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# Risk factors associated with challenging behaviour in people with profound intellectual and multiple disabilities

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## Abstract

**Background** Several factors that correlate with the onset or continuation of challenging behaviour are mentioned in research. These are factors related to persons with ID, but also to direct support professionals and the context. Although many of these factors seem to affect the onset or continuation of challenging behaviour in people with ID in general, results are often inconclusive and have little focus on people with profound intellectual and multiple disabilities (PIMD). The present study aimed to assess the extent to which known factors related to challenging behaviour are also applicable to a group of 198 people with PIMD.

**Method** To determine which factors were associated with challenging behaviour, univariate analyses on associations between known risk factors and challenging behaviour were conducted. The associated factors were then subject to a regression analysis to determine the extent to which they explain the prevalence of challenging behaviour and can thus be seen as factors associated with challenging behaviour.

**Results** The results show that, in particular, factors concerning the personal characteristics of people with PIMD, such as sleeping problems and auditory problems, were related to the variance in mean

frequency of challenging behaviour. Only one factor related to the direct support professionals was found: when these professionals had been offered training on the subject of challenging behaviour in people with intellectual disabilities in general, they identified significantly more withdrawn behaviour. We found no contextual factors related to challenging behaviour.

**Conclusion** These findings are generally consistent with findings reported in other studies, especially concerning the personal characteristics of people with PIMD. Further research should focus on the effects of providing safe auditory environments and appropriate sleep schedules for people with PIMD on the occurrence of challenging behaviour.

**Keywords** challenging behaviour, profound intellectual and multiple disabilities, risk factors

## Introduction

Recent decades have provided ample research findings on the prevalence of challenging behaviour in people with intellectual disabilities. These studies show that individuals with intellectual disabilities are more at risk of displaying challenging behaviour than the average population. Studies show a varying prevalence of challenging behaviour in people with intellectual disabilities, from 5% to 15% in large population-based studies (e.g. Emerson *et al.* 2001; Holden & Gitlesen 2006). Rojahn *et al.* (2001) state that challenging behaviour includes self-injury, stereotypes

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and aggression or destructiveness. Self-injurious behaviour is defined as 'behaviour that can cause damage to the person's own body and that occurs repeatedly and in an essentially unvarying manner' (Rojahn *et al.* 2001) and includes hitting one's head with one's hand or another body part, biting oneself, hair-pulling and so on. Stereotypical behaviour is described as 'repeated uniform body movements or postures that are obviously not part of some goal-directed act' (Rojahn *et al.* 2001) and includes rocking and twirling, twisting or smelling objects.

Aggressive/destructive behaviour is defined as 'an offensive action or a deliberate overt attack directed towards people or objects' and includes grabbing, pulling and hitting others and so on (Rojahn *et al.* 2001). Poppes *et al.* (2010) found that challenging behaviours frequently occurs in people with profound intellectual and multiple disabilities (PIMD). Self-injurious and stereotypical behaviour occurred in most cases on a daily or even hourly basis. Also, socially withdrawn behaviour occurs frequently in people with PIMD. Vlaskamp *et al.* (1997) described 'lack of contact-making' in people with PIMD as a challenging behaviour. When a person abandons all attempts to make contact with their environment, this will influence their capacity to gain life experiences and develop. Challenging behaviour is considered a major problem because the various behaviours can be difficult for direct support professionals (DSPs) to manage and can be harmful both to the person exhibiting them and to others. For the individual, these behaviours may interfere with learning and development and limit participation in social activities (Murphy *et al.* 2005; Holden & Gitlesen 2006).

People with PIMD have an estimated intelligence quotient of 25 or lower and severe or profound motor impairments, reflected in not being able to walk independently and having limited use of hands/arms (Nakken & Vlaskamp 2007). They are non-verbal and have difficulty with receptive or expressive communication. In addition, this target group frequently suffers from sensory problems (Zijlstra & Vlaskamp 2005) and additional problems, such as epilepsy (Codling & MacDonald 2009), constipation (Böhmer *et al.* 2001), sleep disorders (Drenth, Poppes, & Vlaskamp 2007; Hylkema & Vlaskamp 2009), recurring respiratory tract infections or breathing problems (Zijlstra & Vlaskamp 2005), dental problems (Gardner 2002), eating and drinking

problems (Zijlstra & Vlaskamp 2005) and gastro-oesophageal reflux disease (Böhmer *et al.* 2000). Furthermore, they are more likely to suffer from pain because, for example, of constipation, pulmonary or respiratory problems or dental problems (Watt-Smith 2009; Van der Putten & Vlaskamp 2011).

Several factors have been found to be related to the onset or continuation of challenging behaviour (Emerson *et al.* 2001; Došen *et al.* 2007; De Winter, Jansen, & Evenhuis 2011). These factors not only concerned the person with ID but also the DSPs and the context. Personal factors include gender, age, level of ID, level of motor disability, level of functional disability, stress and health problems. With regard to gender, the literature is not conclusive on this issue. According to several authors (Sigafos *et al.* 1994; Emerson *et al.* 2001; Lowe *et al.* 2007), boys and men show more challenging behaviour in general, especially aggressive/destructive behaviour. This relationship appears more pronounced in relation to aggression and property destruction, occurs more often in institutional settings and is more prevalent in people with more severe challenging behaviour. However, Lundqvist (2013) reported that women showed more aggressive/destructive behaviour than men. Other studies (Chadwick *et al.* 2000; Baghdadli *et al.* 2003) found no significant differences between men and women in the occurrence of challenging behaviour. However, these studies focused on people with mild-to-severe intellectual disabilities and were not aimed at people with PIMD.

Studies show that challenging behaviour increases with age, reaching a peak during middle age and then declining with old age (Oliver, Murphy, & Corbett 1987; Holden & Gitlesen 2006; Jones *et al.* 2008). Lundqvist (2013) reported a second peak among those who were 70 years or older. These studies were aimed at people with ID in general, and thus, we lack specific knowledge on how age is related to the occurrence of challenging behaviour in children and adults with PIMD.

Many studies show that the prevalence of challenging behaviour increases when the level of ID is more severe (Emerson *et al.* 2001; Crocker *et al.* 2006; Holden & Gitlesen 2006; Cooper *et al.* 2009; Lundqvist 2013; Tureck, Matson, & Beighley 2013). A study into the prevalence of challenging behaviour in persons with PIMD indeed confirmed high prevalence rates in people with profound and severe ID (Poppes *et al.* 2010).

Commenting on withdrawn behaviour, Oliver *et al.* (1987) noted that the severity of the ID may be linked with the occurrence of this type of behaviour. Wulffaert *et al.* (2009) also concluded that withdrawn behaviour occurs more frequently in people with a severe ID. The same is true for the severity of motor disabilities (Emerson *et al.* 2001). Functional disorders (e.g. difficulty with receptive or expressive communication) can lead to problems with communication and therefore to the occurrence of challenging behaviour (Sheehy & Nind 2005; Forster *et al.* 2011). Failing to regulate stress due to an insecure sense of attachment in relationships also seems to be related to challenging behaviour in people with moderate-to-profound intellectual disabilities (Schuengel & Janssen 2006; De Schipper & Schuengel 2010).

Many health problems are associated with an increase in challenging behaviour although information on how this is related to challenging behaviour in people with PIMD is scarce. Sensory impairments in people with ID (Rojahn 1986; Oliver *et al.* 1993; Emerson *et al.* 2001) are associated with challenging behaviour. Visual impairments increase the risk of self-injurious behaviour (De Winter *et al.* 2011), stereotypical behaviour and aggressive/destructive behaviour (Lundqvist 2013). According to Poppes *et al.* (2010), the mean for self-injurious behaviour was higher in blind people with PIMD than in people who had poor eyesight or no visual problems. Furthermore, people with PIMD who had tactile dysfunctions scored significantly higher on self-injurious behaviour, stereotypical behaviour and challenging behaviour overall than those who had no tactile disorders (Poppes *et al.* 2010). Challenging behaviour has also been found to occur more frequently in children with auditory limitations (Wieseler, Hanson, & Nord 1995; Došen 2007). However, these studies on the effects of auditory problems on the occurrence of challenging behaviour were, again, not specifically aimed at people with PIMD.

Although studies on the influence of epilepsy on challenging behaviour are not conclusive, there are reports of an increased prevalence of challenging behaviour in people with epilepsy and additional impairments such as visual problems and motor impairments, both in general and in relation to specific forms of epilepsy (De Winter *et al.* 2011). Again, these studies were not specifically aimed at people with PIMD. When sleeping problems exist, people with mild-to-profound intellectual disabilities are more likely

to show challenging behaviour (Didden *et al.* 2002; Rojahn *et al.* 2004; Lundqvist 2013). When bowel and/or abdominal problems are present, for example, gastro-oesophageal reflux disease, some studies show significantly more challenging behaviour (Gössler *et al.* 2007). People with PIMD are more likely to suffer from chronic pain because of such issues as bowel and abdominal problems, respiratory disorders, dental problems or deformities of the spine, and this chronic pain can lead to more challenging behaviour (Breau *et al.* 2003; Oliver & Richards 2010). Another factor associated with challenging behaviour is mental health problems (Ross & Oliver 2002; Rojahn *et al.* 2004; Došen 2007). However, studies to date do not focus on people with PIMD.

Factors related to DSPs are work experience, level of education and the number of hours DSPs work. Wanless & Jahoda (2002) found that younger, more inexperienced DSPs identify more challenging behaviour in people with profound ID than older, more experienced DSPs. The number of hours a DSP works per week is also linked to the signalling of challenging behaviour according to research by Lambrechts & Maes (2009). DSPs who work more than 50% of the week identify more stereotypical and aggressive/destructive behaviour in people with profound ID than DSPs who work less than 50% of the week. The educational level of the DSPs showed a non-significant contribution to the identification of the different types of challenging behaviour (Lambrechts & Maes 2009).

With regard to contextual factors, Emerson *et al.* (2001) discuss the correlates between the level of restrictiveness in the person's residential placement and the occurrence of challenging behaviour. Some studies found that smaller scale living arrangements (1–6 places) produced less challenging behaviour, while in larger facilities, more challenging behaviour was seen, especially aggressive and destructive behaviours (Emerson *et al.* 2001). However, the literature on this is not conclusive and not aimed specifically at people with PIMD.

Although many of these factors seem to affect the onset or maintenance of challenging behaviour in people with ID in general, the results are often inconclusive and were mostly aimed at people with ID in general. It is not clear if these factors are also related to the occurrence of challenging behaviour in children and adults with PIMD. Forster *et al.* (2011) found in their research on

behavioural and emotional problems in a group of people with severe and a group of people with profound ID that there are significant differences between these groups regarding challenging behaviour and emotional problems. They suggest that these two groups should be treated as single groups in research. Because the research carried out regarding risk factors related to challenging behaviour so far in this field has not focused on people with PIMD, we were interested in such factors in this specific target group. These factors might give us more insight into the background and development of challenging behaviour in this target group. Furthermore, this knowledge may also guide the development of interventions to diminish or prevent challenging behaviour in people with PIMD. Therefore, the aim of this study was to determine whether known factors for challenging behaviour are also applicable to people with PIMD. The aforementioned known risk factors related to persons with PIMD, DSPs and context were included. In addition, the effect of training on challenging behaviour in people with intellectual disabilities in general was also considered. It is possible that DSPs who are trained to identify and treat challenging behaviour may influence the reported presence or absence of challenging behaviour. The number of day-service sessions was also included as a possible influential contextual factor, as activities structure and give rhythm to the day and reduce the number of 'empty hours'. An association between inactivity and challenging behaviour has been found in several studies (Ogg-Groenendaal, Hermans, & Claessens 2014). Participating in activities promotes opportunities to establish and maintain relationships and to experience positive feelings. It is possible that providing structure and variety by means of activities is thus important in the prevention and reduction of challenging behaviour.

## Method

### Participants

Participants were recruited from 10 organizations throughout the Netherlands on the basis of the following inclusion criteria:

- having a profound ID (IQ of 25 or below);
- a profound or severe motor disability (manifest in an inability to move independently); and

- the age of onset before the 18 years (Nakken & Vlaskamp 2007).

A convenience sample of a total of 198 people with PIMD was retrieved. Fifty-one were children and 146 adults (for one person, the age was missing).

Informed consent, including written permission for participation in this study, was given by the parent(s) or legal representatives of the participating persons.

### Measures

For each participant, a semi-structured questionnaire was completed by the DSP to determine the personal characteristics of the person with PIMD, such as age, gender (male/female), the prevalence of sensory problems and chronic health problems (yes/no/I do not know). Moreover, six questions related to the personal characteristics of the DSPs were included, such as gender (male/female), age of the DSP (in years) and the number of years of work experience with people with ID in general and people with PIMD in particular. We also gathered information about their contract in terms of hours worked per week. For the educational level, DSPs could choose between two options: vocational education or college. Furthermore, we wanted to know whether or not DSPs had received some sort of training on challenging behaviour in people with intellectual disabilities (yes/no). Contextual factors regarding people with PIMD were covered by four questions about the following: (1) living arrangements (residential facility, community living and living at home); (2) size of the group (number of residents); (3) number of staff; and (4) number of day-service sessions per week.

Challenging behaviour was identified using the Dutch revised version of the Behavior Problem Inventory (BPI) (Lambrechts & Maes 2009). The original version of the BPI-01 (Rojahn *et al.* 2001) provides information about the prevalence, frequency and severity of challenging behaviour in people with ID in general. The BPI is an informant-based scale that addresses three types of challenging behaviour: self-injurious behaviour, stereotypical behaviour and aggressive/destructive behaviour. Self-injurious behaviour is defined as 'behaviour that can cause damage to the person's own body and that occurs repeatedly and in an essentially unvarying manner'

(Rojahn *et al.* 2001). Stereotypical behaviour is described as ‘repeated uniform body movements or postures that are obviously not part of some goal-directed act’ (Rojahn *et al.* 2001).

Aggressive/destructive behaviour is defined as ‘an offensive action or a deliberate overt attack directed towards people or objects’ (Rojahn *et al.* 2001). The BPI-01 (Rojahn *et al.* 2001) consists of 52 items within the three specified categories: self-injurious behaviour (14 items), stereotypical behaviour (24 items) and aggressive/destructive behaviour (11 items). Each sub-scale also has an additional item, allowing respondents to add any behaviour not already included in the list of items, as long as it meets the definition of the targeted challenging behaviour. Each item is scored on two scales: (1) a frequency scale, 0 = the behaviour does not occur, 1 = the behaviour occurs every month, 2 = weekly, 3 = daily and 4 = every hour and (2) a severity scale, ranging from slight (1) to severe (3).

Some adaptations were made to the BPI-01 to increase its applicability to people with PIMD. The original version of the BPI includes items that assume a certain level of motor skills: ‘running around’, ‘jumping around’ and ‘pacing up and down’. People with PIMD cannot score positively on these three items, so they were omitted. Three items that were often mentioned in the BPI-01 under the category ‘other’ when administered to people with PIMD – ‘throwing objects’, ‘sucking on objects’ and ‘masturbating in public’ – were included (Poppes *et al.* 2010) because of their frequent occurrence. The item ‘throwing objects’ was added to the aggressive/destructive behaviour sub-scale, and the latter two to the stereotypical behaviour sub-scale. Another frequently mentioned type of behaviour was ‘withdrawn behaviour’, such as having a closed, sagging posture or making repelling gestures in response to activities that were offered. To date, this behaviour could not be scored on the BPI. However, withdrawn behaviour can influence the possibilities of a person gaining experience and actively participating in society as much as behaviours such as self-injurious behaviour, stereotypical behaviour and aggressive/destructive behaviour. Given the frequent mention of such behaviour by professionals, we decided to include withdrawn behaviour in the revised version of the BPI and defined it as ‘behaviour that is hardly outwardly directed and in which a

defensive response is seen as a reaction to contact offered by others and/or a repelling response to stimuli is seen (regardless of the type of stimuli)’ (Kraijer 2004; Poppes *et al.* 2010).

This revised BPI for people with PIMD (BPI-PIMD) consists of 58 items within the four specified categories: self-injurious behaviour (15 items), stereotypical behaviour (22 items), withdrawn behaviour (five items) and aggressive/destructive behaviour (12 items). Each sub-scale also has an additional item allowing respondents to add any behaviour not included in the list of items, as long as it meets the definition of the targeted challenging behaviour. The BPI-PIMD was scored by one DSP who was linked to one person with PIMD.

The psychometric properties of the original BPI are good (Rojahn *et al.* 2001; González *et al.* 2009; Van Ingen *et al.* 2010). These findings are in line with studies by Dumont *et al.* (2014) and Lambrechts & Maes (2009) into the psychometric properties of the Dutch translation of the BPI-01 for people with a profound ID. The internal consistency of the entire scale, measured with Cronbach’s alpha, ranges from good to excellent. The internal consistency of the self-injurious behaviour sub-scale was moderate in all the aforementioned studies, ranging from 0.40 to 0.63. The test–retest reliability of the frequency scale was good to excellent (Lambrechts & Maes 2009). Because the BPI-PIMD was altered and only used for people with PIMD, we calculated the internal consistency in general ( $\alpha = 0.85$ ) and for the different sub-scales (self-injurious behaviour,  $\alpha = 0.48$ ; stereotypical behaviour,  $\alpha = 0.81$ ; withdrawn behaviour,  $\alpha = 0.73$ ; and aggressive/destructive behaviour,  $\alpha = 0.83$ ). These findings are in line with other research into the internal consistency of the BPI (Rojahn *et al.* 2001; Lambrechts & Maes 2009; Dumont *et al.* 2014).

## Procedure

Organizations were asked to participate in this research through mailings but also through calls in information bulletins of a national knowledge network in the field of people with PIMD in the Netherlands. Organizations who indicated that they wanted to cooperate in this study received a letter with more information about the research and practical guidelines. If, after reading the letter, they

still agreed to cooperate, arrangements were made to fill in the questionnaires. The DSPs then completed the BPI with respect to one person with PIMD they worked with. This happened during a meeting of the DSPs concerned and the researcher in 2013. During this meeting, all required data were collected. The participating organizations made sure that approval for the study by their ethical committees was obtained. The study was also approved by the ethical board of the university. Permission to participate in the study was given by parents or legal representatives of the person with PIMD.

### Analyses

Only the frequency scores on the BPI-PIMD were taken into account in the analysis. The mean frequency scores of each sub-scale of the BPI-PIMD (self-injurious behaviour, stereotypical behaviour, withdrawn behaviour and aggressive/destructive behaviour) were calculated in order to analyse the relationship between the occurrence of these behaviours and the factors described.

The factors related to the person with PIMD were as follows: age, gender, the prevalence of visual, auditory and tactile problems, and the prevalence of chronic health problems such as epilepsy, bowel and abdominal problems, sleeping disorders, lung and respiratory disorders, eating and drinking problems, dental problems and mental health problems. Regarding the scores on the sensory problems and health problems, we only included yes and no scores in our analyses and excluded the cases where DSPs said they did not know.

The factors related to the DSPs were as follows: gender, age, the number of years of work experience with people with ID, the number of years of work experience with people with PIMD, size of the contract in hours per week, educational level and received training on challenging behaviour in people with intellectual disabilities.

The contextual factors were as follows: the living arrangements, the size of the group, the number of staff and the number of day-service sessions per week. Regarding living arrangements, only 44 people (22%) with PIMD were living at home. To reduce the number of small groups in the analysis, it was decided that these participants would be grouped under

'community living'. The number of day-service sessions was a continuous variable, but most of the participants in this study were offered 8 to 10 day-service sessions, so we decided to split the group into two: people who received 8 to 10 day-service sessions ( $n = 135$ ) and people who received 0 to 7 day-service sessions ( $n = 38$ ).

*t*-tests and ANOVAS were used to determine which factors were associated with self-injurious behaviour, stereotypical behaviour, withdrawn behaviour and aggressive/destructive behaviour. Pearson's correlation coefficients were calculated for continuous factors. Associations with a  $p$ -value  $\leq 0.10$  were entered into a multiple regression analysis to determine the extent to which these factors could jointly explain the variance in the average frequency of challenging behaviour. Only significant variables ( $p$ -value  $\leq 0.05$ ) were included in the definitive regression model for challenging behaviour, together with significant interaction effects. Logistic regression was performed for non-normally distributed variables.

## Results

### Sample characteristics

A total of 198 people with PIMD participated. The mean age of the participants was 30.4 (SD: 16.1, range 3–67). A total of 106 were male, 92 female. There was a large number and variety of additional health problems (Table 1). On average, children and adults with PIMD were offered 8.6 sessions of day services per week (in the Netherlands, one session of day services is equivalent to 4 h, during which activities are offered to the person with PIMD), and they lived in group homes with an average of 7.8 people (SD: 2.1, range 4–13). In general, two DSPs (SD: 0.5, range 1–4) were present during the day, either in the living unit or at the day service. Most participants ( $n = 132$ ) lived in a community setting, and 61 in a residential facility. Table 1 summarizes all sample characteristics.

A total of 198 DSPs also participated. They were predominantly female (188), only nine were male and for one participant information regarding gender was missing. They had a mean age of 38.6 (SD: 11.3, range: 20–64, missing: 1). Their characteristics are shown in Table 2.

**Table 1** Characteristics of the participants with PIMD ( $n = 198$ )

	People with PIMD		Missing (N/%)
	<i>n</i>	%	
Sensory problems			
Auditory	58	29.3	7 (3.5)
Visual	113	57.1	3 (1.5)
Tactile	80	40.4	8 (4)
Health problems			
Epilepsy	128	64.6	6 (3)
Bowel and abdominal problems	148	74.7	6 (3)
Sleeping disorders	56	28.3	9 (4.5)
Lung and respiratory disorders	50	25.3	6 (3)
Eating and drinking problems	132	66.7	5 (2.5)
Dental problems	56	28.3	6 (3)
Mental health problems	39	19.7	6 (3)
Living arrangements			
Residential	61	30.8	5 (2.5)
Community	132	66.7	
	Mean	SD (range)	
Day-service sessions	8.6	2	3 (1.5)
Number of direct support professionals per home	2	0.5 (1–4)	4 (2)
Number of residents per group	7.8	2.1 (4–13)	3 (1.5)

PIMD, profound intellectual and multiple disabilities.

### Prevalence and mean frequency of challenging behaviour

Self-injurious behaviour was identified in 84.9% ( $n = 168$ ) of the participants, stereotypical behaviour in 93.4% ( $n = 185$ ), withdrawn behaviour in 84.4% ( $n = 167$ ) and aggressive/destructive behaviour in 47% ( $n = 93$ ) of the participants. Table 3 presents the mean frequencies of the different types of challenging behaviour, including items for which DSPs indicated that the behaviour did not occur.

### Associations between personal characteristics of people with profound intellectual and multiple disabilities and challenging behaviour

The average frequency of self-injurious behaviour, stereotypical behaviour, withdrawn behaviour and aggressive/destructive behaviour did not differ significantly ( $p > 0.10$ ) between the groups divided by gender, age, visual impairment and dental problems (Tables 4 and 5). To determine possible risk factors for self-injurious behaviour, the independent variables of auditory problems, tactile problems, sleeping

problems and bowel and abdominal problems were included. For stereotypical behaviour, the following variables were included: auditory problems, tactile problems, sleeping problems, mental health problems and eating and drinking problems. For withdrawn behaviour, the variables were auditory problems, tactile problems, sleeping problems, mental health problems and epilepsy, and for aggressive/destructive behaviour, the variables were auditory problems, tactile problems, sleeping problems, mental health problems and lung and respiratory problems (Tables 4 and 5).

### Associations between personal characteristics of direct support professionals and challenging behaviour

No significant differences were found for age, work experience, number of working hours or educational level of the DSPs with regard to the mean frequencies of self-injurious behaviour, stereotypical behaviour, withdrawn behaviour and aggressive/destructive behaviour (Table 4). DSPs who received training on challenging behaviour in people with an ID had a



**Table 2** Sample characteristics DSPs ( $n = 198$ )

DSPs			Missing (N/%)
Work experience (in years)			
With people with ID (mean/SD)	13.7	9.4	2 (1)
With people with profound intellectual and multiple disabilities (mean/SD)	11.0	7.7	1 (0.5)
With participant (mean/SD)	5.2	4.6	1 (0.5)
Working hours			
Working hours per week (mean/SD)	26.6	6.1	5 (2.5)
Level of education			
Vocational education (n/%)	122	61.6	19 (9.6)
College (n/%)	57	28.8	
Training on challenging behaviour in people with ID			
Training (n/%)	83	41.9	6 (3)

DSPs, direct support professionals.

higher mean frequency score on withdrawn behaviour and aggressive/destructive behaviour than DSPs without training (Table 4). This variable was included in further analyses to identify risk factors for challenging behaviour.

#### Associations between contextual factors and challenging behaviour

No significant differences were found for living arrangements, number of DSPs per home and number of residents per group in relation to mean frequencies of challenging behaviour. The mean frequency scores on aggressive/destructive behaviour were significantly higher in people who received 8–10 sessions of day services per week than people who participated in fewer sessions (Table 4). The more hours a DSP worked, the more self-injurious behaviour was identified (Table 5). The number of

day-service sessions and the number of working hours were included in further analyses.

#### Risk factor identification

Table 6 presents the final, best fitting models. Auditory problems were a risk factor for self-injurious behaviour and stereotypical behaviour; sleeping problems were a risk factor for all four types of challenging behaviour. Bowel and abdominal problems were associated with self-injurious behaviour only. Having eating and drinking difficulties increased the frequency of stereotypical behaviour. Aggressive/destructive behaviour was non-normally distributed; therefore, logistic regression was performed. More aggressive/destructive behaviour was found in people who had mental health problems and sleeping problems. However, sleeping problems and mental problems were heavily correlated in people who showed aggressive/destructive behaviour. Therefore, they could

**Table 3** Mean frequency of challenging behaviour

	Self-injurious	Stereotypical	Withdrawn	Aggressive/destructive
<i>n</i>	193	195	194	194
Mean	0.35	0.71	1.11	0.27
Median	0.31	0.59	1.00	0.00
SD	0.28	0.57	0.82	0.43
Range	0.00–1.25	0.00–3.05	0.00–3.33	0.00–2.85

Table 4 Test results for the bivariate associations between challenging behaviour variables and the personal characteristics of people with PIMD, DSPs and context

	Self-injurious behaviour			Stereotypical behaviour			Withdrawn behaviour			Aggressive/destructive behaviour		
	M (SD)	t (df)	M (SD)	t (df)	M (SD)	t (df)	M (SD)	t (df)	M (SD)	t (df)	M (SD)	t (df)
People with PIMD												
Gender												
Male	0.36 (0.28)	0.46 (191)	0.72 (0.61)	0.48 (193)	1.19 (0.83)	1.38 (192)	0.28 (0.42)	0.30 (192)				
Female	0.34 (0.34)		0.68 (0.52)		1.02 (0.80)		0.26 (0.44)					
Auditory												
No	0.32 (0.26)	-2.63 (142) <sup>***</sup>	0.64 (0.49)	-2.13 (144) <sup>**</sup>	1.01 (0.74)	-1.72 (143) <sup>*</sup>	0.22 (0.34)	-1.92 (143) <sup>*</sup>				
Yes	0.44 (0.28)		0.83 (0.61)		1.24 (0.85)		0.35 (0.52)					
Visual												
No	0.35 (0.26)	-0.06 (155)	0.71 (0.54)	-0.45 (157)	1.03 (0.72)	-0.85 (156)	0.30 (0.33)	1.34 (156)				
Yes	0.35 (0.29)		0.76 (0.62)		1.15 (0.89)		0.22 (0.37)					
Tactile												
No	0.29 (0.26)	-2.45 (142) <sup>***</sup>	0.58 (0.49)	-2.85 (144) <sup>***</sup>	0.88 (0.75)	-3.52 (144) <sup>***</sup>	0.19 (0.42)	-2.13 (144) <sup>**</sup>				
Yes	0.41 (0.29)		0.84 (0.84)		1.37 (0.88)		0.35 (0.45)					
Epilepsy												
No	0.33 (0.28)	-1.00 (184)	0.75 (0.62)	0.36 (186)	0.95 (0.77)	-2.17 (185) <sup>**</sup>	0.24 (0.31)	-0.78 (185)				
Yes	0.37 (0.28)		0.72 (0.55)		1.23 (0.83)		0.29 (0.48)					
Bowel and abdominal												
No	0.28 (0.25)	-1.75 (180) <sup>*</sup>	0.65 (0.57)	-0.67 (182)	0.94 (0.86)	-1.56 (181)	0.22 (0.37)	-0.64 (181)				
Yes	0.37 (0.28)		0.72 (0.57)		1.17 (0.81)		0.27 (0.43)					
Sleeping												
No	0.32 (0.27)	-2.57 (165) <sup>***</sup>	0.63 (0.55)	-2.79 (162) <sup>***</sup>	0.94 (0.73)	-3.09 (161) <sup>***</sup>	0.21 (0.35)	-2.86 (161) <sup>***</sup>				
Yes	0.44 (0.29)		0.90 (0.66)		1.36 (0.95)		0.41 (0.57)					
Eating and drinking												
No	0.35 (0.26)	-0.11 (187)	0.82 (0.59)	1.77 (187) <sup>*</sup>	1.09 (0.83)	-0.25 (187)	0.28 (0.37)	0.25 (187)				
Yes	0.35 (0.29)		0.66 (0.56)		1.13 (0.82)		0.26 (0.46)					
Dental												
No	0.34 (0.26)	-0.62 (166)	0.67 (0.54)	-1.62 (168)	1.06 (0.82)	-0.53 (167)	0.28 (0.45)	0.88 (167)				
Yes	0.37 (0.30)		0.82 (0.61)		1.13 (0.78)		0.22 (0.35)					
Mental health												
No	0.32 (0.28)	-1.40 (136)	0.63 (0.53)	-2.36 (138) <sup>**</sup>	0.88 (0.74)	-3.74 (137) <sup>***</sup>	0.19 (0.33)	-2.17 (137) <sup>**</sup>				
Yes	0.39 (0.24)		0.89 (0.60)		1.45 (0.91)		0.33 (0.41)					

Table 4. (Continued)

	Self-injurious behaviour		Stereotypical behaviour		Withdrawn behaviour		Aggressive/destructive behaviour	
	M (SD)	t (df)	M (SD)	t (df)	M (SD)	t (df)	M (SD)	t (df)
DSPs								
Level of education								
Vocational	0.34 (0.28)	-1.58 (173)	0.74 (0.61)	0.45 (175)	1.12 (0.83)	-0.99 (174)	0.26 (0.40)	-1.00 (174)
College	0.41 (0.28)		0.69 (0.49)		1.26 (0.78)		0.36 (0.52)	
Training CB								
No	0.37 (0.28)	1.28 (186)	0.69 (0.56)	-0.39 (188)	1.01 (0.77)	-2.14 (187)**	0.22 (0.35)	-1.89 (134)*
Yes	0.32 (0.27)		0.73 (0.60)		1.27 (0.87)		0.34 (0.52)	
Context								
Living arrangements								
Residential	0.31 (0.26)	-1.27 (187)	0.64 (0.51)	-1.20 (189)	1.14 (0.90)	0.20 (188)	0.26 (0.39)	-0.34 (188)
Community	0.37 (0.28)		0.74 (0.59)		1.12 (0.78)		0.28 (0.45)	
Day services								
0–7 sessions	0.32 (0.26)	-0.65 (189)	0.61 (0.51)	-1.17 (191)	1.09 (0.91)	-0.19 (190)	0.17 (0.28)	-2.02 (94.6)*
8–10 sessions	0.36 (0.28)		0.73 (0.58)		1.12 (0.80)		0.29 (0.46)	

M, mean; t, T-statistic; PIMD, profound intellectual and multiple disabilities; DSPs, direct support professionals.

\* $p < 0.10$ .

\*\* $p < 0.05$ .

\*\*\* $p < 0.01$ .

**Table 5** Correlation matrix between challenging behaviour variables and the personal characteristics of people with PIMD, DSPs and context

Models	Self-injurious behaviour	Stereotypical behaviour	Withdrawn behaviour	Aggressive/destructive behaviour
	<i>r</i>	<i>r</i>	<i>r</i>	<i>r</i>
People with PIMD				
Age ( <i>N</i> = 192)	-0.04	-0.06	-0.02	-0.13
DSPs				
Age ( <i>N</i> = 197)	-0.11	-0.03	0.09	0.00
Work experience ID ( <i>N</i> = 196)	-0.09	-0.03	-0.05	0.03
Work experience PIMD ( <i>N</i> = 197)	-0.14	-0.12	-0.09	0.00
Work experience person ( <i>N</i> = 197)	0.07	0.04	0.01	-0.03
Working hours ( <i>N</i> = 193)	0.15*	0.10	0.05	0.09
Context				
Size of the group ( <i>N</i> = 195)	-0.11	-0.02	0.04	0.00
Number of staff	-0.05	-0.06	-0.05	0.01

PIMD, profound intellectual and multiple disabilities; DSPs, direct support professionals; *r* = Pearson's correlation coefficient.

\**p* < 0.10.

\*\**p* < 0.05.

\*\*\**p* < 0.01.

**Table 6** Final model of risk markers for SIB, SB, WB and ADB in people with PIMD

Dependent variables	Independent variables	<i>B</i> (SE)	<i>P</i>	Model adjusted <i>R</i> <sup>2</sup>
Linear regression				
SIB	Auditory problems	-0.13 (0.05)	0.02	0.13
	Sleeping problems	-0.14 (0.05)	0.01	
	Bowel and abdominal problems	-0.11 (0.06)	0.05	
SB	Auditory problems	-0.24 (0.10)	0.02	0.08
	Sleeping problems	-0.22 (0.11)	0.04	
	Eating and drinking problems	-0.23 (0.11)	0.03	
WB	Sleeping problems	-0.42 (0.13)	0.00	0.07
	Training CB	-0.28 (0.13)	0.03	
Logistic regression		Odds ratio		
ADB	Mental health problems	2.78	0.07	

SIB, self-injurious (frequency scores); SB, stereotypical (frequency scores); WB, withdrawn (frequency scores); ADB, aggressive/destructive (prevalent or not prevalent scores); *B*, estimated regression coefficients; SE, corresponding standard error.

not both be included in the model. When DSPs received training on challenging behaviour in people with intellectual disabilities, they identified more withdrawn behaviour in people with PIMD. We did not find any interaction effects between the independent variables.

## Discussion

This study explored the relationship between identified challenging behaviour and factors in people

with PIMD. Furthermore, factors related to DSPs and factors related to contextual factors were also explored. In particular, factors regarding personal characteristics of people with PIMD were found to be related to the frequency of challenging behaviour. We found that auditory problems were related to a higher mean frequency of self-injurious behaviour and stereotypical behaviour. This is partly in line with the findings of Lundqvist (2013), who reported that people with auditory were more likely to exhibit self-

injurious and stereotypical behaviour. Having sleeping problems was associated with a higher frequency of all types of challenging behaviour (self-injurious, stereotypical, withdrawn and aggressive/destructive behaviour). Lundqvist (2013) also found that sleeping problems were a risk marker for self-injurious and stereotypical behaviour, while De Winter *et al.* (2011) concluded that people with challenging behaviour show sleep disturbances. Bowel and abdominal problems increased the frequency of self-injurious behaviour in our study. A possible explanation for this could be that conditions such as dysphagia, reflux and constipation can cause pain. Several studies have suggested that self-injury relates to pain (Breau *et al.* 2003; Symons & Danov 2005; Symons *et al.* 2009a, 2009b). For example, there is evidence that gastroesophageal reflux disease (common in people with PIMD) can cause severe visceral pain, resulting in self-injurious behaviour as a mechanism to engage descending inhibitory circuits to quell visceral pain (Peebles & Price 2012). Stereotypical behaviour has a higher frequency in people with eating and drinking problems than in people without these problems. It is not clear from the data whether these eating and drinking problems have a medical cause. It might be that the eating and drinking problems present a form of challenging behaviour. This makes it difficult to interpret the data.

When mental health problems such as anxiety and mood swings are present, aggressive/destructive behaviour is identified more frequently. This is in line with the results of Rojahn *et al.* (2004) who found that adults with a severe or profound ID who also showed self-injurious behaviour, stereotypical behaviour or aggressive/destructive behaviour generally had higher psychopathology scores than people who did not exhibit these types of behaviour. In their study, the presence of challenging behaviour increased the likelihood of almost all psychiatric conditions up to threefold. However, it is important to keep in mind that determining mental health problems in people with PIMD is extremely difficult because of the huge communicative problems they have. In addition, mental health problems in people with PIMD might have an atypical form of expression that makes it difficult to accurately diagnose these problems. It is therefore possible that mental health problems are much more common in this group than our data reflect.

In this study, we found only one factor related to the DSP. When DSPs had been offered training on the subject of challenging behaviour in people with intellectual disabilities in general, they identified significantly more withdrawn behaviour. Lowe *et al.* (2007) noted that extreme withdrawal or social avoidance often remains undiagnosed and untreated despite its large impact on a person's development and quality of life. Our results may mean that training results in a greater sensitivity to withdrawn behaviour, even if such behaviour is not as obvious as self-injurious behaviour and aggressive/destructive behaviour. Our study found no contextual factors related to challenging behaviour. Living arrangements, the number of residents the participants lived with, the number of staff and the number of day-service sessions per week seem to have no influence on whether challenging behaviour occurs or not.

There are some limitations to this study. The informants had a good knowledge of the individuals and their situation; however, it is conceivable that health problems in people with PIMD go unnoticed or undiagnosed. DSPs who worked with the participants in this study have access to the latter's individual education plans but were asked to fill out the questionnaire on health problems without these plans at hand. This could have led to the description of fewer health problems than there actually were. Moreover, diagnosing mental health problems in people with PIMD, especially in young children, is extremely difficult. Future studies should record a detailed medical history to avoid the risk of incorrect information as much as possible and should include specialized practitioners (such as psychiatrists) to identify potential mental health problems. Furthermore, young children should be considered as a single group in future research on challenging behaviour in PIMD. Also, this study had a cross-sectional design, which does not provide answers regarding the direction of causality. This makes it impossible to determine whether, for example, auditory problems cause challenging behaviour or challenging behaviour causes auditory problems.

This study was conducted with a convenience sample, and this may reduce the generalizability of the results. However, the sample consisted of 10 organizations across the country, there was a wide age range and there was an even distribution regarding

men and women. Furthermore, there were fewer missing data, and this increases the generalizability of the data.

It is remarkable that almost no factors related to DSPs and context accounted for the variance in the frequency of challenging behaviour. However, in this study, we only analysed the number of hours a person attended daytime activities; we did not include information on the content of these daytime activities. Research shows that more than half of the activities offered to people with PIMD in day services are targeted at relaxation and few activities are offered to promote development (Vlaskamp *et al.* 2007). Other studies have found an association between inactivity and challenging behaviour (Ogg-Groenendaal *et al.* 2014). It is possible that the content of activities is a more decisive factor with regard to the occurrence of challenging behaviour than the number of activities offered to people with PIMD. Future research should further explore whether there is a relationship between the type and aim of the activities offered and challenging behaviour in people with PIMD. In our study, we included participants from a wide age range (between 3 and 67 years old). It is possible that the risk factors of challenging behaviour may be different for a child than for an adult. Future research should take this into account to obtain in possible differences in factors relating to challenging behaviour between adults and children with PIMD.

Moreover, when auditory problems are present in people with PIMD, it is more likely that it will be difficult for them to develop a 'sense of place' (Van den Bosch, Andringa, & Vlaskamp 2014; Van den Bosch *et al.* 2014). A sense of place allows a person to generate expectations about the location and situation he or she is in. It is entirely possible that the auditory environment is not appropriately adapted to the needs of people in this target group, especially because we also know that visual impairments frequently occur in people with PIMD. An auditory environment that is not tailored to the individual characteristics of people with PIMD (such as a hypersensitivity to sounds) will soon lead to discomfort and a higher likelihood of challenging behaviour, such as self-injurious behaviour and withdrawn behaviour. It can also mean that people with PIMD are not able to pick up on important information and gain experience and therefore will be hindered in their development. Knowledge about creating a safe auditory

environment in group homes for people with PIMD should be provided to DSPs.

One other factor that contributed to challenging behaviour in our study was problems with sleep. Hylkema & Vlaskamp (2009) found that the cause of sleep disturbances in people with PIMD may lie in the way in which care is organized. Several studies have shown that people with intellectual disabilities often spend large amounts of time in bed because of the way routines are organized (e.g. work schedules of DSPs) within settings where they live. By implementing a non-pharmaceutical intervention that entailed an improved sleep schedule, a more suitable daily routine and/or increasing the number and extent of activities during the day, Hylkema & Vlaskamp (2009) found a significant decrease in sleeping problems. It would be interesting to analyse whether improving sleep routines in such a manner leads to a decrease in challenging behaviour in people with PIMD.

Training on challenging behaviour in people with ID seems to have an impact on the identification of withdrawn behaviour in people with PIMD. We know from earlier research that DSPs are not inclined to see challenging behaviour in people with PIMD as of serious consequence (Poppes *et al.* 2010), although the prevalence and frequency rates indicate that challenging behaviour is very common in people with PIMD. Withdrawn behaviour, in particular, is often labelled as 'being content' or 'being a quiet type of person' by DSPs. Furthermore, DSPs actually do not include challenging behaviour in their individual educational plans (Poppes, Van der Putten, & Vlaskamp 2014). Thus, it is probable that DSPs lack knowledge about challenging behaviour and its consequences in people with PIMD. Other studies (Ross & Oliver 2002) have shown that there is a tendency to see challenging behaviour as resulting from the ID rather than being symptomatic of other causes. DSPs might view challenging behaviour as a given and consequently do not feel that specific forms of support or intervention need to be undertaken. DSPs' causal attributions for challenging behaviour are likely to be important to any decision about a particular treatment for the behaviour. Tynan & Allen (2002), for example, found that staff attributed aggressive behaviour in people with severe intellectual disabilities to a biomedical model. This could mean that DSPs are less inclined to implement behavioural

interventions and may be more likely to provide pharmacological treatment (Tynan & Allen 2002). It would be interesting to aim future research at the DSPs' understanding of the causes of challenging behaviour in people with PIMD and to analyse whether training about challenging behaviour, influential risk factors and the consequences of challenging behaviour leads DSPs to label the behaviour differently and notice it more often.

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