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Inventory of assessment practices in people with profound intellectual and multiple disabilities in three European countries

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Abstract

Background: Knowledge about the quality of assessment methods used in the support of people with profound intellectual and multiple disabilities (PIMD) is scarce. This study aimed to provide an overview of the assessment methods used in practice and to examine whether these instruments were studied for their psychometric properties for people with PIMD.

Method: Professionals ($N = 148$) from three European countries completed a survey on assessment practices. We performed a literature search to find information about the psychometric properties of the instruments that were identified in the survey.

Results: Of the participants, 78.1% used assessments that were not developed for people with PIMD. Documentation on psychometric properties was found for 8 out of 116 instruments.

Conclusions: Most of the instruments in use were not designed for people with PIMD, and information about their quality is lacking. Guidelines are needed regarding the use and development of assessment methods for people with PIMD.

KEYWORDS

assessment instruments, assessment practices, inventory, people with PIMD, psychometric properties

1 | INTRODUCTION

People with profound intellectual and multiple disabilities (PIMD) have a profound intellectual disability combined with a severe or profound motor disability (Nakken & Vlaskamp, 2007). Often, they also have several additional impairments and medical complications (Van Timmeren et al., 2016), such as sensory impairments (Van Splunder et al., 2006), gastro-oesophageal reflux disease, dysphagia (Crawford, 2009), and epilepsy (Codling & MacDonald, 2009). Moreover, people with PIMD experience significant challenges in communication. They generally do not use and have little understanding of verbal language, but communicate in an idiosyncratic

and nonverbal way, using signals such as facial expressions, sounds, and physiological signals (Bellamy et al., 2010; Chadwick et al., 2018; Nakken & Vlaskamp, 2007). Assessment is of crucial importance for people with PIMD in order to define their needs, preferences and abilities and to be able to offer tailor-made support, as this is a vulnerable group that is completely dependent on personal assistance in everyday life (Van der Putten et al., 2017). Assessment can be defined as the systematic collecting, ordering and interpreting of information about a person and their situation, in order to obtain a satisfactory picture of their abilities, needs and preferences (Kendall & Norton-Ford, 1982). Assessment can be implemented in a variety of ways; it encompasses the use of standardised tests or scales,

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as well as interviews and observations, with or without a scheme. An assessment can be carried out for different purposes; for example, screening, intervention planning, and programme evaluation (Neisworth & Bagnato, 2004).

Although assessment is important for people with PIMD, there are few standardised assessment instruments that have been specifically developed and adapted to their needs. If instruments are used that have not been specifically developed for this group, this may lead to an inadequate representation of people with PIMD (Carnaby, 2007), as these instruments may not take into account their specific characteristics and multiple disabilities. This has consequences if the assessment is used for aims such as formulating goals in support and to plan and evaluate interventions. For example, the Vineland Adaptive Behaviour Scales (Sparrow et al., 2005) or the Bayley Scales (Bayley, 2006) may be less suitable for goals such as treatment monitoring and intervention planning in people with PIMD (Nakken & Vlaskamp, 2007; Visser et al., 2014). These instruments contain items that rely on visual or motor abilities while aiming to measure different underlying constructs such as cognitive or adaptive functioning.

As people with PIMD have a motor disability and often a visual disability as well, these items may fail to provide adequate information about the construct they were developed to measure. An example is an item: 'the person looks at the face of a parent or support person'. For people with PIMD who have a severe visual impairment, this item may not be scored positively, even if they show for example socialisation skills by vocalisation or touching another person to make contact. Moreover, it is important to adapt assessment instruments to the possible different development patterns of people with PIMD, as it is currently insufficiently clear whether their skills development is only delayed or both delayed and atypical (Van Braeckel et al., 2010; Van der Putten et al., 2017; Visser et al., 2017). In addition to standardised instruments, non-standardised assessment methods may be used, such as observations or interviews (of a proxy) with or without self-developed schemes. However, similar complexities resulting from the communication problems of people with PIMD apply to these types of assessment methods, since it is difficult to interpret signals such as body movements and sounds (Bellamy et al., 2010; Chadwick et al., 2018).

Moreover, because of the unique and complex needs of this group, many professionals are involved in supporting them. These professionals may have different backgrounds and perspectives regarding the needs and wishes of a person with PIMD. It has therefore been suggested that the assessment of this group should be interdisciplinary, with all the professionals who are involved contributing to the assessment process (Lyons et al., 2016). However, little is known about the extent to which assessment methods are attuned to the disabilities and needs of this group. In sum, in order to adequately adapt the support to the abilities and needs of people with PIMD, assessment methods are needed that are specifically developed or adapted for people with PIMD, and whose psychometric properties have been subjected to analysis.

A topic related to the quality of assessment methods is the extent to which present models of human functioning and disability, support

and quality of life are reflected in assessment methods for people with PIMD. In recent decades, support has become individualised, due to an approach described as 'person-centred' (Ratti et al., 2016; Waters & Buchanan, 2017). In this approach, services are based on the needs and preferences of the individual rather than on formulating support goals (Hogg & Langa, 2005; Mansell & Beadle-Brown, 2004). Consequently, the focus has broadened to include an individual's capacities and aspirations, in addition to impairments. Person-centred planning attempts to mobilise the individual's family and wider social network (Mansell & Beadle-Brown, 2004; Ratti et al., 2016).

Within this context, the American Association on Intellectual and Developmental Disabilities (AAIDD) developed a multidimensional framework of human functioning, in 1992. According to this model, support is a key factor in enhancing individual functioning and is inseparable from assessment (Buntinx & Schalock, 2010). It was suggested that assessment instruments should be used not only for diagnosis and indication analysis, but also as a starting point for intervention (Buntinx & Schalock, 2010). Person-centred planning aims to improve the quality of life of people with an intellectual disability (Ratti et al., 2016). Quality of life is a complex construct regarding which is no single universal definition. A model that is often used in support of people with intellectual disabilities is based on Schalock et al., (2008). Schalock et al., (2008) outline a framework with three factors (independence, social participation and wellbeing) and eight domains (personal development, self-determination, interpersonal relations, social inclusion, rights, material wellbeing, physical wellbeing and emotional wellbeing). Basic domains of quality of life are also relevant for people with PIMD, although there are differences as to how domains are operationalised in this group (Petry et al., 2005). In short, several aspects are consistent with the person-centred approach: the assessment focuses on quality of life; the assessment is linked to support; a person's social network is important in assessment practices; and there is a focus on assessing multiple domains. There is a stronger emphasis on the person and their needs, aspirations and capacities, instead of only on the disabilities. It is not known to what extent these aspects of the person-centred approach are reflected in current assessment methods for people with PIMD. Although Carnaby (2007) stated that assessment instruments for people with PIMD are scarce, research focusing on this group has increased in recent decades, as has research on the development and analysis of psychometric properties of assessment instruments. Examples are the Quality of Life PMD (QOL-PMD; (Petry et al., 2009), the Alertness Observation List (AOL; (Munde et al., 2011), the Pain Behaviour Checklist (PBC; (Van der Putten & Vlaskamp, 2011), the Behavioural Appraisal Scales (BAS; (Vlaskamp et al., 2002) and the Scale for Dialogical Meaning Making (S-DMM; (Hostyn et al., 2009). The QOL-PMD is a questionnaire that is filled in by different informants to assess the objective component of quality of life in people with PIMD. The AOL is an observation instrument to assess the alertness in people with PIMD. In addition, the PBC is an observation instrument to assess pain. The BAS was developed to assess the functional abilities of

people with PIMD. The S-DMM was developed to assess dialogue between two persons in contact. It is unknown to what extent these instruments are used in practice. The aim of our study was to compile an overview of the assessment methods used in practice. This is important, as it provides insight into assessment practices. By providing an overview of assessment practices, we can determine the quality of the assessments and whether professionals need guidance on using valid and reliable assessment methods that are adapted to the needs of people with PIMD. This can serve as a starting point to improve the quality of support of people with PIMD. Using high-quality methods could facilitate support that is adequately attuned to the preferences, wishes and needs of this group, which could, in turn, increase their quality of life (Lyons et al., 2016). Penne et al. (2007) compiled an inventory of scales and tests that are used to support people with PIMD. However, they only evaluated standardised instruments. They described the evaluation of the Dutch Committee of Test Affairs (COTAN), that reviews the quality of psychological tests that are available for use in The Netherlands, but did not include international peer-reviewed studies that evaluated psychometric quality. Moreover, their study focused only on standardised assessment methods in Belgium and did not consider the suitability of the instruments for the specific target group and the person-centred approach. No study has yet provided an overview of assessment methods, both standardised and non-standardised, used in practice for people with PIMD in different European countries. The present study focused on the following research questions:

- What assessment methods are used in practice for people with PIMD?
- For what purpose is an assessment used among people with PIMD?
- What barriers are experienced by professionals in practice when assessing people with PIMD?
- Are assessment methods used in practice adapted to the characteristics of people with PIMD?
- What information is available about the psychometric properties of assessment instruments that are used in practice regarding people with PIMD?

2 | METHODS

2.1 | Design

The present study has two components: a survey and a literature search. More specifically, the study is based on the descriptive information that professionals provided about their assessment methods and on a literature search for evidence about the psychometric quality of the assessment methods mentioned by professionals. The study collected data on assessment methods used to support people with PIMD. The results did not include the personal data of people with PIMD or their direct support

professionals. Professionals were informed about the study aims and the length and content of the survey. This study was approved by the Ethics Committee of Pedagogical and Educational Sciences, University of Groningen.

2.2 | Participants

The target population of this study comprised professionals who work with people with PIMD. The sample was a convenience sample based on professional networks and it consisted of professionals in The Netherlands, Germany and the United Kingdom. The main inclusion criterion for professionals was that they had to be involved in the support of people with PIMD. We used the definition of PIMD as formulated by Nakken and Vlaskamp (2007), who define PIMD as:

- A profound intellectual disability (to such a degree that it cannot be measured using existing standardised instruments)
- A severe or profound motor disability (not being able to move independently and having severe limitations in the functional use of their arms and hands)

People with PIMD often have several additional impairments and medical complications, such as sensory impairments, seizures and reflux disease. The participants' characteristics can be found in Table 1. Information about demographic characteristics was only available for respondents who completed the entire survey.

2.3 | Instrument

Data were collected by means of an online survey. The online questionnaire was developed using Qualtrics software (Qualtrics, Provo, UT). The survey began with an introduction outlining the aim of the study, a definition of people with PIMD and a description of assessment. This was followed by the part of the questionnaire that focused on the assessment methods used by professionals, and the part containing follow-up questions for each assessment method (see Appendix A). Seven field experts (four researchers and three healthcare psychologists) provided feedback on the draft version of the questionnaire in order to improve clarity, completeness and applicability. The feedback was discussed by the first and second author of this article, which resulted in some minor adjustments (e.g., the addition of response options for several questions, and a more detailed explanation of terminology). An overview of the questions included in the final version of the survey can be found in Appendix A. All questions contained an 'other' option. After every question, professionals were given an opportunity to clarify their answers. The survey was originally written in Dutch, and subsequently translated into English and German by native speakers. The respective translations were reviewed by an English and a German field expert.

TABLE 1 Sample characteristics (Total N = 148)

	Category	Number (%) / Mean (SD), min-max
Gender (N = 81)	Male	12 (14.8)
	Female	67 (82.7)
	I would rather not say	2 (2.5)
Profession (N = 81)	Clinical/developmental/healthcare psychologist	34 (42.0)
	Direct support professional/teacher	13 (16.0)
	Therapist	22 (27.2)
	Physician/nurse	11 (13.6)
	Other	1 (1.2)
Work setting (N = 81)	Residential facility	12 (14.8)
	Activity centre	5 (6.2)
	School/child day centre	17 (21.0)
	Multiple	23 (28.4)
	Hospital/health services/clinic/treatment centre	20 (24.7)
	Other	4 (4.9)
Age (N = 75)		42.9 (11.1), 23–64
Years of work experience in PIMD (N = 80)		15.5 (9.8), 2–36

Note: Of the 148 participants, 81 filled in demographic information section. Of these 81 participants, six did not fill in their age. For one participant, the years of work experience was unknown.

2.4 | Procedure

The online questionnaire was distributed between March and October 2018. A convenience sample was drawn up and potential candidates were contacted by the first author using several strategies and approaching different platforms. Firstly, several online platforms for professionals working with people with an intellectual disability were contacted: the Ernstig Meervoudig Gehandicapten platform [Severe Multiple Disabilities platform], Klik platform, and the PAMIS (Promoting A More Inclusive Society) website. Secondly, a message was posted on the Twitter page of Research Centre EMB [Research Centre for Severe Multiple Disabilities], and the first author emailed the IASSIDD Special Interest Research Group PIMD (SIRG PIMD) to ask whether they could distribute the questionnaire by email. Thirdly, the first author contacted healthcare institutions that provide support for people with PIMD and professionals through the professional networks of the first and second authors. These professionals and healthcare institutions were explicitly requested to further distribute the questionnaire through their own networks.

2.5 | PART 1

2.5.1 | Data analysis of survey data

We calculated how many professionals answered each question. For questions 1.1 – 1.3 and 1.6 – 1.9, we calculated the percentage of professionals who mentioned the different categories at least once, based on the total number of professionals who responded to the specific

question. For the question about the aims of assessment (1.4), we calculated the percentage of professionals who reported that they often or always used assessment for that purpose; for the question about the rationale for choosing a certain assessment method (question 1.5), we calculated the percentage of professionals who reported that a rationale was important or very important at least once; and for question 2, we calculated the percentage of professionals who reported that a barrier was problematic or very problematic. Where possible, the answers given in the open fields under 'other' were recoded under existing categories of the questionnaire or summarised by defining new categories. In addition, we evaluated whether specific types of methods were mentioned more often for specific domains by calculating the percentage of professionals who mentioned a type of method per domain, based on the total number of times that a domain was mentioned. We analysed whether parents were included in specific domains more often (percentage of times parents were involved per domain, based on the total number of times that a domain was mentioned). We also evaluated whether there were differences per setting and based on work experience (10 years or less versus more than 10 years) in the percentage of professionals who reported a barrier as being problematic.

2.6 | PART 2

2.6.1 | Information sources and search strategies for published assessments

Based on the results of the first question in the questionnaire, an overview was compiled of all assessment methods mentioned by

professionals who filled in the survey. Next, we collected data on the content of these assessment methods from scientific databases such as the COTAN documentation system, as well as information about assessment methods on websites and scientific literature. Based on this information, we categorised instruments as published or unpublished. By 'published methods', we mean instruments for which a published document is available, with guidelines on the assessment procedure and information about the construct that the instrument aims to measure. Examples are articles in peer-reviewed journals, book chapters, or protocols that are published online. For the analysis of information about psychometric properties, assessment methods were excluded if they were:

- Unclear or if no information could be found (for example: sometimes the professional did not mention an instrument, but a domain, such as 'alertness').
- Interventions or frameworks
- Documentation systems
- Unpublished assessment methods, defined as assessment methods that are not accompanied by a protocol or manual (e.g., if a professional filled in 'observation without a scheme'), self-developed schemes or scales, or assessment methods developed by an organisation that is the employer of the professional concerned, and which were not published or generally available.

For each included assessment method, a search was conducted using the databases of Google Scholar, Pubmed, ERIC and Psychinfo from 1990 onward, in order to determine whether it was developed or adapted for the target population (people with PIMD), and whether its psychometric properties had been subjected to analysis. The keywords were ('Profound Intellectual and Multiple Disabilit*', OR 'Profound and Multiple Learning Disabilit*', OR 'Intellectual Disabilit*') AND ('the name of the assessment method'). For the Dutch and German instruments, 'PIMD' and 'Intellectual Disability' were translated into Dutch and German. In addition, we examined the COTAN database for information about psychometric properties. The COTAN is a Dutch national central organisation that evaluates the properties of instruments used for assessment.

For a study to be included, several inclusion criteria had to be met. The study had to:

- Report on psychometric properties (reporting on any reliability or validity parameter led to inclusion)
- Be published in a scientific peer-reviewed journal
- Describe the group of people with PIMD as a sample, using Nakken and Vlaskamp's (2007) definition: people with a profound intellectual disability in combination with a severe or profound motor disability

For every study that was included according to the inclusion criteria, the results regarding validity and reliability were described. Moreover, in line with COTAN (Evers et al., 2010), we described the following aspects for quality: principles of test construction,

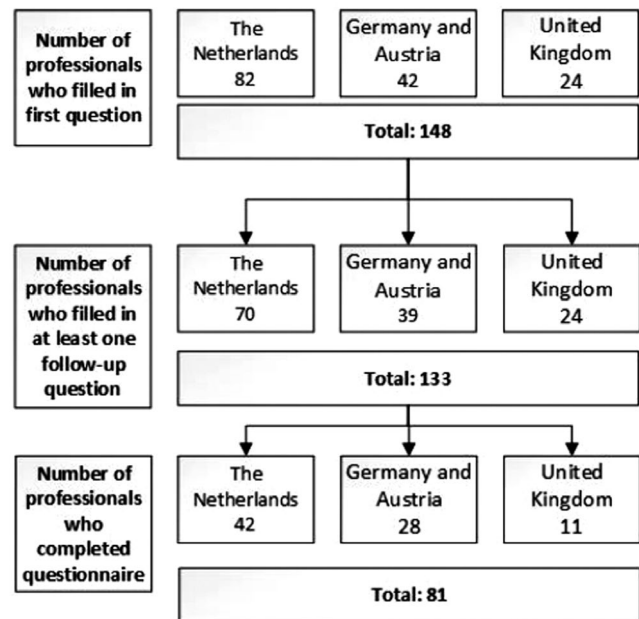


FIGURE 1 Dropout flowchart. Number of professionals who filled in the different parts of the survey, per country

reliability, norms and validity; which are marked 'insufficient', 'sufficient' or 'good'.

3 | RESULTS

Fifty-five percent of the respondents ($N = 81$) answered all the questions of the online questionnaire (see Figure 1 for more details). If a professional only filled in part of the questionnaire, we included all the responses that were provided, as we analysed the data per question. This way, we included as much information as possible. One of the participants lived in Austria and information from both German-speaking countries was merged in the figure for the sake of simplicity.

3.1 | Assessment methods

3.1.1 | Domains that were measured

The number of unique domains listed per respondent ranged from 1 to 10. Of all listed domains, 'communication' was mentioned most frequently (83.5%) and 'mental health' least frequently (45.9%) (see Table 2). Although the differences are subtle, the 'communication' domain was often mentioned in conjunction with other domains, most frequently with 'cognition', 'functional abilities', 'sensory skills', 'social adaptive skills', and 'motor skills'. Moreover, functional abilities were often mentioned together with motor skills, sensory skills, communication and social adaptive skills. Of the respondents, 94.8% reported at least once that they assessed multiple domains. Of all assessments, 23.4% measured one domain, and 76.6% measured multiple domains. Of the assessments that measured multiple domains, 79.7% measured more than two.

TABLE 2 The percentage of times a type of assessment was used, reported per domain and per percentage of professionals who mention assessing the different domain at least once

Domains (number of times mentioned)	Cognition (139)	Social adaptive behaviour (137)	Social emotional development (136)	Communication (195)	Physical health (112)	Quality of life (96)	Functional skills (177)	Motor skills (173)	Mental health (84)	Sensory skills (142)	Other (60)
Test	25.9	11.7	13.2	15.4	16.1	12.5	20.3	25.4	7.1	19.7	13.3
Questionnaire	25.9	31.4	23.5	24.6	19.6	24.0	22.6	24.3	34.5	23.2	26.7
Interview	34.5	35.0	39.7	34.4	36.6	47.9	31.1	27.2	35.7	34.5	25.0
Checklist	25.2	29.9	28.7	28.2	34.8	36.5	28.2	28.3	27.4	25.4	30.0
Observation	51.8	47.4	55.9	52.8	58.0	58.3	57.1	50.3	46.4	60.6	43.3
Other	10.8	1.5	13.2	9.7	18.8	13.5	15.8	16.2	11.9	12.7	15.0
Percentage of professionals who mention assessing the domain at least once	63.9	62.4	60.9	83.5	55.6	53.4	75.2	72.2	45.9	63.9	22.6

Note: The percentage of times a type of assessment was used per domain was calculated based on the total number of times that that domain was mentioned. For example, the 'cognition' domain was mentioned 139 times and of these 139, a test was used 36 times (as one of the methods to assess cognition), resulting in a percentage of 25.9.

3.1.2 | Developed and adapted for people with PIMD

Of the 148 professionals, 96 answered the question about whether assessment methods were developed for people with PIMD. Of these 96, 75 (78.1%) reported using assessment methods that were not specifically developed for this group. Moreover, 95 professionals answered the question about whether they adapted an assessment method to the characteristics of this group. Of these 95, 78 (82.1%) reported that they adopted at least one of the assessment methods that they mentioned. Forty-three of the 95 (45.3%) reported using assessment methods that were neither developed nor adapted for people with PIMD.

3.1.3 | Types of assessment method

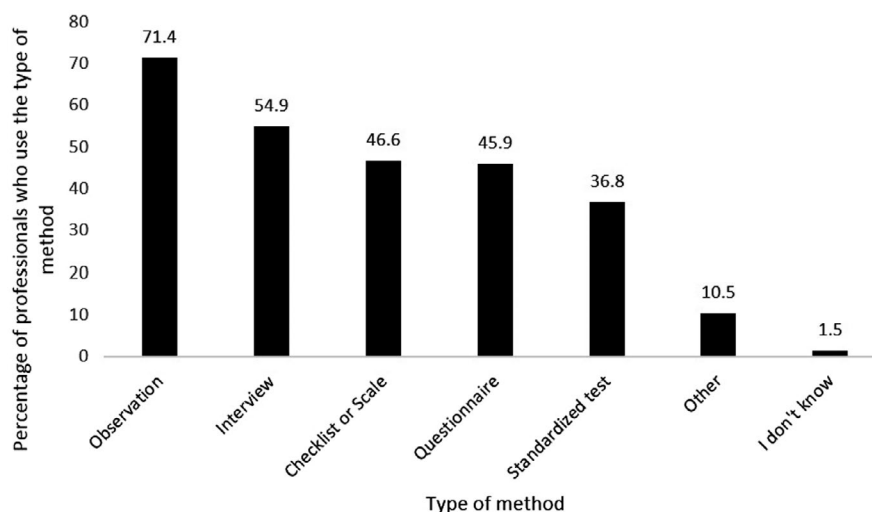
Figure 2 shows the different types of assessment method used. Observation was mentioned most often and standardised tests least often. In total, 60.2% of the professionals reported using a combination of methods. Standardised observation schemes were used by 34.4% of the professionals who used observations, self-developed schemes were used by 36.7%, and observation without a scheme by 46.7%. Moreover, 7.5% of the observations were categorised as 'other', such as a combination (mentioned five times) or an observation without a scheme but with a focused question (mentioned once). Some types of instruments were used more often in certain domains (see Table 2). A test was used most often in the 'cognitive skills' (25.9%) and 'motor skills' (25.4%) domains; a questionnaire was used most often in the domains of 'mental health' (34.5%) and 'social adaptive behaviour' (31.4%); an interview was used most often in the domain of 'quality of life' (47.9%); a checklist was used most often in the 'quality of life' (36.5%) and 'physical health' (34.8%) domains; and 'observation' was most often mentioned in the 'sensory skills' domain (60.6%).

3.1.4 | Professionals involved in assessment

Psychologists/developmental psychologists (mentioned at least once by 58.7% of the professionals) and direct support professionals (mentioned at least once by 60.3% of the professionals) were most often involved in assessment, followed by parents/ legal guardians (50.4%), physiotherapists (45.5%), speech therapists (40.5%), and physicians (33.1%). This includes both the professionals who administered the assessment and the professionals who completed the assessment. Parents were most often included in the assessment of the 'quality of life' domain (see Table 3). For this domain, the 'other' category was selected more frequently (42.1%) than for the other questions. A variety of different types of professionals were mentioned here, with teachers and occupational therapists listed most frequently (mentioned by 12 and 17 respondents respectively).

Of the respondents, 86.8% indicated that they used assessment methods that were completed by multiple professionals, including parents. Of the respondents who used assessment methods involving multiple professionals, 87.6% reported that they integrated information from different professionals into one report. The mean number

FIGURE 2 Percentage of professionals who selected a particular type of assessment method



of different types of people (professionals and parents) involved was 2.38 (SD = 1.52). Moreover, of all assessment methods mentioned, professionals reported that 61.6% were filled in by multiple persons.

3.1.5 | Rationales for choosing assessment methods

Of the eight reasons that respondents could select, the following six were considered to be important or very important by the vast majority of the professionals: 1) the method can be easily adapted for people with PIMD; 2) feasibility; 3) specific outcomes; 4) availability; 5) knowledge about the instrument; and 6) the method was developed for people with PIMD (See Figure 3). Several other rationales were also mentioned, such as the lack of alternatives (7×) and the non-invasive procedure of the assessment method (4×).

3.1.6 | Aims of assessment

Professionals reported that they used an assessment method most often for progress monitoring (mentioned at least once by 88.1% of the professionals), or programme planning (mentioned at least once by 76.2% of the professionals), followed by programme evaluation (70.3%) and screening (67.3%). Eligibility (32.7%) and diagnosis (56.1%) were mentioned least often. Several other aims were mentioned (11.3% of the professionals) in the open field, such as obtaining an adequate representation of the person (4×); being able to adapt the behaviour of the support persons to the needs of the individual with PIMD (1×); and the transfer of information to other professionals (1×). Some professionals did not mention an aim but stated the domain that the assessment method measured, such as wellbeing or quality of life.

3.1.7 | Barriers experienced in assessment of people with PIMD

Eighty-five professionals answered the question about barriers. Both organisational factors (e.g., lack of resources, lack of

available assessment methods, number of professionals involved in the support of people with PIMD), and characteristics of people with PIMD (e.g., communication problems, alertness, health problems, motor disabilities) were experienced as a barrier in assessing people with PIMD. Several remarks and other barriers were mentioned under 'other': a lack of standardised assessment methods (4×); the subjectivity of measurements (1×); a lack of resources (3×); a lack of knowledge (2×); and the higher alertness of some people with PIMD (1×). One professional reported that the involvement of many professionals could be regarded as a strength of assessment, if they are able to work together. The number of professionals who reported a certain barrier as being problematic differed across settings (see Table 4). Communication problems were most often reported as problematic in a hospital/clinic/health centre; whereas health problems and a lack of resources were most often reported as problematic in residential facilities. There were differences between the groups with 10 years' worth or less of work experience and more than 10 years' worth of work experience in terms of the number of professionals who reported a barrier as being problematic (see Table 5). Those with less than 10 years'

TABLE 3 Involvement of parents in assessment procedures per domain

Domain	% Completed by parents
Cognition	31.1
Social adaptive behaviour	35.8
Social emotional behaviour	37.9
Communication	33.9
Physical health	31.8
Quality of life	43.0
Functional skills	30.3
Motor skills	29.5
Mental health	39.8
Sensory/perceptual skills	32.9

Note: The percentages of times parents were involved in assessment are based on the total number of times the domain was mentioned.

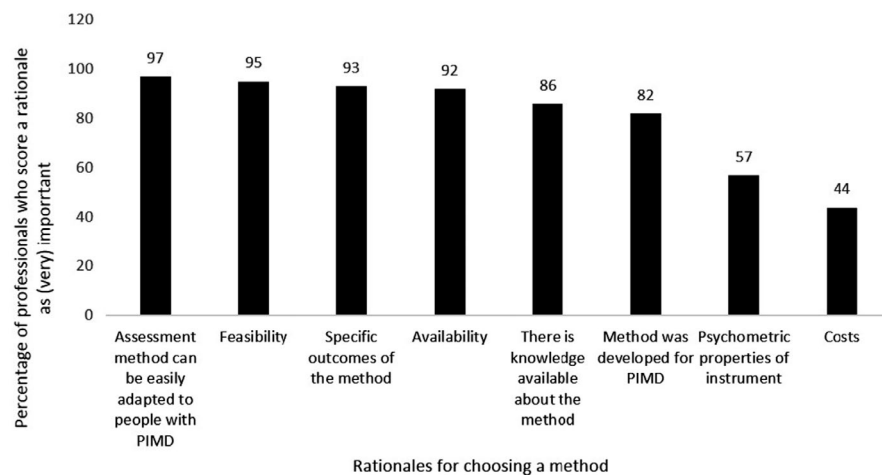


FIGURE 3 Percentage of professionals who deemed a rationale to be important

TABLE 4 Percentage of professionals who report a specific barrier as (highly) problematic per setting

Experienced barrier	Setting						Total (N = 85)
	Residential facility (n = 12)	Activity centre (n = 5)	School/child daycare centre (n = 17)	Multiple (n = 23)	Hospital/clinic/health centre (n = 20)	Other (n = 4)	
Communication problems	75.0	60.0	52.9	47.8	80.0	50.0	63.6
Motor disabilities	58.3	60.0	29.4	52.2	50.0	50.0	49.4
Lack of alertness	66.7	40.0	47.1	60.9	55.0	25.0	56.5
Health problems	83.3	40.0	52.9	52.2	45.0	50.0	54.1
Lack of resources	75.0	40.0	58.8	60.9	50.0	50.0	58.8
Lack of instruments	33.3	60.0	64.7	73.9	75.0	50.0	64.7
Many people involved	41.7	0	29.4	43.5	25.0	25.0	32.9

Note: Four participants did not indicate the setting they worked in.

worth of work experience reported more often that a specific barrier was problematic, with the exception of health issues and the many professionals involved in support of people with PIMD.

3.2 | Information about psychometric properties

Figure 4 shows the flowchart of the selection process for published instruments. In total, 116 unique published instruments were reported. A list of the names of unique published assessment instruments that were mentioned by professionals can be found in the online supplement. For eight of these, studies were available that reported on psychometric properties for people with PIMD; for the other 108, no studies were found.

Information about the psychometric properties of the eight assessment methods can be found in Table 6. The domains measured by these instruments are muscle tone and spasticity, motor abilities, pain, challenging behaviour, alertness, functional abilities and (the context of) support/general needs and abilities of a person with PIMD. For seven of the eight instruments, only one study on

psychometric properties had been found. For the Inventory of the personal Profile and Support (IPS), content validity was sufficient, but results were based on a small group (n = 6). For the other aspects of psychometric properties, no information could be found. The Behavioural Appraisal Scales (BAS) had good reliability in terms of interrater reliability and Cronbach's alpha and sufficient content validity. The construct validity in terms of dimensionality was deemed sufficient, but convergent validity was insufficient. Although norms are provided for the BAS, these are outdated. The Pain Behaviour Checklist (PBC) had sufficient inter-rater and intra-rater reliability. Convergent validity was good for children but insufficient for adults. For the AOL, only inter-rater and intra-rater reliability were studied, which were sufficient. Both the Modified Ashworth Scale (MAS) and the Modified Tardieu Scale (MTS) were studied for inter-rater and intra-rater reliability, which were good for the MAS but insufficient for the MTS. The Movakic had good content validity, sufficient inter-rater and intra-rater reliability and good convergent validity. Criterion validity was good. Finally, reliability as measured by Cronbach's alpha was evaluated as good for the Behaviour Problem Inventory (BPI).

TABLE 5 Percentage of professionals who report a barrier as (highly) problematic, reported in terms of years of work experience

	10 years or less (n = 32) (%)	More than 10 years (n = 48) (%)
Lack of instruments	24 (75.0)	27 (56.3)
Communication problems	22 (68.8)	27 (56.3)
Motor disabilities	16 (50.0)	22 (45.8)
Lack of alertness	22 (68.8)	21 (43.8)
Many people involved	8 (25.0)	18 (37.5)
Health issues	16 (50.0)	27 (56.3)
Lack of resources	22 (68.8)	24 (50.0)

Note: For five participants, the years of work experience was missing

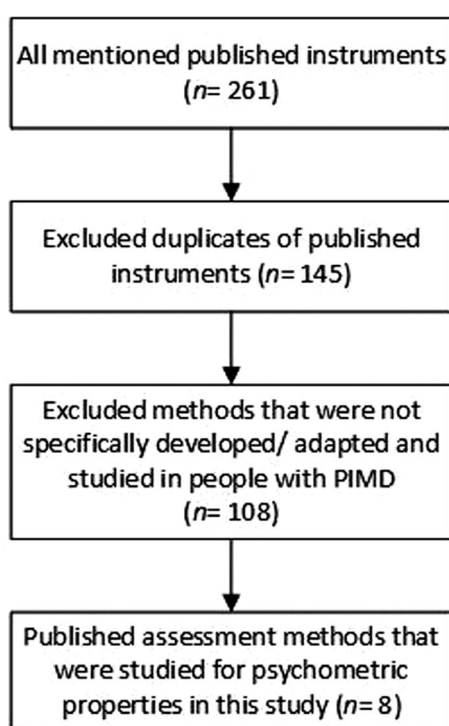


FIGURE 4 Flowchart of the selection process for assessment instruments that were included in the review of the current study

4 | DISCUSSION

This study aimed to create an overview of assessment methods used in practice in three European countries and to evaluate whether the psychometric properties of the instruments were examined for people with PIMD. The results suggest that many different types of assessment are used by professionals to assess multiple domains. A combination of different types of methods are often used and a wide range of informants, including parents, are involved in assessment procedures. Assessment is used for different goals, most often for progress monitoring and programme planning. However,

for the majority of assessment instruments used, there is little or no scientific evidence relating to the psychometric properties for people with PIMD. In general, the overview of assessment practices that professionals provided seems to be consistent with aspects that are important in the person-centred approach (Buntinx & Schalock, 2010). For example, assessment is used for a wide range of domains, including quality of life. A domain for which development of instruments and analysis of the psychometric properties of those instruments may need specific attention is mental health, as this was the least mentioned domain, even though comorbidity between an intellectual disability and mental health problems is high (Emerson & Hatton, 2007; Poppes et al., 2010). Moreover, assessment seems to be linked to support, as we found that assessment was used frequently to plan (76.2% of professionals) and evaluate (70.3% of professionals) support and progress. These results are in accordance with the results of Chadwick et al., (2018), who analysed assessment approaches used with people with PIMD to assess communication. Chadwick et al., (2018) suggest that assessments are often used to plan interventions and evaluate progress. In addition, person-centred planning attempts to mobilise the wider social network of the individual with an intellectual disability (Buntinx, 2013; Ratti et al., 2016). The importance of parental participation for the quality of support and quality of life has been emphasised in several studies on people with disabilities (Espe-Sherwindt, 2008) and, more specifically, people with PIMD (Jansen et al., 2012). The inclusion of parents in assessment methods is a positive development, as parents are experts in supporting their children and in articulating their wishes and needs. Given the complexity of disabilities and communication problems among people with PIMD, this expert knowledge is of crucial importance in providing appropriate support (Jansen et al., 2012). Although we found that 50.4% of the professionals mentioned an assessment method that included parents, the participation of parents could be increased in view of the benefits and importance of their involvement in the assessment process. Moreover, although we did not collect data on this in the current study, the participation of siblings as meaningful others in the assessment process is important as well, as they have a unique perspective on the wishes, needs and abilities of the person with PIMD and form an important part of the social network of a person with PIMD (Luijckx et al., 2016; Nijs et al., 2016). And, although challenging, the participation of people with PIMD themselves in the assessment process is paramount. There has been an increased emphasis on including the voices of people with intellectual disabilities in research and practice. Although including the perspective of people with PIMD in the assessment procedure is challenging, there are several approaches in which their perspectives can be incorporated, such as including their parents as advocates, or using observations (Maes et al., 2020). We found that the inclusion of parents in assessment and observation was frequently mentioned as an assessment method. In addition, the perspective of people with PIMD can be included in support by carefully listening to their communication signals, such as gestures, facial expressions and sounds. In our study, we found that communication is often the focus of assessment, indicating that

TABLE 6 Assessment instruments for which information on psychometric quality was available for people with PIMD

Name of instrument	Type	Domain	Target group for which it was developed	Information about psychometric properties
Inventory of the Personal Profile and Support (IPS) (Vlaskamp et al., 2016)	Questionnaire	The support the person with PIMD receives and the context of support, the abilities of the person with PIMD in relation to significant others	Children and adults with PIMD	In a pilot study, feasibility ($N = 8$) and content validity ($N = 6$) was evaluated in five men and three women (aged 22–68) with PIMD. Direct support professionals and healthcare psychologists were asked to fill in two questionnaires about the feasibility and content validity of the IPS. The majority of the professionals indicated that items of the IPS were clear and understood and that the IPS provided a good impression of the support profile of a person with PIMD. In general, usability and content validity were rated as good (Wessels & Van der Putten, 2017).
Behavioural Appraisal Scales (BAS) (Vlaskamp et al., 1999)	Observation, test and questionnaire	Functional abilities, in five domains: emotional communicative behaviour, receptive language behaviour, general communicative behaviour, visual behaviour and exploratory behaviour	Children and adults with PIMD	Using a principal component analysis with varimax rotation ($N = 96$), five factors were found that explained 55% of the variance. Cronbach's alpha was .96 or higher for all factors. The same study looked at interrater reliability for 44 participants. Correlation coefficients were .93 or higher for the scores on four of the five subscales and .47 for the other subscale. Convergent validity was studied by correlating the BAS with the IPS. Reliability was good and content validity acceptable, but further studies are needed for convergent validity (Vlaskamp et al., 2002).
Pain Behaviour Checklist (Terstegen, 2004)	Observation	Pain	Children with profound cognitive impairments	Validity and interrater reliability of measuring pain in daily practice were evaluated in children and adults with PIMD. As measured with Spearman's rho, both interrater reliability ($.63, p < .05$) and intrarater reliability ($.88, p < .05$) were satisfactory. Validity was analysed by correlating the PBC with the Visual Analogue Scale (VAS). Phi was calculated as a measure of agreement and was .75 ($p < .05$) for children ($n = 16$) and .28 ($p < .05$) for adults ($n = 16$). Validity was stated as good for children, but insufficient for adults (Van der Putten & Vlaskamp, 2011).
Alertness Observation List (Munde et al., 2011)	Observation	Alertness	Children/ adolescents with a profound intellectual disability	Alertness was scored by two observers in 23 children with PIMD in 39 situations to investigate inter-observer reliability. For another 39 situations, intra-observer agreement was calculated. Inter-observer reliability was $r = 81\%$ ($Mdn = 81.44$; $M = 81.46$; $SD = 13.88$) and intra-observer reliability was $r = 87\%$ ($Mdn = 86.79$; $M = 85.23$; $SD = 11.75$). However, it was noted that there were large differences between individuals: inter-observer reliability ranged from 50% to 100% ($SD = 13.88$) and intra-observer reliability ranged from 61.1% to 100% ($SD = 11.75$). It was recommended that usefulness in clinical practice should be further studied (Munde et al., 2011).

(Continues)

TABLE 6 (Continues)

Name of instrument	Type	Domain	Target group for which it was developed	Information about psychometric properties
Movakic (Mensch et al., 2015a; Mensch et al., 2016; Mensch et al., 2015b)	Questionnaire	Motor abilities	Children with severe, multiple and complex disabilities	Intra-class correlations (ICC) to evaluate test-retest reliability in children with PIMD were $ICC = .72-.98$ ($n = 50$). Moreover, adequate test-retest reliability was reflected in the small differences in the mean Movakic scores, for the test-retest reliability 6.8 ($SD = 6.4$, $n = 50$) and interrater reliability 8.6 ($SD = 8.7$, $n = 19$) (Mensch et al., 2015). Construct validity was evaluated as good by correlating the Movakic with expert judgement ($N = 60$ children), which resulted in correlations of $r = .50-.71$. Mean score changes and intra-class correlations were analysed to assess responsiveness in a 3-month interval (in which some children experienced meaningful events for developing motor abilities and others did not) (Mensch et al., 2016). Mean scores were significantly higher after events than when such events did not occur ($t = 2.21$; $p = .03$). ICCs of T0 and T1 were lower in the event group ($ICC = 0.78$) than in the group in which no events occurred ($ICC = 0.95$). Responsiveness was evaluated as good (Mensch et al., 2016). In an expert focus group, content validity and feasibility were determined as good in people with PIMD (Mensch et al., 2015).
Modified Ashworth Scale (MAS) (Bohannon & Smith, 1987)	Observation	Spasticity and muscle tone	Patients with neurological conditions	Feasibility of the MAS was good in adults with PIMD. Both the interrater reliability ($N = 23$) and test-retest reliability ($N = 33$, $N = 35$) were sufficient, with a substantial to almost perfect quadratically weighted kappa (>0.8) and an acceptable ICC (>0.8). The MAS was determined as a good measurement for evaluating daily movements in people with PIMD (Waninge et al., 2011).
(Modified) Tardieu Scale (Haugh et al., 2006; Mackey et al., 2004)	Observation	Spasticity and muscle tone	Children and adults with cerebral palsy	A modified version of the Tardieu Scale was developed by Waninge and colleagues. Feasibility of the Modified Tardieu Scale was good in adults with PIMD. Because of the insufficient ICCs, Spearman's correlations and large limits of agreements, which are clinically unacceptable, intrater reliability ($N = 33$, $N = 34$) was insufficient. The ICCs for the interrater reliability were sufficient ($N = 23$, $N = 24$), but limits of agreements were large, which was reported as being clinically unacceptable (Waninge et al., 2011).
Behavior Problem Inventory (BPI) (Rojahn et al., 2001)	Behaviour rating scale	Challenging behaviour	People with varying degrees of intellectual disability	A revised version of the BPI was developed for people with PIMD by Poppes et al., (2016). Reliability was measured with Cronbach's alpha in general ($\alpha = .85$) and for the different subscales (Self Injurious Behaviour, $\alpha = .48$; Stereotypical Behaviour, $\alpha = .81$; Withdrawn Behaviour, $\alpha = .73$; Aggressive Destructive Behaviour, $\alpha = .83$) ($N = 198$). These findings are in accordance with values of Cronbach's alpha found in other studies. Therefore, reliability as measured with Cronbach's alpha was evaluated as good.

understanding the communication signals is an important domain in supporting people with PIMD.

This study focused on the extent to which assessment is adapted to the needs of people with PIMD. Based on our results, we can conclude that assessment in this group is generally of an interdisciplinary nature (Lyons et al., 2016), as many different professionals are involved in the assessment process and information from the various professionals is often integrated into one report (Vlaskamp, 2005). In addition, it has been suggested that assessment instruments should take into account the complexity and interrelatedness of disabilities and the possible atypical development of people with PIMD (Van der Putten et al., 2017). Instruments developed for other groups may not be applicable to this group for aims such as support planning, because of the complex and unique disability pattern of people with PIMD (Van der Putten et al., 2017). The majority of professionals reported using assessment methods that were not specifically developed for this group. The results of the current study show that professionals use both published and unpublished methods for assessing people with PIMD. The same was shown by the findings of Chadwick et al., (2018), who found that speech and language therapists often use unpublished methods to assess communication in people with PIMD. In our study, professionals most frequently used observations that can provide valuable information about the individual concerned. Observations have advantages over other assessment methods for people with PIMD, as they take into account the idiosyncratic and unconventional communication of this group. Nevertheless, there are also general disadvantages associated with observing people with PIMD (Munde et al., 2011). Observation is time-consuming and is based on ascribing meaning to behaviour, which means that it relies on interpretation. Several factors, such as previous experiences and expectations, can bias interpretation, which can lead to low reliability for the observation (Hiemstra et al., 2007; Munde et al., 2011). For example, Vlaskamp and Cuppen-Fontaine (2007) studied the reliability of an adjusted checklist to assess the sensory perception of children with PIMD, and found that the reliability of the checklist was dependent on whether or not the person who rated the behaviour was familiar with the child. They suggested that not knowing the child may result in overlooking certain signals or misinterpreting that child's behaviour. Therefore, although observation can yield valuable information, it is important to critically reflect on the observation schemes and outcomes.

Finally, we investigated whether the psychometric properties of assessment instruments were examined for people with PIMD. For 108 of 116 different instruments, no information could be found about their psychometric properties for this group. Initial results about aspects of psychometric properties were promising for only seven of the instruments, but further studies that examine different aspects of psychometric properties, using a variety of methods, are needed. Therefore, we conclude that information about the psychometric properties of assessment instruments used in practice for people with PIMD is scarce, which means that the quality of the instruments that are used is unknown. The majority of professionals considered this lack of available instruments problematic or highly problematic.

This is consistent with the conclusions of Carnaby (2007), who started 12 years ago that there were few standardised assessment methods that were relevant to the assessment of abilities and developmental functioning in people with PIMD. Although the number of published studies in this area have increased in recent decades (Van der Putten et al., 2015), several challenges regarding research in the field of PIMD remain, including a lack of available instruments and a paucity of theoretical models that are necessary for the development of assessment instruments. Moreover, the lack of information about the reliability and validity of measures, has major implications in terms of ensuring the quality of research (Maes et al., 2020). In line with the study by Maes et al., (2020), we found that a lack of available assessment instruments is still viewed as a barrier by most professionals who work with people with PIMD. This lack of evidence-based practice is consistent with the findings of other studies in the field of PIMD. Van Alphen et al., (2019) examined the quality of motor initiatives used by professionals in the support of people with PIMD. Results of that study showed that a wide variety of motor initiatives were used, although their effectiveness is unknown. Chadwick et al., (2018) studied the communication assessment practices, and concluded that more research is needed focusing on the quality of assessment instruments. A remarkable finding was that no published methods whose psychometric properties were subjected to analysis were mentioned at all for some domains, such as quality of life, despite instruments being available whose psychometric properties were analysed for people with PIMD. An example is Quality of Life-PMD (Petry et al., 2009; Petry et al., 2016). The quality of assessment methods that are used in practice for people with PIMD could therefore be improved. Of the assessment instruments whose psychometric properties were examined, the majority focus on a single domain instead of taking a holistic perspective which one would expect from a person-centred approach. As a consequence, professionals are forced to search for and use (and combine) information from different instruments and assessment methods in order to gain a more holistic understanding of the needs, aspirations and preferences of persons with PIMD.

4.1 | Methodological reflection

The person-centred approach is a complex, multicomponent construct, and the operationalisation we used for the questions in our survey, may have affected the input professionals provided. For example we did not specifically ask to what extent professionals assessed the aspirations, needs and preferences of people with PIMD. Nevertheless, to our knowledge, our study is the first to provide an overview of the extent to which assessment is in line with several aspects of the person-centred approach, such as the focus on assessing multiple domains and on the inclusion of the social network. or our literature search, we formulated quite strict inclusion criteria for our target group. However, studies use various definitions to describe this target group (Nakken & Vlaskamp, 2007); for instance, 'people with severe intellectual and motor disabilities' or 'people with severe multiple disabilities'. As a consequence, we may have missed some articles by using the definition PIMD (Nakken

& Vlaskamp, 2007) as a search term. However, we also included the search term 'intellectual disability' and checked the participant description of articles found when using these terms to ensure that these articles were included if they focused on people with PIMD. In this way, we tried to limit the risk of overlooking relevant information about our target group. However, we may well have missed information on published manuals, as these manuals, though available from test developers and publishers, are often not yielded by an online literature search. Moreover, as information about psychometric properties reported in manuals is not always published in peer-reviewed journals, this information is often not readable accessible. As the availability of relevant information is essential for professionals and researchers in order to better determine which instrument to use, this information should be made more easily accessible, for example, through an open-access database. Professionals can use this information to make informed decisions about which instruments are most appropriate to use. We also examined the Dutch digital database of COTAN, which contains excerpts of research conducted on psychological tests that are available for use in The Netherlands. However, we did not find any additional results. It should be noted that some of the published instruments identified in this study were developed for a target group closely related to that of people with PIMD, for example people with profound intellectual or with severe intellectual disabilities and behavioural problems. However, due to the complex and intertwining (e.g. behavioural, biological, environmental, interactional) factors related to PIMD, and the complex support needs of persons with PIMD, the results obtained using instruments that were developed for a slightly different group need to be interpreted with caution until the psychometric properties for the specific PIMD subgroup are known. Nevertheless, these instruments are potentially promising for use with people with PIMD and could serve as a starting point when developing assessment instruments for this group.

A strength of our study is that we managed to assemble a varied group of professionals by recruiting internationally, on different platforms, and that we included professionals across a wide range of occupations and types of organisation. In order to obtain a realistic and adequate overview of assessment methods, we allowed multiple entries, as professionals often use multiple methods. However, several limitations of this study need to be considered when interpreting the results. Firstly, the authors of the present article are all from The Netherlands. Although an extensive search was conducted to find information on every relevant assessment instrument, more information may have been found on instruments that were developed in The Netherlands, which were perhaps more familiar to the authors. Moreover, data are missing since some respondents did not complete all the questions in the survey. Missing data were handled by including all of the information that professionals had filled in. This approach has disadvantages as it can lead to bias, depending on whether missingness is 'missing at random' or 'missing not at random'. As demographic information was collected in the last part of the questionnaire, we did not have information about the group with missing data, and we could therefore not analyse whether there were differences between the groups with and without missing data. The way participants handle the questionnaire can also potentially

lead to bias (finishing the questionnaire versus dropping out). A possible reason for dropout is participant fatigue, due, for example, to the considerable length of our questionnaire. Another reason could be that the questions were difficult to understand for some participants (Hochheimer et al., 2016; Rolstad et al., 2011). It is plausible to assume that professionals who were more involved in the research and more aware of the importance of the (psychometric) quality of the instruments they use, were more likely to finish the questionnaire. This could imply that the number of valid and reliable assessment methods used in practice is even lower than was found in this study. This study was performed in three European countries. Consequently, the results cannot be generalised to other contexts, such as other countries. International collaboration, for example within the Special Interest Research Group PIMD and sharing research results on an international level, is crucial for knowledge development in this field. Future studies could focus on other countries as well, as instruments from other countries may have been missed.

4.2 | Implications for practice

There is a clear need for more guidelines in assessing people with PIMD and for increased visibility of suitable and available high-quality methods. Several instruments have been developed and analysed for people with PIMD (Van der Putten et al., 2015), but the results of the present study suggest that these are not used in practice. The transfer of information from scientific studies about assessment methods into practice needs to be improved further, so as to stimulate the use of assessment instruments with sound psychometric properties.

4.3 | Future directions for research

The current study focused on the assessment practices and information about psychometric properties of assessment instruments that are used in The Netherlands, Germany and the United Kingdom. As a next step, it would be advisable to provide an overview of all assessment methods that are available globally, as in this way, guidance could be provided to professionals on the use of instruments whose psychometric properties were examined, and that are suitable for assessment in people with PIMD. Future research could expand on our findings by performing an international, systematic review. Further studies could also focus on the development of assessment instruments with sound psychometric properties that can be used for people with PIMD, preferably instruments that aim to gain a holistic view of the needs, preferences and aspirations of the person with PIMD. Several published assessment methods in this study were developed for subgroups related to people with PIMD, and they, therefore, seem promising in terms of providing reliable and valid information about the needs, wishes and abilities of people with PIMD. Some instruments may contain practice-based evidence about their quality, and some studies on psychometric properties

may not have been published in a scientific peer-reviewed journal. These studies and instruments could also be a starting point for the further analysis of psychometric quality.

5 | CONCLUSION

The person-centred approach seems to be reflected in the assessment practices described by professionals for people with PIMD in everyday practice in three European countries. However, the quality of the assessment methods for this group is uncertain, as no information about psychometric properties is available for most of the assessment methods used. Of all 116 assessment instruments mentioned by professionals, information about the psychometric properties of instruments suitable to assess people with PIMD was found for only eight instruments. Of these eight, the majority focused on one single domain rather than taking a holistic view. Initial results on psychometric properties were promising for seven instruments, and only one instrument was evaluated in several studies. Moreover, some instruments that were not examined for people with PIMD were not mentioned as being used at all. In conclusion, for the instruments that are used for people with PIMD in everyday practice in Germany, The Netherlands and the United Kingdom, little information could be found about their psychometric properties for this group, even though there are some instruments available whose psychometric properties were subjected to analysis for this group. It is therefore paramount that the validity and reliability of assessment methods should be examined, as this would lead to a more accurate assessment of the skills, needs and preferences of people with PIMD, and make a form of support possible that is better adapted to their needs.

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CONFLICT OF INTEREST

There are no conflicts of interest.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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APPENDIX A

Table A1. Questionnaire about assessment methods in people with PIMD

Question	Categories	Scoring options
1. Which assessment instruments/assessment procedures do you use most frequently? <i>For each assessment instrument/assessment method, the following follow-up questions were asked:</i>		Open question, maximum of five assessment methods
1.1 What does the instrument/assessment method measure? (Multiple answers possible)		Communication, functional abilities, motor skills, sensory/perceptual skills, social adaptive behaviour, social emotional development, cognitive functioning, physical health, quality of life, mental health, other
1.2 What is the type of instrument/assessment method? (Multiple answers possible)		Standardized test, questionnaire, checklist or scale, observation, interview, other
1.3 Who fills in the instrument/assessment method? (Multiple answers possible)		(Developmental) psychologist, physician, direct support professional, physiotherapist, speech therapist, parents (legal guardians).
1.4 How often do you use this instrument/assessment procedure for the purposes mentioned below?	Screening, eligibility, programme planning, progress monitoring, programme evaluation, diagnosis, other	Never, seldom, sometimes, often or always
1.5 What are the reasons for choosing this specific assessment instrument/assessment method?	Feasibility, the specific outcomes of the method, availability, knowledge about the method within the organization, possibility of adapting the method to PIMD, psychometric qualities, costs and that the method was specifically developed for PIMD	Not important, of little importance, neutral, important, very important
1.6 Was this instrument/assessment method specifically developed for the target group?		Yes, no, I don't know
1.7 Did you adapt it for people with PIMD?		Yes, no, I don't know
1.8 Is this instrument/assessment method filled in by more than one person?		Yes, no, I don't know
1.9 Has information from the different people been integrated?		Yes, no, I don't know
2. Could you indicate to what extent you experience the barriers mentioned below?	Lack of available methods, communication problems of people with PIMD, health problems of people with PIMD, low alertness of people with PIMD, large number of professionals involved, lack of appropriate resources	Not challenging, slightly challenging, neutral, challenging, very challenging