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Looking at possibilities

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CHAPTER 6

General discussion

General discussion

Assessment is a vital part of adapting support to the wishes, needs and abilities of people with PIMD and stimulating their development. However, the complex pattern of disabilities in this group makes assessment challenging. The aim of this thesis was to increase knowledge about the assessment of people with PIMD. This chapter will summarize the main findings and provide a critical reflection. In addition, it will discuss the implications of the knowledge generated in this thesis for research and practice.

Main findings

In the first part of this thesis we focused on acquiring an overview of assessment practices in people with PIMD in an international context (**see chapter 2**). Professionals reported using a wide range of different assessment methods to assess multiple domains. We found that, in general, assessment was linked to support, as it was used to evaluate and plan support. Professionals indicated that they regularly carried out assessments in an interdisciplinary fashion, by including different professionals who supported the person with PIMD. Input from parents was often included in the assessment process. However, many assessment instruments in frequent use were not specifically developed for and applicable to people with PIMD. For the majority of instruments, professionals reported that they adapted versions made for other people with disabilities. Consequently, for the majority of instruments there was no information available regarding psychometric properties for people with PIMD. Most of the professionals viewed the lack of available assessment instruments that are applicable to this group and that have been studied for psychometric properties as a barrier to assessment. Therefore, although the past decade has seen an increased development of assessment instruments (Van der Putten et al., 2015), we concluded, based on our results, that instruments are often used in practice whose quality for people with PIMD is unknown.

In a second study, **described in chapter 3**, the main focus was analysing the content validity and usability of the Inventory of the personal Profile and Support (IPS) (Vlaskamp et al., 2016). The IPS evaluates an individual's characteristics and development and identifies future support goals. The results of this pilot study indicate that the usability and content validity of the IPS are acceptable when used in combination with the Behavioural Appraisal Scales (BAS). If the IPS is used together with the BAS, information from all support persons is used to define a personal profile of the person with PIMD. Based on this personal

profile, goals can be formulated in support of that person. This approach can also be described as goal-oriented and interdisciplinary. Such approaches have been found to be effective in other studies as well (Lyons et al., 2016; Vlaskamp et al., 2015).

The BAS is regularly used in practice, but research into its psychometric properties is rather limited. Therefore, in our next study (**see chapter 4**) we focused on this lack of knowledge by studying the construct validity and convergent validity of the BAS (Vlaskamp et al., 1999). In that study, we found support for the subscale structure of the BAS. In addition, reliability estimated using Cronbach's alpha was evaluated as good, except for the emotional communicative behaviour subscale. Convergent validity of the BAS was good. However, when studying the factor structure of the BAS, we found that some items could be reassigned to another subscale, or removed. In addition, based on a comparison of factor structure in two subgroups of people with PIMD (adults with severe visual impairments and young children with less severe visual impairments), we found differences in factor structure and order of difficulty of the items in the two groups.

Based on the results of the third study, we decided to evaluate the content validity of the BAS in a following study (**see chapter 5**). In this fourth study, we used the input from three groups of experts (parents, researchers and support professionals) who participated in a Delphi study. We found that the content validity of the BAS could be enhanced as several items were not applicable to people with PIMD and the link to functional behaviour in daily life could be specified more closely. In addition, several aspects limited the feasibility according to participants. A new version of the BAS was developed, the BAS-R, and the main conclusion of the study was that the content validity of the new version was evaluated as good. In the BAS-R, items were adapted in such a way that they were attuned to the combination of disabilities that characterize people with PIMD. The link between the items and functional behaviour was strengthened.

In general, support professionals felt that there is a lack of assessment instruments whose psychometric properties have been studied for people with PIMD. It seems that although support professionals acknowledge the importance of using assessment methods that are adapted to the needs of this group, instruments are often used that have not been studied for their psychometric properties. The first results for the construct and content validity

of the BAS-R and the feasibility and content validity of the IPS are a promising first step towards overcoming this knowledge gap.

Theoretical reflection

In our overview of assessment practices, we found that professionals often used assessment methods whose quality is unknown. This result is in accordance with a more general view that there is a need for support for people with PIMD that is based on scientific evidence. For example, a study by Chadwick et al. (2018) explored assessment practices in communication and concluded that there is a need for more empirical support for the assessments used in practice. In addition, Van Alphen et al. (2019), who studied the content and quality of motor interventions in people with PIMD, found that little is known about the effectiveness of a wide variety of motor interventions that are used with people with PIMD. This thesis is a first step both in providing more information about current assessment practices for this group and in developing an instrument that has been studied for psychometric properties and which assesses functional abilities.

In our studies, we used the framework of the person-centred approach, which has been associated with higher quality of support and positive outcomes in individuals with an intellectual disability, such as participation in activities and choice-making (Ratti et al., 2016). Although it has been suggested that a clearer description is needed of the components of the person-centred approach (Ratti et al., 2016; Waters & Buchanan, 2017), this approach centres on individually tuned support and knowing the person well. Thus, we argue that assessment is a crucial part of the person-centred approach as it entails an evaluation of a person's preferences, abilities and needs. In our studies about assessment, we decided to include several components that are important in the person-centred approach and relevant in the assessment process. We found that professionals have a broad focus of assessment that includes all the possible domains of functioning. We also found that assessment did not focus solely on the individual, but on the individual in their environment, for example by including the perspective of parents and by using an interdisciplinary approach (Buntinx & Schalock, 2010; Lyons et al., 2016). Based on our results, we conclude that the person-centred approach and a multidimensional perspective were indeed reflected in the assessment of people with PIMD. We argue that this is important because only assessment that is person-centred and multidimensional can provide a complete and adequate overview of a person's needs and abilities in their context and can be a starting point for support that is adapted to individual needs.

Although assessment can have several aims, the aim of assessment within the person-centred approach has shifted towards providing support. We found this link to support in our study about assessment practices, as assessment was frequently used with the aim of making interventions or defining support goals. We believe that assessment should not be seen as a stand-alone process, but should be linked to support, as combining assessment and support could result in adapting support to an individual's needs and abilities. Moreover, with adequate support, these needs and abilities could change over time. Therefore, assessment is a dynamic and ongoing process linked to support. Although several aims of assessment can be relevant in different situations, one of the main aims should be to identify what support is needed to facilitate a person's development (Kulesza, 2015; Poehner, 2008). This is in accordance with the dynamic assessment approach, where the focus is not only on the abilities mastered thus far, but also on the possibilities of learning skills in the near future (Kulesza, 2015). The BAS, which was studied in this thesis, was built on these principles as the individual is assessed in interaction with the person who fills in the instrument, who demonstrates the behaviour that is assessed and who provides support (Vlaskamp et al., 2002). Preference material can be used in the BAS procedure, as this provides more opportunity for the person with PIMD to show their maximum abilities (Tullis et al., 2011). The BAS results in a profile of an individual's strengths and weaknesses, which is the starting point for providing support to reduce weaknesses or to use strengths to compensate these weaknesses. The focus of the BAS is thus not only on skills that can be performed but also on skills that an individual is already able to perform, for example with support (Buntinx, 2013; Lim, 2020).

Although it is important to take into account the person-centred approach in assessing people with PIMD, there are more aspects that should be considered in people with such unique needs and characteristics (Van der Putten et al., 2017). The assessment of this group is associated with specific challenges (Chadwick et al., 2018; Vlaskamp, 2005b). We obtained an overview of the knowledge needed in assessing people with PIMD in practice, in order to develop an assessment instrument that is adapted to those needs. Given the characteristics of this group, several aspects are important in their assessment. We took these into account in our analyses of assessment practices and when further developing existing instruments. The disabilities of people with PIMD are severe and complex, resulting in individual patterns of abilities and disabilities (Van der Putten et al., 2017). It is crucial that items in assessment instruments only measure the construct they were developed to measure and not rely on

other abilities. Assessment should take account of the large differences between individuals with PIMD (Nakken & Vlaskamp, 2007; Van der Putten et al., 2017). For example, considering the difference in factor structure of the BAS in two subgroups that we found, our explanation was that BAS items relied on a person's visual abilities, even though the subscales were developed to measure a different construct. Therefore, the main finding of our study was that the construct validity and convergent validity of the BAS were sufficient, but further studies were needed concerning the content and applicability of the items, as some items possibly measure a different construct in specific subgroups of people with PIMD. As a consequence, in order to improve the BAS, items needed to be formulated in such a way that they allow for a broad range of behaviours to endorse them. For example, a blind person may respond to a sound by moving their ear in the direction of the sound rather than by looking in that direction. These aspects were improved in the BAS-R, therefore providing more opportunity for the person with PIMD to show their maximum potential and an opportunity for the support persons to adapt support to the individual's needs.

A specific characteristic of this group – their unconventional communication – has serious consequences for the assessment process (Chadwick et al., 2018; Dhondt et al., 2020). Because of their idiosyncratic communicative signals, which are mainly nonverbal and very difficult to interpret, assessment should be interdisciplinary. Knowledge that is primarily generated by experiences from all individuals involved is integrated in this interdisciplinary approach (Lyons et al., 2016; Soorya et al., 2018). This is of particular importance for this group because the many people involved have their own specific tacit knowledge (Lyons et al., 2016). Although the main focus of the second study in this thesis was the psychometric quality of the IPS, that study is also an example of an assessment approach that is person-centred and goal-oriented and which uses an interdisciplinary approach. The interdisciplinary approach is used in combining the BAS with the IPS, as information from all people involved is integrated into a personal profile of the person with PIMD.

In a group with such heterogeneity in terms of abilities and disabilities, we cannot assume the same developmental pattern that is found in people without disabilities or with less severe disabilities. There is little knowledge available about the development of people with PIMD and indications of an atypical development have implications for the assessment process (Dhondt et al., 2020; Visser et al., 2017). Professionals in practice frequently reported using instruments developed for a different or broader group, such as people

with a severe or profound intellectual disability but without motor disabilities. These assessment instruments, such as the Bayley III, often contain basal rules or ceiling rules, which are based on the assumption that there is an order of difficulty in the items. We argue that these instruments are not applicable to this group as little is known about the development of people with PIMD (Van der Putten et al., 2017). The possible atypical developmental pattern was taken into account when developing the BAS and the adaptations that resulted in the BAS-R, as there are no stopping rules or order of difficulty and no age limit, since it cannot be assumed that certain skills are mastered or are no longer relevant at a certain age.

Finally, an aspect to consider when assessing people with PIMD is the focus of assessment. Because people with PIMD are able to develop their abilities and have a right to do so, the focus should be on abilities that are functional and meaningful in daily life (Munde & Vlaskamp, 2019; Soorya et al., 2018; Van der Putten et al., 2017). We argue that only skills that a person with PIMD can use in their daily life can support their development in terms of autonomy. Functional abilities therefore have a central role in this thesis, which has focused for a large part on the BAS, which measures functional abilities. Moreover, functional behaviour was an imperative aspect in improving the BAS: researchers, parents and practice professionals reported in the study about content validity that they would like to improve the link between the behaviours measured by the BAS items and how these behaviours can be functional in daily practice. This was enhanced in the development of the BAS-R, as we believe these aspects are important in assessing people with PIMD since they provide information on starting points for support.

Methodological reflection

The different studies that form part of this thesis are closely related, which is a strength. The second, third and fourth studies were each based on the results of the preceding study. In that way, we aimed to address research questions that could not be answered within a single study. It also allowed us to focus on different aspects of the central aim: to increase knowledge about the assessment of people with PIMD. Combining different research methods made it possible to evaluate different aspects of our research aim. For example, based on the oblique multiple group method, we found that the BAS may not be applicable to all people with PIMD. We were able to explore this further using a qualitative approach – a Delphi study.

When the original version of the BAS was developed, the perspectives of different groups of experts were not taken into account. We believe that including these perspectives is imperative in developing an assessment instrument for people with PIMD. Parents can provide invaluable information about their child (Jansen et al., 2018; Kruithof et al., 2020). Moreover, combining different perspectives – from researchers, parents and practice professionals – leads to higher-quality conclusions (Lyons et al., 2016; Parratt et al., 2016; Powell, 2003). Therefore, when evaluating the content validity of the BAS and developing the BAS-R, we included different perspectives in the development of the BAS-R, including those of groups that have an important role in practice in the assessment process for people with PIMD, thereby enhancing the applicability and content validity of the instrument. An important addition that was not directly considered when developing the BAS-R was the perspective of the person with PIMD. Even though it has become increasingly important over the years to include the voices of people with an intellectual disability (Embregts et al., 2018), this is highly complex in the case of people with PIMD (Maes et al., 2020) because of their limited use of verbal language and their unconventional and idiosyncratic communication (Chadwick et al., 2018). Nevertheless, their perspective could be included using other approaches, including observations, or the perspective of their direct support persons (Maes et al., 2020). In our study about the further development of the BAS-R, the perspective of people with PIMD was taken into account in a more indirect way, through the perspective of their direct support persons. Their perspective is also taken into account in several ways in the assessment procedure of the BAS-R: using observation, a test situation and the perspective of proxies. Although the person's behaviour in a daily situation can be assessed using observations, which take account of the context, observation is a highly complex matter (Maes et al., 2020; Munde et al., 2011). In addition, a test can provide objective information about a person's abilities (Visser et al., 2012), but it is not administered in a daily situation. Moreover, although the use of proxy perspectives means including the expertise of those who know the person with PIMD best, it can be challenging to determine the extent to which this aligns with the perspective of the person with PIMD (Maes et al., 2020). As the different ways of collecting information have both advantages and disadvantages, the BAS procedure uses a combination of a test, an observation and an interview with a proxy.

Defining and demarcating the target group has proven to be particularly challenging. Currently, different terminology is used for the same target group and the same terminology is sometimes used for a different group (Maes

et al., 2020; Nakken & Vlaskamp, 2007). This results in bias in selecting the correct studies when conducting a review. In our study about the inventory of assessment methods (see **chapter 2**), we used a narrow description of people with PIMD, based on Nakken and Vlaskamp (2007) definition. Many instruments used were developed for a related group, for example people with profound intellectual disabilities or severe multiple disabilities, but without specifying additional disabilities such as motor disabilities. Although some of the instruments by respondents may be applicable to people with PIMD, this is not certain insofar as this aspect has not been specifically studied, as we believe that people with PIMD are a unique group who need a unique approach in terms of support (Van der Putten et al., 2017). We believe that assessment instrument manuals should provide a detailed description of the target group. Moreover, although there is an operational definition and criteria that allow us to describe the target group, these criteria are difficult to assess adequately in people with PIMD because of the severity and complexity of their disabilities. In other words, the complexity of disabilities makes it impossible to draw strict boundaries as to who belongs to this group and it may be difficult to apply to very young children (Dhondt et al., 2020; Nakken & Vlaskamp, 2007). For the sake of transparency, we were as specific as possible in the different studies when describing our sample and target group, as exact demarcation was not possible. All studies were performed within a European context, which limits generalizability. This is especially relevant for the inventory of assessment practices. All participants were from Western European countries and differences in assessment practices could be expected in other contexts, as the focus and content of assessment practices are context-dependent (Buntinx & Schalock, 2010). Nevertheless, by including different European countries, we were able to provide an overview of assessment practices for people with PIMD that is relevant in an international context.

Convenience samples were used in all the studies. Ideally, a random sample would have been selected, but this was not possible for feasibility reasons. We attempted to include representative samples for the target populations in the different studies. For example, in the Delphi study, all groups who played an important role in supporting people with PIMD were included. Moreover, in the study about the construct validity of the BAS (see **chapter 4**), we provided a detailed description of the participants and analysed differences between subgroups to evaluate whether the BAS has sound psychometric properties in different subgroups of people with PIMD. In the study about the construct validity of the BAS, we included 78 people with PIMD. As the group of people

with PIMD is small, this sample size is relatively large when compared to the total group (Vugteveen et al., 2014). As the population of people with PIMD is small (Vugteveen et al., 2014), and because of their health problems and the high care load of support persons, which can have implications for the decision to participate in research (Maes et al., 2020), a small sample size is common in this research field. This has implications for the analysis techniques that can be applied. A larger sample size would allow for a more detailed analysis in evaluating the psychometric properties of the instruments, using a more advanced technique such as item response theory. Nevertheless, we selected our methods with a small sample size in mind and formulated our conclusions carefully. Also, both the study about the construct validity of the BAS and the study about the content validity of the IPS were exploratory. These studies were a first, important step in generating knowledge in an area where information is scarce.

Finally, analysing the psychometric properties of assessment instruments for people with PIMD is highly complex because of the lack of available instruments that can be used as a standard to compare outcomes (e.g. for evaluating convergent validity) and the lack of knowledge about the development of people with PIMD (Van der Putten et al., 2017). Ideally, we would have analysed convergent validity of the BAS using instruments that measure a related construct in people with PIMD and which have been studied for psychometric properties, but as these instruments are not available, we had to choose options that are second-best. The same will be true when studying an instrument's sensitivity, as a reference measure, which is currently not available, is needed to formulate conclusions about sensitivity. This is important because studies about assessment instruments are intrinsically linked to many other research areas, including intervention studies and longitudinal studies, as the quality of research is to a large extent dependent on the reliability and validity of the assessment instruments that are used (Maes et al., 2020). The results of this thesis are therefore an important first step, and continued research about the quality of assessment methods is necessary. In this way, this research area can be lifted by its own bootstraps.

Future directions for research

The results of this thesis have generated several themes for further studies, namely obtaining an overview of assessment instruments that are available for people with PIMD, the importance of continually re-evaluating different aspects

of psychometric properties of instruments for people with PIMD and the need to replicate our studies in different contexts.

First, the next step could be a systematic review of available assessment instruments for people with PIMD and of their quality. We have provided an overview of the assessment methods that are used in practice; an important next step could be to provide a complete overview of what is available. This would allow us to accurately evaluate the areas where there is a lack of assessment instruments, which could be a starting point for the further development of such instruments. This will also give us an international overview of available assessment methods. As a next step, these available instruments should be implemented in practice and further studied for their psychometric quality.

Second, the thesis points out the importance of continually re-evaluating different aspects of psychometric properties within a changing context of support for people with PIMD. Otherwise, there is a risk of using an instrument that is not applicable or does not provide adequate information about a person's abilities. First of all, based on our adaptations of the BAS, several suggestions for further studies were provided by the experts who participated. For example, experts reported a high degree of similarity between several items in the BAS-R. Further studies could evaluate whether these items are indeed highly correlated and could be merged. Second, we studied several aspects of psychometric quality using specific techniques, the Delphi method and tools from classical test theory. There is a need to study different aspects of psychometric properties, that were outside the scope of our study, using a variety of methods. For example, a study could investigate whether there are items in the BAS-R that are too easy or too difficult for people with PIMD. In addition, we recommend that future research should focus on the sensitivity of assessment instruments for people with PIMD, for example to assess the effects of an intervention, or to measure change at several measurement points in a longitudinal study. For the BAS-R, it is therefore important to study its sensitivity when it comes to measuring changes in functional abilities, as this is important for use in practice and in research studies. It can also produce more knowledge about the development of people with PIMD. With regard to the IPS, the study about the content validity of the IPS was a pilot study. It would be relevant to study a larger sample to find out whether the use of instruments for establishing an integral personal profile, such as the assessment procedures based on the IPS and the BAS, does indeed provide starting points to formulate support goals,

and whether this assessment procedure leads to a better understanding of the wishes, needs and abilities of the person with PIMD.

Finally, there is a need to extend our results to different contexts. In our study about assessment practices, we focused on three European countries. Future studies could focus on assessment practices in people with PIMD in other contexts as well, such as the United States or non-Western countries. Moreover, the Dutch version of the BAS-R is available and has been studied for content validity. The BAS-R will be translated into English and, ideally, into other languages as well. We recommend that psychometric properties be studied for the versions in other languages as this will accomplish frequent use of a limited number of instruments. The standardized use of instruments is important as it could enhance the comparability of results of an individual's assessment at different times, and will increase the comparability of different research studies. In addition, it will provide a better starting point for central registration and epidemiological studies (Kraijer & Plas, 2014).

Implications for practice

Based on the results of this thesis, we conclude that the collaboration between research and practice is highly important. An important finding was that some high-quality instruments, developed for people with PIMD and studied for psychometric properties, were not reported as being used at all. Therefore, we underline the importance of establishing a systematic close collaboration between research and practice in the support of people with PIMD as this will improve the dissemination of scientific knowledge and products/tools. Moreover, initiatives involving practice-based evidence should be utilized by further studying these initiatives. An overview of instruments that are developed and studied for their psychometric properties should be easily accessible for support professionals, for example in a database. Moreover, the target group should be described clearly and as specifically as possible in the manual accompanying the instrument. Developing a training programme to learn what methods are available and how to apply interventions and assessment instruments could be helpful in the further implementation of research products. Finally, research projects could benefit from the expertise of researchers who also work as professionals in practice or from the expertise of parents and other relatives.

The development of assessment instruments is highly relevant for support professionals, as these professionals reported in our inventory study that they

found the lack of assessment methods for people with PIMD to be problematic. This issue was addressed by evaluating the psychometric properties of the BAS and the IPS and by further revising the BAS. The BAS could be used in the support of people with PIMD to assess functional abilities. It could be used in combination with the IPS to obtain a complete overview of the wishes, needs and abilities of a person with PIMD. This can provide points of departure for providing adequate support. In general, assessment is related to a wide range of different domains, as adequate support can result in the development or retention of skills, higher alertness (Munde & Vlaskamp, 2015) and a reduction in challenging behaviour (Poppes et al., 2010), pain (Van der Putten & Vlaskamp, 2011) or sleeping problems (Hylkema & Vlaskamp, 2009). For people who are highly dependent on support from others, assessment can lead to better adapted support and a higher quality of life (Lyons et al., 2016).