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 communica-
Summary

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 ob-
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 fol-
low 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.