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Challenging practices

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Challenging practices

Challenging behaviour in people with Profound Intellectual and Multiple Disabilities and its consequences for practice

Petra Poppes

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Challenging practices

Challenging behaviour in people with Profound Intellectual and Multiple Disabilities and its consequences for practice

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Voor mijn vader en moeder

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Chapter 1

Introduction

This chapter is partly based on:

Poppes, P. (2014) Wat is het probleem nu? In: Sporen van de reiziger. Opvoeding en ondersteuning van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen nader onderzocht [What seems to be the problem? In: Traces of a traveller. Educating and supporting people with profound intellectual and multiple disabilities] (eds B. F. Van der Meulen, A. A. J. Van der Putten, P. Poppes & K. Reynders), pp. 205-219. Garant, Antwerp..

There are many recent studies concerning the nature, extent and impact of challenging behaviour in people with intellectual disabilities (Crocker et al., 2001; Emerson et al., 2001; Jones et al., 2008; Lowe et al., 2007; Lundqvist, 2013; McClintock, Hall & Oliver, 2003; Rojahn, Matson, Lott, Esbensen & Smalls, 2001). Emerson (2001) defines the term challenging behaviour as 'culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson, 2001, p. 3). It appears that challenging behaviour in people with intellectual disabilities is a common phenomenon. Studies show varying prevalences for challenging behaviour in people with intellectual disabilities, from 5 to 62 percent in large population based studies (e.g. Emerson et al., 2001, Holden & Gitlesen, 2006; Lundqvist, 2013), to around 70 percent in specific settings (e.g. Csorba, Radvanyi, Regenyi & Dinya, 2011; Rojahn et al., 2001). Challenging behaviours are therefore a major concern for a significant number of people with intellectual disabilities and their environment. The consequences of challenging behaviour can be far-reaching. Firstly, it can lead to physical harm to the person and his surroundings. In addition, challenging behaviour can hinder personal development and the establishment and maintenance of social relations (González et al., 2009). Furthermore, challenging behaviour could limit a person's opportunities for integration into society (Rojahn et al., 2001). All these effects could substantially decrease quality of life.

Research shows that people with more severe intellectual disabilities are at greater risk of exhibiting challenging behaviour (Chadwick, Kusel & Cuddy, 2008; Chadwick, Piroth, Walker, Bernard & Taylor, 2000; Emerson, 2001; Holden & Gitlesen, 2006; McClintock et al., 2003; Wulfaert et al., 2009). The literature also shows that there is a relationship between the occurrence of challenging behaviour and various factors such as the presence of motor and/or sensory disabilities (Chadwick et al., 2000; Došen, 2007; Holden & Gitlesen, 2006), seizure disorders (Došen, 2007), communicative problems (McIntyre, Blacher & Baker, 2002; Totsika, Felce, Kerr & Hastings, 2010), sleep disturbances (Doran, Harvey & Horner, 2006), chronic pain and psychiatric problems (Došen, 2007; Oliver & Richards, 2010).

Although challenging behaviour has thus proved to be more common among individuals frequently suffering from these types of co-morbidity (Gardner, 2002; McClintock et al., 2003; Schroeder, Reese, Hellings, Loupe & Tessel, 1999), it is striking that very little is known about the prevalence of challenging behaviour in people with profound intellectual and multiple disabilities (PIMD). Nakken and Vlaskamp (2007) define these people as having a profound intellectual disability (estimated intelligence quotient of 25 points or below), profound or severe motor disabilities (manifesting in an inability to move independently) and sensory impairments.

Furthermore, people with PIMD often suffer from various health problems, such as seizure disorders (Codling & MacDonald, 2009), pulmonary and respiratory disorders (Wallis, 2009), bowel and abdominal problems (Crawford, 2009), and are more likely to suffer from pain due, for example, to constipation, pulmonary or respiratory problems, or dental problems (Van der Putten & Vlaskamp, 2011; Watt-Smith, 2009). As a consequence, people with PIMD rely heavily on others (family but also direct support professionals) for all the activities of daily living (Nakken & Vlaskamp, 2007). We would therefore expect challenging behaviour to be a central topic in practice and research on individuals with PIMD. However, although challenging behaviour is a common experience in practice, to our knowledge the topic is rarely discussed and numbers on the prevalence of challenging behaviour within this group remain unknown. The magnitude and impact of challenging behaviour in people with PIMD is therefore currently unclear.

Furthermore, even though an increasing amount of research has been conducted into factors that related to the onset or continuation of challenging behaviour in people with intellectual disabilities in 'general' (e.g. Došen, Gardner, Griffiths, King & Lapointe, 2007; De Winter, Jansen & Evenhuis, 2011; Emerson 2001), the risk factors associated with the development of challenging behaviour in people with PIMD are not yet known. This lack of knowledge is a cause for concern, because these risk factors could provide insight into the background and development of challenging behaviour in this target group and could also guide the development of interventions to diminish or prevent challenging behaviour in people with PIMD. Staff beliefs/attributions regarding the causes of challenging behaviour could also affect the steps staff take or refrain from taking in relation to people displaying challenging behaviour, as it is assumed that staff behaviour is determined by emotional responses and cognitions (beliefs/attributions) about the challenging behaviour (Hastings, 2002; Hastings & Remington, 1994; Hastings, 2005; Snow, Langdon & Reynolds, 2007). Staff attributions/beliefs about challenging behaviour might not only affect their responses to the challenging behaviour displayed, but might also affect their beliefs about effective intervention strategies as well (Dowey, Toogood, Hastings & Nash, 2007; Hastings, 1997). The steps which staff may or may not take in their work with people with PIMD as a result of these beliefs could determine, at least in part, the emergence and persistence of challenging behaviour (Hastings & Remington, 1994; Hastings, 2002). Since the research carried out so far in this field has not focused on people with PIMD, and given the expected high prevalence of such behaviour, it is important to gain a better understanding of the explanations staff have for challenging behaviour in people with PIMD because this could also offer clues for the reduction or prevention of this behaviour and consequently for developing an intervention designed to reduce or prevent it.

Interventions specifically aimed at reducing or preventing challenging behaviour in people with PIMD are unsurprisingly rare. A recent review study into the effects of the pharmacological, psychotherapeutic and contextual interventions applied to treat challenging behaviour in people with intellectual disabilities shows that there is evidence for the effectiveness of all interventions, used alone or in combination with others (Heyvaert, Maes & Onghena, 2010). The interventions included in this study were targeted at people with mild to profound intellectual disabilities, but did not focus on people with PIMD specifically. Therefore, it is not yet clear which interventions can best be used to support people with PIMD who display challenging behaviour. This overall lack of knowledge regarding challenging behaviour in people with PIMD is a cause for concern, as challenging behaviour does not only have physical consequences for the person him or herself, but can also have serious consequences on the ability of people with PIMD to establish relationships with the world around them. These relationships are vital to people with PIMD as they allow them to gain experiences and exert control over their own lives (Vlaskamp & Van der Putten, 2009). More insight into the prevalence and impact of challenging behaviour, possible risk markers related to the onset or continuation of the behaviour, the beliefs/attributions staff have regarding the explanations of challenging behaviour in people with PIMD and how staff deal with challenging behaviour in practice is therefore required. This knowledge must be obtained in order ultimately to develop an intervention tailored to people with PIMD to reduce or prevent challenging behaviour specifically.

This thesis focuses on children and adults with PIMD and their direct support staff and aims to gain insight about the abovementioned gaps in knowledge. Knowledge about the prevalence, frequency and impact of challenging behaviour in people with PIMD was an important and necessary first step. Information on how practice addresses challenging behaviour in people with PIMD was then needed to gain insight into the way in which reduction or prevention of challenging behaviour is part of daily routines. Knowledge about the extent to which known risk factors for challenging behaviour was also applicable to people with PIMD was also needed to give more insight into the background and development of challenging behaviour in this target group. Furthermore, knowledge of the causal explanations staff favour for challenging behaviour in people with PIMD was also important because this could provide insight into whether staff choose to treat challenging behaviour in people with PIMD. Finally, we examined whether staff training might be an important tool to address potentially unhelpful attributions. All this knowledge helps us understand the extent and impact of challenging behaviour within this group so that appropriate interventions to reduce or prevent challenging behaviour can be deployed in practice in future, which is of great importance to the quality of life and support of people with PIMD.

The overall aim of this research project was to develop more knowledge on the prevalence and prevention of challenging behaviour in people with PIMD. Five main research questions were our guides:

1. What is the prevalence, frequency and severity of challenging behaviour in people with PIMD?
2. How do staff address challenging behaviour in people with PIMD in daily practice?
3. Which known risk factors for challenging behaviour are also applicable to people with PIMD?
4. Which explanations are offered by staff for challenging behaviour in people with PIMD?
5. What effects does staff training have on the assessment of challenging behaviour in people with PIMD in terms of severity and the causal explanations of behaviour?

1.1 Outline of the thesis

After this introductory first chapter, Chapter 2 reports on the prevalence, frequency and perceived severity of challenging behaviour in people with PIMD. Challenging behaviour was measured using the Behaviour Problem Inventory (Rojahn et al., 2001). The Behaviour Problem Inventory is a behaviour problems rating scale used for people with various degrees of intellectual disability of all ages. It is an informant-based scale which addresses three types of challenging behaviour: self-injurious behaviour, stereotypical behaviour and destructive or aggressive behaviour.

Chapter 3 presents a study of how self-injurious, stereotypical, aggressive/destructive behaviour are addressed in daily practice.

Chapter 4 describes risk markers associated with the occurrence of self-injurious, stereotypical, withdrawn and aggressive/destructive behaviour in people with PIMD.

Chapter 5 reports on the causal explanations staff attribute to challenging behaviour in people with PIMD. Direct support professionals were asked to explain challenging behaviour in people with PIMD in accordance with five causal explanatory models of challenging behaviour measured using the Challenging Behaviour Attributions Scale.

Chapter 6 describes an exploratory study on the effects of psycho-education on the assessment of challenging behaviour in people with PIMD in terms of severity and causal explanations of behaviour.

This thesis concludes with Chapter 7, which reflects on the main findings of the five studies. The limitations of the research and the implications for practice and further research are discussed.

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Chapter 2

Frequency and severity of challenging behaviour in people with profound intellectual and multiple disabilities.

Poppes, P., Van der Putten, A. A. J. & Vlaskamp, C. (2010). Frequency and severity of challenging behaviour in people with profound intellectual and multiple disabilities. Research in Developmental Disabilities, 31(6), 1269-1275.

Abstract

- Background* Although challenging behaviour is expected to be more common amongst people with profound intellectual and multiple disabilities (PIMD), very little is known about the prevalence of challenging behaviour for this specific category.
- Aim* The main goals of this study were to determine the prevalence, frequency and severity of challenging behaviour in people with PIMD. Because in the literature several health problems and sensory impairments are associated with the onset and existence of challenging behaviour, this relationship was also examined.
- Method* This study involved 181 people with PIMD (age: mean:35, SD:19, 56% male). The Behaviour Problem Inventory was used to determine prevalence, frequency and severity of self-injurious (SIB), stereotypical and aggressive/destructive behaviour, and an additional questionnaire was used to determine the presence of sensory impairments and health problems among the participants.
- Results* Results show a prevalence of 82% for SIB and stereotypical behaviour in the sample. Aggressive/ destructive behaviour was seen in 45% of the participants. Concerning the frequency, on average SIB occurs on a daily or weekly basis. Stereotypical behaviour is seen on a daily basis and aggressive/destructive behaviour is usually reported once a week. All three types of challenging behaviour also occur on an hourly basis. The severity of challenging behaviour is usually rated by staff as of minor consequence for the person with PIMD. Furthermore, a relationship was found between having visual, tactile or psychiatric problems and the occurrence of challenging behaviour. Participants with visual impairments, tactile impairments or psychiatric problems showed significantly higher mean scores regarding challenging behaviour.
- Conclusion* Challenging behaviour within the target group of people with PIMD is very common. The prevalence figures are high, but direct support professionals are not inclined to rate such behaviour as of serious consequence.

2.1 Introduction

In recent decades, a large number of studies concerning the nature, extent and impact of challenging behaviour shown by individuals with intellectual disabilities have been carried out (Crocker et al., 2001; Emerson et al., 2001; Lowe, Jones, Brophy, Moore & James, 2007; McClintock, Hall & Oliver, 2003; Rojahn, Matson, Lott, Esbensen & Smalls, 2001). According to Emerson (2001) the term challenging behaviour is defined as 'culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson, 2001, p. 3). Emerson and colleagues (2001) state that challenging behaviour includes aggression, self-injury, destructiveness, over activity, inappropriate social or sexual conduct, bizarre mannerisms and the eating of inappropriate objects.

The above-mentioned studies provide, inter alia, an overview of the prevalence of challenging behaviour in people with intellectual disabilities in general. The studies show that individuals with intellectual disabilities are three to five times more at risk of displaying challenging behaviour than the average population. Challenging behaviour is therefore a major concern for a substantial number of people with intellectual disabilities and can lead to a situation in which a person harms him or herself or others, resulting in physical injury and often a restriction of personal development. Also, challenging behaviour leads to diminished opportunities to integrate in the community (Matson, Cooper, Malone & Moskow, 2008; Rojahn et al., 2001; Symons, 2008).

Several factors are associated with the onset of challenging behaviour, such as the presence of physical and/or sensory problems (Chadwick, Kusel & Cuddy, 2008; Chadwick, Piroth, Walker, Bernard & Taylor, 2000; Cormack, Brown & Hastings, 2000; Rojahn, 1986) and epilepsy (Došen, 2007; Gardner, 2002). Chronic or recurrent pain, due, for example, to constipation, pulmonary and respiratory problems or dental problems (Bosch, Van Dyke, Smith & Poulton, 1997; Breau et al., 2003; Carvill & Marston, 2002; Gardner, 2002; Stallard, Williams, Lenton & Velleman, 2001; Watt-Smith, 2009;), and communicative shortcomings when expressing wishes and needs (Van Gemert & Minderaa, 2000) are also associated. Sleep problems (Didden & Sigafos, 2001; Doran, Harvey, & Horner, 2006) and mental health problems are also mentioned in the literature (Došen, 2007; Richman, 2008; Ross & Oliver, 2002). In addition to these factors, some genetic syndromes, such as Rett syndrome and Cornelia de Lange syndrome, are known to influence the occurrence of challenging behaviour.

Although challenging behaviour is thus expected to be more common amongst individuals frequently suffering from these types of co-morbidity, such as people with profound intellectual and multiple disabilities (PIMD) (Gardner, 2002; Kraijer,

2004; McClintock et al., 2003; Schroeder, Reese, Hellings, Loupe & Tessel ,1999), very little is known about the prevalence of challenging behaviour for this specific category. Nakken and Vlaskamp (2007) define this category as having a profound intellectual disability (IQ of 25 or below), profound or severe motor disabilities (manifesting in the inability to move independently) and sensory impairments. Furthermore, people with PIMD often suffer from various health problems, such as seizure disorders (Codling & MacDonald, 2009), pulmonary and respiratory problems (Wallis, 2009), bowel and abdominal problems (Crawford, 2009), and are more likely to suffer from pain due, for example, to constipation, pulmonary or respiratory problems or dental problems (Watt-Smith, 2009). One would therefore expect challenging behaviour to be a central topic in practice and research on individuals with PIMD. But although practice experiences challenging behaviour, the topic is hardly discussed and as yet interventions or treatments for challenging behaviour and their effects have not been described for individuals with PIMD but are limited to people with less severe disabilities. In addition, information about the type, frequency and severity of this behaviour in people with PIMD is lacking. This lack of knowledge is problematic because the presence of challenging behaviour is not only literally damaging for the person, it also influences the ability of individuals to engage in activities and to build meaningful relationships (Vlaskamp, Poppes & Zijlstra, 2005), thus directly influencing their quality of life (González et al., 2009; Petry, Maes & Vlaskamp, 2005).

The purpose of this study has been twofold; (1) to determine the prevalence, frequency and severity of self-injurious, stereotypical and aggressive behaviour in people with PIMD; and (2) to examine the relationship between the occurrence of challenging behaviour and the presence of sensory impairments and general health problems.

2.2 Method

2.2.1 Participants

This study includes 181 people with PIMD, aged between 3 and 62 years (mean: 35, SD: 19). A total of 56% were male, 44% female. The participants were recruited from seven facilities throughout the Netherlands. They all have a profound intellectual disability and a profound or severe motor disability. Table 1 shows the prevalence of sensory problems and health problems among the participants.

Table 1 Sensory problems and health problems in the participants

| N=181 | n | % |
|-------------------------------|-----|----|
| <i>Sensory problems</i> | | |
| Visual problems | 132 | 73 |
| Auditory problems | 71 | 39 |
| Tactile problems | 61 | 34 |
| <i>Health problems</i> | | |
| Bowel and abdominal problems | 137 | 78 |
| Epilepsy | 120 | 66 |
| Lung and respiratory problems | 49 | 27 |
| Dental problems | 47 | 26 |
| Pain | 47 | 26 |
| Sleeping problems | 39 | 22 |
| Mental health problems | 35 | 20 |

2.2.2 Instruments

Challenging behaviour is identified using the Dutch translation of The Behavior Problems Inventory (BPI-01; Rojahn et al., 2001). The BPI is a behaviour problems rating scale for use with people of all ages with various degrees of intellectual disability. It is an informant-based scale that addresses three types of challenging behaviour: self-injurious behaviour (SIB), stereotypical behaviour and destructive or aggressive behaviour. SIB 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). SIB includes, for example, hitting the head with the hand or other body part; biting oneself; hair-pulling; regurgitating; and hitting the head with or against objects. 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; twirling or twisting objects; smelling objects; and screaming and yelling. Aggressive/destructive behaviour is defined as 'an offensive action or a deliberate overt attack directed towards people or objects' (Rojahn et al., 2001). Aggressive/destructive behaviour includes, for example, grabbing, pulling and hitting others.

The BPI-01 consists of 52 items within the three specified categories: SIB

(14 items), stereotypical behaviour (24 items) and aggressive/destructive behaviour (11 items). Each subscale also has a residual item, so that respondents can include any behaviour not included in the list of items that meets the definition of the targeted challenging behaviour. Each item is scored on two scales: a frequency scale ranging from never (0) to hourly (4); and a severity scale ranging from slight (1) to severe (3). The behaviour must have appeared at least once in the past two months in order for it to be rated. The clinical criterion validity of the BPI-01 is good according to Rojahn et al. (2001). According to a study by Lambrechts, Kuppens and Maes (2009) into the psychometric properties of the Dutch translation of the BPI-01 for people with a profound intellectual disability, the internal consistency of the scale measured with Cronbach's alpha ranges from good to excellent. The test-retest reliability of the frequency scale was good to excellent (Lambrechts et al., 2009).

In addition to the BPI-01, a questionnaire was completed by the direct support professional (DSP) for each participant to determine the medical diagnosis, the participant characteristics age and gender, the degree and prevalence of sensory problems and chronic health problems.

2.2.3 Procedure

Various facilities were asked by phone to participate in the research. Healthcare psychologists selected participants with PIMD within their facility and consequently all participants were recruited through informed consent. During a meeting, the facilities concerned were introduced to the BPI-01 and were given information about the instrument and the supplementary list regarding diagnosis and additional disorders. Written instructions on how to use the lists were handed out. Both the BPI-01 and the additional list were completed by a DSP who had known the individual with PIMD for at least two months. Personal information on the participants and DSPs was coded to guarantee anonymity.

2.2.4 Analyses

First, the descriptive results on the prevalence, frequency and severity of the total scale as well as for the three subscales are presented. The prevalence of challenging behaviour was calculated on the basis of dichotomous (occurrence/non-occurrence) data. The frequency and severity percentages were determined by taking the average of all items within the three subscales for all participants. In order to examine the impact of various sensory and health problems and the occurrence of SIB, stereotypical and aggressive/destructive behaviour, an analysis of variance (one-way independent anova) was conducted. Therefore, participants were divided into groups based on the prevalence of sensory problems and health problems. For example, the group was divided into a blind group, a group who have impaired vision and a group who do not have a visual problem. Because there were no specific a priori predictions about the collected data, the Bonferroni correction on Type I

errors was carried out if there was a significant difference in the mean score between different groups to analyse which groups differed significantly. The effect was said to be significant if the probability level of a type I error was .05 or less. Finally, for significant differences, the effect sizes (r) were calculated to measure the magnitude of the observed effect. An $r=.10$ was judged as small, an $r=.30$ as medium and an $r=.50$ was considered a large effect (Field, 2005).

2.3 Results

2.3.1 Prevalence of challenging behaviour

In 166 (82%) participants, one or more types of challenging behaviour were observed. On average, nine items were scored per participant (range 0-31, SD 7); three items on SIB (range 0-11, SD 2), five on stereotypical behaviour (range 0-16, SD 4) and one on aggressive/destructive behaviour (range 0-9, SD 2).

The prevalence rates for the three subscales are presented in Table 2. The prevalence of SIB (i.e. at least one SIB item was rated positively) was 82%. Within this category 'refusing food' (48%), 'hitting oneself against the head' (31%), 'biting oneself' (27%) and 'grinding one's teeth' (27%) are most common. The prevalence of stereotypical behaviour was also 82%, whereby 'screaming and shouting' (50%) and 'repetitive hand movements' (40%) occur most often. The prevalence of aggressive/destructive behaviour was 45%. Items most frequently scored were 'pulling and grabbing others' (26%) and 'pinching others' (19%).

Table 2 prevalence of challenging behaviour

| N=181 | Number of participants (%) |
|---|-----------------------------------|
| Self injurious behaviour | 148 (82) |
| Refusing food | 86 (48) |
| Hitting oneself against head | 56 (31) |
| Biting oneself | 48 (27) |
| Grinding teeth | 49 (27) |
| Stereotypical behaviour | 148 (82) |
| Screaming and shouting | 90 (50) |
| Repetitive hand movements | 73 (40) |
| Aggressive/destructive behaviour | 81 (45) |
| Pulling and grabbing others | 47 (26) |
| Pinching others | 34 (19) |

2.3.2 Frequency and severity

Table 3 shows that on average in respectively 34% and 30% of all positively scored behaviour, SIB is seen on a daily and weekly basis. Stereotypical behaviour is usually seen on a daily basis and aggressive/destructive behaviour is most often observed once a week. All three types of challenging behaviour can also occur on an hourly basis whereby stereotypical behaviour is seen hourly in 21% of the participants.

Table 3 Frequency of challenging behaviour in %*

| Frequency | Monthly | Weekly | Daily | Hourly |
|--------------------------------------|---------|--------|-------|--------|
| Type of challenging behaviour | | | | |
| Self-injurious | 26 | 30 | 34 | 10 |
| Stereotypical | 10 | 23 | 45 | 21 |
| Aggressive/destructive | 32 | 33 | 30 | 5 |

*The sum of the percentages does not always equal 100 because of rounding off.

When asked, DSPs rate the severity of challenging behaviour overall as of minor consequence (see Table 4). Moderate or severe consequences were rated of less consequence. For example, in only 14% of the participants is stereotypical behaviour rated as having a moderate or severe impact on the participant.

Table 4 Severity of challenging behaviour in %*

| Severity | Slight | Moderate | Severe |
|--------------------------------------|--------|----------|--------|
| Type of challenging behaviour | | | |
| Self-injurious | 58 | 28 | 11 |
| Stereotypical | 81 | 12 | 2 |
| Aggressive/destructive | 56 | 33 | 7 |

*The sum of the percentages does not always equal 100 because of rounding off.

2.3.3 The occurrence of challenging behaviour and sensory and general health problems

As shown in Table 5, a statistically significant difference in the mean number of positively scored items in the SIB subscale among the three groups regarding visual problems ($F(2, 173) = 5.55, p < .05, r = .25$) was found. This effect can be called 'small'. The mean number of SIB was higher in blind participants than in participants who had poor eyesight or no visual problems.

Furthermore, participants who had tactile problems (either being highly sensitive when touched or not sensitive at all) scored significantly higher on SIB ($F(2, 164) = 13.57, p < .05, r = .38$), stereotypical behaviour ($F(2, 164) = 13.49, p < .05, r = .38$) and challenging behaviour overall ($F(2, 164) = 14.52, p < .05, r = .39$) than participants who had no tactile problems. These effects can be called 'medium'.

Finally, participants with mental health problems scored significantly higher on SIB ($F(1, 175) = 11.30, p < .05, r = .25$) and they scored higher on challenging behaviour overall ($F(1, 175) = 4.66, p < .05, r = .16$) than participants without mental health problems. These effects can be called 'small'.

No significant difference was seen regarding the presence of auditory problems, bowel and abdominal problems, epilepsy, pulmonary and respiratory problems, dental problems, sleeping problems and pain and the occurrence of challenging behaviour (see Table 5, next page).

Table 5 Mean scores (M) and standard deviation (SD) on different types of challenging behaviour and additional health problems

| Health problems N | M (SD) | | |
|-------------------------------------|-----------------------------|----------------------------|---|
| | Self-injurious behaviour | Stereotypical behaviour | Aggressive/ destructive behaviour |
| Auditory problems | | | |
| Deaf (N=9) | 3.33 (3.39) | 4.22 (3.19) | 1.56 (2.74) |
| Hard of hearing (N=41) | 3.07 (2.79) | 4.87 (4.41) | 1.61 (2.11) |
| Hypersensitive (N=21) | 2.62 (1.72) | 4.71 (3.80) | 0.71 (1.85) |
| None (N=97) | 2.27 (1.97) | 4.93 (4.22) | 1.34 (1.76) |
| Visual problems | | | |
| Blind (N=18) | 4.22* (3.30) | 6.44 (3.97) | 1.50 (2.09) |
| Weak-sighted (N=114) | 2.42* (2.17) | 4.68 (4.38) | 1.25 (1.96) |
| None (N=44) | 2.30* (1.78) | 4.80 (3.76) | 1.32 (1.65) |
| Tactile problems | | | |
| Hypersensitive (N=42) | 3.10* (2.60) | 5.57* (3.79) | 1.24 (1.91) |
| Undersensitive (N=18) | 4.56* (2.57) | 9.00* (5.67) | 2.22 (2.51) |
| None (N=107) | 1.99** (1.75) | 3.99** (3.58) | 1.15 (1.74) |
| Epilepsy | | | |
| Yes (N=120) | 2.52 (2.25) | 4.81 (4.34) | 1.12 (1.77) |
| None (N=58) | 2.59 (2.36) | 4.93 (3.93) | 1.60 (2.09) |
| Bowel and abdominal problems | | | |
| Yes (N=137) | 2.63 (2.38) | 4.76 (4.21) | 1.18 (1.78) |
| None (N=41) | 2.27 (1.92) | 5.15 (4.19) | 1.61 (2.21) |

| Health problems N | M (SD) | | |
|---------------------------------------|-----------------------------|----------------------------|---|
| | Self injurious behaviour | Stereotypical behaviour | Aggressive/ destructive behaviour |
| Sleeping problems | | | |
| Yes (N=39) | 2.59 (2.62) | 3.79 (4.38) | 1.33 (2.16) |
| None (N=139) | 2.53 (2.19) | 5.14 (4.11) | 1.27 (1.81) |
| Pulmonary/respiratory problems | | | |
| Yes (N=49) | 2.06 (2.12) | 3.45 (3.49) | 1.57 (2.11) |
| None (N=129) | 2.73 (2.32) | 5.38 (4.33) | 1.17 (1.79) |
| Dental problems | | | |
| Yes (N=47) | 3.00 (2.51) | 5.79 (4.18) | 1.15 (1.89) |
| None (N=131) | 2.38 (2.18) | 4.51 (4.17) | 1.33 (1.89) |
| <i>Chronic pain</i> | | | |
| Yes (N=47) | 2.62 (2.24) | 5.00 (4.62) | 1.40 (2.14) |
| None (N=131) | 2.52 (2.31) | 4.79 (4.06) | 1.24 (1.79) |
| Mental health problems | | | |
| Yes (N=35) | 3.69** (2.81) | 5.57 (4.69) | 1.71 (2.56) |
| None (N=142) | 2.27** (2.06) | 4.66 (4.08) | 1.18 (1.68) |

* : significant difference at .05 level

** : significant difference at .01 level

2.4 Discussion

This study shows a high prevalence of challenging behaviour in people with PIMD. More specifically, SIB and stereotypical behaviour are observed in 82% of the sample. Aggressive/ destructive behaviour is reported less often, 45%. Concerning the frequency of challenging behaviour, on average SIB occurs on a daily or weekly basis. Stereotypical behaviour is seen on a daily basis and aggressive/destructive behaviour is usually reported once a week. All three types of challenging behaviour also occur on an hourly basis. The severity of challenging behaviour is usually rated by DSPs as of minor consequence for the person with PIMD.

In this study a relationship was found between having visual, tactile or psychiatric problems and the occurrence of challenging behaviour. Participants with visual impairments, tactile impairments or psychiatric problems showed significantly higher mean scores regarding challenging behaviour, with small to medium clinically relevant effects (Field, 2005).

Although in this study, the sample size was rather substantial, the conclusions must nevertheless be treated with caution. The participants in this study are mainly from residential facilities. Because living environment and the prevalence of challenging behaviour are related (Borthwick-Duffy, Lane & Widaman, 1997), one should be careful when generalizing the current results to people with PIMD who are living in more community-based settings.

The BPI was used to collect data even though this instrument was not developed specifically for people with PIMD, which could be a threat to the internal validity of the findings. The BPI includes items that need a certain amount of motor skills, for example 'running around' and 'pacing up and down'. People with PIMD will not be able to score on these items. It is also possible that certain behaviour does occur in people with PIMD that cannot be scored on the BPI, for example withdrawn behaviour. Vlaskamp, Zijlstra and Smets (1997) describe 'lack of contact-making' in people with PIMD as problematic behaviour. When a person abandons all attempts to make contact with his or her environment, this will influence his/her capacity to gain experiences and develop. Oliver, Murphy, and Corbett (1987) when commenting on withdrawn behaviour in their research note that the severity of the intellectual disability can be linked with the occurrence of withdrawn behaviour, stereotypical behaviour and hyperactive behaviour. Wulffaert et al. (2009) also conclude that withdrawn and self-injurious behaviour occurs more in people with a severe intellectual disability. Withdrawn behaviour is not usually included in the BPI, but it is advisable to do so for this particular group of participants.

This study is based on DSP reports of challenging behaviour displayed by participants. Although the clinical criterion validity of the BPI-01 is good according to

Rojahn et al. (2001), it is of course possible that the DSPs do not acknowledge some behaviour as problematic and as a consequence have not reported this behaviour. This may have biased our results, and data from direct observations will probably show different prevalence rates.

Research by Rojahn et al. (2001) to establish prevalence rates on challenging behaviour using the BPI shows similar trends as the current study. His research sample consisted of 432 participants, of whom 66% had a profound intellectual disability and 44% were less severely disabled. Rojahn's findings indicate that 43% of the participants showed SIB, 54% displayed stereotypical behaviour and 43% showed aggressive/destructive behaviour. Although these prevalence figures are smaller than those in the present study, this could be explained by the fact that in the present study only participants with profound intellectual and multiple disabilities were included. Several studies have shown that there is a positive relationship between the severity of the intellectual disability and the occurrence of challenging behaviours (Gardner, 2002; Bosch & Ringdahl, 2001). In the present study, a relatively lower prevalence of aggressive/destructive behaviour was found in comparison with the results of Rojahn et al. (2001). This lower incidence of aggressive/destructive behaviour is probably due to the severe or profound motor disabilities of the participants. These disabilities mean that participants are physically unable, for example, to hit others, throw things at others or break things.

Even though this study shows that SIB and stereotypical behaviour is common (it often occurs on a daily, even hourly basis), DSPs find that the behaviour is of little consequence to people with PIMD. A possible explanation is that DSPs might not label stereotypical behaviour as problematic because it is seen as a stimulatory activity (Hastings, Reed, & Watts, 1997). However, according to Didden, Duker and Seys (2003) stereotypical behaviour is a less salient but no less threatening form of challenging behaviour with regard to the development of the person in question.

Within the category SIB, 'refusing food' was most commonly reported. This high incidence for the present sample may have a different aetiology to the other self-injurious behaviours. It might be caused by medical problems, such as reflux disease, and it is possible that this is the reason DSPs do not report 'refusing food' as of moderate or severe consequence.

Another reason why DSPs may ignore challenging behaviour is when this behaviour is judged as 'belonging to the person' or part of the disability. This may particularly be the case when self-injurious or stereotypical behaviour is displayed. Noone, Jones and Hastings (2006) found in their study that DSPs are more likely to define behaviour as challenging when this behaviour is directed at the environment instead of at the person him/herself. The consequence of labelling SIB or stereotypical behaviour as

'just the way a person is' are grave, as the literature associates challenging behaviour with the inability to acquire different experiences (Gardner, 2002) and aggravates participation in work and leisure activities, increasing isolation (Holden & Gitlesen, 2006).

Although challenging behaviour within the target group of people with PIMD is very common and the prevalence figures are staggering, DSPs are not inclined to rate such behaviour as of serious consequence. This is perhaps due to a lack of knowledge about the effects of challenging behaviour on the possibility to develop, but also about the health effects of challenging behaviour. Hitting oneself on the head repeatedly can lead, for example, to a detached retina. Therefore, it is important to make staff aware through training not only of the manifestation of challenging behaviour but also the possible impacts of this behaviour.

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Chapter 3

Addressing challenging behaviour in people with profound intellectual and multiple disabilities: analyzing daily practice.

Poppes, P., Van der Putten, A. A. & Vlaskamp, C. (2014). Addressing Challenging Behavior in People With Profound Intellectual and Multiple Disabilities: Analyzing the Effects of Daily Practice. Journal of Policy and Practice in Intellectual Disabilities, 11(2), 128-136.

Abstract

- Background* As some people with profound intellectual and multiple disabilities (PIMD) are at a high risk of developing a challenging behaviour, it is useful to look at measures taken to prevent or diminish this type of behaviour.
- Aim* The authors undertook a study of how self-injurious, stereotypical, destructive or aggressive behaviour are addressed in daily practice in residential facilities.
- Method* A stratified sample of 30 people with the most severe and frequently reported challenging behaviours was selected from a data set of 181 children and adults with PIMD. Individual comprehensive service plans were used to determine whether challenging behaviours were present and how these problems were addressed.
- Results* In total, only 51.8% of the challenging behaviours that occurred were described in the individual plans, and for 53.7% of the challenging behaviours, strategies or interventions were included in the individual service plans. Only 17.2% of the cases contained goals formulated to prevent or diminish such behaviour. A significant positive relationship was found between the severity of challenging behaviour and the extent to which it was described in the individual comprehensive service plans.
- Conclusion* This study showed that although all of the participants exhibit challenging behaviours on an hourly or daily basis, 48.2% (189) of the challenging behaviours that were observed by direct support staff were not mentioned in the individual service plans. The authors noted that interventions that are aimed at diminishing or preventing challenging behaviour were highly simplistic, and virtually no goals were formulated to document, diminish or prevent challenging behaviour in people with PIMD.

3.1 Introduction

A combination of profound intellectual and profound or severe motor disability and sensory impairments characterize people with profound intellectual and multiple disabilities (PIMD) (Nakken & Vlaskamp, 2007). People with PIMD often have a greater number of health problems such as seizures (Codling & MacDonald, 2009), respiratory problems (Wallis, 2009), and abdominal problems (Crawford, 2009), and are more likely to experience pain due to, for example, constipation, respiratory problems or dental problems (Watt-Smith, 2009). Chronic or recurrent pain (Breau et al., 2003; Carvill & Marston, 2002; Gardner, 2002; Stallard, Williams, Lenton & Velleman, 2001; Watt-Smith, 2009) is also a noted problem. A confounding factor is that many have communicative shortcomings when trying to express wishes and needs (Matson, Dixon & Matson, 2005; McIntyre, Blacher & Baker, 2002; Totsika, Felce, Kerr & Hastings, 2010). These conditions are often associated with the occurrence of challenging behaviour. Challenging behaviours have been defined by Emerson (2001, p. 3) as 'culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities'.

Challenging behaviours include 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, Matson, Lott, Esbensen & Smalls, 2001). It includes, for example, hitting one's head with one's hand or another body part, biting oneself, hair-pulling etc. 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 (Rojahn et al., 2001). Research has shown that challenging behaviour is very common in people with PIMD (Poppes, Van der Putten & Vlaskamp, 2010). In a study conducted among 181 children and adults with PIMD, we found self-injurious and stereotypical behaviour in 83% and aggressive/destructive behaviour in 45% of the participants. This behaviour was also shown very frequently (Poppes et al., 2010).

Although challenging behaviour is a complex and serious problem, it is unclear which measures are taken in daily practice to diminish or prevent such behaviour in children and adults with PIMD. Addressing these problems needs to be done in a transparent and systematic way in order to increase practice-based knowledge and guarantee continuity in the provided support. Therefore, we assume that when these problems are prevalent in practice, they will be addressed as part of the

clinical planning for the individual. After all, such individual clinical planning is important to shape services for people with intellectual disabilities (Adams, Beadle-Brown & Mansell, 2006), and written plans are now a required central component in most services.

In the Netherlands, individualised comprehensive service plans (IPs) are compulsory and used to attune the support given to the wishes and needs of a child or adult with intellectual disabilities (Collins, Mowbray & Bybee, 1999; Robertson et al., 2007). In the Netherlands, support for children and adults with intellectual disabilities is person-centred to ensure that they can 'do whatever they want when they are adequately supported' (Mansell & Beadle-Brown, 2004; Parley, 2001). Under the Dutch regulatory system, all available information about the person, his or her limitations, possibilities, desires and needs, contextual information, and the support offered are to be included in the IPs. Behavioural treatment programs/behavioural intervention programs and goals are also part of the plan, hence the name 'individual comprehensive service plan'. In the Netherlands, IPs are mandatory, and they are the only plans used to shape the support provided. The IPs are digitized so they can be fully accessible to all direct support staff.

Although the content of the plans and the goals are determined by the person with intellectual disabilities and/or his parents or legal representatives and direct support staff, a variety of people may contribute to the plan (e.g. parents, physical therapist, psychologist, speech therapist). Once a year the plan is drawn up by all direct support staff and family and discussed with all stakeholders to obtain consensus about the contents of the plan. While the health care psychologist is ultimately responsible for the contents of the plan, the manager is responsible for the implementation of the plan. Once a year, this plan is evaluated with all the support staff concerned along with the person with intellectual disability and/or his parents/legal representatives. This procedure is mandatory in The Netherlands. All information about the child or adult is bundled in one document as the IPs are a vital component in the support of people with intellectual disabilities, shaping it in a systematic and methodical manner (Van der Putten, Vlaskamp & Poppes, 2009). Challenging behaviours, if present, should be described in an IP, together with, interventions or strategies to prevent or diminish this behaviour.

Research has not only shown that challenging behaviour is common in people with PIMD, it has also shown that staff usually believe the challenging behaviour to be of minor consequence for the person with PIMD, even though especially self-injurious and stereotypical behaviour predominantly occurs on a daily, even hourly basis (Poppes et al., 2010). It is not clear why this is the case, given the high prevalence and frequency rates of this behaviour. This is worrisome, because challenging behaviour is not only physically damaging to the person or others, but also adversely influences

the ability of the person to engage in normal activities (Denis, VanDenNoortgate & Maes, 2012; Emerson, 2001; Jones, Cooper, Smiley, Allan, Williamson & Morrison, 2008; McGill, Murphy & Kelly-Pike, 2009). Notably, when challenging behaviour seems to 'occupy' the attention of the person with PIMD for a large part of the day, the consequences are that this negatively influences the ability to build and maintain meaningful relationships (Vlaskamp, Poppes & Zijlstra, 2005). Such relationships are of vital importance because of the extensive dependency upon others of people with PIMD. Due to their profound intellectual and motor impairments, they are not able to gain experiences by exploring the world themselves; they need people to bring the world to them. When, for example, stereotypical behaviours, such as constantly making hand movements in front of the eyes, occupy the larger part of the day, the person is unable to be socially engaged in other activities (Poppes et al., 2010).

Why direct support staff, in general, believes challenging behaviour of less consequence for people with PIMD is unclear. Do they not know how to address such behaviour and therefore just leave it be? Do they believe that this type of behaviour is 'part of who this person is' and consequently accept this type of behaviour? Are there strategies or interventions that have been tried out in the past but have proven to be ineffective? Are efforts to use strategies or set goals to prevent or diminish challenging behaviour only undertaken when the behaviour has significant consequences according to direct support staff?

To gain a better understanding how daily practice responds to challenging behaviour, we constructed a study to determine which measures are actually taken in daily practice to prevent or diminish challenging behaviour in children and adults with PIMD. We formulated the following questions: (1) To what extent is evident self-injurious, stereotypical and aggressive or destructive behaviour described in IPs for people with PIMD? If it is recorded in IPs, (2) which relationship does exist between the frequency, severity and type of challenging behaviour (self-injurious, stereotypical and destructive or aggressive behaviour) and whether or not the challenging behaviour is described in IPs.

3.2 Method

3.2.1 Participants and setting

Participants were selected from an existing data base (data gathered in 2010) containing data about the prevalence, frequency and severity of challenging behaviour in 181 children and adults with PIMD recruited from six care facilities throughout the Netherlands (see Poppes et al., 2010, for details). The participating facilities served exclusively children and adults with intellectual disabilities and offered a wide range of activities (such as swimming, games and various kinds of

therapy; physiotherapy, occupational therapy, speech therapy and music therapy). All of the facilities had comparative standards and a similar array of activities and therapies. Direct support staff has access to health care psychologists in all participating facilities. The facilities do not have separate grades or group programs, nor do they use a set curriculum. They all use IPs that are drawn up by direct support staff under responsibility of the health care psychologist.

In this sample, challenging behaviour was identified using the Dutch version of the Behavior Problem Inventory (BPI-01; Rojahn et al., 2001). The BPI is an informant-based scale that addresses three types of challenging behaviour: self-injurious behaviour, stereotypical behaviour and destructive or aggressive behaviour. The BPI-01 consists of 52 items within these three categories. Each item is scored on two scales: a frequency scale ranging from never (0) to hourly (4), and a perceived severity scale ranging from slight (1) to severe (3). The behaviour must have occurred at least once in the past two months in order for it to be rated. The psychometric properties of the BPI-01 and the Dutch version of the BPI are good (Lambrechts, Kuppens & Maes, 2009; Rojahn et al., 2001).

From this database, we selected a sample of 25% of the 'most severe' cases (i.e., people with PIMD with the highest prevalence, and highest frequency: the behaviour was seen on a daily or hourly basis, and perceived severity: the highest scores staff gave to the severity of the challenging behaviour) of challenging behaviour as identified with the BPI. To increase generalization across the six care facilities, the participants were stratified by the total number of people per participating institution and by frequency and severity of the existing challenging behaviour. This resulted in 40 participants. Some parents or legal representatives failed to give their consent and one person with PIMD died, which meant that of 30 participants included in the study, 20 were men and 10 were women. The seven children and 23 adults were aged between 2 and 65 (mean: 29, SD: 17). Table 1 shows the distribution of the participants across the facilities and the occurrence of coincident health and sensory problems.

Table 1 distribution of the participants across the facilities and additional sensory and health problems

| N=30 | | No. of participants | % |
|-------------------------------|----------|---------------------|------|
| Facility | 1 | 3 | |
| | 2 | 4 | |
| | 3 | 1 | |
| | 4 | 9 | |
| | 5 | 11 | |
| | 6 | 2 | |
| Gender | Female | 10 | |
| | Male | 20 | |
| Sensory impairments | Auditory | 10 | 33.3 |
| | Visual | 18 | 60.0 |
| | Tactile | 14 | 46.6 |
| Epilepsy | | 18 | 60.0 |
| Gastrointestinal problems | | 17 | 56.6 |
| Sleeping problems | | 3 | 10.0 |
| Lung and respiratory problems | | 7 | 23.3 |
| Eating and drinking problems | | 18 | 60.0 |
| Pain | | 8 | 26.7 |
| Psychiatric problems | | 3 | 10.0 |

A total of 392 behaviours were scored for the selected participants on the BPI. This is the sum of all positively scored items for the 30 participants (range: 5-27, mean: 13, SD: 5.3). The 392 challenging behaviours were categorized thus: 106 self-injurious, 219 stereotypical, and 67 aggressive or destructive behaviours. The data gathered with the BPI showed that self-injurious behaviour was observed in 29 of the 30 participants (see Table 2). On average, four items were scored positively in this behaviour category (range 0-9). The prevalence of stereotypical behaviour in the total sample was 100% (range: 2-16 positively scored items, mean: 7), and the prevalence of aggressive/destructive behaviour was 70% (range: 0-6, mean: 2). Table 2 summarizes the prevalence of challenging behaviour in the selected 30 participants and shows the mean frequency and severity of the different types of behaviour.

Table 2 prevalence, frequency and severity of challenging behaviour according to the BPI

| Type of challenging behaviour | No. of participants* (%) | Frequency [%]** | | | | Severity [%]** | | |
|-------------------------------|--------------------------|-----------------|--------|-------|--------|----------------|----------|--------|
| | | monthly | weekly | daily | hourly | slight | moderate | severe |
| Self-injurious | 29 (97) | 20 | 36 | 34 | 10 | 52 | 24 | 24 |
| Stereotypical | 30 (100) | 4 | 20 | 50 | 26 | 82 | 14 | 4 |
| Aggressive/ destructive | 21 (70) | 22 | 39 | 33 | 6 | 45 | 39 | 15 |

* Number of participants that scored positively within this category of challenging behaviour.

** % of all positively scored items

The BPI shows that self-injurious behaviour is seen on a weekly and daily basis in, respectively, 36% and 34% of all positively scored behaviour. Stereotypical behaviour is seen (76%) on a daily (50%) and hourly (26%) basis, and aggressive/destructive behaviour is most observed on a weekly and daily basis. All three types of challenging behaviour can also occur on an hourly basis, whereby stereotypical behaviour is seen hourly in 26% of all scored behaviour. When asked, the direct support staff rated challenging behaviour as of slight consequence overall (see Table 2). Half of the scored self-injurious and aggressive/destructive behaviours were perceived as having a moderate or severe impact on the participant.

3.2.2 Procedure

After we had selected the participants who exhibited the most serious and most frequent instances of challenging behaviours on the BPI, we contacted the facilities where the selected participants live or attended school to ask if they wanted to participate in this study. The parents or legal representatives of the participants were then asked for permission to allow the researchers to analyse the IPs of their children/family members.

Recent IPs (plans that were being used to support children and adults with PIMD and were no older than two years in 2011) were used for the analyses. In the Netherlands, an IP contains the personal history of a person, including means and measures that are taken when (behavioural) problems occur. Medical interventions are also part of the individual plan. In general, IPs are meant to encourage direct support staff to consider their clients' needs more carefully and how they can meet them. Such a plan makes it easier to follow and to manage the support process as all those involved in supporting the person with PIMD know what the support entails and what effects

are expected or previously realized (Poppes, Vlaskamp, De Geeter & Nakken, 2002). These plans are also used to justify the financial means deployed, and they are used to demonstrate the quality of the support to the health inspectorate. Challenging behaviour should therefore be described in an IP along with interventions or strategies to prevent or diminish this behaviour, given the detrimental consequences of these behaviours.

3.2.3 Analyses

To identify which behaviours occurred within the research group, frequency tables were constructed for the behaviours (item-level) scored on the BPI. All plans were then systematically analysed to determine whether the behaviours identified with the BPI for a particular person were also described in that person's IP. On average, the IP consists of 25 pages. All words/phrases related to the challenging behaviour that was scored in the BPI were shaded in the text, for example, 'she pinches her skin', 'he tends to grab your hair', 'he rocks back and forth' but also 'she can be very restless'. Then, the total behaviours in the plan were divided by the total behaviours in the BPI (x100) to calculate the percentage of behaviour reported in the support plans. If the challenging behaviour was described in the plan, then we also examined whether information was given about the setting in which the behaviour occurred (e.g., 'she hits herself at dinnertime', 'he throws his plate on the floor during breakfast', 'he hits staff during bath time'), the frequency (e.g., 'she hits herself every day', 'he makes persistent hand movements in front of his eyes all through the day', 'she grinds her teeth persistently') and the consequences of the behaviour (e.g., 'due to self-mutilation, he is unable to attend daytime activities', 'due to self-mutilation, she has scars on her forehead', 'due to stereotypical behaviour, he is withdrawn'). We then analysed whether intervention (e.g., applied behaviour analyses) or a specific method of supporting a person (e.g., 'if he starts to scream take him on your lap and sing a song') was described in the IP and whether goals aimed at reducing or preventing challenging behaviour had been formulated. We also analysed whether psychotropic medications were used to prevent or diminish challenging behaviour.

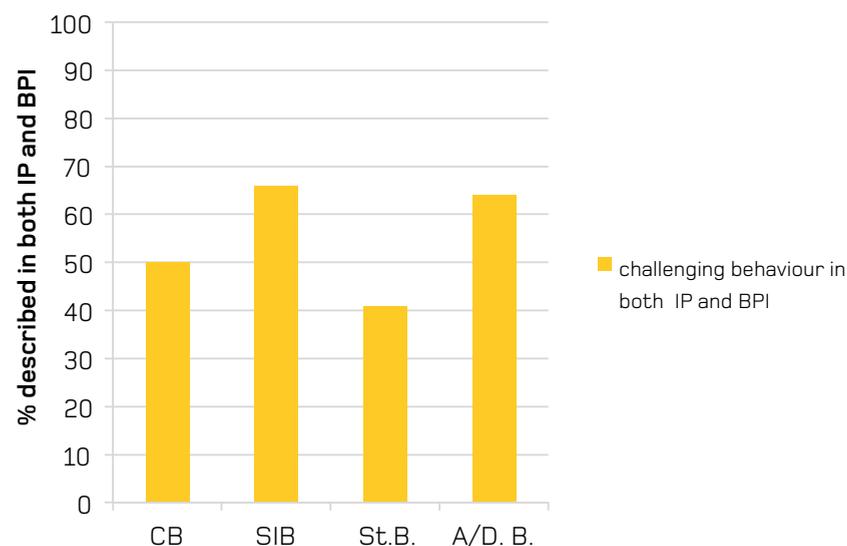
All of the information was extracted by one rater. The interrater reliability of this procedure was analysed in a previous pilot study and, with an overall agreement of 80%, is adequate (Van der Putten, Ten Brug & Vlaskamp, 2009). The distribution of whether or not challenging behaviour identified in the BPI was described in the IP was analysed by means of a chi-square test² test (α 0.05), which examined whether challenging behaviour and the description in the IP deviated from the expected count. The test detected whether there was a significant association between the variables. Because the chi-square does not show the strength of the association, we calculated the Cramer's V as measure of the effect size (Field, 2005).

3.3 Results

3.3.1 Description of challenging behaviour

Of the 392 behaviours that scored positively in the BPI (106 self-injurious, 219 stereotypical and 67 aggressive/destructive behaviour), a total of 189 (48.2%) were not described in the IPs. 203 behaviours (51.8%) were scored on the BPI and also described in the participants' plan. Eight challenging behaviours were described in the plans but were not scored in the BPI.

Figure 1 shows the percentage of challenging behaviours (and different types of challenging behaviour) identified in both the BPI and IPs. If we divide these into the three categories of the BPI, we see that self-injurious behaviour is described in 66% (n=70) of the 106 scored self-injurious behaviours on the BPI, stereotypical behaviour in 41.1% (n=90) and aggressive/destructive behaviours in 64.2% (n=43).



CB overall = challenging behaviour overall
 SIB = selfinjurious behaviour
 St. B. = stereotypical behaviour
 A/D. B. = aggressive/destructive behaviour

Figure 1: percentage of challenging behaviour in both IP and BPI divided by type

3.3.2 Information provided in the IPs on challenging behaviour

Figure 2 shows whether information is provided about the setting and frequency of the challenging behaviour and the consequences of the behaviour for the person or his or her surroundings. It also shows whether the support offered and goals to prevent or diminish this challenging behaviour are included in the plans. Overall, 203 challenging behaviours are described in the plans. Figure 2 shows that information about the setting is provided for 38.4% (n=78) and information about the frequency also for 38.4% (n=78) of all the challenging behaviours included in the plans. The consequences of challenging behaviour are mentioned for only 13.3% (n=27) of the challenging behaviours. For 53.7% (109) of the challenging behaviours, a description of how to deal with them appears in the plans, and for 17.2% (n=35) of the challenging behaviours, goals have been formulated to prevent or diminish them. Eleven persons (37%) with PIMD receive psychotropic medication to reduce or prevent one or more types of challenging behaviour.

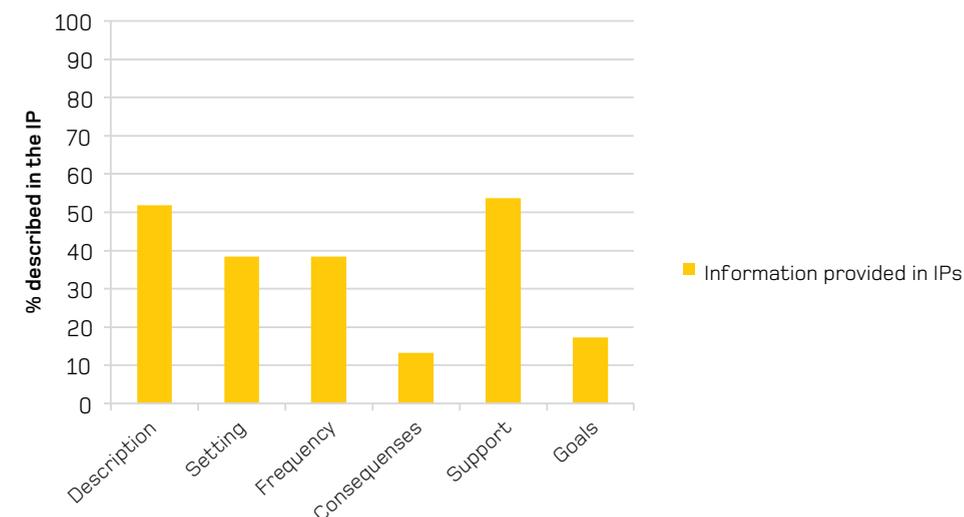


Figure 2: challenging behaviour overall, type of information in IPs

3.3.3 Information provided in the IPs per type of challenging behaviour

Challenging behaviours are subdivided into self-injurious, stereotypical, and aggressive /destructive behaviour (see Figure 3). Regarding self-injurious behaviour, the setting in which this behaviour occurs was described for 31.4% (n=22) of all self-injurious behaviours included in the plans (n=70); for example, 'he hits his head at dinnertime'. For 68.6% (n=48) of the reported self-injurious behaviour, there was no information in the plan about its setting. The frequency at which self-injurious behaviour occurs was mentioned for 31.4% (n=22) of the self-injurious behaviours recorded in the plans (e.g., 'he scratches his arms every day'). Information about the consequences of self-injurious behaviour was mentioned for 15.7% (n=11) of the self-injurious behaviours included in the plans, for example, 'scars on forehead due to scratching the skin' or 'due to self-injurious behaviour she wears splints which limit her ability to move'. For 45.7% (n=32) of all of the reported self-injurious behaviours, a form of support was suggested for dealing with it, for example, 'put on splints', 'offer a fixed daily routine', 'take him/her on your lap', and 'sing a song'. Finally, goals were formulated to prevent or diminish self-injurious behaviour for 20.0% (n=14) of the self-injurious behaviours included in the IPs, for example, describing certain behaviour: 'we know in which situations she hits herself', 'we know how often she hits herself'. For the remaining 80.0% (n=56) of the self-injurious behaviours no such goals were formulated. A total of five participants (three children and two adults) received psychotropic medication to reduce or prevent self-injurious behaviour.

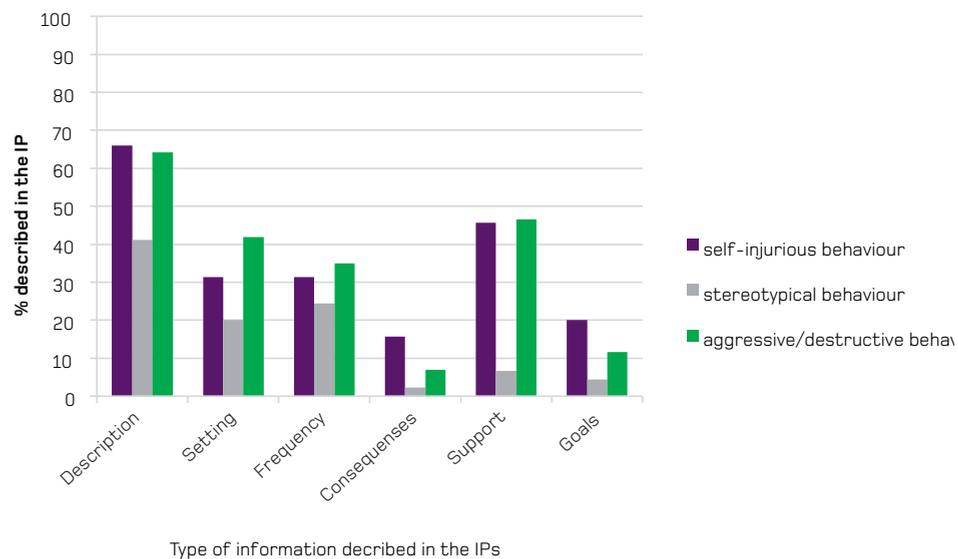


Figure 3 Type of information in the IPs about challenging behaviour

With respect to stereotypical behaviour, Figure 3 shows that the situation in which this behaviour occurs was mentioned for 20.0% (n=18) of all the stereotypical behaviours recorded in the plans (e.g., 'in a hectic situation he rocks back and forth') and that something was said about the frequency of the behaviour for 24.4% (n=22) of all the stereotypical behaviours ('he screams on a daily basis'). Consequences of this behaviour were mentioned for 2.2% (n=2) of all the stereotypical behaviours, for example, 'he can't use his hands for activities because he constantly waves them in front of his eyes'. Ways to deal with this type of behaviour were documented for 6.7% (n=6) of all stereotypical behaviours included in the IPs, for example, 'if he is very restless take him to his room, put on some music, and close the door'. Goals to prevent or reduce the stereotypical behaviour were rarely mentioned in the IPs (4.4%: n=4). Three participants were given psychotropic medication to prevent or diminish yelling and screaming (two adults, one child).

With respect to the last of the three, aggressive/destructive forms of behaviour (see Figure 3), the setting in which it takes place was mentioned for 41.9% (n=18) of all aggressive/destructive behaviours reported in the plans (e.g., 'the transition from one activity to another'). The frequency was described for 34.9% (n=15) of the behaviours (for example, 'he is aggressive towards others on a daily basis'), the consequences (e.g., 'group members are afraid of him') for only 7.0% (n=3) of the behaviours, and ways to deal with them for 46.5% (n=20) of the behaviours (e.g., 'offer an alternative activity', 'isolate him from the group', 'react in a neutral, confident and calm manner'). Goals to prevent or diminish these behaviours were formulated for 11.6% (n=5) of all aggressive/destructive behaviour included in the plans, and thus for 88.4% (n=38) of these types of behaviour, there were no goals to prevent or diminish such aggressive/destructive behaviour. Five participants (one child, four adults) received psychotropic medication to reduce or prevent aggressive/destructive behaviour.

3.3.4 Association between type, frequency or severity of challenging behaviour and mention in IPs

A significant association was found between the type of challenging behaviour and the description in the IPs ($\chi^2=23.39$; $df=2$; $p=0.00$). Self-injurious and aggressive/destructive behaviour was described significantly more often in the plans than stereotypical behaviour (Cramer's V as measure of the effect size: .25). However, no significant association was found between the frequency of the behaviour and a mention in the plans ($\chi^2=6.12$; $df=3$; NS). Challenging behaviour that was perceived as more severe, according to the data from the BPI, was mentioned more often in the plans ($\chi^2=37.43$; $df=2$; $p=0.00$). For these data, Cramer's V is .31.

3.4 Conclusion and Discussion

This study showed that although all of the participants exhibit challenging behaviours on an hourly or daily basis (according to the BPI), 48.2% (189) of the challenging behaviours that were observed by direct support staff were not mentioned in the IPs. Overall, 51.8% of the behaviours were mentioned but only to a certain extent. When challenging behaviour was described, information about its setting and frequency, its consequences for the person or others, and how to treat or deal with the behaviour including goals to prevent or diminish it were not mentioned, or if mentioned, only in very vague terms. For example: in the statement ‘when Jean is extremely restless during the day, be calm and take her on your lap,’ information about the magnitude of this problem and the urgency for intervention is missing. Also, it is not clear what exactly the direct support staff should do, which leaves too much room for personal interpretation and can cause discontinuity in the support. Although psychotropic medication to prevent or diminish challenging behaviour was given to 37% of the participants, its effectiveness is also not mentioned in the IPs. We may conclude, given that challenging behaviours still exists in high frequencies, the application of this medication was apparently not effective enough to prevent further challenging behaviours.

A significant association with a moderate effect size (Field, 2005) was found between the type of challenging behaviour and a description in the IP. Forms of self-injurious and aggressive/destructive behaviour were described significantly more often in the plans than stereotypical behaviours. No significant association was found between the frequency of the challenging behaviour and whether it was described in the plans, but challenging behaviour that was perceived as more severe was described more often in plans (with a moderate effect size).

When considering the results, limitations of the present study need to be kept in mind. Firstly, we did not employ a random sample but selected children and adults with PIMD who showed the most frequent and serious challenging behaviours. Secondly, the sample size of this study might appear relatively small, which would have consequences for the external validity of our findings. We need to emphasize that we extracted 30 participants (those that exhibited the most frequent and most severe challenging behaviour according to the BPI) from a large sample across several different care facilities. The information was extracted from bulky documents in a very detailed way. In the Netherlands, a child or adult with an intellectual disability only has one plan. This plan should contain all relevant information and any behaviour management plans are part of these documents. One would expect challenging behaviour, as was the case in our sample, that occurs on a daily or hourly basis to be described in IPs including goals or written intervention or behaviour management programs to diminish or prevent challenging behaviour because of the detrimental consequences of such behaviour. When a person with PIMD hits himself

on an hourly basis, this will have consequences for his health, but it will also limit his possibilities to engage in relationships and to enjoy different experiences, thus reducing the already limited opportunities to develop. Our results show, however, that this is not the case.

We found that with these 30 ‘serious cases,’ only half of the challenging behaviours identified were mentioned in their plans. It could be that if we had included participants who exhibited less serious and frequent challenging behaviour in our study, the outcome would have been still negative. It is striking that even behaviours such as ‘scratching oneself on an hourly basis’ or ‘pulling one’s toenails out on a daily basis’ are not always perceived as ‘serious’ enough by staff to be described in the IPs. It could therefore be that the seriousness of the matter keeps being underestimated for years. As the behaviour is not mentioned in the IP, chances are that staff have become inured to the behaviour and see it as ‘belonging to a person’ and thus not worth mentioning in the IP and, consequently, not labeled as of serious consequence.

Our results are in line with Emerson et al. (2008) who, in their research into the treatment and management of 265 people with intellectual disabilities and challenging behaviour, found that only 15% of the participants had a written behaviourally oriented treatment program. Of this limited number of written plans, the majority were rated ‘highly simplistic’ (Emerson et al., 2008). Oliver, Murphy and Corbett (1987) reported that only 11 of the 596 people with self-injurious behaviour in the mid-1980s had any form of written intervention plan. This corresponds with our findings with regard to the lack of a description of challenging behaviour along with its setting, frequency, consequences, interventions, and goals in the IPs.

Challenging behaviour is to be considered a problem that has a large impact on the quality of life of people with PIMD. Describing these behaviours and description of interventions or strategies to prevent or diminish such challenging behaviour would be expected. Although prevalence and frequency rates indicate that challenging behaviour is very common in people with PIMD, we found no evidence of this in their plans. The plans in which challenging behaviour was described lacked clarity concerning the setting, frequency and consequences of the behaviours. Furthermore, goals to diminish or prevent challenging behaviour are more or less absent. Even though research indicates that treatment effectiveness of psychotropic medication is questionable and adverse effects are common (Matson & Mahan, 2010; Matson & Neal, 2009), no evaluation of medication use was part of the analysed IPs. This might be due to the fact that plans are sometimes seen as a ‘paper exercise’ (Mansell & Beadle-Brown, 2004) and are not necessarily used to plan and effect support. This could mean that direct support staff do notice challenging behaviour, see it as a problem and work towards diminishing or preventing it but that they do not see any need to write their actions down. This means, however, that if action is being taken

to prevent or diminish challenging behaviour, it is unclear what this action consists of and what its effect entails. This can lead to discontinuity and a lack of transparency in the support of people with PIMD.

Another explanation for the lack of information about challenging behaviour in plans is that staff, as stated before, view challenging behaviour as a given and consequently do not feel that specific forms of support or intervention need to be undertaken. Whether challenging behaviour is included in plans therefore seems to depend on how the staff perceives it. Stereotypical behaviour, for example, which was seen on a daily or hourly basis according to our study, is mostly perceived as behaviour that has few or no consequences for the person with PIMD. Whether this perception is correct is doubtful because, for example, if a person with PIMD constantly rocks back and forth, it renders him or her unable to engage in meaningful relationships (Vlaskamp et al., 2005). This can also be an explanation of the general low perceived severity of the challenging behaviour, although frequency rates are high. Even when we selected the most severe cases out of the database of 181 persons the mean perceived severity was mostly moderate.

The lack of information in IPs about challenging behaviour might also be caused by lack of knowledge of staff about challenging behaviour and its consequences. Knowledge transfer on the effects of challenging behaviour and vision development seems to be necessary.

Addressing challenging behaviour in IPs needs to be done in a transparent and systematic way in order to increase practice-based knowledge and guarantee continuity in the provided support. However, challenging behaviour can only be addressed in this way when health care professionals are fully aware of the consequences of such behaviour for people with PIMD. It would be interesting to analyse whether for example psychological training on the manifestations and consequences of challenging behaviour would cause direct support staff to label behaviour differently. This might then lead to an increase of staff reporting it in IPs. If direct support staff saw challenging behaviour in a different light, it would probably become an accepted part of the IP, and actions would be undertaken to prevent or diminish such behaviour in a methodical and systematic manner. Direct support staff and family members should be involved in drawing such a plan up under the responsibility of a healthcare psychologist.

Furthermore, it is very important to document challenging behaviour more frequently and clearly because only then can we begin to understand how such behaviour can be influenced and the effects of intervention. Such systematic documentation within plans would make it possible to attune the support to the wishes and needs of the person with PIMD. Well-written plans should consist of a detailed description of the

challenging behaviour; including the setting in which it occurs, triggering factors and the frequency in which it occurs. Furthermore, consequences for the person and his or her surroundings and very explicit and clear ways to deal with the behaviour should be described. By explicitly paying attention to challenging behaviour and its consequences in children and adults with PIMD and including this type of behaviour in the personal profile of the IPs, chances are that goals will be formulated to influence the behaviour. This assumption should be further explored in future research. IPs are said to be the basis of the support given to children and adults with PIMD. The lack of mention of the behaviour identified, and thus the lack of guidelines, approaches, and interventions relating to how to cope with these behaviours, results in not treating behaviour. This situation will greatly affect the quality of life of people with PIMD as the consequences of not treating challenging behaviour are severe. In the literature, challenging behaviour is linked to an inability to acquire different experiences (Gardner, 2002; González et al., 2009), it hampers participation in work and leisure activities, increases isolation (Holden & Gitlesen, 2006), and limits the ability to build and maintain meaningful relationships (Vlaskamp et al., 2005). For people in particular who are totally dependent on relationships with others to acquire experiences and thus develop, it is not an option to leave their challenging behaviour unidentified and untreated, because when we do, we cannot assist children and adults with PIMD to achieve their life goals and goals that are valued by their family and loved ones.

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3.5 References

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Chapter 4

Risk markers of 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 intellectual disability, but also to direct support staff and the context. Although many of these factors seem to affect the onset or continuation of challenging behaviour in people with intellectual disability in general, results are often inconclusive and have little focus on people with profound intellectual and multiple disabilities (PIMD).
- Aim* The present study aimed to assess the extent to which known risk factors for 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 risk markers.
- 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 risk marker related to the direct support staff was found: when staff 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 risk markers 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 could focus on the effects of providing safe auditory environments and appropriate sleep schedules for people with PIMD on the occurrence of challenging behaviour.

4.1 Introduction

People with profound intellectual and multiple disabilities (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, Klinkenberg-Knol & Meuwissen, 2001), sleep problems (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 have pain due, for example, to constipation, pulmonary or respiratory problems or dental problems (Van der Putten & Vlaskamp, 2011; Watt-Smith, 2009). Challenging behaviour also occurs frequently in people with PIMD (Poppes, Van der Putten & Vlaskamp, 2010).

Challenging behaviour is defined as 'culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson 2001, p. 3). Challenging behaviour is considered a major problem because the various behaviours are difficult for direct support staff to handle and can be harmful both to the person exhibiting them and to others. For the individual, challenging behaviour may interfere with learning and development and limit participation in social activities (Holden & Gitlesen, 2006; Murphy et al., 2005).

Poppes et al. (2010) found that challenging behaviour, such as self-injurious behaviour (SIB), stereotypical behaviour (SB) and aggressive/destructive behaviour (ADB), frequently occur in people with PIMD. SIB and SB occurred in most cases on a daily or even hourly basis. Also, socially withdrawn behaviour (WB) occurs frequently in people with PIMD. Vlaskamp, Zijlstra and Smets (1997) described 'lack of contact-making' in people with PIMD as problematic behaviour. When a person abandons all attempts to make contact with their environment, this will influence their capacity to gain life experiences and develop. Commenting on WB, Oliver, Murphy and Corbett (1987) noted that the severity of the intellectual disability may be linked with the occurrence of WB, SB and hyperactive behaviour. Wulffaert et al. (2009) also concluded that WB and SIB occur more frequently in people with a severe intellectual disability.

Other factors have also been found to be related to the onset or continuation of challenging behaviour (De Winter, Jansen & Evenhuis, 2011; Došen, Gardner, Griffiths, King & Lapointe, 2007; Emerson, 2001). These factors not only concerned the

person with intellectual disability but also the direct support staff and the context. Personal risk markers include gender, age, level of intellectual disability, 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 (Emerson, 2001; Lowe et al., 2007; Sigafos, Elkins, Kerr & Attwood, 1994), boys and men show more challenging behaviour in general, especially ADB. 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 ADB than men. Other studies (Baghdadli, Pascal, Grisi & Aussilloux, 2003; Chadwick, Piroth, Walker, Bernard & Taylor, 2000) 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 (Holden & Gitlesen, 2006; Jones et al., 2008; Oliver et al., 1987). Lundqvist (2013) reported a second peak among those who were 70 or older. These studies were aimed at people with intellectual disability 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 intellectual disability is more severe (Cooper et al., 2009; Crocker et al., 2006; Emerson, 2001; Holden & Gitlesen, 2006; 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). The same is true for the severity of motor disabilities (Emerson, 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 (Forster, Gray, Taffe, Einfeld & Tonge, 2011; Sheehy & Nind, 2005). 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 (De Schipper & Schuengel, 2010; Schuengel & Janssen, 2006).

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 (Emerson 2001; Oliver, Murphy, Crayton & Corbett, 1993; Rojahn, 1986) are associated with challenging behaviour. Visual impairments increase the risk of SIB (De Winter et al., 2011), SB and ADB (Lundqvist, 2013). According to Poppes et al. (2010), the mean for SIB 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 SIB, SB and challenging behaviour overall than those who had no tactile problems (Poppes et al., 2010). Challenging behaviour has also been found to occur more frequently in children with auditory limitations (Došen, 2007; Wieseler, Hanson & Nord, 1995). 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, Korzilius, Van Aperlo, Van Overloop & De Vries, 2002; Lundqvist, 2013; Rojahn, Matson, Naglieri & Mayville, 2004). When bowel and/or abdominal problems are present, for example, gastro-oesophageal reflux disease, some studies show significantly more challenging behaviour (Gössler, Schalamon, Huber-Zeyringer & Höllwarth, 2007). People with PIMD are more likely to suffer from chronic pain due to such issues as bowel and abdominal problems, respiratory problems, 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 risk marker for challenging behaviour is mental health problems (Dôsen, 2007; Rojahn et al., 2004; Ross & Oliver, 2002). However, studies to date do not focus on people with PIMD.

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

With regard to contextual risk markers, Emerson (2001) discusses 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, 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 intellectual disability in general, the results are often inconclusive and few focus on PIMD. This lack of knowledge is a cause for concern because these risk 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 risk factors for challenging behaviour are also applicable to people with PIMD. The above-mentioned known risk factors related to persons with PIMD, direct support staff 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 direct support staff 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.

4.2 Method

4.2.1 Participants

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

- having a profound intellectual disability (IQ of 25 or below)
- a profound or severe motor disability (manifest in an inability to move independently)
- the age of onset before the age of 18 (Nakken & Vlaskamp, 2007)

A convenience sample of a total of 198 people with PIMD was retrieved. Direct support staff was then randomly assigned to a person with PIMD they already worked with by the healthcare psychologist or the manager of the facility. Informed consent, including written permission for participation in this study, was given by the parent(s) or legal representatives of the participating persons.

4.2.2 Measures

For each participant, a semi-structured questionnaire was completed by a member of direct support staff 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 direct support staff were included, such as gender (male/female), age of direct support staff (in years) and the number of years of work experience with people with intellectual disability 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, direct support staff could choose between two options: vocational education or college. Furthermore, we wanted to know whether or not direct support staff 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: 1. living arrangements (residential facility, community living, 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, Matson, Lott, Esbensen & Smalls, 2001) provides information about the prevalence, frequency and severity of challenging behaviour in people with intellectual disability in general. The BPI is an informant-based scale that addresses three types of challenging behaviour: SIB, SB and ADB. SIB 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). SB is described as 'repeated uniform body movements or postures that are obviously not part of some goal-directed act' (Rojahn et al., 2001). ADB 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: SIB (14 items), SB (24 items) and ADB (11 items). Each subscale 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: (i) a frequency scale, 0 = the behaviour does not occur, 1 = the behaviour occurs every month, 2 = weekly, 3 = daily and 4 = every hour; and (ii) 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 ADB subscale, and the latter two to the SB subscale. 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 SIB, SB and ADB. Given the frequent mention of such behaviour by professionals, we decided to include withdrawn behaviour (WB) 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: SIB (15 items), SB (22 items), WB (5 items) and ADB (12 items). Each subscale 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 member of staff who was linked to one person with PIMD.

The psychometric properties of the original BPI are good (Van Ingen, Moore, Zaja & Rojahn, 2010; Rojahn et al., 2001; González et al., 2009;). These findings are in line with studies by Dumont, Kroes, Korzilius, Didden and Rojahn (2014) and Lambrechts and Maes (2009) into the psychometric properties of the Dutch translation of the BPI-01 for people with a profound intellectual disability. The internal consistency of the entire scale, measured with Cronbach’s alpha, ranges from good to excellent. The internal consistency of the SIB subscale was moderate in all the abovementioned 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 subscales (SIB, $\alpha = 0.48$; SB, $\alpha = 0.81$; WB, $\alpha = 0.73$; ADB, $\alpha = 0.83$). These findings are in line with other research into the internal consistency of the BPI (Dumont et al., 2014; Lambrechts & Maes, 2009; Rojahn et al., 2001).

4.2.3 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 direct support staff then completed the BPI with respect to one person with PIMD they worked with. This happened during a meeting of the direct support professionals concerned and the researcher. The participating organizations made sure approval for the study by their ethical committees and permission of parents or legal representatives was obtained.

4.2.4 Analyses

Only the frequency scores on the BPI-PIMD were taken into account in the analysis. The mean frequency scores of each subscale of the BPI-PIMD (SIB, SB, WB and ADB) were calculated in order to analyse the relationship between the occurrence of these behaviours and the risk markers described.

The risk markers related to the person with PIMD were: 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 problems, lung and respiratory problems, 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 direct support staff said they did not know.

The risk markers related to the direct support staff were: gender, age, the number of years of work experience with people with intellectual disability, 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 risk markers were: 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 SIB, SB, WB and ADB. Pearson’s correlation coefficients were calculated for continuous risk variables. Associations with a p -value $\leq .10$ were entered into a 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 $\leq .05$) were included in the definitive regression model for challenging behaviour, together with significant interaction effects. Logistic regression was performed for non-normally distributed variables.

4.3 Results

4.3.1 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 (see 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 four hours, during which activities are offered to the person with PIMD) and they lived in group homes with an average of 7.8 people. In general, two direct support staff 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.

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

| | n | % | Missing (N/%) |
|---|------|------|---------------|
| <i>Sensory problems</i> | | | |
| Auditory | 58 | 29.3 | 7 (3.5) |
| Visual | 113 | 57.1 | 3 (1.5) |
| Tactile | 80 | 40.4 | 8 (4.0) |
| <i>Health problems</i> | | | |
| Epilepsy | 128 | 64.6 | 6 (3.0) |
| Bowel and abdominal problems | 148 | 74.7 | 6 (3.0) |
| Sleeping problems | 56 | 28.3 | 9 (4.5) |
| Lung and respiratory problems | 50 | 25.3 | 6 (3.0) |
| Eating and drinking problems | 132 | 66.7 | 5 (2.5) |
| Dental problems | 56 | 28.3 | 6 (3.0) |
| Mental health problems | 39 | 19.7 | 6 (3.0) |
| <i>Living arrangements</i> | | | |
| Residential | 61 | 30.8 | 5 (2.5) |
| Community | 132 | 66.7 | |
| | mean | SD | |
| Day-service sessions | 8.6 | 2 | 3 (1.5) |
| Number of direct support staff per home | 2 | 0.5 | 4 (2.0) |
| Number of residents per group | 7.8 | 2.1 | 3 (1.5) |

A total of 198 direct support staff 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 2 Sample characteristics direct support staff (n = 198)

| | Mean (SD) | Missing (N/%) |
|---|------------|---------------|
| <i>Work experience (in years)</i> | | |
| With people with ID | 13.7 (9.4) | 2 (1) |
| With people with PIMD | 11.0 (5.2) | 1 (0.5) |
| With participant | 5.2 (4.6) | 1 (0.5) |
| <i>Working hours</i> | | |
| Working hours per week | 26.6 (6.1) | 5 (2.5) |
| <i>Level of education</i> | | |
| | N(%) | |
| Senior secondary vocational education | 122 (61.6) | 19 (9.6) |
| Vocational education | 57 (28.8) | |
| <i>Training on CB in people with ID</i> | | |
| Training | 83 (41.9) | 6 (3) |

ID=intellectual disability

PIMD= profound intellectual and multiple disability

CB= challenging behaviour

4.3.2 Prevalence and mean frequency of challenging behaviour

SIB was identified in 84.9% ($n = 168$) of the participants, SB in 93.4% ($n = 185$), WB in 84.4% ($n = 167$) and ADB in 47% ($n = 93$) of the participants. Table 3 presents the mean frequencies of the different types of challenging behaviour, including items for which direct support staff indicated that the behaviour did not occur.

Table 3 Mean frequency of challenging behaviour

| | Self-injurious | Stereotypical | Withdrawn | Aggressive/ destructive |
|--------|----------------|---------------|-----------|----------------------------|
| n | 193 | 195 | 194 | 194 |
| Mean | .35 | .71 | 1.11 | .27 |
| Median | .31 | .59 | 1.00 | .00 |
| SD | .28 | .57 | .82 | .43 |
| range | .00-1.25 | .00-3.05 | .00-3.33 | .00-2.85 |

4.3.2 Associations between personal characteristics of people with PIMD and challenging behaviour

The average frequency of SIB, SB, WB and ADB did not differ significantly ($p > .10$) between the groups divided by gender, age, visual impairment and dental problems (see Tables 4 and 5). To determine possible risk factors for SIB, the independent variables of auditory problems, tactile problems, sleeping problems, and bowel and abdominal problems were included. For SB, the following variables were included: auditory problems, tactile problems, sleeping problems, mental health problems, and eating and drinking problems. For WB, the variables were auditory problems, tactile problems, sleeping problems, mental health problems and epilepsy; and for ADB, the variables were auditory problems, tactile problems, sleeping problems, mental health problems, and lung and respiratory problems (see Tables 4 and 5).

4.3.3 Associations between personal characteristics of direct support staff and challenging behaviour

No significant differences were found for age, work experience, number of working hours or educational level of the direct support staff with regard to the mean frequencies of SIB, SB, WB and ADB. Direct support staff who received training on challenging behaviour in people with an intellectual disability had a higher mean frequency score on WB and ADB than direct support staff without training (see Table 4). This variable was included in further analyses to identify risk markers for challenging behaviour.

4.3.4 Associations between contextual factors and challenging behaviour

No significant differences were found for living arrangements, number of direct support staff per home and number of residents per group in relation to mean frequencies of challenging behaviour. The mean frequency scores on ADB were significantly higher in people who received 8-10 sessions of day services per week than people who participated in fewer sessions (see Table 4). The more hours a staff member worked, the more SIB was identified (see Table 5). The number of day-service sessions and the number of working hours were included in further analyses.

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

| | self-injurious | | Stereotypical | | Withdrawn | | Aggressive/ destructive | |
|------------------------------|----------------|---------------|---------------|---------------|-----------|---------------|----------------------------|---------------|
| | M(SD) | t(df) | M(SD) | t(df) | M(SD) | t(df) | M(SD) | t(df) |
| People with PIMD | | | | | | | | |
| <i>Gender</i> | | | | | | | | |
| Male | .36(.28) | .46(191) | .72(.61) | .48(193) | 1.19(.83) | 1.38(192) | .28(.42) | .30(192) |
| Female | .34(.34) | | .68(.52) | | 1.02(.80) | | .26(.44) | |
| <i>Auditory</i> | | | | | | | | |
| No | .32(.26) | -2.63(142)*** | .64(.49) | -2.13(144)** | 1.01(.74) | -1.72(143)* | .22(.34) | -1.92(143)* |
| Yes | .44(.28) | | .83(.61) | | 1.24(.85) | | .35(.52) | |
| <i>Visual</i> | | | | | | | | |
| No | .35(.26) | -.06(155) | .71(.54) | -.45(157) | 1.03(.72) | -.85(156) | .30(.33) | 1.34(156) |
| Yes | .35(.29) | | .76(.62) | | 1.15(.89) | | .22(.37) | |
| <i>Tactile</i> | | | | | | | | |
| No | .29(.26) | -2.45(142)*** | .58(.49) | -2.85(144)*** | .88(.75) | -3.52(144)*** | .19(.42) | -2.13(144)** |
| Yes | .41(.29) | | .84(.84) | | 1.37(.88) | | .35(.45) | |
| <i>Epilepsy</i> | | | | | | | | |
| No | .33(.28) | -1.00(184) | .75(.62) | .36(186) | .95(.77) | -2.17(185)** | .24(.31) | -.78(185) |
| Yes | .37(.28) | | .72(.55) | | 1.23(.83) | | .29(.48) | |
| <i>Bowel & abdominal</i> | | | | | | | | |
| No | .28(.25) | -1.75(180)* | .65(.57) | -.67(182) | .94(.86) | -1.56(181) | .22(.37) | -.64(181) |
| Yes | .37(.28) | | .72(.57) | | 1.17(.81) | | .27(.43) | |
| <i>Sleeping</i> | | | | | | | | |
| No | .32(.27) | -2.57(165)*** | .63(.55) | -2.79(162)*** | .94(.73) | -3.09(161)*** | .21(.35) | -2.86(161)*** |
| Yes | .44(.29) | | .90(.66) | | 1.36(.95) | | .41(.57) | |
| <i>Eating & drinking</i> | | | | | | | | |
| No | .35(.26) | -.11(187) | .82(.59) | 1.77(187)* | 1.09(.83) | -.25(187) | .28(.37) | .25(187) |
| Yes | .35(.29) | | .66(.56) | | 1.13(.82) | | .26(.46) | |
| <i>Dental</i> | | | | | | | | |
| No | .34(.26) | -.62(166) | .67(.54) | -1.62(168) | 1.06(.82) | -.53(167) | .28(.45) | .88(167) |
| Yes | .37(.30) | | .82(.61) | | 1.13(.78) | | .22(.35) | |
| <i>Mental health</i> | | | | | | | | |
| No | .32(.28) | -1.40(136) | .63(.53) | -2.36(138)** | .88(.74) | -3.74(137)*** | .19(.33) | -2.17(137)** |
| Yes | .39(.24) | | .89(.60) | | 1.45(.91) | | .33(.41) | |

(Table continues)

Table 4 (continued)

| | self-injurious | | Stereotypical | | Withdrawn | | Aggressive/ destructive | |
|---------------------------------------|----------------|------------|---------------|------------|-----------|--------------|----------------------------|--------------|
| | M(SD) | t(df) | M(SD) | t(df) | M(SD) | t(df) | M(SD) | t(df) |
| Direct support staff | | | | | | | | |
| <i>Level of education</i> | | | | | | | | |
| Vocational | .34(.28) | -1.58(173) | .74(.61) | .45(175) | 1.12(.83) | -.99(174) | .26(.40) | -1.00(174) |
| College | .41(.28) | | .69(.49) | | 1.26(.78) | | .36(.52) | |
| <i>Training challenging behaviour</i> | | | | | | | | |
| No | .37(.28) | 1.28(186) | .69(.56) | -.39(188) | 1.01(.77) | -2.14(187)** | .22(.35) | -1.89(134)* |
| Yes | .32(.27) | | .73(.60) | | 1.27(.87) | | .34(.52) | |
| Context | | | | | | | | |
| <i>Living arrangements</i> | | | | | | | | |
| Residential | .31(.26) | -1.27(187) | .64(.51) | -1.20(189) | 1.14(.90) | .20(188) | .26(.39) | -.34(188) |
| Community | .37(.28) | | .74(.59) | | 1.12(.78) | | .28(.45) | |
| <i>Day services</i> | | | | | | | | |
| 0-7 sessions | .32(.26) | -.65(189) | .61(.51) | -1.17(191) | 1.09(.91) | -.19(190) | .17(.28) | -2.02(94.6)* |
| 8-10 sessions | .36(.28) | | .73(.58) | | 1.12(.80) | | .29(.46) | |

*p < 0.10 ***p < 0.01 t = T-statistic
 **p < 0.05 M = mean

Table 5 Correlation matrix between challenging behaviour variables and the personal characteristics of people with PIMD, direct support staff and context

| | Models | | | |
|----------------------------------|--------|-------|-------|-------|
| | SIB | SB | WB | ADB |
| | r | r | r | r |
| People with PIMD | | | | |
| Age (N = 192) | -0.04 | -0.06 | -0.02 | -0.13 |
| Direct support staff | | | | |
| Age (N = 197) | -0.11 | -0.03 | 0.09 | 0.00 |
| Work experience ID (N = 196) | -0.09 | -0.03 | -0.05 | 0.03 |
| Work experience PIMD (N = 197) | -0.14 | -0.12 | -0.09 | 0.00 |
| Work experience person (N = 197) | 0.07 | 0.04 | 0.01 | -0.03 |
| Working hours (N = 193) | 0.15* | 0.10 | 0.05 | 0.09 |
| Context | | | | |
| Size of the group (N = 195) | -0.11 | -0.02 | 0.04 | 0.00 |
| Number of staff | -0.05 | -0.06 | -0.05 | 0.01 |

*p < 0.10 ***p < 0.01
 **p < 0.05 r = Pearson's correlation coefficient

4.3.5 Risk marker identification

Table 6 presents the final, best fitting models. Auditory problems were a risk marker for SIB and SB, sleeping problems were a risk marker for all four types of challenging behaviour. Bowel and abdominal problems were a risk marker for SIB only. Having eating and drinking difficulties increased the frequency of SB. An increased frequency of ADB 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 ADB. Therefore, they could not both be included in the model. When direct support staff received training on challenging behaviour in people with intellectual disabilities they identified more WB in people with PIMD. We did not find any interaction effects between the independent variables.

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

| Dependent variables | Independent variables | B ² (SE) | p | Model adjusted R ² |
|----------------------------|----------------------------|---------------------|------|-------------------------------|
| <i>Linear regression</i> | | | | |
| <i>SIB¹</i> | | | | |
| | Auditory problems | -0.13(0.05) | 0.02 | 0.13 |
| | Sleeping problems | -0.14(0.05) | 0.01 | |
| | Bowel & abdominal problems | -0.11(0.06) | 0.05 | |
| <i>SB¹</i> | | | | |
| | Auditory problems | -0.24(0.10) | 0.02 | 0.08 |
| | Sleeping problems | -0.22(0.11) | 0.04 | |
| | Eating & drinking problems | -0.23(0.11) | 0.03 | |
| <i>WB¹</i> | | | | |
| | Sleeping problems | -0.42(0.13) | 0.00 | 0.07 |
| | Training CB | -0.28(0.13) | 0.03 | |
| Odds ratio | | | | |
| <i>Logistic regression</i> | | | | |
| <i>ADB¹</i> | | | | |
| | Mental health problems | 2.78 | 0.07 | |

¹SIB = self-injurious SB = stereotypical WB = withdrawn ADB = aggressive/destructive

²B = estimated regression coefficients; SE: corresponding standard error

4.4 Discussion

This study explored the relationship between identified challenging behaviour and risk markers in people with PIMD. Furthermore, risk markers related to direct support staff and risk markers related to contextual factors were 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 SIB and SB. This is in line with the findings of Lundqvist (2013), who reported that people with auditory, olfactory and tactile hypersensitivity were more likely to exhibit any type of challenging behaviour. Having sleeping problems was associated with a higher frequency of all types of challenging behaviour (SIB, SB, WB and ADB). Lundqvist (2013) also found that sleeping problems were a risk marker for SIB and SB, while De Winter et al. (2011) concluded that people with challenging behaviour show sleep disturbances. Bowel and abdominal problems increased the frequency of SIB in our study. A possible explanation for this could be that conditions such as dysphagia, reflux and constipation can cause pain. People with PIMD are not able to express pain in words, which might lead to SIB. SB 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, ADB 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 intellectual disability who also showed SIB, SB or ADB 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 which makes it difficult to accurately diagnose these problems. It is quite possible that mental health problems are much more common in this group than our data reflect.

In this study, we found only one risk marker related to the direct support staff. When direct support staff had been offered training on the subject of challenging behaviour in people with intellectual disabilities in general, they identified significantly more WB. 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 WB, even if such behaviour is not as obvious as SIB and ADB. Our study found no contextual risk markers 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 the frequency of challenging behaviour.

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. Direct support staff who worked with the participants in this study have access to the latter's individual comprehensive service 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 is 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. 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.

Almost no factors related to direct support staff 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, Hiemstra, Wiersma & Zijlstra, 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.

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, 2014; Van den Bosch, Andringa & Vlaskamp, 2013). A sense of place allows a person to generate expectations about the location and situation he/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 since 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) could lead to discomfort and a higher likelihood of challenging behaviour, such as SIB and WB. It could 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 direct support staff.

One other factor that contributed to challenging behaviour in our study was problems with sleep. Hylkema and 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 direct support staff) within settings where they live. By implementing a non-pharmaceutical intervention which entailed an improved sleep schedule, a more suitable daily routine and/or increasing the number and extent of activities during the day, Hylkema and 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 intellectual disability seems to have an impact on the identification of WB in people with PIMD. We know from earlier research that direct support staff report the majority of identified challenging behaviour in people with PIMD as to be of minor consequence (Poppes et al., 2010), although the prevalence and frequency rates indicate that challenging behaviour is very common. Furthermore, half of the identified challenging behaviours are not included in individual comprehensive service plans by direct support staff and virtually no goals are formulated to prevent or diminish challenging behaviour (Poppes, Van der Putten & Vlaskamp, 2014). This could be caused by a lack knowledge about challenging behaviour and its consequences for people with PIMD. A study by Ross and Oliver (2002) has shown that there is a tendency to see challenging behaviour as resulting from the intellectual disability rather than being symptomatic of other causes. Direct support staff might view challenging behaviour as a given and consequently do not feel that specific forms of support or intervention need to be undertaken. Direct support staffs causal attributions for challenging behaviour are likely to be important to any decision about a particular treatment for the behaviour. Tynan and Allen (2002), for example, found that staff attributed aggressive behaviour in people with severe intellectual disabilities to a biomedical model. This could mean that direct support staff 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 direct support staff understanding of the causes of challenging behaviour in people with PIMD and to analyse whether training about challenging behaviour, influential risk markers and the consequences of challenging behaviour leads direct support staff to label the behaviour differently and notice it more often.

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4.5 References

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Chapter 5

Staff attributions of the causes of challenging behaviour in people with profound intellectual and multiple disabilities.

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Staff attributions of the causes of challenging behaviour in people with profound intellectual and multiple disabilities.

Abstract

- Background* A study has shown that staff do not generally perceive challenging behaviour in people with profound intellectual and multiple disabilities (PIMD) as being of serious consequence.
- Aim* In this study we aimed to gain a better understanding of the causal explanations that direct care and support staff give for challenging behaviour in this group. The purpose of this study was twofold: (1) to determine the way staff attribute challenging behaviour in children and adults with PIMD; and (2) to analyse whether more experienced staff attribute challenging behaviour in children and adults with PIMD differently than less experienced staff.
- Method* In total, 195 direct support staff and an equal number of children and adults with PIMD participated in the study. Direct support staff filled out the Challenging Behaviour Attribution Scale (five causal explanatory models of challenging behaviour) to explain challenging behaviour in one individual that they supported.
- Results* The results show that direct support staff as a whole report the biomedical model as the most plausible explanation for challenging behaviour in children and adults with PIMD.
- Conclusion* In the present study the mean scores on all models are low. This might indicate that a large number of staff found none of the models particularly useful as possible explanations of challenging behaviour in people with PIMD. This could mean that staff have difficulties stating the cause of challenging behaviour in this group. Another possible explanation could be that there is little scientific knowledge about causing and maintaining factors of challenging behaviour in people with PIMD. It could also mean that staff have additional explanations for challenging behaviour in this target group that are not mentioned in the instrument used. Future research should address these issues. No differences were found between more experienced and less experienced direct support staff.

5.1 Introduction

Recent decades have provided ample research findings on the prevalence and prevention 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 62% in large population-based studies (e.g. Emerson et al., 2001, Holden & Gitlesen, 2006; Lundqvist, 2013) to around 80% in specific settings (e.g. Csorba, Radvanyi, Regenyi & Dinya, 2011; Poppes, Van der Putten & Vlaskamp, 2010; Rojahn, Matson, Lott, Esbensen & Smalls, 2001). Emerson (2001, p. 3) defines challenging behaviour as 'culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities'. The Royal College of Psychiatry, British Psychological Society & Royal College of Speech & Language Therapists (2007) has updated this definition to: 'Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion' (RCP, BPS, & RCSLT, 2007, p.10). This definition emphasizes the social construction of challenging behaviours as a product of an interaction between the individual and their environment.

Factors described in the literature as influential in the onset and maintenance of challenging behaviour are the degree of intellectual disability (Chadwick, Kusel & Cuddy, 2008; Holden & Gitlesen, 2006; McClintock, Hall & Oliver, 2003; Wulffaert et al. 2009), the degree of motor impairment and the presence of sensory impairments (Chadwick, Piroth, Walker, Bernard & Taylor, 2000; Došen, 2007; Holden & Gitlesen, 2006), additional health problems (e.g. epilepsy, mental health problems, sleeping problems) (Doran, Harvey & Horner, 2006; Došen, 2007; Oliver & Richards 2010) and communicative problems (McIntyre, Blacher & Baker, 2002; Totsika, Felce, Kerr & Hastings, 2010).

These factors are all present in children and adults with profound intellectual and multiple disabilities (PIMD). This group has an estimated intelligence quotient of 25 points or lower (meaning that they need comprehensive support) and severe or profound motor impairments, which is reflected in not being able to move independently and having limited use of their hands/arms (Nakken & Vlaskamp, 2007). People with PIMD have major difficulties with receptive or expressive communication, resulting in them understanding and using a small number of words at most or relying completely on non-symbolic forms of communication. In addition, this group frequently has sensory problems and many additional health problems such as epilepsy, bowel and abdominal problems and pulmonary and respiratory problems

(Böhmer, Taminiau, Klinkenberg-Knol & Meuwissen, 2001; Codling & MacDonald, 2009; Van der Putten & Vlaskamp, 2011; Watt-Smith, 2009).

Challenging behaviour is thus expected to be more common amongst individuals who frequently have these types of co-morbidity, such as people with PIMD. A study (Poppes et al., 2010) conducted into the prevalence rates for all types of challenging behaviour in 181 children and adults with PIMD shows that prevalence rates are indeed high (self-injurious 82%, stereotypical 82%, withdrawn 84% and aggressive/destructive behaviour 45%). Examples of behaviours that occur with high frequency (i.e. on a daily or hourly basis) include hitting themselves on the head, screaming and shouting and being apathetic for much of the day. Even though challenging behaviour seems to be very common in people with PIMD, staff usually report it as being of minor consequence for the individuals themselves (Poppes et al., 2010). One of the consequences of this perceived low severity could be that challenging behaviour is not systematically addressed in daily practice, as shown in a study by Poppes, Van der Putten and Vlaskamp (2014). Where interventions aimed at reducing or preventing challenging behaviour are included in individual comprehensive service plans, they seem simplistic, and there are virtually no goals to document, reduce or prevent challenging behaviour in people with PIMD (Poppes et al., 2014). This is a cause for concern, as challenging behaviour not only has physical consequences for the individuals themselves, but can also have serious consequences for their ability to establish a relationship with the world around them. For example, stereotypical behaviour that occurs on an hourly basis may 'capture' the attention of the person with PIMD for much of the day, and consequently hinder communication with their environment and therefore reduce opportunities to build and maintain relationships with others. These relationships are vital to people with PIMD as a means of gaining experience and exerting influence on their own lives (Vlaskamp & Van der Putten, 2009).

In general, it is believed that challenging behaviours are social behaviours that can be influenced by the actions of others in the environment (Hastings & Remington, 1994). Staff beliefs/attributions regarding the cause of challenging behaviour may affect the actions staff undertake in relation to people displaying challenging behaviour. Heider (1958) developed an attribution theory that assumes that when people perceive an event, they try to find a cause for it or attribute responsibility. Direct support staff's attributions/beliefs about challenging behaviour might affect their responses to the challenging behaviour displayed, as well as their beliefs about effective intervention strategies (Dowey, Toogood, Hastings & Nash, 2007; Hastings, 1997). It is assumed that the behaviour of direct support staff is determined by emotional responses and cognitions (beliefs/attributions) about the challenging behaviour (Hastings, 2002; Hastings, 2005; Hastings & Remington, 1994; Snow, Langdon & Reynolds, 2007; Weiner, 1985). The things that direct support staff

may or may not do in their work with people with PIMD as a result of these beliefs may determine, at least in part, the emergence and persistence of challenging behaviour (Hastings & Remington, 1994; Hastings, 2002; Weiner, 1985). Hastings (1997) proposed five causal models of challenging behaviour: learned behaviour (negative and positive reinforcement processes), biomedical (e.g. physical or medical problems), emotional (e.g. anger, stress, fear), physical environment (e.g. auditory environment, bright lights) and self-stimulation (e.g. boredom, not being offered activities) (Hastings, 1997). If staff attribute challenging behaviour to an internal cause that is difficult to modify (e.g. biomedical), they might respond differently to the behaviour than if they believe it has an external, modifiable cause. Attributions by direct support staff and subsequent responses to challenging behaviour may even lead to a situation where attributions and consequent responses endorse that behaviour and contribute to its long-term maintenance (Hastings & Remington, 1994; Jones & Hastings, 2003).

Tynan and Allen (2002) found in their study that the severity of the intellectual disability influenced the attributions staff made regarding aggressive behaviour. Staff considered the biomedical model of more causal relevance for aggressive behaviour in people with severe intellectual disabilities than in people with mild intellectual disabilities. Hastings, Remington and Hopper (1995) found differences between attributions in experienced and inexperienced staff. More experienced staff were more likely to give behavioural and biological explanations for challenging behaviour than less experienced staff. Research indicates that staff see behaviour as more problematic if it has a direct impact on themselves or is inconvenient for the organization (Elgie & Hastings, 2002; Hastings, 2005; Lowe, Felce & Blackman, 1995; Poppes et al., 2014). Hastings (2005) suggests that staff are therefore less inclined to intervene in behaviour that has little or no effect on themselves or their organizations, such as stereotypical behaviour.

Forster, Gray, Taffe, Einfeld and Tonge (2011) found in their research on behavioural and emotional problems in people with severe and profound intellectual disability that there are significant differences between groups of people with severe and profound intellectual disabilities regarding challenging behaviour and emotional problems. They suggest that these two groups should be treated as single groups in research. Since the research carried out regarding staff attributions on challenging behaviour so far in this field has not focused on people with PIMD, we were interested in direct support staff's attributions regarding challenging behaviour in this target group. Two studies conducted in the Netherlands (Poppes et al., 2010; Poppes et al., 2014) show that staff do not generally perceive challenging behaviour in children and adults with PIMD as being of serious consequence and they rarely include goals aimed at reducing or preventing such behaviour in individual comprehensive service plans. It is important to gain a better understanding of the

explanations staff give for challenging behaviour in children and adults with PIMD because it may offer clues for the reduction or prevention of this behaviour and consequently for developing an appropriate intervention. The purpose of this study has been twofold: (1) to determine the way staff attribute challenging behaviour in children and adults with PIMD; and (2) to analyse whether more experienced staff attribute challenging behaviour in children and adults with PIMD differently than less experienced staff.

5.2 Method

5.2.1 Participants

Direct support staff were recruited from ten organizations across the Netherlands using the following inclusion criteria: supporting a person with a profound intellectual disability (IQ of 25 or below) and a profound or severe motor disability (manifested in the inability to move independently), where the age of onset was before their 18th birthday (Nakken & Vlaskamp, 2007). In addition, the direct support staff had to support a person with PIMD who exhibited challenging behaviour at least once in the previous two months (scored using the Behaviour Problem Inventory for people with PIMD: see Poppes et al., 2010; Rojahn et al., 2001). Informed consent, including written permission to take part in the study, was given by the parent(s) or legal representatives of the individuals with PIMD and informed consent was given by participating staff.

A convenience sample was retrieved from a total of 195 direct support staff. The participating direct support staff were predominantly female (186, 95.4%). Their mean age was 38.5 (SD: 11.3, range: 20-64). Data on the direct support staff's level of education was missing for 18 participants. Most participants had attended senior secondary vocational education (n = 122, 62.2%); the remaining participants (n = 55, 28.2%) had attended vocational college. On average the direct support staff had 14 years of working experience, with a minimum of 1 year and a maximum of 40 (SD: 9.1). Data on working experience was missing for one participant.

The direct support staff completed a semi-structured questionnaire to determine the personal characteristics of the person with PIMD – age, gender (male/female) – as well as the prevalence of sensory problems and chronic health problems (yes/no/I do not know) for the person they supported.

Of the people with PIMD, 105 were male and 90 were female. Their mean age was 30.4 years (SD: 16.1 range: 3-67, missing data: 6). In our study 44 participants, all children, lived at home. The remaining 145 people with PIMD lived in group homes, with an average of 7.8 people per residential unit. In general, two direct support staff were present during the day, either in the unit or at the day-service setting. Most

of the 145 individuals with PIMD lived in a community setting (a total of 84), and 61 in a residential facility. Table 1 presents information on additional health problems.

Table 1 Additional health problems of children and adults with PIMD (n=195)

| | Number of people with PIMD (N missing data) | % (% missing data) |
|-------------------------------|---|--------------------|
| <i>Sensory problems</i> | | |
| Auditory | 57 (6) | 29.2 (3.1) |
| Visual | 111 (2) | 56.9 (1.0) |
| Tactile | 79 (7) | 40.5 (3.6) |
| <i>Health problems</i> | | |
| Epilepsy | 128 (5) | 65.6 (2.6) |
| Bowel and abdominal problems | 146 (5) | 74.9 (2.6) |
| Sleeping problems | 55 (8) | 28.2 (4.1) |
| Lung and respiratory problems | 49 (5) | 25.1 (2.6) |
| Eating and drinking problems | 132 (4) | 67.7 (2.1) |
| Dental problems | 56 (5) | 28.7 (2.6) |
| Mental health problems | 39 (5) | 20.0 (2.6) |

5.2.2 Measures Attributions

Direct support staff completed the translated version of the Challenging Behaviour Attributions Scale (CHABA; Hastings, 1997; translated version Lambrechts, Kuppens & Maes, 2009). The questionnaire consists of 33 items, each of which states a possible reason as to why a person with intellectual disability may engage in challenging behaviour. The 33 items relate to five causal models: learned behaviour (beliefs that challenging behaviours are maintained by positive and negative enforcement processes; six items, e.g. he/she wants attention); medical/biological factors (beliefs that challenging behaviours are related to biological/medical causes; six items, e.g. because of the medication that he/she is given); emotional factors (beliefs that challenging behaviours are related to emotional factors; seven items, e.g. because he/she is angry); aspects of the physical environment (beliefs that challenging behaviours are related to environmental circumstances; eight items, e.g. because high humidity makes him/her uncomfortable); and self-stimulation (beliefs that challenging behaviours are related to self-stimulatory functions; six items, e.g. because he/she is bored).

Direct support staff were asked to rate each of the 33 items on a five-point scale (-2=very unlikely, -1=unlikely, 0=equally likely/unlikely, 1= likely and 2=very likely). Each subscale score was calculated by summing the number of individual items within a particular subscale and dividing by the number of items. A subscale score above zero suggests that the particular causal model is considered applicable to the behaviour. A subscale score below zero suggests that the respondent considers the particular causal model as unlikely to apply to the behaviour. The internal consistency of the five subscales was assessed using Cronbach's alpha. For all five scales, the values of alpha were between .75 and .80, which indicates an acceptable internal consistency (Field, 2009). These values compared favourably with the alpha values originally described by Hastings (1997), which ranged from .65 to .87 and those found by Tynan and Allen (2002), which ranged from .65 to .74. Although there is a lack of specific studies on the validity of the CHABA, the instrument is used in a wide variety of research on staff attributions (e.g. Lowe et al., 2007; McGill, Bradshaw & Hughes, 2007; Schmidt, Balandin, Reed & Sigafos, 2007; Tierney, Quinlan & Hastings, 2007).

5.2.3 Procedure

Arrangements were made with organizations that were willing to participate to fill in the questionnaires. The direct support staff then completed the CHABA with respect to one person with PIMD who they worked with. This happened at a meeting of the direct support staff and the researcher. The participating organizations made sure that they obtained approval for the study from their ethical committees, as well as permission from parents or legal representatives.

5.2.4 Analysis

Only participants who filled in more than 75% of the items of the CHABA were included in the analysis. This meant that 15 participants were excluded; two of those participants only filled in four or six items of the questionnaire, and 13 participants did not fill in any items. The analysis was performed on 180 participants, 40 of whom did not fill in all 33 items of the CHABA. For these 40 people, the scale descriptives were calculated based on the items they filled in.

There was no significant difference between the 15 excluded participants and the 180 participants included in the analysis in terms of the age ($t(190)=-.50, p = .62$) or gender ($\chi(1)=2.75, p = .10$) of the children and adults with PIMD. A comparison of the age ($t(193)=-.60, p = .55$), gender ($\chi(1)=.78, p = .38$), educational level ($\chi(1)=2.65, p = .10$) and working experience ($t(192)=.88, p = .38$) of the direct support staff also showed no difference.

Scale means were calculated for each causal model of the CHABA by adding up the scores of the items belonging to the causal models and dividing them by the number of items. A subscale score of less than zero means that the direct support

professional does not consider this causal model to be a likely explanation for the behaviour and a subscale score of more than zero means that he or she considers this causal model a likely explanation (Hastings, 1997). Descriptive statistics were given on the scales. Mean, SD and range were calculated. The frequency of direct support professional's scoring [-2 to -1.01], [-1.0 to -0.01], [0.0], [0.01 to 0.99] or [1.0 to 2.0] was also given for the five scales.

To determine which CHABA scale the direct support staff attributed the most behaviour to, significant differences in mean scores between the scales were analysed. Ten paired sample t-tests were performed in order to see whether there were significant differences between the scores on the scales. Significance levels are reported at $p \leq .005$ (Bonferroni correction was used because of the number of comparisons). 95% confidence intervals were calculated around the mean differences between scales that differed significantly from each other. The relationship between the five CHABA subscales and the number of years' experience of working with people with ID was calculated using five Pearson's correlation coefficients.

5.3 Results

Table 2 shows that the mean score on the biomedical scale is above zero and mean scores on the other scales are below zero, indicating that participants on the whole considered the biomedical model to be applicable in accounting for challenging behaviour in children and adults with PIMD. When looking at the frequency distribution of the scores in the different scales, we see that a total of 55.6% direct support staff (n =100) scored the biomedical model as a likely explanation (see Table 2). A total of 41.1% (n=75) scored the emotional scale as a likely explanation. 38.9% of direct support staff (n=71) scored learned behaviour as a likely explanation for challenging behaviour in children and adults with PIMD. Stimulation and physical environment models were rated as least relevant, with 29.4 (n=53) and 27.2% (n=50) of direct support staff scoring these scales as likely explanations.

| Scale | N | Descriptives | | | Frequency distribution (%) | | | | |
|----------------------|-----|--------------|-------|------|----------------------------|-------------|-----------|--------|------|
| | | range | Mean | SD | -2 to -1.01 | -1 to -0.01 | 0 to 0.99 | 1 to 2 | |
| Biomedical | 180 | -2 to 2 | 0.08 | 0.85 | 8.9 | 29.4 | 6.1 | 40.0 | 15.6 |
| Emotional | 180 | -2 to 2 | -0.12 | 0.75 | 11.1 | 38.9 | 8.9 | 33.3 | 7.8 |
| Learned behaviour | 180 | -2 to 1.8 | -0.20 | 0.84 | 15.0 | 36.7 | 9.4 | 30.6 | 8.3 |
| Stimulation | 180 | -2 to 1.7 | -0.33 | 0.81 | 18.3 | 40.6 | 11.7 | 24.4 | 5.0 |
| Physical environment | 180 | -2 to 1 | -0.39 | 0.68 | 17.8 | 47.8 | 7.2 | 26.1 | 1.1 |

Table 2 Mean scores and frequency distribution on the challenging behaviour attribution scale (CHABA)

Table 3 shows that the mean score on the biomedical model differs significantly from the other four models. The score on the physical environment model is lowest, and differs significantly from all but one model. This model can therefore be considered the least relevant. When looking at the differences between the other three scales, we note one significant difference in mean scores, with the emotional model scoring significantly higher as an explanation for challenging behaviour than the stimulation model.

Table 3 Differences between the five attribution scales, calculated using a paired samples t-test

| | Scales | | | | | | | | | | | |
|----------------------|----------------------|-----|------------|-----------|------|--------------|-------------------|------|--------------|-------------|------|------------|
| | Physical environment | | | Emotional | | | Learned behaviour | | | Stimulation | | |
| | t | MD | CI | T | MD | CI | t | MD | CI | t | MD | CI |
| Biomedical | 9.95 ** | .48 | .38 to .57 | 3.65 ** | .20 | .09 to .31 | 4.57 ** | .29 | .16 to .41 | 6.82 ** | .41 | .29 to .53 |
| Physical environment | - | - | - | -6.94 ** | -.27 | -.35 to -.20 | -3.48 * | -.19 | -.29 to -.08 | -1.34 | -.06 | ns |
| Emotional | - | - | - | - | - | - | 1.81 | .09 | ns | 4.07 ** | .21 | .11 to .32 |
| Learned behaviour | - | - | - | - | - | - | - | - | - | 2.34 | .13 | ns |
| Stimulation | - | - | - | - | - | - | - | - | - | - | - | - |

df = 179, MD = mean difference, CI = 95% confidence interval, ns = not significant

* $\alpha < .005$

** $\alpha < .001$

There were no significant correlations between the direct support staff's number of years of working experience with people with intellectual disability and the different CHABA models. Correlations between the variables ranged from -0.01 for physical environment to -0.08 for the biomedical model.

5.4 Discussion

The results show that direct support staff as a whole report the biomedical model as the most plausible explanation for challenging behaviour in children and adults with PIMD. The mean score on this particular model is above zero, suggesting that staff think the biomedical model is likely to apply to challenging behaviour displayed

by this group. The mean scores on the other models are below zero, suggesting that staff consider these particular models as unlikely to apply to the behaviour. The score on the physical environment model is lowest. This model can therefore be considered the least relevant explanation for challenging behaviour according to staff. These findings are in line with Tynan and Allen (2002), who found that staff working with people with severe intellectual disability attributed aggressive behaviour significantly more to a biomedical model than other models. They suggest as a possible explanation that people with severe intellectual disabilities are not seen as having control over their own behaviour in general, and are thus unable to control any challenging behaviour that might occur. Given the severity of the disabilities among people with PIMD, direct support staff may think it even less likely that people with PIMD can influence their own behaviour. This could mean that staff view challenging behaviour as 'belonging' to the person and are therefore less inclined to take into account other factors that might influence that behaviour. Ascribing challenging behaviour to biomedical factors could also explain why frequently occurring challenging behaviours are not described in individual comprehensive service plans (Poppes et al., 2014). If the behaviour is considered non-changeable, there may appear to be no point including it in the plans. Bailey, Hare Hatton and Limb (2006) suggest that staff may feel they need to take especially good care of people with intellectual disability, but mainly in a practical sense. This could apply even more to people with PIMD as direct support staff are engaged for much of the day in taking care of their physical and medical needs – feeding, washing, moving, changing diapers and giving medication.

However, in the present study the mean scores on all models are low compared to other research on staff perceptions of challenging behaviour (e.g. Hastings, 1997; Hastings, et al., 1995; Tierney, et al., 2006). The frequency distribution on all scales of the CHABA also shows that few direct support staff score in the extremes on the items per scale. Per scale, only 18.9 to 24.5% of the direct support staff gave a lower mean score than -1, or a higher score than +1. This, and the low mean scores on all scales, might indicate that a large number of staff found none of the models particularly useful as possible explanations for challenging behaviour in people with PIMD. This could mean that staff have trouble stating the cause of challenging behaviour in this group. A possible explanation could be that there is little scientific knowledge about the causing and maintaining factors of challenging behaviour in people with PIMD. It could also mean that staff have additional explanations for challenging behaviour in this target group that are not mentioned in the CHABA items. Future research should address these issues.

The current study found no differences in causal explanations for challenging behaviour between more and less experienced staff. This is not consistent with the findings of Hastings et al. (1995), who found that more experienced staff were more likely to give behavioural and biological explanations for challenging behav-

our. However, their study included students with less than three months' working experience, most of whom had never worked with people with intellectual disabilities. The present study did not include inexperienced staff members such as students, and participants had at least one year's experience. This might explain why we found no significant differences between (relatively) inexperienced and experienced staff.

Our results should be interpreted with some caution because direct support staff filled out the Behaviour Problem Inventory for the person with PIMD they supported and were subsequently asked to fill out the CHABA for the behaviours they scored on the Behaviour Problem Inventory. It is theoretically possible that withdrawn or stereotypical behaviour for example, such as rocking back and forth, was only observed once a month. It is doubtful whether such behaviour can be characterized as a problem. However, in this study, all stereotypical and withdrawn behaviours occurred more frequently than once a month. It is also important to bear in mind that staff completed the CHABA without linking it directly to one particular type of challenging behaviour. It was therefore not possible to relate certain causal models of explanation to a specific type of challenging behaviour. Future research should clarify the relationship between challenging behaviour topography and attributions made by staff working with people with PIMD.

In the present study the CHABA was used as a tool to identify attributions on challenging behaviour in children and adults with PIMD. Although the reliability of this instrument has been examined and approved, its validity has not yet been established. This could also explain our results. Future research could focus on the validity of the instrument for staff supporting children and adults with PIMD by using the CHABA as a tool to monitor changes in staff attributions as they go through training in understanding and treating challenging behaviour, as Hastings (1997) suggested. Furthermore, even though direct support staff prioritize medical issues as a possible explanation for challenging behaviour when filling out the CHABA, they may take into account additional possible reasons for challenging behaviour in people with PIMD. Future research should include interviews with direct support staff on explanations for challenging behaviour combined with observations of challenging behaviour displayed by the child or adult with PIMD.

Weiner's model of helping behaviour (1985) could also be used in future research to understand the relationship between attributions and actual interventions carried out by direct support staff. Weiner identifies three types of attributions: internal and external attributions; stable (permanent) or unstable (temporary) attributions; and attributions referring to controllability (person is in control of his or her behaviour) or uncontrollability (person is not in control of his or her behaviour). According to Weiner's model (1985), stability attributions have been assumed to influence staff optimism and controllability attributions have been assumed to influence

reactions of sympathy and anger. This could further deepen the understanding of how direct support staff perceive challenging behaviour in children and adults with PIMD.

In addition, this study did not examine the relationship between frequency of challenging behaviour and attributions. However, challenging behaviour was mainly attributed to a biomedical model. Nonetheless, it would be interesting to examine in future research the extent to which high-frequency challenging behaviours are attributed differently than challenging behaviours with a lower frequency. Future research should also focus on investigating other possible influences on staff attributions. Factors that may be of interest are the policies adopted by organizations, the culture within an organization and possible peer pressure amongst staff regarding accepted ideas about the explanation for challenging behaviour in people with PIMD.

Beliefs about the causes of challenging behaviour may influence direct support staff's beliefs about effective or desirable interventions (Hastings, 1997). It seems important to systematically reflect on the possible causes and consequences of challenging behaviour in children and adults with PIMD in practice. Williams, Dagnan, Rodgers and McDowell (2012) reviewed the evidence of changes in the attributions offered by staff for the behaviour of people with intellectual disabilities following training in challenging and complex behaviour. They found that training (regardless of its specific content or duration) had a clear effect on the attributions reported by direct support staff. They suggested that the process of obtaining information which enables the reformulation of the challenging behaviour of a particular person or in general is a key element to changing attributions. Therefore it would be interesting to determine to what extent such an information exchange on and reformulation of challenging behaviour could lead to changes in staff attributions and whether such changes lead to different interventions to reduce or prevent challenging behaviour and ultimately to changes in the frequency and perceived severity of challenging behaviour in children and adults with PIMD in practice.

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5.5. References

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Chapter 6

Relabeling behaviour. The effects of psycho-education on the perceived severity and causes of challenging behaviour in people with profound intellectual and multiple disabilities.

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Abstract

- Background* Prevalence rates of challenging behaviour are high in children and adults with profound intellectual and multiple disabilities (PIMD). Moreover, many of these behaviours are observed daily. Direct support staff report that most challenging behaviour identified has little impact on the person with PIMD and attribute challenging behaviour in children and adults with PIMD mainly to a biomedical model.
- Aim* The purpose of this study was to evaluate whether an intervention (psycho-education) had any effect on direct support staff's assessment of challenging behaviour in terms of its severity and their biomedical causal explanations (attributions) for this behaviour.
- Method* A stepped wedge study design was used to evaluate the effects of a psycho-education intervention on the perceived severity and the attributions offered for challenging behaviour of people with PIMD by 198 direct support staff. We used questionnaires assessing the perceived severity of challenging behaviour and staff views of its causes. Data on the dependent variables were collected at four one-month intervals.
- Results* The intervention was found to have an effect on the perceived severity of challenging behaviour identified in people with PIMD in the sense that staff generally scored challenging behaviour as more severe in its consequences after the intervention. However, this effect was very small. No significant effects were found in terms of reduction in the biomedical scale scores.
- Conclusion* No evidence for the effectiveness of a psycho-educational approach on the assessment of challenging behaviour in terms of severity and the biomedical attributions for behaviour was found. More research is required to explore further the effects of more elaborate training using methods to enable direct support staff to reflect on the behaviour of people with PIMD and on their own behaviour.

6.1 Introduction

People with profound intellectual and multiple disabilities (PIMD) possess little or no ability to support themselves and are dependent on others to explain the world around them and to make the world accessible. This category of people has an estimated intelligence quotient of 25 points or less and severe or profound motor impairments, which is reflected in not being able to move independently and in having limited use of their hands and arms (Nakken & Vlaskamp, 2007). They frequently suffer from sensory problems and many additional health problems (Böhmer, Taminiau, Klinkenberg-Knol & Meuwissen, 2001; Codling & MacDonald, 2009; Van der Putten & Vlaskamp, 2011; Watt-Smith, 2009). In addition, people with PIMD have difficulty expressing themselves due to their inability to communicate verbally.

A study by Poppes, Van der Putten and Vlaskamp (2010) has shown that challenging behaviour is common in people with PIMD. According to this study, self-injurious and stereotypical behaviour is observed in 82% of people with PIMD, withdrawn behaviour in 98% and aggressive/destructive behaviour in 45% (Poppes et al., 2010; Poppes, Van der Putten, Post & Vlaskamp, manuscript submitted). Moreover, many of these behaviours are observed on a daily basis (Poppes et al., 2010). The effects of challenging behaviour can be far-reaching. Firstly, it can lead to physical injury – such as injury to the retina due for example to eye poking – injury to the skin and physical malformations, caused for example by the people hitting themselves or banging their heads. In addition, challenging behaviour, which occurs frequently, can limit their personal development and may hamper the establishment and maintenance of social relationships (González et al., 2009). Relationships with others are vital to people with PIMD, as through these relationships they gain experience and can exert some influence over their lives (Vlaskamp & Van der Putten, 2009). These relationships are threatened by challenging behaviour.

However, even though challenging behaviour is common in people with PIMD and occurs very regularly, these behaviours are usually reported as having little impact on the person with PIMD by direct support staff (Poppes et al., 2010). The beliefs/explanations held by direct support staff on the causes of challenging behaviour can impact on the actions they take in relation to people with intellectual disability who display challenging behaviour (Dowey, Toogood, Hastings & Nash, 2007; Hastings, 1997). A recently conducted study on the attributions offered by the direct support staff for the behaviour of persons with PIMD demonstrated that staff found most of the causal models for challenging behaviour proposed by Hastings (1997) – learned behaviour (negative and positive reinforcement processes), emotions (e.g. anger, stress and fear), physical environment (e.g. auditory environment and bright lights) and self-stimulation (e.g. boredom and not being offered activities) – of little use in explaining challenging behaviour in children and adults with PIMD. However, more than half of the participating direct support staff

reported a biomedical model as being the most appropriate causal explanation of challenging behaviour (Poppes, Van der Putten, Ten Brug & Vlaskamp, manuscript submitted). If direct support staff assume that challenging behaviour is caused by biomedical problems, this could mean that they view behaviour as 'belonging' to the person and will thus be less inclined to take other factors into account which could influence this behaviour. Furthermore, they might not notice the communicative function this behaviour can have. Moreover, direct support staff could be less likely to regard their own behaviour as a possible reinforcer of the onset or persistence of challenging behaviour (Tynan & Allen, 2002). One of the consequences of these attributions and the low perceived severity of challenging behaviour by staff might be that these behaviours are not systematically addressed in daily practice (Poppes, Van der Putten & Vlaskamp, 2014). It therefore seems necessary to offer training to direct support staff targeted at changing their beliefs and attitudes towards these behaviours in people with PIMD, before commencing training on the appropriate interventions to apply to reduce or prevent this behaviour.

Williams, Dagnan, Rodgers and McDowell (2012) reviewed the evidence of changes in the attributions offered by staff for the behaviour of people with intellectual disabilities following training in challenging and complex behaviour. The majority of the 11 studies included in this review focused on applied behavioural approaches (Williams et al., 2012). The key elements of this training consisted of trying to understand the behaviour and identifying factors which could influence it. The causal explanations that staff offered for challenging behaviour changed significantly after training as a result (Williams et al., 2012). The only study where no significant changes were observed in the attributions offered was for training where the focus was not on explaining the causes of challenging behaviour. Two studies did not stress a behavioural approach. In one study (Smidt, Balandin, Reed & Sigafoos, 2007) communication training was provided in which staff formulated their own communicative guidelines, and required them to challenge their attitudes and beliefs. Psycho-education on dementia was provided in the other study (Kalsy, Heath, Adams & Oliver, 2007): information on the health problems associated with ageing and on the background, prevalence, presentation and course of dementia was provided. These studies also found changes in attributions after training. The main conclusion of this review is that training (regardless of its specific content or duration) has a clear effect on attributions offered by staff. Williams et al. (2012) suggested that the process of acquiring information which enables the reformulation of a staff member's understanding of challenging behaviour in general or of a particular person is a key element in achieving changes in attributions.

The present study aimed to analyse the effects of psycho-education which considers the possible causes and consequences of challenging behaviour in people with PIMD and how direct support staff could affect this challenging behaviour.

We hypothesized that this psycho-educational approach would result in a different assessment of challenging behaviour in terms of severity and discourage the use of biomedical causal explanations for this behaviour.

6.2 Method

6.2.1 Participants

A convenience sample of 198 direct support staff was retrieved from ten organizations throughout the Netherlands. They all support people with PIMD. The 198 participating direct support staff were predominantly female (188), nine were male and gender information was missing for one participant. They had a mean age of 38.6 (SD: 11.3, range: 20-64, missing: 1). See Table 1 for additional information on the participating direct support staff.

Table 1 Sample characteristics of the direct support staff (N=198)

| | Mean (SD) | Missing (N/%) |
|---------------------------------------|------------|---------------|
| <i>Work experience (in years)</i> | | |
| With people with ID | 13.7 (9.4) | 2 (1.0) |
| With people with PIMD | 11.0 (5.2) | 1 (0.5) |
| With person | 5.2 (4.6) | 1 (0.5) |
| <i>Working hours</i> | | |
| Working hours per week | 26.6 (6.1) | 5 (2.5) |
| <i>Education level N (%)</i> | | |
| Senior secondary vocational education | 122 (61.6) | 19 (9.6) |
| Vocational college | 57 (28.8) | |

Direct support staff were each assigned by the healthcare psychologist or facility manager to a person with PIMD, defined on the basis of the following criteria:

- a profound intellectual disability (IQ of 25 or below)
- a profound or severe motor disability (manifest in an inability to move independently)
- aged 18 or younger at onset (Nakken & Vlaskamp, 2007)
- informed consent, including the written permission for the people with PIMD in this study, obtained from the parents or legal guardians
- informed consent obtained from the direct support professional
- the direct support staff had worked with the person with PIMD for at least two months

Of the people with PIMD, 106 were male and 92 were female. Their mean age was 30.4 (SD: 16.1; range: 3-67; missing: 6). Table 2 presents information on their additional health problems.

Table 2 Characteristics of the participants with PIMD (N=198)

| | N | % | Missing (N/%) |
|-------------------------------|-----|------|---------------|
| <i>Sensory problems</i> | | | |
| Auditory | 58 | 29.3 | 7 (3.5) |
| Visual | 113 | 57.1 | 3 (1.5) |
| Tactile | 80 | 40.4 | 8 (4.0) |
| <i>Health problems</i> | | | |
| Epilepsy | 128 | 64.6 | 6 (3.0) |
| Bowel and abdominal problems | 148 | 74.7 | 6 (3.0) |
| Sleeping problems | 56 | 28.3 | 9 (4.5) |
| Lung and respiratory problems | 50 | 25.3 | 6 (3.0) |
| Eating and drinking problems | 132 | 66.7 | 5 (2.5) |
| Dental problems | 56 | 28.3 | 6 (3.0) |
| Mental health problems | 39 | 19.7 | 6 (3.0) |

6.2.2 Procedure

Organizations were asked to participate in this study via mailings and via information bulletins published by a national knowledge network in the field of people with PIMD in the Netherlands. A total of twelve organizations indicated that they wished to participate. They subsequently received a letter with more information about the study and practical guidelines. If they continued to wish to participate after having read the letter, arrangements were made to collect data and to implement the intervention. The participating organizations ensured approval for the study was obtained from their ethics committees and informed consent was obtained from direct support staff and parents or legal guardians.

Beforehand, organizations pre-specified the number of people (those with PIMD and the direct support staff linked to them) that they thought could participate in the research. The organizations were then allocated to three clusters (A, B & C) of four organizations based on their size (three large organizations, three small organizations and six medium-sized organizations were allocated evenly across the four clusters), and the participating children and adults were distributed evenly across these clusters to reflect the study design. Of the twelve participating organizations, two organizations dropped out during the study due to lack of time and financial cutbacks.

6.2.3 Design

A stepped wedge design was used in this study (Brown & Lilford, 2006). Stepped wedge randomized trial designs involve a sequential roll-out of an intervention to

participants (individuals or clusters) over a number of periods. By the end of the study, all the participants (or clusters) will have received the intervention, although the order in which participants receive the intervention is determined at random for each cluster. Every point at which a new cluster receives the intervention is called a 'step', and all the clusters will have received the intervention after the final step. The dependent variables of interest are measured for all clusters before and after each step. This design was chosen because it was impossible to deliver the intervention to all the participants or clusters simultaneously. The stepped wedge design enables us to model the effect of time on the effectiveness of an intervention by comparing between and within clusters differences (Brown & Lilford, 2006).

The intervention was implemented in the three participating organization clusters (A, B & C) in random order (see Table 3 for an outline of the study design). All three clusters started the study simultaneously and acted as controls until the moment they were randomly determined to switch from control to intervention. Data regarding the dependent variables were collected at four points at one-month intervals.

Table 3 The stepped wedge randomized controlled design.

| Clusters | Time points | | | | |
|----------|-------------|------|------|----|----|
| | A | T0 X | T1 | T2 | T3 |
| B | T0 | T1 X | T2 | T3 | |
| C | T0 | T1 | T2 X | T3 | |

T=measurement

X=intervention

Light yellow cells represent control periods and dark yellow cells represent data collection after the intervention

6.2.4 Intervention

The psycho-education was a one-and-a-half hour workshop session, comprising experiential and didactic teaching. A total of seventeen separate workshops were provided and each training group averaged 8.5 participants (range 4-26). Each workshop was conducted by the same person at all organizations and information was provided of fixed content, structure and sequence. Two main topics were discussed during the workshops: 1) information on people with PIMD and challenging behaviour, and 2) direct support staff attributions. The following summarizes the content of the workshop components:

1. Information on people with PIMD and challenging behaviour.

- The characteristics of people with PIMD, their additional disabilities and health problems.
- Background to challenging behaviour, including definitions, causes and

consequences.

- The prevalence and presentation of challenging behaviour in people with PIMD and discussion of the low perceived severity of these behaviours by direct support staff.
2. Direct support staff attributions.
- Discussion of challenging behaviour on the basis of comments commonly heard in practice. For example 'this behaviour is just part of him', 'this behaviour is part of her intellectual disability' and 'these behaviours cannot be changed'.
 - Video presentations on three people with PIMD displaying different types of self-injurious, stereotypical, withdrawn and aggressive or destructive behaviours. Discussion of whether this behaviour is problematic and whether it has serious effects.
 - Intervention options for when people with PIMD display challenging behaviour based on an Individual Support Programme specially developed for people with PIMD (Vlaskamp & Van der Putten, 2009).
 - A case study to exemplify intervention options to reduce or prevent challenging behaviour in people with PIMD.

6.2.5 Data collection

Perceived severity of challenging behaviour

The perceived severity of different types of challenging behaviour was identified using the adapted version of the Behavior Problem Inventory (BPI) (Rojahn, Matson, Lott, Esbensen & Smalls, 2001), the BPI-PIMD (Poppes et al., manuscript submitted). The BPI-PIMD is an informant-based scale which addresses four types of challenging behaviour: self-injurious, stereotypical, withdrawn, and aggressive or 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). Withdrawn behaviour is described 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). Aggressive or destructive behaviour is defined as 'an offensive action or a deliberate overt attack directed towards people or objects' (Rojahn et al., 2001).

The BPI-PIMD consists of 58 items within the four specified categories: SIB (15 items), SB (22 items), WB (5 items) and ADB (12 items). Each subscale also contains 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. When behaviour was scored on the BPI-PIMD, direct support professionals were asked to rate the severity of the behaviour, in the range slight (1), medium (2) or severe (3).

The psychometric properties of the original BPI are good (González et al., 2009; Mascitelli et al., 2015; Rojahn et al., 2001; Van Ingen, Moore, Zaja & Rojahn, 2010). These findings are in line with studies by Dumont, Kroes, Korzilius, Didden and Rojahn (2014), and Lambrechts and Maes (2009) into the psychometric properties of the Dutch translation of the BPI-01 for people with a profound intellectual disability. The internal consistency of the entire scale, measured using Cronbach's alpha (0.89), is good (Dumont et al., 2014). The internal consistency of the SIB subscale was moderate in all the above-mentioned 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 had been altered and only used for people with PIMD, we calculated the internal consistency in general ($\alpha=0.85$) and for the different subscales (SIB, $\alpha=0.48$; SB, $\alpha=0.81$; WB, $\alpha=0.73$; ADB, $\alpha=0.83$). These findings are in line with other research into the internal consistency of the BPI (Dumont et al., 2014; Lambrechts & Maes 2009; Mascitelli et al., 2015; Rojahn et al., 2001).

Attributions

Direct support staff attributions were analysed using the Dutch version of the Challenging Behaviour Attributions Scale (CHABA; Hastings, 1997; Lambrechts, Kuppens & Maes, 2009). The questionnaire consists of 33 items which each state a possible reason why people with intellectual disability engage in challenging behaviour. Direct support staff were asked to rate each of the 33 items on a five-point scale (-2=very unlikely, -1=unlikely, 0=equally likely/unlikely, 1=likely and 2=very likely) of how likely an explanation was of why a specific person engaged in challenging behaviour. The statements relate to five causal models: learned behaviour (six items), medical/biological factors (six items), emotional factors (seven items), aspects of the physical environment (eight items) and self-stimulation (six items). Each subscale score was calculated by summing the number of individual items within a particular subscale and dividing this by the number of items. A subscale score above zero suggests that the particular causal model was considered applicable to the behaviour. A subscale score below zero suggests that the respondent considers the particular causal model as unlikely to apply to the behaviour. The internal consistency of the five subscales was assessed using Cronbach's alpha. The alpha values were between .75 and .80 for all five scales, meaning that the internal consistency can be described as acceptable (Field, 2009). These alpha values compared favourably with the alpha values described in other studies (e.g. Hastings, 1997; McGill, Bradshaw & Hughes, 2007; Tynan & Allen, 2002). There are no specific studies on the validity of the CHABA; however, the instrument is used in a wide variety of research on staff attributions (e.g. Lambrechts et al., 2009; Lowe et al., 2007; McGill et al., 2007; Tynan & Allen, 2002).

6.2.6 Analysis

Two dependent variables were taken into account: the direct support staff's perceived severity scores for the challenging behaviour, and the direct support staff's biomedical attributions for this behaviour.

The total severity scores on the BPI-PIMD were taken into account in the analysis. The mean severity scores (and range and SD) of the BPI-PIMD were calculated for the three clusters (A, B & C) and for each measurement point. The mean scores on the CHABA biomedical scale were also calculated at each measurement point. Both the mean severity scores and the mean scores on the biomedical scale were visualized using box plots.

Multilevel models were then used to estimate the effect of the intervention on the perceived severity of the observed problem behaviour, as well as the direct support staff's biomedical attitudes towards the problem behaviour. Three models were constructed for each of the dependent variables, one without explanatory variables (grand mean model), one using time of measurement as a fixed factor (time dependent model) and the final model was constructed according to the description provided in Hussey and Hughes (2007). The model postulated by Hussey and Hughes (2007) includes a random cluster effect and fixed time and intervention effects. In addition to the model that Hussey and Hughes (2007) proposed, we relaxed the compound symmetry assumption between time points to allow for correlations between measurements over time. The covariance between the clusters was fixed at zero, as the study design rules out the possibility of correlations between clusters. As expected, no significant correlations were found between the clusters.

Finally, for comparative purposes, the final model was also estimated for individuals who were included in the study and were present during the intervention (per protocol analysis). The residuals for the full model were inspected to check the model assumptions. We distinguished between these two groups in the analysis: all the participants fall within the 'intention to treat group', while those participants who actually attended the intervention are also part of the 'by protocol group'.

6.3 Results

Ten organizations participated in the research, divided into cluster A (three organizations), cluster B (four organizations) and cluster C (three organizations) with a total of 198 participants distributed across the three clusters. Three participants were excluded at T0 because they failed to complete the BPI-PIMD, meaning that a total of 195 participants ultimately participated (see Table 4, first column).

At the first measurement point, there were no significant differences between the three clusters in the mean scores on the dependent variable severity and on the

biomedical scale. Table 4 has some missing data (missing BPI-PIMD and/or CHABA data) at various measurement points. There were relatively few dropouts and the dropouts are randomly distributed across the clusters.

Table 4 overview of the number of participants at the four measurement points

| Cluster | T0 | T1 | T2 | T3 |
|---------|----|----|----|----|
| A | 42 | 35 | 35 | 33 |
| B | 96 | 89 | 80 | 79 |
| C | 57 | 53 | 53 | 46 |

The majority of the participants in the three clusters (79%) attended the intervention. However, a small sample did not attend the psycho-education (for various reasons, such as illness) although they did complete the BPI-PIMD and the CHABA questionnaires before and after the intervention (see Table 5). We distinguished between these two groups in the analysis: all the participants fall within the 'intention to treat group', while those participants who actually attended the intervention are also part of the 'by protocol group' (see Table 5).

Table 5 overview of participants who attended the intervention and those who did not

| Cluster | Intention to treat | By protocol |
|---------|--------------------|-------------|
| A | 42 | 31 |
| B | 96 | 72 |
| C | 57 | 51 |
| Total | 195 | 154 |

6.3.1 Perceived severity of challenging behaviour

Table 6 shows the mean challenging behaviour severity scores for the three clusters (A, B and C) at the four measurement points, divided into the 'intention to treat' and the 'by protocol' groups. In addition, this table shows mean scores for the pre- and post-test periods (for example the mean scores at T0 (pre-test) and T1, T2 and T3 (post-test) is provided for cluster A). Figures 1a and 1b present the mean severity over time per cluster for both groups.

Table 6 severity scale scores per cluster per time point

| | | Severity of challenging behaviour | | | |
|----------------------------------|------------------------------|-----------------------------------|--------------------|-------------------|--------------------|
| | | | Intention to treat | By protocol | |
| Cluster A | T0 | Mean (SD) | 1.31 (.86) | 1.42 (.90) | |
| | | N | 42 | 31 | |
| | T1 | Mean (SD) | 1.50 (.91) | 1.60 (.95) | |
| | | N | 35 | 27 | |
| | T2 | Mean (SD) | 1.47 (.85) | 1.51 (.87) | |
| | | N | 35 | 25 | |
| T3 | Mean (SD) | 1.23 (.87) | 1.19 (.92) | | |
| | N | 33 | 24 | | |
| <i>mean (SD) T1, T2 & T3</i> | | | <i>1.38 (.84)</i> | <i>1.40 (.85)</i> | |
| Cluster B | T0 | Mean (SD) | 1.31 (1.07) | 1.42 (1.08) | |
| | | N | 97 | 75 | |
| | T1 | Mean (SD) | 1.31 (1.00) | 1.38 (1.04) | |
| | | N | 89 | 75 | |
| | <i>mean (SD) T0 & T1</i> | | | <i>1.28 (.98)</i> | <i>1.40 (1.02)</i> |
| | T2 | Mean (SD) | 1.26 (1.05) | 1.37 (1.09) | |
| N | | 80 | 66 | | |
| T3 | Mean (SD) | 1.16 (.91) | 1.26 (.95) | | |
| | N | 79 | 65 | | |
| <i>mean (SD) T2 & T3</i> | | | <i>1.22 (.94)</i> | <i>1.32 (.98)</i> | |
| Cluster C | T0 | Mean (SD) | 1.12 (.86) | 1.11 (.87) | |
| | | N | 57 | 51 | |
| | T1 | Mean (SD) | 1.00 (.97) | 1.05 (.99) | |
| | | N | 53 | 49 | |
| | T2 | Mean (SD) | 1.12 (.88) | 1.12 (.89) | |
| | | N | 53 | 51 | |
| <i>mean (SD) T0, T1 & T2</i> | | | <i>.09 (.82)</i> | <i>1.09 (.84)</i> | |
| T3 | Mean (SD) | 1.17 (1.08) | 1.18 (1.09) | | |
| | N | 46 | 45 | | |

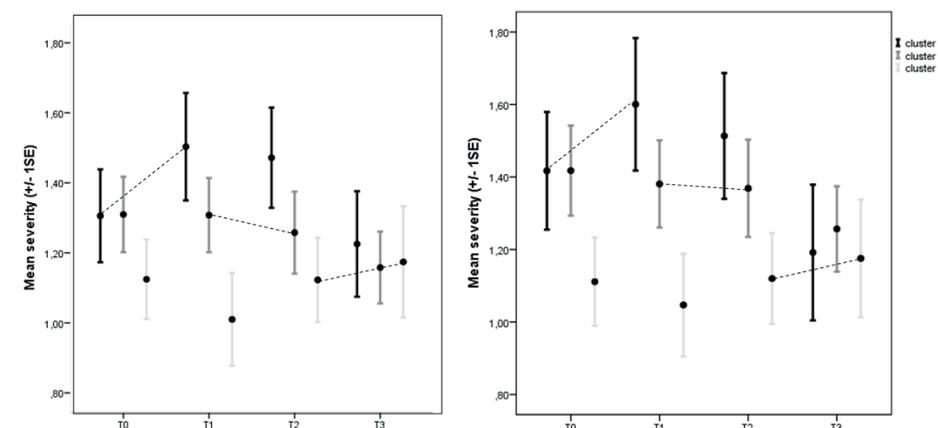


Figure 1a (intention to treat) and 1b (by protocol): mean challenging behaviour severity scores for clusters A, B and C. The dotted lines in the figure represent the change in scores before and after the intervention.

Based on the sample descriptives, a small increase was observed in the severity scores in clusters A and C after the intervention (respectively after T0 for cluster A and after T2 for cluster C). This increase is most prominent in cluster A (see dotted lines, Figure 1a and b). A slight decrease in severity scores in cluster B was observed over time regardless of the intervention (see also Table 6). The average score at T3 for clusters A and B is lower than at T0. This is not the case for cluster C: here a slight increase is observed. Based on these box plots, there is no apparent difference between the intention-to-treat and the by-protocol groups within the clusters (see also Table 6).

6.3.2 Multi-level model for challenging behaviour severity

Table 7 shows the results of the multi-level analysis of the severity of challenging behaviour as predicted by time and intervention. The results show a downward trend in perceived severity over time which is significant at the second and third measurement points. The direct support staff appear to be evaluating behaviour as less serious as time passes. The results also show a significant positive effect for the intervention. The direct support staff appear to evaluate the behaviour as having more serious effects after the intervention, though this effect is very small. The full model is not a significant improvement over the grand mean model, $\chi^2(20, N=699)=29.8, p=.07$, but does show a significant improvement compared to the time-dependent model, $\chi^2(17, N=699)=28.7, p=.04$, as is evident from the differences we observed in deviance. Small differences were found between the 'intention to treat' and 'attended intervention' (by-protocol) models: specifically, if we exclude the direct support staff who did not attend the intervention, a small increase is observed in the severity scores after the intervention compared to the group

which includes direct support staff who did not attend the intervention.

Table 7: multi-level analysis results of the observed challenging behaviour severity scores

| | Grand mean model (intention-to-treat) | Time-dependent model (intention-to-treat) | Full model (intention-to-treat) | Full model (by-protocol) |
|------------------------|---------------------------------------|---|---------------------------------|--------------------------|
| Intercept | 1.24 (.062) | 1.25 (.068) | 1.23 (.067) | 1.31 (.077) |
| Time Point1 | | -.01 (.049) | -.04 (.049) | -.05 (.051) |
| Time Point2 | | -.01 (.050) | -.12 (.069) | -.15 (.073)* |
| Time Point3 | | -.05 (.051) | -.20 (.084)* | -.27 (.091)* |
| Intervention | | | .16 (.066)* | .20 (.072)* |
| N (time points)/ total | 699/792 | 699/792 | 699/792 | 580/624 |
| Deviance (-2 LL) | 1396.6 | 1395.5 | 1366.8 | 1136.3 |

* Significant at $\alpha=.05$

6.3.3 Biomedical attribution

Table 8 presents the mean scores on the CHABA biomedical scale over time for the three clusters (A, B and C) at the four time points, divided into the intention-to-treat and the by-protocol groups. Mean scores, pre- and post-test (for example, for cluster A, a mean score for T0 (pre-test) and a mean score for T1, T2 and T3 (post-test) are provided) are also presented. Figures 2a and 2b visualize the mean biomedical scale scores per cluster for both groups.

Table 8 biomedical scale and severity scale scores per cluster per time point

| | | | Biomedical | |
|----------------------------------|----------------------------------|------------|--------------------|-------------|
| | | | Intention-to-treat | By-protocol |
| Cluster A | T0 | Mean (SD) | .01 (.97) | .22 (.87) |
| | | N | 38 | 30 |
| | T1 | Mean (SD) | .14 (.77) | .25 (.75) |
| | | N | 33 | 25 |
| | T2 | Mean (SD) | .12 (.66) | .13 (.68) |
| | | N | 32 | 22 |
| T3 | Mean (SD) | .20 (.72) | .21 (.82) | |
| | N | 31 | 22 | |
| | <i>mean (SD) T1, T2 & T3</i> | | .15 (.59) | .17 (.63) |
| Cluster B | T0 | Mean (SD) | .15 (.74) | .14 (.75) |
| | | N | 91 | 72 |
| | T1 | Mean (SD) | .05 (.84) | .09 (.78) |
| | | N | 85 | 73 |
| | <i>mean (SD) T0 & T1</i> | | .08 (.73) | .11 (.71) |
| | T2 | Mean (SD) | .23 (.75) | .24 (.74) |
| N | | 75 | 64 | |
| T3 | Mean (SD) | .03 (.80) | .08 (.76) | |
| | N | 74 | 63 | |
| <i>mean (SD) T2 & T3</i> | | .10 (.77) | .15 (.73) | |
| Cluster C | T0 | Mean (SD) | .01 (.94) | .02 (.98) |
| | | N | 52 | 47 |
| | T1 | Mean (SD) | -.14 (.87) | -.11 (.89) |
| | | N | 51 | 47 |
| | T2 | Mean (SD) | -.04 (.84) | -.03 (.87) |
| | | N | 50 | 48 |
| <i>mean (SD) T0, T1 & T2</i> | | -.06 (.85) | -.04 (.77) | |
| T3 | Mean (SD) | -.05 (.86) | -.05 (.87) | |
| | N | 43 | 42 | |

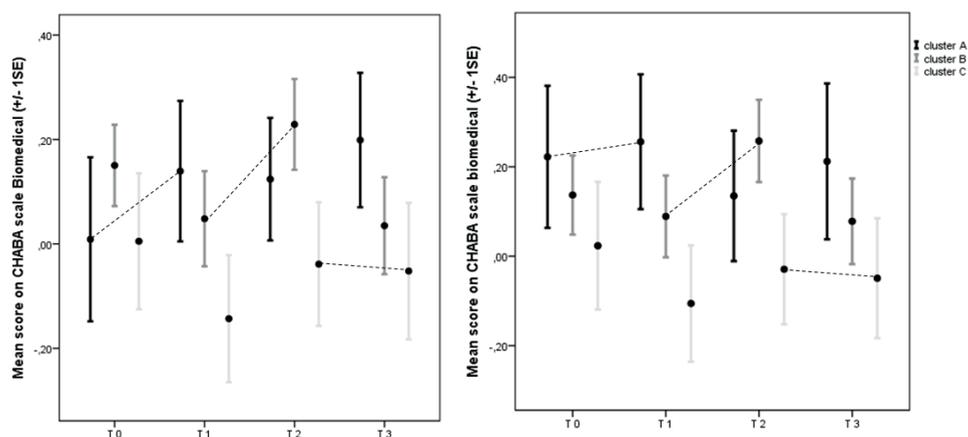


Figure 2a (intention to treat) and 2b (by protocol): mean biomedical scale scores for clusters A, B and C. The dotted lines in the figure represent the change in score before and after the intervention.

Table 8 and Figures 2a and 2b show that the scores on the biomedical scale increased after the intervention in clusters A and B. A small decrease is visible in cluster C. The clusters vary by mean scores at the different time points. Furthermore, the cluster A by-protocol group scored significantly higher on the biomedical scale than the cluster A intention-to-treat group at T0.

6.3.4 Multilevel model of direct support professionals challenging behaviour biomedical attributions

Table 9 shows the results of the analysis of the total biomedical scores as predicted by time and intervention. The results show a small downward trend over time which becomes significant at time point 3. No significant effect for the intervention was found. The full model is not a significant improvement over either the grand mean model, $\chi^2(20, N=655)=29.9, p=.07$, or the time-dependent model, $\chi^2(17, N=655)=26.9, p=.06$, as can be seen in the differences in deviance. There were small differences between the 'intention to treat' and the 'attended intervention' models (see Table 8).

Table 9: Results of the multi-level analysis of the biomedical scores

| | Grand mean model (intention-to-treat) | Time-dependent model (intention-to-treat) | Full model (intention-to-treat) | Full model (by-protocol) |
|-----------------------|---------------------------------------|---|---------------------------------|--------------------------|
| Intercept | .05 (.052) | .07 (.060) | .07 (.062) | .12 (.068) |
| Time Point1 | | -.06 (.052) | -.08 (.060) | -.08 (.062) |
| Time Point2 | | -.02 (.054) | -.05 (.071) | -.10 (.074) |
| Time Point3 | | -.04 (.055) | -.14 (.088) | -.20 (.090)* |
| Intervention | | | .10 (.067) | .12 (.072) |
| N (time points)/total | 655/792 | 655/792 | 655/792 | 552/624 |
| Deviance (-2 LL) | 1278.2 | 1275.2 | 1248.3 | 1016.9 |

* Significant at $\alpha=.05$

6.4 Conclusion and discussion

The present study examined the effect of a psycho-educational intervention covering two main topics. One targeted the prevalence and severity of various types of challenging behaviour and their possible consequences. The second targeted the possible causes for challenging behaviour (both internal and external). We hypothesized that this intervention would result in changes to direct support staff assessments of challenging behaviour in terms of its severity and the biomedical causal explanations offered for it. Our results show that severity scores display a downward trend over time with a small but significant increase in severity scores after the intervention. The downward trend in severity scores and the small increase following the intervention cannot be explained by differences between the clusters. There were no significant differences between the clusters at the baseline measurements. Moreover, the intervention was always carried out by the same person and in a similar format. No significant effects were found in the reductions in the biomedical scale scores. This is not in line with a review conducted by Williams et al. (2012), who found that training (regardless of its specific content or duration) had a clear effect on the attributions reported by direct support staff. They suggested that the process of obtaining information which enables the reformulation of the challenging behaviour of a particular person or in general is a key element to changing attributions. Although the intervention provided in the present study focussed on the reformulation of challenging behaviour in people with PIMD, the time during which direct support staff could do so was limited. This could explain the lack of effects found. Another possible reason for this lack of

effects could be that an immediate post-intervention measurement of the participating staff was not conducted. It is possible that ideas about severity and causal attributions had changed but that these effects were not maintained over a one-month period. Many intervention studies measured the effects of interventions targeting changing attributions immediately after the intervention was conducted (e.g. Berryman, Evans & Kalbag, 1994; Dowe et al., 2007; Kalsy et al., 2007; Schmidt et al., 2007). The effects measured might have been short term which later decreased over time (Lowe et al., 2007). However, future research should include both the immediate post-intervention period and later follow-up measurement points because it is important to obtain information about which effects remain, which diminish and why some effects diminish. This information will help plan for the maintenance of the desired effects (Tierney, Quinlan & Hastings, 2007). We also considered the frequency of challenging behaviour, but found that the intervention had only a minor and non-significant effect.

When interpreting our results, the following issues should be considered. In intervention studies, like the one reported here, it is impossible to deliver the intervention to all the participants or clusters simultaneously by the same trainer. If more than one trainer would conduct the intervention, this could result in a bias of the results which could pose a threat to the internal validity. Therefore we opted for a stepped wedge design. The stepped wedge design enables us to model the effect of time on the effectiveness of an intervention by comparing between and within clusters differences (Brown & Lilford, 2006). Within this design, there is a risk of contamination between parallel groups located at the same organization, because people from different groups could exchange information and experiences, thereby potentially diminishing the differences in the responses elicited before and after intervention. We attempted to mitigate this contamination risk by implementing the intervention for all the groups within the same organization simultaneously. Where the intervention was offered at different times within the same organization, we ensured a substantial geographical distance between the groups. The probability that these groups were able to communicate with each other about the intervention was therefore reduced.

The organizations which participated in the research were not randomly selected. Although the range of participating organizations represents Dutch conditions, we can assume that organizations which voluntarily enroll are more eager to participate in research, which could distinguish them from the organizations which did not sign up. This could undermine the generalizability of the results. However, a total of 195 direct support staff from ten organizations participated in the research. This number is substantial given the total population of adults with PIMD living in facilities in the Netherlands (Vugteveen, Van der Putten & Vlaskamp, 2014).

We used a study design which had the dependent variables measured repeatedly. Direct support staff were required to complete the same questionnaires four times over a period of four months. It is possible that this repeated completion of the same questionnaire caused a learning effect to develop. This might have affected how staff perceived and responded to challenging behaviour in people with PIMD in daily practice. It is possible that the perceived severity of the behaviour decreased because the identified behaviour was dealt with in practice. However, given the relatively short period and the persistence of challenging behaviour in people with PIMD, this seems unlikely.

Repeatedly completing the same questionnaires could also have led to questionnaire fatigue. However, relatively little data was missing from the severity and attribution scores and we found no evidence that the missing data was related to specific characteristics of the organizations included in the clusters or individual participants. The only exception seems to be the participants who attended the intervention and their mean scores on attributions in cluster A. The eight participants from cluster A who did not attend the intervention scored significantly lower on the CHABA biomedical scale than the other direct support staff. The absence of this group from the intervention could have biased the results. Furthermore, the CHABA was used in this study as a tool to identify attributions for challenging behaviour in children and adults with PIMD. Although the reliability of this instrument has been investigated and approved, the validity has not yet been established. This could also explain our results. Future research could explore the validity of the instrument for staff working with children and adults with PIMD.

The intervention used was brief and only aimed at increasing direct support staff's knowledge; staff were not taught any specific skills which could be used in practice during the intervention. Given the regularity of challenging behaviour in people with PIMD, training staff using generic lectures, modelling and role play alone may be insufficient to change the beliefs direct support staff hold about challenging behaviour in people with PIMD (e.g. McDonnell et al., 2008; Tierney et al., 2007). Direct support staff training is regarded in the literature as an important, although only an initial step in changing staff beliefs and attributions (Williams et al., 2012). It turns out that offering a relational framework from which behaviour can be interpreted is important but not sufficient to change direct support staff's attributions about people with PIMD. Embregts (2002, 2003) successfully used video feedback to achieve improvement in staff behaviour when dealing with challenging behaviour in children with mild intellectual disabilities. Lambrechts (2010) also used video feedback to encourage staff to reflect on their behaviour, and staff reported that they found this to be helpful. Extensive training, presenting a bio-psychosocial framework from which behaviour can be interpreted, along with information on the causes and consequences of behaviour, should be combined with on-the-job

training during which direct support staff can reflect on the behaviour of people with PIMD but also on their own behaviour. The effects of such training should be addressed in future research.

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Chapter 7

General Discussion

7.1 Summary of main findings

The overall aim of this research was to acquire knowledge about the impact and prevalence of challenging behaviour in people with profound intellectual and multiple disabilities (PIMD), in order to develop interventions to reduce or prevent such behaviour in the future.

The literature has shown that studies into the prevalence of challenging behaviour in people with intellectual disabilities in general have resulted in a broad range of prevalence statistics. From 5% to 60% in large population-based studies (e.g. Emerson et al., 2001; Holden & Gitlesen, 2006; Lundqvist, 2013) to around 70% in specific settings (e.g. Csorba, Radvanyi, Regenyi & Dinya, 2011; Rojahn, Matson, Lott, Esbensen & Smalls, 2001). Several studies have found a positive correlation between the severity of the intellectual disability and the occurrence of challenging behaviours (Emerson et al., 2001; Holden & Gitlesen, 2006; Lundqvist, 2013). Based on these studies, challenging behaviour was expected to be highly prevalent in people with PIMD (Gardner, 2002; McClintock, Hall & Oliver, 2003; Schroeder, Reese, Hellings, Loupe & Tessel, 1999).

Our results do indeed find a high prevalence of challenging behaviour in people with PIMD (see Chapter Two). The majority of the participants included in this study showed several types of self-injurious and stereotypical behaviour. These prevalence rates (more than 80%) were higher than expected based on previous studies. We found a relatively low prevalence of aggressive/destructive behaviour compared to the results of Rojahn et al. (2001). This lower prevalence for this specific type of challenging behaviour is probably due to the severe or profound motor disabilities people with PIMD have, as this means that they are physically less able to display such behaviours. The same study (see Chapter Two) also found that challenging behaviour was not only highly prevalent but also occurred very frequently. However, the majority of challenging behaviour which occurred at high prevalence and frequency rates was not perceived by direct support staff as of serious consequence for the children and adults with PIMD.

It was important to determine the extent to which behaviours which are so frequently encountered in day-to-day practice were addressed during daily routines. To gain insight into the interventions made in practice to prevent or reduce these behaviours, we analysed the extent to which goals pursuing this end are included in individual comprehensive service plans. This study (Chapter Three) revealed that although all the participants exhibited challenging behaviours on an hourly or daily basis, a substantial part of these behaviours was not mentioned in the individual plans. When challenging behaviour was described in these plans, it predominantly concerned self-injurious and aggressive/destructive behaviour considered to be of serious consequence by direct support staff. Stereotypical behaviour was

described to a lesser extent. The frequency with which a behaviour occurred did not appear to be related to whether it was described in the plans. Furthermore, interventions and goals which aimed to prevent or diminish such behaviour were not included in the plans, or if included, only in vague terms, for example 'when he hits his head, act neutrally and calmly'. Our findings correspond to those of Emerson et al. (2008), who found that only 15% of participants had a written behaviourally oriented treatment programme in their research into the treatment and management of 265 people with intellectual disabilities and challenging behaviour. Of this limited number of written plans, the majority were rated 'highly simplistic' by Emerson et al. (2008).

The lack of defined goals and interventions to reduce or prevent challenging behaviour in people with PIMD could be related to gaps in the available knowledge about potential risk factors for challenging behaviour in children and adults with PIMD. A study by Ross and Oliver (2002) showed that there is a tendency to view challenging behaviour as resulting from the intellectual disability rather than as being symptomatic of other causes. Direct support staff may be viewing challenging behaviour as a given and consequently may not believe that specific forms of support or intervention need to be undertaken. The direct support staff's causal attributions for challenging behaviour are likely to be important to any decision about a particular treatment for the behaviour. In a study (reported in Chapter Four) we found that factors concerning the personal characteristics of children and adults with PIMD, such as sleeping problems, auditory problems and mental health problems, were related to the frequency of challenging behaviour. These findings are generally consistent with findings reported in other studies (De Winter, Jansen & Evenhuis, 2011; Hylkema & Vlaskamp, 2009; Lundqvist, 2013; Rojahn, Matson, Naglieri & Mayville, 2004). Only one risk factor related to direct support staff was found, namely staff training. Direct support staff who had received training on challenging behaviour in people with intellectual disabilities in general noticed more withdrawn behaviour compared to those who received no such training.

We further elaborated on the role of direct support staff in Chapter Five. The ways staff attribute challenging behaviour in people with PIMD was examined. The results showed that direct support staff did not find the majority of the causal models for challenging behaviour proposed by Hastings (1997) – namely learned behaviour (negative and positive reinforcement processes), emotional (e.g. anger, stress, fear), physical environment (e.g. auditory environment, bright lights) and self-stimulation (e.g. boredom, not being offered activities) – particularly useful for explaining challenging behaviour in children and adults with PIMD. However, more than half of the participating direct support staff selected a biomedical model as the most applicable causal explanation for challenging behaviour. Explanations related to the physical environ-

ment (e.g. being left alone, the number of people in the group home) were reported as being the least likely. These findings are in line with Tynan and Allen (2002), who found that direct support staff working with people with severe intellectual disability attributed aggressive behaviour significantly more often to biomedical causes than they did for people with mild intellectual disability. If direct support staff assume that challenging behaviour is caused by biomedical problems, this could mean that they might regard such behaviour as 'belonging' to the person and as a consequence will be less inclined to take other factors which could influence the behaviour into account. Furthermore, they might not notice the communicative function the behaviour may have.

One of the consequences of these attributions and the low perceived severity of challenging behaviour by direct support staff could be that these behaviours are not perceived as of serious consequence and are not always systematically addressed in daily practice. It therefore appears necessary, prior to the development and implementation of appropriate interventions to reduce or prevent challenging behaviour in people with PIMD, to first offer training which focuses on changing beliefs and attributions regarding challenging behaviour in people with PIMD (Chapter Six). In this study, we analysed the effects of psycho-education. We assumed this psycho-educational approach would lead to different assessments of challenging behaviour in terms of severity and biomedical explanations of behaviour. This intervention was found to have an effect on the perceived severity of challenging behaviour observed in people with PIMD. Our results show that direct support staff reported challenging behaviour as being less severe over time. This downward trend over time was broken after psycho-education. Direct support staff then reported a higher perceived severity. Though significant, these results are very small. No effects on the biomedical attributions could be found to result from psycho-education.

7.2 Methodical reflection

Although the studies presented in this thesis provide important knowledge on the prevalence and impact of challenging behaviour in people with PIMD, some general limitations should be noted. The organizations which participated in the research for this thesis were not randomly selected. Although the range of participating organizations represents Dutch conditions, we can assume that organizations which voluntarily enrol are more eager to participate in research, which could distinguish them from the organizations which did not sign up. This could undermine the generalizability of the results.

A total of 370 people with PIMD participated in the research. This number is substantial given the total population of adults with PIMD living in facilities in the Netherlands (Vugteveen, Van der Putten & Vlaskamp, 2014). People with PIMD with

a wide age range and from seventeen different organizations and different types of settings were included. As our results relate only to children and adults who live in institutions and receive daycare and only a small number of children who still live at home, it would be interesting in future research to gain further knowledge on how the findings in this thesis compare with findings in other settings, such as schools or where children with PIMD live at home. This could enable us to increase our knowledge of the relationship between challenging behaviour, age and environmental factors, such as the quality of support.

The studies in this thesis are based on direct support staff reports of challenging behaviour displayed by participants using the Behavior Problem Inventory (BPI-01; Rojahn et al., 2001). The BPI-01 was not developed specifically for people with PIMD, which could undermine the internal validity of the findings. The BPI-01 includes items which require a certain level of motor skills, for example 'running around' and 'pacing up and down', which are not applicable to people with PIMD. It is also possible that certain behaviours which are displayed by people with PIMD cannot be scored on the BPI-01, for example withdrawn behaviour. Furthermore, although the clinical criterion validity of the BPI-01 is acceptable according to Rojahn et al. (2001), it is possible that direct support staff did not acknowledge some behaviour as being problematic and as a consequence did not report it. This may have led to bias in our results. In this thesis, therefore, slight adjustments were made regarding the expression of certain types of challenging behaviour in people with PIMD. Expressions which assume a certain level of motor skills were omitted. Furthermore, 'withdrawn behaviour' was added as a fourth category of challenging behaviour in people with PIMD, because it can influence a person's opportunities to gain experience and actively participate in society just as much as other behaviours such as self-injurious, stereotypical and aggressive/destructive behaviour (Oliver, Murphy & Corbett, 1987; Vlaskamp, Zijlstra & Smets, 1997; Wulffaert et al., 2009). The adaptation of the BPI-01 made the instrument more applicable to children and adults with PIMD and has allowed us to gain a broad insight into behaviours which occur within this target group. Because these adjustments can impact on the psychometric quality of the instrument, we analysed the internal consistency of the adapted BPI-PIMD, obtaining positive results in line with other research into the internal consistency of the BPI (Dumont, Kroes, Korzilius, Didden & Rojahn, 2014; Lambrechts & Maes 2009; Rojahn et al., 2001). However, further research is needed into the reliability and validity of the BPI-PIMD and its usability as an assessment and screening tool to identify challenging behaviour in people with PIMD and to evaluate treatment outcomes in practice. Lambrechts and Maes (2009) found that staff members differed in their reports on the frequency of challenging behaviour, especially stereotypical behaviour. Our research collected data on challenging behaviour displayed by people with PIMD from only one direct support staff member per person. This also might

have compromised our results. It would thus be interesting for future research to include reports from several staff members on the frequency and severity of challenging behaviour.

Finally, we reflect on the definition and operationalization of challenging behaviour and its consequences. In this thesis we have adopted the definition of challenging behaviour proposed by Emerson (2001), where different types of challenging behaviour are operationalized from the classification of Rojahn et al. (2001). In the literature (e.g. Borthwick-Duffy, Lane & Widaman, 1994; Emerson et al., 2001; Holden & Gitlesen, 2006; Jones, Cooper, Smiley, Allen, Williamson & Morrison, 2008), the term 'challenging behaviour' is generally used when at least one behaviour problem perceived as severe has occurred, and the term severe challenging behaviour is used when at least one behaviour perceived as severe occurs on a daily basis. However, 'challenging behaviour' according to this definition remains a difficult term in the support of people with PIMD. The emphasis is generally on what direct support staff perceives as problematic behaviour. This measure is more or less subjective and at least partly determined by individual knowledge of challenging behaviour, staff experience, how staff attribute behaviour and the vision staff have for the support of people with PIMD. Even though behaviour may not be perceived by direct support staff as severe, frequently occurring behaviour such as stereotypical behaviour can still have major clinical, social and educational consequences (Crocker et al., 2006; Lowe et al., 2007; Lundqvist, 2013). Accordingly, we feel that it is not primarily the extent to which a behaviour is disruptive to the environment but the extent to which the behaviour creates barriers to the individual to gain experience in relationships with others that should determine whether behaviour can be considered to be problematic. Future debate and research should focus on whether frequency is a more appropriate operationalization of the term challenging behaviour in people with PIMD.

7.3 Theoretical reflections

Our research has yielded knowledge on challenging behaviour in children and adults with PIMD, with a clear focus on the role of direct support staff. Much research shows that the causal and maintaining mechanisms underlying challenging behaviour are multifactorial. The origin of challenging behaviour is normally understood using a multifactorial biopsychosocial model (e.g. Došen, Gardner, Griffiths, King & Lapointe, 2007; Lambrechts, 2010). This model does not regard challenging behaviour as a characteristic of the person with intellectual disability, but as a result of the dynamic interaction between the individual and his environment (Emerson, 2001). The behaviour of the person with intellectual disabilities and the behaviour of the direct support staff who support him or her are intertwined. This model suggests that biological, psychological and environmental factors explain challenging behaviour. These factors can influence each other to a greater or lesser extent. Behaviour is viewed as an observable phenomenon of interaction between an individual and

his or her external world, whose components are defined as follows: 1. the person (biological and psychological factors and medical, functional and psychological problems), 2. the environment (material, personal, social, educational and cultural factors, and system characteristics) and 3. the interaction between person and environment (the externalized behaviour resulting from processes between the person and the environment). Within this triangle, factors adverse to the person (e.g. a mood disorder) can have a significant effect on how the person relates to others in the social environment (e.g. a change in normal conditions). This can then lead to negative reactions from the environment (e.g. staff behaviour based on attributions). These reactions can result in the creation of a particular pattern of interaction (for example, aggression) between these two components. Adverse environmental conditions (e.g. an environment which does not provide stimulation) can also lead to an interaction pattern which has negative impacts on the person (e.g. boredom). As a result, existing interaction patterns can change and be accompanied by maladaptive behaviours (e.g. stereotypical behaviour). The role of direct support staff is crucial in terms of identifying challenging behaviour, providing meaning and responding adequately to it. Challenging behaviour can be caused by seemingly unmodifiable factors within the person with PIMD (e.g. auditory impairment, sleeping problems or mental health problems), but if this is considered from the perspective of a multifactorial biopsychosocial model (Došen et al. 2007), having a hearing impairment (a biological factor), for example, could be understood as leading to the person feeling unsafe and displaying challenging behaviour. If direct support staff fail to understand the cause of this behaviour, or fail to adapt the environment to ensure that a safe auditory environment is created, the person with PIMD will continue to display challenging behaviour. Personal, environmental and interactional factors are thus intertwined, and one cannot be considered without the other.

Furthermore, given the great dependency children and adults with PIMD have on others, it seems important to view behaviours in this target group from a relational perspective. Relationships are of the utmost importance for people with PIMD, because the world around them can be made recognizable and predictable through these relationships (Vlaskamp & Van der Putten, 2009). These relationships ultimately provide them with the opportunity to develop. Behaviours which make it difficult or impossible to enter into these relationships should therefore be viewed as problematic. Direct support staff are, first and foremost, instrumental to establishing such relationships and through these relationships, they can respond adequately if challenging behaviour occurs. Understanding staff attributions and their immediate responses when managing challenging behaviours is not the only factor in trying to prevent or diminish challenging behaviour in people with PIMD, but it is a very important one.

7.4 Implications for practice

Staff training is regarded in the literature as an important though initial step to changing beliefs and attributions (Williams, Dagnan, Rodgers & McDowell, 2012). Our study showed, however, that a brief training course which covers the possible causes and consequences of challenging behaviour in people with PIMD and how direct support staff can affect challenging behaviour in people with PIMD had only minor effects on the assessment of the perceived severity of challenging behaviour. Deveau and McGill (2015) showed that training 'on the job' had more impact on practice than formal training. Embregts (2002; 2003) and Lambrechts (2010) used video feedback to achieve improvement in staff behaviour when dealing with challenging behaviour. It seems important that extensive formal training is combined with on-the-job training, during which direct support staff can reflect on the behaviour of people with PIMD, but also on their own behaviour. Raising awareness in direct support staff of challenging behaviour in people with PIMD is of great importance, as direct support staff play a key role in both identifying and treating challenging behaviour. Providing them with knowledge and time to reflect on behaviour from a relational perspective could be an important first step.

In order to identify challenging behaviour and reflect on the extent to which the behaviour is problematic for the person with PIMD, an interdisciplinary personal profile should be drawn up, in which information must be gathered on the person (biological and psychological factors, and possible medical, functional and psychological problems), the environment (material, personal, social, educational and cultural factors, and system characteristics) and on the interaction between the person with PIMD and significant others. The challenging behaviours displayed, their origin and their possible consequences should be included in such a personal profile. An instrument which could help in this process is the BPI-PIMD. To obtain an accurate picture of the challenging behaviour in a person with PIMD, the BPI-PIMD should preferably be scored by more than one member of staff, meaning that more than one report on challenging behaviour should be considered (Lambrechts, 2010). Subsequently, during interdisciplinary meetings involving parents, direct support professionals, medical staff, allied health professionals and behavioural scientists, the effect of the identified challenging behaviours on the possibilities of building and securing relationships with people with PIMD can be discussed. Staff attributions for challenging behaviour and their implications should also be an important topic. Our study showed that most of the existing explanatory models were not particularly useful to direct support staff in explaining challenging behaviour in children and adults with PIMD. More than half of the participating direct support staff reported a biomedical model as the most applicable causal explanation of challenging behaviour. Although this model was chosen over other models by direct support staff to explain challenging behaviour in people with PIMD, a tendency toward neutrality within this biomedical model was found. This could mean that direct support

staff have additional explanations for challenging behaviour in people with PIMD, which should be explored. This process could influence how people perceive or react to the behaviour identified. The outcome of such a meeting could be recorded in the individual comprehensive service plan to formulate goals on preventing or diminishing challenging behaviour. To enable people with PIMD to build and maintain relationships, their support needs to be planned to a substantial extent (Vlaskamp & Van der Putten, 2009). Explicit and planned actions, as well as systematic and goal-oriented evaluation, are required to take full account of the needs of people with PIMD. Priorities need to be set and what resources will be required and how goals will be achieved should be established in an interdisciplinary manner.

This thesis has focussed on prevalence, frequency and the severity of challenging behaviour in people with PIMD, and on how direct support staff perceive and/or manage such behaviours. This is a necessary first step towards the development and implementation of an intervention to prevent or reduce these behaviours in people with PIMD. This information can now be used to develop an appropriate intervention to reduce or prevent challenging behaviour in people with PIMD.

7.5 References

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Summary

The term 'challenging behaviour' is generally used to refer to 'culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson, 2001, p.3). The consequences of challenging behaviour can be far-reaching. First of all, challenging behaviour can cause physical harm to the individual or their environment. It can limit personal development and can make it difficult for the individual to form and maintain social relationships. The result can be a severely reduced quality of life. The literature shows a correlation between the presence of challenging behaviour and various factors such as motor and/or sensory impairments, epilepsy, communication problems, sleep problems, chronic pain and psychiatric problems. Research also shows that people with a profound intellectual disability and/or communication problems are at greater risk of exhibiting stereotypical and self-injurious behaviour. In addition to these conditions, some genetic syndromes, such as Rett syndrome and Cornelia de Lange syndrome, also involve challenging behaviour.

It is therefore clear that people with many of the above conditions also exhibit challenging behaviour. This is certainly true of the category children and adults with profound intellectual and multiple disabilities (PIMD), who are characterized by a profound intellectual disability and profound motor impairments, which manifest as a complete or almost complete lack of ambulant mobility. In addition, they frequently have sensory impairments and additional health problems (constipation, reflux, chronic respiratory infections), with chronic pain as a possible consequence. People with PIMD are also unable or barely able to use language to explain what they want and/or need. Despite all this, little has been known thus far about challenging behaviour in this group. We need to have a good picture of the prevalence, frequency and severity of challenging behaviour in people with PIMD in order to understand the nature and background of such behaviour and the factors that may influence it and to offer tools for its prevention or reduction.

This thesis describes research that was designed to shed light on the prevalence, frequency, severity, nature and background of challenging behaviour in children and adults with PIMD. It also outlines the development of an intervention to identify, prevent or reduce challenging behaviour in this group.

Chapter one is an introductory chapter describing the research context.

Chapter two reports on the prevalence, frequency and severity of challenging behaviour in children and adults with PIMD. The study looks at 181 participants in total (56% men and 44% women, with a mean age of 35 years; SD: 19 years) from seven facilities in the Netherlands. The Behavior Problems Inventory (BPI; Rojahn, Matson, Lott, Esbensen & Smalls, 2001; Lambrechts & Maes, 2009) was used to chart the prevalence, frequency and severity of three different types of challenging behaviour (self-injurious, stereotypical and aggressive/destructive behaviour). In addition, an analysis was made of the correlation between challenging behaviour and the presence of additional sensory and general health problems. The results show that the prevalence of all three types of challenging behaviour was high: 82% of participants displayed one or more kinds of self-injurious and stereotypical behaviour. In all, 45% of participants exhibited one or more forms of aggressive/destructive behaviour. The frequency of challenging behaviour was also high for all three types of challenging behaviour. Despite high prevalence and frequency figures, direct support staff generally viewed the consequences of this behaviour for the person with PIMD as 'not severe'. Finally, the study found a positive correlation between the mean number of positively scored items on the BPI and the presence of visual, tactile and psychiatric problems. On average, there were higher scores on the BPI for people with these disabilities than for participants without these problems. We can conclude that challenging behaviour is common in people with PIMD, in terms of both prevalence and frequency. However, direct support staff generally regard the consequences of this behaviour as minor.

Chapter three describes an analysis of practical interventions by direct support staff aimed at preventing self-injurious, stereotypical and aggressive/destructive behaviour. This involved a stratified sample of 30 participants with PIMD (20 men, 10 women, mean age: 29 years, SD: 17 years) who had the highest scores for both frequency and severity of challenging behaviour. An analysis was made of their individualised comprehensive service plans to determine the extent to which the challenging behaviour was described in the plans and to identify which aims and interventions were used to prevent or reduce existing problems. An analysis was also made of the degree of correlation between the type of behaviour, its frequency and perceived severity and whether or not the behaviour was described in the personal plans. The analyses showed that the plans contained nothing about almost half (48.2%) of all identified challenging behaviours (BPI). For 53.7% of the challenging behaviours that were described in the plans, some form of strategy and/or intervention was outlined to influence these behaviours. Specific aims were recorded in the plans for 17.2% of these behaviours. A positive correlation was found between the type of challenging behaviour, the severity of the problems experienced by direct support staff and the degree of reporting in the plans. Self-injurious and aggressive/destructive behaviour was mentioned more frequently in the plans than stereotypical behaviour. Finally, behaviour which staff

judged to have more serious consequences was mentioned more frequently than behaviour whose consequences were regarded as less serious. We concluded from these results that the support given to people with PIMD who display a high frequency of challenging behaviour was scarcely or not aimed specifically at reducing this problem.

Chapter four describes the risk factors that correlate with the presence of challenging behaviour in people with PIMD. In total, 198 people (106 men, 92 women with a mean age of 30.4 years; SD: 16.1, range: 3-67) from ten facilities were investigated. Prompted by the literature, we looked at the relationship between the occurrence of challenging behaviour and factors relating to the individual with disabilities (age, sex, and presence of sensory and general health problems), factors relating to direct support staff (age, sex, number of years' work experience, scope of the employment contract, level of education and training in dealing with challenging behaviour) and environmental factors (type of facility, group size, number of direct support staff and number of working hours). The presence of challenging behaviour was established using the BPI-PIMD, a modified version of the Behavior Problems Inventory (BPI). Items that assumed particular motor skills (such as jumping or pacing up and down) were omitted from the inventory. 'Withdrawn behaviour' was added as a fourth category of challenging behaviour in people with PIMD. It was selected because this type of behaviour – together with self-injurious, stereotypical and aggressive/destructive behaviour – could have a negative impact on an individual's opportunities to build relationships, gain experiences and take part in society. Withdrawn behaviour is defined as behaviour that is almost exclusively directed inward and where the individual reacts defensively to contact offered by others and/or to stimuli (irrespective of the type of stimulus). Regression analyses showed that the mean frequency of occurrences of challenging behaviour could primarily be explained by factors relating to the individual, such as sleep problems and auditory problems. Auditory impairments correlated with a higher frequency of self-injurious and stereotypical behaviour, while sleep problems correlated with a higher score for all types of challenging behaviour. Only one factor relating to direct support staff was shown to correlate with the occurrence of challenging behaviour. Staff who had taken part in a training course on challenging behaviour in people with general intellectual disabilities, reported higher scores on withdrawn behaviour among participants. The present study found no correlation between the occurrence of challenging behaviour and environmental factors.

Chapters five and six examine the role of direct support staff in greater depth. Chapter five analyses direct support staff's attributions concerning the possible causes and/or explanations of challenging behaviour in people with PIMD. The participants were 195 direct support staff (a majority of women; n=188, mean age of 38.5 years; range: 20-64) employed to care for people with PIMD. The Attribution

Scale for Challenging Behaviour (CHABA) (Hastings, 1997) was used to present care professionals with 33 statements about a range of causes of challenging behaviour. The statements were divided into five causal models: biomedical, physical environment, learned behaviour, self-stimulation and emotional explanatory models. Direct support staff indicated what they felt were the most likely explanations for the challenging behaviour of the person with PIMD who they supported. The results show that on average staff chose the biomedical model as the most plausible explanation for challenging behaviour in children and adults with PIMD, although the mean scores on all possible explanatory models were low. This could mean that none of the models were considered especially plausible explanations for challenging behaviour in people with PIMD. This may suggest that staff find it hard to account for such behaviour. The results proved to be independent of the number of years' work experience.

Chapter six describes research that explored the extent to which direct support staff's attributions and their views on the consequences of challenging behaviour are influenced by a short-term intervention to address challenging behaviour in people with PIMD. The study involved 198 care professionals from ten organizations across the Netherlands. The participants were predominantly female (n=188), and the mean age was 38.6 (SD: 11.3, range: 20-64). They were offered a psycho-education course designed to change their attitudes and improve their knowledge about challenging behaviour in people with PIMD. Multi-level analyses were used to investigate whether, following this intervention, staff made fewer attributions on the basis of medical/biological factors. We also determined whether the consequences of challenging behaviour were viewed as more serious after the intervention. The results showed that, following the intervention, staff rated behaviour as being more serious, but this effect was limited. The short-term training of staff did not lead to a change in the explanations they gave for challenging behaviour in people with PIMD.

Chapter seven, the final chapter, reflects on the findings of the five studies and their theoretical and practical implications. Emerson's (2001) general definition of challenging behaviour (2001) was followed for this thesis. In the literature, this definition is sometimes specified more closely: the term 'challenging behaviour' is only used to refer to the occurrence of at least one behaviour that the care professional regards as serious. The term 'severe challenging behaviour' is used if at least one of the behaviours occurs daily and is viewed as serious by the care professional. In our view, this specification of 'challenging behaviour' is not suitable when supporting people with PIMD because of the strong emphasis on what direct support staff experience as serious. This evaluation is rather subjective and is at least partly determined by the staff's knowledge of challenging behaviour and their view of how people with PIMD should be supported. Behaviour that occurs very

frequently, such as stereotypical behaviour, might not be viewed as serious by staff but it can nevertheless have major clinical and social consequences. We therefore feel that the primary factor in deciding whether behaviour is problematic should not be the extent to which the behaviour is disruptive to others, but rather the extent to which it hampers the person with PIMD from gaining experiences and forming relationships with others.

In the literature, the training of staff is seen as an important first step in thinking about and adequately addressing challenging behaviour. However, our study showed that brief training in the possible causes and consequences of challenging behaviour in people with PIMD had only a minor effect on assessing the severity of challenging behaviour. It appears that comprehensive formal training about challenging behaviour in this target group should be combined with on-the-job training in which care professionals are given scope to reflect on the behaviour of people with PIMD, as well as on their own behaviour. Awareness of challenging behaviour – behaviour that impedes the building of relationships – is immensely important because direct support staff play a key role in both identifying and preventing or reducing such behaviour in this target group. An interdisciplinary personal profile needs to be drawn up to identify challenging behaviour and to reflect on the degree to which it is problematic for the person with PIMD. The profile should provide information on the individual (biological and psychological factors and possible medical, functional and psychological problems), the environment (material, personal, social, educational and cultural factors, and system characteristics) and the interaction between the individual with PIMD and significant others. The personal profile should also include the challenging behaviour identified for that individual, together with its possible explanations and consequences. The BPI-PIMD can be a useful tool in this process. During interdisciplinary sessions with parents, supporters, medical/paramedical care and behavioural scientists, the outcomes of this inventory can serve as the starting point for discussing the consequences of certain behaviour for an individual's opportunities to build and maintain relationships. The explanations of staff and parents/legal representatives for the behaviour can also be addressed during this session. The session outcome could be incorporated into the individual support plans. Objectives can then be formulated for the prevention or reduction of this behaviour.

This thesis has focused on the prevalence, frequency and severity of challenging behaviour in people with PIMD, and on how direct support staff observe and respond to this behaviour. Gathering this information has been an essential first step in the further development and implementation of an intervention to prevent or reduce challenging behaviour in this target group.

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Samenvatting (Summary in Dutch)

In het algemeen wordt gesproken van probleemgedrag als er sprake is van 'cultureel abnormaal gedrag van dusdanige intensiteit, frequentie of langdurigheid dat het de fysieke veiligheid van de persoon zelf of anderen (ernstig) bedreigt of gedrag dat het gebruik van gemeenschappelijke voorzieningen ernstig beperkt of zelfs leidt tot een ontzegging van de toegang tot dergelijke voorzieningen'(Emerson, 2001. p.3). De gevolgen van probleemgedrag kunnen verstrekkend zijn. In de eerste plaats kan het leiden tot fysieke beschadigingen van de persoon zelf en zijn omgeving. Daarnaast kan probleemgedrag de persoonlijke ontwikkeling beperken en het aangaan en in stand houden van sociale relaties bemoeilijken. Deze gevolgen kunnen leiden tot een (sterk) verminderde kwaliteit van bestaan. Uit de literatuur blijkt dat er een relatie bestaat tussen het ontstaan van probleemgedrag en verschillende factoren zoals de aanwezigheid van motorische en/of sensorische beperkingen, epilepsie, communicatieve problemen, slaapstoornissen, chronische pijn en psychiatrische problemen. Uit onderzoek blijkt tevens dat personen met een ernstige verstandelijke beperking en/ of communicatieve problemen een groter risico lopen op het vertonen van stereotiep en zelfbeschadigend gedrag. Naast deze factoren worden bij sommige genetische syndromen, zoals Rett syndroom en het syndroom van Cornelia de Lange, gedragsproblemen beschreven.

Het ligt dus voor de hand dat bij mensen waarbij sprake is van veel van bovengenoemde factoren ook veel gedragsproblemen voorkomen. Dit geldt zeker voor de categorie kinderen en volwassenen met (zeer) ernstige verstandelijke en meervoudige beperkingen, die worden gekenmerkt door een zeer ernstige verstandelijke beperking en (zeer) ernstige motorische beperkingen, zich uitend in niet of nauwelijks ambulante zijn. Daarnaast is er veelvuldig sprake van sensorische beperkingen en bijkomende gezondheidsproblemen (obstipatie, reflux, chronische luchtweginfecties) met als mogelijk gevolg chronische pijnklachten. Ook zijn mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen niet of nauwelijks in staat door middel van taal duidelijk te maken wat hun wensen en/of behoeften zijn. Toch is over probleemgedrag bij deze groep tot op heden weinig bekend.

Een goed beeld van de prevalentie, frequentie en ernst van probleemgedrag bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen is noodzakelijk om de aard en achtergrond van het gedrag en de mogelijke factoren die hierop van invloed zijn in kaart te brengen en handvatten te bieden om probleemgedrag te voorkomen of te verminderen.

In dit proefschrift wordt onderzoek beschreven dat tot doel had inzicht te krijgen in de prevalentie, frequentie, ernst, aard en achtergrond van probleemgedrag

bij kinderen en volwassenen met (zeer) ernstige verstandelijke en meervoudige beperkingen en het ontwikkelen van een interventie ter signalering, voorkoming of vermindering van gedragsproblemen bij deze groep.

Hoofdstuk één is een inleidend hoofdstuk waarin de context van het onderzoek wordt beschreven.

In *hoofdstuk twee* wordt verslag gedaan van een onderzoek gericht op de prevalentie, frequentie en ernst van gedragsproblemen bij kinderen en volwassenen met (zeer) ernstige verstandelijke en meervoudige beperkingen. In totaal zijn binnen dit onderzoek 181 participanten geïncludeerd (56% mannelijke en 44% vrouwelijke participanten met een gemiddelde leeftijd van 35 jaar; SD: 19 jaar) uit zeven voorzieningen in Nederland. Door middel van de 'Lijst Gedragsproblemen' (LGP; Rojahn, Matson, Lott, Esbensen & Smalls, 2001; Lambrechts & Maes, 2009) is zowel de prevalentie, de frequentie als de ernst van drie verschillende typen gedragsproblemen (zelf verwondend, stereotiep en agressief/destructief gedrag) in kaart gebracht. Daarnaast is geanalyseerd in hoeverre er een relatie bestond tussen de aanwezigheid van gedragsproblemen en bijkomende zintuiglijke- en algemene gezondheidsproblemen. De resultaten laten zien dat de prevalentie van alle drie typen gedragsproblemen hoog is: 82% van de participanten vertonen één of meerdere soorten zelf verwondend en stereotiep gedrag. Totaal vertoont 45% van de participanten één of meerdere vormen van agressief/destructief gedrag. Ook de frequentie van de gedragsproblemen is hoog, voor alle drie de typen probleemgedrag. Ondanks hoge prevalentie én frequentiecijfers worden in het algemeen de gevolgen van deze gedragsproblemen voor de persoon met ernstige verstandelijke en meervoudige beperkingen zelf door zorgprofessionals als 'niet ernstig' beschouwd. Tenslotte werd binnen de uitgevoerde studie een positieve relatie gevonden tussen het gemiddeld aantal positief gescoorde items op de LGP en de aanwezigheid van visuele- tactiele- en psychiatrische problemen. Er werden gemiddeld hogere scores gezien op de LGP bij personen met deze beperkingen ten opzichte van participanten zonder deze problemen. Geconcludeerd werd dat gedragsproblemen veel voorkomen; zowel wat betreft prevalentie als frequentie bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Echter, de gevolgen van deze gedragingen worden door zorgprofessionals in het algemeen als gering beschouwd.

In *hoofdstuk drie* wordt een analyse beschreven van de wijze waarop binnen de praktijk door zorgprofessionals geïntervenieerd wordt bij het voorkomen van zelf verwondend, stereotiep en agressief/destructief gedrag. Hiertoe is een gestratificeerde steekproef getrokken van 30 participanten met (zeer) ernstige verstandelijke en meervoudige beperkingen (20 mannen, 10 vrouwen, gemiddelde leeftijd: 29 jaar, SD: 17 jaar) met de hoogste scores op zowel frequentie als ernst van de aanwezige gedragsproblemen. Door middel van een analyse van persoonlijke plannen is

bepaald in hoeverre aanwezige gedragsproblemen beschreven werden in de plannen en welke doelen en interventies gericht waren op het voorkomen of reduceren van bestaande problemen. Ook is bepaald in hoeverre er een relatie bestond tussen het type gedrag, de frequentie van voorkomen en de ervaren ernst van het gedrag en het al dan niet beschreven worden van het gedrag in de persoonlijke plannen. Uit de analyses is gebleken dat over bijna de helft (48.2%) van het totale aantal geïdentificeerde gedragsproblemen met de LGP, niets beschreven werd in de persoonlijke plannen. Van de gedragsproblemen die wel beschreven waren binnen de plannen, werden bij 53.7% op enige wijze strategieën en/of interventies beschreven om deze gedragsproblemen te beïnvloeden. Bij 17.2% van deze gedragsproblemen waren concrete doelen geformuleerd binnen de persoonlijk plannen. Er werd een positieve relatie gevonden tussen het type gedragsprobleem, de door zorgprofessionals ervaren ernst van de problemen en de mate van rapportage binnen de plannen. Zelf verwondend en agressief/destructief gedrag werden meer beschreven binnen de plannen ten opzichte van stereotiep gedrag. Gedrag waarvan zorgprofessionals de gevolgen als ernstiger inschatten werd tenslotte vaker beschreven in de persoonlijke plannen ten opzichte van gedrag waarvan de gevolgen als minder ernstig werden beschouwd. Op basis van de beschreven resultaten wordt geconcludeerd dat de ondersteuning van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen waarbij gedragsproblemen in hoge frequentie aanwezig zijn, niet of nauwelijks specifiek gericht is op de reductie van deze problematiek.

In *Hoofdstuk vier* wordt beschreven welke risicofactoren samenhangen met de aanwezigheid van gedragsproblemen bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Er zijn in totaal 198 personen betrokken (106 mannen, 92 vrouwen met een gemiddelde leeftijd van 30.4 jaar; SD: 16.1, range: 3-67) afkomstig uit tien voorzieningen. Op basis van de literatuur werd de relatie onderzocht tussen het voorkomen van gedragsproblemen en factoren gerelateerd aan de persoon met beperkingen (leeftijd, geslacht en aanwezige zintuiglijke- en algemene gezondheidsproblemen), factoren gerelateerd aan zorgprofessionals (leeftijd, geslacht, aantal jaren werkervaring, omvang van het dienstverband, opleidingsniveau en training gericht op gedragsproblemen) en omgevingsfactoren (type voorziening, groepsgrootte, aantal zorgprofessionals en aantal uren dagbesteding). De aanwezigheid van gedragsproblemen werd vastgesteld met een aangepaste versie van de LGP, namelijk de LGP-ZEVMB. In deze lijst zijn items die bepaalde motorische vaardigheden veronderstellen weggelaten (bijvoorbeeld springen, ijsberen). Bovendien werd 'teruggetrokken gedrag' toegevoegd als een vierde categorie van probleemgedrag bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Hiervoor is gekozen omdat dit type gedrag, evenals zelf verwondend, stereotiep en agressief/destructief gedrag, de mogelijkheden van een persoon om relaties op te bouwen, ervaringen op te doen en te kunnen deelnemen aan de samenleving negatief kunnen beïnvloeden. Teruggetrokken gedrag is gedefinieerd als gedrag dat vrij

wel niet naar buiten gericht is en waarbij afwerend gereageerd wordt op contact aangeboden door personen en/of afwerend gereageerd wordt op stimuli (ongeacht de soort stimulus). Uitgevoerde regressieanalyses laten zien dat de gemiddelde frequentie van voorkomende gedragsproblemen vooral verklaard kon worden door persoonsgebonden factoren als aanwezige slaapproblemen en auditieve problemen. Auditieve beperkingen hingen samen met een hogere frequentie op zelf verwondend en stereotiep gedrag. Aanwezige slaapproblemen hingen samen met een hogere score bij alle typen gedragsproblemen. Slechts één factor gerelateerd aan zorgprofessionals bleek samen te hangen met het voorkomen van gedragsproblemen. Indien een zorgprofessional een training had gevolgd op het gebied van gedragsproblemen bij personen met verstandelijke beperkingen in het algemeen werden hogere scores gerapporteerd op teruggetrokken gedrag bij de participanten. Binnen de uitgevoerde studie werd geen relatie gevonden tussen het voorkomen van gedragsproblemen en omgevingsfactoren.

Op de rol van zorgprofessionals wordt verder ingegaan in hoofdstuk vijf en zes van dit proefschrift. *Hoofdstuk vijf* betreft een analyse van de attributies van zorgprofessionals ten aanzien van de mogelijke oorzaken en/of verklaringen van gedragsproblemen bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. De participanten bestonden uit 195 zorgprofessionals (merendeel vrouw; n=188, gemiddelde leeftijd van 38.5 jaar; range: 20-64 jaar) die werkzaam zijn binnen de ondersteuning voor mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Door middel van de 'Attributieschaal voor Probleemgedrag' (APG) (Hastings, 1997) zijn 33 stellingen over uiteenlopende oorzaken van gedragsproblemen voorgelegd aan zorgprofessionals. De stellingen zijn ingedeeld in vijf causale modellen, namelijk biomedische, fysieke omgeving, aangeleerd gedrag, zelfstimulatie en emotionele verklaringenmodellen. Zorgprofessionals gaven aan welke verklaringen zij het meest aannemelijk vonden voor gedragsproblemen bij de persoon met (zeer) ernstige verstandelijke en meervoudige beperkingen die zij ondersteunden. De resultaten laten zien dat de zorgprofessionals gemiddeld het biomedische model als de meest plausibele verklaring voor gedragsproblemen bij kinderen en volwassenen met (zeer) ernstige verstandelijke en meervoudige beperkingen kiezen, al waren de gemiddelde scores op alle mogelijke verklaringenmodellen laag. Dit kan betekenen dat geen van de modellen bijzonder plausibel werden gevonden als verklaring van gedragsproblemen bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Mogelijk betekent dit dat het voor zorgprofessionals moeilijk is een verklaring voor het gedrag te geven. De gevonden resultaten bleken niet afhankelijk te zijn van het aantal jaren werkervaring.

Hoofdstuk zes beschrijft onderzoek waarbij geëvalueerd wordt in hoeverre attributies van zorgprofessionals én hun mening over de gevolgen van aanwezige gedragsproblemen beïnvloed worden door een kortdurende interventie met

betrekking tot gedragsproblemen bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. In totaal zijn 198 zorgprofessionals geïncludeerd, afkomstig uit tien organisaties in heel Nederland. De deelnemende zorgprofessionals waren overwegend vrouwelijke (n=188), ze hadden een gemiddelde leeftijd van 38.6 jaar (SD: 11.3, range: 20-64). Deze zorgprofessionals kregen psycho-educatie aangeboden gericht op visieverandering en kennisvermeerdering over gedragsproblemen bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Met multi level analyses is onderzocht of zorgprofessionals na het volgen van de interventie minder ten gunste van medische/ biologische factoren attribueren. Daarnaast is bepaald of de gevolgen van gedragsproblemen als ernstiger worden gezien na de interventie. De resultaten laten zien dat zorgprofessionals na het volgen van de interventie gedrag als ernstiger beoordelen, maar dit effect is beperkt. Het kortdurend opleiden van zorgprofessionals leidt niet tot een verandering in de verklaringen die zij geven voor gedragsproblemen bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen.

Dit proefschrift wordt afgesloten met *hoofdstuk zeven*, waarin wordt gereflecteerd op de bevindingen van de vijf onderzoeken, en de theoretische en praktische implicaties ervan worden weergegeven. In dit proefschrift is de algemene definitie voor gedragsproblemen van Emerson (2001) aangehouden. In de literatuur wordt deze definitie ook wel nader gespecificeerd door de term 'probleemgedrag' alleen te gebruiken wanneer ten minste één gedraging voorkomt die door de zorgprofessional als ernstig wordt beschouwd. De term 'ernstig probleemgedrag' wordt gebruikt als tenminste één gedraging dagelijks voorkomt en als ernstig wordt beschouwd door de zorgprofessional. In onze optiek is deze specificering van de term 'gedragsproblemen' niet goed bruikbaar in de ondersteuning van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen omdat de nadruk sterk ligt op wat zorgprofessionals ervaren als ernstig. Deze beoordeling is min of meer subjectief en wordt ten minste gedeeltelijk bepaald door de kennis over probleemgedrag en de visie op de ondersteuning van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen van zorgprofessionals. Zeer frequent voorkomend gedrag, bijvoorbeeld stereotiep gedrag, wordt mogelijk niet als ernstig ervaren door zorgprofessionals maar kan toch grote klinische en sociale gevolgen hebben. Daarom zijn wij van mening dat niet primair de mate waarin gedrag storend is voor de omgeving, maar de mate waarin het gedrag de persoon met (zeer) ernstige verstandelijke en meervoudige beperkingen belemmert om relaties aan te gaan met anderen en ervaringen op te doen, bepalend zou moeten zijn om gedrag te beschouwen als problematisch.

In de literatuur wordt training van zorgprofessionals gezien als een belangrijke, zij het eerste stap, in het denken over en adequaat reageren op probleemgedrag. Onze studie toonde echter aan dat een korte training over de mogelijke oorzaken

en gevolgen van gedragsproblemen bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen slechts een gering effect had op de beoordeling van de ernst van waargenomen probleemgedrag. Het lijkt belangrijk dat een uitgebreide formele opleiding over gedragsproblemen bij deze doelgroep wordt gecombineerd met on-the-job training, waarin zorgprofessionals de ruimte krijgen te reflecteren op het gedrag van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen, maar ook op hun eigen gedrag. Bewustwording van problematisch gedrag, dus gedrag dat het opbouwen van relaties belemmert, is van groot belang omdat zorgprofessionals een belangrijke rol spelen bij zowel het identificeren als het voorkomen of verminderen van probleemgedrag bij deze doelgroep.

Om probleemgedrag te identificeren en om na te denken over de mate waarin het gedrag problematisch is voor de persoon met (zeer) ernstige verstandelijke en meervoudige beperkingen, dient een interdisciplinair persoonlijk profiel opgesteld te worden. Hierin wordt informatie beschreven over de persoon zelf (biologische en psychologische factoren en mogelijke medische, functionele en psychologische problemen), de omgeving (materiaal, persoonlijke, sociale, educatieve en culturele factoren, en systeemkenmerken) en de interactie tussen de persoon met (zeer) ernstige verstandelijke en meervoudige beperkingen en belangrijke anderen. Ook geïdentificeerd probleemgedrag, mogelijke verklaringen voor en gevolgen van dat gedrag worden opgenomen in een dergelijk persoonlijk profiel. Een bruikbaar hulpmiddel in dit proces kan de LGP-ZEVMB zijn. De uitkomsten van deze lijst kunnen, tijdens interdisciplinaire bijeenkomsten met ouders, begeleiders, (para)medici en gedragswetenschappers, een onderlegger vormen om de gevolgen van bepaald gedrag op de mogelijkheden van de persoon om relaties op te bouwen en te bestendigen, te bespreken. Ook de verklaringen die zorgprofessionals en ouders/wettelijk vertegenwoordigers geven voor het gedrag kunnen tijdens deze bijeenkomst aan de orde komen. De uitkomst van een dergelijke bijeenkomst zou kunnen worden opgenomen in de individuele ondersteuningsplannen. Vervolgens kunnen doelen om dergelijk gedrag te voorkomen of te verminderen worden geformuleerd.

Dit proefschrift heeft zich gericht op de prevalentie, frequentie en de ernst van probleemgedrag bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen, en op de manier waarop zorgprofessionals het gedrag waarnemen en erop reageren. Het verzamelen van deze kennis was een noodzakelijke eerste stap voor de verdere ontwikkeling en implementatie van een interventie ter voorkoming of vermindering van probleemgedrag bij deze doelgroep.

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About the author

Petra Poppes was born in Enschede in 1970. In 1987, the author received her HAVO diploma from the Gemeentelijke Scholengemeenschap in Emmen. She finished a teacher training college (PABO) and went on to study at the Department of Special Needs Education and Youth Care at the University of Groningen, where she received her master of science degree. In addition she received a post-master degree as a health care psychologist. In 1997 she started working as a teacher and researcher at the Department of Special Needs Education and Youth Care in Groningen. In 2002 she combined her work at the university with work as a health care psychologist in practice. Currently she works as a health care psychologist at the 's Heeren Loo Zorggroep in Bedum.