Chapter 8

General discussion
Physical activity has been an important topic of research in people with ID for many years. The aim of this dissertation was to broaden our knowledge on this topic with a specific focus on people with PIMD. We began with a cross-sectional study to investigate the motor activation of people with PIMD in daily practice. This study was followed by a systematic review to summarize the current knowledge base concerning the facilitators of and barriers to physical activity for people with ID from different stakeholder perspectives. As the research progressed, the results led us to believe that physical activity research should not only focus on the physical activity behavior of people with ID/PIMD but also (and maybe even predominantly) on the behavior of their direct support professionals. Qualitative and quantitative approaches were applied to elaborate on direct support professional behavior regarding the physical-activity support for people with ID/PIMD. The last study evaluated a promising intervention for people with PIMD which has been initiated by professionals in daily practice. In the present chapter, the main findings will be summarized and complemented by a methodological and theoretical reflection. Subsequently, directions for future research and policy will be discussed.

Main findings

From studying motor activation in people with PIMD, we found that their activation in daily practice was limited. The results in Chapter 2 present very low mean numbers of motor activities (including transfers and relocations) per day between breakfast and dinner, and the length of time for all the motor activities offered averaged 45.5 minutes per day. Similar to studies in people with ID (Finlayson et al., 2009; Peterson, Janz, & Lowe, 2008), we found relationships with personal and environmental variables (especially age and day of the week). People with PIMD appear to be at a particularly high risk of being motorically inactive at the living unit and during the weekend, in much the same way as men and the elderly are at greater risk. However, we consider that the main finding of our work on people with PIMD is that, in general, they are characterized by even lower levels of activation than people with ID. Furthermore, the results demonstrate not only a variation in motor activation among participants but also between the different observation days. Motor activation was not only limited but also not a structural part of the daily support provided.

Chapter 3 enhanced our understanding of the low levels of activation by identifying barriers and facilitators in people with ID. We attempted to assess whether the barriers and facilitators varied among people with different levels of ID, and we explored different stakeholder perspectives. The thorough scan of the literature addressing these three different perspectives (factors, levels of intellectual disability, and stakeholders) can be summarized as follows. The 24 studies we included suggested a broad range of personal and environmental barriers and/or facilitators. However, this topic was mainly studied in people with mild or moderate ID. Since very few studies (n=2) included people with severe or profound ID, no comparison could be made vis-à-vis the level of intellectual disability. The results nevertheless demonstrated that stakeholders reported lower intellectual capacity in the target group as a barrier. The stakeholder comparison reveals that the different groups involved tend to describe factors as barriers when they themselves have little influence over this factor. Likewise, Chapter 3 demonstrated that the supporting role of direct support professionals appears to be minimized in the current literature.

It is our opinion that the above-mentioned findings call for a better understanding of the role of direct support professionals. The findings in Chapter 4 provide valuable insight into the experiences of these professionals with regard to the (motor) activation of people with mild to profound ID. The analysis of interviews with 25 direct support professionals resulted in an overview of 30 factors that might influence – either facilitate or impede – them in supporting people with mild to profound ID in engaging in motor activation. The influencing factors were classified into four categories: capability, opportunity, motivation, and characteristics of the target group. Five of the influencing factors were related to the professionals’ ability to implement physical activity in daily support. The majority of the professionals interviewed
noted that they were aware of the importance of physical activity in people with ID and thus in their own supporting role. However, many mentioned that they felt incapable of thinking of suitable physical activities for people with ID, or that they had difficulties with performing or implementing physical-activity support. The factors within this theme were, in general, often mentioned as impediments by the professionals interviewed. Eight of the influencing factors were related to the opportunities the professionals had to engage in physical-activity support. The factors mentioned included practical support, social influences, and various factors in the environmental context (i.e., materials and resources, time scheduled, season/weather, and group organizational aspects and the physical plan). A total of 11 influencing factors were related to the motivation of the professionals to engage in physical-activity support. The factors that related to the opportunities and motivation experienced by the professionals were, on average, mainly stated as facilitating. Another six were isolated cases, relating to specific characteristics of the target group (intellectual disabilities, physical disabilities, physical and mental health, age, and preferences or motivation), and were predominantly classified as impeding. The factors in themselves do not only play a role in, but also negatively affect and interact with, the factors related to direct support professionals’ capability, opportunity, and motivation.

In Chapters 5 and 6, we elaborated on the crucial role of direct support professionals. The richness of qualitative data was used to develop a self-report questionnaire to measure the influencing factors on direct support professionals in a quantitative way. The questionnaire that we developed was validated in Chapter 5; more specifically, we analyzed the construct validity and (marginal) reliability of the three behavior scales (i.e., capability, opportunity, and motivation) using item response theory models. These findings support the construct validity of the three different behavior scales and prove that the scales, in their current stage, can reliably distinguish between direct support professionals across the entire range of capability, opportunity, and motivation levels. The study’s data were then used to explore the reasons behind the differences in the levels of capability, opportunity, and motivation that direct support professionals report regarding the physical activity support that they provide to people with ID. Chapter 6 reports on the relationship between the three behavior components and potential explanatory factors related to the characteristics of the people with ID, as well as to the characteristics of the professionals. Interestingly, the findings show that the professionals’ characteristics were found to be associated with the components generating their behavior. Direct support professionals’ age and whether they had physical activity plans for the people with ID appeared to be related to variations in capability, opportunity, and motivation. The capability and motivational levels were higher for direct support professionals who received additional training in physical activity support. The findings also show that working in an activity center is related to higher levels of capability, opportunity, and motivation as compared with working in a living unit. Contrary to the findings in Chapter 4, the characteristics of the people with ID, such as their level of ID and the presence of additional motor disabilities, did not contribute to the variance in the questionnaire data on direct support professionals’ behavior.

To address the lack of evidence-based interventions focusing on motor activation for people with PIMD, we finally investigated a potential initiative embedded in ongoing practice. Chapter 7 introduces an intervention that uses different powered-exercise machines to support people with PIMD in performing specific movements. Performing specific movements using powered-exercise machines can be considered as a form of continuous passive motion, which had been suggested as an effective alternative for people who cannot perform regular physical activity by themselves (White, Christian, & Bemben, 2004). The content of these interventions has been adapted from the support of elderly people in the general population (Jacobson et al., 2012). Scientific proof of its efficacy for people with PIMD is lacking, however. The purpose of the intervention programs was not only to increase the level of motor activation in daily practice but, more importantly, to achieve beneficial results in various aspects of the functioning of people with PIMD. Studying this intervention for a twenty-week period revealed several important findings. The intervention was indeed
feasible in daily practice; the participants in the intervention group, on average, attended 81.5 percent of the sessions over the twenty-week program. The intervention was shown to significantly increase the level of oxygen saturation during movement in people with PIMD, which suggests that physiological mechanisms in people with PIMD can be positively influenced by assisting them with powered machines rather than having to enact a motor activity by themselves. Additionally, one notable finding was that the levels of oxygen saturation were extremely low, on average, in people with PIMD. The study findings did not support any of the other expected beneficial outcomes, such as increases in functional abilities, alertness, and quality of life. Finally, the study provided us with insight into the feasibility of conducting a randomized controlled trial in people with PIMD. The findings show a very high rate of willingness to participate, along with the acceptance of randomization by the parents or legal representative of the individuals with PIMD. Furthermore, the rate of ability to participate and the completion rates of the outcomes were surprisingly high. For the very first time, as far as we know, a randomized controlled trial featuring people with PIMD has been successfully carried out.

Methodological reflection

The main methodological strength of this thesis is that each study was anchored in the results of the previous one. Moreover, different research methods were used to more thoroughly investigate the relatively unexplored, but complex, domain of physical activity in people who are characterized by severe and profound disabilities, as well as dependency on others. The search for greater insight into the role of the direct support professional has particularly benefited from the triangulation of methods used. The qualitative data in this dissertation have provided a good reflection of the reality for direct support professionals, along with interesting hypotheses for further quantitative investigations. Quantitative data were subsequently collected to elaborate on the reasons hypothesized as being behind the differences in direct support professionals’ behavior regarding the physical activity support they provided to people with ID. In this case, method triangulation generated a contradictory research result regarding the influence arising from the characteristics of the people that the direct support professionals work with. It is an intriguing result, which both deepens our understanding of the research phenomenon and suggests that future research for the design of a training program for direct support professionals is strongly recommended in order to evaluate its effectiveness through both qualitative and quantitative measurements. Additionally, although it was not the main reason for using method triangulation, the psychometric results of the validated questionnaire have addressed theoretical support for the qualitative results about the behavior of direct support professionals in physical-activity support for people with ID.

Clarity is needed when combining both qualitative and quantitative methods within a study. We decided that a qualitative analysis was most suitable for answering the research questions in our systematic review. The data synthesis proved to be of great value in providing an overview of a large body of research on barriers to and facilitators for people with ID engaging in physical activity, but there are some caveats to be considered in terms of this approach. Qualitative research findings are usually context-specific, and interpretation of the individual study findings leads to loss of contextual information. In addition, there is a risk involved in treating the individual study findings as equivalent, without taking into account the quality of each study. We have tried to limit these risks in the data synthesis by constantly reflecting on what we were doing, looking into differences between studies, and verifying whether differences could be explained by sample, study design, or quality. A useful tool for this was a data extraction table that describes – in addition to the individual study results – all relevant contextual data as well as a quality rating for each study. For the reasons above, we needed to be wary when assigning value to the quantitative comparison with regard to the differences among stakeholders. What helped us, however, was emphasizing the differences in the various perspectives so as to arrive at a deeper insight into the network of
stakeholders who are able to positively or negatively influence or maintain physical activity in people with ID, and specifically in people with PIMD.

Further methodological reflection is also warranted when it comes to using a randomized controlled trial in people with PIMD. A randomized controlled trial design is an evidence-gathering strategy that has been ranked the highest in various existing taxonomies and hierarchies of methodological quality (Grossman & Mackenzie, 2005). It has been considered the gold standard of evidence-based practices for a long time now. At this juncture, however, we would like to touch upon a discussion involving the conceptualization of valuable evidence in the field of people with PIMD and how future intervention studies might benefit from this. The question needs to be raised, based on our results, as to whether randomized controlled trial designs can do justice to the heterogeneity of people with PIMD (Nakken & Vlaskamp, 2007). Our results have indicated quite a variety in the effects from the power-assisted exercise intervention at the individual level, which might well be explained by the very heterogeneity of the participants. For example, additional visual impairments in participants could be a more prominent explanatory variable influencing explorative behavior than the effect of the intervention itself. Furthermore, whether or not severe health problems are related to the level of alertness might well influence the measurement of alertness. On top of this, the age range of the participants in both the intervention and control groups was broad. There is good reason to expect that younger people with PIMD might in fact be able to make more progress in functional abilities due to the power-assisted exercise intervention than older people. The above-mentioned factors might, in turn, explain the variety found at the individual level; it is difficult, however, to consider all of the various variables that may influence an intervention’s effect in people with PIMD in a randomized controlled trial design. This could be successfully tackled, though, by a multi-center randomized controlled trial with subpopulations based on the various impairments known in the target group. However, researchers might then run up against other difficulties. The challenge involved in recruiting a research population of a reasonable size and the need to include explanatory organizational characteristics in the research design immediately spring to mind, not to mention that the control group might differ per facility.

Furthermore, and in addition to this, it is doubtful whether the correct statistical conclusions are drawn in a randomized controlled trial when researchers do not thoroughly investigate individual-level variability first (Fisher, Medaglia, & Jeronimus, 2018). However, the variances between participants with PIMD are difficult to break down. In our data on the alertness outcome, for example, we found that 66 percent of the total variance in alertness could be attributed to the variance between the participants with PIMD (Wessels, Bossink, & Van der Putten, 2017). Using best-fit analysis for this sort of data (i.e., multilevel analysis), we were unable to find any relationship between the potential factors of variance in individuals with PIMD and the intervention’s effect. More broadly stated, it is our opinion that evidence is particularly useful when it can be translated into its clinical context. This was also why we, as suggested by Dunst and Hamby (2012), provided effect sizes and confidence intervals to understand and elaborate on the clinical relevance of our findings in terms of contextual meaningfulness. However, within the group of people with PIMD, the operationalization of an intervention’s effectiveness can consist of minor changes in a specific outcome and can vary per individual (i.e., what is best for whom, when, and in which context). With aggregated data – as is used in a randomized controlled trial – we may have failed to detect clinically relevant findings at the intra-individual level of the power-assisted exercise intervention.

Everything considered, another perspective on evidence for interventional research in people with PIMD seems justified. Future research might benefit from repeated case studies, which have also been ranked at the causal level of evidence (Veerman & Van Yperen, 2007). Repeated case studies compare the effects of an intervention with multiple measurements of the baseline condition of a single participant (Horner et al., 2005; Morgan & Morgan, 2008). Although criticized for having a lack of objectivity and findings that cannot be generalized (i.e., external validity), these case studies allow for a detailed analysis of different participants and thus arrive at more insight into precisely how, when, and which
intervention needs to be provided for each individual with PIMD. Future research might also benefit from an additional measurement method that is sensitive to the unique outcomes of an intervention for people with PIMD. Goal attainment scaling, for example, could be added to a research design in order to evaluate individual changes in outcomes of specific goals.

**Theoretical reflection**

Our research has yielded significant knowledge about the motor activation of people with PIMD and has also led to new insights into physical activity research in people with ID. Previously, physical activity research relied on general physical activity definitions and standards for the population without ID. A well-documented and very widely cited definition of physical activity is that defined by Caspersen, Powell, and Christenson (1985) as "any bodily movements produced by skeletal muscles that result in energy expenditure," which includes activities undertaken while working, playing, managing a household, and during leisure time (World Health Organization, 2018). Accepted global standards for the general population include at least 60 minutes of moderate-to-vigorous physical activity daily for children and adolescents, and at least 150 minutes of moderate physical activity throughout the week for adults (World Health Organization, 2018). There will be no disputing that it is problematic for people with PIMD to independently perform physical activity as described in the definition by Caspersen and colleagues (1985), let alone meet the accepted global standards. An adapted and rather broadly defined definition of physical activity is required to be able to include people with PIMD. Underlying the performance of physical activity is the ability to move your body or parts of it, which is influenced by having or not having acquired the specific motor skills needed for this movement. Our focus thus shifted to all strategies that facilitate change in body position or the movement of the whole body or parts of the body (i.e., motor activation). Using this newly broadened definition, we now have more detailed knowledge about the extent to which people with PIMD are motorically activated in daily practice, and which personal and environmental factors are related to this.

The definition of motor activation includes the strategies offered to a person with PIMD, and implicitly emphasizes the relation to, and the importance of, the support provided. Corresponding to the multidimensional model of human functioning proposed by the American Association on Intellectual and Developmental Disabilities, the support provided was acknowledged for the very first time as an essential environmental factor in the activation of people with ID/PIMD. This has broadened the focus in this dissertation to encompass the person with ID/PIMD as well as the person and their (professional) support environment. It is important to increase understanding of the (professional) support environment when we want to overcome physical and motor inactivity in people with ID/PIMD. Direct support professionals are people who play a key role in the support provided to people with ID/PIMD. The results of our initial studies suggested that the behavior of direct support professionals predominantly explained the degree of motor activation in people with PIMD, which is in accordance with a previous study that found that the attitudes of professionals are associated with levels of physical activity in people with ID (Martin, McKenzie, Newman, Bowden, & Morris, 2011). Only when we have an adequate understanding of their role, related to the barriers that they perceive, can direct support professionals be expected to perform and maintain interventions focusing on physical or motor activation for people with ID/PIMD. This research has made a start in this regard by thoroughly investigating the views and (differences in) behavior of direct support professionals in terms of the support they provide when it comes to motivating people with ID in motor or physical activity.

Moreover, the lack of evidence-based interventions focusing on motor activation is another potential factor that might explain our findings involving people with PIMD (Van Alphen, Van der Putten, Waninge, & Minnaert, *submitted*). It is important to increase our knowledge with regard to the content of physical and motor interventions actually in use for people with PIMD, including their effectiveness. Only then can direct support professionals be expected to use an intervention in a targeted, individually focused, and meaningful way.
Directions for future research and policy

Future research is definitely needed to increase our understanding of the effectiveness of motor interventions in people with PIMD. In particular, we need to know more about which specific characteristics of an intervention lead to specific outcomes in different domains. In addition, there is clearly a need for intervention programming to enable all direct support professionals to structurally support and maintain motor activation in people with PIMD. Direct support professionals can make a meaningful difference, but how does one go about strengthening their role? Our findings provide a theoretical understanding of the behavior involved, and suggest a number of behavioral and environmental factors that need to be targeted in order to empower the physical-activity support for people with PIMD. This is a necessary first step towards the development and implementation of an intervention for optimizing direct support professionals’ behavior. Future research might well aim at assessing whether targeting behavioral and environmental determinants indeed results in changes in direct support professionals’ behavior, and, subsequently, in changes in the physical activity levels and related beneficial outcomes in people with PIMD. We encourage researchers to use the behavior change wheel to guide the selection of intervention functions and policy categories to be developed (Michie et al., 2011). The behavior change wheel proposes various intervention functions and policy categories for addressing factors related to capability, opportunity, or motivation; each intervention function can then be linked to concrete evidence-based behavior change techniques (Michie et al., 2011). Since this would be the first time that this framework is used in the specific context of support for people with ID/PIMD, we also recommend first making an inventory of which intervention functions are currently being applied in training programs for direct support professionals and which policy categories in organizations are already covered for the physical-activity support. In parallel, focus groups with direct support professionals might be employed so as to prioritize the influencing factors that relate to their capability, opportunity, and motivation, which in turn can be used as variables to target in an interventional study. Once this information is successfully integrated into a theory-based intervention program for direct support professionals, future studies should then closely monitor their introduction and assess whether they indeed promotes physical-activity support for people with ID/PIMD within a specific organizational context.

As we look upon these directions for future research, we need to realize that evaluating the effectiveness of interventions is inextricably linked to the need for further instrument development. This thesis has yielded a valid questionnaire to measure direct support professionals’ behavioral determinants in physical-activity support for people with ID. Future research might further validate this questionnaire by conducting interviews with direct support professionals with remarkable scores on, or combinations of, the different subscales, which would also increase the understanding of the phenomenon being researched. However, and most importantly, further psychometric evaluation is warranted before using the tool in interventional research. Future studies need to assess whether the questionnaire reflects the actual support by direct support professionals and the actual physical activity levels in people with ID (i.e., criterion validity). In addition, researchers need to establish which change is considered important and whether the questionnaire has the ability to detect change over time (i.e., responsiveness).

Finally, funding priorities need to be refocused for this research agenda. It is essential for researchers and funding organizations to be open to new perspectives on value evidence in people with PIMD, to recognize the need for applied research in this area, and to acknowledge that this can contribute to well-founded theoretical knowledge.