Challenging practices
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Chapter 3

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

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 in effective? 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 and the support staff concern? (3) Are interventions or strategies to prevent or diminish challenging behaviour only undertaken when the 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 in effective? 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?

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.

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: 2–18 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.
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 break-fast’, ‘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, she 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 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).

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.
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.

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 exist 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 serious 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 285 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 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.

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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 adjust 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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Challenging practices


