoretical exploration without involvement from practice and delivering global knowledge. Following on this, the second part of the thesis succeeded to describe interactions between people with PIMD and their direct support staff by implementing several conceptual frameworks on concrete observations, however, without direct participation of the persons involved. To end, the case study achieved to profoundly grasp the processes occurring in real life interaction with a person with PIMD by closely collaborating with a practitioner.

From these points of view, the case study can be considered as an ultimate completion of the doctoral thesis in all its aspects. The case study implemented general theoretical and methodological knowledge in a concrete case, guaranteeing the involvement of experiential knowledge from a practitioner and guaranteeing the integration of fragmented views into an overarching and in depth

description of interactional processes. 'Finishing a case study is the consummation of a work of art.' (Stake, 1995, p. 136). But, this concluding piece of work could not have been performed without the insights gained from the previous parts of the thesis. Also, as a person, the researcher had to built on the qualities and experiences developed in the previous studies in order to be able to fulfill the qualitative case study's aims. As such, all parts of this thesis had their value in raising comprehension and knowledge on the interaction between people with PIMD and their direct support staff. The different findings and conclusions will be further reflected on in this discussion section. A discussion of the study's limitations will result in suggestions for future research. Finally, implications for practice will be suggested.

# **Empirical findings**

First, by analyzing the findings of current studies about interaction with people with PIMD the literature review (chapter 2) resulted in a methodological characterization of the research on this topic as well as in an overview of important interaction elements. Small sample sizes, the use of video observation or interviews, the determination of interrater reliability in quantitative studies, and the description of conceptual frameworks in qualitative studies, were determined as frequently recurring methodological aspects of studies investigating the interaction between people with PIMD and their proxies. The adopted theoretical backgrounds were either referring to interaction partners influencing and exchanging with each other, or to co-creative interaction dynamics. Furthermore, the literature analysis enabled to construct an explanatory interaction model. Four constituting components, which are considered to be dyadic variables formed through the contribution of both partners, were: sensitive responsiveness, joint attention, co-regulation, and an emotional component (e.g., mutual feelings of warmth or closeness). Three influencing factors concerning the people with PIMD were represented: their individual characteristics, their initiations and responses in the interaction, and their personality. The influencing factors from the interaction partners were: their communicative and interactive strategies, their perceptions and roles, and their knowledge. Contextual factors having an influence on the interaction were the setting and circumstances. Referring to the first research aim of this doctoral research project, we can conclude that the literature review and the resulting model contributed to a comprehensive understanding of key elements in interactions between people with PIMD and their interaction partners.

Second, taking into account the findings of the literature review and as an answer to the second research question of this doctoral study, the usefulness of several methods to describe constituting components of the interaction between people with PIMD and their direct support staff was examined. In a first observation study (chapter 3), three observation tools from parent-infant research were found to be appropriate to describe both interaction partners' behaviours that build up positive and reciprocal interaction. On the condition of sufficient training, the applicability of the Emotional Availability Scales (Biringen et al., 1998), the Maternal and Child Behavior Rating Scales (Mahoney, 1992; 1998),

and the Revised Erickson Scales (Egeland et al., 1990) to interactions with people with PIMD was supported by sufficient interrater reliability and convergent validity, and by an acceptable score range. In continuation of this, the second observation study demonstrated the value of an observation instrument based on the dialogical theory to describe co-regulation and dyadic variables in the interaction between people with PIMD and their direct support staff (chapter 4). The Scale for Dialogical Meaning Making (Hostyn et al., 2009) appeared to be a reliable and versatile tool enabling to describe the occurring interaction processes in dialogical terms. Focussing on the constituting interaction component of joint attention, a third observation study using partial interval coding succeeded to reliably map the frequency and nature of the attention-directing behaviours of the people with PIMD, the attention-directing behaviour of the staff members, and the attention episodes in the dyad (chapter 5).

Third, although the second part of this dissertation mainly consisted of a search for methods to describe the interactions, the application of different observation tools also generated a descriptive image of the quality of the interaction between people with PIMD and their support staff. In first instance, each of the applied observation scales delivered quantitative scoring results. These quantifications were not intended to pass a value judgement about the persons with PIMD or the staff members but to put the observations on a continuum from less to more of a certain interaction aspect. As such, the ratings facilitated to represent which interaction qualities were more available and which were less present in a given interaction. In particular, the instruments enabled to differentiate between interactions scoring higher and interactions scoring rather moderate or low on certain observation subscales. Furthermore, the quantifications made it possible to pick out some interaction trends across the group of people with PIMD and their staff members by calculating descriptive statistics. The empirical findings of the first study indicated rather high mean scores on the subscales measuring to which degree interaction partners perceive and respond to each other's signals and build up a reciprocal and positive emotional interaction (chapter 3). Regarding the dialogical interaction qualities, mean scores around or above the theoretical mean were established, with non-manipulative negotiating having the lowest mean score (chapter 4). The third observation study (chapter 5) revealed that persons with PIMD generally infrequently directed the attention of their staff members, while the staff members frequently showed attention-directing behaviours. Across the group, joint attention was not often observed but shared attention episodes occurred frequently. As a conclusion to these descriptive results, and in contrast to the starting point of this dissertation, the interaction between people with PIMD and their interaction partners generally appeared to be higher quality than have been thought on the basis of previous research. However, the high range in scores obtained with each of the rating scales demonstrated large variation between the interaction partners and the interaction dyads. This occurrence of medium to high mean scores across the group together with large differentiation between higher and lower functioning interactions will be further elaborated on in the next sections of this discussion. In second instance, the detailed argumentations justifying the scores of the different

observation tools formed qualitative descriptions of the interactional processes occurring. The occurrence or absence of several non-verbal behaviours such as eye contact, voice intonation and other prosodic communication aspects, tactile and bodily contact behaviours, etc. were often recurring themes within these descriptions. This possibility to extensively and meaningfully describe positive as well as negative aspects in the interaction was also an indication of the usefulness of the different investigated instruments. However, within the second part of this doctoral thesis, these descriptions were not qualitatively analysed for the group nor for the individual dyads as such. That is why a qualitative single case study was set up at last.

Fourth, in answer to the third research question of this dissertation, the understanding and profound description of interactional processes in a staff-client interaction was demonstrated to yield starting points to support the quality of their interaction. The concluding single-case study was convincing in how strengths and difficulties in an interaction between a boy with PIMD and his support worker could be identified by means of an integrative theoretical framework focusing on all constituting interaction components revealed from the literature review and encompassing all interaction dimensions from the previous observation studies. Certainly because the staff member was directly involved as a supplementary source of information in the video observation analysis, the observations and generated descriptions appeared to be a vehicle to confirm the available qualities in the interaction, to inspire the staff member to discover new perspectives and to experiment with other interactional behaviours.

# Methodological reflections and conclusions

The main aim of this thesis was a methodological one, i.e., searching for justified methods to describe the quality of the interaction between people with PIMD and their direct support staff. As in mixed method social inquiry (Greene, 2007), a plurality of philosophical paradigms, theoretical assumptions, methodological traditions, data gathering procedures, and analysis techniques were involved in this doctoral study to better understand the interaction phenomenon being studied. That the integrative use of the different methods and theoretical backgrounds on one and the same observation yield valuable information with regard to the interaction between people with PIMD and their support staff, was shown in chapter six. In the second part of this doctoral research project, however, the instruments were tested on various video records and in the best possible conditions for the instrument being studied. These experiences gave insight into the own merits, advantages, and disadvantages of the different theoretical and methodological elements that were proposed in Table 1. The reflections and conclusions following from this complementary investigation of several methods to describe the interaction, were partially described in each chapter but will be made explicit in this discussion section. These considerations help to deliberately select (a combination of) observation focuses, theoretical backgrounds, coding levels, recording durations, observation contexts, and reliability calculation strategies in further research, depending on the research aims and questions of interest. As

such, this doctoral dissertation augments researchers' knowledge about justified methods to evaluate interpersonal processes in interactions with people with PIMD.

### Observation focus

The observation focus of some rating scales used in this thesis was on the interactive behaviours of both interaction partners, while others focused on the dyad itself. This discrepancy was also the core of the dual usage problem in studying joint attention (Patterson, 1982; Tasker & Schmidt, 2008), mentioned in chapter five.

The coding of persons' interactive behaviours was done in the study using instruments from parent-infant research (chapter 3) and in the first part of the study on attention directing behaviours (chapter 5). Although the observation focus was on the individuals' behaviour, the interaction unceasingly was the starting point and the different subscales reflected interactional variables. Although one cannot not communicate (Watzlawick, Beavin, & Jackson, 1967) and all one's behaviours have a meaning for another person, only behaviours that were directed towards or in response to the other person in the interaction were coded and not the intra-individual behaviours (e.g., stereotyped behaviours, isolated communicative utterances). For example, a person's eye gaze was not taken into account as such but only when being an initiative or response directed to the other person (e.g., making eye contact). That is why the performed codings could not have been fulfilled by filming only one interaction partner. It was a necessity to have a view on both interaction partners to be able to make conclusions on how their individual behaviours contributed to the interpersonal interaction. The choice to adopt two video camera standpoints, one focusing on the person with PIMD and the other one focusing on the dyad in its context, was certainly valuable in that regard. As was pointed out in the introduction, in comparison to earlier research, the interconnectedness between interaction partners was central in the studies.

The advantage of separately focusing on the partners' interactive behaviours seemed to be that the observations and codings of the people with PIMD and their support staff were free-standing and held apart. Conclusions on the degree of reciprocity between their behaviours were only made indirectly. From the perspective of the staff members, this was beneficial in that their efforts could be highlighted regardless of whether they succeeded in creating mutual and positive interaction. This may be considered to enhance the potentialities of staff to infer cues for action to improve the interaction because of getting a view on their own contributions in the interaction. From the perspective of the people with PIMD, these separate observations helped to understand their unique interactive behaviours, and to see their initiatives and responses without already taking into account the match with the direct support staff member. Contrary to this, when focusing on the interacting dyad, the ratings immediately reflect the between the degree of mutuality or *jointness* between interaction partners. When the interactive behaviours between the interaction partners are in balance with each other, the focus on persons' interactive behaviours or on the dyad as a unity does not make a great

difference. But, in the reverse case, when the resulting ratings on dyadic variables are low, we do not get detailed insight into the attempts of the interaction partners separately. It may be that one of the interaction partners is dropping out while the other interaction partner is doing great effort, but this remains invisible in the dyadic codings. This may be the staff member (e.g., the staff member is doing effort to develop quality interaction, while the person with PIMD is absent or engaging in self-directed behaviour) or the person with PIMD (e.g., the person with PIMD is taking initiatives while the staff member is directed towards a colleague or something in the broader environment). Of course, also in the observations accompanying the dyad's scores, reference can be made to the separate interactive contributions of both interaction partners, but the obtained scores do not reflect these.

The advantage of focusing on the interacting dyad, as was done in chapter four and the second part of the study in chapter five, is that the degree of co-creation between persons is immediately evaluated. This is close to how persons experience their interactions in reality, namely whether there is a match or mismatch between them. Focusing on the dyad in the interaction follows the suggestion of Linell (1998, p. 265) to 'capture aspects of actors' interactions in their joint discourse, rather than individuals' acts considered as autonomous entities'. Their interactive behaviours are seen as joint, coordinated, and mutually interdependent behaviours (Markova & Linell, 1996). This focus enables to describe interaction processes that are not reducible to the sum of the individual contributions and to see the meaning of a certain behaviour within a mutual dynamic system (Fogel, 1993). For example, a touching behaviour does not have the same meaning each time it occurs but may be interpreted then within the continuously changing and co-creative dialogical process.

However, the focus on the dyad and the scoring of dyadic subscales is not self-evident. Although the S-DMM manual and the detailed coding scheme on joint attention enabled to describe dyadic processes in dialogic terms accentuating co-creative processes, we are not used to think and observe in these terms as researchers. We are still inclined to look too much to the contributions of both interaction partners separately. In the attention study in specific, our experiences learned that we were often mainly paying attention to the person with PIMD assuming that the staff member is always directed to and aware of the person with PIMD (because of the observation context), which corresponds to Carpenter et al. (1988) who mention that the adults' attention and awareness of the child may be taken for granted. This dyadic focus is also difficult for practitioners, as appeared from the case study (chapter 6) where the staff member mainly referred to individual interactive behaviours rather than to dialogical processes. There too, the staff member mainly made spontaneous observations pertaining to the person with PIMD.

#### Theoretical background and research traditions

'No method is without theoretical assumptions' (Jordan & Henderson, 1995, p. 40). Our literature review (chapter 2), of which the results were used as a blueprint for the observation studies, primarily found research traditions about early communication and development together with systemic and

ecological traditions in studies investigating the interaction with people with PIMD. Taking into account the presymbolic communication and the low level of developmental functioning of people with PIMD, it is not surprising that the theoretical backgrounds of parent-infant research, dialogicality, and early development were arising when searching for valuable starting points to study the interaction between people with PIMD and their direct support staff.

Within all the frameworks used, basal interactional processes between persons are studied with each having their own emphasis and value. Parent-infant and attachment theory enabled to approach the reciprocity between the interaction partners by focussing on sensitivity, responsivity, and emotional attunement. Knowledge from parent-infant interaction, which also formed the basis of the Intensive Interaction approach (Nind & Hewett 1996), helps then to recognize the style of interaction considered best for person at different levels of development (Hodapp, Burack, & Zigler, 1990), and stresses less the chronological age of the persons. Developmental psychology and joint attention theory, too, rather start from thinking of the developmental needs and capacities of people with PIMD. The dialogical approach facilitates to think of two equal individuals inevitably experiencing asynchrony and continuously searching for shared meaning.

Our studies showed that significant descriptions were obtained with each of the theoretical frameworks as an inspirational background. The different perspectives enabled to describe the interactional processes between people with PIMD from a variety of perspectives, without wanting to preferably pick one out. They each contribute to our understanding of interaction with people with PIMD, as was clear from the case study and will be further elaborated on in the subjoined section on theoretical reflections and conclusions.

## Coding level

The first and second observation study (chapter 3 & 4) applied a global coding system, using 'large coding units that require coders to synthesize the interaction and apply a global judgement' (Lindahl, 2001, p. 24). The study in chapter four used partial interval coding. This corresponds to the difference Mesman (2010) makes between macrolevel coding, with a global score resulting from the observation of the total interaction, and microlevel coding, with a coding of interactive behaviours in small time segments.

The advantage of the global codings was that they enabled to examine the interaction sequence, regardless of its duration, as one unity. Especially the theoretical backgrounds referring to the dialogue between interaction partners lend themselves to the use of a global coding system. Co-regulative processes between persons cannot be captured on a certain moment but are built up over time and need to be evaluated throughout the dynamic interaction course. Although the interaction reality cannot be totally represented in scientific studies (Markova & Linell, 1996), because of the global measure, the rating scales can be considered to respect the essential dynamics in the interaction between people as much as possible. The attention of the observer is not distracted by one utterance or event but is

directed to the whole atmosphere of the interpersonal contact. These global ratings invite researchers to consider a variety of processes occurring and to argue the observations made in reference to the allocated subscale scores, which contributes to argumentative reliability (Van Ijzendoorn, & Miedema, 1986). The associated disadvantage of global observation scales is that they are regarded as being more inclined to a subjective bias because raters need to make more opinions by themselves (e.g., Biringen & Robinson, 1991; Munson & Odom, 1996). Some researchers defend that the gain of global measures is that they are easy to apply (Munson & Odom, 1996), but this does not correspond to our experience that extensive training was necessary to reliably use these global coding schemes. The main disadvantage of using global observation systems, according to us, is that detailed information on interactive processes gets lost in the overall measures and observations.

A more detailed description of the interaction, i.e. attention in the interaction, could be generated by the application of coding schemes based on partial interval coding. However, our experiences learned that these codings missed the holistic view on the interaction. Also, the observations made, inspired by the rich theoretical frameworks, are seen as less important and decisive as arguments supporting the continuous coding.

It is clear that the considerations of advantages and disadvantages from both coding levels are recurring and contradictory to each other. Therefore, it is not surprisingly that the results from the case study (chapter 6) outline that the supplemental use of global measures and interval coding was found to be valuable in gaining a complete and comprehensive description of the staff-client interaction.

### Recording duration

In this research, the duration of the records was either fixed on twenty minutes (chapter 3), or on ten minutes (chapter 4 & 5), or was decided by the staff member in the interaction (chapter 6). This can be considered average, as in the broader research literature on interaction with people with PIMD, recording durations of three minutes (Clegg et al., 1991a), five minutes (Olsson, 2005), ten minutes (Schepis & Reid, 1995) or even thirty minutes (Vlaskamp, de Geeter, Huijsmans, & Smit, 2003) can be found.

The advantage of a fixed recording duration was that the staff members knew on beforehand how long the observation would last. The fact that they could not immediately stop the interaction when frustrations or difficulties occurred (only when they considered the continuation of the recording as damaging for the client with PIMD), enhanced the chance to observe moments of mismatch and repair. Within the last study, although we explicitly asked to not immediately stop the recording when difficulties occurred, the chance to observe breakdowns and possible repairs in the interaction was reduced a bit. In that regard, the observation of twenty minutes can be considered most ideal to observe possible moments of mismatch. But the engagement in one on one interaction for twenty minutes appeared to be long and exhausting for clients as well as for staff members, which made them possibly a bit more nervous.

In this respect, it is significant to remark that the different recordings made in function of the case study, which were all characterized as having a natural duration because the staff member could decide when to stop the recording, all were somewhat below or around ten minutes. The advantage of the staff member deciding on the duration of the recording is that the interaction has a more natural beginning, ending, and flow together with the fact that the participating staff member is more in control over the interaction being studied.

#### Observation context

All observations made in the second part of the thesis were done in a semi-structured situation, which meant a room in the institution were the participants were alone. This had the advantage that the recordings were not disturbed by other clients or professionals, and the conditions for one on one interaction were maximized. However, although not being a laboratory situation but a familiar location, this was not a natural context for the people with PIMD nor for the support staff who are normally in a group context for most of the day. Therefore, participants could have felt a bit uncomfortable or *being looked at*, certainly in the presence of the two video cameras.

Depending on the studies' research aims, the observation tools being examined, and the observation focus at hand, the available materials for the interaction were selected. New objects evoking a task situation were used in the study with instruments from parent-infant research to be able to observe how staff members provide a scaffold to the people with PIMD (chapter 3). Objects of preference were selected for the examination of attentional processes (chapter 5). Although being well-considered selections, it is difficult to definitely know on beforehand whether the people with PIMD experience these objects as was meant. Physiological measures in this target group also demonstrated how difficult it is to know for sure which emotions a certain object elicits and how this can vary from situation to situation (Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2010).

Participants were asked to behave as they would normally do in a similar situation, and they were told that the objects could be freely used. However, our experience learned that when materials were introduced, staff generally appeared to be more directed towards the materials in interaction with the person with PIMD. Some staff members were inclined to show, as it were, the clients' capabilities (e.g., how the persons with PIMD could handle the objects themselves, or how they could be attentive for the objects). In an observation context without materials (chapter 4), more interpersonal processes and bodily aspects of the interaction were observed.

In contrast to this and to partially meet the limitations associated with the observation contexts of the three group observation studies, the case study recordings were completed in a normal living situation without interference of the researchers. The staff member could freely choose the objects in the interaction. This observation context could be considered a reflection of the daily life of the participants, which is a group context in the presence of other persons with PIMD and colleague staff members. The participating staff member of the case study also reflected afterwards that the processes

occurring in their interaction were only possible because of being embedded in the group and their well-known environment. But, this made the recordings less perfect (e.g., someone else comes into view) and more disturbing and uncontrollable variables were present. Furthermore, in comparison to the three studies performed in a semi-structured situation, this natural context resulted in other interactional processes being observed. With regard to attention episodes, for example, in the group study almost no intervals with attention from the client but not from the staff member (AE-d, code 1b) and almost no intervals without attention from the staff member and the client (AE-d, code 0) were observed, as being in the room alone elicited the staff member's and the client's attention towards each other. In the case study, however, it was more frequently observed that the staff member and/or the person with PIMD were directed towards other occurrences or other people in the environment. This makes clear that the observation context of the study determines part of the research results.

# Reliability calculation

Human interactional processes are difficult to capture and their evaluation involves a certain degree of subjectivity. Our experiences and opinions on high quality interaction are personal. Also, the interaction behaviours focused on in this study are difficult to translate in objective terms and concrete scoring guidelines. In that regard, extensive scoring manuals and/or decision trees were useful. To further guarantee the reliability of the studies' results, two methods were used in this doctoral research project.

First, the classical way of determining interrater agreement between two independent researchers was followed in chapter three and chapter five. This is most ideal with a large amount of data. However, especially because of the idiosyncratic communication of people with PIMD, it is not easy to come to sufficient agreement certainly not when determined with Cohen's kappa (Landis, & Koch, 1977). Extensive and intensive training appeared to be a *conditio sine qua non*, with the chance of the ratings being a result of a well agreed referential framework (Carter & Iacono, 2002) rather than a reflection of the reality. It is possible that by working closely on the project, researchers had developed shared but hidden meanings on the classifications which could artificially magnified the reliability coefficient (Krippendorf, 1980; Stemler, 2001). The request to accompany the scorings with argumentations and to make them explicit with concrete observable behaviours on the scoring sheets, encouraged to stay close to the manual and the observed reality as much as possible. Though this contributes to argumentative reliability (Van Ijzendoorn & Miedema, 1986), the consistency between the qualitative descriptions of the raters were not analyzed and determined when calculating interrater reliability.

Second, a consensus rating procedure or inter-discussion-reliability enables to verify whether raters agree in their allocated scores but also in the observations made. Though a own referential framework between the raters remains a possible pitfall, through the discussion on argumentations and observations a profound understanding of the occurring interaction processes can be agreed upon. The

high rating accuracy (Roch, 2006), the raters' attentiveness caused by the anticipation of group discussion (Wittenbaum et al., 1996), and the contribution to creative thinking (Nemeth et al., 2004) were exhaustively described in the manuscript on dialogue (chapter 4). The integration of observations from an experienced staff member through the staff-researcher dialogue (chapter 6), makes the consensus rating procedure even more valuable as different kinds of knowledge on the person with PIMD are coming together. The disadvantage of this consensus rating procedure is that it is time consuming because all data are double coded and discussed. For studies with a lot of data, a combination of both approaches may be suitable. Then, independent researchers could code all data and the non-comparable ratings could be discussed through consensus rating.

### Theoretical reflections and conclusions

On the basis of the studies accomplished within this doctoral research project, some theoretical reflections and conclusions on the interaction between people with PIMD and their direct support staff can be drawn.

In a first study the exploration and analysis of the research literature on interaction with people with PIMD resulted in an explanatory interaction model. As outlined in chapter two, this model could not be conceived as a comprehensive description of the interaction because of possible gaps in the current research, nor was it a reflection of real-life interaction as it was only based on an integration of current research findings in a variety of research contexts. Also, there was little support for the model for the reason that the available studies had small sample sizes and methodological shortcomings, and each of the key elements resulted from only a few articles. Nonetheless, the review helped to overview and visualize key elements determining interactions with people with PIMD as a start for the empirical studies of this doctoral research project.

The findings of the literature review and the resulting model were a source of inspiration and a general background against which the subsequent observation studies were drafted with respect to their content as well as their methods. With regard to the content, the three observation studies from the second part of the thesis were build around the constituting components of the interaction model, though not being an exact or exclusive copy of these components. The instruments from parent-infant research mainly enabled to describe sensitive responsiveness as well as the emotional component of the interaction (chapter 3). The Scale for Dialogical Meaning Making facilitated the description of coregulation and emotional components of the interaction, but joint attention was partially addressed too (chapter 4). The coding schemes used in the last observation study permitted the observation of joint attention and attention directing behaviours (chapter 5). With regard to the methods, we primarily used video observation and a supplementary staff interview in the last study, which is in agreement with the methodological findings of the literature review.

On their turn, the design and the findings of the observation studies were used as a background against which the integrative conceptual framework of the last study was shaped. Since the explicit

aim of the case study was to describe the interaction from a holistic point of view, the developed conceptual framework was not merely a summary of existing research but was a deliberate and well considered integration of relevant interaction dimensions resulting from the accomplished observation studies. Therefore, it can be considered a good basis to further adapt the explanatory interaction model from the literature review.

Based on the experiences build up through this research project together with reflections resulting from discussions with colleague researchers, a new interaction model may be drafted.

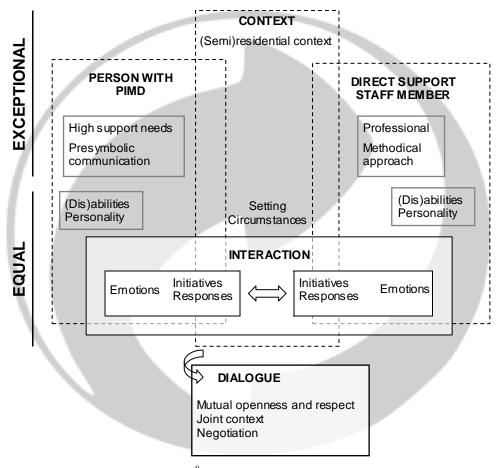


Figure 1. Equal and exceptional.8

The interaction between a person with PIMD and his direct support staff member.

Central to this model are the two interaction partners that were of particular interest in this doctoral research project: the **person with PIMD** and his **direct support staff member**. They are **equal** to all human beings in having their *abilities* and *disabilities*, and in bringing in their *personality* in interaction with others. Just as in all human interaction, the interaction partners come into contact with each other within a certain **context**. This encompasses the *setting*, referring to general organizational variables not necessarily connected to the individuals (e.g., policies, the broad

<sup>&</sup>lt;sup>8</sup> In reference to the title of the third European conference of the International Association for the Education of Deafblind People (IAEDB), Potsdam, Germany, July 31- August 5, 1993.

environment), and certain *circumstances*, pertaining to factors that are directly related to the interaction partners (e.g. their positions, available materials). When engaging in interaction, both interaction partners take *initiatives* and pose *response* behaviours to a greater or lesser extent. They experience certain *emotions* that also part of their initiations and responses to a certain degree. Although being part of persons' initiatives and responses, the emotional component is put as a separate aspect of the interaction because we believe these it is crucial in developing positive interactions. A certain initiating or responding behaviour can be posed (for example directing a person's attention), but its emotional ground is decisive in the course and the succeeding of the interaction. The partners' initiatives, responses, and emotions are in the ideal case as much tuned as possible. As Steenbeek and van Geert (2006) point out for their dyadic interaction model for social interactions in young children, 'actual interaction implies that the involvement actions of one person are reciprocated by those of the other person, and vice versa' (p.17). In comparison to the literature review model where different terminology was used to refer to comparable traits of the person with PIMD and his staff member (chapter 2), the equality between persons with PIMD and their direct support staff is more stressed in this model, also by analogously nominating their interactive behaviours.

In addition to these general human interaction elements, some particular exceptionalities characterize the interaction partners that were central in this dissertation. The person with PIMD has high support needs and communicates in a presymbolic way, as was comprehensively outlined in the introduction. His direct support staff member is a professional. Though it can certainly not be denied that these professionals experience a kind of attachment within their interactions with people with PIMD (Forster & Iacono, 2008) and often engage with them in person, they are doing their job and are only in the facility for a limited period of time. In comparison to the parents or other family members of the person with PIMD, the staff member does not have knowledge from the person from birth on and he is only temporally in the life of the person with PIMD. In line with this, they adopt to a certain degree a methodical approach in their professional conduct, which also filters through their concrete interactions with the person with PIMD (e.g., goal-directedness: engaging in positive interaction in view of a good wellbeing of the person with PIMD). This may also refer to the fact that the staff member has a responsibility 'to enable the less skilled individual ... to fulfil his or her potential to contribute [in the interaction]' (Olsson, 2004, p. 237). They can positively and respectfully stimulate the negotiation of meaning and create the best conditions for quality interaction to occur. Furthermore, the interaction between the direct support staff member and the person with PIMD does not take place in a vacuum. The fact that both interaction partners are in a (semi-)residential context with certain policies (e.g., not using touch to prevent abuse) and allowances (e.g., the staff-client ratio), may also have a promotive or hampering influence on the quality of their interaction.

When the two interaction partners, both with their own (dis)abilities and personalities, within an existing context, and having respect for their particular characteristics, dynamically synchronize their initiations, responses, and emotions, a real **dialogue** can arise. So, within this dialogue, the equalities

(which count for all human interaction) as well as the exceptionalities (which are typical of the interaction investigated in this doctoral study) come into connection with each other. On a continuum from monologue to dialogue, the interaction partners are, to a certain extent, *mutually open* for each other on the basis of which a *joint context* can arise through *negotiation*. Within a dialogue, all human beings are accepted as variations of the human condition. The persons' exceptional characteristics do not exclude the development of mutual understanding but are exactly a reason to negotiate with each other (Linell, 1998). Engaging in dialogue means a dynamic synchronization with respect for a person's individuality and exceptional needs, as well as with respect for his general humanity. As Roelink, Pool, and Grypdonck (2002) indicate, dialogue is present when the authenticity and uniqueness of the client with PIMD is actively searched for and taken into account, while dialogue is totally absent when the client is denied in his being a person.

The general human nature of the interaction between people with PIMD and their direct support staff as well as its unique characteristics are united in this model. Because of this, the model can be considered a modest midway and assimilation of an ordinary life approach, where the equal humanity of the people with PIMD and valuing them *as they are* is emphasized, and a developmental approach, where the low developmental functioning of the people with PIMD and striving towards progression are rather central (Burton & Sanderson, 1998; Goldbart, 2002). The dependency of people with PIMD is integrated within their interactions with others. In view of that, the model meets the meaning of the concept of relational autonomy, as outlined in the introduction. Building on Forster's conclusion (2010), we may argue that within this model the persons with PIMD may be themselves among and in relation with others.

The results from the case study partially confirm the value of the model. Pertaining to the 'interaction' and 'dialogue' box, the combination of the basic interactional dimensions was found to provide a complete and integrative image of the staff-client interaction. By combining initiations, responses, and emotions on the level of the person with PIMD and the direct support staff member, as well as the dialogical processes, patterns in the interaction could be described. Also, almost all observations from the staff member as well as from the researcher resulting from their dialogue could be assembled within the framework, except for elements pertaining to the group which can be put in the model within the (semi-)residential context. However, this interaction model is not validated and should definitely be object of further empirical as well as theoretical research.

#### Limitations

The specific limitations of each of the studies carried out were outlined within the corresponding chapters and were partially addressed in the methodological reflections made in this discussion section. Some overarching limitations of our doctoral research project will be discussed here. They will be further elaborated on in the section on suggestions for future research.

First, the concepts of interaction, communication, dialogue, relationship, etc. were sometimes used variably throughout the different manuscripts. That is because each of the studies started from other conceptual backgrounds, emphasizing own theoretical constructs. Through the course of this doctoral research project we gained more insight into these concepts, though it still remains difficult to grasp the subtle differences between them. We have tried to intelligibly create conceptual clarity in the terminology in the introduction but for further research in the target group of people with PIMD a better and widely agreed conceptualization would be valuable.

Second, the sample size of our studies was rather small and participants were selected through convenience sampling. It is possible that the addressed institutions selected the best functioning interaction dyads to participate in the university study because they wanted to give a positive image of their facility. In addition, the presence of two video cameras may have influenced the participants. On the one hand, this could have evoked some stress or reduced their spontaneity. On the other hand, this could have stimulated the staff members to show their best, which is not necessarily a problem as it can only be applauded that staff members know what this best involves. The effect of the video camera may also explain why rather high mean scores and a ceiling effect in the obtained observations occurred. Nevertheless, the observation tools were able to differentiate between higher and lower function interaction dyads. To avoid the camera influence, it would have been better to have hidden cameras but this was not possible within this research project as we explicitly wanted to film in the institutions themselves. Moreover, except for the case study where several recordings were done and the staff member could select one afterwards, the recordings were momentary and the interaction was only filmed once. Test-recordings were not done because of limited time. Taken together, the research results are not merely generalizable. However, rather than determining the quality of the interaction within the large population, the aim of this thesis was to examine different methods on their usefulness to describe the processes occurring in the reciprocal interaction between people with PIMD and their direct support staff. We wanted to study whether the different theoretical and methodological aspects of the selected observation instruments enabled to differentially and meaningfully describe a variety of interaction dimensions. That is why the limited sample sizes and the possibly non representative records could be considered as less decisive for the studies' quality. In that regard, the adjustment of existing tools and the development of new useful coding schemes was more important.

Third, we chose to focus in this doctoral study on the interpersonal interaction processes between the people with PIMD and their direct support staff. Referring to the interaction model from the literature review (chapter 2), influencing variables on the level of the people with PIMD, their direct support staff, or the context were not taken into account. Critical differences between the persons, especially between the people with PIMD, were not integrated in the data analyses although we knew the demographical characteristics of the participants. However, our research group was not purposefully composed with variation on these variables (e.g., autism spectrum disorders, visual abilities, or age of the persons with PIMD, experience of the staff member, familiarity with each other,

etc.), as the small number of institutions in the field necessitated to work with a convenience sample. We did not work with experimental groups as the emphasis was put on understanding and description.

Fourth, a last but inevitable limitation of our study is the risk of ascribing meaning to the behaviours of the participants, especially the people with PIMD (Grove et al., 1999). We can never be sure that someone poses a behaviour with a certain purpose. Our experience during the trainings learned that observers have a lot of implicit ways to make conclusions on the observed behaviours. Within the scoring manuals these criteria were made as explicit as possible to enhance the validity and the strength of our interpretations regarding a person's intentionality. So, in our studies several criteria were used to make the inferences on the persons' behaviours justified but these could not be exhaustively described in the manuscripts. In first instance, we used criteria for intentionality: goaldirectedness, anticipation of a response or showing satisfaction or dissatisfaction with the response, and the directedness towards the other person (e.g., Daelman, 2003; Iacono, Carter, & Hook, 1998). In second instance, we not only looked at isolated aspects of the behaviours but at all facets simultaneously. The nature of the body movement, facial expression, voice intonation etc. can support the interpretation of an act as being positive or negative, directed towards the interaction partner, and so on. For example, taking a ball in an enthusiastic way with an open glance, while vocalizing and smiling to the staff member, can be considered a positive act in contrast to taking a ball with discouraged eyes and a collapsed posture. In last instance, taking the course of the interaction into account (what comes before and after a certain behaviour), was also helpful to understand people's behaviour. Still, over-interpretation is a pitfall. This strategy of over-interpretation is useful in practice. By constantly ascribing intentionality to the persons' behaviour, by reacting on their behaviour as if it were intentional, and constantly checking the potential meaning of their behaviours, the interactive and communicative development of people with PIMD may be developed (Daelman, 2003; Grove et al., 1999; Snell, 2002). Although this should be avoided in scientific observations, it may be that researchers employ this strategy too because they are used to this way of approaching people with PIMD and because they want to see the capabilities of the people with PIMD. This leads then to an over-assignment of intentionality (Carter & Iacono, 2002). Daelman (2003) for example found that researchers not familiar with a person with PIMD were saw more communicative utterances in comparison to familiar interaction partners. Researchers could also be mislead by the staff member over-interpreting in the interaction being observed. For example, when a staff member says "yeah, that is a high tube", the researcher may be inclined to follow this staff member's observation and to code the client as having attention for the tube, while the client was maybe actually directed towards the lighting in the ceiling. The client information forms used in the group observation studies, the use of the above mentioned criteria for intentionality, the attention for the interaction course, the score argumentations, and the involvement of an experienced staff member in the case study, partially met this limitation.

## **Suggestions for future research**

Several suggestions for future work were indirectly proposed throughout the previous parts of this doctoral dissertation. Here, some remaining suggestions for further research will be discussed, pertaining to methodological aspects as well as to the content of future studies.

First, on a methodological level, it is a challenging future research task to replicate the current studies on a larger sample size to enhance their external validity. A (quasi-)experimental research design could also enable to control and examine a variety of influencing factors on the quality of the interaction. Based on the interaction model and inspired by previous research and theory, this could be interesting influencing factors on the level of the people with PIMD to investigate: the developmental and chronological age of the people with PIMD, their basic cognitive and communication skills, their temperament or behaviour style (Wilder, 2008b), their degree of alertness (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009), and their visual and/or auditory limitations. Evaluating the influence of different staff and context variables on the interaction quality can be considered an interesting continuation of this doctoral research project too. For example: the working experience of the staff, the education and training of the staff, object characteristics (e.g., neutral versus objects of preference, modality of the objects), the multisensory character of the environment (Vlaskamp et al., 2003), or the position of both interaction partners. But also some interactional variables could be considered, such as the time the interaction partners know each other or the frequency of contact they have. Also, the interrelationships between different influencing factors is important to identify (Granlund & Wilder, 2006). This could lead to a more evidence-based interaction model.

Second, although large and more experimental studies could contribute to a broad and general understanding of the interaction with people with PIMD, an opposing direction for future research could be the investigation of individual interaction patterns and their influencing variables. As it is known that the target group of pre-symbolic individuals can fluctuate a lot in their interaction skills over a short time period and over situations, in depth case studies could uncover what the best circumstances are for an individual with PIMD to interact. On the basis of momentary snap shot observations in this doctoral study, we could not grasp whether the obtained results were originating from the fact that the clients could not show their best because of intra-individual factors (e.g., developmental level or other disabilities) or because of inhibiting factors in the context or staff (e.g., directivity of the staff). Investigating a person with PIMD in different situations, on different moments of the day, with different interaction partners, and if necessary longitudinally at different moments in time (Granlund & Wilder, 2006), could give an image of what the best possible conditions are to elicit his interactive capabilities and, on the other hand, what his personal interactive limitations are. Then, the purpose and interest of this kind of research is particularization and not generalization (Stake, 1995). Although quantifications have the advantage of making research results comparative and experimental designs enable to draw conclusions on general causal relationships, qualitative analyses

are essential for this kind of research. Through qualitative in-depth case studies the dynamic flow of interaction processes can be taken into account, the participants' perspective and the particular context can be understood (Maxwell, 1996), and a nuanced image of the complex reality can be build up.

Third, a last methodological suggestion for future research is to include parents and other family members in the coding of the observations. The combination of observational data and an interview with the participating staff member (Granlund & Olsson, 1993) appeared to be valuable in the case study. But, the specific expertise and important knowledge of parents, who know people with PIMD from birth on and are unconditionally constant in the life of people with PIMD, could further enhance the quality of the observations. Parents in the study of Granlund, Olsson, Von Dardel, and Anderson (1990) were found to have accurate perceptions of their children's abilities even when their children were living away from home for a long time. An integration of familiar and independent observers to investigate interaction could be most interesting (e.g., Lyons, 2003; Petry & Maes, 2006).

Fourth, with regard to the content of future research, it would be interesting to further examine the occurrence and the potential of humor in interactions between people with PIMD and their direct support staff, which occurred as a new interaction element in our case study (chapter 6). The possibilities and limitations of using touch (Hewett, 2007; Petitpierre & Hauenstein, 2010) could be focused on too. In the study on dialogue (chapter 4) close bodily contact was raised as contributing to quality interaction. From previous research as well as from our attention study (chapter 5) and case study (chapter 6), however, it appeared that while staff members consider touch a significant and preferred strategy (Forster & Iacono, 2008; Healy & Noonan-Walsh, 2007) they actually do not often use it in interaction with people with PIMD. It should be clarified how touch can be used not just as a functional act but in a non-anxious, non-intrusive, and sensitive responsive manner.

Fifth, our research showed that the translation of the dialogical view for practitioners should be further elaborated and concretized. Dialogue is a trendy word in our current society but is often used simplified without clear insight into its genuine meaning. Therefore, an attempt must be undertaken to discuss the real dialogical principles, e.g. by introducing the strategy of immediate imitation (e.g., Hart, 2006) as a means or an example to obtain dialogue. Also, the fact that the point of reaching a shared meaning is of minor significance in comparison with the process of meaning making itself, may be liberating for professionals who are sometimes frustrated about the feeling of not always coming to shared understanding with people with PIMD. However, this may also not lead to a waiting or *laissez-faire* attitude as staff still has a responsibility to create the best possible conditions for dialogue to occur. Only after more effort is done for this translation to practice, it can be concluded whether it is possible to use the dialogical theory to inspire direct support staff or else, whether this is a framework for research only.

Sixth, as we made a choice to focus on people with PIMD and their direct support staff, it can also be a valuable extension of this doctoral study to use the gained knowledge to understand interactions between people with PIDM and other interaction partners such as parents, family

members, or teachers. Additionally, it would be interesting to examine to which degree the different perceptions, roles, and knowledge of family members and professionals influence their interaction patterns. Moreover, the study of peer interactions between people with PIMD and their (non-)disabled peers (e.g., Arthur-Kelly et al., 2008) opens an important field for future research.

# **Implications for practice**

In view of the quality of life of people with PIMD, it is important to support staff in their relational competencies and to enhance their expertness to build up quality interactions (Jahr, 1998). Hence, the original purpose of this doctoral research project was to develop a group intervention program for staff members to improve the quality of the interaction with people with PIMD by working more evidence-based. However, because of the conceptual indistinctness and the absence of useful methods to evaluate the outcomes of the training on interactional and relational variables, the idea of an intervention program was left. Since, the staff-client interaction rather than the individual contributions to it must be the focus in staff training assessment (Jahr, 1998). Consequently, the research aims were reformulated from a conceptual and methodological perspective. As a result, the studies done were necessary preceding work and the findings of this doctoral research project can be considered the starting point of what was initially aimed for.

That this doctoral research may contribute to better and more reasoned methodological choices for further research was already described in the former. But the transfer to practice remained an important concern always at the background of the studies performed, and culminated in the case study. The case study's method can be considered an observation protocol, useful in research as well as in practice, to describe the interaction between persons with PIMD and their proxies on different variables. The practical relevance of the case study's method was situated in how the involvement of the staff member as a means to validate the codings, already affected the staff member and led to new understandings and directions for her future practice. The study showed that being able to better describe interactional processes, is already a first step towards further professionalization. The staff's participation in the observations offers a space for thinking and watching themselves in interaction with the client without already engaging in a profound interaction program (Vliegen, 2006). As such, the interaction observations can be regarded as a bridge between research and practice, as Vliegen (2006) convincingly described.

Rather than standardized intervention programs, we plea for individualized support programs where the staff member as well as the supervisor can exchange their knowledge through mutual discussion. As such, the intervention is not a top-down process from expert to novice, but a dialogical process in which the role of expert and novice are dynamically interchanging. This makes staff feeling respected and also guarantees that the questions and demands from the staff members themselves are taken as a starting point, which can enhance their motivation and active participation (Granlund et al., 1990).

This research has the potential to give practitioners a language to talk about something as difficult as interpersonal interaction processes. Although staff often believe that interaction is a matter of a feeling, they should be stimulated to become aware of relevant interaction processes. As they often have intuitive knowledge on high quality interaction with people with PIMD in general or with an individual with PIMD in specific, it is important to give them a framework and accessible terminology to make their existing knowledge explicit (Granlund et al., 1990). This shared language and referential framework make it possible to share their knowledge with each other and to develop new insights. We believe our study contributes to this, not only by the separate observation tools but mainly by the integrative framework proposed in chapter six and the new interaction model.

Furthermore, as the results of the performed studies showed a lot of strengths in current interaction patterns, it is most important to validate positive aspects in the interaction. Therefore, rather than starting from the conviction that the interaction between people with PIMD and their support staff is of low quality and staff members should be changed, our research may be supportive to confirm the available qualities in the interactions. The observation tools are especially useful then to make practitioners more aware of what functions already well in the interaction with their clients with PIMD. For that reason, the observation protocol should not be used to evaluate people but to enable description of interactional dynamics, to strengthen positive aspects in the interaction, and to offer directions to improve less available characteristics. The way to give concrete feedback to staff members on the observations made during video analysis, i.e. video-feedback, remains an area for further exploration (e.g., Damen, Kef, Worm, Janssen, & Schuengel, 2011; Van Oorsouw, Embregts, Bosman, & Jahoda, 2009).

In addition, this research offers starting points to inspire staff members by offering new possible perspectives on the interaction with people with PIMD. The applied observation methods as well as the research results may give them new eyes and offers scope to look beyond their habits. The aim of intervention then should not be to give staff recipes, as interaction does not work by means of standardized principles. But, the theoretical frameworks, the description of subscales in the observation tools, exemplary qualitative descriptions of the research results, etc. must be used as tools for reflection. It enables to reflect with staff on their attitudes, opinions, and interpretations, by which people develop professionalism. Roelink, Pool, and Grypdonck (2002) concluded that staff members who were more able to reflect on their own work, were more engaging in dialogical interaction. Therefore, the key to enhance the interaction quality is certainly raising consciousness and reflection in practitioners. Video-analysis appeared to contribute to this reflection, for example because of its playback capabilities and because verifiable observation offers an ideal basis to develop knowledge (Jordan & Henderson, 1995). The video observations enable to look to the interaction several times, from several perspectives, and possibly with several persons involved. As such, an image of the interaction can be build up, hypotheses can be developed, and new understandings and supportive cues for action can arise. In particular, good functioning interactions can be a starting point for reflection, as

was the case in the case study, but also a highly atypical case could contribute to more profound and new understanding (Stake, 1995). Of course, enough time for this reflection and a secure environment are important too.

More in particular, the observation tools, the integrative conceptual framework, and the interaction model developed, provide a guidance for this reflection on important elements in the interaction. The interaction model, for example, suggests starting points to think of and to discuss alternatives to optimize the interaction quality. From the perspective of the person with PIMD, for example, it may be important to trace the available abilities and confirm them through interaction or to model how he can use them within interaction. From the perspective of the direct support staff, for example, it may be relevant to think of the own personality in relation to the personality of the client with PIMD. From the perspective of the context, for example, it may be significant to adjust the environment or the materials to maximize the chance of positive interaction. From the perspective of the interaction and dialogue itself, for example, it may be appropriate to reflect on how more joint attention or being enjoyably together may be promoted. How the model and the different observation tools additionally may inspire for concrete interaction strategies was extensively described in a book chapter for practitioners (Hostyn & Daelman, 2011).

Lastly, our research results may wrongly suggest that high quality interaction must be constantly strived for. However, organizational factors (e.g., the group context, the high amount of time for feeding and care, etc.) inhibit this. Also, just as every person is not always 'open' for others, people with PIMD also want to have time to be on their own too. The staff member participating in the case study, exemplary, reflected afterwards that the client with PIMD was a bit 'interaction tired' after our intensive recordings of one on one interaction. It is key to be attentive for the person with PIMD, to create an optimal interactional climate, and to engage in quality interaction when the best possible conditions occur. As outlined, starting points for this can be found in this doctoral dissertation. Also, it is important to do something valuable with the moments of one on one contact that are inevitable part of the daily routine (such as moments of feeding or care). These functional moments can be build out as enjoyable moments of being genuinely together. Moreover, maybe the principle of 'client of the day', which some institutions use and which means that people can experience some exceptional activities (e.g., joining the staff member to the kitchen), could also be translated in interactional terms. We agree with Forster (2008) that spending ten minutes with a person with PIMD while giving them one hundred percent of your attention creates the best possible conditions for quality interaction. By this intensive intimate contact, both interaction partners, the staff member and the person with PIMD, can further develop and feel worthy of being. As Tutu describes, people become more human throughout mutual and positive interaction with others. 'The fundamental law of human beings is inter-dependence. A person is a person through other persons.

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