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Individuals with Profound Intellectual and Multiple Disabilities at Work?! Activities in Special Day Service Centers in Germany

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Abstract

All individuals have the right to participate in activities. Therefore, productive work or other meaningful activities can promote the individuals' quality of life. While realizing work related activities for individuals with profound intellectual and multiple disabilities (PIMD) is an issue in clinical practice in general, special day service centers in Germany intend to provide work related activities for all individuals of the target group. The aim of the present study was to analyze the activities of all special day service centers in a northern urban region of Germany, in order to describe to what extent such activities could promote the work related quality of life of the individuals with PIMD. Four special day service centers participated in the present study. Data were collected in a diary for one individual with PIMD per group ($n = 30$). Goals and content were analyzed focusing on the relation with a work related quality of the life model (operationalized as interaction, experience of competences, and self-determination). The results show that communication and self-efficacy (as parts of interaction and experience of competences) are often goal and/or content of the presented activities. Stimulation of self-determination was rarely ticked as a goal. The most important conclusion of the present study is that participation in work related activities of individuals with PIMD is possible. Including elements such as communication, motor activation, and experience of self-efficacy, the activities can be described as activities promoting the quality of life in individuals with PIMD. Still, different types of special day service centers are needed. Focusing on either work related activities, education, and/or leisure activities accounts for the different needs of individuals with PIMD according to their different characteristics and different phases of life.

Keywords: day services, profound intellectual and multiple disabilities, work related activities

Introduction

All individuals have the right to participate in activities (United Nations, 2006). However, this right is not always fulfilled for individuals with profound intellectual and multiple disabilities (PIMD) (Vlaskamp, Hiemstra, & Wiersma, 2007). Individuals with PIMD form a target group with the main characteristic being a combination of profound intellectual and profound motor disabilities (Nakken & Vlaskamp, 2007). In addition, sensory impairments (such as visual impairments, deaf-blindness, or hypersensitivity of the skin) and health problems (such as epilepsy, skeletal malformations, or chronic pulmonary infections) are common (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; van Schojenstein-Lantman de Valk, Metsemakers, Haveman, & Crebolder, 2000; van Splunder, Stilma, Bernsen, & Evenhuis, 2006). Because of the complexity of the disabilities, a joint characteristic of all individuals with PIMD is the dependency on others for almost all activities in their daily life. Still, the

combination and severity of the disabilities vary for each person. As a consequence, direct support persons (DSPs) have to adapt all activities to individual needs and abilities of the person with PIMD (Nakken & Vlaskamp, 2007).

Looking closer at the content and value of activities, all individuals with disabilities have the right to be involved in productive work or other meaningful activities (United Nations, 2006). Productive work often becomes part of the individual's identity and gives meaning to the individual's life. Only an activity that supports an individual to reach a personal goal can promote the individual's quality of life. Therefore, work is defined as a productive and meaningful activity according to the individual's perspective. Work or work related activities hold the potential to promote individual fulfillment. When effort is needed to participate in these activities, the product of the work process illustrates the competences of the individual (Schalock, Keith, Verdugo, & Gómez, 2010; Velde, 1997).

Still, most individuals with PIMD will not be able to construct their personal goals and, furthermore, do not use spoken language to express their wishes and needs. Consequently, we do not know explicitly about their individual perspective, but we have to rely on the suggestions of familiar others. When

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these familiar others describe that an activity is deemed to have the potential to be productive and meaningful for the individual with PIMD, we can expect to approach the individual's perspective (Nakken & Vlaskamp, 2007).

In addition, realizing work related activities for individuals with PIMD is an issue in service and support practice in general. The reasons for this problem lie on different levels: staff and organization. Knowledge and skills of the DSPs may be insufficient in providing work-related activities because of their education (Vlaskamp, Hiemstra, Wiersma, & Zijlstra, 2007). Only DSPs with special trainings and/or special experiences are able to design and implement work-related activities accounting for the abilities and needs of individuals with PIMD. In addition, the organizational structure may lead to a low client-staff-ratio and, therefore, not enough time for individual activities. Furthermore, lack of materials and assistive tools to facilitate participation in work related activities for individuals with PIMD may aggravate the problem (Zijlstra & Vlaskamp, 2005).

At the same time, special day service centers in Germany intend to realize participation in work related activities for individuals with PIMD. In these day service centers, the problems on the staff and organizational level which prohibit a realization of work related activities are minimalized. DSPs attended trainings to take into account the special needs of individuals of the target group. In addition, organizations want individuals with PIMD to be able to participate in work related activities such as production processes and services. Client-staff-ratio and equipment are in line with the demand to realize the participation of all clients. One DSP is responsible to support two individuals with PIMD; the working environment is complemented with devices such as adapted handles and switches as well as visual and tangible explanations to facilitate participation of all clients. These preconditions on the staff and organizational level may promote the realization of work related activities for individuals with PIMD.

An example of a work related activity in the special day service centers is the following. Clients of several groups shred paper. The process is illustrated in terms of pictograms or tactile references according to the needs of the clients involved. The shredder can be turned on by either pushing the button on the machine or by pushing a switch which is linked to the machine according to the possibilities of the clients involved. As such, all clients can follow and actively participate in the productive process. In a next step, the shredded paper is used to fill coffin cushions and the clients deliver their product to the funeral director. Because the activity is embedded in the entire organization and the larger community, it may be experienced as meaningful by the clients and their environment. While this example shows how these activities hold the potential to be valuable for the clients, it has not been analyzed yet whether they do.

For such an analysis of activities, the concept of quality of life can be used. Quality of life has been divided into an objective and a subjective component (Felce & Perry, 1995; Schalock et al., 2010). For individuals with PIMD, it is difficult to investigate their subjective perspective. Because most of them are not able to use spoken language, we cannot involve them in an interview procedure. While observations may be a solution to

TABLE 1

Number of clients and groups in the four special day service centers

Special day service centers	Total number of clients	Number of groups	Number of clients per group
1	70	8	7–9
2	65	7	7–10
3	52	9	5–7
4	37	6	6–7
Total	224	30	

investigate the individuals' perspective indirectly, observations are always for some part influenced by the subjective perspective of the observer (Hogg, Reeves, Roberts, & Mudford, 2001). Consequently, a reflection of those who provide the support and activities on the objective component can be a first step to understand the specific value of this type of activities for individuals with PIMD.

The aim of the present study was to analyze the activities of all special day service centers in a northern urban region of Germany, in order to describe to what extent such activities could promote the quality of life of the individuals with PIMD. Because the special day service centers fulfill the preconditions on the staff and organizational level to realize work related activities for individuals with PIMD, they were chosen as setting for the present study. First, information from the DSPs about goals and content of the activities was needed to give a general description of the activities. Second, a model of work related quality of life was used to reflect on the activities' contribution to the individuals' quality of life.

Two research questions have been formulated:

- How do DSPs describe the goals and the content of the activities provided at the special day service centers?
- To what extent do the activities fit within a work related quality of life model?

Method

Setting

The present study was realized in all four special day service centers in a northern urban region of Germany. Centers were located in diverse areas (such as gentrified and middle-class, bordering a forest and in a residential neighborhood). A total of 224 clients attend the four special day service centers with 37–70 clients per center. The number of groups within one special day service center ranges from 6 to 9 while the number of clients per group ranges from 5 to 10. The total number of participating groups was 30. Table 1 displays an overview of the exact numbers for each special day service center.

One individual from each group participated in the present study resulting in a total number of 30 participants. The participant was selected by the DSPs of the group as a representative

person of all clients of the special day service center. Thereby, DSPs were asked to select individuals with different competencies to represent the entire range of different abilities of their clients and individuals with different disabilities to represent the focus of the special day service center. Two special day service centers focused on individuals with severe motor disabilities, another center on individuals with profound intellectual disabilities and the fourth on individuals with severe challenging behavior. Still, the clients of all centers could be described as individuals with PIMD according to the definition of Nakken and Vlaskamp (2007). In the group of participants, the distribution of gender was almost equal (16 women and 14 men). The mean age of the participants was 35,8 years, ranging from 19 to 53 ($sd = 9,3$). Twenty participants were showing challenging behavior, such as aggressive and/or stereotypical behavior. While all participants experienced health problems, like constipation, dysphagia, and epilepsy, the problems with eating and digestion were mentioned most often (for 17 and 18 of the participants, respectively). Informed consent for participation in the present study was given for all individuals with PIMD by their legal representatives. (Legal representatives were relatives, mostly parents and sometimes brothers or sisters, or professional legal representatives who are responsible for an individual person, but who are no part of the daily support system.)

Instrument

Data were collected in a diary which was developed based on the day activities classification developed by Zijlstra and Vlaskamp (2005) and the modifications used in previous studies (Lamers, Terflooth, & Prokop, 2008; Maes, Penne, & Vos, 2010; van der Putten & Vlaskamp, 2011). The overall reliability of the diary was described as good in two of these studies (Cohen's kappa for inter-rater reliability 0.83 and for intra-rater reliability 0.85; van der Putten & Vlaskamp, 2011; and the degree of correspondence 91.1%; Zijlstra & Vlaskamp, 2005).

The diary consisted of two parts. First, activities provided in one exemplary week were registered including a description of the activity in codes. Therefore, a list of codes was provided (see Table 2). These codes are based on Cavet (1995) and have been adapted and used in previous studies (Lamers et al., 2008; Maes et al., 2010; van der Putten & Vlaskamp, 2011). For the present study, only those codes that were relevant were included (such as work related and educational activities). This list had to ease the work of the DSPs on the one hand and help to reveal more comparable results on the other hand. DSPs were asked to make the description in terms of one main code with the optional complementation of one or two other codes. For example, a physiotherapeutic session could be described by the main code "therapy" whereas the codes for "activities stimulating motor function" and "activities stimulating communication" could be added.

The second part of the diary contained a detailed description of one activity per day of the exemplary week. DSPs were asked to choose the activity as representative of their daily work. Therefore, the DSPs were asked to write down the goals of the activity, the role of the participants (main actor or observer, alone, or in a group), and elements of the presentation of the activity (such as

TABLE 2

List of codes to describe the content of the activities

Code	Description of the activity
1	Care
2	Eating and drinking
3	Welcome/goodbye
4	Transfer
5	Therapy (i.e. physiotherapy, occupational therapy, or psychological consultation)
6	Providing explicit concepts of support (i.e. Basic stimulation or sensory integration)
7	Activities stimulating perception
8	Activities stimulating motor functioning
9	Activities stimulating cognition
10	Artistic and creative activities (i.e. music, art, or dance)
11	Educating activities
12	Work related activities
13	Play and games
14	Activities outside the facility
15	Recreational activities
16	Cultural activities outside the facility
17	Activities stimulating skills of daily living
18	Activities stimulating communication
0	No specific activity

the use of augmentative and alternative communication or motivation of the participant). Because the two latter topics included a large percentage of missing data, only the goals of the activity were included in the present analysis. Again, a list of possible answers was provided (see Table 3). One main goal could be complemented by two optional additional goals.

Procedure

After the special day service centers confirmed their participation in the present study, a meeting to inform DSPs about the procedure was planned for each center separately. During this meeting, the aim of the study, the process, and the instrument were explained. To align the interpretations of the possible answers in the diary, DSPs were given the possibility to ask questions and, thereby, clarify their understanding.

To fill in the diary, DSPs were asked to choose 1 week within a selected period of 4 weeks. In this week, all DSPs of a group completed the diary for one client of their group. They started every morning when the client entered the facility and stopped when the client left in the afternoon. Consequently, data of about 7 h for each of the 5 days of the week (a total of about 35 h) per client were available. There was no missing data in the notes of codes and goals.

Analysis

Descriptive statistics were used to analyze the data in terms of content and goals. Frequencies of the main codes were

TABLE 3
List of goals to describe the activities

Number	Goals
1	Participation
2	Learning skills of daily living
3	Work
4	Independence in care
5	Personality development
6	Compensation for consequences of the disabilities
7	Development of social skills
8	Stimulation of self-determination
9	Stimulation of independence
10	Development of new skills
11	Starting interaction with others
12	Strengthening of self-esteem
13	Implementation and redevelopment of needs
14	Experience of self-efficacy
15	Adult education
16	Contact with the environment
17	Self-awareness
18	Conservation of skills
19	Support in regressive development
20	Perception
21	Motor activation
22	Communication
23	Prevention of challenging behavior

compared to the frequencies of the additional codes; frequencies of the main goals were compared to the frequencies of the additional goals. Therefore, we did not differentiate between the additional code that was mentioned first and that which was mentioned in the second position. The additional codes were treated as one group in comparison to the group of main codes. Similarly, we did not differentiate between the additional goal that was mentioned first and that which was mentioned in the second position. The additional goals were summarized in one group in comparison to the group of main goals. To specify the results for the second research question, codes, and goals were related to the concept of quality of life according to the model of Sabo and Terfloth (2011). Based on the work of Felce and Perry (1995) and Schalock et al. (2010), they described work related activities as those who support the quality of life of the participants. In the model, work related quality of life comprised two general (individualization and respectful approach) and three additional components (interaction, experience of competences, and self-determination) (see Figure 1). Only when DSPs adapt the activity to the individual needs and possibilities of the person with PIMD and approach the individual of the target group respectfully, can the activity be of high quality and, therefore, support the quality of life. During the activity, DSPs should focus on making the individual with PIMD experience his or her competences and enable self-determination. Furthermore, the interaction between the DSP and the individual with PIMD is crucial in the realization of the activity. The present study focused on these three additional components. Only if work

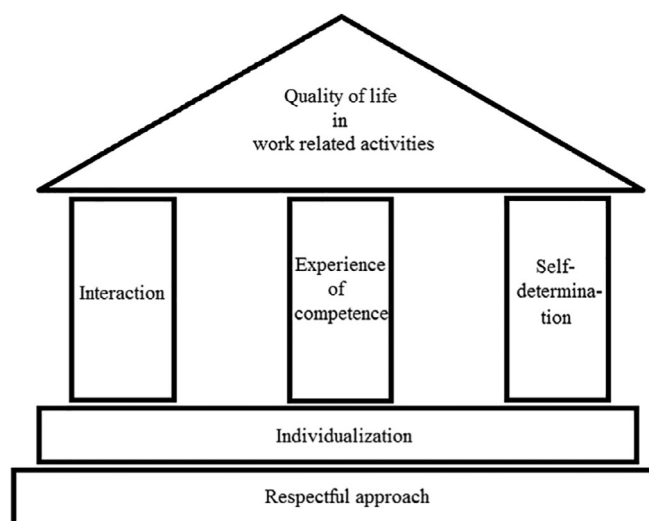


FIGURE 1

Model of quality of life (Sabo & Terfloth, 2011).

related activities include these components, can they be described as activities promoting the individual's quality of life.

Results

As all 30 groups sent back their completed forms, the response rate was 100% and the following analyses are based on the diaries of 30 individuals with PIMD. A total 2,599 main codes and 3,656 additional codes were documented during the entire week. For the detailed description of the activities (one per day), DSPs ticked 444 boxes for the goals (149 main goals and 295 additional goals).

Analyzing the goals of the activities according to the diaries, two goals were ticked most often as main goals: work (19%) and motor activation (13%). Another three were ticked quite often: participation (7%), experience of self-efficacy (9%), and perception (8%). While three goals were not mentioned at all (independence in care, implementation, and redevelopment of needs, and support in regressive development), the number of times the other goals were ticked ranged from 1 to 9 (0–6%). The analysis of the additional goals revealed that “experience of self-efficacy” was the additional goal mentioned most often (13%). This means that a large number of the activities with the main goal of work or communication were going together with the additional goal of supporting the experience of self-efficacy. For another 36% of the activities, starting interaction with others, conservation of skills, perception, and motor activation were ticked as implicit goals (9, 10, 9, and 8% of the additional goals, respectively). The goals mentioned less often as additional goals were the following: independence of care, implementation, and redevelopment of needs, and support in regressive development (all mentioned only once). An overview of all responses is displayed in Figure 2.

Analyzing the content of the activities according to the diaries, two codes were mentioned as the main code for the largest

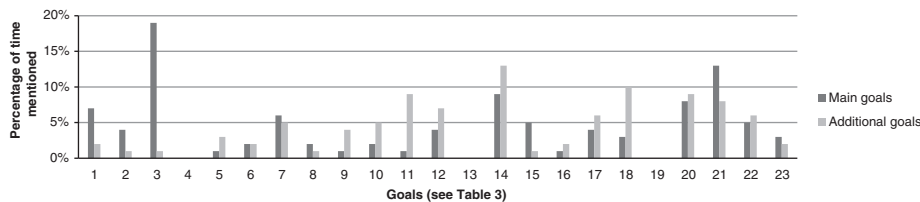


FIGURE 2
Goals (main and additional).

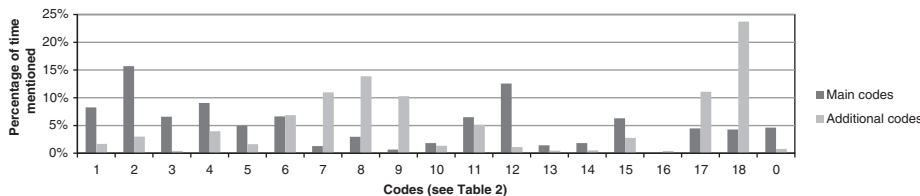


FIGURE 3
Codes (main and additional).

amount of time: eating and drinking (16% of all main codes) and work related activities (13% of the main codes). Besides these two activities which took up most of the time, care and welcome/goodbye were also mentioned quite often (8 and 9% of the main codes, respectively). The analysis of the additional codes revealed an important complementation to the results of the main codes. A large amount of the activities (24% of the additional codes) were described as “activities stimulating communication”. That means that mostly activities with the explicit content of eating and drinking, welcome/goodbye, and work related activities were seen as activities stimulating communication implicitly. Another 45% of the activities implicitly stimulate motor functioning, perception, cognition, or self-help skills (14, 11, 10, and 11% of the additional codes, respectively) according to the diaries. While the codes “activities stimulating perception” and “activities stimulating cognition” were almost never mentioned as main codes (< 2%), the codes “care,” “welcome/goodbye,” “therapy,” and “work related activities” were almost never mentioned as additional codes (< 2%). The codes mentioned the less often for both main and additional codes were the following: artistic and creative activities, play and games and (cultural) activities outside the facility (< 2%). For 5% of the time, no specific activity was provided. An overview of all responses is displayed in Figure 3.

According to the second research question, the results concerning the goals and codes which go together with the three additional components of the model of Sabo and Terfloth (interaction, experience of competences, and self-determination) were considered in detail. Communication (as part of the component “interaction”) was mentioned most often as additional code (24% of the activities). The main codes mostly indicated together with these activities were the following: welcome/goodbye (21%), eating and drinking (17%), providing explicit concepts of support (8%), educating activities (9%), and work

related activities (9%). “Self-efficacy” (as part of the component “experience of competences”) was ticked most often as additional goal in the present study. These were mostly activities focusing on work (31%). Other main goals that went most often with these activities were the following: communication (13%), motor activation (8%), and perception (8%). The goal “stimulation of self-determination” which goes with the third additional component of the model by Sabo and Terfloth has only been ticked three times as main goal and four times as additional goal. These activities were also described as “social activities” (such as participation or starting interaction with others), one activity was described as focusing on perception, another on independence in care.

Conclusion and Discussion

The aim of the present study was to analyze the activities provided in all special day service centers for individuals with PIMD in a northern urban region of Germany, in order to describe to what extent such activities could promote the work related quality of life of the individuals with PIMD. Thereby, we took the perspective of the DSPs to describe the objective component of quality of life (Schalock et al., 2010).

The analyses show that work related activities play a central role. While “work related activities” was the second most mentioned code, “work” was the most ticked goal. This result supports the extraordinary position of the special day service centers with their aim to provide work related activities for individuals with PIMD in Germany. Similarly, the special day service centers have an extraordinary position in the European landscape of day services. In previous studies conducted in several bordering countries, diaries were used as well, but work related activities were only provided for a very low percentage

of the time (1,8% in schools and 0,04% in day service centers other than schools, Belgium) (Maes et al., 2010) or not at all (The Netherlands) (van der Putten & Vlaskamp, 2011).

Bringing the results back to the model of quality of life by Sabo and Terfloth (2011) reveals great correspondence between theory and practice. In the present study, the codes “eating and drinking” as well as “care” were comparable to the results of several studies in bordering countries. While the present study revealed 16% of eating and drinking activities and 8% of care activities, previous studies found only slightly higher percentages in the Netherlands (25 and 11%, respectively) and Belgium (16 and 14%, respectively) (Maes et al., 2010; van der Putten & Vlaskamp, 2011). However, in the present study, DSPs were able to mention additional codes to further describe the activity. Looking at the additional codes shows that most of the activities concerning eating and drinking were also seen as activities stimulating communication, and communication can be seen as part of interaction in the model of Sabo and Terfloth. While all European studies agree about the large amount of time that is necessary for eating and drinking and care in the support of individuals with PIMD (Maes et al., 2010; van der Putten & Vlaskamp, 2011), using frequently recurring situations to introduce and elaborate communication, is a valuable combination. Similarly, in the present study, welcome/goodbye activities have been described as activities stimulating communication as well. Including individuals with PIMD in communication during daily recurring moments is an effective way of promoting the interaction between DSPs and individuals of the target group and, thereby, presenting high quality activities to individuals with PIMD.

Another result of the present study that can be related to the theoretical model of quality of life (Sabo & Terfloth, 2011) concerns the additional goal “self-efficacy”. While activities were described with the main goal of “work” or “communication,” “self-efficacy” was ticked most often as additional goal in the present study. Using work and communication situations to enable individuals with PIMD to experience their competences can be another way of positively influence the quality of life of the individuals of the target group.

However, the goal “stimulation of self-determination” which goes with the third additional component of the model by Sabo and Terfloth (2011) has only been ticked three times as main goal and four times as additional goal. This is especially surprising, because all four special day service centers formulated in their concepts the support of self-determination of their clients as one of their goals. Consequently, integrating this third component in their daily support should be a point of interest for the special day service centers in the future.

Furthermore, another striking result should be highlighted. In the present study, a high frequency of activities with the goal of motor activation has been reported. While other studies mostly found a lack of motor activation in the daily support of individuals with PIMD (Bossink, Frans, & van der Putten, 2016), moments of motor activation and therapy are explicitly included in the day structure of the special day service centers. This can be realized, because multi-professional teams including educational professionals and therapists shape the daily activities in the groups. Motor activation is especially important when

it comes to individuals who are not able to move independently. While the stimulation of motor development can be a directly related aim, indirect effects of motor activation on other domains (such as cognition and language) have been suggested (Houwen, Visser, & Vlaskamp, 2016).

In summary, the results of the present study confirm the extraordinary position of the special day service centers. According to the DSPs, the special day service centers put work related activities in the center of their daily support and care. This may be seen as an innovative approach to provide age-appropriate activities for adults of the target group. Furthermore, in contrast to many other day services (van der Putten & Vlaskamp, 2011; Vlaskamp & Nakken, 2008), activities stimulating motor functioning were integrated in the day structure. In addition, the provided activities support interaction and experience of competences for the clients and, thereby, can be classified as activities promoting quality of life for individuals with PIMD.

When interpreting the results of the present study, a number of limitations have to be taken into account. First, only four special day service centers have been included in the present study. While the generalizability of the results could be rated as limited, still, the high response rate for the participating centers gives a comprehensive picture of the region concerned. Furthermore, the diversity of the surrounding areas (such as gentrified and middle-class, bordering a forest and in a residential neighborhood) of the different centers enlarges the generalizability. Consequently, comparisons with facilities working with similar conditions may be possible. Second, additional information about reliability and validity of the procedure is needed. To ensure the reliability of data collection, the initial meeting with DSPs was realized and optional support by the research team was offered during the period of filling in the diaries. Reliability information about the coding categories is available from previous studies (van der Putten & Vlaskamp, 2011; Zijlstra & Vlaskamp, 2005). Still, as a combination of the coding categories from several previous studies has been used, additional research into the entire procedure of the present study should complement this information. Third, the DSPs filled in the diaries and provided the data for the present study. Although they all attended a meeting including an introduction to the process and the possibility to solve ad hoc questions, individual differences in interpretations may have influenced the results. Knowing about the aim of the study may have had an impact as well. In addition, DSPs were reporting about their own work. Therefore, social desirability of the answers should be taken into account. Furthermore, the data of the present study only tell us about the perspective of the DSPs. No conclusions can be formulated about the experiences from the perspective of the individuals with PIMD. While observations by the researchers may have reduced these limitations, they would have been very time-consuming. Therefore, the possibility to include a larger number of participants using diaries was preferable for the present study.

In future studies, a qualitative analysis of the content of the activities may reveal complementary information. Analyzing the interaction between individuals with PIMD and DSPs in depth may explain how the activities are realized. Furthermore, clarifying the reaction of the participants to the work related activities

may help to understand how the covering theoretical components of the concept of quality of life according to Sabo and Terfloth (2011) lead to high quality activities for individuals with PIMD.

The results also have implications for the daily practice of day services. The present study confirms the importance of communication and interaction in the support of individuals with PIMD. Only through their relationship with proxies can individuals of the target group get in contact with their environment (Vlaskamp, Hiemstra, & Wiersma, 2007). Consequently, integrating communication and interaction in daily activities, such as eating and drinking and care, can be highly valuable. Similarly, integrating motor activation in the general day structure may have an impact on much more than the motor functioning only. The most important conclusion of the present study is that participation in work related activities of individuals with PIMD is possible. Including elements such as communication, motor activation, and experience of self-efficacy, the activities may promote the quality of life of the individuals of the target group. Still, an additional note is necessary. While Sabo and Terfloth (2011) specified five components of work related quality of life, these same components are crucial in education as well. In addition, educational and work related activities often go together. In that way, one of the participating special day service centers already describes their activities as “work related education” based on the concept of lifelong learning in cooperation between individuals with PIMD and their DPSs (Praschak, Eggers, & Gruber, 2011). Furthermore, leisure activities promoting relaxation should not be disapproved in and of themselves. Elderly with PIMD possibly enjoy this type of activities in contrast to their former educational and work related activities. In the end, different types of special day service centers are needed. Focusing on work related activities, education, and/or leisure activities accounts for the different needs of individuals with PIMD according to their different characteristics and different phases of life.

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