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## Motor activation in people with profound intellectual and multiple disabilities in daily practice

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### ABSTRACT

**Background** People with profound intellectual and multiple disabilities (PIMD) are at risk of being motorically inactive. This study investigated the degree and type of motor activation in daily practice and its relationship to personal and contextual factors.

**Method** A total of 58 participants with PIMD participated in the study. Data concerning the motor activation were collected by means of a diary over a period of 14 days. Relationships to personal and contextual factors were analysed using multilevel analyses.

**Results** The mean number of transfers was 3.1 times per day (range: 0–9,  $SD = 1.4$ ), the mean number of relocations was 7.7 times per day (range: 2–13,  $SD = 2.5$ ), and the mean number of motor activities offered was 1.5 per day (range: 0–10,  $SD = 1.9$ ). Relationships to age, gender, location, and day of week were found.

**Conclusion** Motor activation seems to be a minor part of the support provided to people with PIMD.

### KEYWORDS

intellectual disability; profound intellectual and multiple disabilities; motor activation; movement; physical activity

### Introduction

In both the general population as well as in people with intellectual disability, it is generally acknowledged that being physically active on a regular basis is important because of the positive effects on physical and mental health (Bartlo & Klein, 2011). Bartlo and Klein (2011) conducted a review into the effects of physical activity programs (balance training, aerobic training, and resistance training) for adults with intellectual disability and found evidence of an increase in balance and muscle strength (e.g., Carmeli, Kessel, Coleman, & Ayalon, 2002; Carmeli, Merrick, & Berner, 2004; Carmeli, Zinger-Vaknin, Morad, & Merrick, 2005), heart rate (e.g., Cluphf, O'Connor, & Vanin, 2001), functional mobility and gait (e.g., Podgorski, Kessler, Cacia, Peterson, & Henderson, 2004), and physical fitness (e.g., Rimmer, Heller, Wang, & Valerio, 2004). In addition to these positive effects in physical variables, evidence of positive effects in the domain of mental health was also found (Bartlo & Klein, 2011), such as a reduction in anxiety (Carmeli, Barak, Morad, & Kodesh, 2009), an increase in life satisfaction (Heller, Hsieh, & Rimmer, 2004), wellbeing (Carmeli et al., 2005), and quality of life (Carmeli et al., 2009; Heller et al., 2004). The participants in the studies included were, however,

only adults of whom the majority had a mild to moderate intellectual disability.

A few studies, however, have found that children and adults with more severe levels of intellectual disability can also profit from movement-oriented interventions (Houwen, van der Putten, & Vlaskamp, 2014; Jones et al., 2007; van der Putten, Vlaskamp, Reynders, & Nakken, 2005). For example, Jones et al. (2007) found positive effects on problem behaviour in adults with a profound intellectual disability after a rebound therapy-based exercise program. Van der Putten et al. (2005) found that implementing a program that integrates training in functional movement skills into daily life – skills such as sitting down, being seated, standing (up), and walking – and by different professionals, enhanced the independence and participation of children with profound intellectual and multiple disabilities. Moreover, training in motor skills enables a person to experience, explore, and understand the world around them (Reimer & Siemonsma-Boom, 2013; Schellingerhout, Smitsman, & Cox, 2005) as well as increasing self-control and autonomy. However, several studies have demonstrated that people with intellectual disability have significantly fewer opportunities to experience movement and/or have lower rates of physical activity than those without disability (Draheim, Williams, &

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McCubbin, 2002; Emerson, 2005; Hilgenkamp, Reis, van Wijck, & Evenhuis, 2012; Lahtinen, Rintala, & Malin, 2007; Messent, Cooke, & Long, 1998; Robertson et al., 2000; Temple, Frey, & Stanish, 2006). These studies indicate that the rate of physical activity varies with the level of impairment: in general, when the intellectual disability is more severe the level of physical inactivity increases (Emerson, 2005; Peterson, Janz, & Lowe, 2008; Robertson et al., 2000). In most studies, however, people with severe or profound intellectual and multiple disabilities were excluded either in the recruitment phase, because of their assumed inability to be physically active or their associated impaired mobility, or in the data analysis, because of the low number of participants (Hilgenkamp et al., 2012; Robertson et al., 2000).

Therefore, the extent to which people with the most severe disability – such as people with profound intellectual disability – are physically active or motor activated in daily practice is still unknown. This study focuses on people with profound intellectual and multiple disabilities (PIMD). In the majority of these people, a profound intellectual disability is accompanied by severe or profound motor disabilities and sensory impairments, such as visual and auditory problems (Nakken & Vlaskamp, 2007). Consequently, performing physical activities independently is problematic for them and they are at particular risk of deficient levels of movement. In fact, they have limited opportunities for compensation as they usually lack the internal drive to move by themselves due to their intellectual disability, and have limited awareness of external cues due to, for example, a visual impairment. Thus, they are usually completely dependent on others, such as direct support persons, to be motorically activated.

To date, no data are available focusing on the extent to which these people are motorically activated in daily practice. Research shows that motor training and activation does not seem to be a primary objective of the support offered to people with PIMD (van der Putten, Vlaskamp, & Poppes, 2009; Vlaskamp & Nakken, 2008). An analysis of the support offered indicates that in the short term, staff mainly focus on expanding their understanding of the individual person by formulating short-term goals for gathering knowledge. They rarely use existing knowledge to activate the person with PIMD (van der Putten et al., 2009). Furthermore, Vlaskamp and Nakken (2008) found in an overview of the use of various interventions that hardly any of these interventions focus on motor activation. Additionally, people with PIMD have a considerable number of “empty hours” (hours in which no activities take place) in their daily life (Zijlstra & Vlaskamp, 2005) and the activities offered are characterised by sedentariness and little variation (Vlaskamp, Hiemstra,

Wiersma, & Zijlstra, 2007). The activities offered mainly consist of lying on a water mattress, watching television, listening to music, or just being present when cooking activities are being carried out by others, without being engaged in an active way. This inactivity may negatively influence physical health problems (e.g., sleeping problems) as well as mental health problems (e.g., challenging behaviour); both are seen frequently in people with PIMD (Hylkema, Petitiaux, & Vlaskamp, 2011; Poppes, van der Putten, & Vlaskamp, 2010). All of these problems negatively affect the quality of life of persons with PIMD.

The main aim of the present study was to analyse the degree and type of motor activation in persons with PIMD. The relationships to personal factors such as age (Finlayson et al., 2009) and gender (Emerson, 2005), and contextual factors such as facility, setting, and day of week (Peterson et al., 2008; Robertson et al., 2000) were also explored. This knowledge can be used in the structural implementation of movement-oriented activities in the support of persons with PIMD.

## Method

### Study design and participants

A cross-sectional approach was used. Data were collected within one group over one period of 4 weeks. A convenience sample of 58 persons with PIMD (42 males and 16 females) participated in this study ( $M$  age = 34.6,  $SD$  = 13.6, range: 11–63 years). The participants were recruited from four different residential facilities – A ( $n$  = 27), B ( $n$  = 14), C ( $n$  = 8), and D ( $n$  = 9) – based on the following criteria (from Nakken & Vlaskamp, 2007):

- (1) Profound intellectual disability: estimated IQ below 20–25 or a developmental age of up to 24 months.
- (2) Profound or severe motor disabilities in such a way that the functional use of arms and legs is very limited and they are heavily or completely dependent on personal assistance for everyday tasks.

Approval for this research was granted by the institutional review board of all residential facilities. For all participants, written informed consent was obtained from parents or legal representatives. All facilities were large-scale 24-hour residential facilities offering support to people with intellectual disability, ranging from mild to severe and profound intellectual disability. The majority of people living in these facilities go to a day activity centre on weekdays (usually from 9:00 a.m. until 4:00 p.m.), where they engage in a variety of activities, such as physically oriented activities (e.g., massage), artistic and creative activities (e.g., making music,

storytelling), and audiovisual activities (e.g., listening to music, watching television; Vlaskamp et al., 2007).

### Variables

This study takes a broad perspective on motor activation with strategies that facilitate changes in body position, the movement of the whole body or parts of the body, such as rolling over, manipulating material, and moving legs, all considered as motor activation. Additionally, activities in which the body position is changed, for example, from sitting in a chair to a standing position, are also considered as motor activation. Finally, moving from one place to another without changing body position (“relocation”), with or without equipment, is regarded as motor activation. Motor activation was thus distinguished in terms of three different variables, namely, “relocation,” “transfer,” and “motor activity.” A relocation was defined as a displacement from one place to another, without changing body position, with or without equipment (including a wheelchair). Relocations were subdivided into “relocation inside,” “relocation inside-outside,” and “relocation outside-inside.” A transfer was defined as a relocation in which the body position of the participant changes, such as a change from a standing to a lying position. Motor activity was defined as activities with the purpose of facilitating the movement of the whole body or parts of the body. For example, stimulating someone to play with a mobile, manipulating objects, playing on a mat, or rolling around in a pool of plastic balls. In addition, the duration in minutes of the motor activities offered was included as a variable.

### Data collection and measurements

Data regarding the number of relocations, the number of transfers, and the number of motor activities offered were collected with the use of a diary. Regarding the motor activities offered, the specific activity and its duration was described. Because there was no instrument available to collect data concerning motor activity in persons with PIMD, this diary was developed within the current study. The diary consisted of two sections. The first recorded the starting times of a transfer or relocation. In the second, a direct support person described the motor activity offered and the starting time. “Interrater reliability” was calculated by using Cohen’s kappa (Cohen, 1960), which was established using the data collected by two independent observers of one participant during a 5-day period. The reliability was adequate (Cohen’s kappa: 0.7; Landis & Koch, 1977). Furthermore, its relationship to heart rate patterns, measured using heart rate monitoring, contributed to the validation of the diary (Waninge et al., 2013).

The diary was filled in on 14 days over a period of 4 weeks, including weekdays and weekend days at the living unit as well as at the activity centre. Data collection started after breakfast and ended at dinnertime. If the participant was tube fed, data collection started immediately after dressing in the morning and ended at dinnertime. On weekdays, the diary was filled in by the direct support person at the living unit for 3 hours and by the direct support person at the activity centre for 6 hours. On weekend days, the diary was only filled in by the direct support person at the living unit for 9 hours. For each participant, the facility received two diaries: one for the living unit and one for the activity centre. To ensure the completeness of the data and to ensure reliability, the researchers instructed the direct support persons on how to fill in the diary. To ensure validity, the definition of motor activation used in this study was also explicitly clarified to the direct support persons and described in the diary. During the study, the researchers visited the facilities regularly to monitor the data collection and to check whether the direct support persons were registering motor activities appropriately.

### Analysis

First, descriptive statistics were computed. For each participant, the mean number of transfers, relocations and motor activities per day were calculated. All of the subdivided variables of relocation were included in these analyses. Furthermore, the duration of the motor activities offered was calculated by determining the time between the start of the motor activity and the next transfer, relocation, or motor activity. Because the final number of observation days differed per participant (ranging from 4 to 14 days), the mean of the total group of participants was calculated over the mean for each dependent variable per participant.

Second, the relationship between the dependent variables and characteristics of the individual and the context was analysed using multilevel analyses. Multilevel analyses are suitable for nested data structures, such as longitudinal datasets. These data structures include multiple sources of variation, for example, there may be variation between individuals, but also between measurements within an individual (Snijders & Bosker, 2012).

Poisson models were used to model the dependent count variables (number of transfers, number of relocations, and number of motor activities offered) to obtain a more appropriate fit between the models and the data distribution. For the same reason, a logarithmic transformation (natural logarithm) was applied to the duration of motor activities. In addition, the model of the duration of motor activities pertains to the average duration per

activity offered for those observations in which the duration was greater than zero (31% of observations). This decision was made in order to separate the effects of the number of activities offered from the duration of activities. The distribution of the number of motor activities contained a large number of zeros compared to a Poisson distribution. As a result, the variance is considerably larger than the mean, a phenomenon that is called “overdispersion” (Snijders & Bosker, 2012, p. 318). To compensate, an additional parameter was included to represent unconditional log-odds that an observation is zero (Bolker, Brooks, Gardner, Lennert, & Minami, 2012).

The first two models were calculated for the number of observations over the whole day, and the third model referred to the number of observations per location. The reasons for this decision will be further elaborated on in the Discussion. In addition, the following were included as independent variables: age (in years), setting (living unit vs. activity centre), day of the week (weekday vs. weekend day), and facility (facility A, B, C, or D). Only mobility activities inside were analysed, as relocations outside generally only occurred when participants were moved to the activity centre. This resulted in almost zero variance for the variable “outside relocations,” which made it unsuitable for modelling. Finally, significance testing of model parameters was done as described in Snijders and Bosker (2012, pp. 94–95), with a significance level set at .05. Deviance tests were used for model comparison (Snijders & Bosker, 2012, p. 97). The size of the effects are expressed in relative differences of the expected count for each outcome variable, as calculated from the model coefficients of the independent variables.

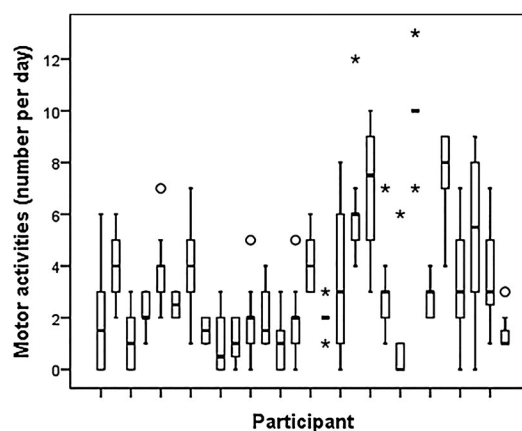
## Results

### Motor activation

The results showed that the mean number of transfers per participant between breakfast and dinner was three times a day ( $SD = 1.4$ , range: 0–9; see Table 1). On average, a person with PIMD changes location (relocation) 7.7 times a day. The number of motor activities offered ranged from 0 to 10 activities a day ( $M = 1.5$ ,  $SD = 1.9$ ), and the mean duration per day was 45.5 minutes for all motor activities offered.

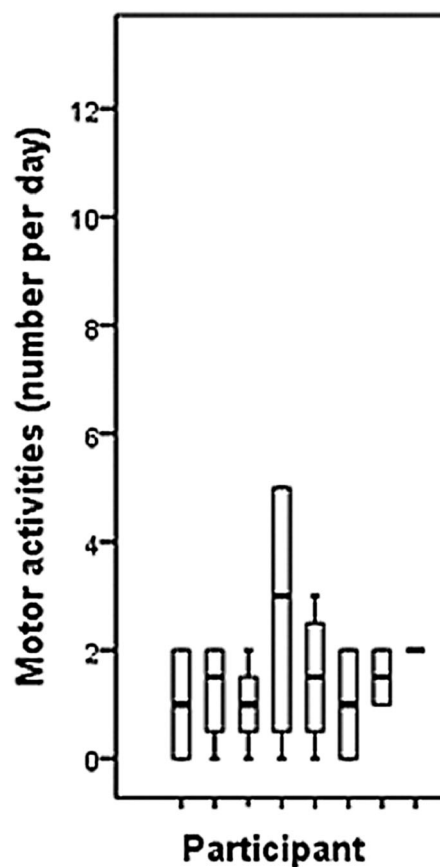
**Table 1.** Results for motor activation: mean number per participant ( $n = 58$ ) per day.

	<i>M</i>	<i>Mdn</i>	Range	<i>SD</i>
Relocations (number)	7.7	7.3	2–13	2.5
Transfers (number)	3.1	2.8	0–9	1.4
Motor activities (number)	1.5	0.8	0–10	1.9
Duration of motor activities (minutes)	45.5	24.0	0–280	57.0



**Figure 1.** Variety of motor activities offered per weekday; only participants with a mean number  $\geq 1$  were included ( $n = 28$ ).

Figures 1 and 2 present the variety of motor activities offered per weekday (see Figure 1) and weekend days (see Figure 2). In 10 participants, data regarding motor activation during the weekend was missing. Therefore, the results for weekend days were limited to a sample consisting of 48 participants. During the weekdays, these 10 participants engaged in, on average, 3.2 motor activities per day. As shown in these figures, there is a



**Figure 2.** Variety of motor activities offered per weekend day; only participants with a mean number  $\geq 1$  were included ( $n = 8$ ).

wide variety between the participants. This variety seems to be more prominent during weekdays compared to weekend days. The average number of motor activities during the observed weekdays was less than one for 30 (52%) of the participants. Four of these 30 participants (equivalent to 7% of the whole sample group; participants 5, 13, 34, & 51) did not engage in any motor activity on a weekday during the period in which they were observed (respectively 10, 10, 10, and 7 weekdays). During the weekend days, 40 of the 48 participants (83%) engaged in, on average, less than one motor activity per day. A total of 20 participants (42%) did not engage in any motor activity on a weekend day during the period in which they were observed (ranging from 1 to 4 days).

On weekdays, the mean number of transfers,  $\chi^2 = 15.1(1)$ ,  $p < .001$ , the mean number of relocations,  $\chi^2 = 435.1(1)$ ,  $p < .001$ , and the mean number of activities offered,  $\chi^2 = 24.3(1)$ ,  $p < .001$ , were higher than on weekend days (see Table 2).

### Relationship with personal and contextual factors

The results of the multilevel models are presented in Table 3. As shown, both gender and day have a significant effect on the expected number of relocations. Women have an expected count that is 1.4 times higher than the men's, but the significant interaction coefficient shows that this effect is less apparent during the weekends. Overall, individuals are expected to be moved 1.2 fewer times during the weekends compared to weekdays. Including these predictors significantly improves model fit,  $\chi^2 = 44.6(3)$ ,  $p < .001$ .

Similarly, the expected number of transfers per individual is reduced by a factor of 1.2 during the weekends. In addition, age has a significantly negative effect on the number of transfers. The older an individual is, the less likely he or she is to be involved in a transfer. This relationship was also significant for the number of motor activities offered to the individual. In general, the expected number of motor activities was reduced by 2.9 and 3.9 times in the living unit compared to the activity centre for weekend days and weekdays, respectively. The models for the number of transfers and for the number of activities both show a significant improvement compared to the respective models without

predictors,  $\chi^2 = 26.9(2)$ ,  $p < .001$ , and  $\chi^2 = 319.5(4)$ ,  $p < .001$ , respectively.

The final column of Table 3 models the logarithm of the average duration of motor activities, conditional on whether an activity was provided at all. The results show that there are no significant differences in activity duration between the living unit and the activity centre, given that an activity is provided. However, older people tend to have a longer duration of activities in the living unit compared to the activity centre. In addition, Facility D generally provided shorter activities compared to the other facilities. Including these explanatory variables in the model significantly increased model fit,  $\chi^2 = 57.9(8)$ ,  $p < .001$ .

### Discussion and conclusion

The main objective of the current study was to analyse the degree and type of motor activation in persons with PIMD. Furthermore, the relationship with personal (age and gender) and contextual factors (setting, day of week, and facility) was also explored. The results showed a low frequency of transfers (in which the body position of the person with PIMD changes), and a low number of motor activities that facilitate the movement of the whole body or parts of the body. During the observation period, a total of 52% of the participants engaged in on average less than one motor activity per weekday. A total of 7% of the participants did not engage in any of those activities at all during the observation period on weekdays, and nearly half of the participants did not engage in these activities during weekend days observed. The mean duration of all motor activities offered per day was 45.5 minutes, although the variations between the participants were extensive (ranging from 0 to 280 minutes).

Moving from one place to another without changing body position (defined as relocation in this study) was seen more frequently; on average, a person with PIMD relocates nearly eight times a day from a position in or outside their environment. However, most of the participants were wheelchair-bound and had little active input. The inclusion of relocation within motor activation might thus be questioned. Within this study, however, it was assumed that a change of position while remaining in the same place, even without active input, gives a person with PIMD an opportunity to experience the environment differently. A change of position may evoke a motor response in the person with PIMD. Furthermore, changing position such that an individual with PIMD sits next to another individual gives them the opportunity to make contact.

Nevertheless, using this broad perspective on motor activation may lead to an overestimation of the "activation"

**Table 2.** Results for motor activation divided by day of week: Mean number per participant per day.

Day	Relocation (number)		Transfer (number)		Motor activity (number)	
	M (SD)	Range	M (SD)	Range	M (SD)	Range
Weekday	8.8 (2.9)	2–19	3.1 (1.6)	0–10	1.7 (2.1)	0–10
Weekend day	3.8 (1.7)	0.7–7.5	2.7 (1.4)	0.3–8	0.4 (0.6)	0–2.8

**Table 3.** Multilevel models of motor activation.

	No. Relocations		No. Transfers		No. Motor activities		Log average duration of motor activities	
	Coefficient (SE)		Coefficient (SE)		Coefficient (SE)		Coefficient (SE)	
	M <sub>1</sub>	M <sub>2</sub>	M <sub>1</sub>	M <sub>2</sub>	M <sub>1</sub>	M <sub>2</sub>	M <sub>1</sub>	M <sub>2</sub>
Intercept	1.26 (.064)	1.22 (.074)	1.05 (.059)	1.61 (.153)	-.84 (.188)	.78 (.471)	3.55 (.090)	3.40 (.168)
Age				-.01 (.004)*		-.03 (.013)*		.00 (.00)
Gender (Female)		.34 (.135)*						
Day (Weekend day)		-.19 (.060)*		-.21 (.054)*				
Weekend day x female		-.29 (.111)*						
Living unit on weekday						-1.35 (.092)*		-.11 (.243)
Living unit on weekend						-1.05 (.127)*		.17 (.304)
Facility (Facility B)								-.10 (.141)
Facility (Facility C)								-.28 (.156)
Facility (Facility D)								-.61 (.198)*
Age x living unit on weekday								.02 (.007)*
Age x living unit on weekend day								.02 (.009)*
Zero inflation						.04 (.025)		
Variance Level 2	.20 (.449)	.18 (.423)	.16 (.394)	.13 (.357)	1.79 (1.337)	1.55 (1.243)	.11 (.331)	.06 (.251)
Variance Level 1							.04 (.197)	.01 (.090)
-2 Log likelihood	2652.6	2608.0	2358.7	2331.8	2410.0	2090.5	774.4	716.5

Note. M<sub>1</sub> = empty model; M<sub>2</sub> = model including fixed effects.

\*Significant at alpha .05 (i.e., coefficient is larger than two times the standard error).

that is actually seen in practice. This overestimated image may be further reinforced by including all of the subdivided relocations in the descriptive results. Because the participants visit the activity centre during weekdays, two relocations are already necessary – leaving the living unit and returning home. This means that half of these activities are already executed for practical reasons.

The results show, especially for weekdays, a wide variety between the participants, indicating that motor activating people with PIMD is not a structural part of the support for these people, and possibly dependent on personal factors such as comorbidity, motor abilities, or contextual factors, such as number of staff. During the weekends, however, this variety seems to decrease, and a more general picture emerges in which only 17% of the participants were offered one or more movement-oriented activities. Moreover, a relationship between motor activation and personal and contextual factors was also found. Older people were less motor activated compared to younger people with PIMD. This was particularly seen during the weekend days. Regarding weekday and weekend days, fewer transfers and relocations were seen during the weekend compared to the weekdays.

Finally, transfers, relocations, and the number of motor activities offered were all seen more frequently at the activity centre than the living unit, whether a weekday or a weekend day, although the mean duration of an activity is shorter at the activity centre compared to those offered at the living unit. This indicates more variety in activities offered at the activity centre. At the living unit,

a relationship between the duration of activities and age was seen; as people age, the mean duration of the activity offered increases, indicating that older people are more uniformly offered motor support than younger people.

A number of remarks should be made about the data collection and the analysis. First, data were gathered using a diary that was developed within the current study and filled in by direct support persons working with the participants in practice. Although the preliminary results related to reliability and validity seem adequate (Verheijen & Brussee, 2009; Waninge et al., 2013), more research is needed into the psychometric properties of this instrument. This study itself employed various strategies in an attempt to increase the validity and reliability of this measurement procedure: the definition of motor activation was explicitly clarified to all of the participating professionals and was also clarified in the diaries. Furthermore, the researchers visited the facilities regularly to monitor data collection and to check the registration of activities by the professionals involved. Temple and Walkley (2003) have also demonstrated that regular recording of physical activity by direct support persons provides meaningful data on the physical activity of people with intellectual disability. Moreover, collecting data by use of a diary is more time- and cost-efficient and less invasive than the collection of data by an external observer (Temple & Walkley, 2003). Additionally, using a diary in a study such as this leads to results that are less influenced by social desirability than are the results obtained from direct observation.



Second, although direct support persons were supported by the provision of the diary for data collection, it might be argued that perhaps more motor activities were performed than were registered because the direct support persons did not consider them to constitute motor activation. To avoid this, in this study the researchers regularly checked whether direct support persons were registering motor activities appropriately. Therefore, the underreporting of activities does not seem likely. It is considered more likely that a possible bias may have arisen should they have attempted to paint a more positive picture (being aware of the aim of the study) than the reality, with the number of activities and transfers overreported rather than underreported.

Third, the duration of the activities was calculated in terms of the time between the start of the motor activity and the next relocation, transfer, or motor activity. Specific information about the activity (e.g., was the person active during the activity) is lacking, and thus the duration of activities may be overestimated. Further studies using close observations are needed to confirm the general picture that emerges from the current results.

Fourth, as stated in the Method section, the number of hours of observation time differed per location and day. Clearly, this difference had to be taken into account when defining the dependent variables. Initially, the number of transfers per location was selected as a dependent variable in order to evaluate the effect of different locations on the number of transfers. However, because the number of transfers clearly varied in line with the length of observation, the number of transfers for the whole day was used. This meant that it was not possible to analyse the influence of location, but it did allow an observation period of equal length. The same approach was taken for the number of relocations. In contrast, the number of motor activities did seem to vary between locations independently of the length of observation. For this reason, the number of motor activities per location was selected as a dependent variable.

Fifth, the variable “motor activity offered” showed a larger variance than would be expected according to the statistical model used. To compensate for this overdispersion, several methods were examined (Snijders & Bosker, 2012, p. 318); the model with the zero-inflation parameter led to the greatest increase in model fit.

Sixth, although the dataset included a three-level structure, namely, measurements within individuals within facilities, facilities were not included as an additional level. As the main goal of this study did not pertain specifically to facility differences but did require

control for any differences, facility was included as a fixed effect in these models. Finally, the data regarding motor activation during the weekend for six of the 10 participants were missing due to practical reasons. It should be noted that these 10 participants engaged in on average 3.2 motor activities per weekday. Although this is slightly above average, the difference is less than one standard deviation from the rest of the sample ( $n = 48$ ). They were a small and nonspecific group in terms of age (range: 11–59) or gender. Therefore, it is not expected that missing data had a large influence on the results of the multilevel analysis.

A number of remarks should also be made about the external validity. These remarks relate to the sample size, age of the participants, the setting in which the study was conducted, and the heterogeneity of the group of persons with PIMD. Although the sample was relatively large when compared to the total population of persons with PIMD (in the Netherlands, estimated numbers vary between 12,000 and 20,000 people), the study sample is still rather small for a multilevel analysis. In addition, the convenience sample consisted of people of a wide variety of ages, although no children younger than 11 years were included and all were living in a residential setting. This limits the extent to which the results of the current study can be generalised to children with PIMD and to other living environments such as small-scale facilities, schools, or home situations. The current study's sample was, however, too small to include other factors that might be associated with motor activation. Further studies are needed to elaborate on this issue.

It is almost impossible to compare our results to other studies on motor activation in persons with PIMD, primarily because the current study seems to be one of the first to focus on this topic. In general, people with intellectual disability are less physically active compared to the general population. Comparing our results to recent studies that examined physical activity in persons with intellectual disability is also difficult because of their use of data collection methods, measurements, and standards that are inapplicable to people with PIMD. For example, Hilgenkamp et al. (2012) examined the level of physical activity in older adults with intellectual disability by measuring executed steps each day, in which the standard for inactivity was set at around 10,000 steps. Other researchers measured physical activity in persons with mild to moderate intellectual disability in terms of the intensity of activities, connected to the categorisation in Ainsworth's Compendium for Physical Activities, which provides estimates for specific activities in metabolic equivalents (METs; Ainsworth et al., 1993; Draheim et al., 2002). Activities offered within our study cannot be categorised in such a system.

Finally, the literature also reported a standard for a substantial gain in physical fitness, where physical activity has to be performed 5 days a week for at least 30 minutes a day with an intensity of more than 55% of the heart rate reserve (Pollock et al., 1998). It is questionable whether this standard is useful in people with PIMD. Waninge et al. (2013) found, for example, that these people used relatively small fractions of their heart rate reserves.

Nevertheless, in our opinion, based on the current results, a general picture emerges of low motor activation in persons with PIMD with a wide variety across the participants. Older persons especially are at risk of being inactive at the living unit and during weekends. The consequences of this inactivity, especially for people with PIMD, can be extensive. First, individuals might lose existing motor skills necessary for activities such as pushing a button to switch stimuli on/off, independent eating, or pointing or reaching as a means of communication and autonomy (Lancioni et al., 2004). Second, there are consequences related to interaction and learning, such as the essential role of the body position as a control parameter for social-communicative interaction between a person with PIMD and the environment. A good posture that maximises movement of the hand, arm, and head as a precondition for learning is also generally neglected (e.g., McEwen, 1992). Third, insufficient motor activation will negatively influence a person's level of alertness, and may eventually lead to stereotypical and self-injurious behaviour (Jones et al., 2007). Finally, inactivity is a major deterioration factor in common health problems such as osteoporosis, contractures, recurrent pulmonary infections, and sleep disorders.

Several factors can explain or can be related to the results. First, the specific knowledge and ideas of direct support persons about the importance of physically activating people with PIMD and the way to execute those activities determine the extent to which they provide daily support (Van der Putten, 2010). Direct support persons can, in general, accept and adopt the principles of physical activation of people with intellectual disability, but to what extent they think these are also applicable to persons with PIMD and implement them is unknown. Research on people with intellectual disability in general shows that the attitudes of direct support persons are associated with levels of physical activity (Martin, McKenzie, Newman, Bowden, & Morris, 2011). The results of this study might be explained by the fact that direct support persons believe that people with such profound intellectual and motor disabilities cannot move, or alternatively, cannot profit from movement-oriented activities, although several studies prove otherwise (Houwen et al., 2014; Jones et al., 2007; Ogg-Groenendaal,

Hermans, & Claessens, 2014; van der Putten et al., 2005). Studies into the role of these direct support persons, related to perceived barriers, current knowledge about the benefits, and ways to activate people with PIMD must be conducted in order to develop movement-oriented interventions.

Second, in addition to the perceptions and knowledge of direct support persons about the importance of providing movement-oriented activities for people with PIMD, the lack of more fundamental knowledge might also be a barrier when implementing motor activities in the support of persons with PIMD (Van der Putten, 2010). For example, there is a lack of fundamental knowledge about the development of motor functioning, the associated factors necessary to determine the best time to implement a motor intervention, and what effects it can generate (Van der Putten, Houwen, & Vlas-kamp, 2015). A recently conducted review covering a period of 30 years found that knowledge regarding the course of motor development in children and adults with severe or profound intellectual disability and accompanying motor disabilities is rather scarce (Van der Putten et al., 2015). Although, a general picture emerged that the motor development in this group is severely delayed and factors such as age, aetiology, and comorbidity were probably associated, the studies offered insufficient information to guide practitioners in choosing the right kind of support at the right time.

Third, another obstacle to physically activating people with PIMD is the lack of evidence-based interventions related to motor activation in people with PIMD (Van der Putten, 2010). Although a whole range of strategies and interventions related to motor activation in people with severe or profound intellectual disability is available (Houwen et al., 2014), the number of well-designed, theory-driven, and evidence-based movement-oriented interventions explicitly for people with PIMD is minimal. To our knowledge, the only existing intervention is the Mobility Opportunities Via Education (MOVE; Bidabe & Lollar, 1995) curriculum. This curriculum was, however, developed for children with PIMD and its effects are limited to changes in the acquisition of motor skills (van der Putten et al., 2005). Another well-known intervention for people with severe and profound intellectual disability is active support (Beadle-Brown, Hutchinson, & Whelton, 2012; Beadle-Brown et al., 2014; Jones et al., 1999), but its applicability and effectiveness in people with PIMD has not yet been studied (Maes, Lambrechts, Hostyn, & Petry, 2007). Further work on the role of professionals, fundamental knowledge about the course of motor development, and the development of movement-oriented interventions is required to reduce inactivity in the daily lives and care

of people with PIMD. Overall, based on the current results, it can be concluded that the motor activation of persons with PIMD in daily practice by direct support persons is rather limited. This picture of inactivity is supported by the results of other studies into the support of persons with PIMD (Vlaskamp et al., 2007; Vlaskamp & Nakken, 2008; Wiersma, Beumer, Koedoot, & Vlaskamp, 2002). When stimulation is provided, it is generally aimed at offering sensory stimuli or stimulation of the cognitive capacities and not motor stimulation, although the former domains are often as severely impaired as the motor domain. It seems that motor activation is often “forgotten,” and that the consequences of this “negligence” are not on the agenda. However, the consequences for people with PIMD can be extensive and are related to nearly all domains of human functioning, such as the motor domain, but also in the domain of communication, adaptive skills (eating and drinking), and physical and mental health. Therefore, the structural implementation of motor activation in the support offered to people with PIMD must be improved, as it is a prerequisite for the improvement of their quality of life.

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