Attention please!

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Alertness in individuals with profound intellectual and multiple disabilities

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1 Introduction

Providing support and education for individuals with profound intellectual and multiple disabilities (PIMD) is a challenging task for direct support persons (DSPs). One of the barriers that DSPs experience is timing. Individuals with PIMD only show short periods of *being focused on the environment* or *being alert* (Guess, Roberts, & Guy, 1999). Moreover, these short moments are often difficult to detect because of individual differences in how alertness is expressed (Mudford, Hogg, & Roberts, 1997). Based on these difficulties, DSPs face recurring questions when they approach individuals in the target group: What is the best moment to start an activity or an interaction? How can we determine the *best moment* or being alert? What is the duration of such a moment? And how can we provoke these moments so that they occur more frequently?

While researchers and DSPs agree upon the importance of alertness in the support and education of individuals with PIMD, they face three main problems that are related to the topic. First, unambiguous terminology and descriptions of these terms are lacking for the target group. In previous studies, different terms have been used to designate the moments of being focused on the environment. Moreover, the descriptions differ for different terms, and even different descriptions for the same term can be found (Foreman, Arthur-Kelly, Pascoe, & King, 2004; Green, Gardner, Canipe, & Reid, 1994; Guess et al., 1993; Mellstrom, Saunders, Saunders, & Olswang, 2005). At the same time, an unambiguous description of alertness is necessary as a basis for all further research and knowledge.

Second, researchers and DSPs wonder how best to determine alertness. While it is difficult to detect the short alert periods of individuals with PIMD, the quick and irregular changes between being alert and not being focused on the environment aggravate this task still more (Guess et al., 1999; Mudford et al., 1997). In addition, an assessment method is needed that is capable of taking individual differences in alertness expressions into account. While observation yields this possibility, DSPs are then obliged to interpret the alertness expressions noted in their observations. Because of this, the subjective component of the interpretation becomes a threat to the reliability of this method (Hogg, Reeves, Roberts, & Mudford, 2001). Alternative assessment methods such as brain measurements and physiological measurements exist, but they are also difficult to implement when it comes to individuals of the target group (Kemner, Van der Gaag, Verbaten, & Van Engeland, 1999). Because measurements can be biased by the disabilities of the individual, interpretation of the results may not be the same as that for a nonclinical population. Based on these issues, the discussion about assessment methods for alertness in individuals with PIMD is an ongoing one.

Finally, only a small number of studies have been conducted to ascertain the possibilities for influencing alertness in individuals with PIMD and, therefore, reaching the alertness levels that are optimal for learning and development. Previous studies often included only a small number of participants, and the research methods used were not always comparable to each other (e.g., Cuvo, May, & Post, 2001; Lindsay, Pitcaithly, Geelen, & Buntin, 1997). Because even similar studies have come up with different results, empirical studies concerning those factors that may have an impact on alertness are badly needed.

1.1 The target group: individuals with PIMD*

A profound intellectual disability is almost always the consequence of neurological impairments arising from trauma or genetic influences (Arvio &

* This section is based on the following article: Munde, V.S. & Vlaskamp, C. (2010). Alertness observations in children with profound intellectual and multiple disabilities. *International Journal of Child Health and Human Development*, *3*(1), 115-124.

Sillanpää, 2003). The implications apply to almost all aspects of the person's functioning. Central nervous system (CNS) damage results in profound intellectual disorders, severe or profound motor disorders (e.g., spastic quadriplegia), and sensory disorders. Characteristically, individuals with PIMD function at the preverbal stage of communication. Only some of them have spoken or signed expressive language and their communicative comprehension is at a low level. Their understanding of causality and space is always limited. Because of the minimal level of their adaptive and self-help abilities, individuals of the target group require pervasive support. Another consequence of such CNS damage is that most individuals with PIMD are wheelchair users. In addition, they have difficulties in maintaining postural balance and the use of hands and arms is very limited. Both gross motor and fine motor functions are profoundly disturbed. Furthermore, sensory impairments are also common. Recent studies show that at least 85% of people with profound intellectual disabilities experience visual impairment (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). In most cases this is caused by damage to the visual cortex in the occipital lobe (cortical blindness). Between 25% and 33% of individuals with profound intellectual disabilities suffer from auditory impairment, but it is suspected that a substantial number of such cases may actually remain unidentified (Evenhuis, Mul, Lemaire, & De Wijs, 1997; Evenhuis et al., 2001). In addition, dysfunctions of taste and smell are also relatively common (Doty et al., 2002). The tactile and coetaneous senses that include the receptors of touch, pressure, temperature, and pain are frequently thought to be impaired to some degree as well (Dunn, 1999; Oberlander, Gilbert, Chambers, O'Donnell, & Craig, 1999). However, assessment of these dysfunctions is difficult and, therefore, they are rarely taken into account. In addition to the intellectual, motor, and sensory disabilities just noted, further concomitant impairments should also be mentioned as they, too, have significant implications for daily functioning. Extensive additional impairments include: seizure disorders, chronic pulmonary infections, and skeletal deformations (Evenhuis et al., 2001; Hogg, 1992; Janicki & Dalton, 1998; Van Schrojenstein Lantman-de Valk, Van den Akker, Maaskant, & Haveman, 1997; Van Splunder et al., 2006).

Since each individual represents a unique configuration of abilities and constraints in regard to functioning, individuals with PIMD form a heterogeneous group in terms of central nervous system integrity, physical growth, development, and behavioral repertoires (Zijlstra & Vlaskamp, 2005). Notwithstanding this huge diversity, individuals with PIMD are comparable in terms of the degree of their profound intellectual disabilities, along with their severe or profound motor disabilities. They form a very vulnerable group with heavy or total dependence on personal assistance for their physical care, education, stimulation, and recreation.

1.2 Aim of the research

The present thesis aims to reach a better understanding of alertness in individuals with PIMD. To this end, the focus is threefold. An unambiguous description of alertness needs to be formulated first, but providing a reliable and valid instrument for DSPs to determine alertness has to be the second step. Based on this, an empirical study should then be able to show which environmental factors may have an impact on alertness in individuals in the target group.

Because the first two aims have a conditional relationship with the third aim, the main research question of the present study is the following:

How can we influence alertness in individuals with PIMD?

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

How can we describe alertness?

How can we determine alertness?

How can we influence alertness?

1.3 Outline of the thesis

The present thesis consists of three parts. First, a review of the literature will summarize previous research and highlight the remaining problems in describing, determining, and influencing alertness. Because this study still left several questions open, a group of experts was asked to discuss the results. This Concept Mapping procedure revealed additional information that could be used to clarify the problems.

In the second part, the Alertness Observation List (AOL) will be presented. To provide an instrument with good psychometric qualities for DSPs, the reliability of the AOL was investigated, calculating the inter-observer and intra-observer agreement for a sample of observations. Subsequently, the validity of the instrument was then able to be described based on a comparison of observations with physiological measurements.

Third, two analyses of an empirical study will be described. By considering stimulation situations in a multisensory environment as a potential activity for influencing alertness levels in individuals with PIMD, the first analysis will focus on the impact of different aspects of a stimulation situation on the various alertness levels. Based on this analysis, we will then look at the sequential effects of alertness and the different stimuli in the stimulation situation.

In the concluding chapter, the results of all the studies will be linked back to the research questions. Limitations, implications for clinical practice, and suggestions for future research will be discussed.

The outline of the thesis is visualized in Figure 1.1.

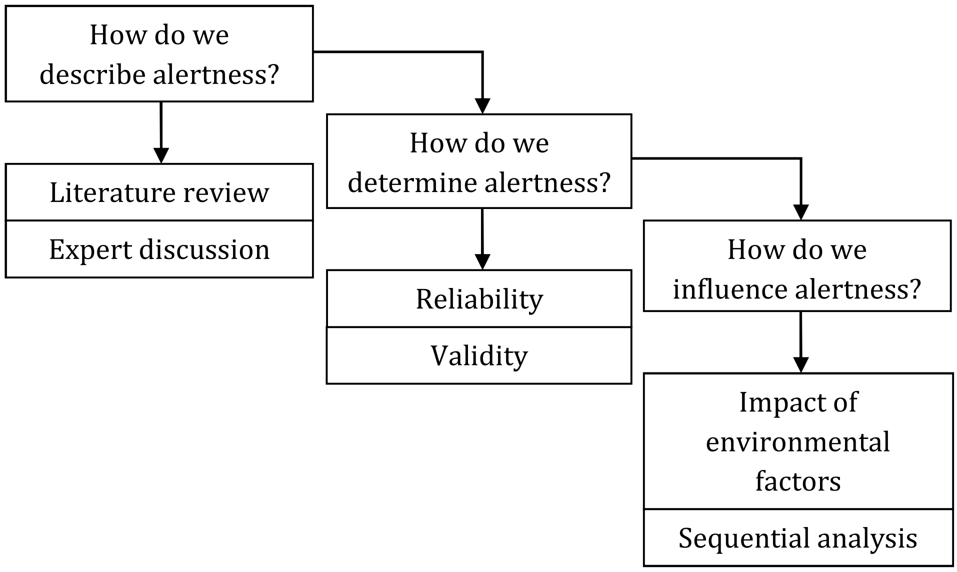

Figure 1.1 Outline of the thesis

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Alertness in individuals with profound intellectual and multiple disabilities: a literature review*

* This chapter has been published as: Munde, V.S., Vlaskamp, C., Ruijssenaars, A.J.J.M., & Nakken, H. (2009). Alertness in individuals with profound intellectual and multiple disabilities: a literature review. *Research in Developmental Disabilities, 30*(3), 462-480.

Abstract

Direct support persons (DSPs) often face problems in observing and determining alertness in individuals with profound intellectual and multiple disabilities (PIMD).

A literature study was carried out to gather information about the problems just described. A search of two electronic databases and the references found in relevant hits revealed 42 relevant publications. The results show that two types of descriptions of alertness can be distinguished: 1) those with a focus on the individual only, or 2) those with a focus on the interaction of individual and environment. Several observation categories were used in the studies that were found. The reliability of the observations turned out to be a core problem in most of the studies. Only a limited number of environmental conditions that were expected to have an impact on alertness in individuals with PIMD were investigated. While modifications of the environment, interaction strategies, stimulation strategies and staff training were found to have a positive impact on alertness, studies about treatment activities led to conflicting results.

Finally, we will formulate the resulting implications for future studies and for the development of an instrument for DSPs in order to observe alertness in individuals with PIMD in clinical practice.

2.1 Introduction

Tom is lying on the floor and is apparently staring without any focus. A direct support person (DSP) places a toy in front of him: "Look, Tom! I brought a beautiful toy for you!" Tom keeps staring without any visible reaction to the toy. As the telephone rings, the DSP leaves him alone. Some seconds later, Tom slowly begins to move. He turns his head towards the toy and tries to reach the toy with his hand.

DSPs often face similar situations when caring for individuals with profound intellectual and multiple disabilities (PIMD). To an observer, the questions that arise at these moments are: did the DSP choose the right moment to start an activity? Was Tom alert but inactive before the toy was presented? Or was he drowsy and did he become alert some seconds after the toy was placed in front of him? What caused the change in his alertness level? Did Tom become alert because of the new stimulus, because of the contact with the DSP, or because of another factor?

DSPs also ask these questions. They experience difficulties in detecting and understanding expressions of alertness in individuals with PIMD because of the complexity and severity of the disabilities of these individuals. Individuals with PIMD not only have profound intellectual and motor disabilities (Nakken & Vlaskamp, 2007), but sensory disabilities, and a broad range of additional health problems (e.g., epilepsy, dysphagia, constipation, gastro-esophageal reflux) are also common (Arvio & Sillanpää, 2003; Kapell et al., 1998; Van Schojenstein Lantman-de Valk et al., 1997; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). One complicating factor is the heterogeneity of the target group: the combination and degree of disabilities vary for every individual. The magnitude of the disabilities of individuals with PIMD also has consequences for the way they communicate. Most of them are not able to use spoken language and, as a consequence, have alternative ways of communicating such as through gestures, muscle tensions, a wink or a blink (Grove, Bunning, Porter, & Olsson, 1999). Their limited repertoire of communicative skills and the fact that one signal may have several meanings make it difficult for the DSP to detect and interpret the communicative signals of individuals with PIMD, such as being interested in the environment or in a toy (Petry, Maes, & Vlaskamp, 2005). Unconventional reactions to stimuli and differences in information processing make it even more difficult for DSPs to determine the right moments, approaches and materials to use when offering an activity (Petitiaux, Elsinga, Cuppen-Fonteine, & Vlaskamp, 2006). Observation is, therefore, the most obvious method for taking these difficulties into account, that is, looking at individual behaviors and interpreting these behaviors based on knowledge of the individual. Still, the reliability and validity of observations may be considered as limited (Vlaskamp, 2005).

The right moment to offer an activity can be related to the level of alertness (Guess & Siegel-Causey, 1995), but knowledge of the conditions for optimal stimulation is still missing. We lack a clear description of what is meant by being alert for this specific target group. In trying to solve the question about *the right moment*, an unambiguous description of the term *alertness* is necessary. Following on that, reliable and valid methods to determine alertness need to be developed. Furthermore, environmental conditions that may have an impact on the level of alertness in individuals with PIMD need to be investigated. Taking into account the relationship between alertness and stimulation (Guess & Siegel-Causey), we searched for factors that would support individuals with PIMD in reaching an optimal level of alertness for learning and, therefore, the opportunity for development.

Alertness is a term that is not exclusively used in behavioral sciences. In medical science, alertness includes cognitive processing and is determined on the basis of physiological brain measurements (Oken, Salinsky, & Elsas, 2006; Thomas et al., 2000). However, by only looking at the internal changes in an individual's functioning, environmental changes and their impact on alertness are not taken into account. Since relationships with the environment are essential for observations of individuals with PIMD (Vlaskamp, 2005), the medical approach will be excluded in this study.

Based on the above-mentioned considerations, this study aims to review the scientific literature about the behavioral dimension of alertness in individuals with PIMD in order to answer the following research questions:

- How is alertness for individuals with PIMD described in the literature?
- Which observation methods, as found in the literature, can be employed to determine alertness levels of individuals with PIMD?
- Which environmental conditions are related to the alertness in individuals with PIMD according to the literature?

2.2 Method

To answer the research questions, a literature review was carried out. Two electronic databases, Education Resource Information Clearinghouse (ERIC) and American Psychological Association (PsycINFO), were searched. The references found in all relevant hits were checked.

During an initial exploration of the field, it became apparent that Guess and his colleagues had published relevant articles since 1993. To include these papers, the search was conducted for the period from January 1993 to December 2007.

Because a number of synonyms are used for alertness, the terms *behavior state*, *attentiveness*, *responsiveness*, *attention* and *on-task behavior* were included. The terms describing alertness were combined with additional terms describing the target group according to Nakken and Vlaskamp (2007). Based on these considerations, the following selection criteria were formulated.

Inclusion criteria:

- literature focusing on the behavioral dimension of alertness;
- studies involving individuals with profound intellectual and multiple disabilities;
- scientific, peer-reviewed publications;
- publications including at least an abstract in English.

Exclusion criteria:

- literature focusing on the medical dimension of alertness;
- studies involving individuals with mild intellectual disabilities; physical disabilities only or multiple sensory impairments;
- unpublished papers;
- publications without an abstract in English.

2.3 Results

Based on the search terms, the search in ERIC and PsycINFO revealed 903 hits. Of these, 736 papers were excluded after reading, as they did not refer to the inclusion criterion alertness (or a similar term) as a behavioral condition for the participating individuals with disabilities. For example, the term attention was mentioned in a number of different senses such as, “We have to pay attention to a particular subject.” The reason for the

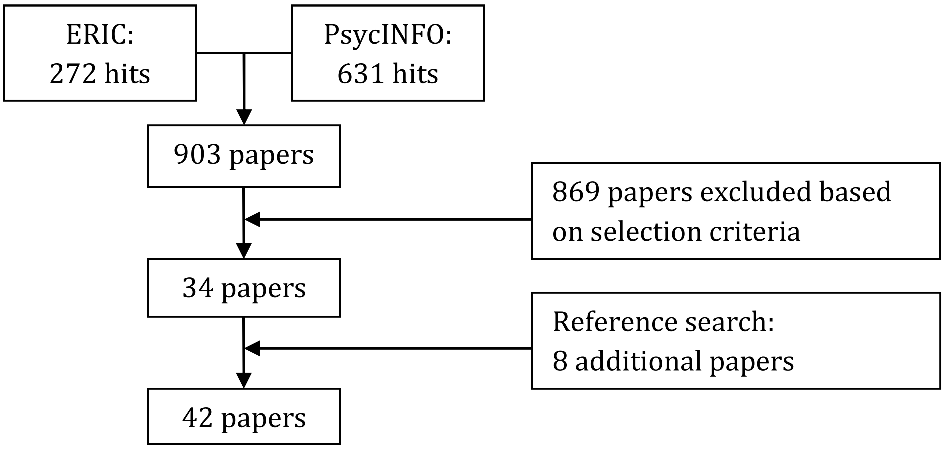

Figure 2.1 Search process and results

exclusion of 117 of the remaining studies was that they did not focus on individuals in the target group. In addition, it turned out that 16 studies did not fulfill the other two selection criteria. Thirty-four papers were marked as relevant for this study. Eight additional papers were found in the reference lists of these hits. An overview of the search process and the results can be found in Figure 2.1. The results include 34 empirical studies, five literature reviews and three comments on earlier studies with several key authors contributing a number of papers.

In all but one of the empirical studies, observation methods were employed to determine alertness and environmental factors. The exception concerned Mattie and Kozen (2007), who based their study on file analysis, interviews with teachers and daily students' schedules. The other 33 authors conducted observation studies. Participants were observed in naturalistic settings (22 studies), in experimental settings (six studies) or on videotape (five studies). Research designs differed in application of a treatment activity (yes or no), moment of measurement (pre-activity, post-activity, pre- and post-activity) and the use of a neutral condition (activity versus no activity). Twenty authors employed some kind of control condition. All 33 authors used different observation methods. These differences were related to the number of alertness categories and the different operationalizations used. Furthermore, interval and continuous scoring, as well as momentary-time-sampling and observations of post-activity task performance, were employed. Observation time varied from three minutes to five hours. Scores were noted in intervals of three seconds up to five minutes.

Most of the studies involved a small number of participants. Twenty-five studies included a maximum of ten participants. Sixteen of these authors described a case study.

The methodological characteristics of the research methods and results for all the studies included are listed in Table 2.1.

Descriptions of alertness

The first findings concerning alertness in individuals with PIMD were published by Guess et al. (1993). They give two descriptions of the notion of a *behavior state* that both focus on the individual and their internal conditions. Behavior state is thus a theoretical concept. Internal processes provoke the different states that become visible in the behavior of an individual. Wolff (1959, cited in Guess et al., 1993) describes behavior state as “a series of behavioral and physiological conditions that range from sleeping to awake and crying among infants.” According to Helm and Simeonsson (1989, cited in Guess et al., 1993) behavior states are “expressions of maturity, status and organization of the central nervous system […] which mediate the child’s ability to respond to the environment and stimulation.” In 17 papers included in this review, researchers used the same descriptions as Guess et al. (1993). Guess and several other authors do not equate

Table 2.1

Overview of the characteristics of the studies included in the literature review

Author(s)	**Number of participants**	**Term used**	**Type of description**	**Observation method**	**Research results**
Arthur (2000)	-	behavior state	focus on individual	comment	-
Arthur (2003)	10	behavior state	focus on individual	naturalistic setting, duration ~ 5h, 9 behavior state codes, interval coding	low proportion of awake and alert states related to low proportion of communication and activity
Arthur (2004)	10 students	behavior state	focus on individual	naturalistic setting, duration ~ 5h, 9 behavior state codes, interval coding	several patterns of behavior states and/or activity categories became apparent
Arthur, Hook, & Butterfield (1995)	-	behavior state, alertness, attention	different focus for different terms	literature review	implications for practice, such as the need to train teachers to observe behavior state in order to improve education
Ashby et al. (1995)	8	concentration, responsiveness	focus on interaction with the environment	naturalistic setting, observation of a simple task for 5 min. following a Snoezelen session	increased alertness following a Snoezelen session, but changes were not always expected to be related to the Snoezelen environment

Ault , Guy, Guess, Bashinski, & Roberts (1995)	10 students, 8 teachers	behavior state, alertness	different focus for different terms	naturalistic setting, duration 7.5 min., 8 behavior state codes, interval coding	based on the ABLE model, teachers can learn to observe behavior state reliably and to influence behavior state by external variables
Bailey (1994)	3 women	responsiveness	focus on interaction with the environment	naturalistic setting, observation during use of assistive devices	new activity leads to higher levels of alertness, responsiveness and enthusiasm; level of alertness can be predictive for success in using technology
Belfiore, Browder, & Mace (1993)	4	alertness	focus on interaction with the environment	naturalistic setting, 20 min. each setting, 4 categories, partial-interval coding	environmental settings (segregated classroom setting versus low stimulation versus high stimulation community settings) can affect rates of adaptive (alert) and non-adaptive behavior
Cuvo, May, & Post (2001)	4 adults	engagement	focus on interaction with the environment	naturalistic setting, sessions of 20 min.	higher levels of engagement in Snoezelen rooms versus living rooms; highest levels of engagement following outdoor activities

Foreman et al. (2004)	16 students	alertness, behavior state	different focus for different terms	naturalistic setting, duration ~ 5h, 9 behavior state codes, interval coding	students in general classrooms were more alert than students in special classrooms; higher alertness levels were related to more communication and involvement (more frequently with peers and aids) and more conceptual activity
Green, Gardner, Canipe, & Reid (1994)	5 women	alertness	focus on individual	experimental setting, for 3 min. before, 3 min. duration, 3 min. after training session, 5 levels on alertness continuum, interval coding	increasing alertness based on training; no differences for active or inactive environments; no relationships between stimulus assessment and alertness
Guess et al. (1993)	25 students	behavior state, alertness	focus on individual	naturalistic setting, duration ~ 5h, 9 behavior state codes, interval coding	short-term cyclicity in behavior states; no cyclicity in time; influence of physiological/environmental and internal factors on behavior state

Guess, Roberts, Siegel-Causey, & Rues (1995)	66 students	behavior state, alertness	focus on individual	naturalistic setting, duration ~ 5h, 9 behavior state codes, continuous coding	6 behavior state profiles
Guess, Roberts, & Guy (1999)	-	behavior state, alertness	focus on individual	literature review	DSPs can use the *model of endogenous and exogenous factors influencing behavior state* to gather information about behavior states of clients
Guess, Roberts, & Rues (2002)	24	behavior state, alertness	focus on individual	naturalistic setting, 1h every 4-6 weeks during 1st year of life and 3rd/4th, 9 behavior state codes, continuous coding	4 behavior state profiles; more state stability across the years
Guess & Siegel-Causey (1995)	66 students	behavior state, alertness	focus on individual	naturalistic setting, duration ~ 5h, 9 behavior state codes, continuous coding	6 behavior state profiles; 35% of shifts from one state to another followed environmental changes
Guess, Roberts, Behrens, & Rues (1998)	-	behavior state, alertness	focus on individual	comment	-

Jones et al. (2007)	8 adults	alertness	focus on individual and on interaction with the environment	naturalistic setting, duration 1h, 4 alertness levels, time sampling	participants spent less time unengaged after a 16-week rebound therapy-based exercise program
Kennedy & Haring (1993)	4 students	alertness	focus on interaction with the environment	videotape, continuous coding	increase in alertness in situations with self-chosen preferred stimuli
Lancioni, Dijkstra, & O'Reilly (2000)	1 woman, 1 man	on-task behavior	focus on interaction with the environment	experimental setting, 2 sets of 4 tasks, on-task behavior, momentary time-interval sampling	on-task behavior was consistently higher under the frequent prompt condition (versus non-frequent prompt condition)
Lancioni, O'Reilly, Campodonico, & Mantini (1998)	3 women	on-task behavior, alertness	focus on interaction with the environment	experimental setting, momentary time-interval sampling	higher levels of on-task behavior and alertness for 1 participant in a preferences assessment of mobility versus sedentariness task arrangements

Lancioni, O'Reilly, Van Dijk, & Klaa-se (1998)	2	attention	focus on in-teraction with the en-vironment	experimental setting, observations of adap-tive responses	based on an environmental en-richment program, adaptive (alert) behavior increased, but relative instability in responding was seen across settings
Lancioni, O'Reilly, & Mantini (1999)	1 woman, 1 man	on-task behavior	focus on in-teraction with the en-vironment	experimental setting, momentary time-interval sampling	levels of on-task behavior were higher in the sessions with mo-bility (versus no mobility) for both participants
Lancioni, Singh, O'Reilly, Oliva, & Severini (2005)	1 woman	alertness	focus on in-teraction with the en-vironment	experimental setting, observations of signs of learning	higher alertness levels and signs of learning were promoted by micro switch-based stimulation involving preferred stimuli
Lindsay et al. (1997)	8	concen-tration	focus on in-teraction with the en-vironment	naturalistic setting, therapy sessions of 20 min. were followed by observing engagement in an occupational task for 5 min.	improvements in alertness fol-lowing Snoezelen and relaxation; no changes following hand mas-sage/aromatherapy and active therapy (on a bounce castle)

Mattie & Kozen (2007)	1 girl, 1 boy	alertness, behavior state	different focus for different terms	no observations	the Individual Educational Program Evaluation Checklist can be used to make teachers aware of behavior state and behavior state patterns in students
Mellstrom et al. (2005)	3 adult women	behavior state, attention, alertness	different focus for different terms	videotape, for 1 min., 5 behavior state codes, continuous coding	3 behavior state patterns before switch introduction; for 1 participant switch introduction may have influenced behavior state; more switch use during alert states
Mudford, Hogg, & Roberts (1997)	3 adults	behavior state	focus on individual	naturalistic setting, 20 sessions of ~ 1h, 13 codes for data collection, 6 for analysis, continuous coding	low rates of inter-observer agreement (except for *sleep*) and different state profiles for all participants
Mudford, Hogg, & Roberts (1999)	-	behavior state	focus on individual	comment	-
Murphy, Saunders, Saunders, & Olswang (2004)	2 women, 1 man	behavior state	focus on individual	videotape, 30 min. each setting, 5 behavior state codes, interval coding	no differences in results for alertness in natural setting versus reduced visual stimuli versus reduced visual and auditory stimuli

Parsons, Rollyson, & Reid (2004)	30 students	on-task behavior	focus on interaction with the environment	naturalistic setting, before, during and after interaction, on-task behavior, momentary time-sampling	increased number of students receiving teaching interactions; increased on-task behaviors based on staff training
Perry (2003)	10 children	attention	focus on interaction with the environment	naturalistic setting, observations of music therapy sessions	shifting to different activities and diverting the child from self-absorbed activities helped maintain attention to the musical interaction
Realon, Bligen, LaForce, Helsel, & Goldman (2002)	11 DSPs, 19 individuals with PIMD	alertness, engagement	different focus for different terms	naturalistic setting, for 5 min., 3 alertness levels, partial interval coding	following staff training (Positive Environmental Program), improvements in level of alertness and engagement with leisure materials

Reese (1997)	1 man	behavior state	focus on individual	naturalistic setting, sessions of 30 min., 8 behavior state codes, interval coding	no stimulation in alert states and stimulation in non-alert states can lead to high rates of self-injurious behavior (SIB); stimulation in alert states and no stimulation in non-alert states can lead to low rates of SIB; stimulation can decrease rates of non-alert states and SIB
Richards & Richards (1997)	-	behavior state	focus on individual	literature review	recording behavior state is time-consuming, but necessary; teachers can use existing scales, can arrange environmental variables prior to the delivery of instruction
Roberts, Arthur-Kelly, Forman, & Pascoe (2005)	-	behavior state	focus on individual	literature review	many studies investigating communicative and contextual involvement and behavior states; little is known about behavior state and school types, other settings and exogenous factors

Sandler & Voogt (2001)	6 children	alertness, attention	focus on interaction with the environment	naturalistic setting, observe and compare performance of children on various attention tasks with and without prior vestibular stimulation	5 children tracked a visual or auditory stimulus more frequently following vestibular stimulation; no effects on performance with other tasks
Sarimski (2007)	7 infants	attentional behavior	focus on interaction with the environment	videotape, at ~ 8.8 months of life -> 4 attention categories, at ~ 33.3 months of life -> 6 attention categories, time-sampling	more object-related attention than socially related attention in infants with Cornelia-de-Lange syndrome; differences stable for both times
Saunders, McEntee, & Saunders (2005)	3 adult men	on-task behavior	focus on interaction with the environment	naturalistic setting, 4 days every week, 20 min., 3 classes of behavior, continuous coding	highest on-task behavior following preferred reinforcer delivery under structured conditions

Siegel-Causey & Bashinski (1997)	-	behavior state	focus on individual	literature review	Tri-Focus-Framework (understanding the learner, broadening the communication partner's role, improving the environmental context) can facilitate alert and responsive behavior in interaction
Vlaskamp, De Geeter, Huijsmans, & Smit (2003)	177 and 19	alertness	focus on individual and on interaction with the environment	naturalistic setting, sessions of 30 min., living environment versus MSE, 5 alertness levels, momentary time sampling	no increase in alertness level as a result of the use of MSEs
Woodyatt, Marinac, Darnell, Sigafoos, & Halle (2004)	8 and 3 girls	behavior state	focus on individual	videotape, duration ~ 2.5h, 5 behavior state codes, continuous coding	low rates of inter-observer agreement versus high rates of inter-observer agreement based on individual definitions of behavior states

alertness and behavior state. They conclude from research results that behavior state has a significant impact on the levels of alertness and responsiveness (Guess & Siegel-Causey, 1995) and that behavior state assessment can result in a better understanding of alertness and involvement for individuals with PIMD (Foreman et al., 2004).

Mellstrom, Saunders, Saunders and Olswang (2005) describe behavior state differently to Guess et al., focusing on the individual again. Introducing the description of behavior state by Guess et al., they additionally make mention of the "internal state of attention" investigated by Dattilo and Rusch (1985). In contrast to the above-mentioned descriptions, two authors give descriptions of behavior state that emphasize the relationship between the individual's behavior and the environment. The focus broadens from the individual alone to the individual within the context of his or her environment. Ault et al. (1995, including Guess) use the description of Thoman et al. (1981, cited in Ault et al., 1995): "Behavior state is a theoretical description of an individual's ability to mediate interactions with the environment, both external and internal." Foreman et al. (2004) mention the same observation categories as Guess et al. (1993), but their description is different: "Behavior state is a measure of his or her functional level of engagement at any given point in time." Four studies (Green et al., 1994; Mattie & Kozen, 2007; Sandler & Voogt, 2001; Vlaskamp et al., 2003) introduce descriptions of *alertness* that focus on the individual and the environment. They describe alertness in a similar fashion to Guess et al.'s (1993) description of behavior state. Alertness is then observable at the same levels as behavior states, but the focus is on reaching the optimal level for learning and development in terms of interacting with the environment.

Five terms other than alertness and behavior state, which describe similar conditions, are also introduced. No explicit descriptions are given for these terms. All of them link the individual's behavior to the environment. With a focus on interaction, the term attention is used to determine the relatedness of an individual to objects or persons (Dattilo & Rusch, 1985, cited in Mellstrom et al., 2005; Perry, 2003; Sarimski, 2007). To describe the reaction of an individual to stimuli and materials offered in the direct environment, the level of *responsiveness* (Ashby et al., 1995; Bailey, 1994) and *engagement* (Cuvo, May, & Post, 2001; Kennedy & Haring, 1993; Realon et al., 2002), respectively, were scored. Observations are directed towards physical touch and the visual focus on stimuli, as well as on the appropriate use of materials. In the educational and working context, the term *on-task behavior* is frequently used. During their observations, Parsons, Rollyson and Reid (2004) scored on-task behavior when an individual is "working on a task assigned by a staff member (manipulating instructional or work materials), interacting with a staff person (gesturing to a teacher) or receiving an interaction from a staff member (being prompted to complete an activity," verbally, gesturally or physically). Additions to this description given by the authors are the functionality and adequacy of the behavior. Only functional activities employing functional materials (Parsons et al., 2004; Saunders et al., 2005) and activities fitting the intention of the task (Lancioni, Dijkstra, & O'Reilly, 2000; Saunders et al.) are called on-task behavior. Similarly, Ashby et al. (1995) and Lindsay et al. (1997) score the level of *concentration* based on the number of meaningful movements that an individual makes to engage in a task.

Alertness observations

In all but one of the empirical studies included in this review, observations (including behavior interpretation of parents and DSPs) are used to investigate alertness within the target group. In the following sections, three aspects of these studies will be described. First, the observation scales containing a different number of categories with different operationalizations will be presented. Second, reliability scores will be related to methods of scoring for the different scales. Finally, observation results such as alertness patterns and profiles in individuals with PIMD will be indicated.

Based on the Neonatal Behavioral Assessment Scale from Brazelton (1984), Guess and his colleagues developed the Behavior State Observation Scale. The observation instrument contains nine different codes for behavior state conditions. These are: Asleep-Inactive, Asleep-Active, Drowsy, Daze, Awake Inactive-Alert, Awake Active-Alert, Awake-Active/Stereotypy, Crying/Agitated and Seizures. In other studies, they employed 13 categories that were condensed into six categories for analysis (Guess et al., 2002). Additionally, Guess et al. (1993) defined four environmental codes: the occurrence or nonoccurrence of direct interaction with an adult or a peer; the type of activity (with three subcategories: self-help, maintenance or play/instructional/other); the presence or absence of material; and the student's body position.

The categories for observing behavior state found in the study by Guess et al. (1993) can be characterized as a standard scale. In 16 of the articles found in this literature search, the authors adapted the observation scale developed by Guess et al. for their own purposes, resulting in observation scales containing three (Realon et al., 2002) to 14 categories (Mudford et al., 1997). It should be mentioned that in the study by Mudford et al. the number of categories used for analysis was reduced to six.

Several authors discuss the position of stereotype behavior within the observation categories. Woodyatt et al. (2004) exclude the two observation categories concerning stereotype and agitated behavior because they expect this behavior to occur in all states. Siegel-Causey and Bashinski (1997) even suggest that stereotypy is a form of communication instead of a behavior state.

Operationalizations of the given categories are pointed out in Green et al. (1994). Position and movement of the eyes, gross body movements and vocalization have to be noted to obtain a score on the alertness continuum. Other authors introduced similar observation categories using different terms. In this vein, Belfiore et al. (1993) recorded inactivity (behaviors associated with sleep and/or drowsiness), head orienting towards a specific stimulus, movement without orienting, and eye contact to determine alertness.

Several researchers conduct observational studies to investigate the reliability of the observation scale developed by Guess et al. (1993). Before starting the observations, staff training (Mudford et al., 1997) is necessary until a level of inter-observer agreement of at least 80% is obtained. In observations by Guess et al. (1993, 1995, 2002), an observation scale of nine different categories is used to score alertness in intervals (Guess et al., 1993) or continuously (Guess et al., 1995, 2002) for approximately five hours. In the study by Mudford, Hogg and Roberts (1997), the 13 observation categories are condensed into six categories for analysis. Twenty observations of approximately one hour each are included. Woodyatt et al. (2004) scored five different observation categories in approximately 2.5 hours. In both studies, observations were conducted continuously. The results from Guess et al. (1993, 1995, 2002) comprise high levels of inter-observer agreement (> 90%) for different groups of 25, 66 and 24 individuals. Mudford et al., as well as Woodyatt et al., have doubts about these results and do not succeed in supporting them. When they involve groups of three and eight participants respectively, only the behavior state *sleep* is scored with an acceptable reliability (89%, Mudford et al.).

In 1993, Guess and his colleagues aimed to observe the likelihood of a particular state following another particular state over time and the likelihood of the repetition of such patterns. The behavior states of Asleep-Active, Asleep-Inactive and Drowsy are followed by either of the other. Individuals with PIMD often move through the Awake-Inactive-Alert state as part of the process of changing from one state to another. Generally speaking, quick changes between states are observed. Arthur (2004) partly confirms the findings of Guess et al.. But in his study, Arthur also mentions some other results. Shifts from the Awake-Active-Alert state to the Awake-Inactive-Alert state or the other way around are regularly followed by a return to the original state. In general, there is a high probability of a particular state following upon itself in subsequent or later intervals.

In 1995, Guess and Siegel-Causey, as well as Guess and other colleagues, searched for behavior state profiles. They formulated six profiles in a group of 66 participants. Each profile included one behavior state or a specific combination of several behavior states for a significantly dominant percentage of the observation time. Arthur (2003) confirmed these findings for a group of ten students observed in a segregated classroom setting. A longitudinal study of the first four years of life, observing 24 participants, revealed four different profiles (Guess et al., 2002). More state stability over the years became apparent, since the profile did not change for eight of the 24 participants from three to four years of age.

The impact of environmental conditions on alertness

Several studies point out the impact of environmental conditions on alertness levels. Physiological and/or environmental conditions explain a greater amount of change in alertness than does the impact of internal conditions (Guess et al., 1993). Thirty-five percent of shifts from one behavior state to another follow upon environmental changes (Guess & Siegel-Causey, 1995). All studies described in the following section will be focusing on conditions that may have an impact on the interaction of the individual with PIMD and the environment.

One conclusion of the study by Guess et al. (1995) is that environmental interaction (primarily with adults, i.e., parents and other DSPs) may be more consistently related to changes in an alert state than to any other environmental change. In individuals with higher levels of cognitive, communication, social and self-help skill development, especially, stereotype behavior can be changed by means of interaction. While the results of a study by Arthur (2004) show an overall agreement with the finding by Guess et al. (1995), some aspects do contrast with the earlier data. The Awake-Active-Alert state often follows a communicative interaction as in Guess et al., but the same link becomes apparent for Crying in Arthur's study (2004). After interaction with a partner, individuals with PIMD are more in the Awake-Active-Alert state and less in the Awake-Inactive-Alert and Awake-Active/Stereotypy states, whereas no activity can lead to a higher frequency of Awake-Inactive-Alert, Daze, Awake-Active/Stereotypy and Agitated/Crying behavior states (Arthur).

The results of the comparison of behavior states and socio-communicative conditions in 16 students with PIMD who were enrolled in special versus general classroom programs make clear that students in general classes are more Awake-Active-Alert and Active-Alert-Self-stimulatory. These students show more conceptual activity. Furthermore, they are more often involved in communication in general, and in communication with peers and aids specifically (Foreman et al., 2004). Observations of ten students in a segregated classroom setting supported these findings. Arthur (2003) found that students were solitary and that no activity was occurring for large proportions of time, which was related to low alertness levels.

When Murphy et al. (2004) tried to confirm the hypothesis of environmental impact on alertness levels, they did not find consistent effects on alertness scores from reduced visual and reduced visual and auditory stimuli settings. Comparing these two conditions to a natural setting, the results differed for all participants. But the sample size of three participants limits the generalizability of these results.

According to Green et al. (1994), DSPs have to be encouraged to train individuals with PIMD regardless of their prior level of alertness. Responsiveness to the training, progress on training programs and results of preference assessment are unrelated to the alertness level before training. Green and his colleagues demonstrated an increase in alertness level during training for five individuals. Modifications of the environment that can have a positive impact were formulated by Siegel-Causey and Bashinski (1997) in their literature review. Combinations of sensory stimuli, movement and orientation of the learner's body and the learning atmosphere were considered to increase alertness levels in individuals with PIMD. In contrast, Reese (1997) only found positive results when interaction and high levels of stimulation were introduced at alert moments of the individual with PIMD. No interaction and low stimulation in alert moments, as well as high stimulation in non-alert moments, were associated with high rates of self-injurious behavior. These results are, however, based on a single case study.

To increase the alertness of individuals with PIMD in their interaction with other individuals and the environment, individualization and active choice-making when offering different stimuli can be effective (Kennedy &

Haring, 1993). When preferred stimuli are assessed and employed in an Environmental Enrichment Program, participants show increased adaptive responding (Lancioni, O'Reilly, Van Dijk, & Klaase, 1998). Micro switch-based stimulation can result in higher response frequencies and higher levels of alertness compared to caregiver-based and other forms of stimulation (Lancioni et al., 2005). Bailey (1994) found higher levels of responsiveness and enthusiasm when employing switch-controlled assistive devices and introducing new activities. The studies have been realized with four, two, one and three participants respectively. Mellstrom et al. (2005) could not fully support these findings. They also found high rates of switch use in situations of alert states *a priori*, but only in one of the three participants might the introduction of a switch have caused changes to more desirable states.

Furthermore, observations of two, ten and three individuals, respectively, showed that frequent prompts (Lancioni et al., 2000), diverting the individual from self-absorbed activities (Perry, 2003) and shifting to different activities (Bailey, 1994; Perry) can help maintain alertness during interaction or task engagement.

Focusing on intervention methods, studies to confirm the intended effects of different methods on the level of alertness show different results. Employing conditions with and without prior vestibular stimulation, Sandler and Voogt (2001) compared the performances of children with PIMD in various attention tasks. Consistent with earlier findings for both preterm infants and healthy full-term infants, five of the six participants track a visual/auditory stimulus more frequently following vestibular stimulation. The performance on other tasks is similar with and without vestibular stimulation.

To determine the effects of Snoezelen on alertness, Ashby et al. (1995) measured engagement in a simple task immediately after a therapy session. Concentration and responsiveness were observed to determine the level of alertness. The number of meaningful movements the subject makes in order to engage in the task is the score for assessing concentration. The subject's enjoyment, relaxation and comfort, and general interest in and responsiveness to the environment are noted on a five-point scale to rate responsiveness. The results showed increased concentration for all eight participants on average. But these changes were not always related to rated responsiveness and enjoyment in the Snoezelen environment according to the researchers.

Vlaskamp et al. (2003) evaluated the hypothesis that multisensory environments (MSEs) can be used to increase the alertness of individuals with PIMD in their interaction with the environment. In a combination of the observation categories established by Guess et al. (1993) and Green et al. (1994), they obtained five levels of alertness: Asleep – Inactive – Not Alert; Awake – Inactive – Not Alert; Active – Self-directed; Sensory active – directed at environment; and Sensory and motor active – directed at environment. Comparing observations in the MSEs to observations in the normal living environment, they did not find a higher level of alertness as a result of the use of MSEs. In general, the 19 participants reacted more frequently to personal stimuli than to material stimuli, but large individual differences were seen.

In a crossover design, Lindsay et al. (1997) found improvement in alertness following Snoezelen and relaxation. The eight participants did not show higher levels of alertness following hand massage/aromatherapy and active therapy on a bounce castle. In their conclusion, Lindsay et al. did not expect that time and therapy caused these results. The relative effectiveness of the procedure may have had an impact as well.

Based on the results of earlier studies that showed the positive impact of exercise on physical, mental health and behavioral outcomes, Jones et al. (2007) investigated the impact of rebound therapy (therapeutic use of a trampoline) on eight individuals with PIMD. In a pre-post three-month follow-up design, individuals spent less time unengaged and demonstrated a higher level of alertness after the therapy.

In support of the above-mentioned findings, four adults with PIMD demonstrated increased on-task behavior during a leisure activity following ten minutes of outdoor activities. Alertness was higher in Snoezelen rooms than in living rooms, and highest during and after outdoor activities. Based on these results, Cuvo et al. (2001) posited that calisthenics (physical condition training) would be more effective when compared to brief periods of relaxation. Lancioni and his colleagues (Lancioni et al., 1998; Lancioni et al., 1999) supported these findings, recording higher levels of on-task behavior for three of the five participants engaging in mobility versus sedentary tasks.

Staff training has been shown to be effective according to ten studies from different authors. In a one-year follow-up study in four program sites (including 30 students and 7 teachers) training to identify and modify desired student and staff behavior resulted in an increased number of students receiving teaching interactions and, as a consequence, increased on-task behavior (Parsons et al., 2004).

During staff training, several points need to be broached. By introducing the Tri-Focus-Framework (i.e., concentrating on the learner, the partner and the environmental context), the staff's attention can be focused on what the learner with PIMD understands, on broadening the communication partner's role and on improving the environmental context. A consistent manner of responding to alert, responsive behavior can enhance sensitivity. Initiated pauses in interactions when the learner is in alert and attentive behavior states can lead to increased opportunities. The framework was developed based on a literature review (Siegel-Causey & Bashinski, 1997). Computer-supported pictorial instructions and prompts for promoting task engagement were useful in reaching higher levels of on-task behavior in two individuals with PIMD, when comparing measures of task performance after training at the baseline measurements (Lancioni et al., 2000). Arthur and his colleagues concluded from a literature review and an observation study of ten students that teaching staff can increase the time that individuals with PIMD spend in desirable behavior states by using the existing research data on influencing environmental variables and interactions (Arthur, 2004; Arthur, et al., 1995).

A number of staff training programs and models for determining and enhancing alertness in individuals with PIMD have been developed. In their study, Ault et al. (1995) used an intervention to facilitate alert, responsive behavior and to establish an initial communication repertoire, the ABLE model (Analyzing Behavior State and Learning Environments). Implementing the ABLE model, ten teachers were first trained and then found to be able to observe eight students' behavior state reliably. According to Realon et al. (2002), employing the Positive Environment Program (PEP) in a 28-month follow-up study for eleven staff members leads to improvement in levels of alertness, engagement with leisure materials, *happiness index* and distribution of staff interactions among residents for 19 individuals with PIMD. Roberts and Rues (1999) developed a model for intervention that early intervention teams can use to maximize the amount of time infants and young children spend in the most optimal states for learning and engaging with the environment. Guess et al. (1999) summarized their findings from a nine-year research history in a *model showing the interaction of behavior state organization with endogenous and exogenous variables*. The variables were subdivided into factors with unidirectional and bidirectional impact. Based on the model, DSPs can collect information about demographic, medical and developmental characteristics, behavior state quality and organization, shift data, environmental factors and instructional implications. Implications of the literature review by Richards and Richards (1997) included the use of either of the systems developed by Guess et al. (1993) or Richards and Sternberg (1992). Recording is always time-consuming, but the results are necessary for determining the effectiveness of instruction and the student's progress. As a subsequent step, teachers can arrange environmental variables prior to the delivery of instruction in order to promote alert states in students (Richards & Richards).

2.4 Conclusion

Based on the results of this literature review, the three questions that were formulated at the beginning of this study will be answered.

How is alertness for individuals with PIMD described in the literature?

The alertness descriptions that we found in the literature show, in general, two different kinds of focus: alertness as the state of an individual, which becomes manifest and observable in the individual's behavior (see, e.g., Guess et al., 1993) and alertness as the level of an individual's interaction and engagement with the environment (see, e.g., Foreman et al., 2004).

In contrast to the descriptions of the first type that include terms focusing on an internal state of an individual, those of the second type emphasize the relationship with the environment. All descriptions of the second type show a focus on the highest level of alertness. The functionality of the contact with the environment is essential.

Looking at the terms that focus on the relationship between the individual's behavior and the environment, alertness and behavior state integrate two aspects of related terms. Whereas on-task behavior, concentration and engagement describe the reaction of an individual to a stimulus or task, and attention and responsiveness underline the focus on interaction, alertness and behavior state include both. In Figure 2.2, the different terms are listed and the relationships between them are visualized.

Which observation methods, as found in the literature, can be employed to determine the alertness levels of individuals with PIMD?

Different observation categories have been employed in the empirical studies. Ten different scales of observation categories were found, while the scale of nine categories developed by Guess et al. (1993) is the one most cited in all of the studies. This scale can be characterized as a standard. In 22 papers, observations were conducted in naturalistic settings, while six researchers arranged experimental settings and five researchers based their findings on videotaped situations. When videotapes were used, one observer scored both alertness levels and environmental conditions by observing the same situation twice. Seven of the observations were scored continuously, and another 17 in intervals between 15 seconds and five minutes. In nine studies, alertness was observed based on task performance. All focused on the interaction of an individual and the environment, but results differed noticeably in their reliability. No clear explanation for these differences was given (Arthur, 2000; Guess et al., 1998; Mudford et al., 1999). Quick changes in alertness levels (Arthur; Guess et al., 1993) and different alertness profiles (Arthur; Guess et al., 2002; Guess & Siegel-Causey, 2005; Guess et al., 1995) in individuals with PIMD underline the need for continuous individual scoring.

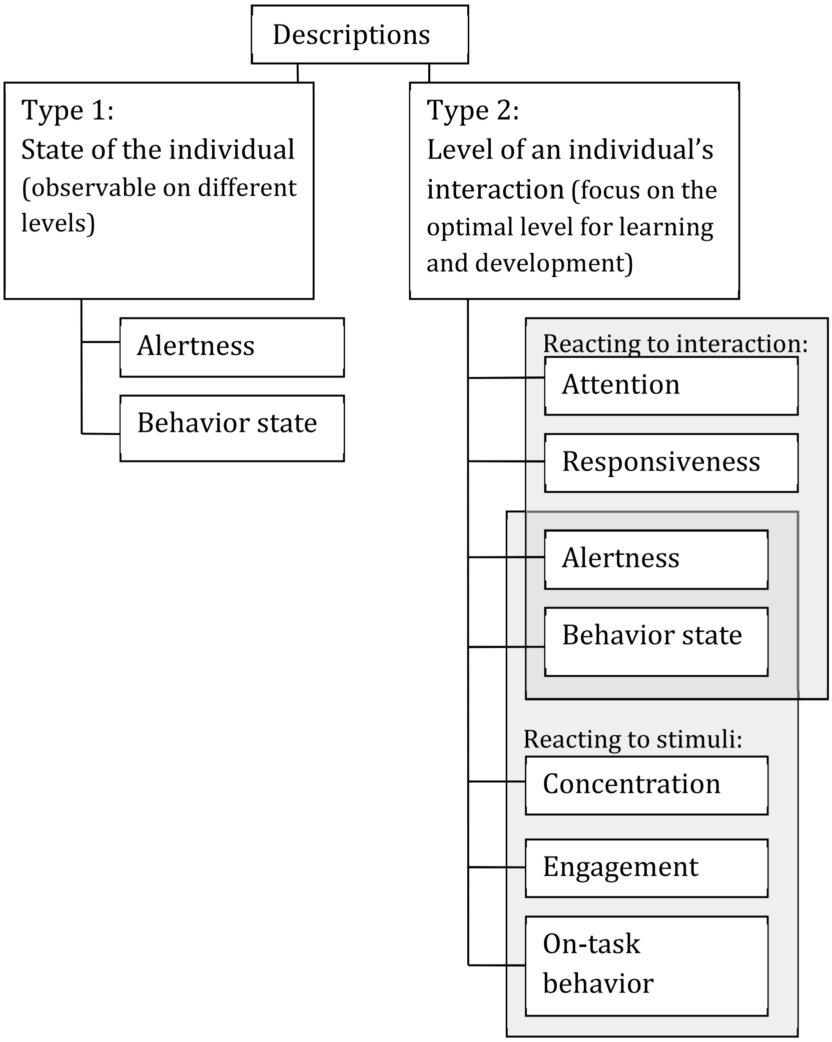

Figure 2.2 Model of alertness descriptions

Which environmental conditions are related to the alertness of individuals with PIMD according to the literature?

We found 23 environmental conditions that were expected to have a positive impact on alertness in individuals with PIMD. Of these, there were six modifications in the direct environment of the individual with PIMD (Belfiore et al., 1993; Foreman et al., 2004; Green et al., 1994; Murphy et al., 2004), four interaction strategies (Bailey, 1994; Kennedy & Haring, 1993; Lancioni et al., 2000; Lancioni et al., 2005; Mellstrom et al., 2005) and five stimulation strategies (Lancioni et al., 1998; Lancioni et al., 1999; Reese, 1997; Saunders et al., 2005), related to higher alertness levels. Eight treatment activities were subjects of research (Ashby et al., 1995; Cuvo et al., 2001; Jones et al., 2007; Lindsay et al., 1997; Perry, 2003; Sandler & Voogt, 2001; Vlaskamp et al., 2003), but of these only four (rebound therapy, outdoor activities, relaxation and music therapy) resulted in an increase in alertness level. Results for multisensory stimulation were different in four studies.

In seven other studies authors found that staff training can indirectly have a positive impact on alertness levels of individuals with PIMD. Teaching DSPs to observe alertness and allowing them to become conscious of the impact of environmental conditions resulted in higher levels of alertness in individuals with PIMD in seven implementation studies (Arthur, 2004; Arthur et al., 1995; Ault et al., 1995; Lancioni et al., 1998; Parsons et al., 2004; Realon et al., 2002; Siegel-Causey & Bashinski, 1997). In five literature reviews, recommendations for DSPs and trainers were formulated (Guess et al., 1999; Guess et al., 1993; Richards & Richards, 1997; Roberts et al., 2005; Siegel-Causey & Bashinski, 1997). One formulation of the environmental conditions that may have an impact on alertness in individuals with PIMD is presented in Table 2.2.

2.5 Discussion

In order to determine the alertness in individuals with PIMD, it is essential to describe the term alertness unambiguously and to have clear instructions about how to observe alertness in individuals with PIMD. In addition, it is important to know if environmental factors can positively influence alertness in individuals with PIMD and, if so, which ones. The literature review was carried out to gather this information, but conflicting results were found.

A number of limitations need to be taken into account when interpreting the results of this study. In the beginning, we formulated and applied selection criteria to exclude non-relevant studies. However, several authors did not give a clear description of the participants. We cannot be sure that we always made the right choice about the exclusion and that all papers included in this literature review investigated individuals in the target group. Consequently, the generalizability of the results of this review is limited. Furthermore, inconsistent use of descriptions of the central concept and differences in observation methods were significant obstacles in interpreting and comparing the studies in this review. Because of these differences in methodological characteristics, research results need to be interpreted with caution and results of the studies cannot be compared directly to each other.

The results of this literature review reveal a number of problems in the interpretation of research data and underline the difficulties in investigating alertness in individuals with PIMD. All observations focused on alertness levels and environmental conditions. Results of intervention studies also confirmed the relationship between alertness and environmental conditions. Consequently, the usefulness of alertness descriptions of the first type can be cast into doubt, because the focus on an individual's state alone was not continuous through observations and interventions. The discussion by Guess et al. (1998), Mudford et al. (1999) and Arthur (2000) underlines the problem of the strong variation in levels of reliability in the observations recorded. Possible explanations for this may be found in different

Table 2.2

Environmental conditions that may have a positive impact on alertness in individuals with profound intellectual and multiple disabilities

Category of conditions	**Conditions investigated in the included studies**
Modifications of the direct environment	- segregated classroom versus low stimulation versus high stimulation community settings (Belfiore et al., 1993) - special versus general classrooms (Foreman et al., 2004) - active versus inactive environments (Green et al., 1994) - natural setting versus reduced visual stimuli versus reduced visual and auditory stimuli (Murphy et al., 2004)
Interaction strategies	- powered assistive devices (Bailey (1994) - (micro)switches (Kennedy & Haring, 1993; Lancioni et al., 2005; Mellstrom et al., 2005) - frequent versus infrequent verbal prompts (Lancioni et al., 2000)
Stimulation strategies	- mobility versus sedentariness in task arrangements (Lancioni et al., 1998; Lancioni et al., 1999) - stimulation versus no stimulation in alert versus non-alert states (Reese, 1997) - reinforcement schedules (Saunders et al., 2005)
Treatment activities	- multisensory stimulation (Ashby et al., 1995; Cuvo et al., 2001; Lindsay et al., 1997; Vlaskamp et al., 2003) - outdoor activities (Cuvo et al.) - rebound therapy (Jones et al., 2007) - relaxation (Lindsay et al., 1997) - hand massage/aroma therapy (Lindsay et al., 1997) - active therapy (on a bounce castle, Lindsay et al., 1997) - music therapy (Perry, 2003) - vestibular stimulation (Sandler & Voogt, 2001)
Staff training	- observation training (Ault et al., 1995; Parsons et al., 2004) - training about the impact of environmental conditions on alertness (Arthur, 2004; Arthur et al., 1995; Lancioni et al., 1998; Parsons et al., 2004; Realon et al., 2002; Siegel-Causey & Bashinski, 1997) - training about the use of theoretical models (about observing and influencing alertness) in practice (Guess et al., 1999; Guess et al., 1998; Richards & Sternberg, 1992; Roberts & Rues, 1999)

operational definitions of behavior states, different observational recording procedures, differences in participants and settings (Mudford et al.), different techniques for calculating the agreement estimates (Arthur, 2000; Mudford et al.) and the occurrence of the different behavior states. The four states with the lowest inter-observer agreement percentages were among the five states that were observed as occurring least often. Furthermore, these states displayed the most rapid changes vis-à-vis other states (Guess et al.). Differing observer training is another explanation (Guess et al.; Mudford et al.). This was compared during a meeting of the researchers, but could not be indicated as the cause for the differences in inter-observer agreement (Mudford et al.). As stated by Vlaskamp (2005), reliability results can be enhanced by observing the individual's behavior and related environmental conditions or by using videotapes. Although the authors did employ these methods, results for reliability remained low in a number of studies (Mudford et al.; Woodyatt et al., 2004). Looking at the heterogeneity of the target group and taking into account the problem that the interpretation of observations is always subjective, reliability may have to be standardized anew for individuals with PIMD.

The results of the observation studies confirm the need to clarify the impact that specific environmental conditions have on alertness. Alertness is an important precondition in learning and in creating the opportunity for development, but answering the question "when should an activity be started?" remains difficult. As a result of changes in the environment, patterns of change in alertness levels have become apparent (Arthur, 2004). In observation studies, different results for stimulation in non-alert moments were found (Green et al., 1994; Reese, 1997). The resulting behavior was different or even idiosyncratic for all participants in five of the 12 studies investigating three or fewer individuals with PIMD. Furthermore, eight of the 34 empirical studies did not show significant results. But one striking fact is the positive effect that interaction and movement activities have on alertness (Cuvo et al., 2001; Guess et al., 1995; Lancioni et al., 1999). Consequently, the type of stimulus and the way it is presented may be more important than the moment when stimulation designed to influence the level of alertness is begun.

The problems that became apparent in this literature review lead to a number of implications for future research. In future studies investigating alertness in individuals with PIMD, it will be important to clearly describe the target group, the concept used (alertness or a similar term) and the observation method. Describing case studies or involving a large number of participants may lead to both useful and significant results. Studies employing the same concepts and methods are needed to make results comparable. Investigating the reliability and validity of the methods used is, therefore, an essential precondition. Furthermore, studies need to focus on the relationship between specific environmental conditions and alertness in individuals with PIMD, based on a clear description and observation method.

In order to construct an observation instrument that DSPs can use in future, this literature review has revealed some points of interest. First, because of the heterogeneity of the group of individuals with PIMD and the different alertness profiles that were found, alertness levels have to be described individually. Second, observations should be conducted continuously. If they are not, the frequent changes in alertness level in individuals with PIMD can lead to unclear scores. To observe alertness in practice and obtain scores that are as clear as possible, employing small intervals can be an alternative. Finally, for every individual, observations that focus on the relationship between alertness levels and different environmental conditions are necessary, given the different research results for studies investigating similar treatment activities and the positive results for preferred stimuli.

3

Experts discussing "alertness in individuals with profound intellectual and multiple disabilities": a Concept Mapping procedure*

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Abstract

The alertness of individuals with profound intellectual and multiple disabilities is a recurring issue for both researchers and direct support persons. A literature review reveals that alertness is an ambiguous concept, and information about environmental conditions that may have an impact on alertness is lacking. However, joint agreement about the concept is important for researchers and DSPs.

To generate an expert discussion we employed the method of Concept Mapping. Two Concept Maps were developed based on the following two questions: How can we describe alertness for individuals in the target group? What are the environmental conditions that can have an impact on alertness? The first map shows that descriptions should include a behavioral and an internal aspect of alertness. According to the second map, environmental conditions can be classified into four clusters: 1) interaction, 2) stimulation and activities, 3) communication, and 4) a cluster that emphasizes the importance of taking individual differences into account.

3.1 Introduction

In studies on individuals with profound intellectual and multiple disabilities (PIMD), researchers face recurring questions concerning the alertness of the individuals. Previous studies show imprecision about this central concept in that these studies introduce different terms and offer descriptions of conditions similar to alertness (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009a). When caring for individuals with PIMD, parents and other direct support persons (DSPs) encounter a similar problem. Because DSPs miss an unambiguous description, they wonder which of their clients’ expressions can be judged as alertness. Additionally, DSPs are not sure how to influence alertness. Offering stimulation to individuals of the target group is a daily issue, because DSPs do not know which the optimal moment to start an activity is. Is it necessary to wait until the child is alert and active before starting an activity, or is it possible for a drowsy child to become alert by introducing a stimulus (Arthur, 2004)? Furthermore, it is not clear which aspect of an activity can be expected to reveal changes in or maintenance of alertness levels (Roberts, Arthur-Kelly, Foreman, & Pascoe, 2005). Again, the literature does not present general solutions to these issues (Munde et al., 2009a).

The above mentioned questions are related in part to the characteristics of individuals of the target group themselves. In addition to profound intellectual and motor disabilities, sensory disabilities along with a broad range of additional health problems (e.g., epilepsy, dysphagia, constipation, gastro-esophageal reflux) are common (Arvio & Sillanpää, 2003; Kapell et al., 1998; Nakken & Vlaskamp, 2007; Van Schrojenstein Lantman-de Valk, Van den Akker, Maaskant, & Haveman, 1997; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). The magnitude of the disabilities also has consequences for the way individuals with PIMD communicate. Most of them are not able to use spoken language and have alternative ways of communicating, such as gestures, muscle tensions, a wink or a blink (Grove, Bunning, Porter, & Olsson, 1999). The limited repertoire of communicative skills and the fact that one signal may have several meanings make it difficult to detect and interpret the communicative signals of individuals with PIMD, signals such as being interested in the environment or in a stimulus (Petry, Maes, & Vlaskamp, 2005). Since the combination and degree of disabilities varies for every individual, heterogeneity is a characteristic of this target group (Nakken & Vlaskamp, 2007). Expressions that can be interpreted as alertness can differ for each individual. Non-conventional reactions to stimuli make it even more difficult to determine the right moments, approaches and materials when it comes to offering an activity (Petitiaux, Elsinga, Cuppen-Fonteine, & Vlaskamp, 2006). While it is difficult to detect these expressions, quick and irregular changes aggravate the ability to determine alertness levels as well (Guess, Roberts, & Guy, 1999).

Additionally, the behavioral expressions of individuals with PIMD are difficult to denominate, because alertness is an ambiguous concept in and of itself. Some authors describe alertness as a theoretical concept (Arthur, 2004; Green, Gardner, Canipe, & Reid, 1994; Guess et al., 1999; Guess, Roberts, & Rues, 2002); others determine alertness as observable behavior (Belfiore, Browder, & Mace, 1993; Kennedy & Haring, 1993; Lancioni, Singh, O'Reilly, Oliva, & Severini, 2005; Sandler & Voogt, 2001). Moreover, a number of studies focus on internal processes that are supposed to provoke different alertness levels (Arthur; Guess et al., 1999, 2002), while in other studies observers look at environmental conditions that they expect will lead to a certain level of alertness (Belfiore et al.; Sandler & Voogt). Alertness descriptions found in the literature can be classified into two types (Munde et al., 2009a): alertness as the internal state of an individual, or alertness as the level of interaction with the environment. In contrast to the descriptions of the first type, which include terms focusing on the internal processes of an individual, those of the second emphasize the relationship with the environment. All descriptions of the second type show a focus on the highest level of alertness. Therefore, the functionality of the contact on this level is essential.

Although authors of several studies expect changes in alertness levels to occur following environmental changes, general implications and guidelines about how to influence alertness are still lacking (Munde et al., 2009a). Several intervention studies that investigated the impact of environmental conditions on alertness levels in individuals with PIMD have revealed conflicting results. Modifications of the direct environment of the individual with PIMD (i.e., reduced stimuli setting, Murphy, Saunders, Saunders, & Olswang, 2004) may lead to increases in alertness level. Interaction strategies (i.e., micro switches, Kennedy & Haring, 1993; Lancioni et al., 2005) and stimulation strategies (i.e., settings with mobility, Lancioni, O'Reilly, & Mantini, 1999) can result in higher levels of alertness. However, the impact of different treatment activities on alertness was not significant in several studies (Cuvo, May, & Post, 2001; Jones et al., 2007; Lindsay, Pitcaithly, Geelen, & Buntin, 1997; Perry, 2003; Vlaskamp, De Geeter, Huijsmans, & Smit, 2003).

Since studies found in the literature are based on different descriptions of the central concept, the results cannot be compared (Munde et al., 2009a). However, joint agreement about the concept is important for researchers and DSPs. Only based on an unambiguous description, future studies to answer continuative, empirical questions can be set up. To formulate such an unambiguous description, integration of the entire broad range of theoretical and practical aspects of the problems is necessary, as well as including differing opinions. Subjective opinions, therefore, may amend results from the literature in a valuable way. Furthermore, the importance of and the relationship between these different opinions need to be clarified. A research method that fulfills these demands is Concept Mapping (Trochim, 1989). To clarify a concept, a number of experts can be asked to give their subjective opinion based on their experience. Participants with a broad range of opinions concerning the subject of interest are desirable in order to cover the broad range of the problems and, at the same time, to give differing opinions equal importance. The aim is to find the lowest common denominator. Finally, the resulting Concept Map is supposed to help in understanding the subject better and in deciding which of its aspects are of greater or lesser importance (Severens, 1995; Trochim). In the present study, our aim was to develop two Concept Maps, focusing on the following questions: 1) how can we describe alertness in individuals with PIMD; and 2) which environmental conditions may have an impact on alertness in individuals with PIMD?

3.2 Method

Participants

All the participants were experts on the target group, individuals with PIMD. We invited two groups of participants to take part in the discussion: experts from science and experts from practice. Experts from science included participants who were conducting research in relation to individuals with PIMD. The group of experts from practice consisted of parents, DSPs, teachers, therapists and other professionals directly involved with individuals with PIMD.

Although interest in the group of individuals with PIMD has been growing in the past decades, the number of studies concerning the target group remains limited (Nakken & Vlaskamp, 2007). Knowledge about issues that are specific to individuals with PIMD is lacking, and there are only a small number of experts available within one country. Consequently, we decided to organize an international discussion. The experts were selected from a list of members and contacts of an international special-interest research group for individuals with PIMD from IASSID (International Association for the Scientific Study of Intellectual Disabilities). With the aim of covering all viewpoints concerning the central concepts rather than selecting a representative sample of the population, we employed theoretical sampling (Strauss & Corbin, 1990). Experts from different countries with different professions and possibly a different point of view were chosen so as to cover a broad spectrum of opinions. Concept Mapping can be optimally realized for 10–40 participants (Kane & Trochim, 2007). Consequently, we invited 40 experts to take part in the discussion at the outset. Twelve Dutch-speaking experts, eighteen German-speaking and ten English-speaking experts were asked to take part in the discussion. When two scientists and three practitioners indicated that they would not like to participate, a group of 35 experts remained as participants (see Table 3.1).

Procedure

Concept Mapping is a standardized method for the conceptualization of a specific subject. It can be used to create a visual map of ideas based on the opinions of different groups of experts (Kane & Trochim, 2007). The following five steps need to come about: (1) Preparation, (2) Brainstorming, (3) Structuring the statements, (4) Analysis, and (5) Interpretation (Severens, 1995).

First, all experts received an invitation to take part in the discussion. We supplied information about the procedure and the topic. The problems described above were reformulated into two general questions:

How can we describe alertness in individuals with PIMD?

Which environmental conditions may have an impact on alertness in individuals with PIMD?

Letters were written in Dutch, German, and English.

In a second step, ideas and statements were generated. We started the brainstorming on answers to these questions based on the findings of a recent literature review (Munde et al., 2009a). This review revealed fourteen statements describing alertness and similar conditions in individuals with PIMD and 27 statements describing environmental conditions that may have an impact on alertness. Throughout the entire procedure, the two groups of statements (alertness descriptions and environmental conditions) were presented separately, with the aim of developing two Concept Maps. The experts were asked to judge the statements by marking all those they agreed with. Furthermore, it was possible for the experts to add statements to each group. The participants were then, in a third step, asked to structure the statements. After analysis of the results of the first round, the two revised groups of statements were presented to the experts. Statements from the first round were included when at least one participant agreed. Furthermore, the statements that the participants wrote down were added. The participants were asked to rank the statements according to importance and content. First, participants were asked to note the importance of each statement on a five-point scale. The judgments ranged from *most important* to *relatively least important*. Then, the participants were asked to group the statements according to their content. In this step, they were free to choose a number of groups.

For the last two steps of the procedure, results of the discussion were analyzed and interpreted. The Ariadne program for Concept Mapping (Severens, 1995) was used to conduct the statistical analysis. The analysis was carried out in a number of steps, consisting of multidimensional scaling (MDS) and cluster analysis. First, data concerning the structuring of statements according to their content was used. For each participant, a table was set up consisting of as many rows and columns as there were statements. If two statements had been placed in the same group by the participant, a *1* was marked in the table. Otherwise, the score was *0*. This analysis resulted in a binary symmetric similarity matrix. Second, all individual matrixes were combined in a group similarity matrix. The numbers then indicated how many participants placed two statements together in the same group. Third, the group matrix was used as input for MDS. Based on this analysis, the observed distances between the statements were represented as point on a two-dimensional map. The location of each item on the map was a function of perceived similarity. The items that were most frequently sorted together were closer to one another than those that were seldom or never sorted together. In the last step, the coordinates of the items in the map were distributed into clusters using hierarchical cluster analysis. The depth of each cluster indicated the average importance of ratings across all items in that particular cluster. Averages represented by the depth were actually double averages, being averaged across all the participants and across all the items in a cluster. Therefore, even slight differences in clusters were considered meaningful (Trochim, 1989). On the resulting map, the distance between the points and clusters was fixed in MDS. However, the directionality of the map was arbitrary, and the map could be rotated in any direction without adjusting for distances. The function of the axes was, therefore, to show the distances in space rather than to determine content dimensions. To answer the two questions formulated in the introduction, the clusters of the two resulting Concept Maps were labeled by the researchers.

Table 3.1

Characteristics of the participants in the Concept Mapping (n=35)

	Practitioners		Scientists	
	Austria	1	Australia	2
	Germany	8	Belgium	3
	Japan	1	Germany	3
	Mexico	1	Great Britain	4
	Switzerland	1	Switzerland	1
	The Netherlands	6	Taiwan	1
			The Netherlands	1
			USA	2
Total		18		17

Note. The practitioners included 6 direct support persons, 1 parent, 1 teacher, 1 occupational therapist, 1 physiotherapist, 5 educational psychologists, 1 day care manager, 1 residential care manager, 1 doctor

3.3 Results

After a written reminder, the response rate of the brainstorming session was 66% (23 answers from 35 participants). The participants agreed with all the statements given, but the number of participants who marked a statement as being correct differed for each statement. For the alertness descriptions, the range ran from one participant (for one statement) to 20 participants (for one statement). The number of participants who agreed with statements concerning environmental conditions varied from 5 (one statement) to 23 (one statement). In total, participants added 23 statements. Eleven new alertness descriptions and 12 new environmental conditions were formulated. All statements that were included in the discussion are listed in Tables 3.2 and 3.3.

When we asked participants to structure the new sets of statements, the response rate was 60% (21 answers) for the alertness definitions and 54% (19 answers) for the environmental conditions. Again, we had sent a written reminder before we received these reactions. The different response rates are visualized in Figure 3.1.

The two resulting Concept Maps will be described below. The Concept Map for the alertness definitions is displayed in Figure 3.2. The seven-cluster solution best fits the data in terms of interpretability. The map included the following clusters: (1) alertness as the optimal level of interaction with the environment, (2) behavior state as theoretical concept, (3) alertness as observable reaction to interaction, (4) alertness-related conditions, (5) alertness as functional reaction to stimuli, (6) different terms for reactions to the environment, and (7) alertness as cognitive processes. The five statements that were judged as *most important* are given in Table 3.4.

The second Concept Map is presented in Figure 3.3. Environmental conditions that may have an impact on alertness have been visualized. Again, dividing the data into seven clusters was the most appropriate basis for the interpretation. The clusters were titled as follows: (1) interactional aspects, (2) contact and interaction with DSPs, (3) stimulation levels of the overall environment, (4) leisure time activities, (5) assisted communication, (6) treatment activities, and (7) individual differences in reactions. The five statements that were marked as *most important* by the participants are listed in Table 3.5.

Table 3.2

Statements concerning alertness descriptions

No	Statement
1	Behavior state can result in a better understanding of the alertness and involvement of individuals with PIMD.
2	Behavior state is a series of behavioral and physiological conditions that range from sleeping to being awake and crying, in terms of infants.
3	Attention is the relatedness of an individual to objects or persons.
4	Responsiveness is observable in enthusiastic and positive reactions of an individual with PIMD to stimuli offered in interaction with other individuals.
5	Behavior states are expressions of maturity, status and organization of the CNS, which mediate the child's ability to respond to the environment and stimulation.
6	On-task behavior is when an individual is functionally working on a task assigned by a staff member (manipulating instructional or work materials), interacting with a staff person (gesturing to a teacher) or receiving an interaction from a staff member (being prompted to complete an activity, verbally, gesturally or physically).
7	Behavior state has a significant influence on levels of alertness and responsiveness.
8	Alertness is the internal state of attention.
9	Behavior state is a theoretical description of an individual's ability to mediate interactions with the environment.

10	Alertness is observable at the same levels as behavior states (ranging from sleeping to being awake and crying), but the focus lies on reaching the optimal level for learning and development, that is, being awake.
11	Behavior state is a measure of an individual's functional level of engagement at any given point in time.
12	Engagement with materials is when the individual with PIMD physically touches a stimulus with hand or arm, faces a stimulus, or appropriately uses the presented materials.
13	Concentration can be observed in the number of meaningful movements an individual makes to engage in a task.
14	Responsiveness is observable in positive or negative reactions of an individual with PIMD to stimuli offered in interaction with other individuals.
15	Behavior state is equal to alertness.
16	The level of alertness has a significant influence on behavior state and responsiveness.
17	The four major ways to respond to stimuli are (from the least to the most complex): alertness, orientation, distance behavior and exploration.
18	Alert behavior does not allow for the buildup of information concerning the location and the nature of the stimulus. It is only an elementary sign of the presence of the stimulation and a reflection of the functioning of one’s own sense modalities.
19	Alertness is a state of attention, but not an internal state of attention.
20	Engagement can become visible in individually different reactions.

21	Observational codes of behavior states can serve as indicators of alertness.
22	There is interplay between the phenomena of alertness and behavior state.
23	Concentration is a cognitive process.
24	Internal and external conditions can have an impact on alertness.
25	There is a relationship between being alert, *being active* and *reacting*.

Table 3.3

Statements concerning environmental conditions

No	Statement
1	Individualization and active choice-making, when offering different stimuli, increase the general level of alertness in individuals with PIMD.
2	There is a relationship between high levels of alertness and strong responses of individuals with PIMD towards stimuli provided by staff (touching, talking to the individual).
3	Staff training to make staff aware of alertness levels of students with PIMD is accompanied by increases in the students' on-task behavior.
4	Conditions of reduced visual and auditory stimuli in the environment outside of direct task arrangements are valuable in promoting active and alert behavior states.
5	Modifications to the environment (considering combinations of sensory stimuli, movement, and orientation of the learner's body and learning atmosphere) improve alert and responsive behavior states in individuals with PIMD.

6	Low rates of self-injurious behavior and alert behavior states can be observed during high levels of stimulation (such as music and a vibrating cushion in the chair with or without dim lights flashing).
7	Micro switch-based stimulation (making an individual with PIMD obtain preferred stimulation by responding using a small, very sensitive electronic switch) promotes alertness.
8	A consistent manner in which DSPs respond to alert, responsive behavior promotes the occurrence of these behavior states.
9	In behavior-state observations of individuals with PIMD, interaction (primarily with an adult, i.e., a DSP) is more consistently related to changes in an alert state than any other environmental change that evokes a state change.
10	A continuing active behavior state can be observed in individuals with PIMD following active engagement in a communicative interaction.
11	Frequent verbal prompts (frequently encouraging the individual with PIMD to fulfill a certain task) foster a higher level of on-task behavior as compared to an infrequent verbal prompt condition.
12	Active and alert behavior states are highly likely to be observed in the period immediately following an activity.
13	Introducing new activities during music therapy sessions can help maintain attention to interaction.
14	Initiated pauses in interactions when the learner is in alert and attentive behavior states can help maintain these behavior states.
15	Diverting individuals with PIMD from self-absorbed activities can help maintain attention to music-therapy activities.
16	Vestibular stimulation (e.g., 3 minutes of rocking in an adaptive swing) can be related to increased visual and auditory alertness.

17	Multisensory environments can be applied to increase the level of alertness in individuals with PIMD.
18	Outdoor activities have a more positive effect on stereotypic behavior and engagement in individuals with PIMD than activities in a Snoezelen room.
19	We can compare two experimental settings to each other: In Setting 1, individuals have to reach the place independently where they have to fulfill a task (mobility task arrangement). In Setting 2, individuals receive the materials to fulfill a task while they are sitting at a table (sedentariness task arrangement). Higher levels of responsiveness and on-task behavior can be measured in individuals with PIMD in mobility task arrangements.
20	Twenty minutes of relaxation therapy (lying on a mat or sitting supported by cushions with the therapist sitting close by, modeling and encouraging the individual to adopt a relaxed position for head, face, neck, shoulders, arms, hands, torso, legs and feet) can have a positive effect on concentration during a simple task following the session.
21	Computer-supported pictorial instructions promote task engagement in individuals with PIMD.
22	Settings with different levels of stimulation (a different number of people being present, high or low levels of visual and auditory stimulation) lead to higher percentages of adaptive (alert) behavior and to lower percentages of non-adaptive behavior.
23	In observing behavior state, students with PIMD enrolled in general classes tended to be active and alert for a larger portion of the day and spent less time in inactive, drowsy and asleep states compared with their peers in special classes.

24	Individuals with PIMD show higher levels of responsiveness to therapists and activities following the introduction of new activities.
25	Improvement in concentration and responsiveness in a simple task can be observed in individuals with PIMD after a twenty-minute Snoezelen session.
26	Increases in alertness can be seen after an individualized sixteen-week rebound therapy-based exercise program (therapeutic use of a trampoline to improve gross motor skills, posture and balance) for individuals with PIMD.
27	Calisthenics (physical condition training) are more effective in reducing self-stimulation and in increasing on-task behavior as compared to brief periods of relaxation.
28	Looking at the impact of environmental conditions on alertness levels, individual differences in preferences and reactions should be taken into account. Whereas a certain condition can increase alertness in one individual, the same condition may decrease alertness in another individual.
29	All kinds of interaction with other individuals raise alertness.
30	DSPs can indirectly raise alertness by registering behavior state.
31	Multisensory activities can lower alertness.
32	DSPs can see and cause changes in alertness by observing the individual needs of an individual with PIMD and adapting their own behavior to these needs.
33	Presenting one stimulus only can increase alertness.
34	Presenting several stimuli at the same time can increase alertness.
35	Developing authentic routines is important in fostering alertness and goal-oriented behavior in individuals with PIMD.

36	Feelings of success increase alertness.
37	Snoezelen can increase alertness especially in individuals with visual impairments.
38	Outdoor activities can be effective in increasing alertness in all individuals with PIMD.
39	Assisted communication can have a positive impact on alertness.

3.4 Conclusion and discussion

To clarify the concept of alertness for individuals with PIMD and also those environmental conditions that may have an impact on alertness, we invited experts to discuss their opinions and experiences concerning these two topics. Results of the discussion were visualized in two Concept Maps. According to the experts, two aspects must be part of an alertness description: a theoretical concept that describes the internal processes which cause different alertness levels and reactions to the environment which become visible in the behavioral aspects of alertness. Interaction was judged as the most important condition influencing alertness. Therefore, it is essential to take individual differences into account.

Looking at the Concept Map of alertness descriptions, the seven clusters can be further stratified and interpreted. The clusters on the left side of the map all focus on the observable aspects of alertness. Statements describing observable reactions to the environment have been included. In contrast, the clusters on the right and lower right side of the map consist of theoretical descriptions of alertness, with a focus on internal processes. If we display the results for practitioners and scientists separately, the distinction becomes even clearer. Practitioners judged descriptions of alertness as visible behavior in interaction as being very important, whereas scientists mainly emphasized the theoretical aspects. These two aspects correspond to the two different types of alertness descriptions found in the literature (Munde et al., 2009a). However, the five statements that were rated as *most important* generally stress two points: the relatedness of alertness to other functions and alertness as observable reactions to stimuli that differ for each individual with PIMD. Given these ratings, experts stressed the importance of the observable aspect of alertness. Consequently, this aspect has to be the central part of any alertness description. This is notably true for descriptions that are used in clinical practice, since experts from practice in particular emphasize the observable aspect. Furthermore, a theoretical concept is expected to form the basis of the observable behavior and to influence the outcomes (Pennington, 2002). The two aspects of the descriptions provide information about two different levels of the concept. Therefore, it is more difficult to reach consensus about the background processes than about the behavior, because the latter is clearly visible.

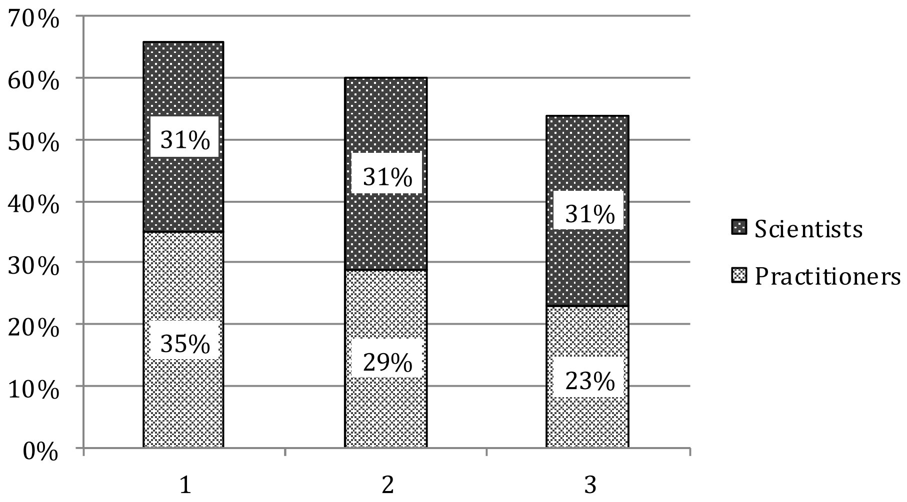

Figure 3.1 Response rates for the three rounds

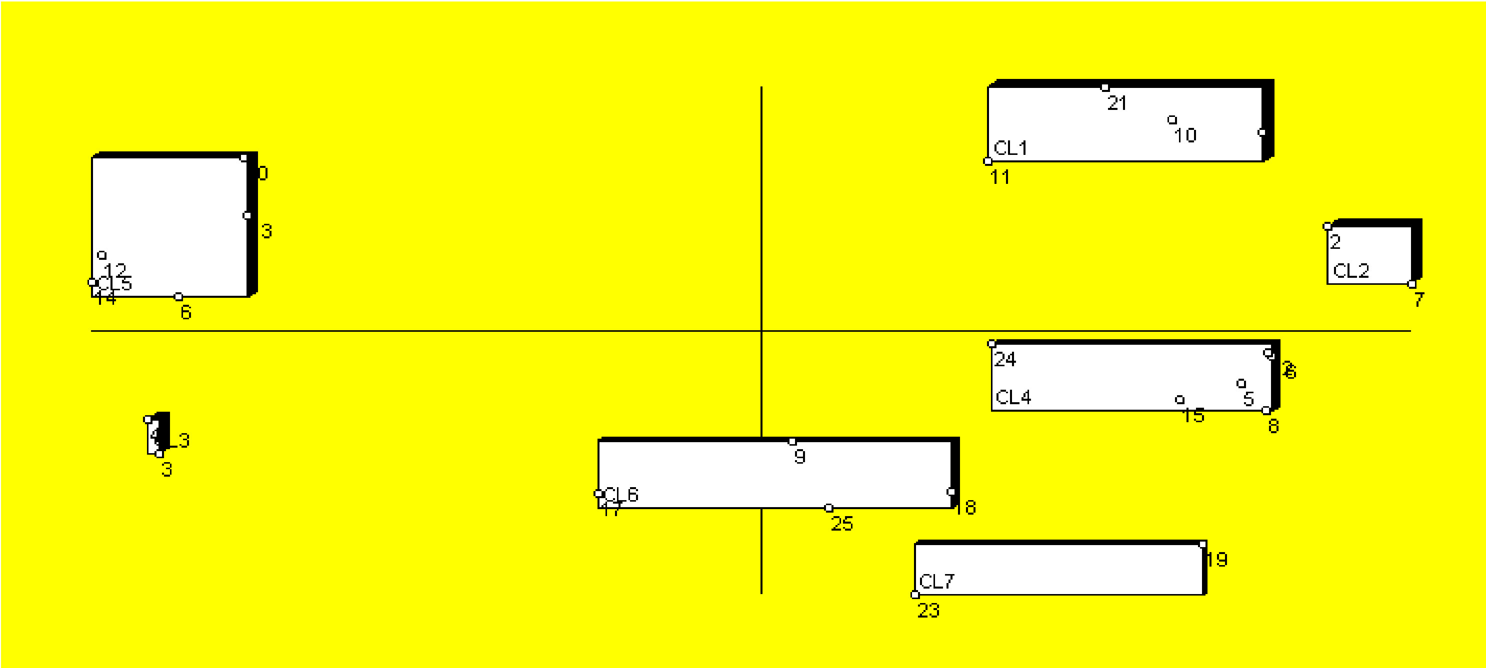

Figure 3.2 Concept Map showing alertness descriptions

Note. The numbers refer to the statements according to Table 3.2. Clusters are presented as *CL* followed by the associated number. The thickness of the shadow of a cluster is based on the importance rating of the experts. A thicker shadow indicates a more important cluster.

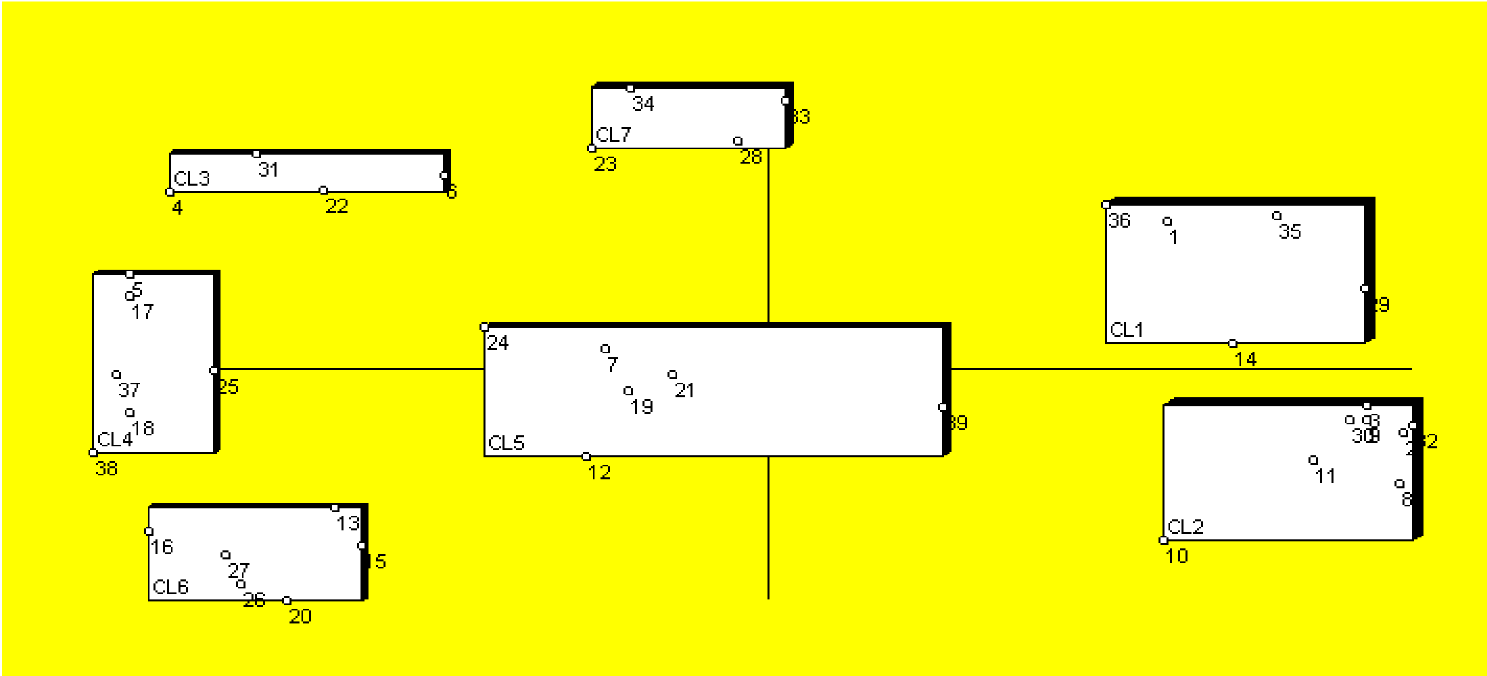

Figure 3.3 Concept Map showing environmental conditions

Note. The numbers refer to the statements according to Table 3.3. Clusters are presented as *CL* followed by the associated number. The thickness of the shadow of a cluster is based on the importance rating of the experts. A thicker shadow indicates a more important cluster.

By further stratifying clusters of the Concept Map of environmental conditions, four superclusters (Borgen & Barnett, 1987) become visible on the map. On the right-hand side of the map, the two clusters concerning *interaction* (Clusters 1 and 2) form one supercluster. The three clusters on the other side of the map (Clusters 3, 4 and 6) can be combined into a supercluster concerning *stimulation and activities* that have an impact on alertness. In the center of the Concept Map, Cluster 5, which is entitled *communication*, connects the two superclusters. Cluster 7, concerning *individual differences*, is situated separately. Whereas the three other super-clusters focus on observable behavior, Cluster 7 describes the individually different quality of the behavior. In general, looking at the five statements that have been judged as *most important*, we see the central cluster (Cluster5) and

Table 3.4

Statements about alertness descriptions that were judged most important

No	Pref.*	SD	Item
1	4.29	1.25	Behavior state can result in a better understanding of the alertness and involvement of individuals with PIMD.
24	4.29	.97	Internal and external conditions can have an impact on alertness.
7	4.14	1.27	Behavior state has a significant influence on levels of alertness and responsiveness.
20	4.14	1.17	Engagement can become visible in individually different reactions.
14	3.95	1.28	Responsiveness is observable in positive or negative reactions of an individual with PIMD to stimuli offered in interaction with other individuals.

* mean preference of all participants

Table 3.5

Statements about environmental conditions that were judged most important

No	Pref.*	SD	Item
28	4.67	.89	Looking at the impact of environmental conditions on alertness levels, individual differences in preferences and reactions should be taken into account. Whereas a certain condition can increase alertness in one individual, the same condition may decrease alertness in another individual.
1	4.61	.35	Individualization and active choice-making, when offering different stimuli, increase the general level of alertness in individuals with PIMD.
32	4.61	.24	DSPs can see and cause changes in alertness by observing the individual needs of an individual with PIMD and adapting their own behavior to these needs.
2	4.39	.57	There is a relationship between high levels of alertness and strong responses of individuals with PIMD towards stimuli provided by staff (touching, talking to the individual).
3	4.39	.57	Staff training to make staff aware of alertness levels of students with PIMD is accompanied by increases in the students' on-task behavior.

* mean preference of all participants

the separated cluster (Cluster 7) again. Three of these statements focus on the communication of DSPs and of individuals with PIMD, which is supposed to have a positive impact on alertness. The other two statements are rated as most important by almost all the participants (mean preference = 4.67 and 4.61, respectively): “individual differences in preferences and reactions have to be taken into account,” because “individualization when offering different stimuli increases the general level of alertness.”

Comparing the results of the second map to the results of previous studies, correspondence becomes apparent. Individual interaction has been mentioned as a central topic for contact with individuals with PIMD in general (Arthur-Kelly, Bochner, Center, & Mok, 2007; Wilder & Granlund, 2003) and for influencing alertness specifically (Maes, Lambrechts, Hostyn, & Petry, 2007; Vlaskamp et al., 2003). In previous observation studies, authors thus found that individual differences have to be taken into account. When observing alertness, individual categories have to be formulated to obtain interpretable results (Roberts et al., 2005). Looking at intervention studies, we see that individual differences in reactions on environmental conditions are common for the target group. When providing individualized activities, alertness almost always improves (Kennedy & Haring, 1993).

Comparing the map to the results of our literature study (Munde et al., 2009a), the distinction between the different environmental conditions that can have an impact on alertness and the interrelatedness of these conditions is more explicit in the results of the Concept Mapping. Results of the present study thus give a clearer picture of the different aspects that must be taken into account when influencing alertness in individuals with PIMD. Furthermore, the different ratings of multisensory environments (MSEs) are a striking fact. Experts placed statements concerning MSEs in groups of leisure activities, treatment activities, and descriptions of the overall environment. This fact may reflect the different and sometimes unclear use of MSEs. At the same time, it may be one explanation for the different research results concerning the relationship between alertness and MSEs.

A number of limitations should be noted when interpreting the results of this study. The small number of participants in general and the decreasing number of participants (on the part of the practitioners) in each subsequent round specifically may be seen as a limitation, but Concept Mapping can be implemented for small groups and response rates always exceeded 50 percent. Therefore, the different participants for each round do not violate the assumptions of Concept Mapping (Trochim, 1989). Additionally, the larger number of DSPs and educational therapists within the group of expert from practice is a striking fact. However, since those form the largest group of experts from practice concerned with individuals with PIMD, we considered a larger number of participants from these groups of experts to bring in valuable information from different points of view. Another, more serious limitation was the validity of the statements. The participants, and especially the practitioners, mentioned that they faced difficulties in making a judgment. When they had different individuals with PIMD in mind, who might show completely different reactions to a treatment activity, they were not sure how to judge the impact of the activity on alertness. In the end, we do not know how the different participants actually solved this problem.

Results of this study, however, do help to clarify the ambiguous concept of alertness in individuals with PIMD. In future studies, observable aspects should be taken into account. Investigations of the impact of different kinds of stimulation and activities can reveal valuable information for the care and support for individuals with PIMD. The use of multisensory stimulation especially should be clarified, and the relationship with alertness should be determined. In all studies investigating the impact of environmental conditions on alertness levels, DSPs and researchers have to provide all kinds of stimulation and activities in individual interaction. Thereby, observations can be judged as an optimal assessment method for alertness in individuals with PIMD. A precondition to determine alertness is, then, the operationalizations of the theoretical concept into observable behavior. Generally speaking, it is important to observe alertness. While DSPs can discern individual differences in alert moments and the impact of different stimuli on alertness through observations alone, to bring about these observations in clinical practice it is necessary to develop a useful instrument of gathering information about alertness in individuals with PIMD.

4

Determining alertness in individuals with profound intellectual and multiple disabilities: the reliability of an observation list*

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Abstract

In the support of individuals with profound intellectual and multiple disabilities (PIMD), assessing the level of alertness is a recurring issue for parents and other direct support persons. Although observations show clear advantages above and beyond other assessment methods, there are problems related to this method as well. Subjectivity of interpretation and low reliability results have been described as the main problems.

In the present study, our aim was to estimate the reliability of the Alertness Observation List (AOL) while, at the same time, minimizing the problems entailed in observations. We calculated both the inter-observer agreement and intra-observer agreement for 39 situations. Since the results exceeded the formulated 80%-criterion, we concluded that the AOL was a reliable instrument. However, the large range found in the results was striking. Moreover, observers with different information about the observed individuals came up with different reliability scores. To determine the value of observation of individuals with PIMD, it might well be necessary to judge the actual usefulness that the instrument has in clinical practice, besides the reliability of the results.

4.1 Introduction

While stimulation to promote communication and learning is essential for the support of individuals with profound intellectual and multiple disabilities (PIMD; Guess et al., 1993), direct support persons (DSPs) regularly wonder how to determine the right moment for starting such stimulating activities. By the same token, it is important for an activity to be started at the right moment so as to allow time for the stimuli that are presented to enter the consciousness of the individual with PIMD (Nelson, Van Dijk, McDonnell, & Thompson, 2002). The right moment has also been described as being focused on the environment or as being alert (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009a). The questions that arise, then, refer to a number of topics: How does an individual show that he or she is focused on the environment? How can individual differences in alertness signals be interpreted? Can we determine an optimal moment during the day for stimulation of an individual with PIMD? There is an additional problem in that research shows that reduced levels of alertness and quick, irregular changes in alertness levels over time are common for individuals in the target group (Guess, Roberts, & Guy, 1999). These factors may even aggravate the problem of determining alertness reliably in individuals with PIMD.

Despite agreement about the importance of determining alertness for the support of individuals in the target group, it is not obvious *how* different alertness levels ought to be determined. Since individuals with PIMD do not express their needs by means of spoken language, self-report cannot be used (Vlaskamp, 2005). Similarly, physiological measurements often show unusual patterns and do not reveal the necessary information about the complex behavior of individuals in the target group (Mudford, Hogg, & Roberts, 1997). In contrast, most authors do agree that alertness can be described in terms of observable behavior. Consequently, most instruments used to investigate and determine alertness in individuals with PIMD are based on observations (Munde et al., 2009a).

Observations clearly have a number of advantages above and beyond other assessment methods for individuals with PIMD. As a consequence of the severity of their disabilities, individuals with PIMD are not able to use spoken language, and so they express themselves by means of body language. Consequently, individuals in the target group often cannot fulfill the requirements of standardized assessment instruments in terms of motor and speech abilities (Vlaskamp, 2005). The communication of individuals with PIMD mostly consists of subtle signals that are difficult to detect for DSPs (Wilder & Granlund, 2003). The same signal may have a different meaning for different individuals (Vlaskamp). While physiological measurements can help to register these subtle signals, the results do not reveal the necessary information about the meaning of these signals for individuals in the target group (Mudford et al., 1997). Looking at the individual's reactions in different situations, DSPs can learn to interpret the different kinds of behavior (Grove, Bunning, Porter, & Olsson, 1999). Only observations allow DSPs to take the meaning of the individual's behavior into account. Detailed registration of the behavior and, at the same time, of the influencing factors are especially important when observing individuals with PIMD.

However, general problems are related to observations in individuals with PIMD as well. Observations often lack an unambiguous description of their focus. When observations are based on theoretical concepts, these cannot be directly linked to visible behavior. Consequently, observers are forced to interpret the visible behavior, and ascribing meaning to behavior is, in turn, always interpretation (Vlaskamp, 2005). Interpretation, then, can be specified as yet another problem to do with observations. While it is important for DSPs to take the meaning of the behavior of their clients into account, several factors can bias the interpretation. DSPs interpret the behavior of the individual with PIMD based on their knowledge of the individual and previous experiences with the individual in similar situations. Since this knowledge differs for each DSP, observations of the same situation may result in different scores (Grove et al., 1999). Additionally, general expectations of reactions and contextual factors in a specific situation can also influence the DSP's judgment (Hogg, Reeves, Roberts, & Mudford, 2001). While DSPs' overall judgments remain similar in situations with and without contextual information, DSPs judge the individual's expressions more positively when they expect the individual with PIMD to enjoy an activity than when they do not know about the content of the activity. Furthermore, and as a consequence of the subjectivity of the interpretations, observations of individuals with PIMD regularly result in low reliability. As a result, researchers find themselves still involved in discussions about influencing factors and explanations (Vlaskamp).

The general problems that we experience in observations of individuals with PIMD also become apparent in the alertness observations of individuals in the target group. In the literature, no unambiguous description of alertness has been found (Munde et al., 2009a). Although the authors all agreed that it was possible to observe alertness in the behavior of individuals with PIMD, different terms with different descriptions were found to have been introduced. Additionally, different scoring categories were used to determine alertness levels. Another point of discussion is scoring frequency. Because of quick and irregular changes in alertness levels, some authors plead the case for continuous scoring (Guess et al., 1999; Mudford et al., 1997). However, the difference in content information based on interval scoring is not yet made evident here, and, above all else, it should be remembered that interval scoring is actually more useful in clinical practice. To measure and compare the impact of these differences, researchers found themselves obliged to determine the reliability of their observations. For a number of the studies, reliability did not exceed the formulated criterion (Mudford et al.; Woodyatt, Marinac, Darnell, Sigafoos, & Halle, 2004). Although different explanations for these results have been discussed (Arthur, 2000; Guess, Roberts, Behrens, & Rues, 1998; Mudford, Hogg, & Roberts, 1999), no solution for the problem of low reliability in alertness observations has been offered.

Taking the above-mentioned problems into account, the Alertness Observation List (AOL) has been developed accordingly (Vlaskamp, Fonteine, & Tadema, 2005). Within the AOL, a clear description of alertness is employed. Alertness is described as the "level" of being open to the environment. DSPs are thus able to use the AOL to formulate an individual alertness profile. Alertness is scored on four different levels in order to search for alertness patterns over the period of a day and to find out about changes in alertness based on the impact of different stimuli. Thereby, scoring frequency increases for each of the three subsequent scoring forms of the AOL.

The aim of the present study was to estimate the reliability of the AOL. In a previous study, the AOL was proved to be reliable in five cases (Petitiaux, Elsinga, Cuppen-Fonteine, & Vlaskamp, 2006). In the present study, we determined the general reliability of the instrument for a larger sample. In doing so, we strived to reach adequate reliability results while, at the same time, minimizing the problems with observations mentioned above.

4.2 Method

Participants

A Dutch school for special education volunteered to use the instrument. In this school, four classes were randomly selected. All 23 students of the four classes (12 girls and 11 boys) were included in the study. The children's ages ranged from 6 to 16 years (M = 11, 57, SD = 3, 25). All the children could be described as individuals with PIMD. In addition to profound intellectual and profound motor disabilities (Nakken & Vlaskamp, 2007), individuals in the target group suffer from additional sensory impairments and a broad range of health problems (e.g., epilepsy, dysphagia, constipation, gastro-esophageal reflux, Arvio & Sillanpää, 2003; Kapell et al., 1998; Van Schrojenstein Lantman-de Valk, Van den Akker, Maaskant, & Haveman, 1997; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). For the children involved in the present study, the diagnoses included a number of different syndromes such as West's syndrome and Battered Child Syndrome. For 60% of the children, no clear medical diagnosis had been formulated. Visual and auditory impairments were assessed in 57% and 13% of the children, respectively. Additionally, 22% of the participants suffered from epilepsy. For all the children, informed consent to take part in this study was obtained from their parents or legal representative.

To take into account the possible impact the observers' knowledge might have and, as a result, to determine reliability as objectively as possible, the observations were conducted by three types of observers: teachers, an external observer who had received additional information about the children and an external observer who did not know the children with PIMD at all. All the observers were familiar with the AOL and were aware of the aim of the research.

Instrument

The Alertness Observation List was used to determine alertness. In the AOL, four levels of alertness are distinguished: 1) active, focused on the environment; 2) inactive, withdrawn; 3) sleeping, drowsy; and 4) agitated, discontented. Each level is assigned a color: green, orange, red and blue, respectively. More detailed descriptions of the different levels are given in Table 4.1. Four different forms are used to develop a complete alertness profile. The first form was completed before starting the observations. The overall state of the individual on the day before the planned observation and on the day of the observation itself was determined. If the individual had recently been ill or had had an unusual epileptic seizure the same day, observations were not conducted. The second form was used to observe an individual for three days, scoring alertness every 15 minutes, starting when the individual entered the school and stopping when he or she left. Before using the third form, DSPs first chose the optimal moment in a day for offering an educational activity to the individual. The stimulation was then presented for 15 minutes with the precondition that the score had to have been green or orange, thus that the individual had been awake during the preceding 15 minutes. The alertness level was scored every five minutes during the activity and for 15 minutes following that (Form 3). The fourth form was similar to the third one, except that the observer scored every 20 seconds for a period of five minutes, during which the child was offered the activity. Finally, using all the information gathered on the observation forms, an alertness profile could be formulated and written down in a *traffic light*. This overall description of all the alertness categories of the individual was complemented with concrete examples of behavior for each category (Vlaskamp et al., 2005).

Table 4.1

Descriptions of the different alertness "levels" according to the Alertness Observation List (Vlaskamp, Fonteine, & Tadema, 2005)

Alertness level	**Color**	**Description**	**Examples of behavior**
Active, focused on the environment	Green	The individual is engaged in sensory activities. That means he or she is looking, listening, touching or smelling. These activities are directed toward the environment. As a result, the individual is able to be focused on other individuals or on materials in the room.	Open eyes, focusing with the eyes, turning the head or the eyes in the direction of a stimulus, the body is tensed, the individual is reaching or grasping an object, the individual is eating or drinking.
Inactive, withdrawn	Orange	The individual may be engaged in sensory or motor activities. These activities are *not* directed to the environment. Activities can be focused on the individual him/ herself or without any focus.	Looking at one's hands, stereotypical movements, sensing one's clothes, staring, fiddling with one's body, the head down or turned aside, thumb-sucking, groaning softly, rubbing the eyes, rolling the head, rocking him/ herself.
Sleeping, drowsy	Red	The individual is sleeping. Movements and sounds correspond to sleep.	Sleeping, eyelids are shut, eyes are opening and closing slowly, snoring, limbs are limp and loose.
Agitated, discontented	Blue	The individual expresses discomfort.	Shouting, crying, screaming, hitting or kicking materials or persons, banging with the head, hitting, biting, scratching, or kicking himself or herself.

Procedure

The AOL was completed for all 23 children. Since the first three forms of the AOL are conditional relative to Form 4, the fourth form is the one that is expected to reveal the most relevant information. Consequently, we have only included the observations of the fourth form in the present study. All observations using this form were videotaped. The observations were conducted in the classroom and in a multisensory room. In these two different settings, five and two observations, respectively, were completed for each child. A number of videotapes were excluded from the study because of the low quality of the recordings. The remaining pool of observations consisted of 120 situations. To investigate the reliability of the AOL, 39 situations were randomly selected from the pool of 120 observations. For every situation, we asked two observers to score alertness for the individual with PIMD with the Media Coder (Bos & Steenbeek, 2008). Using the general formula for agreement, we estimated the inter-observer agreement. Since we investigated an individual judgment, a minimum value of 80% was applied in order to interpret the results (Mudford et al., 1997). Additionally, the intra-observer agreement was calculated for another 39 situations. The situations were again selected at random from the pool of 120 observations. Observers were asked to complete the observation form twice for the same situation, six weeks apart. The same formula and the same interpretation criteria as for the inter-observer agreement were used to estimate and interpret agreement percentages.

4.3 Results

All 78 situations were scored using the fourth form of the AOL. Employing the general formula for agreement in order to calculate the inter-observer reliability for 39 of the situations, we found r = 81% (Mdn = 81.44; M =

81.46; *SD* = 13.88). The intra-observer reliability for the other half of the situations was *r* = 87% (*Mdn* = 86.79; *M* = 85.23; *SD* = 11.75). Although the median exceeded the formulated criterion of 80%, individual results showed large differences. Inter-observer reliability ranged from 50% to 100% with a standard deviation of 13.88. These results were similar to those for the intra-observer reliability that had a range from 61.11% to 100% and a standard deviation of 11.75. In addition, those observers who received more information about the children scored higher results for the inter-observer reliability, whereas the scores of the observer who did not know the children at all were higher for the intra-observer reliability. An overview of all the results including the percentages for each situation and each type of observer is presented in Tables 4.2 and 4.3.

4.4 Conclusion and discussion

The present study does show that the AOL is a reliable instrument for determining alertness in individuals with PIMD. However, a number of details need to be discussed. Although the overall results of the present study are sufficient, the large range of results for the different situations is striking. The differences can be partially explained by the severity of the disabilities of the target group. One example of this is that visual impairments are common in people with PIMD, and so those in the target group with visual impairments most likely will not show their focus on the environment by directing their eyes or head. It is therefore difficult to determine their alertness levels. Another example is that uncontrolled movements of individuals with spasticity also aggravate alertness observations. When individuals are not able to show their focus by pointing

Table 4.2

Results for inter-observer reliability

Observers	**Situations**													***M***	***Mdn***	***SD***
	1	2	3	4	5	6	7	8	9	10	11	12	13			
T&E+	83.33	75.00	87.50	75.17	80.00	100.0	75.00	62.50	100.0	87.50	62.50	100.0	87.50	***82.77***	***83.33***	***12.80***
T&E-	50.00	75.00	70.83	79.17	83.33	91.67	100.0	100.0	87.50	91.67	79.16	66.67	75.00	***80.77***	***79.17***	***13.98***
E+&E-	83.33	80.00	86.67	75.86	93.33	100.0	50.00	64.86	81.82	94.74	64.44	100.0	76.00	***80.85***	***81.82***	***14.86***
													TOTAL	**81.46**	**81.44**	**13.88**

Note. The letters in Tables 4.2 and 4.3 refer to the different types of observers. Teachers are designated by a *T*, the external observed who received additional information about the children is designated by an *E+* and the external observer who did not know the children at all is designated by an *E-.* The situations were not similar for the different observers.

Table 4.3

Results for intra-observer reliability

Observers	**Situations**													***M***	***Mdn***	***SD***
	1	2	3	4	5	6	7	8	9	10	11	12	13			
T	70.83	70.83	91.67	100.0	79.17	83.33	70.83	70.83	100.0	70.83	100.0	91.67	83.33	***83.33***	***83.33***	***12.15***
E+	95.83	66.67	76.67	93.10	93.55	100.0	88.89	61.11	87.10	78.95	86.36	100.0	85.00	***85.63***	***87.10***	***12.02***
E-	91.07	96.77	63.64	72.88	95.16	82.98	100.0	90.48	91.53	86.05	97.73	86.84	72.22	***86.72***	***90.48***	***11.09***
													TOTAL	**85.23**	**86.97**	**11.75**

or grasping, DSPs might well interpret the individual's behavior as being not alert. The frequency of changes in alertness levels is another explanation for the large individual differences in reliability. When the individual with PIMD showed a clear focus during the entire observation, reliability was always 100%. In contrast, frequent changes in alertness levels were associated with lower reliability. As Guess et al. (1999) and Mudford et al. (1997) already found in previous studies, the differentiation between orange and green alertness levels was especially difficult. Therefore, observations concerning situations with numerous changes between these two levels can lead to low reliability results.

Individual differences in terms of alertness expressions may also have an impact on the reliability of the results. Although observers are expected to take these differences into account, idiosyncratic behavior can aggravate observations of individuals in the target group (Hogg et al., 2001). Turning away the head may be an indication of dislike for the stimulus presented, but, by the same token, an individual with visual impairments may also express his or her interest in this way, especially as a reaction to an auditory stimulus. In such situations, the proxies' knowledge of the children may be seen as an advantage in interpretation of their behavior. However, looking at the higher intra-observer reliability for the observer who did not know the children at all, we are obliged to amend this statement. Since external observers were not influenced by their knowledge about the child and recent experiences with the child, their observations were mainly based on the observable behavior and their interpretations were actually more consistent. However, there is no real standard for judging the correctness of the interpretations. Consequently, observations by proxies and external observers might well be used to greater advantage as complementary sources of information (Petry & Maes, 2006).

The present study has confirmed that observing individuals with PIMD reliably is an enduring challenge for DSPs and researchers. The subjectivity of the interpretations remains a threat to their reliability. Additionally, several practical problems aggravate the implementation of alertness observations for individuals in the target group. The scoring systems are experienced as being too complex for use in clinical practice. The observations themselves are found to be time-consuming as well and, therefore, often not practicable in day-to-day situations (Petry & Maes, 2006). However, based on the example of the AOL, we can conclude that reliable observations are in fact possible. While alertness observations remain an effort, DSPs also confirmed the importance of determining alertness in their clients. Furthermore, investigating the value of the results of the traffic light for DSPs may reveal additional information about the usefulness of the AOL in clinical practice.

5

Physiological measurements as validation of alertness observations: an exploratory case study in three individuals with profound intellectual and multiple disabilities*

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Abstract

Assessing the functioning of individuals with profound intellectual and multiple disabilities (PIMD) presents special challenges for researchers and assessors. One method that largely takes into account the needs and abilities of individuals with PIMD is observation. While observation has some clear advantages over other methods, a number of difficulties and disadvantages are related to this assessment method as well. Our aim in the present study, therefore, was to investigate what possibilities the use of physiological measurements make available in order to validate the alertness observations made for individuals with PIMD.

Video observations of three individuals with PIMD were conducted in six different situations. In addition to this, non-invasive ambulatory LifeShirt® technology was used to measure five parameters of heart rate and respiration. The means of the physiological measurements were compared for different alertness levels and for moments of change versus no change in alertness levels.

All three participants showed a higher heart rate when they were alert. Additionally, sustained high-alertness levels were related to low respiratory sinus arrhythmia (RSA) levels, and different RSA scores were found during changes to the alert *alertness level compared to moments without changes. Since these first findings are broadly in line with studies involving nonclinical individuals, we hypothesize that physiological measurements of heart rate and respiration can be used to validate alertness observations in individuals with PIMD. Future studies are needed to compensate for the limitations of the present study and to answer those questions which follow from the field of physiological research itself when it comes to individuals in the target group.*

5.1 Introduction

Assessing the functioning of individuals with profound intellectual and multiple disabilities (PIMD) presents special challenges for researchers and assessors. Individuals in the target group experience a combination of severe intellectual and motor disabilities (Nakken & Vlaskamp, 2007). These disabilities are complicated by severe sensory disabilities and a broad range of health problems such as epilepsy, chronic pulmonary infections, and gastro-esophageal reflux (Arvio & Sillanpää, 2003; Van Schrojenstein Lantman-de Valk, Van den Akker, Maaskant, & Haveman, 1997; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). As a consequence of their disabilities, individuals with PIMD do not use spoken language. They communicate by means of body language, using subtle gestures, sounds, or movements to express themselves (Petry, Maes, & Vlaskamp, 2005). Because of these disabilities, individuals with PIMD do not fulfill the requirements of standardized assessment instruments in terms of motor and speech abilities (Vlaskamp, 2005). At the same time, differences in combination and severity of the disabilities result in a broad heterogeneity for this target population in terms of abilities and constraints (Nakken & Vlaskamp). This diversity also aggravates the development of specialized and standardized instruments that might be usable for this target population (Vlaskamp & Cuppen-Fonteine, 2007).

One method that largely takes into account the needs and abilities of individuals with PIMD is observation. While the subtle expressions of individuals in the target population are difficult to register, it is even more important to be able to combine any registration with an interpretation of the signal. The meaning of a signal may be different for different individuals; even the same expression on the part of one individual may be interpreted differently in another, different situation. Consequently, assessors need to take the individual's communication into account as well as any possible contextual influences (Hogg, Reeves, Roberts, & Mudford, 2001; Petry & Maes, 2006). Only observation makes this possible.

However, there are also a number of disadvantages related to observation as an assessment method. First, making observations is very time-consuming. Although assessors may often confirm the value of the results of observation, they do not always see themselves able to realize observations as part of their daily work (Petry & Maes, 2006). Second, all observations entail subjectivity on the part of the observer (Hogg et al., 2001). While it is important for assessors to take the meaning of the behavior of their clients into account, several factors can bias their interpretation. Assessors interpret the behavior of the individual with PIMD based on their knowledge of the individual, taking into account their own previous experiences with the individual in similar situations. Since this knowledge differs for each assessor, observations made of the same situation may result in different scores given by different assessors. At the same time, general expectations concerning reactions and contextual factors in a specific situation can also influence the assessor's judgment. This subjectivity is a threat to the reliability of this kind of assessment method. As a result, researchers find themselves continually involved in discussions about influencing factors and explanations (Vlaskamp, 2005). Moreover, studies that compare proxy reports to the self-reports of individuals whose job it is to formulate them have shown that these reports are not always in agreement with each other (Lewis & Morrissey, 2010; Lunsky & Bramston, 2006; Perkins, 2007). Proxies' judgments should, therefore, be interpreted with caution.

In support and education for individuals with PIMD, observation is also used to determine alertness. Alertness has been described as an individual's level of interaction and engagement with the environment, which becomes manifest and observable in the individual's behavior (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009a). DSPs need to know about the individual's alertness level before they begin to offer stimulation. Only if individuals are alert and focused on the environment can they be expected to process the stimuli presented to them on a conscious level (Nelson, Van Dijk, McDonnell, & Thompson, 2002). Consequently, alertness is one of the most important preconditions for learning and development (Munde et al., 2009a; Munde, Vlaskamp, Ruijssenaars, & Nakken, 2011).

At the same time, assessing alertness presents challenges to both researchers and assessors. While authors of previous studies have confirmed that it was indeed possible to determine alertness based on the behavior of individuals with PIMD (Munde et al., 2009a), alertness observations in individuals with PIMD run up against problems similar to those related to observation in general. No consensus has been arrived at for the scoring categories that determine alertness levels. The position of *self-injurious behavior*, for example, has been discussed in several studies about alertness observations. While some researchers expect this behavior to occur at all alertness levels (Woodyatt, Marinac, Darnell, Sigafoos, & Halle, 2004), others suggest that self-injurious behavior should not be described as an alertness level at all but as a form of communication (Siegel-Causey & Bashinski, 1997). Moreover, researchers and assessors still wonder which expressions of an individual with PIMD should be interpreted as an indication of which particular level of alertness. When an individual looks at a stimulus, for example, it can be unclear to the observer whether the individual is alert and concentrating on the stimulus, or just staring in the direction of the stimulus without any actual focus. Differentiating between the situations of being alert and *being withdrawn* is especially difficult in such circumstances (Munde et al.). Another point of discussion revolves around scoring frequency. Because of quick and irregular changes in alertness levels, some authors plead the case for continuous scoring (Guess, Roberts, & Guy, 1999; Mudford, Hogg, & Roberts, 1997). However, the difference in content information when continuous as compared to interval scoring is not so obvious. Moreover, continuous scoring is difficult to do in actual clinical practice. To measure and compare the impact of these differences, researchers have calculated the reliability of their observations. For a number of the studies, the result was that reliability did not exceed the formulated criterion (Mudford et al.; Woodyatt et al., 2004). Although different explanations for these results have been discussed (Arthur, 2000; Guess, Roberts, Behrens, & Rues, 1998; Mudford et al., 1999), no solution for the problem of low reliability in alertness observations has been offered.

Because of the ongoing discussion about the difficulties and disadvantages of alertness observations, several studies have stated the need for complementary assessment methods to validate the observations (Mudford et al., 1997; Munde et al., 2011). However, finding methods that are in line with the needs and abilities of individuals with PIMD presents another challenge. In the literature, two alternative methods are regularly described to determine alertness in nonclinical groups: brain measurements and physiological measurements (Beauchaine, 2001; Dykman, Ackerman, Holcomb, & Boudreau, 1983). But because severe brain damage is the very cause of their disabilities, brain measurements in individuals with PIMD are rarely carried out, and interpretations of the results remain a point of discussion (Kemner, Van der Gaag, Verbaten, & Van Engeland, 1999). Similarly, no studies using physiological measurements to determine alertness levels in individuals with PIMD are available to date.

At the same time, a large number of studies can in fact be found for nonclinical individuals (e.g., Beauchaine, 2001; Boiten, 1998; Dykman et al., 1983; Thayer & Lane, 2000). Looking at the literature about physiological measurement in detail, a number of relationships between alertness and physiological expressions have been described. While higher alertness accompanies a higher heart rate (Dykman et al., 1983; Thayer & Lane, 2000), changes in alertness are also often accompanied by changing heart rate levels (Bradley, 2009). Studies focusing on breath as a measurement of alertness have found that nonclinical individuals showed a quick and shallow respiration when they were alert (Beauchaine; Boiten). Consequently, high respiration rate, low tidal volume, and minute ventilation have been linked to high alertness levels. Those findings also accompany differences in respiratory sinus arrhythmia (RSA; Beauchaine), combining both the measurements of heart beat and respiration in one parameter. RSA measurements describe heart rate variability by using the ratio of the heart rate during the expiration of an individual (Berntson, Cacioppo, & Quigley, 1993).

Moreover, the only study focusing on the target group of individuals with PIMD found that participants' physiological measurements differed for positive versus negative emotions. The authors have also suggested a relationship between emotions and alertness. While participants focused their attention when presented with positive stimuli, they withdrew their alertness when presented with negative stimuli (Vos, De Cock, Petry, Van den Noortgate, & Maes, 2010).

Based on those previous findings, the aim of the present study was to explore the possibility of validating alertness observations in individuals with PIMD by using physiological measurements. Similar patterns in both methods could indicate convergent validity for the alertness observations.

Moreover, the results could shed more light on the feasibility of physiological measurements when assessing individuals with PIMD.

5.2 Method

Participants

In two daycare facilities in Flanders, the Dutch-speaking part of Belgium, the participants were selected based on the following criteria. All participants had to be diagnosed as individuals with PIMD according to the definition of Nakken and Vlaskamp (2007). From these, individuals with daily epilepsy, hypersensitivity of the skin, and behavioral problems were excluded, because any interference with the measurements might lead to invalid results. Moreover, for each client, one DSP who had known the client for at least one year had to be willing to participate in the study as well.

Out of the pool of clients who met the criteria described above, three were selected at random. Participant 1 was a 23-year-old man with a developmental age of less than 6 months. His motor abilities were restricted by severe spasticity; he was not known to have any sensory problems. Because he experienced difficulties with swallowing, he only received mashed food. The second participant was a 23-year-old woman. Her mental age had been determined to be 3.5 months. Following research, it was supposed that she was most likely also suffering from a visual impairment. However, as yet this had not been able to be confirmed. In addition to severe motor disabilities, feeding and airway problems had also been diagnosed. She received her food via a stomach tube. Participant 3 was a man of 52 years of age. His developmental age was between 6 and 12 months. Because of serious hypertension in his whole body, he was restricted in his movements. No sensory problems were known. He was given thickened food and drinks to avoid swallowing problems. All three participants suffered from epilepsy which was kept under control with medical treatment.

Informed consent for participation in this study and video registration was obtained from the parents or legal representatives.

Instruments

The Alertness Observation List (AOL; Vlaskamp, Fonteine, Tadema, & Munde, 2010):

Based on the scoring system of the AOL, alertness levels were scored. The four levels of alertness were each assigned a color: 1) active, focused on the environment (green); 2) inactive, withdrawn (orange); 3) sleeping, drowsy (red); and 4) agitated, discontented (blue). When four different observation forms had been completed, an individual alertness profile was able to be formulated. The individual descriptions of each alertness level were complemented with concrete examples of behavior. Previous research has shown that the AOL is a reliable instrument for determining alertness levels in individuals with PIMD (Munde et al., 2011; Petitiaux, Elsinga, Cuppen-Fonteine, & Vlaskamp, 2006).

LifeShirt®:

The non-invasive ambulatory LifeShirt technology (VivoMetrics, Inc., Vantura, CA) was used to collect the physiological data. Various sensors woven into the LifeShirt continuously register a range of cardiopulmonary parameters. In the present study, measurements of pulmonary functioning and the electrical activity of the heart were included. These measurements were based on respiratory bands using inductance plethysmography and electrocardiography (ECG), respectively. Additionally, the participants' activity levels were recorded using an accelerometer. An overview of the parameters is given in Table 5.1.

Procedure

The study was conducted over four weeks. The first week was the preparation phase. The participants wore the LifeShirt for 30 minutes every day in order to become accustomed to the shirt and to minimize its effects on their functioning. During these sessions, DSPs filled in a questionnaire about the clients reactions to the LifeShirt. After the first week, the participants no longer showed any effects from wearing the shirt. In the subsequent three weeks, six different situations of 15 minutes each were videotaped for each of the participants while they were wearing the LifeShirt. The aim was to gather an at-random selection of situations that were illustrative of the everyday life of the participant. While all the situations included stimulation of the participant, the content was chosen according to the preferences and possibilities of each participant separately. In order to make the situations comparable for all participants, one situation of individual stimulation, one group activity, a meal, and a situation where the participant was alone with a stimulus were included. Each type of situation was videotaped and recorded three times. In the end, one situation of each type (six situations per person) was chosen at random to be used for further analysis.

Two observers, trained in the use of the AOL and familiar with the aim of the study, scored the videotapes using the Media Coder (Bos & Steenbeek, 2008). Individual alertness profiles had previously been formulated by the DSPs and were now used as a framework for the scoring. To calculate the inter-observer agreement, 20% of the videotapes were scored by two observers. The agreement, based on the general agreement formula (Mudford et al., 1997), was 82.6%.

To prepare the physiological data for analysis, all irregularities were removed. The data were calibrated using the qualitative calibration method available in the Vivologics software. Because some of the sensors were sus-

Table 5.1

Physiological parameters

Parameters	**Abbreviation**	**Explanation**	**Measure**
Heartbeat parameter	HR	Heart rate	Beats per minute
Respiration parameters	RR Vt/ Ti Vent	Respiration rate Tidal volume Minute ventilation	Breaths per minute Milliliters per second Breaths per minute
Combination parameter	RSA	Respiratory sinus arrhythmia	Milliseconds
Movement parameter	AccM	Accelerometer	Weight per unit of mass

ceptible to movement, all values above 2.5 on the accelerometer (indicating the same amount of movement as walking) were excluded. All periods that included vocalization were also removed to avoid artefacts in the data. Finally, values for all parameters were extracted per breath.

Analysis

Based on previous studies, two patterns were explored in the data: differences in physiological measurements were observed for the various alertness levels in nonclinical samples, and changes in alertness levels were associated with changes in heart rate and RSA.

SPSS 16 was used to explore the descriptive statistics of the data. Means of the physiological measurements of heart rate (HR), respiration rate (RR), respiratory sinus arrhythmia (RSA), tidal volume, and minute ventilation were compared to each other for the different alertness levels. In addition, the means of HR and RSA during changes to the alert alertness level were compared to moments without changes. For this purpose, five seconds before and after the actual change were scored as the moment of change. Only those moments without any changes between the other alertness levels were coded as *no change*. Explorative analyses were conducted per person per situation.

5.3 Results

Because none of the participants was asleep during the situations, this particular alertness level had to be excluded from further analysis. In addition, only those situations that revealed information relevant for the present study were described in the analysis. Concerning the first part of the analysis, Participant 1 did not show *withdrawn* behavior in Situations 2, 4, and 6. In Situations 2 and 4, no changes in alertness levels on the part of Participant 1 were observed for the second part of the analysis. Similarly, Participant 2 did not show any changes in terms of alert alertness level in Situation 2 either. Consequently, six situations had to be excluded in total.

Participant 1

On comparing the means of HR for the different alertness levels with each other, Participant 1 showed higher scores when he was alert than when he was withdrawn in two of the three situations. When he was agitated, HR scores were even higher in two situations, while lower in one situation.

In two of the three situations, the respiration parameters RR and RSA were lower for the alert moments as compared to those moments when Participant 1 was withdrawn, while tidal volume and minute ventilation were higher during the alert moments. When the participant was agitated, the means of the respiration parameters differed in all situations.

Furthermore, HR during changes to the alert alertness level was higher than during moments without changes in two of the four situations. RSA scores, in contrast, were lower for three of the four situations.

Participant 2

Participant 2 showed higher HR during alert moments compared to the withdrawn moments in three of the six situations. As in HR, Participant 2 showed a higher RR in three of the six situations. Scores for tidal volume and minute ventilation were higher during alert moments than during withdrawn moments in five of the six situations. RSA scores, in contrast, were lower in five situations when the participant was alert, while higher when she was withdrawn. Participant 2 only showed agitated behavior in one situation.

Similar to Participant 1, Participant 2 showed higher HR during changes to the alert alertness levels than during moments without changes in three of the five situations. In four of the six situations, RSA scores were lower when she was changing alertness levels.

Participant 3

HR levels were higher in alert than in withdrawn moments for Participant 3 in four of the six situations. Mean scores for tidal volume, minute ventilation, and RSA were lower for the alert as compared to the withdrawn alertness level in four of the six situations. For RR, scores were higher. When Participant 3 was agitated (in three of the six situations), he showed even higher scores for all four parameters in two of these situations.

Table 5.2

Means of the physiological measurements per alertness level per situation for Participant 1

		Alertness		
		Alert	Withdrawn	Agitated
Physiological measurements	**Situation**			
Heart rate	1	85.8	88.3	89.8
	2	85.6	-	-
	3	75.8	72.7	67.0
	4	100.3	-	-
	5	70.0	65.1	74.1
	6	78.6	-	77.7
Respiration rate	1	0.710	0.686	0.680
	2	0.721	-	-
	3	0.837	0.845	0.913
	4	0.613	-	-
	5	0.881	0.927	0.832
	6	0.784	-	0.790
Tidal volume	1	170.6	200.7	203.7
	2	230.7	-	-
	3	376.7	317.5	334.2
	4	160.1	-	-
	5	102.1	69.7	108.7
	6	126.8	-	136.5
Minute ventilation	1	3.97	5.40	4.75
	2	6.07	-	-
	3	9.63	8.46	9.35
	4	4.09	-	-
	5	2.58	1.97	2.83
	6	3.32	-	3.48
Respiratory sinus arrhythmia	1	94	64	61
	2	94	-	-
	3	111	122	121
	4	87	-	-
	5	207	252	199
	6	134	-	189

Table 5.3

Means of the physiological measurements per alertness level per situation for Participant 2

		Alertness		
		Alert	Withdrawn	Agitated
Physiological measurements	**Situation**			
Heart rate	1	96.8	95.4	-
	2	101.7	102.3	-
	3	86.6	85.7	-
	4	85.9	88.6	-
	5	82.0	80.4	80.6
	6	82.7	84.3	-
Respiration rate	1	0.623	0.633	-
	2	0.595	0.586	-
	3	0.694	0.700	-
	4	0.700	0.679	-
	5	0.735	0.749	0.746
	6	0.728	0.714	-
Tidal volume	1	208.8	200.2	-
	2	219.7	182.1	-
	3	172.0	183.7	-
	4	216.3	209.4	-
	5	177.4	170.5	205.1
	6	153.8	144.4	-
Minute ventilation	1	4.61	4.37	-
	2	4.77	4.03	-
	3	3.47	3.74	-
	4	4.19	3.54	-
	5	3.58	3.63	4.07
	6	2.87	2.48	-
Respiratory sinus arrhythmia	1	41	39	-
	2	43	63	-
	3	46	47	-
	4	52	57	-
	5	63	67	58
	6	53	62	-

Table 5.4

Means of the physiological measurements per alertness level per situation for Participant 3

		Alertness		
		Alert	Withdrawn	Agitated
Physiological measurements	**Situation**			
Heart rate	1	82.0	79.7	75.5
	2	63.1	62.9	77.6
	3	71.2	74.7	-
	4	83.2	82.8	-
	5	75.0	74.6	75.1
	6	82.0	83.1	-
Respiration rate	1	0.743	0.763	0.798
	2	0.962	0.959	0.801
	3	0.850	0.804	-
	4	0.728	0.724	-
	5	0.806	0.809	0.808
	6	0.763	0.723	-
Tidal volume	1	373.9	419.4	303.9
	2	515.9	530.0	737.7
	3	451.2	468.4	-
	4	473.3	315.8	-
	5	443.7	408.8	508.6
	6	428.5	500.3	-
Minute ventilation	1	8.22	9.11	7.13
	2	13.60	14.92	20.13
	3	9.37	9.63	-
	4	10.06	5.47	-
	5	10.07	8.26	12.88
	6	9.42	10.69	-
Respiratory sinus arrhythmia	1	43	59	53
	2	45	28	192
	3	67	103	-
	4	45	51	-
	5	43	40	48
	6	77	206	-

Table 5.5

Means of heart rate and respiratory sinus arrhythmia for changes in alertness levels per situation for Participant 1

		Alertness	
		Change to alert	No change
Physiological measurements	**Situation**		
Heart rate	1	86.6	85.9
	2	-	85.6
	3	73.4	75.7
	4	-	100.3
	5	72.1	70.7
	6	76.0	77.6
Respiratory sinus arrhythmia	1	76	92
	2	-	94
	3	103	111
	4	-	98
	5	197	199
	6	153	131

Note. A hyphen in Table 5.2 to 5.4 indicates that an alertness level did not occur in a situation and, therefore, no physiological data are available. A hyphen in Table 5.5 to 5.7 indicates that a change to alert did not occur in a situation and, therefore, no physiological data are available.

When he changed to the alert alertness levels, HR was lower than during moments without changes in four of the six situations. RSA scores, in contrast, were higher in five of the six situations.

An overview of the results per participant and per situation is given in Tables 5.2 to 5.7. Two tables are displayed for each participant, including the different alertness levels and the changes to the alert alertness level, respectively.

5.4 Conclusion and discussion

The aim of the present study was to explore the possibility of validating alertness observations by using physiological measurements. Based on the results, the following links were found. HR was higher when the participants were alert than when they were withdrawn from the environment in 10 of the 15 situations. Furthermore, no clear differences in HR were found during changes to the alert alertness level compared to moments without changes. In seven situations, means of HR were higher during changes, while scores were lower in eight situations. For the respiration parameters, a tendency became apparent for three parameters. Participants showed higher tidal volume and minute ventilation (nine of the 15 situations) and lower RSA (11 situations) when they were alert. Because RR was only

Table 5.6

Means of heart rate and respiratory sinus arrhythmia for changes in alertness levels per situation for Participant 2

		Alertness	
		Change to alert	No change
Physiological measurements	**Situation**		
Heart rate	1	98.4	96.6
	2	-	101.8
	3	86.1	86.4
	4	88.9	85.6
	5	80.7	82.1
	6	83.7	81.9
Respiratory sinus arrhythmia	1	42	39
	2	-	43
	3	46	45
	4	60	50
	5	62	66
	6	61	48

Table 5.7

Means of heart rate and respiratory sinus arrhythmia for changes in alertness levels per situation for Participant 3

		Alertness	
		Change to alert	No change
Physiological measurements	**Situation**		
Heart rate	1	74.6	81.2
	2	63.6	63.0
	3	69.8	71.6
	4	78.3	83.4
	5	75.1	74.2
	6	79.0	82.4
Respiratory sinus arrhythmia	1	58	49
	2	36	45
	3	60	70
	4	49	45
	5	47	43
	6	250	72

higher in eight of the situations, no conclusions can be drawn for this parameter. For the agitated moments, the means of the respiration parameters of the participants did not show any pattern.

Comparing the results to previous studies, our study is in line with the findings for the nonclinical population that revealed a relationship between high alertness levels and high HR (Dykman et al., 1983; Thayer & Lane, 2000). Freeman, Horner, and Reichle (1999) even stated that heart rate measurements were the most reliable method for determining alertness. Based on the results of the present study, we can hypothesize that this measurement might be reliable for the group of individuals with PIMD as well. When the different alertness levels were linked to the respiration parameters, a similar pattern became apparent for two of the participants. During alert moments, two of the three participants showed a higher tidal volume and higher minute ventilation. Scores of the two parameters were lower during the withdrawn moments. While this relationship contradicts the literature, previous studies have also shown that patterns may differ for individuals with respiratory disorders (Beauchaine, 2001; Boiten, 1998). Since such disorders had been diagnosed in Participant 2, this might be an explanation for the different results found in the respiration parameters. For Participant 1, the small number of situations (three) that could be included in this comparison might explain the differences between the findings in the literature and the findings for him. Furthermore, the scores of Participant 3 were in line with the pattern that studies of nonclinical individuals have revealed previously. During the alert moments, he had a decreased depth of breathing that became visible in the form of a lower tidal volume and lower minute ventilation. Looking at the different alertness levels and means of RSA, the patterns found in our study are again similar to the results of nonclinical studies. While sustained high alertness levels in nonclinical studies were related to low RSA levels, different RSA scores were found during changes to the alert alertness level as compared to moments without changes (Beauchaine; Thayer & Lane, 2000). Those results were also found in the present study for 11 and 10 of the 15 situations, respectively. However, the position of the *agitated* alertness level in relation to the different parameters needs to be discussed. It would seem that the different results for the participants and parameters confirm the adjunct position of this alertness level (Vlaskamp, Fonteine, Tadema, & Munde, 2010). At the same time, however, RSA has been described as a measurement of the regulation of attention and emotion (Beauchaine; Thayer & Lane). Possibly, then, this regulation may be linked to the different functions of the agitated and sometimes self-injurious behavior of individuals with PIMD (Barrera, Violo, & Graver, 2007). While individuals in the target group can show self-injurious behavior when they withdraw their attention from the environment in some situations, they may also use self-injurious behavior as an instrument to increase their alertness levels in other situations.

Although the results of this first exploratory study of ours are promising, a number of limitations need to be mentioned. No baseline measurements were included in the present study. Consequently, no comparisons were possible between participants, but only within participants. To strengthen our results and gather general information about physiological measurements in individuals with PIMD, baseline measurements are necessary. Therefore, research into the health problems of an individual should precede the measurements. When the individual with PIMD experiences airway problems, for example, the results of the respiration parameters have to be interpreted with caution. Future studies including all alertness levels would be especially useful to determine whether we can find an ongoing line in physiological measurements along the three different alertness levels. Furthermore, because of the large heterogeneity of the target group and our small sample, the results of the present study cannot be generalized to the entire population. Therefore, future studies with larger samples are needed.

Although the present study is only an exploratory case study, we feel able to hypothesize that heart and respiration measurements can be used to validate alertness observations in individuals with PIMD. The similarities between the results of the observations and the physiological measurements confirm that alertness and changes in alertness levels are observable. For assessment purposes, the results of the present study can be a valuable contribution to the ongoing discussion concerning the disadvantages and difficulties of observations. Just as individuals in the target group need pervasive support from the environment (Nakken & Vlaskamp, 2007), they also require assistance during the assessment. This may, in turn, lead to a biased picture of the functioning of the individual with PIMD. When the assessors judge the functioning of their client, they have to judge their own behavior at the same time. Physiological measurements can thus be used as a more objective complementation of the observations made. In clinical practice, physiological measurements can support the DSP's alertness observations. Physiological measurements can be especially helpful in differentiating between *alert inactive* and withdrawn alertness levels, because these levels are difficult to detect simply through observation (Mudford et al., 1997). Including these measurements in scientific studies can greatly increase the validity of the research. The present study may be seen as a one of the first steps in the area of physiological research on individuals with PIMD; however, a large number of resulting questions will need to be answered in the future.

6

Observing and influencing alertness in individuals with profound intellectual and multiple disabilities in multisensory environments*

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Abstract

Alertness is widely acknowledged as one of the most important preconditions for learning and development in individuals with profound intellectual and multiple disabilities (PIMD). Individuals within this target population, however, experience a wide range of difficulties in the contact with their environment. Because they are alert for only short periods, and because expressions of alertness are difficult to notice and interpret, the promotion and maintenance of optimal alertness levels poses a recurring challenge to their direct support persons (DSPs). A clear protocol for approaching the interrelated tasks of DSPs involving determining and influencing alertness levels could thus be a first step in solving this problem. The aim of the present study was to identify aspects of stimulation provided in multisensory environment (MSE) sessions that influence the alertness levels of individuals in the target population, as investigated according to a predefined observation list.

Video recordings were made of each of the 24 participants during one-on-one interaction with a DSP in the MSE. Alertness levels and environmental conditions were described based on the first five minutes of each session. Multilevel logistic regression analysis was used to identify the aspects of the stimulation situation that were related to occurrence of alertness.

While participants were generally alert for 76.3% of the time, results show that visual stimuli (optimally in combination with auditory stimuli) produced the highest alertness levels. Furthermore, large individual differences were found in reactions to different approaches and stimuli.

The results show that the effects of stimuli dominated the effect of time. The role of DSPs is thus especially important in alertness stimulation of individuals with PIMD. Future studies are necessary in order to formulate definite conclusions.

6.1 Introduction

Alertness is one of the most important preconditions for development and learning in individuals with profound intellectual and multiple disabilities (PIMD, Guess, Roberts, & Guy, 1999). Only if individuals are alert and focused on their surroundings can they be expected to process presented stimuli at a conscious level (Nelson, Van Dijk, McDonnell, & Thompson, 2002). Alertness can be described as an individual's level of interaction and engagement with the environment, which becomes manifest and observable in the individual's behavior (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009a).

The promotion and maintenance of alertness levels that are optimal for development and learning in individuals with PIMD poses a recurring challenge to direct support persons (DSPs). Guidelines for DSPs can provide information about how the stimulation can be optimally adapted to the needs and abilities of individuals with PIMD and, consequently, how the alertness of the client can be influenced.

While DSPs agree with researchers regarding the importance of alertness in the education and support of individuals with PIMD (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009b), they face a number of problems. On one hand, DSPs are not always sure how to determine alertness levels in their clients. Alertness observations reported in previous studies can be reduced to three general levels (e.g., Green, Gardner, Canipe, & Reid, 1994; Guess, Roberts, & Guy, 1999; Mudford, Hogg, & Roberts, 1997): 1) being alert and actively focused on the environment; 2) being awake, but focused on oneself and not in contact with the environment; and 3) being asleep, without any focus or contact. In practice, however, DSPs are faced with the complex task of linking particular expressions of alertness in individuals in the target population to one of these three levels. Because of the severity of their disabilities, individuals with PIMD do not use spoken language (Nakken & Vlaskamp, 2007). They show only subtle signals (e.g., sounds or changes in facial expression or muscle tension) in order to express themselves. These signals can easily go unnoticed by DSPs, and they are often difficult to interpret. Not only can the meaning of a particular signal differ across individuals, it can also have different meanings in different situations for the same individual (Hogg, Reeves, Roberts, & Mudford, 2001; Petry & Maes, 2006). The determination of alertness in individuals with PIMD is further complicated by rapid and irregular shifts between being alert and n*ot being in contact with the environment* (Mudford et al.).

Another issue faced by DSPs involves the task of influencing the level of alertness in order to make decisions about the timing of activities. Because of the severity and complexity of their disabilities, individuals with PIMD exhibit only short periods of alertness (Mudford et al., 1997), thus making it difficult for DSPs to determine *when* they should start an activity. They may also be uncertain whether to continue the stimulation when the alertness of their clients decreases. They must further determine *how* they can optimally influence the alertness of an individual with PIMD. According to the literature (Munde et al., 2009a), influencing factors can be described in five categories: modifications of the direct environment, interaction and stimulation strategies, treatment activities, and staff training. The same approach can produce different results in terms of alertness, however, due to the heterogeneity of the target population. Individual differences in preference and reaction make it difficult to influence alertness in individuals with PIMD (Munde et al., 2009a).

An additional aggravating factor involved in determining and influencing alertness is the interrelatedness of all of the issues described above. From the perspective of a DSP, a change in the alertness level of an individual with PIMD can be seen only as a reaction of the individual to influencing factors. At the same time, DSPs need information about individual expressions of alertness in order to adapt the timing and content of stimulation to the abilities and needs of individual clients. The task of determining and influencing alertness levels in individuals with PIMD is consequently challenging and time-consuming.

While previous studies have shown that stimulation in general can help to influence alertness in individuals with PIMD (Munde et al., 2009a), stimulation situations also yield the potential to reveal valuable information in the process of determining and influencing alertness in individuals of the target group. During stimulation in one-on-one interaction, DSPs can engage in the careful observation of individuals with PIMD. When they notice changes in alertness levels, they can immediately adapt the situation to the preferences and needs of the individual. In addition to allowing DSPs time to notice and interpret the communicational signals of their clients, such situations allow the clients time to express themselves (Munde et al., 2009b). For example, previous research suggests that self-initiation of activities is particularly likely to generate increased and prolonged alertness and engagement (Lancioni, Singh, O'Reilly, Oliva, & Severini, 2005; Mellstrom, Saunders, Saunders, & Olswang, 2005). The actual stimulation can be individualized as well. Different kinds of stimuli (e.g., auditory, visual, tactile, vestibular, olfactory, or gustatory) can be presented separately or in combination, repeatedly or alternately. Adapting the stimulation to the individual is particularly important, given the wide variety of sensory impairments in individuals with PIMD (Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). The difficulties that these individuals experience in processing information can cause them to become quickly overwhelmed when confronted with multiple, unstructured stimuli. Because they are not always aware of their wider surroundings, stimulation aimed at the basic senses can be a first step in exposing individuals with PIMD to their environment (Hulsegge & Verheul, 1987). While experts in the study of the target population have described sensory stimulation in a structured environment as one possibility for promoting alertness levels, they attach primary importance to the consideration of individual differences in preferences and reactions (Munde et al., 2009b).

Because multisensory environments (MSEs) comply with the assumptions described above concerning determining and influencing alertness, these were chosen as the setting for the present study. With the goal of investigating the relationship between alertness and stimulation situations, the central question of this study is as follows: Which aspects of stimulation provided in an MSE are related to the occurrence of alertness in individuals with PIMD?

6.2 Method

Participants

Nine daycare centers and schools for special education situated in Flanders (the Flemish speaking part of Belgium) and the Netherlands participated in this study. The facilities were randomly selected from the overall population of care centers and schools for individuals with PIMD that provide MSE sessions to activate their clients. Within each facility, DSPs choose between one and four clients, for a total of 24 participants. The number of male and female participants was equal. The mean age was 15.66 years (*SD=12.02*), ranging from 4 to 49. All participants could be described as individuals with PIMD according to the definition of Nakken and Vlaskamp (2007). Fifteen of the participants had epilepsy; 17 had been diagnosed with visual impairments, and 4 had auditory impairments. An overview of the characteristics of the participants is provided in Table 6.1. Informed consent for participation in this study and video registration was obtained from the parents or legal representatives.

Instruments

The Alertness Observation List (AOL; Vlaskamp, Fonteine, Tadema, & Munde, 2010) was used to determine alertness levels. The observation list distinguishes four levels of alertness, each of which is associated with a color: 1) active, focused on the environment (green); 2) inactive, withdrawn (orange); 3) sleeping, drowsy (red); and 4) agitated, discontented (blue). Information recorded on four different forms is used to formulate an individual alertness profile. The overall description of each of the individual's alertness levels is supplemented with concrete examples of behavior.

Previous research shows that the AOL is a reliable instrument for determining alertness in individuals with PIMD. Both inter-observer and intra-observer agreement exceeded the 80% criterion when 78 videotapes of 23 children with PIMD were included (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2011). In addition, similar results for alertness observations with the AOL and physiological measurements suggest that the instrument fulfills the aim of determining alertness and is, thus, valid (Munde et al., submitted).

Procedure

In the present study, data were gathered in two steps. First, the AOL was completed for all participants. Second, at least three MSE sessions were videotaped for each participant. In these sessions, participants were offered stimuli during one-on-one interaction with a DSP. The DSPs were instructed to consider the individual's alertness profile when choosing stimuli. The choice as well as the presentation of the stimulus had to be based on

Table 6.1

Characteristics of the participants

	Gender	Age (years)	Epilepsy	Visual impairment	Auditory impairment
1	male	10		x	
2	male	4		x	
3	male	16		x	
4	female	23		x	
5	female	13	x	x	
6	male	11	x	x	
7	male	47	x		x
8	male	28	x		
9	male	20	x		
10	female	31	x	x	
11	male	49	x	x	
12	male	10		x	
13	male	10			x
14	female	12	x	x	
15	male	10	x	x	
16	female	13			
17	male	15		x	
18	female	6	x		
19	female	11	x	x	
20	female	13	x		
21	female	13	x	x	x
22	female	16		x	x
23	female	6	x	x	
24	female	5	x	x	

the preferences of the individual participant in order to include only stimuli that were expected to be salient for the participant and, therefore, increase the participant's alertness. Because the DSPs were free to discontinue the activity whenever they deemed it appropriate for the client, the length of sessions varied from 5 to 30 minutes.

A total of 76 MSE sessions were videotaped. Because of low quality of the recording or the absence of interaction with a DSP, 14 tapes were excluded from further analyses. From the remaining pool of 62 tapes, one session of each participant (24 sessions in total) was selected at random and scored by one of the observers using the Media Coder (Bos & Steenbeek, 2008). Five tapes (20%) were scored by a second observer, employing the general agreement formula (Mudford et al., 1997). Inter-observer agreement was 86.2%. Because of the short alert periods experienced by individuals with PIMD, the first minutes of the sessions were expected to reveal a maximum of information. For this reason, only the first five minutes after the start of the activity were included in the further analyses. Event sampling was used for the observations, and the data were prepared with one score per second for the analyses.

Videotapes were scored by three observers. All of the observers had been trained in the use of the AOL, and they were familiar with the aim of the study. Individual alertness profiles were employed as frameworks for determining alertness levels. For scoring purposes, the alertness level alert was subdivided into two levels (i.e., *actively alert* and *passively alert*), in order to separate reactions including or excluding motor action. The MSE was described according to three aspects: 1) the focus of the DSP (*on the individual with PIMD*, *on the material*, and *other*); 2) the initiation of the activity (*by the individual with PIMD* and *by the DSP*); and 3) the presented stimuli (differentiating between visual, auditory, tactile, vestibular, olfactory, and gustatory). Depending on the preferences and abilities of the individual with PIMD, stimuli could range from a bubble tube to a colored stuffed animal for the visual stimuli and from music to the voice of the DSP for auditory stimuli. Examples of tactile and vestibular stimuli are receiving a massage and swinging in a hammock, respectively.

Additional analyses of this data have been described in Munde, Vlaskamp, Maes, & Ruijssenaars (submitted).

Analysis

We began by exploring the data according to descriptive statistics, using SPSS 16. Percentages of the various alertness levels and aspects of the stimulation situation were compared to each other. We then performed multilevel modeling on these data, using MLwIN software (version 2.20). A multilevel logistic regression model was necessary in order to estimate more unbiased effects and to consider dependencies within subjects (Snijders & Bosker, 1999). In the present study, the occurrence of alertness was nested within the subjects. To test the associations between the occurrence of alertness and aspects of the Snoezelen sessions, the aspects were used as predictors, with alertness as the dependent variable. Scores were dichotomized into the categories alert and not alert, in order to compare higher percentages and thus ensure robust estimations. A number of different models were developed initially, and the final model was selected according to interpretability and complexity. Although the ordinal logistic regression model and the multinomial model did not reveal plausible results, the logistic regression model (based on the occurrence of alertness) did. The model was developed by adding the separate aspects of the stimulation situation, as well as interaction effects. Fixed and random effects were considered, and only significant effects were included in the model. The effects were estimated using MCMC (Markov Chain Monte Carlo) method. The Deviance Information Criterion (DIC) diagnostic was used (Browne, 2009) to compare different models.

6.3 Results

The alertness observations showed that most of the individuals with PIMD were passively alert during the first five minutes of the stimulation situation. The frequencies were 52.9% (passively alert), 23.4% (actively alert), 18.3% (withdrawn), and 5.3% (*asleep*), without any effect of time. In addition, the majority of the participants (75%) exhibited irregular and sometimes rapid shifts. In most cases, shifts occurred between two adjacent levels, with shifts between passively alert and actively alert or withdrawn occurring most frequently.

To examine the alertness observations in relation to the stimuli, mean alertness levels of all those participants who received a certain stimulus at one moment were compared to the mean alertness levels of all those participants who did not receive that kind of stimulus at the same moment. Making these comparisons for every second of the first five minutes of the stimulation situations reveals several patterns. Visual stimuli were associated with considerably higher alertness levels at all times (see Figure 6.1). Only slight positive effects were observed for tactile stimuli (see Figure 6.2). The effects of these stimuli were greater for individuals with auditory and/or visual impairments than they were for those without these types of impairments. While auditory stimuli did not produce any difference in alertness levels in the beginning of the stimulation situation, their impact increased with time (see Figure 6.3). Vestibular stimuli were presented only rarely, and olfactory and gustatory stimuli were not presented in any of the selected stimulation situation.

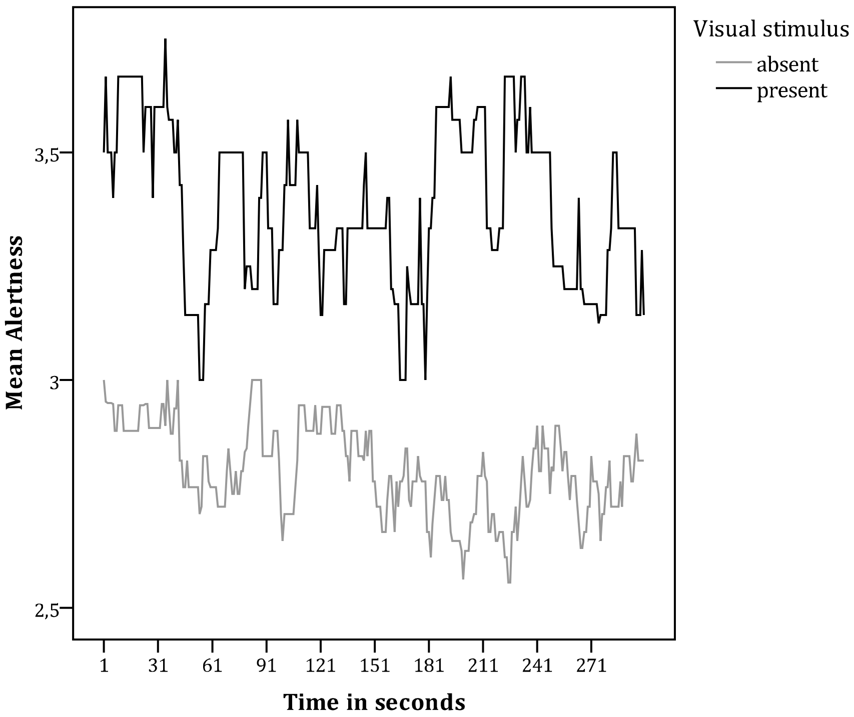

Figure 6.1 Alertness related to visual stimuli

Note. In Figures 6.1 to 6.3, the mean alertness is displayed for the entire group of participants. Alertness levels are scored as follows: *actively alert* (4), *passively alert* (3), w*ithdrawn* (2), and *asleep* (1).

The number of stimuli was also associated with different levels of alertness (see Figure 6.4). The individuals with PIMD were alert in most cases involving the presentation of one (83.0%) or two (91.9%) stimuli, including a large observed percentage of passive alertness (57.3% and 66.0%, respectively). The combination of three stimuli (which occurred during only 6.6% of the sessions) was always associated with alert behavior, with high percentages (56.7%) of active alertness. In all cases, this combination included a tactile stimulus. Situations in which no stimulus was presented tended to generate withdrawn behavior (46.9% of the time) and passive alertness (30.3% of the time).

Although the DSPs were focused on the individuals with PIMD for the major portion of the stimulation situation (91.2% of the time), only briefly turning their attention to the material (0.4%) or other matters (8.4%), the alertness levels of the individuals with PIMD showed high observed percentages of passive alertness in all three conditions (53.5%, 100%, and 44.5%, respectively). Focusing on the individual with PIMD also led to frequent active alertness (23.7%), while focusing on other things resulted in a relatively large percentage of withdrawn behavior (33.4%). This data is illustrated in Figure 6.5.

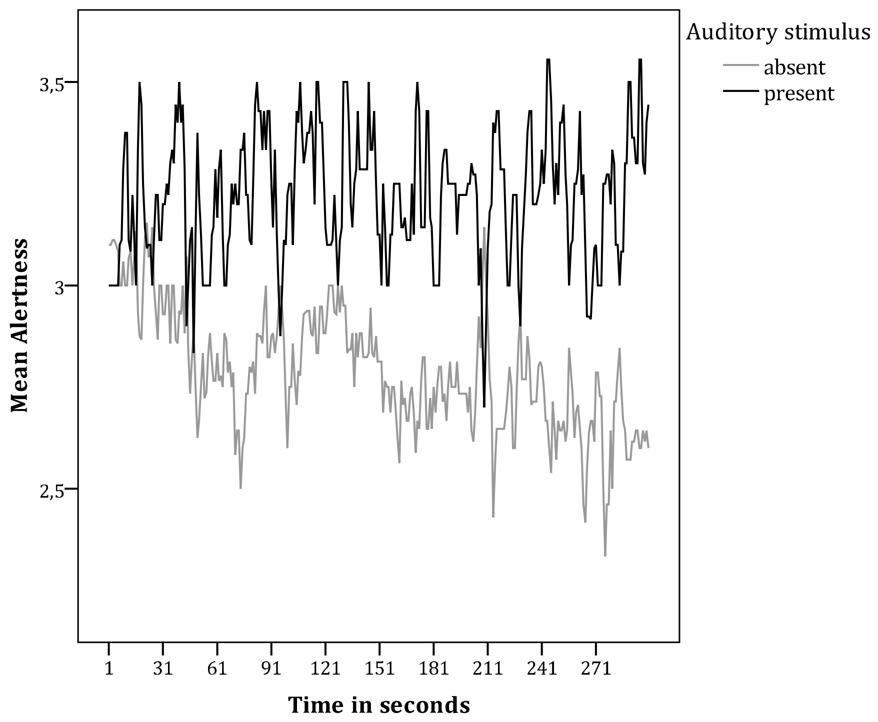

Figure 6.2 Alertness related to auditory stimuli

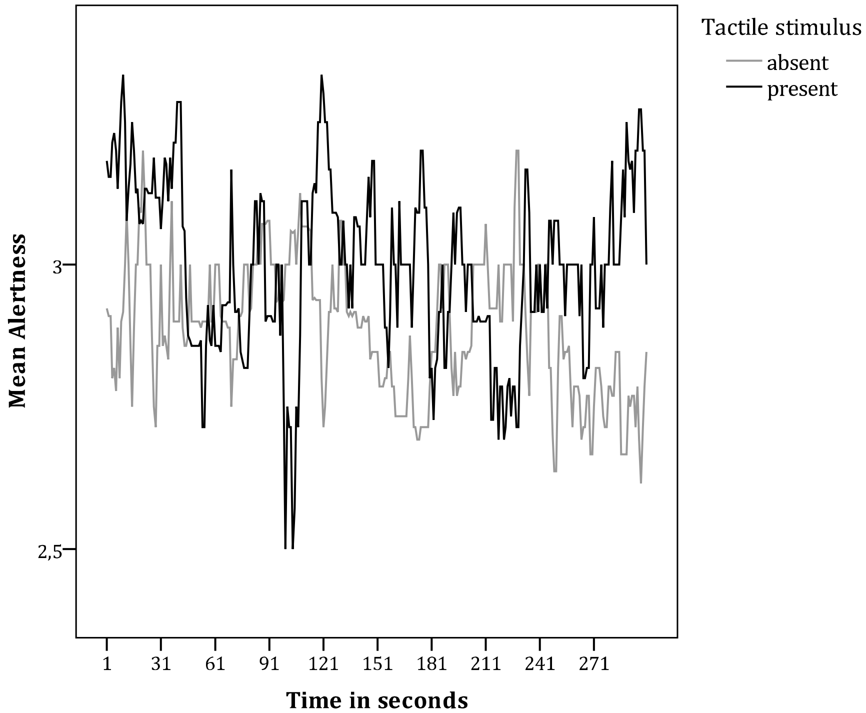

Figure 6.3 Alertness related to tactile stimuli

The examination of alertness observations according to the initiation of the activities reveals a number of differences (see Figure 6.6.). When activities were initiated by the DSP, as in the majority of cases (79.3%), observed alertness levels were generally high. Individuals with PIMD were alert for 72% of the time during the activities initiated by the DSPs, although they exhibited more passive alertness (58.6%) than active alertness (13.4%). When individuals with PIMD initiated the activity themselves, as in 20.7% of the cases, they were more frequently alert (93%) and more frequently active (61.9%). For the remaining 7% of the time in cases in which they had initiated activities themselves, individuals with PIMD were withdrawn. In cases involving DSP-initiated activities, the clients tended to be more withdrawn (21.3% of the time) or to fall asleep (6.7% of the time).

The trends described above were tested in a multilevel logistic regression model. The model reveals a number of relationships. Alertness was highly associated with visual stimuli, meaning that visual stimuli increased the likelihood of being alert. The combination of visual and auditory stimuli was also associated with significantly higher levels of alertness. No significant results were found for tactile and auditory stimuli, although there was considerable variation in the reactions of individual participants to these stimuli. This was demonstrated by large random effects (not shown in the table). When interaction effects for all three stimuli were added to the model, only the combination of visual and auditory stimuli produced significantly higher alertness levels. Combinations of tactile and visual or tactile and auditory stimuli did not result in significant changes in the occurrence

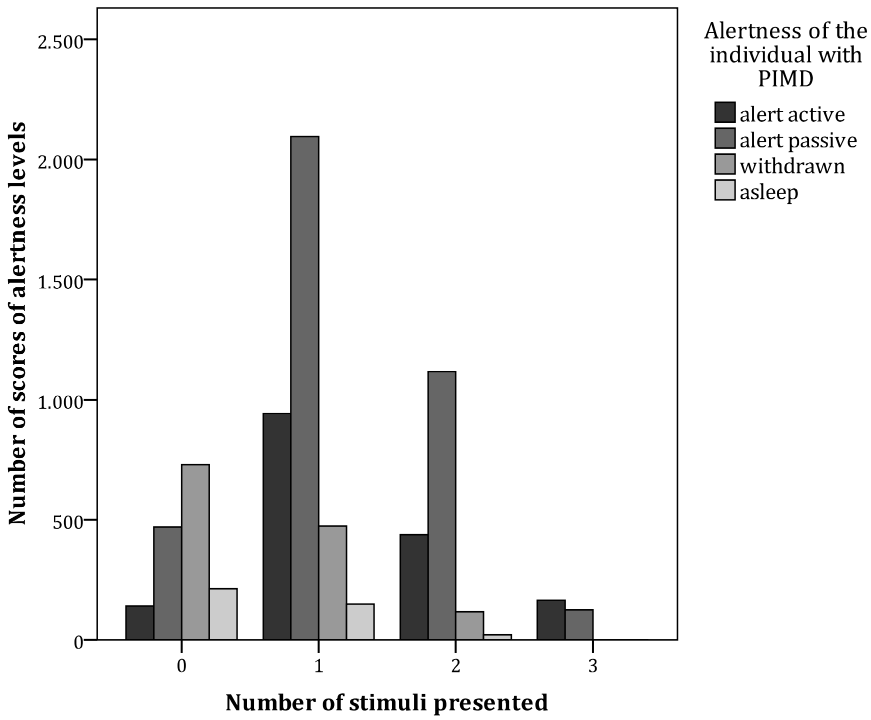

Figure 6.4 Alertness related to the number of stimuli

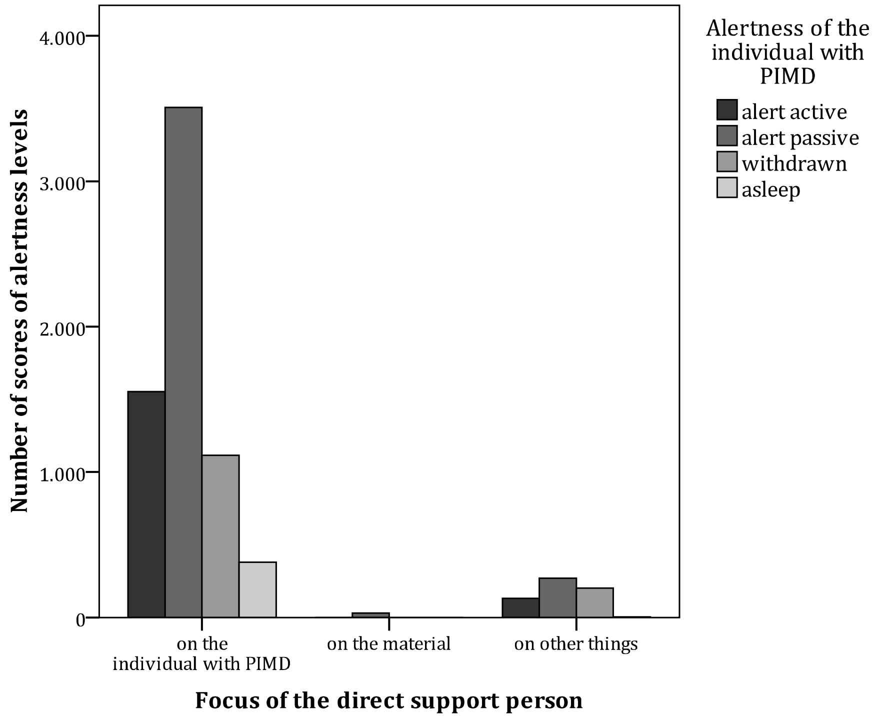

Figure 6.5 Alertness related to the focus of the direct support person

of alertness. No associations were found for the other stimuli, the focus of the DSP, or the initiation of the activity.

The multilevel logistic regression model is displayed in Table 6.2.

6.4 Conclusion and discussion

The aim of the present study was to identify aspects of stimulation situations that influence alertness in individuals with PIMD. Based on observations of 24 individuals with PIMD, the results of the present study point to some clear conclusions. First, one-on-one interaction with a DSP can generally reveal a high percentage of alert behavior in an individual with PIMD during the first five minutes of a stimulation situation. Second, activities initiated by the individual with PIMD seem to be related in more prolonged, higher alertness levels than do activities initiated by DSPs. Third, visual stimuli are associated with significantly higher alertness levels than other stimuli, also when they are combined with auditory levels. Other combinations of stimuli are not significantly more likely to be related to changes in alertness levels.

While the overall percentages of alert behavior confirm the potential of stimulation situations to promote alertness, the results concerning the various aspects of these situations are not in line with previous studies (Lindsay, Pitcaithly, Geelen, & Buntin, 1997; Vlaskamp, De Geeter, Huijsmans, & Smit, 2003). Only visual stimuli (optimally in combination with auditory stimuli) were clearly effective in increasing the occurrence of alertness. In

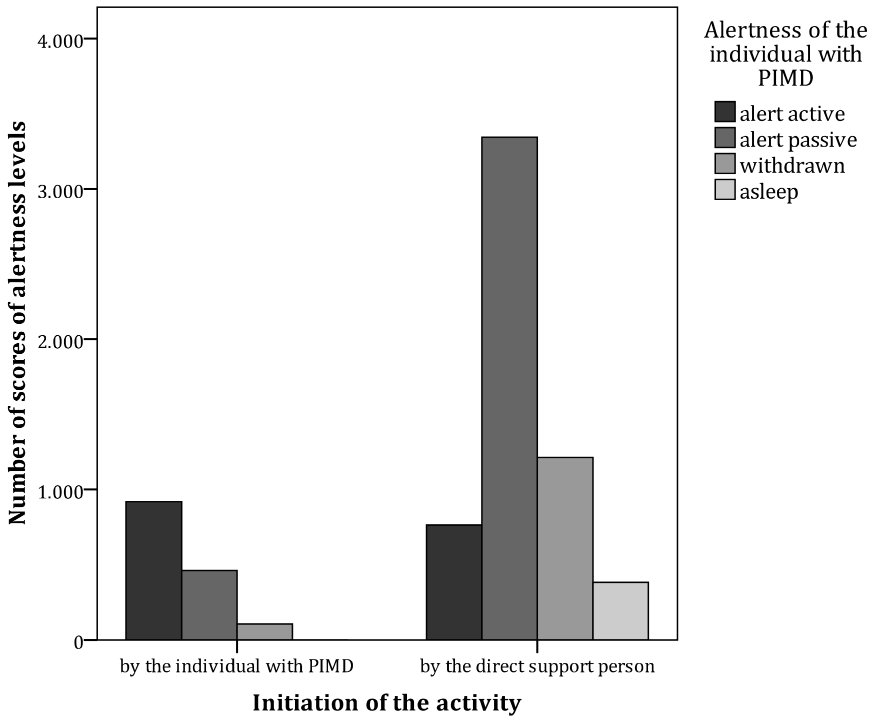

Figure 6.6 Alertness related to the initiation of the activity

Table 6.2

Association of alertness and different aspects of the multisensory environment in a multilevel logistic regression model

	Empty model	Final model
Intercept	2.974 (1.078)	3.903 (1.515)
Fixed		
Visual		1.691 (0.388)
Tactile		-0.419 (0.976)
Auditory		0.835 (0.794)
Interaction		
visual-auditory		2.351 (0.934)
DIC	3358.91	2929.78

Note. With the exception of those for deviance (DIC, Deviance Information Criterion), all cells contain the regression coefficient and the standard error. Random effects are not included in this table.

previous studies, experts have suggested that visual stimulation in an MSE can reveal higher percentages of alert behavior, especially in individuals with visual impairments (Munde et al., 2009b), although no studies to date have provided evidence to support this suggestion. Even though tactile stimuli were presented most frequently in the present study (in contrast to the low frequencies reported in previous studies), the present data do not confirm previous findings that these stimuli produce the largest effects (Vlaskamp et al.). An explanation could involve the fact that tactile and auditory stimuli are often part of the communication. For example, when DSPs talk to their clients while introducing activities, or when they touch clients in order to help them explore objects, clients with PIMD may not clearly notice these functional stimuli. Reactions in terms of alertness may therefore be less clear than those exhibited in response to explicitly presented visual or other stimuli. At the same time, the interaction effect of visual and auditory stimuli may indicate the importance of supporting communication during activities. Furthermore, previous studies were conducted in environments including several simultaneous stimuli (Vlaskamp et al.). Comparing the results, we may hypothesize that visual stimuli can be effective in single-stimulus situations, while individuals with PIMD could be better at distinguishing tactile stimuli from a larger number of stimuli.

Another striking finding in this study involves the absence of a time effect. Although previous studies (Guess et al., 1999; Mudford et al., 1997) have shown that individuals with PIMD can be alert for only short periods of time, the present data suggest that DSPs are able to keep their clients alert for at least five minutes. Even though individuals with PIMD showed changes between alertness levels throughout the entire time of the observations, the effect of the stimuli did not differ over time. The effects of the stimuli thus dominated the effect of time.

Descriptive results for the initiation of activities confirm previous suggestions that the individualization and self-initiation of activities may also affect levels of alertness (Lancioni, O'Reilly, & Martini, 1999; Lancioni, Cuvo, & O'Reilly, 2002; Lancioni et al., 2005; Munde et al., 2009b). While it is not surprising that participants showed high levels of alertness when they were allowed the opportunity and time to determine the situation as much as possible, additional aspects of the stimulation situation may have led to passive alertness or even to withdrawn behavior in such situations.

This study has several limitations that should be noted when interpreting the results. Because of the small sample size, not all conditions were present in equal amounts. The frequencies of some combinations were too low to allow further analysis. It was therefore not possible to include all aspects of a stimulation situation in the multilevel model. However, our study was meant as an initial exploration of the data, and future experimental studies that control for these aspects could complement the present results. In addition, the choice of a stimulus and the way of interacting was different for each participant. Because individualized stimulation is especially important for individuals in the target group, DSPs were instructed to adapt their behavior to the needs and abilities of the individual with PIMD. Consequently, stimuli were only comparable regarding their salience for the individual participant. While the design of our study did not allow for a control group, comparing similar stimuli or ways of interaction to individualized situations may yield supplementary information. The small sample size in combination with the high variation between individuals also prevented us from deriving robust estimates of the random effects. Future studies that include differentiation between subgroups (e.g., individuals with and without auditory impairments) may reveal a more distinct picture. Furthermore, sequential aspects of the situations were not taken into account. For example, the results produced by repetition may differ from those produced by presenting a stimulus only once. The exclusion of the sequential aspect from the present model may have distorted the actual effects. The present analysis should therefore be seen as an initial exploration of the data. In future studies, the limitations will be approached by searching for a better design of the model and conducting sequential analyses.

Despite the limitations of this study, the results reveal valuable information for education and support of individuals with PIMD. One recommendation is to advise DSPs to take the time to engage in short individual interactions in stimulation situations. Such situations can be helpful in observing and determining the alertness levels of individuals with PIMD. In addition, the clients need the DSPs in order to become and remain alert. Because stimulation always has the potential to bring an individual with

PIMD back to a higher level of alertness, DSPs should not discontinue activities in response to irregular changes between alertness levels. At the same time, individuals with PIMD should be given the time to determine the situation themselves as much as possible, both directly and indirectly. Stimuli should be presented explicitly, while adapting the choice of stimuli to the needs and preferences of individual clients. As one of the most frequently applied activities in education and support of individuals with PIMD (Vlaskamp & Nakken, 2008), MSEs make the realization of the presented procedure quite feasible in clinical practice. The use of stimulation situations as a diagnostic method for determining alertness in individuals with PIMD can be further developed in the future.

7

Catch the wave! Time-window sequential analysis of alertness stimulation in individuals with profound intellectual and multiple disabilities*

* This chapter has been submitted as: Munde, V.S., Vlaskamp, C., Maes, B., & Ruijssenaars, A.J.J.M. Catch the wave! Time-window sequential analysis of alertness stimulation in individuals with profound intellectual and multiple disabilities. *Child: Care, Health and Development*.

Abstract

While optimally activities are provided at those moments when the individual with profound intellectual and multiple disabilities (PIMD) is focused on the environment or alert, detailed information about the impact that the design and timing of the activity has on alertness is lacking. Therefore, the aim of the present study is to shed light on the sequential relationship between different stimuli and alertness levels in individuals with PIMD.

Video observations were conducted for 24 participants during one-on-one interactions with a direct support person (DSP) in multisensory environments. Time-window sequential analyses were conducted for the 120 seconds following four different stimuli.

For the different stimuli, different patterns in terms of alertness became apparent. Following visual stimuli, the alertness levels of the individuals with PIMD changed in waves of about 20 seconds from active alert to passive alert. While auditory and tactile stimuli led to alert reactions shortly after the stimulation, alertness levels decreased between seconds 20 and 120. Reactions to vestibular stimuli were only visible after 60 seconds; these were active alert or withdrawn.

The results of the present study show that individuals with PIMD show their reactions to stimuli only slightly, so that "waves" might reflect the optimal alertness pattern for learning and development. Consequently, it is especially important that DSPs follow and stimulate these individual alertness waves in the activities they provide to their clients.

7.1 Introduction

While previous studies have revealed that the optimal moments for activities are those when the individual with profound intellectual and multiple disabilities (PIMD) is focused on the environment or alert (Guess, Roberts, & Guy, 1999; Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009a), detecting those moments in individuals of the target group is difficult for researchers and direct support persons (DSPs). Individuals with PIMD experience a combination of profound intellectual, motor, and sensory disabilities (Nakken & Vlaskamp, 2007). Because of the severity and complexity of the disabilities, individuals of the target group only have a limited repertoire of body language signals for expressing themselves. In addition, alertness expressions are often subtle signals that can easily go unnoticed (Guess et al.; Mudford, Hogg, & Roberts, 1997). To complicate matters further, the same alertness expression can have a different meaning for different individuals; and even the same expression can have a different meaning for the same person in different situations (Hogg, Reeves, Roberts, & Mudford, 2001; Petry & Maes, 2006).

Furthermore, DSPs are left wondering how to promote those very alertness levels that are optimal for providing an activity. Previous studies have shown that stimulation in general can lead to higher alertness levels in individuals with PIMD (Arthur, 2004; Ault, Guy, Guess, Bashinski, & Roberts, 1995; Belfiore, Browder, & Mace, 1993; Guess et al., 1999; Lancioni, O'Reilly, & Mantini, 1999). However, the same stimulation can lead to broadly varying reactions depending on the individual (Munde et al., 2009a; Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009b). On top of that, the very way of presenting the activity can have an impact as well (Munde et al., 2009a). Integrating the use of assistive communication devices in order to choose an activity can, for example, result in other reactions in terms of alertness, as compared to a situation where the DSP chooses the activity unaided. Consequently, activities have to be adapted to the individual's preferences and needs.

In addition to the problem of the design of the stimulation, questions about its timing also remain unanswered. DSPs are not sure whether being alert is a strict precondition for providing stimulation. Starting an activity when the individual with PIMD is withdrawn may also be a possibility in order to make that individual alert. Moreover, alert periods of individuals with PIMD last only for a short time (Mudford et al., 1997). When an individual withdraws from the environment after being alert, DSPs may interpret this behavior as a loss of interest on the part of the person with PIMD. This makes them inclined to stop the activity. However, quick and irregular changes between being alert and being withdrawn from the environment are common (Guess, Roberts, Siegel-Causey, & Rues, 1995; Mudford et al.), and the individual with PIMD might be alert again quite quickly after withdrawing attention from the activity. Determining the adequate duration of an activity is therefore another issue for DSPs.

While only general information about the design of stimulation has been available up until now (e.g., Lindsay, Pitcaithly, Geelen, & Buntin, 1997; Perry, 2003; Sandler & Voogt, 2001) and since previous studies (Arthur, 2004; Guess et al., 1995; Guess et al., 1999) have focused only on the overall effect of stimulation, a detailed comparison of the timing of reactions to different stimuli in terms of alertness should be able to reveal important additional information. Detailed analyses of different stimuli and alertness levels in individuals with PIMD could help in determining the optimal combination of *how* and *when* to provide stimulation. In addition, detailed information about the timing of changes in alertness levels could provide an answer to DSPs' questions about when to start an activity and its duration.

The aim of the present study is to shed light on the sequential relationship between different stimuli and alertness levels in individuals with PIMD. For these analyses, we needed data from a situation where the stimulation could be controlled and alertness levels could be observed in detail. Because multisensory environments (MSEs) yield such possibilities, these were chosen as the experimental condition. Different kinds of stimuli (e.g., auditory, visual, tactile, vestibular, olfactory, or gustatory) are able to be presented separately or in combination, repeatedly or alternately. Distractions by other individuals or stimuli beyond the actual stimulating situation can be excluded. At the same time, accurate registration of the individuals' behavior and reactions is possible. This then leads to the central question of the present study: What is the sequential relationship between different alertness levels in individuals with PIMD and the different kinds of stimuli presented in an MSE?

7.2 Method

Participants

Nine daycare centers and schools for special education situated in Flanders (the Flemish-speaking part of Belgium) and the Netherlands participated in this study. The facilities were randomly selected from the overall population of care centers and schools for individuals with PIMD that use MSE sessions for sensory stimulation. Between one and four clients within each facility participated in the study, for a total of 24 participants. The number of male and female participants was equal. The mean age was 15.66 years (*SD=12.02*), ranging from 4 to 49. All participants could be described as individuals with PIMD according to the definition of Nakken and Vlaskamp (2007). Fifteen of the participants had epilepsy, 17 had been diagnosed with visual impairments, and 4 had auditory impairments. An overview of the characteristics of the participants is provided in Table 6.1. Informed consent for participation in this study, including video registration, was obtained from their parents or legal representatives.

Instruments

The Alertness Observation List (AOL; Vlaskamp, Fonteine, Tadema, & Munde, 2010) was used to determine alertness levels. The observation list distinguishes four levels of alertness, each of which is associated with a color: 1) active, focused on the environment (green); 2) inactive, withdrawn (orange); 3) sleeping, drowsy (red); and 4) agitated, discontented (blue). Information recorded on four different forms was used to formulate an individual alertness profile. The overall description of each of the individual's alertness levels was supplemented with concrete examples of behavior.

Previous research has shown that the AOL is a reliable instrument for determining alertness in individuals with PIMD. Both inter-observer and intra-observer agreement exceeded the 80% criterion when 78 videotapes of 23 children with PIMD were scored (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2011).

Procedure

In the present study, data were gathered in two steps. First, the AOL was completed for all participants. Second, at least three MSE sessions were videotaped for each participant. In these sessions, participants were offered stimuli during one-on-one interaction with a DSP. The DSPs were instructed to consider the individual's alertness profile when choosing stimuli. The choice as well as the presentation of the stimulus had to be based on the preferences of the individual participant in order to include only stimuli that were expected to be salient for the participant and, therefore, increase the participant's alertness. Because the DSPs were free to discontinue the activity whenever they deemed it appropriate for the client, the length of sessions varied from 5 to 30 minutes.

A total of 76 MSE sessions were videotaped. Due to low quality of the recording or the absence of interaction with a DSP, 14 tapes were excluded from any further analyses. From the remaining pool of 62 tapes, one session for each participant (24 sessions in total) was selected at random and scored by one of the observers. Employing event sampling, the Media Coder (Bos & Steenbeek, 2008) was the computer tool that facilitated the registration of the observations. Five tapes (20%) were scored by a second observer, employing the general agreement formula (Mudford et al., 1997). Interobserver agreement was 86.2%. Based on the length of the shortest session (five minutes) and to make all sessions comparable to each other despite the varying lengths, only the first five minutes after the start of the activity were included in the subsequent analyses.

The videotapes were scored by three observers. All of these observers had been trained in the use of the AOL, and they were familiar with the aim of the study. Individual alertness profiles were employed as frameworks for determining alertness levels. For scoring purposes, the alertness level alert was subdivided into two levels (i.e., active alert and passive alert), in order to separate reactions including or excluding motor action. Based on previous analysis about the stimulation most frequently presented to individuals of the target group (Guess et al., 1999; Vlaskamp & Cuppen-Fonteine, 2007; Vlaskamp, Hiemstra, Wiersma, & Zijlstra, 2007), four kinds of stimuli were chosen to be scored in the MSEs: visual, auditory, tactile, and vestibular. Depending on the preferences and abilities of the individual with PIMD, these could range from a bubble tube to a colored stuffed animal for the visual stimuli and from music to the voice of the DSP for auditory stimuli. Examples of tactile and vestibular stimuli are receiving a massage and swinging in a hammock, respectively.

Additional analyses of this data have been described in Munde, Vlaskamp, Post, Ruijssenaars, Maes, & Nakken (accepted).

Analysis

The data were analyzed employing time-window sequential analysis (Yoder & Tapp, 2004). Sequential analysis in general reveals information about sequences in the behavior observed. To investigate whether a given behavior causes a target behavior to occur more or less often than expected by chance, expected transitional probabilities are compared to observed transitional probabilities. In this way, the transitional probability is the chance that the target behavior will occur relative to the given behavior. The expected transitional probabilities are calculated based on the total number of possible event sequences and on the chance that one specific behavior will occur in this sequence. For time-window sequential analysis, a time window is defined in relation to the given behavior. The frequency of the target behavior only in this time window is then included in the analysis. In a subsequent step, Yule's Q (Bakeman & Gottman, 1997) shows whether the observed probabilities differ significantly from the expected ones. The value of Yule's Q can range from -1 to 1, whereby probabilities with a negative Yule's Q occur less often than expected by chance and probabilities with a positive Yule's Q occur more often. A Yule's Q of zero indicates no significant difference. Yule's Q can only be calculated when the marginal sums of the frequency table of the two behaviors are larger than 5 (Bakeman & Gottman).

In the present study, the different alertness levels were treated as target behaviors and the four different kinds of stimuli as the given behaviors. Time windows of 10 seconds were defined in relation to each stimulus at a time, ranging from 0 to 10 seconds to 110 to 120 seconds. For each time window, the transitional probabilities for the different alertness levels were calculated. In addition, the values of Yule's Q were able to indicate whether the observed probabilities differed significantly from the observed ones. Because our aim was to determine overall tendencies and because marginal sums were low in the individual data, Yule's Qs were calculated for pooled data.

7.3 Results

Visual stimuli (see Table 7.2 and Figure 7.1)

Following visual stimuli, participants showed low percentages of withdrawn or asleep behavior. These were always smaller than expected. While most participants were observed in the active alert alertness level in the first 30 seconds after the stimulus, passive alert behavior also occurred more often than expected during the first 10 seconds. In the next 20 seconds (from seconds 30 to 50), participants were passively alert most of the time. After significant percentages for both active alert and passive alert behavior from seconds 50 to 60, the highest percentages of the active alert alertness level were observed again. Another similar change was observed for seconds 80 to 120, with significantly more passive alert behavior for the first 10 seconds and significantly more active alert behavior for the last 30 seconds.

Auditory stimuli (see Table 7.3 and Figure 7.2)

After the presentation of auditory stimuli, participants mostly showed passive alert behavior. Significant percentages of active alert and withdrawn behavior were also observed in the first 20 seconds. While a substantial portion of the participants began to withdraw thereafter, there were others who even fell asleep after 30 seconds. Both behaviors were observed significantly more often than expected up until 120 seconds had passed. Seconds 90 to 100 form an exception to this; in this time window, no alertness level occurred more often than expected. Furthermore, large percentages of active alert behavior were found in seconds 60 to 90.

Tactile stimuli (see Table 7.4 and Figure 7.3)

The observed sequential relationship between the different alertness levels and tactile stimuli was similar to the one featuring auditory stimuli. In the first 20 seconds following the stimulation, participants showed significantly more active alert and passive alert behavior than expected. In seconds 20 to 60, most of the observed behavior was passive alert. Thereafter, high percentages of withdrawn behavior occurred in the time windows from 40 to 60 seconds as well. Starting at 60 seconds, participants were either actively alert or withdrawn or asleep. While in the following 30 seconds through to 110 seconds after the tactile stimulus, withdrawn behavior was the only behavior that we observed significantly more often than expected, most of the participants were passively alert during seconds 100 to 120.

Vestibular stimuli (see Table 7.5 and Figure 7.4)

In the time windows following vestibular stimuli, participants were mostly passively alert during the first 30 seconds after the stimulation. Passive alert behavior as well as withdrawn behavior occurred significantly more

Table 7.2

Transitional probabilities and Yule's Q of the different alertness levels following the visual stimuli

	Time window (in seconds)											
	0-10	**10-20**	**20-30**	**30-40**	**40-50**	**50-60**	**60-70**	**70-80**	**80-90**	**90-100**	**100-110**	**110-120**
Target												
Active alert	**0.52 (0.70)**	**0.55 (0.72)**	**0.18 (0.05)**	0.15 (-0.05)	0.15 (-0.09)	**0.24 (0.21)**	**0.29 (0.35)**	**0.18 (0.05)**	0.10 (-0.29)	**0.20 (0.11)**	**0.39 (0.53)**	**0.30 (0.37)**
Passive alert	**0.27 (0.21)**	0.16 (-0.12)	0.15 (-0.14)	**0.21 (0.05)**	**0.35 (0.38)**	**0.22 (0.07)**	0.01 (-0.93)	0.06 (-0.56)	**0.26 (0.20)**	0.19 (-0.01)	0.05 (-0.62)	0.10 (-0.37)
With-drawn	0.00	0.00	0.05 (-0.04)	0.00	0.00	0.00	0.00	0.00	0.03 (-0.38)	0.00	0.00	0.00
Asleep	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00

Note. In Table 7.2 to 7.5, all transitional probabilities that have a Yule's Q > 0, thus higher than expected by chance, are marked in bold letters.

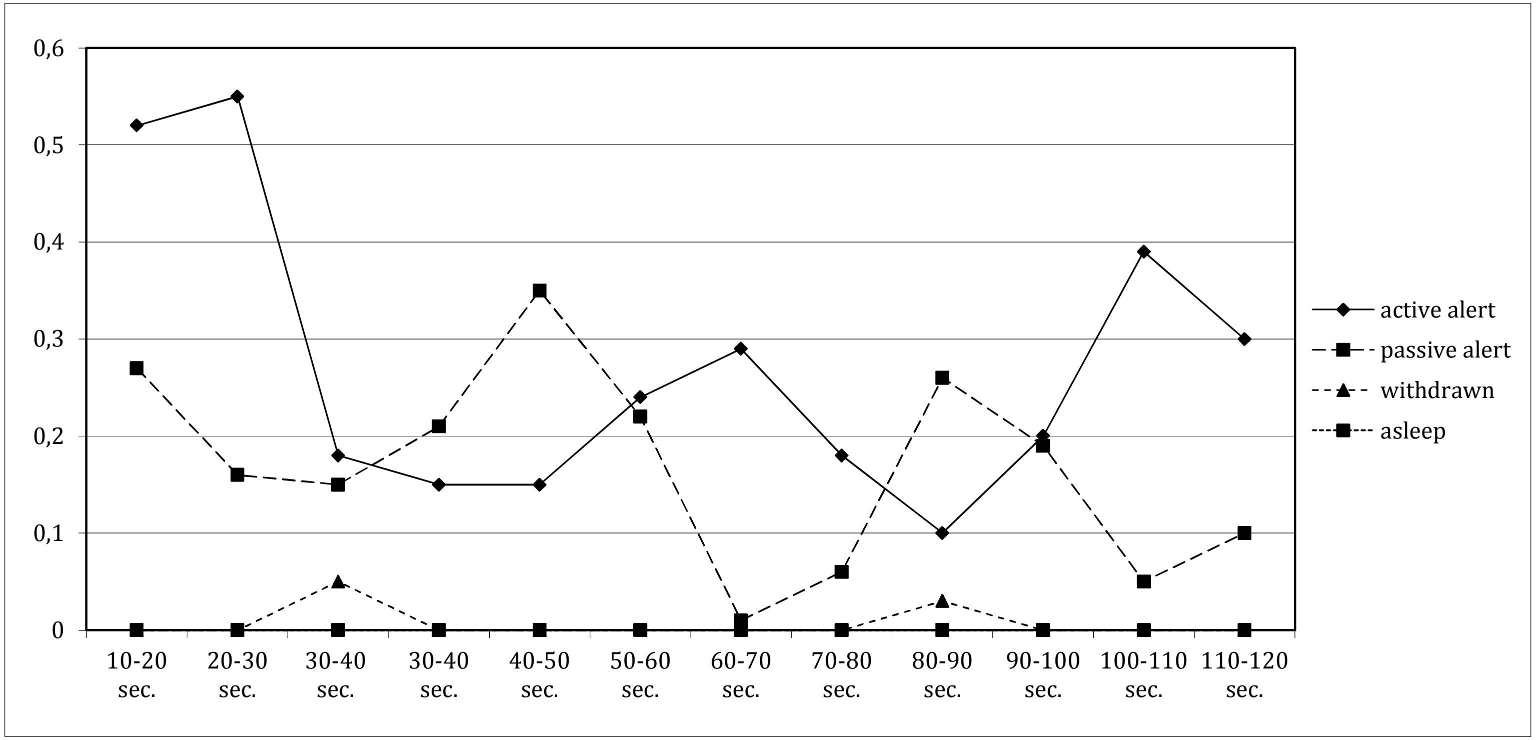

Figure 7.1 Plotted transitional probabilities of the different alertness levels following the visual stimuli

Table 7.3

Transitional probabilities and Yule's Q of the different alertness levels following the auditory stimuli

	Time window (in seconds)											
	0-10	**10-20**	**20-30**	**30-40**	**40-50**	**50-60**	**60-70**	**70-80**	**80-90**	**90-100**	**100-110**	**110-120**
Target												
Active alert	**0.19 (0.09)**	**0.19 (0.08)**	0.11 (-0.27)	0.12 (-0.22)	0.13 (-0.15)	0.15 (-0.09)	**0.24 (0.22)**	**0.21 (0.16)**	**0.17 (0.01)**	0.11 (-0.23)	0.13 (-0.13)	0.15 (-0.06)
Passive alert	**0.51 (0.64)**	**0.45 (0.57)**	**0.20 (0.03)**	**0.23 (0.11)**	**0.24 (0.15)**	0.19 (-0.02)	0.12 (-0.30)	0.11 (-0.35)	0.13 (-0.24)	0.15 (-0.15)	0.18 (-0.04)	0.15 (-0.18)
With-drawn	**0.07 (0.06)**	0.05 (-0.04)	**0.06 (0.03)**	**0.09 (0.22)**	**0.08 (0.15)**	**0.14 (0.48)**	**0.15 (0.50)**	0.03 (-0.42)	0.01 (-0.80)	0.02 (-0.55)	**0.06 (0.03)**	**0.10 (0.31)**
Asleep	0.00	0.00	0.00	**0.02 (0.33)**	**0.05 (0.76)**	**0.03 (0.54)**	**0.01 (0.14)**	**0.04 (0.66)**	**0.04 (0.63)**	0.00	0.00	0.00

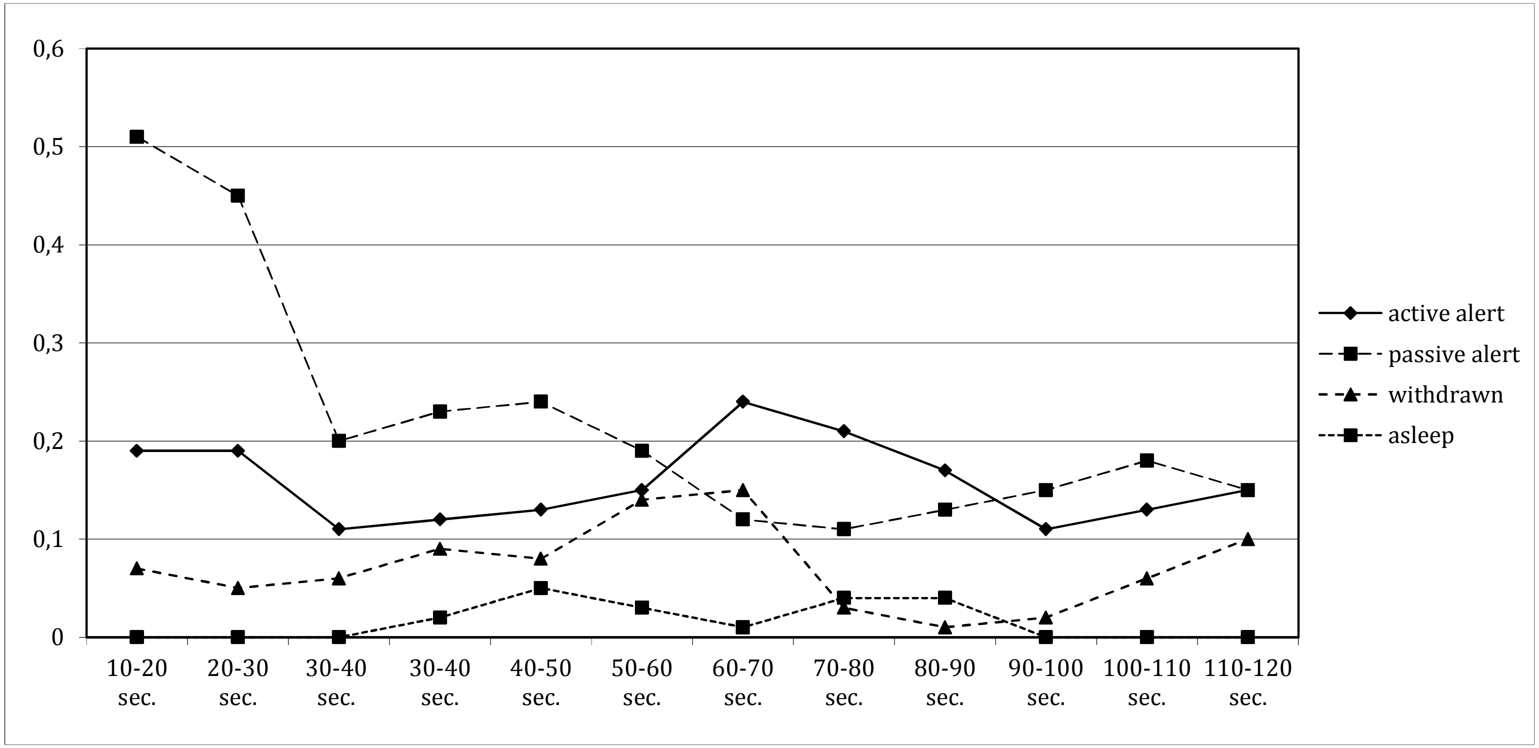

Figure 7.2 Plotted transitional probabilities of the different alertness levels following the auditory stimuli

Table 7.4

Transitional probabilities and Yule's Q of the different alertness levels following the tactile stimuli

	Time window (in seconds)											
	0-10	**10-20**	**20-30**	**30-40**	**40-50**	**50-60**	**60-70**	**70-80**	**80-90**	**90-100**	**100-110**	**110-120**
Target												
Active alert	**0.23 (0.21)**	**0.23 (0.20)**	0.06 (-0.53)	0.07 (-0.49)	0.07 (-0.45)	0.12 (-0.20)	**0.22 (0.16)**	**0.17 (0.01)**	0.12 (-0.22)	0.08 (-0.39)	0.04 (-0.67)	0.05 (-0.60)
Passive alert	**0.36 (0.42)**	**0.30 (0.29)**	**0.21 (0.05)**	**0.26 (0.18)**	**0.28 (0.25)**	**0.26 (0.19)**	0.12 (-0.27)	0.17 (-0.07)	0.18 (-0.05)	0.15 (-0.18)	**0.25 (0.17)**	**0.26 (0.20)**
With-drawn	**0.17 (0.57)**	**0.13 (0.43)**	0.04 (-0.21)	0.05 (-0.12)	**0.11 (0.35)**	**0.12 (0.38)**	**0.08 (0.15)**	**0.08 (0.20)**	**0.12 (0.41)**	**0.12 (0.41)**	**0.10 (0.28)**	0.05 (-0.12)
Asleep	0.00	0.00	0.00	**0.01 (0.17)**	0.00	0.00	**0.04 (0.63)**	**0.04 (0.63)**	0.00	0.00	0.00	0.00

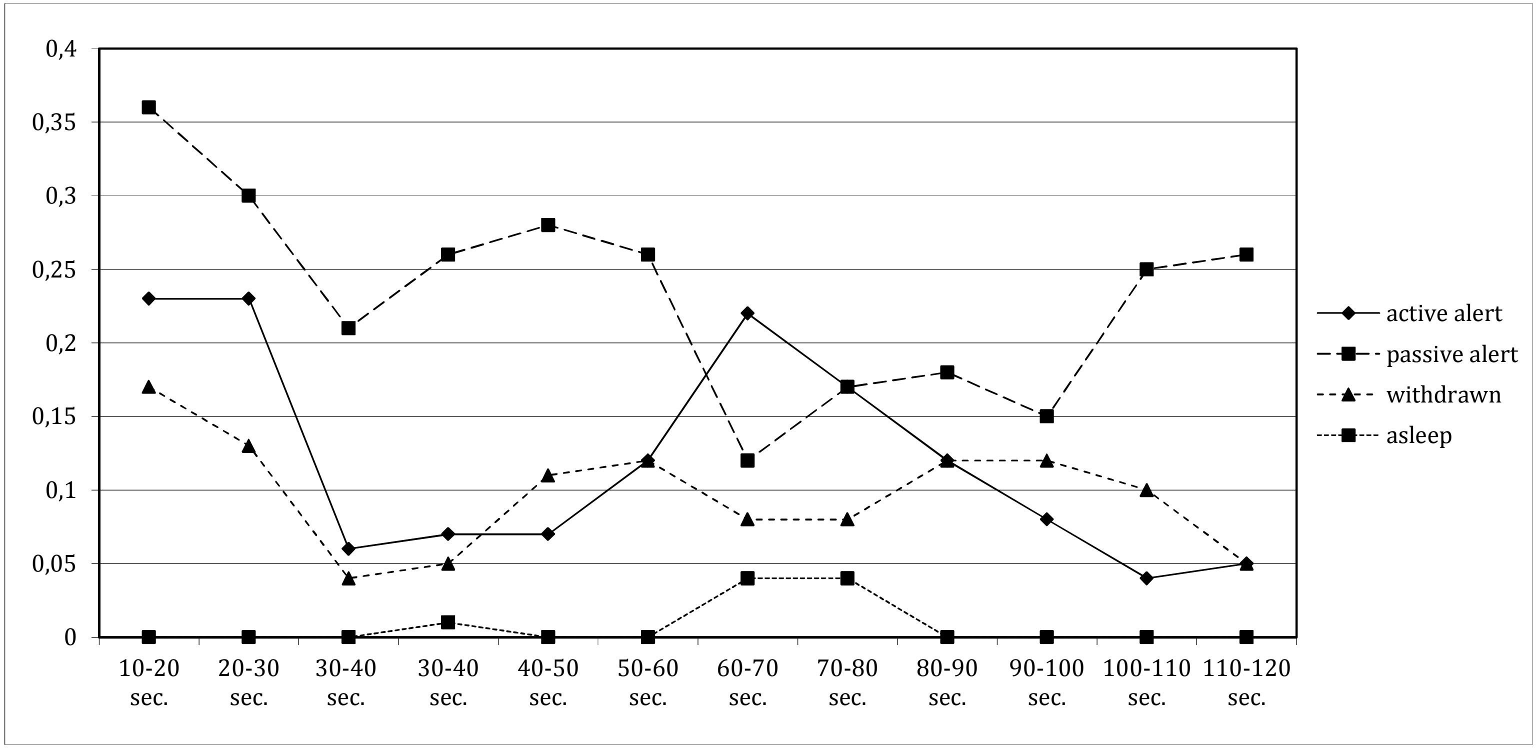

Figure 7.3 Plotted transitional probabilities of the different alertness levels following the tactile stimuli

Table 7.5

Transitional probabilities and Yule's Q of the different alertness levels following the vestibular stimuli

	Time window (in seconds)											
	0-10	**10-20**	**20-30**	**30-40**	**40-50**	**50-60**	**60-70**	**70-80**	**80-90**	**90-100**	**100-110**	**110-120**
Target												
Active alert	0.16 (-0.04)	**0.18 (0.05)**	0.07 (-0.43)	0.04 (-0.65)	0.16 (-0.03)	**0.30 (0.37)**	**0.25 (0.24)**	0.02 (-0.83)	0.13 (-0.16)	**0.20 (0.11)**	**0.19 (0.08)**	0.15 (-0.09)
Passive alert	**0.37 (0.43)**	**0.21 (0.06)**	**0.23 (0.11)**	**0.27 (0.22)**	0.18 (-0.06)	0.06 (-0.56)	0.02 (-0.86)	0.13 (-0.25)	0.17 (-0.07)	**0.20 (0.02)**	**0.29 (0.26)**	**0.32 (0.32)**
With-drawn	**0.09 (0.24)**	**0.10 (0.28)**	**0.07 (0.13)**	0.03 (-0.29)	0.03 (-0.39)	0.04 (-0.25)	**0.10 (0.29)**	0.05 (-0.13)	0.00	**0.15 (0.50)**	**0.11 (0.33)**	0.05 (-0.13)
Asleep	0.00	0.00	0.00	0.00	0.00	**0.05 (0.68)**	**0.10 (0.86)**	**0.06 (0.77)**	0.00	0.00	0.00	0.00

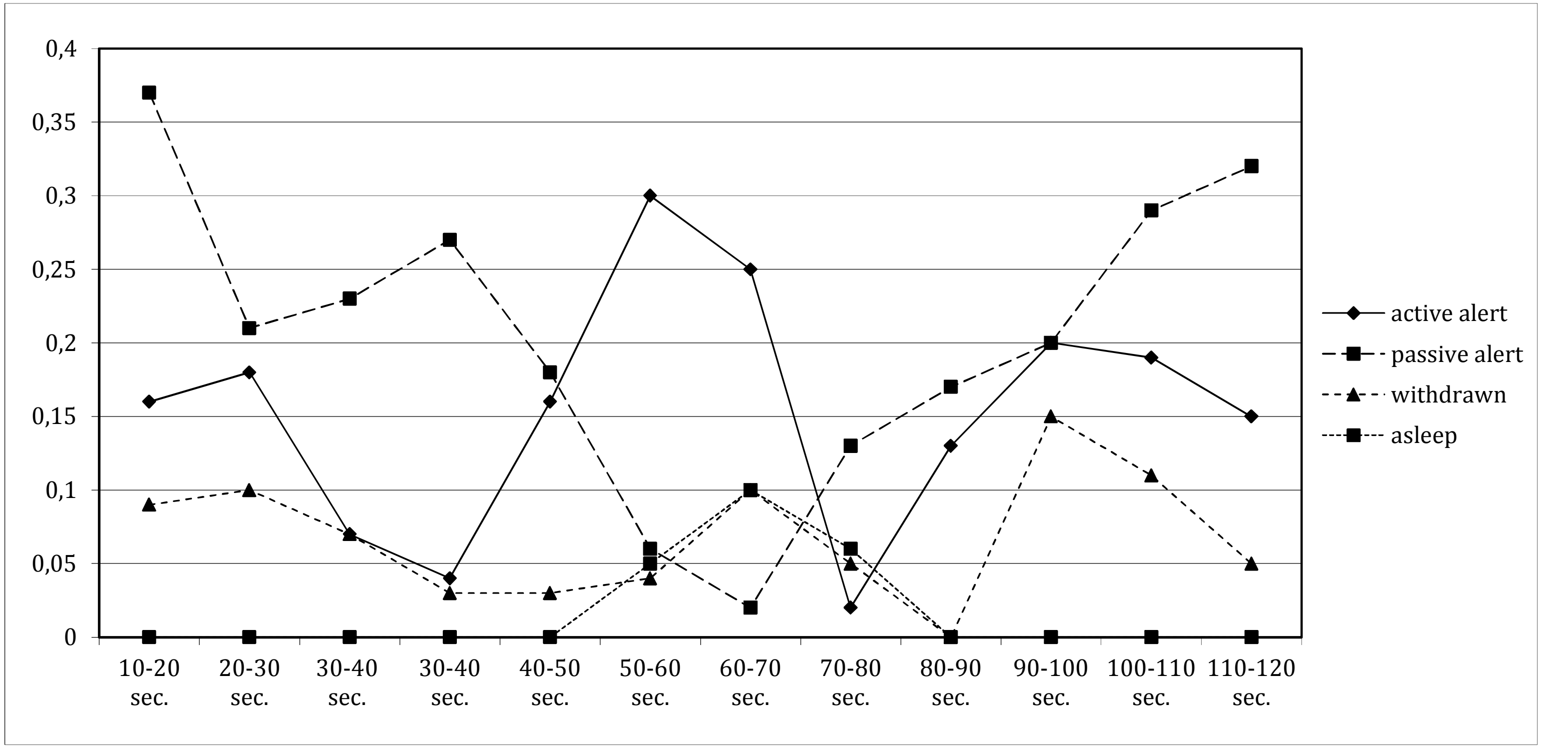

Figure 7.4 Plotted transitional probabilities of the different alertness levels following the vestibular stimuli

often than expected. Participants also showed significantly more active alert behavior in seconds 10 to 20 and passive alert behavior in seconds 30 to 40. In the 50 to 80 seconds following vestibular stimuli, most of the participants were either actively alert or asleep. After 90 seconds, significant occurrence of active alert, passive alert, and withdrawn behavior was observed. For the time windows at 40 to 50 seconds and 80 to 90 seconds, no alertness level was observed significantly more often than expected.

7.4 Conclusion and discussion

To elaborate on our knowledge about the optimal combination of design and timing of activities for individuals with PIMD, the aim of the present study was to gather detailed information about the sequential relationship between different alertness levels and different stimuli as presented in an MSE. Looking at the time windows for each stimulus, different patterns became apparent. Following visual stimuli, alertness levels changed between active alert and passive alert in waves. Immediately following the stimulation, participants were mostly actively alert with two additional peaks at 50 to 80 and 90 to 120 seconds. In between, percentages for passive alert behavior were significantly higher than expected. These results confirm an approximate duration of alertness levels of 20 seconds, which has been found in previous studies as well (Guess et al., 1993; Mudford et al., 1997). In addition, the waves might reflect an optimal alertness pattern for learning and development, because active engagement, on the one hand, and passive alert behavior, on the other, have been described as the most important alertness levels for effective learning (Guess et al., 1999). The sequential patterns following auditory and tactile stimuli showed a great many similarities. While most participants were either actively or passively alert in the first 20 seconds after the stimulation, only a small percentage showed withdrawn behavior and only during the first 10 seconds after the stimulation. Alertness then gradually decreased from seconds 20 to 120. While participants remained passively alert during seconds 20 to 50/60, they began and kept on withdrawing their attention, or even fell asleep, shortly thereafter. Those findings are again in line with previous studies that found that individuals of the target group can only remain alert for short moments (Guess et al., 1995; Mudford et al.). However, the period of the active alert alertness level in seconds 60 to 80/90 should be highlighted. It is quite possible that individuals with PIMD need time to process a stimulus displayed during withdrawn or passive alert behavior before being able to be actively alert again. On the other hand, those who dislike the stimulus may also only show their reaction after about 60 seconds. Looking at the different patterns as a reaction to vestibular stimuli, the different nature of the stimuli might be an explanation. While withdrawn, active alert, and passive alert alertness levels were observed immediately after the stimulation, reactions after approximately one minute differed in two directions. One group of participants showed active alert behavior, whereas the other withdrew their attention from the stimulation. Because processing the vestibular stimulus might have taken the participants longer than it did the auditory or visual ones, the resulting reaction might not have been visible before the point one minute after the stimulation (Barnett-Cowan & Harris, 2009). Furthermore, the less explicit reaction at seconds 90/100 to 120 that was visible for all stimuli as another wave of alert behavior might be explained by the meaning of the different stimuli for the person with PIMD. While a stimulus can be salient and, therefore, meaningful for a person at the first moment it is presented, salience may decrease over the course of time (Mitchell & Le Pelley, 2010).

Comparing the reactions with each other in terms of alertness to the different stimuli, we may conclude that visual stimuli are especially effective in promoting high alertness levels in individuals of the target group. It is striking that visual stimuli were never followed by asleep alertness levels; percentages of withdrawn behavior only occurred during two time windows and were not significantly higher than expected. Additionally, visual stimuli were followed by large percentages of active alert alertness levels, whereas the participants were passively alert most of the time after the presentation of auditory or tactile stimuli. Vestibular stimulation, in contrast, should be provided with utmost care. While previous studies have emphasized the importance of vestibular stimulation for motor and sensory development (MacLean & Baumeister, 1982; Rues, 1986), vestibular stimulation applied for a longer period and with higher frequency may result in a sensory overload (Ottenbacher, 1982). The participants might have withdrawn their attention from those stimuli in order to express their dislike, while others might have needed stimulation at a higher frequency to become active. Therefore, an individualized design for the activity when presenting vestibular stimuli is especially important.

A number of limitations should be noted when it comes to interpreting the results. Because of the small sample size, not all conditions were present to an equal degree. The frequencies of some combinations were too low and thus had to be excluded from subsequent analysis. Future experimental studies that control for these aspects would be able to complement the present results. In addition, the choice of a stimulus and the way of interacting was different for each participant. Because individualized stimulation is especially important for individuals in the target group, DSPs were instructed to adapt their behavior to the needs and abilities of the individual with PIMD. Consequently, stimuli were only comparable regarding their salience for the individual participant. Comparisons including similar stimuli or ways of interaction may reveal supplementary information. Furthermore, no chains of stimuli were taken into account. For example, the results produced by repetition may differ from those produced by presenting a stimulus only once. Moreover, the onset of several stimuli at the same time may well bring about different reactions. Because we did not control for additional stimuli that were presented after the first one in the subsequent time windows, these might also have influenced the reactions in terms of alertness levels. By including chains of stimuli in the analysis, future studies could reveal even more elaborated information.

The results of the present study reveal a number of important implications for support and education in individuals with PIMD. Because all the stimuli were followed by high percentages of active alert and passive alert behavior, we might suggest that DSPs always provide stimulation to make their clients alert. In that case, adapting the stimulation to the individual's waves would be necessary. The short period of the different alertness levels immediately after the stimulation shows that reactions in terms of changes in alertness levels are only slight. In addition, the peak of alert behavior after approximately one minute emphasizes the wave structure of those changes. As the DSPs continue providing stimulation, they should be able to observe whether a client is able to focus on the stimulus or whether he/she withdraws their attention. Only after a minimum of 90 seconds should the DSPs decide whether the stimulation is appropriate for the client. In short, DSPs need to take their time when observing alertness so as to ascertain the optimal timing of an activity for their clients. Following and stimulating the clients' waves of alertness thus becomes even more important. Based on such an approach, the long-term effects of supporting their clients, along with the educational activities vis-à-vis the cognitive and motor development of the individual concerned, could be fruitfully investigated in the future.

8 General discussion

8.1 Introduction

As was stated in Chapter 1, alertness is a recurring topic in research on and support for individuals with profound intellectual and multiple disabilities (PIMD). Because the research does not provide an unambiguous description of being alert, direct support persons (DSPs) are uncertain as to how to describe alertness in clinical practice. In addition, alert periods in individuals of the target group endure only for a short time, which aggravates the detection and interpretation of alertness expressions. Searching for appropriate assessment methods, researchers mainly discuss two topics: which scoring categories to include and how to reach sufficient reliability in alertness observations. Furthermore, information about the impact of environmental factors on alertness is limited. The studies available are often case studies that do not allow for generalization to the entire target population. In addition, the results of available studies often differ even for those studies using similar research methods. These problems result in a large number of questions for DSPs concerning the *when* and *how* of presenting alertness stimulation to individuals with PIMD. Therefore, the aim of the present study was to broaden our knowledge about the three interrelated topics of describing, determining, and influencing alertness in individuals with PIMD.

In this final chapter, the major findings will be summarized and complemented by a critical reflection on the study. Furthermore, implications for clinical practice and recommendations for future research will be formulated.

8.2 Major findings

Describing alertness

The literature review (Chapter 2) as well as the expert discussion (Chapter 3) revealed two types of alertness descriptions: alertness as a theoretical concept regarding internal processes and alertness as the interaction of the individual with the environment, observable in the individual's behavior. However, the descriptions that focus on the individual do not seem to take into account the special characteristics of the target group. Because of the severity and complexity of their disabilities, the internal processes of individuals with PIMD cannot be assessed with those methods commonly used for nonclinical populations (e.g. brain measurements). Consequently, registering alertness expressions in terms of the individual's behavior can serve as an alternative. However, focusing on alertness expression alone is not sufficient either. Because the meaning of a certain alertness expression can differ from individual to individual, and even for the same individual in different situations, persons who are familiar with the meaning of an alertness expression for a specific person are needed in order to interpret the behavior. This makes individuals of the target group greatly dependent on their environment. While it is important to include interaction with the environment as an aspect of the alertness description in general, this is especially true for those descriptions that are used in clinical practice, because these mainly focus on the observable component of alertness that becomes visible in the individual's behavior.

Determining alertness

Based on the findings of previous studies (Green & Reid, 1999; Guess, Roberts, & Guy, 1999; Vlaskamp, De Geeter, Huijsmans, & Smit, 2003), we developed the Alertness Observation List (AOL, Vlaskamp, Fonteine, Tadema, & Munde, 2010). Because individual differences in the heterogeneous target group need to be taken into account, the purpose of the AOL is to formulate an individual alertness profile. To make the instrument readily usable in clinical practice, the number of alertness categories has been limited to four. For education and support, DSPs mostly strive to reach the optimal alertness level for learning and development which is scored as being focused on the environment in the AOL. At the same time, being withdrawn has regularly been observed before becoming alert again or alert for the first time (Arthur, 2004; Guess, Roberts, Siegel-Causey, & Rues, 1995). Although individuals are not yet focused on the environment when they are withdrawn, this alertness level yields the potential that the individual will become alert thereafter and is, therefore, important for DSPs to register. The third alertness level that is included in the AOL is asleep. Because individuals with PIMD are not focused on the environment at all at that level, DSPs should question the effectiveness of starting an activity when they score this alertness level for their clients. In addition to these expressions of alertness, DSPs regularly register self-injurious behavior on the part of their clients. Self-injurious behavior can occur when individuals of the target group try to increase their alertness, but also when they withdraw their attention from the environment. Because the function of self-injurious behavior can differ (Barrera, Violo, & Graver, 2007), this behavior is often difficult to score using one of the basic AOL alertness categories. Therefore, this special situation of self-injurious behavior leads to a fourth level: agitated.

The video observations in our various studies showed that the AOL was a reliable instrument. While the overall inter-observer and intra-observer agreement exceeded the 80% criterion, agreement percentages for the individual situations ranged from 50 to 100%. Therefore, methods to complement these observations are needed. The scores of the different observers indicated that the observations of proxies and external observers can be used to that effect (Chapter 4). Furthermore, similarities in the patterns of observations and physiological measurements lead us to conclude that these measurements might also be valid in order to supplement and validate alertness observations (Chapter 5).

Influencing alertness

The present study revealed that the DSPs' role is especially important when it comes to influencing alertness in individuals with PIMD. One initial step could be that of a training session for DSPs geared to raising their consciousness about the topic (Ault, Guy, Guess, Bashinski, & Roberts, 1995; Guess et al., 1999; Parsons, Rollyson, & Reid, 2004). Teaching DSPs about the concept of alertness and how to observe different alertness levels can indirectly increase the alertness of individuals with PIMD. In the direct contact between DSPs and their clients, interaction has been found to be especially important. In line with previous studies (Arthur, 2004; Guess et al., 1995), our results show that interaction can lead to high percentages of active alert behavior; in contrast, the absence of an activity can result in passive and self-injurious behavior. It is only through individual interaction that DSPs are able to carefully observe their clients' alertness expressions and so subsequently be able to react to these expressions by adapting the stimulation to their clients' needs and abilities.

Furthermore, the choice of a stimulus can optimally be based on the preferences of the individual with PIMD and the ability of the stimulus to influence the individual's alertness level (Kennedy & Haring, 1993; Lancioni, O'Reilly, Van Dijk, & Klaase, 1998). While previous studies (Arthur, 2003; Guess et al., 1999; Lancioni, O'Reilly, Campodonico, & Mantini, 1998; Lancioni, O'Reilly, & Mantini, 1999; Parsons et al., 2004; Sandler & Voogt, 2001) showed that stimulation in general can make individuals of the target group (more) alert, our study complements this information with new detailed information (Chapter 6). Visual stimuli were followed most frequently by high alertness levels in all participants. In an additional analysis done on the subgroup of individuals with visual impairments, the observed relationship between visual stimuli and high alertness levels was even stronger. While we may conclude that all individuals with PIMD can perceive those stimuli better when they are presented explicitly, presenting visual stimuli in clear contrast to the overall environment might be especially important for individuals with visual impairments. Possibly, explicit visual stimuli are necessary for individuals with impaired vision so as to make use of their remaining visual skills. Analyzing the combination of visual and auditory stimuli, the reactions of the participants in terms of alertness were even clearer. Because a large percentage of those auditory stimuli entailed the DSPs' actual voice, we hypothesize that complementing visual stimuli with the sound of a familiar voice and explaining words may play an important role in increasing the alertness of the individual with PIMD.

In addition, differences in the effects of the stimuli varied across alertness levels and over time. Similar to previous studies which revealed that a particular alertness level had a high probability of following upon itself in subsequent or later intervals (Arthur, 2004; Guess et al., 1995; Guess et al., 1999), our results showed that alertness levels developed over time in waves. Again, the present study complements this existing knowledge with new, more detailed information (Chapter 7). These waves showed a recurrent pattern that can be described as follows: Visual, auditory, as well as tactile stimulation revealed the first reaction after 20 seconds, a second alert period after one minute, and a less clear third peak in alertness after two minutes. While visual stimuli resulted in waves of active and passive alertness, reactions to auditory and tactile stimuli were mostly passive alert with gradual decreases to lower levels of alertness within the subsequent two-minute period. Patterns following vestibular stimulation differed significantly from those following the other types of stimuli. Individuals with PIMD only showed reactions in two directions after about 60 seconds: either explicitly active alert or asleep behavior. These differences can be explained by the amount of time needed for the processing of the stimuli (Barnett-Cowan & Harris, 2009).

For the entire stimulation situation, we noted that the effect of the stimuli dominated the effect of time. Even when the individual with PIMD was withdrawn at the start of the stimulation or became withdrawn during the stimulation, (new) stimuli presented by the DSP were regularly followed by alert moments. Consequently, it is especially important that DSPs remain alert during the entire stimulation session in order to make and keep the individual with PIMD alert.

8.3 Reflections on the study

In previous studies that were similar to ours, observation was the most frequently used research method to determine alertness in individuals with PIMD (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009a). By the same token, the optimal way to observe alertness still continues to be a point of discussion (Arthur, 2000; Guess, Roberts, Behrens, & Rues, 1998; Mudford, Hogg, & Roberts, 1999). While researchers may want to employ a great number of alertness levels, our study shows that a small number of observation categories can be especially valuable for use in clinical practice. Because research has also primarily focused on one central category (such as being alert in our studies), researchers may generally seek to limit the number of categories and instead differentiate between subcategories (such as active alert and passive alert) for specific studies. In addition, the individual differences found in such a heterogeneous target group can aggravate the operationalization of observation categories. Based on our study, we would suggest that formulating individual descriptions of the different alertness levels before starting to make the observations could help to increase the reliability of these observations.

Moreover, the optimal scoring frequency can differ for research as opposed to clinical practice. Although continuous observations are difficult to implement in clinical practice, they should always be considered by researchers. The different findings both from previous studies and our own show that detailed analyses of alertness observations are especially important when it comes to providing support for individuals with PIMD. Because of the importance that the smallest details take on, determining the effect of a specific stimulus on the alertness of an individual during a specific moment in a session, instead of an overall score for an entire treatment activity, can reveal valuable information. Analyses of continuous data in scientific studies can be especially helpful in disclosing information that DSPs are unable to gather in clinical practice themselves. As difficult and time-consuming to gather as they are, these data are greatly needed in daily support and education.

Another issue that arises regularly in observation studies is the effect of time. When time series are analyzed, the dependency of succeeding scores has to be taken into account. Otherwise, the results may end up being underestimated. Using ARIMA models (Gottman, 1995) may be one solution, since in the future they could take into account the dependencies of scores in time-series research.

Furthermore, all studies on individuals with PIMD face the problem of a large enough sample. Because the target group is only comprised of a relatively small number of individuals, it is always difficult to come up with large samples. Additionally, individual differences between the participants often aggravate this issue in the case of individuals with PIMD. At the same time, a large number of participants are needed in order to generalize the results to the entire target group or to compare subgroups to each other. Searching for an optimal balance between a large sample and the analysis of subgroups could be a solution in the future. In that case, researchers would need to be careful not to overestimate the value of using statistical techniques. Because of the great heterogeneity of the target group and the importance of individual differences, descriptive analyses can provide especially valuable and meaningful contributions.

The results of our study, moreover, should also be of significance for fields that are indirectly related to alertness in individuals with PIMD. While information about the learning potential and learning processes of the target group of individuals with PIMD is limited, alertness observations can help in gathering information in order to formulate an individual learning profile. The learning potential can be linked to the alertness profile of an individual with PIMD (Guess, Roberts, & Rues, 2002). Because alert alertness levels have been described as optimal moments for learning, the learning potential of an individual with only small percentages of being alert during the day may be limited from the outset. In addition, knowing about how a person with PIMD integrates the sensory information gathered for learning and acting upon the environment is necessary in order to determine the learning potential (Nelson, Van Dijk, McDonnell, & Thompson, 2002). Consequently, DSPs should watch out for the occurrence of alert moments and then provide the stimuli that can make and keep the individual alert in order to determine the learning potential of an individual with PIMD. Furthermore, alertness observations can reveal information about the underlying processes of learning, such as orienting response and information processing (Nelson et al.). The orienting response shows how the individual gathers information from the outside world. For individuals in the target group, the alertness level of the observed person provides information about the appropriateness of the type of stimulation and its intensity. Similarly, the resulting alertness levels can tell observers about the sensory channels involved and the time needed to process the stimuli.

In the long term, alertness is also related to the development of functioning in individuals of the target group (Guess et al., 1993). Only if DSPs present stimulation to promote the learning and development of their clients when the individual is alert, can they expect that stimulation to be effective. Consequently, DSPs and researchers have to take alertness levels into account when they seek to follow the developmental progress of individuals with PIMD.

While the aim of the AOL is to determine alertness, alertness assessment is also closely related to assessment of the overall functioning of individuals of the target group. While alertness has been described as an important precondition for assessment itself (Guess et al., 1999; Munde & Vlaskamp, 2010; Vlaskamp, 2005), assessors can only expect individuals with PIMD to be able to show their skills if they are alert during the assessment. That said, assessment of alertness can also be used to answer questions in related fields. When DSPs employ assessment of alertness in order to monitor the health conditions of the individual with PIMD, a reduced frequency of being alert might, for example, indicate that the individual is experiencing pain (Breau & Burkitt, 2009; Van der Putten & Vlaskamp, in press). Similarly, DSPs can register the frequency of alert moments in order to determine the individual's reaction to a change in medication (Zijlstra & Vlaskamp, 2005). Because of the direct relationship between alertness and sleep, alertness assessment can also be combined with an assessment of the quality of sleep (Hylkema & Vlaskamp, 2009).

8.4 Clinical implications of the study

Based on the present findings, a number of implications for clinical practice can be formulated. Because DSPs have shown to be able to influence the alertness level of their clients, it is especially important for DSPs to be aware of the importance of their role in stimulation situations. Stimulating individuals with PIMD when they are withdrawn can often result in alert behavior. Consequently, DSPs need to be actively engaged in these situations. The withdrawn period in between alert moments can then be seen as a time of rest that individuals of the target group require to have enough energy for the continuation of the activity. Still, stimulation when individuals are asleep should be presented with caution. Individuals can easily be overloaded or frightened and, as a result, withdraw their attention from the environment. In addition, these moments of sleep might be important for individuals with PIMD in order to reload their energy and so be able to be alert (again) afterwards. Self-injurious behavior, on the other hand, should be cut short. While alertness levels often occur in waves, including changes between two or more levels, only active interaction with a DSP can interrupt this pattern. To detect different alertness expressions, DSPs have to create a situation where they can carefully observe their clients' reactions to the presentation of different stimuli. At the same time, it is important to exclude disrupting stimuli that may occur in the broader environment. Situations which yield these possibilities can be used as a diagnostic setting to observe and determine alertness in individuals with PIMD.

When DSPs choose a stimulus, they have to take into account the following: individuals with PIMD first need some time to *receive* the stimulation before they are able to be actively involved. Reactions may, therefore, only be visible after approximately one minute following the stimulation. Moreover, the processing of the information may take a different period of time for different kinds of stimuli. In general, interaction and communication can help the individual with PIMD to keep focused on the stimulation, and self-determination of the individual with PIMD can lead to prolonged high levels of alertness. However, DSPs always need to take individual preferences and abilities into account. The role of the DSP thus becomes especially important; still, to find the optimal balance between actively stimulating the client and following the client's signals remains an especially complex task.

The results of the present study also lead to implications for a related field. While cerebral visual impairments are diagnosed for a large percentage of the target group (Evenhuis, Mul, Lemaire, & De Wijs, 1997; Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001), the present study shows that individuals with visual impairments especially react with alert behavior upon visual stimuli. These results support the fact that any definition and assessment of visual functioning should focus on the functionality of the vision rather than on the anatomy (Boot, Pel, Van der Steen, & Evenhuis, 2010).

8.5 Recommendations for future research

The present study has revealed several questions and recommendations that could be the subject of future research. Based on the difficulties of determining the different alertness levels in different individuals of the target group, undertaking a broad inventory of alertness expressions could be helpful for DSPs. The description of individual alertness expressions of one specific person could then be based on a source with real substance. In addition, the arena of physiological measurements should be further explored for individuals of the target group. While those measurements are in line with nonclinical individuals, they can have a complementary value in terms of the existing research methods for individuals with PIMD. Furthermore, our study has revealed the fact that differences in abilities might be one explanation for differences in results in terms of alertness. Setting up studies with a differentiation between subgroups for different types of disabilities and different ages might then be able to provide new information about internal factors that could have an impact on alertness in individuals with PIMD.

To further investigate external factors that might influence alertness levels, experimental studies could reveal valuable information. When researchers control for separate environmental factors and look at small time intervals, results can be described in even more detail than previously. Employing eye tracking, for example, to follow the focus of the individual with PIMD can clarify whether it is the stimulus itself, the DSP, or other components of the environment playing a central role. In such studies, a number of topics about the design of an activity could and should be addressed. While our study clarified the effects of different types of stimuli, we still lacked detailed information about the different ways of presenting the stimulation. Reactions in terms of alertness may, for example, differ for one stimulus presented repeatedly as opposed to several different stimuli presented in a row. The individual's emotional dimension in terms of a stimulus may also have an impact as well. Providing a meal when the person is not hungry or playing with a favorite toy may then lead to different results in terms of alertness as compared to a situation involving less emotionally charged stimuli. Another related topic that should be investigated in the future is the complexity of a stimulus. Because individuals with PIMD can only stay alert for short periods of time, they may not be able to handle complex stimuli. Previous studies including populations with other disabilities have shown that participants experienced difficulty in processing stimuli when these had to be memorized for analysis first, before the components of the stimulus could be processed separately thereafter (Hessl, Rivera, & Reiss, 2004; O'Hearn, Schroer, Minshew, & Luna, 2010). By contrast, stimuli with a simple structure may well enter the consciousness of the individual with PIMD promptly and therefore within these short alert moments. Furthermore, movement activities, in general (Nelson et al., 2002), and vestibular stimulation, more specifically, seem to have a special impact on alertness in individuals of the target group. Investigating those relationships in detail can reveal more information about how to include these activities in education and support.

Finally, longitudinal studies could clarify the long-term effects of individualized stimulation. When stimulation is presented in a one-on-one situation where the DSP takes individual preferences and timing into account, tracking alertness patterns over time may show whether alert moments can be extended. In this context, detailed analysis may clarify which part of the pattern changes. It is possible that the peak of the wave may not be able to be extended for a longer period, but perhaps the process of the decrease in alertness afterwards can be delayed. Furthermore, the functioning of a large sample of individuals of the target group receiving individualized stimulation should be tracked over time. Differentiation of the results between age groups and combinations of disabilities could then reveal information about the long-term effects of this stimulation on motor, sensory and cognitive development of individuals with PIMD.

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Summary

Background

Ensuring support and education for individuals with profound intellectual and multiple disabilities (PIMD) is a complex task for direct support persons (DSPs). The timing of an activity is one of the recurring issues. The possible questions related to this are as follows: When can we optimally start an activity? What should be the duration of an activity? Which influencing factors should be taken into account when making these choices? DSPs and researchers agree that the best moments for learning and development, and therefore also for activities, are those when the individual is alert. However, expressions of alertness can easily go unnoticed, because individuals in the target group show quick and irregular changes in alert-

ness levels. Individual differences in these expressions may even aggravate how these expressions are interpreted. Moreover, reactions in terms of alertness to influencing factors can differ for each person and each situation. Because of these difficulties, researchers also leave a large number of questions open. Which alertness description is the best choice? Which observation categories should be used? How can optimal alertness levels for learning and development be reached? Consequently, DSPs as well as researchers experience problems in three interrelated domains in regard to support and education of individuals with PIMD as well as in research concerning individuals of the target group: describing alertness, determining alertness, and influencing alertness.

In **Chapter 1**, the background of the present study is given, including a description of the target group. The aim of this study is then presented along with an outline of the entire thesis.

Chapter 2 reviews the literature used to gather existing information about the three central problems before starting the present study. The results show that a large number of different terms have been used, and even the descriptions for one term can often be different. At the same time, alertness descriptions that focus only on the individual can be distinguished from those that include the interaction of the individual with the environment. To determine alertness, observation is the method most frequently used. However, different observation categories have been used in various studies, with reliability being a major problem found throughout. Only a small number of studies have investigated the environmental factors that may have an impact on alertness in individuals of the target group. Those studies are for the most part exploratory and only include a small number of participants. Those factors that have been found are, for example, a quiet environment, movement activities, and assisted communication. These can be further classified into five groups: 1) modifications of the environment, 2) interaction strategies, 3) stimulation strategies, 4) staff training, and 5) treatment activities. While studies about the factors included in the first four categories have mainly been shown to have a positive impact on alertness, the results for the impact of treatment activities were varying.

To clarify the results of the literature review, **Chapter 3** describes an expert discussion using the Concept Mapping method. Together with 35 international experts from the fields of research and practice, statements concerning alertness descriptions and those factors that may have an impact on alertness have been formulated. The grouping and importance ratings of the statements by the experts have resulted in two separate Concept Maps. The first Concept Map shows that the descriptions include a behavioral and an internal aspect of alertness. The second Concept Map reveals four clusters of environmental conditions that may have an impact on alertness: 1) interaction, 2) stimulation and activities, 3) communication, and 4) a cluster that emphasizes the importance of taking individual differences into account. Those statements found in the fourth cluster have been rated as being the *most important*.

Chapter 4 addresses the topic of alertness observation. Individual preferences and possibilities as well as the environment need to be taken into account, because individuals with PIMD only show short alert periods and because these alertness expressions can differ for each person. Since observations take these possibilities into account, they have some clear advantages above other methods. Based on these findings, the Alertness Observations List (AOL) has been developed. The aim of this instrument is to determine the different alertness levels and to formulate an individual alertness profile. For the present study, 39 situations were scored by two different observers, while 39 situations were scored twice by the same observer. Based on this data, the inter-observer and intra-observer agreement was calculated. While the mean scores of the agreement exceeded the previously defined criterion of 80%, the results showed a large spread. The differences for the various individuals observed, the different situations, and observers who had differing amounts of information about the observed persons underline the difficulties in observing individuals in the target group.

Chapter 5 focuses on one possible method to complement and possibly validate alertness observations: physiological measurements. Observation shows some advantages over other methods. However, the subjectivity of the interpretations and the reliability of observation have been described as being serious problems. Because of these, the aim of the present study was to determine whether alertness observations based on the AOL and on measurements of five heart and respiration parameters reveal results with a similar pattern. In an exploratory case study, these data were gathered for three individuals with PIMD. The comparisons of the mean values of the physiological parameters for each alertness level and for moments of *change in alertness level* versus *no change in alertness level* were broadly in line with previous studies including nonclinical individuals. All three participants showed a higher heart rate when they were alert. Furthermore, a relation between high levels of alertness and low respiratory sinus arrhythmia (RSA), and different levels of RSA for moments of change in alertness level versus no change in alertness level was shown. Based on these results, we hypothesized that physiological measurements can be a valuable complementary tool and a validation for alertness observations. Future studies are needed to support this hypothesis and to further explore the new research area of physiological measurements in individuals with PIMD.

The study presented in **Chapter 6** aims to identify those aspects of stimulation that may have an impact on the alertness of individuals with PIMD. This study complements previous studies that revealed general information about the relationship of stimulation and alertness. In our study, video observations of one-on-one interactions between the 24 participants and a DSP were analyzed. To control for the impact of different aspects of the stimulation, observations were conducted in multisensory environments (*Snoezelen* rooms). In addition to descriptive analyses, a multilevel logistic regression analysis was conducted to determine the impact of the different aspects. The data show that the participants were mostly alert during the stimulation situations (76.3% of the time). While visual stimuli were related to high percentages of alert behavior, the combination of visual and auditory stimuli produced the highest percentages of alertness. No significant differences were found between auditory and tactile stimuli. At the same time, the data did show large individual differences in the occurrence of alertness. Because the effect of the stimuli dominated the effect of time, we concluded that the DSP's role is especially important in alertness stimulation of individuals in the target group.

Chapter 7 provides an additional analysis of the data presented in Chapter 6 in order to determine the impact that the different aspects of stimulation have over time. Based on the same video observations of the 24 participants, a time-window sequential analysis was conducted. From this, reactions in terms of alertness in different time windows following the presentation of a specific stimulus were described. These time windows were 10 seconds each, running from 0 to 120 seconds after the presentation of the stimulus. Comparing the different time windows for different stimuli, different patterns of alertness were found. The presentation of visual stimuli resulted in waves of *active alert* and *passive alert* behavior, changing after about 20 seconds. While participants were alert shortly after the presentation of the auditory and tactile stimuli as well, those reactions were mostly passive alert. Moreover, the participants showed *non-alert* behavior especially between 20 and 120 seconds after the presentation of auditory and tactile stimuli. Following vestibular stimulation, the reactions varied widely. One group of individuals with PIMD was active alert; the other group was *withdrawn*. These reactions were only visible after 60 seconds. Based on the present results, we concluded that individuals of the target group showed their reactions to stimuli only slightly. The waves of alertness that were found may be described as optimal patterns for learning and development. DSPs should therefore determine and follow the alertness *waves* of their clients to provide individualized stimulation.

In **Chapter 8**, the research questions concerning the three problems of describing alertness, determining alertness, and influencing alertness are answered. The results of the present study showed that descriptions of alertness should always include the interaction environment so as to take into account the special characteristics of the individuals in the target group. A small number of observation categories can lead to reliable alertness observations, and physiological measurements may be used to validate these observations. To influence alertness in individuals with PIMD, individualizing the situation and, therefore, the position of the DSP is especially important. The discussion of the study explains how the results complement previous studies, while also showing the importance of the results for related research areas. The most important implication of the results for clinical practice is that DSPs must adapt the situation to the needs of their clients. At the same time, they need to find a balance between stimulating and following the alertness of their client. In addition to this, the present study leads to a number of recommendations for future research. To confirm and complement the present results, the use of new technology – such as a LifeShirt for physiological measurements or eye-tracking to follow the individual's visual focus – can be valuable in future studies. Experimental studies can help to determine the impact of different environmental factors on the alertness of individuals in the target group. Furthermore, longitudinal studies are needed to determine the long-term effects of individualized stimulation on the overall motor, sensory, and cognitive development of individuals with PIMD.

Samenvatting
(Summary in Dutch)

Achtergrond

Het bieden van ondersteuning en begeleiding aan mensen met zeer ernstige verstandelijke en meervoudige beperkingen (ZEVMB) is een complexe taak voor begeleiders. De keuze van het juiste tijdstip voor een activiteit is daarbij een terugkerend issue. Mogelijke vragen hierbij zijn: wanneer kan een activiteit het beste beginnen? Hoe lang mag een activiteit duren? En welke beïnvloedende factoren moeten in deze keuzes meegenomen worden? Begeleiders en onderzoekers zijn het erover eens dat momenten waarop een persoon alert is, een belangrijk beginpunt vormen voor leren en ontwikkeling. Daarom speelt alertheid een belangrijke rol in de keuze voor een tijdstip voor een activiteit. Maar alertheidsuitingen zijn vaak niet goed zichtbaar, omdat personen uit de doelgroep veel en onregelmatige wisselingen in alertheid laten zien. Bovendien maken individuele verschillen de interpretatie van deze uitingen bijzonder moeilijk. En ook reacties in termen van alertheid op beïnvloedende factoren kunnen per persoon en per situatie verschillen. Op grond van deze moeilijkheden hebben ook onderzoekers een groot aantal open vragen: welke van de verschillende beschrijvingen van alertheid is de beste keuze? Welke observatiecategorieën kunnen het beste gehanteerd worden? En hoe kan een optimale alertheid voor leren en ontwikkeling bereikt worden? Zowel in de ondersteuning en begeleiding van mensen met ZEVMB als ook in het onderzoek rondom deze doelgroep ervaren begeleiders en onderzoekers dan ook problemen op drie met elkaar samenhangende domeinen: alertheid beschrijven, alertheid meten en alertheid beïnvloeden.

In **hoofdstuk 1** wordt achtergrondinformatie over de onderhavige studie gegeven die onder andere ook een beschrijving van de doelgroep omvat. Bovendien wordt het doel van de studie weergegeven en aangevuld met een overzicht van de gehele dissertatie.

Hoofdstuk 2 bespreekt een literatuuronderzoek waarin als start van de voorliggende studie de bestaande informatie over de drie genoemde problemen bijeen wordt gebracht. De resultaten laten zien dat een groot aantal verschillende termen in gebruik is, waarbij zelfs beschrijvingen voor eenzelfde term kunnen verschillen. Wel zijn de beschrijvingen van alertheid die zich alleen op de persoon richten te onderscheiden van beschrijvingen die ook de interactie van de persoon met de omgeving omvatten. Om alertheid te bepalen worden doorgaans observaties uitgevoerd. Daarbij worden in de verschillende studies echter verschillende observatiecategorieën gehanteerd en geldt de betrouwbaarheid van deze observaties als hoofdprobleem. Over omgevingsfactoren die alertheid van mensen met ZEVMB mogelijk kunnen beïnvloeden is maar een klein aantal studies beschikbaar. Deze studies zijn vaak exploratief en hebben een gering aantal participanten. De gevonden factoren zoals een rustige omgeving, bewegingsactiviteiten en ondersteunende communicatie, zijn te verdelen in vijf categorieën: aanpassingen in de directe omgeving, interactiestrategieën, stimuleringsstrategieën, stafftraining en behandelingsvormen. Terwijl de studies laten zien dat de factoren in de eerste vier categorieën vooral een positieve invloed op alertheid hebben, zijn de resultaten voor de behandelingsvormen wisselend.

In **hoofdstuk 3** is een expertdiscussie beschreven om de uiteenlopende resultaten van de literatuurstudie te verhelderen. Daarbij is gebruik gemaakt van Concept Mapping. Samen met 35 internationale experts uit wetenschap en praktijk zijn uitspraken opgesteld met betrekking tot beschrijvingen van alertheid en omgevingsfactoren die mogelijk van invloed kunnen zijn op de alertheid bij mensen uit de doelgroep. De indeling van de uitspraken in groepen en de bepaling van hun gewicht door de experts leidden tot twee *landkaarten*, zogeheten Concept Maps. De eerste landkaart laat zien dat beschrijvingen een gedragsmatige en een interne component van alertheid omvatten. De tweede landkaart bevat vier clusters van omgevingsfactoren die mogelijk een invloed op de alertheid hebben: 1) interactie, 2) stimulering en activiteiten, 3) communicatie en 4) een cluster dat benadrukt dat begeleiders met individuele verschillen rekening moeten houden. De uitspraken in de vierde cluster zijn als *meest belangrijk* beoordeeld.

Hoofdstuk 4 richt zich op alertheidsobervaties. Omdat mensen met ZEVMB vaak maar kort alert zijn en alertheidsuitingen per persoon kunnen verschillen, is het van belang om zowel met individuele voorkeuren en mogelijkheden als ook met de omgeving rekening te houden. Observaties omvatten deze mogelijkheden en bieden zo een aantal duidelijke voordelen tegenover andere methoden. Op basis van deze bevindingen is de Lijst Alertheid ontwikkeld. Het doel van dit instrument is om de verschillende vormen van alertheid te bepalen en een individueel alertheidsprofiel te formuleren. Voor de voorliggende deelstudie zijn 39 situaties door twee verschillende observatoren en 39 situaties twee keer door dezelfde observator gescoord. Vervolgens is respectievelijk de inter- en intrabeoordelaarsbetrouwbaarheid berekend. Terwijl de gemiddelde overeenstemming het van tevoren geformuleerde 80%-criterium overstijgt, laten de resultaten een grote spreiding zien. De verschillen tussen de verschillende geobserveerde personen, de verschillende situaties en de observatoren met een verschillende hoeveelheid informatie over de geobserveerde persoon bevestigen de moeilijkheden in observaties bij personen uit de doelgroep.

In **hoofdstuk 5** wordt aandacht besteed aan één mogelijke methode om alertheidsobservaties aan te vullen en eventueel te valideren: fysiologische metingen. Hoewel observaties een aantal voordelen tegenover andere methoden hebben, worden de subjectiviteit van de interpretaties en de betrouwbaarheid van observaties als serieuze problemen ervaren. Op grond van deze problemen is het doel van de voorliggende deelstudie te bepalen of alertheidsobservaties op basis van de Lijst Alertheid en metingen van vijf hart- en ademhalingsparameters resultaten met soortgelijke patronen opleveren. In een exploratieve casestudie zijn deze data verzameld bij drie personen met ZEVMB. De vergelijkingen van de gemiddelden van de fysiologische maten per alertheidsniveau en voor de momenten van *verandering in de alertheid* versus *geen verandering in de alertheid* laten overeenkomsten met de resultaten van non klinische groepen zien. Alle drie participanten vertoonden een hogere hartslag wanneer zij alert waren. Daarnaast is een verband gevonden tussen hoge alertheid en lage respiratoire sinus aritmie (RSA) en tussen een veranderende RSA voor de momenten van verandering in de alertheid versus geen verandering in de alertheid. Op basis van de resultaten veronderstellen wij dat fysiologische metingen als waardevolle aanvulling en validering van alertheidsobservaties gehanteerd kunnen worden. Toekomstige studies moeten deze hypothese nog bevestigen en het nieuwe onderzoeksgebied van fysiologische metingen bij mensen met ZEVMB verder exploreren.

De deelstudie die in **hoofdstuk 6** gepresenteerd wordt, heeft als doel om verschillende aspecten van stimulering te identificeren die mogelijk van invloed zijn op de alertheid bij mensen met ZEVMB. Deze studie dient als aanvulling op eerdere studies die algemene informatie hebben opgeleverd over het verband tussen stimulering en alertheid. Hiertoe zijn video-observaties van 1:1-situaties van 24 deelnemers en hun begeleiders geanalyseerd. Om de verschillende aspecten van de stimulering onder controle te houden, zijn de observaties gerealiseerd in multisensorische ruimtes (snoezelruimtes). Naast een beschrijvende analyse is een multilevel-logistische regressieanalyse uitgevoerd om de invloed van de verschillende aspecten te bepalen. De data laten zien dat de deelnemers tijdens de stimulering meestal alert waren (76,3% van de tijd). Terwijl visuele stimuli met hoge percentages alert gedrag samengaan, leidt de combinatie van visuele en auditieve stimuli tot de hoogste percentages van alertheid. Voor auditieve en tactiele prikkels alleen zijn geen significante resultaten gevonden. Wel laten de resultaten grote individuele verschillen in het voorkomen van alertheid zien. Omdat het effect van de stimuli groter is dan het effect van de tijd, concluderen wij dat de rol van begeleiders bijzonder belangrijk is bij de stimulering van alertheid bij mensen uit de doelgroep.

In **hoofdstuk 7** wordt een aanvullende analyse weergegeven van de in hoofdstuk 6 gepresenteerde data om ook de invloed van de verschillende aspecten van stimulering over de tijd heen te bepalen. Op basis van dezelfde video-observaties van de 24 deelnemers is een sequentiële analyse uitgevoerd. Hierbij worden de reacties in termen van alertheid op meerdere momenten (zogeheten "time windows") na het aanbieden van een bepaalde stimulus beschreven. Deze time windows omvatten elk 10 seconden en lopen van 0 tot 120 seconden na het aanbieden van de stimulus. In de vergelijking van de verschillende time windows voor de verschillende stimuli zijn verschillende patronen van alertheid zichtbaar. Het aanbieden van visuele stimuli leidt tot golven van *actief alert* en *passief alert* gedrag met overgangen na ongeveer 20 seconden. Terwijl de deelnemers ook kort na het aanbieden van auditieve en tactiele stimuli alert zijn, zijn deze reacties meestal passief alert. Bovendien tonen de participanten 20 seconden tot en met 120 seconden na het aanbieden van auditieve en tactiele stimuli vooral *niet alert* gedrag. Na het aanbieden van vestibulaire stimuli zijn de reacties sterk uiteenlopend. Een deel van de personen met ZEVMB is actief alert en ander deel is *in zichzelf gekeerd*. Deze reacties zijn echter pas na 60 seconden zichtbaar. De voorliggende resultaten leiden tot de conclusie dat personen uit de doelgroep hun reacties op de stimuli pas met enige vertraging laten zien. De gevonden golven in de alertheid geven wellicht een optimaal patroon aan voor leren en ontwikkeling. Het is voor geïndividualiseerde stimulering dan ook bijzonder belangrijk dat begeleiders deze golven vaststellen en ze volgen.

In **hoofdstuk 8** wordt antwoord gegeven op de onderzoeksvragen met betrekking tot de drie problemen bij het alertheid beschrijven, alertheid meten en alertheid beïnvloeden. De resultaten van de onderhavige studie laten zien dat beschrijvingen van alertheid de interactie met de omgeving moeten omvatten om met de bijzondere eigenschappen van personen uit de doelgroep rekening te houden. Een klein aantal observatiecategorieën kan dan tot betrouwbare observaties van alertheid leiden en fysiologische metingen kunnen mogelijk ter validering van alertheidsobservaties gebruikt worden. In het beïnvloeden van alertheid bij personen met ZEVMB is de individualisering van de situatie en daarom de positie van de begeleider bijzonder belangrijk. De bespreking van de studie maakt duidelijk welke aanvullingen de resultaten op eerdere studies geven, maar ook in hoeverre de resultaten voor andere gerelateerde onderzoeksgebieden van belang kunnen zijn. Voor de praktijk betekenen de gevonden resultaten dat begeleiders de situatie vooral aan de behoeften van hun cliënten moeten aanpassen. Tegelijk is het van belang dat zij een balans vinden tussen het stimuleren en volgen van de alertheid van hun cliënt. Bovendien leidt de voorliggende studie tot een aantal aanbevelingen voor vervolgonderzoek. Om de gevonden resultaten te bevestigen en aan te vullen, kan het gebruik van nieuwe technieken – zoals een LifeShirt voor fysiologische metingen of eye-tracking om de visuele focus van de persoon te volgen – in toekomstige studies een meerwaarde hebben. In experimentele studies kan de invloed van verschillende omgevingsfactoren op de alertheid bij personen uit de doelgroep onderzocht worden. Daarnaast zijn longitudinale studies nodig om de lange termijn effecten van geïndividualiseerde stimulering op de algemene motorische, sensorische en cognitieve ontwikkeling van personen met ZEVMB te bepalen.

Zusammenfassung
(Summary in German)

Hintergrund

Menschen mit schwerst mehrfacher Behinderung Unterstützung und Begleitung bieten ist eine komplexe Aufgabe für Betreuer und Betreuerinnen. Dabei ist die zeitliche Abstimmung von Aktivitäten ein wiederkehrendes Problem. Mögliche Fragen, die damit zusammenhängen, sind die folgenden: wann können wir eine Aktivität am besten beginnen? Wie lange sollte eine Aktivität dauern? Welche beeinflussenden Faktoren sollten wir berücksichtigen, wenn wir diese Entscheidungen treffen? Betreuer/ Betreuerinnen und Forscher/ Forscherinnen sich einig sind, dass Momente, in denen die Klienten aufmerksam sind, eine wichtige Voraussetzung für Lernen und

Entwicklung sind und somit auch eine wichtige Rolle in der zeitlichen Abstimmung spielen. Während es oft, aufgrund von schnellen und unregelmäßigen Veränderungen in der Aufmerksamkeit bei Personen der Zielgruppe, jedoch schon schwierig ist, Aufmerksamkeitsäußerungen zu sehen, kommen individuelle Unterschiede in diesen Äußerungen als erschwerender Faktor für die Interpretation hinzu. Zusätzlich können auch Reaktionen auf beeinflussende Faktoren je nach Person und Situation unterschiedlich ausfallen. Aufgrund dieser Schwierigkeiten ergeben sich auch für Forscher/ Forscherinnen eine große Zahl von offenen Fragen: welche der verschiedenen Beschreibungen von Aufmerksamkeit ist die beste Wahl? Welche Beobachtungskategorien können am besten eingesetzt werden? Und wie kann die optimale Aufmerksamkeit für Lernen und Entwicklung gefördert werden? Forscher/ Forscherinnen und Betreuer/ Betreuerinnen stehen somit in der Unterstützung und Begleitung von Menschen mit schwerst mehrfacher Behinderung sowie in der Forschung bezüglich dieser Zielgruppe immer wieder vor Problemen auf drei miteinander verbundenen Gebieten: Aufmerksamkeit beschreiben, Aufmerksamkeit feststellen und Aufmerksamkeit beeinflussen.

Im **ersten Kapitel** werden Hintergrundinformationen zur Studie gegeben, die unter anderem auch eine Beschreibung der Zielgruppe beinhalten. Außerdem wird das Ziel der Studie beschrieben, ergänzt mit einer Übersicht der gesamten Dissertation.

Das **zweite Kapitel** bespricht die Literatur, um alle zu Beginn der Studie verfügbaren Informationen in Bezug auf die drei zentralen Probleme zusammenzubringen. Die Ergebnisse zeigen auf, dass eine große Zahl verschiedener Begriffe sowie verschiedene Beobachtungskategorien eingesetzt werden, wobei sogar unterschiedliche Beschreibungen für den gleichen Begriff vorkommen. Dabei können Beschreibungen, die nur die Person fokussieren, von denen unterschieden werden, die auch die Interaktion der Person mit ihrer Umgebung einbeziehen. Um Aufmerksamkeit festzustellen, werden meist Beobachtungen eingesetzt, wobei die verschiedenen Beobachtungskategorien, die in den Studien eingesetzt werden, sowie die Reliabilität der Beobachtungen als Hauptprobleme beschrieben werden. Nur eine kleine Zahl von Studien hat Umgebungsfaktoren, die Aufmerksamkeit von Menschen der Zielgruppe möglicherweise beeinflussen können, untersucht. Diese Studien sind oft sondierend und beziehen sich nur auf eine kleine Anzahl von Teilnehmern und Teilnehmerinnen. Die gefundenen Umgebungsfaktoren, wie zum Beispiel eine ruhige Umgebung, Bewegungsaktivitäten und unterstützte Kommunikation, können in fünf Gruppen unterteilt werden: Veränderungen in der direkten Umgebung, Interaktionsstrategien, Stimulierungsstrategien, Mitarbeiterschulungen und Behandlungsverfahren. Während die Studien, die Faktoren der ersten vier Gruppen fokussieren, vor allem zu positiven Resultaten führten, schwanken die Ergebnisse für Behandlungsverfahren.

Um die Ergebnisse der Literaturstudie zu verdeutlichen, wird im **dritten Kapitel** eine Diskussion von Experten – unter Einsatz der Methode Concept Mapping – beschrieben. Nachdem die Aussagen bezüglich Beschreibungen von Aufmerksamkeit und Umgebungsfaktoren, die Aufmerksamkeit möglicherweise beeinflussen, zusammen mit 35 internationale Experten aus Wissenschaft und Praxis formuliert und, im zweiten Schritt, in Gruppen eingeteilt und bezüglich ihrer Wichtigkeit beurteilt waren, entstanden zwei separate *Landkarten*, sogenannte Concept Maps. Die erste Landkarte zeigt auf, dass Beschreibungen von Aufmerksamkeit einen inneren Aspekt und einen Verhaltensaspekt umfassen. Während die zweite Landkarte vier Gruppen von Umgebungsfaktoren – 1) Interaktion, 2) Stimulierung und Aktivitäten, 3) Kommunikation und 4) eine Gruppe, die unterstreicht, dass Betreuer individuelle Unterschiede berücksichtigen sollten

– deutlich werden ließ, wurden die Aussagen in der vierten Gruppe als *am wichtigsten* beurteilt.

Das **vierte Kapitel** widmet sich der Beobachtung von Aufmerksamkeit. Da Personen mit schwerst mehrfacher Behinderung meist nur für eine kurze Zeit aufmerksam sein können und Aufmerksamkeitsäußerungen individuelle Unterschiede vorweisen können, ist es wichtig, individuelle Vorlieben und Möglichkeiten sowie die Umgebung miteinzubeziehen. Da Beobachtungen diese Möglichkeiten bieten, hat diese Methode deutliche Vorteile gegenüber anderen Alternativen, und wurde, aufgrund dieser Befunde, der Beobachtungsbogen „Aufmerksamkeit" entwickelt. Das Ziel dieses Instruments ist es, die verschiedenen Formen von Aufmerksamkeit festzustellen und ein individuelles Aufmerksamkeitsprofil zu formulieren. Für die vorliegende Studie wurden 39 Situationen von zwei verschiedenen Beobachtern beurteilt und 39 Situationen zwei Mal von demselben Beobachter bewertet. Die Berechnungen von Übereinstimmung zwischen zwei Beobachtungen der gleichen Situation von des/ der gleichen Beobachters/ Beobachterin und zwei Beobachtungen der gleichen Situation von zwei verschiedenen Beobachtern/ Beobachterinnen aufgrund dieser Daten ergaben, dass alle Durchschnittswerte den zuvor formulierten Beurteilungsmaßstab von 80% überschritten, jedoch eine große Streuung sichtbar war. Diese großen Unterschiede zwischen den Ergebnissen für verschiedene Personen, die beobachtet wurden, verschiedene Situationen, in denen die Beobachtungen stattfanden und verschiedenen Personen, die unterschiedlich viele Informationen über die zu beobachtende Person hatten, bevor sie die Beobachtungen ausführten, unterstreichen jedoch die Schwierigkeiten, die Beobachtungen bei Menschen der Zielgruppe mit sich bringen.

Das **fünfte Kapitel** fokussiert eine der denkbaren Möglichkeiten, die als Ergänzung und möglicherweise auch Validierung von Beobachtungen von

Aufmerksamkeit eingesetzt werden können: physiologische Messungen. Während Beobachtungen einige Vorteile gegenüber anderen Methoden bieten, sind die Subjektivität der Interpretationen und die Reliabilität gleichzeitig ernstzunehmende Probleme. Wegen dieser Probleme war das Ziel der vorliegenden Studie, festzustellen, ob Beobachtungen von Aufmerksamkeit mit dem Beobachtungsbogen „Aufmerksamkeit" und Messungen von fünf Kennwerten der Herzfunktion und der Atmung, Ergebnisse mit einem ähnlichen Muster aufzeigen. In einer sondierenden Fallstudie wurden diese Daten bei drei Personen mit schwerst mehrfacher Behinderung erhoben. Der Vergleich der Durchschnittswerte der physiologischen Kennwerte für die verschiedenen Formen von Aufmerksamkeit sowie für die Momente von *Aufmerksamkeitsveränderung* gegenüber *keine Aufmerksamkeitsveränderung* stimmen im Wesentlichen mit den Ergebnissen von Studien in Bezug auf nichtklinische Gruppen überein. Alle drei Teilnehmer/Teilnehmerinnen hatten einen höheren Herzschlag, während sie aufmerksam waren. Außerdem fanden wir einen Zusammenhang zwischen einem hohen Maße von Aufmerksamkeit und niedrigen Werten der respiratorischen Sinusarrhythmie (RSA) sowie Unterschiede in der RSA für die Momente von Aufmerksamkeitsveränderung gegenüber keine Aufmerksamkeitsveränderung. Aufgrund dieser Ergebnisse vermuten wir, dass physiologische Messungen eine wertvolle Ergänzung und Validierung von Beobachtungen von Aufmerksamkeit sein können. Zukünftige Studien müssen diesen Zusammenhang jedoch weiter bestätigen und das neue Forschungsgebiet der physiologischen Messungen bei Menschen mit schwerst mehrfacher Behinderung erforschen.

Die Studie, die im **sechsten Kapitel** präsentiert wird, richtet sich auf die Ermittlung von Aspekten von Stimulierung, die möglicherweise die Aufmerksamkeit bei Menschen mit schwerst mehrfacher Behinderung beeinflussen können. Diese Studie dient als Ergänzung von früheren Studien, die allgemeine Informationen bezüglich des Zusammenhangs zwischen Stimulierung und Aufmerksamkeit deutlich machen. Beobachtungen anhand von Videoaufnahmen, auf denen 1:1-Kommunikationen der 24 Teilnehmern mit einem Betreuer/ einer Betreuerin zu sehen ist, liegen der Analyse zugrunde. Um die verschiedenen Aspekte der Stimulierung unter Kontrolle zu halten, wurden die Beobachtungen in multisensorischen Räumen (auch Snoezelräume genannt) ausgeführt. Es wurden beschreibende Analysen und eine logistische Mehrebenen-Regression berechnet, um den Einfluss der verschiedenen Aspekte zu bestimmen. Die erhobenen Daten zeigen auf, dass die Teilnehmer den Großteil der Zeit der Stimulierung aufmerksam waren (76,3%). Während visuelle Reize einen deutlichen Zusammenhang mit hohen Prozentanteilen von Aufmerksamkeit aufwiesen, führte das Anbieten einer Kombination von visuellen und akustischen Reizen zu den verhältnismäßig höchsten Prozentanteilen von aufmerksamem Verhalten. Für akustische und taktile Reize wurden keine signifikanten Ergebnisse gefunden. Gleichzeitig zeigten die Teilnehmer/ Teilnehmerinnen große Unterschiede bezüglich des Vorkommens von Aufmerksamkeit. Da die Daten verdeutlichen, dass der Einfluss der Reize größer als Einfluss der Zeit ist, können wir folgern, dass die Rolle des Betreuers/ der Betreuerin in der Stimulierung von Aufmerksamkeit bei Menschen der Zielgruppe besonders wichtig ist.

Im **siebten Kapitel** wird eine ergänzende Analyse der im sechsten Kapitel präsentierten Daten beschrieben, um auch den Einfluss von Aspekten von Stimulierung im Verlauf der Zeit festzustellen. Basierend auf den gleichen Beobachtungen der Videoaufnahmen der 24 Teilnehmer wurde eine Sequenzanalyse ausgeführt. Dafür wurden Aufmerksamkeitsreaktionen in mehreren Zeitfenstern nach dem Anbieten eines bestimmten Reizes beschrieben. Alle Zeitfenster umfassen jeweils 10 Sekunden und decken die Zeit von 0 bis 120 Sekunden nach dem Anbieten der verschiedenen Reize ab. Der Vergleich zwischen den verschiedenen Zeitfenstern für die verschiedenen Reize zeigt verschiedene Muster in den Aufmerksamkeitsäußerungen auf. Das Anbieten von visuellen Reizen führte zu Wellen von *aktiv aufmerksamem* und *passiv aufmerksamem* Verhalten, die nach ungefähr 20 Sekunden wechselten. Während die Teilnehmer/ Teilnehmerinnen auch kurz nach dem Anbieten von akustischen und taktilen Reizen Aufmerksamkeit zeigten, waren diese Reaktionen meist passiv aufmerksam. Außerdem war meist *nicht aufmerksames* Verhalten zwischen der 20. und 120. Sekunde nach dem Anbieten von akustischen und taktilen Reizen zu sehen. Auf vestibuläre Stimulierung reagierten die Personen mit schwerst mehrfacher Behinderung sehr unterschiedlich. Ein Teil der Teilnehmer/ Teilnehmerinnen war meist aktiv aufmerksam, ein anderer Teil war vor allem *in sich selbst gekehrt*. Diese Reaktionen zeigten sich jedoch erst nach 60 Sekunden. Die vorliegenden Daten führen zu dem Schluss, dass sich Aufmerksamkeitsreaktionen bei Personen der Zielgruppe erst verzögert zeigen. Da die Wellen in den Aufmerksamkeitsäußerungen möglicherweise das optimale Muster für Lernen und Entwicklung darstellen, ist es wichtig, dass Betreuer diese Wellen feststellen und ihnen folgen, um die angebotene Stimulierung auf die individuellen Bedürfnisse ihrer Klienten abzustimmen.

Im **achten Kapitel** werden die Forschungsfragen bezüglich der drei Probleme Aufmerksamkeit zu beschreiben, Aufmerksamkeit festzustellen und Aufmerksamkeit zu beeinflussen, beantwortet. Die Ergebnisse der vorliegenden Studie zeigen auf, dass Aufmerksamkeitsbeschreibungen immer auch die Interaktion mit der Umgebung miteinbeziehen sollten, um den besonderen Eigenschaften der Personen der Zielgruppe gerecht zu werden. Eine geringe Zahl von Beobachtungskategorien kann zu reliablen Beobachtungen führen, und möglicherweise können physiologische Messungen zur Validierung dieser Beobachtungen angewandt werden. Um die Aufmerksamkeit von Menschen mit schwerst mehrfacher Behinderung zu beeinflussen, ist es wichtig, die Situation an die individuellen Bedürfnisse und Möglichkeiten der Person anzupassen, was indirekt die Position des Betreuers/ der Betreuerin besonders wichtig werden lässt. Die Betrachtung der Studie erklärt, wie die Ergebnisse bisherige Studien ergänzen können, aber verweist auch auf deren Nutzen für anverwandte Forschungsgebiete. Für die Praxis ist die wichtigste Schlussfolgerung aufgrund der Ergebnisse die, dass Betreuer/ Betreuerinnen die Situation an die Bedürfnisse ihrer Klienten anpassen sollten, wobei sie dabei ein Gleichgewicht zwischen Aufmerksamkeit stimulieren und Aufmerksamkeit folgen finden müssen. Des Weiteren führen die Ergebnisse der vorliegenden Studie zu Empfehlungen für zukünftige Studien. Um die vorliegenden Ergebnisse zu bestätigen und zu ergänzen, können neue Technologien – wie zum Beispiel ein LifeShirt, um physiologische Messungen auszuführen oder Eye-tracking, um die visuelle Fokussierung der Person zu verfolgen – in zukünftigen Studien nützlich sein. Experimentelle Studien können helfen, den Einfluss von verschiedenen Umgebungsfaktoren auf die Aufmerksamkeit von Menschen der Zielgruppe zu erforschen. Außerdem werden Langzeitstudien gebraucht, um die langfristigen Effekte von individualisierter Stimulierung auf die allgemeine motorische, sensorische und geistige Entwicklung bei Menschen mit schwerst mehrfacher Behinderung festzustellen.

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"Being a PhD student and writing your doctoral thesis is a long, hard and lonely path." That's what I heard regularly during my first year. But there are a number of people who caused this year to be very "leerzaam", positive, and, to say the least, "gezellig" for me. So the following section is dedicated to you! :)

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Curriculum vitae

Vera S. Munde was born on May 12, 1983, in Münster, Germany. She attended primary and secondary school in Münster. During her time in secondary school, she spent six months in Rouen, France. After finishing school, she worked for one year as a volunteer at a care center for elderly with disabilities. In 2003, she began her degree in Pedagogical Sciences at the University of Groningen. During her studies, she was a member of several committees. In 2006, she was a member of the prize jury of the "Citizens for Münster" foundation. In addition, she worked at a care center for children and youth with profound intellectual and multiple disabilities. In Groningen as well as in Münster, she supported individuals with different disabilities in their daily lives and on their vacations. After conducting research for her Master's degree program at the Fundashon Verriet, a care center for individuals with disabilities on Curacao, Dutch Antilles, she received her degree in August 2007. From 2007 to 2011, she worked on her dissertation at the University of Groningen. During that time, she spent six months at the Parenting and Special Education Research Group in Leuven, Belgium. She currently holds a postdoc position at the Department of Special Education and Youth Care of the University of Groningen.