

Quality-enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research literature

BEA MAES, GREET LAMBRECHTS, INE HOSTYN & KATJA PETRY

Catholic University of Leuven, Belgium

Abstract

Background This study provides an overview of empirical research on the effectiveness of quality-enhancing interventions for people with profound intellectual and multiple disabilities (PIMD).

Method Through computerised searches of the PsycINFO and ERIC databases, and using several search criteria specifically relating to the target group and to the subject of this review, 16 studies were identified.

Results The interventions described are targeted at the physical and material well-being, emotional well-being, social interactions, choices, and personal development of individuals with PIMD, but do not address community participation and rights. The majority of the studies report positive effects of the interventions on staff and/or client behaviour. However these effects should be interpreted with caution because of methodological and other considerations.

Conclusions Current research gives only limited insight into the effectiveness of quality-enhancing interventions for people with PIMD. To foster evidence-based practice, further studies of larger groups and with more robust designs are warranted. The potential differential effects associated with client characteristics and the context of the implementation should also be considered.

Keywords: *quality of life, quality of support, quality-enhancing strategies, interventions, profound intellectual and multiple disabilities, review*

Introduction

Quality of life and quality of support for people with intellectual disability have both been important research topics during recent decades. Yet in the growing body of literature in this area, people with profound intellectual and multiple disabilities (PIMD) have received only limited attention. By the term “people with PIMD” we refer, in accordance with the working definition developed by the Special Interest Research Group of IASSID (Nakken & Vlaskamp, 2002), to individuals with profound cognitive disabilities ($IQ < 20$), profound neuromotor dysfunctions (such as spastic quadriplegia), and often sensory impairments and medical problems (such as seizures, respiratory problems and/or feeding problems). These conditions may result from genetic disorders, metabolic abnormalities, developmental disorders of brain formation, or intrauterine or neonatal disorders. People with PIMD are a very heterogeneous group with regard to functional abilities. A common characteristic, however, is that they are totally dependent on support from others for all aspects of their daily

needs. They communicate mostly in a pre- or proto-symbolic way, using facial expressions, movements, sounds, body posture or muscle tension. Because of the idiosyncratic and context-bound nature of their communicative behaviour, their wishes, needs and preferences are difficult to interpret, and often remain misunderstood (Grove, Bunning, Porter, & Olsson, 1999; Hogg, Reeves, Roberts, & Mudford, 2001).

In studies on the quality of life of individuals with intellectual disability in general, it has become obvious that people with PIMD are a vulnerable group. Personal ability is considered to be the most powerful predictor of variation in quality of life outcomes, and individuals with lower adaptive skills achieve on average fewer personal outcomes than those with higher levels of social adaptation. They also have fewer opportunities to live in a typical community environment, less variety in their day-to-day and leisure activities, less choice, fewer opportunities for social participation, a less active life-style, and a lower level of engagement in meaningful daily activities (Emerson et al., 2000; Felce, Lowe,

Beecham, & Hallam, 2000; Felce, Lowe, & Jones, 2002; Hatton, Emerson, Robertson, Henderson, & Cooper, 1996; Mansell, Beadle-Brown, Macdonald, & Ashman, 2003; Stancliffe & Lakin, 1998). People with lower adaptive and communicative skills and a lower activity level also receive less positive staff contact and affection, are offered less stimulating activities, and experience more custodial care (Emerson et al., 2000; Hatton et al., 1996; Seys, Duker, Saleminck, & Franken-Wijnhoven, 1998).

In the limited number of studies that have evaluated more specific aspects of the life situation of people with PIMD in day care and residential services, similar problem areas have emerged. First of all, staff/client interactions are often characterised by neutral affection and instructions (Seys et al., 1998), resulting in a lack of connectedness and value or in social distance between staff and clients (De Waele & Van Hove, 2005; Seifert, 2002). Staff are said to be insufficiently responsive to clients' individual needs and to take inadequate account of clients' capacities and perspectives (De Waele & Van Hove, 2005; Seifert, 2002). A second problem pertains to the limited number and lack of variation in developmental and leisure activities, resulting in boredom and repetitive routines (De Waele & Van Hove, 2005; Seifert, 2002; Seys et al., 1998; Zijlstra & Vlaskamp, 2005). People with PIMD have only limited opportunities to participate in everyday activities, and only a small proportion of their leisure time is spent away from the living unit (Campo, Sharpton, Thompson, & Sexton, 1997; Seifert, 2002; Zijlstra & Vlaskamp, 2005). In addition, their preferences, interests and capacities are not sufficiently taken into account when designing programs and selecting activities (Seifert, 2002; Zijlstra & Vlaskamp, 2005). A third problem involves the limited opportunities for choice. Several studies have demonstrated that people with PIMD lack control over their life situation (Carnaby & Cambridge, 2002; De Waele & Van Hove, 2005; Seifert, 2002), and have few opportunities to make choices regarding everyday activities and major life events. Finally, people with PIMD have limited social networks, which mostly include professionals, co-residents and family members (Campo et al., 1997; Seifert, 2002).

Quality of life outcomes for the target group have also been linked with support and setting characteristics. The specialist orientation of a facility is associated with higher levels of staff assistance and higher levels of positive contact between clients and staff, but also with lower levels of activity outside the facility (Hatton et al., 1996). In addition, procedures for individualised planning and scheduling of activities seem to be crucial (Emerson et al., 2000;

Hatton et al., 1996), and are associated with higher levels of staff assistance and higher levels of positive contact between clients and staff. They also result in an improved participation of clients in daily, leisure and community activities. Equally, the amount of staff training and support is associated with higher levels of positive contact between staff and clients (Emerson et al., 2000). Less institutional environments are associated with lower levels of staff assistance, higher levels of positive staff contact, and higher levels of community activities (Emerson et al., 2000; Hatton et al., 1996). Living in small, dispersed, domestic-style housing in the community provides better quality of life outcomes for clients with PIMD than living in residential campuses. These outcomes include more choice availability, wider social networks and more family contact, higher levels of engagement in constructive activity, a greater number and variety of leisure activities, and higher levels of activity outside the facility (Emerson et al., 2000; Hatton et al., 1996; Kearney, Bergan, & McKnight, 1998; Spreat & Conroy, 2001). It is also clear that small, dispersed, domestic-style housing in the community is associated with more positive support characteristics, and specifically with higher levels of activity planning and individual goal-setting, higher levels of staff training and support, and a less institutional environment (Emerson et al., 2000; Spreat & Conroy, 2001).

In the literature, it has become clear that people with PIMD present a particular challenge in designing and implementing high quality support. Supporting these individuals is difficult and demanding. A clear perspective is often lacking, as generally accepted views on autonomy and community participation of people with intellectual disability are not so easily realised for these clients. This tends to make support workers feel insecure and confine their actions to nursing, therapies and custodial or medical care (Fornfeld, 1998; Vlaskamp, 1993). Individuals with PIMD have complex and specific support needs relating to their development and social participation. Knowledge in these areas, however, remains implicit and intuitive; support workers do not arrive at shared views and objectives (Orelve & Sobsey, 1996). The high turnover of staff, and the fact that several disciplines are involved, may result in organisational discontinuity (Zijlstra, Vlaskamp, & Buntinx, 2001). In order to optimise the life situation and support for people with PIMD, it is important to build up knowledge of strategies that may improve their quality of life.

In this review, we wish to provide an overview of empirical research aimed at evaluating the

effectiveness of quality-enhancing strategies and interventions for people with PIMD. More specifically, we wish to address the following three research questions:

- Which strategies or interventions have been described and implemented? What are their main characteristics?
- What are the effects of these quality-enhancing strategies or interventions on support staff and/or individuals with PIMD?
- What are the necessary conditions for an effective implementation of these quality-enhancing strategies or interventions?

Method

The studies were identified through computerised literature searches of the PsycINFO and ERIC databases in August 2006. Three sets of keywords were used. The first related to the target group: 'profound mental retardation', 'profound learning disabilities or difficulties', 'profound intellectual disabilities', 'multiple disabilities' or 'high support need'. The two other sets of keywords referred to the subject of this review: (1) 'support', 'care', 'quality of life', 'staff' or 'services', and (2) 'effect*', 'improv*' and 'change'. We considered both US and UK terminology, and where appropriate, singular and plural forms. We limited the search to articles in peer-reviewed journals because this guarantees the scientific value of the studies and the reliability and trustworthiness of the data. We confined our search to the period 1995–2006, as the care system has changed radically during the last decade and we wanted to focus on the current situation of individuals with profound intellectual and multiple disabilities (PIMD). This search resulted in 152 articles.

We further narrowed our selection using exclusion criteria relating to the characteristics of participants and subject of the studies reported in the articles. First of all, we excluded any publications that did not report an empirical study ($n=13$). These included reviews, discussion articles, letters or book reviews. Next, in accordance with our working definition, participants of the study had to have profound cognitive disabilities and profound neuro-motor dysfunctions, often in addition to sensory impairments and medical problems. A study might either focus exclusively on the target group or might include the target group as part of a larger cohort of participants. In the latter case, a separate analysis of the data for the target group was necessary for

inclusion. By this process, we excluded 21 studies which focused on a different target group (e.g., people with intellectual disabilities and mental health needs, or with dual sensory impairments, or with intellectual disabilities and autism spectrum disorders), and 14 studies which addressed a much broader target group (e.g., people with all levels of intellectual disability), but which did not include a separate data analysis for the target group. Finally, several studies were excluded because the subject differed from the subject of this review, which focuses solely on the effectiveness of strategies that may improve the quality of life of the target group in day care, community and/or residential services. On this basis, we excluded 9 studies on the development of diagnostic instruments and 5 on the family situation. A further 43 studies discussed individual treatment programs for functional skills acquisition or the reduction of problem behaviour of clients, while 8 studies evaluated the effects of moving from an institution to more community-based homes on (mal)adaptive behaviour of people with profound intellectual disabilities. In 22 studies there was no (detailed) description and/or evaluation of a quality-enhancing intervention. Of the remaining 17 articles, 5 were not available. In addition to the computerised searches, we screened the bibliographies of the selected articles using the same criteria described above, and 4 articles were added based on this manual search.

In the end, 16 articles were selected for this review. Because of the variation in designs and nature of the data, a statistical meta-analysis was not possible. We therefore analysed the studies by means of a narrative thematic synthesis. A systematic narrative review summarises different primary studies from which conclusions may be drawn into a holistic interpretation informed by the reviewer's own experience, existing theories and models (Jones, 2004). Results are qualitative rather than quantitative. This approach offers the possibility of comprehending the diversities and similarities of understandings in a particular field. In Table 1, we set out for each study the authors and year of publication, characteristics of the participants, objectives of the study, study design, intervention strategies, and methods that have been used to measure the effectiveness of the interventions.

We will present the results of these studies using a quality of life framework, since all the interventions should ultimately result in positive quality of life outcomes for people with PIMD. Although there are several models of quality of life, an international panel of experts has reached consensus on eight core domains: physical well-being, material well-being,

Table 1. Overview of studies on the effectiveness of strategies and interventions aimed at optimising quality of life and/or support for individuals with PIMD

Authors, date	Participants	Objectives	Intervention	Design	Evaluation methods
<i>Physical and material well-being</i>					
Neilson, Hogg, Malek, & Rowley, 2000	<ul style="list-style-type: none"> 27 participants with profound ID and one or more physical and/or sensory disability aged 2–55 years (M=19 years) 	<ul style="list-style-type: none"> to evaluate the costs and effects of surgical and orthotic interventions on function and behaviour 	<ul style="list-style-type: none"> surgical procedures seating interventions orthotic interventions indoor/outdoor powered wheelchairs 	<ul style="list-style-type: none"> single subject design evaluation pre- and post-intervention (3–6 and 6–12 months) 	<ul style="list-style-type: none"> SF-36 questionnaire on health status (administered by carers) time trade-off approach video-analysis of changes in biomechanical aspects of function and behaviour, using visual analogue scales carers' satisfaction with the results
<i>Emotional well-being</i>					
Favell, Realon, & Sutton, 1996 (first phase)	<ul style="list-style-type: none"> 20 non-ambulatory participants with severe/profound ID and at least one additional sensory or medical problem 	<ul style="list-style-type: none"> evaluate the effects of the Positive Environment Program on indices of (un)happiness of clients 	<ul style="list-style-type: none"> Positive Environment Program involves: <ul style="list-style-type: none"> – staff making leisure materials available – frequent social interactions with clients – distributing attention evenly among clients 	<ul style="list-style-type: none"> AB-design 	<ul style="list-style-type: none"> direct observation of expressions of positive and negative emotions (2 × 45min.) 15-second partial interval recording
Favell et al., 1996 (second phase)	<ul style="list-style-type: none"> 1 non-ambulatory participant with severe/profound ID and at least one additional sensory or medical problem 	<ul style="list-style-type: none"> evaluate the effects of social interaction on indices of (un)happiness of clients 	<ul style="list-style-type: none"> 30 one-minute intervals of casual conversation between client and staff members 	<ul style="list-style-type: none"> ABA-design 	<ul style="list-style-type: none"> direct observation of expressions of positive and negative emotions
Green & Reid, 1996	<ul style="list-style-type: none"> 3 non-ambulatory participants with profound ID and physical impairment day care centre 	<ul style="list-style-type: none"> evaluate the effects of the Fun Time Program on indices of (un)happiness of clients 	<ul style="list-style-type: none"> presentation of preferred items or activities social interaction planned initiation and termination of stimuli presentation 	<ul style="list-style-type: none"> AB-design Follow-up at 22–24 weeks 	<ul style="list-style-type: none"> direct observation of indices of happiness and unhappiness during leisure activities 10-second partial interval recording during 10-minute sessions
Ivancic, Barrett, Simonow, & Kimberley, 1997	<ul style="list-style-type: none"> 7 non-ambulatory participants with profound ID and at least one additional disability aged 25–47 years 	<ul style="list-style-type: none"> evaluate the effects of the Fun Time Program on indices of (un)happiness of clients 	<ul style="list-style-type: none"> replication of Green & Reid, 1996 	<ul style="list-style-type: none"> ABAB-design in two sub-groups 	<ul style="list-style-type: none"> direct observation of indices of happiness and unhappiness during leisure activities 10-second partial interval recording during 10-minute sessions

Table 1. (Continued)

Authors, date	Participants	Objectives	Intervention	Design	Evaluation methods
Green, Gardner, & Reid, 1997	<ul style="list-style-type: none"> • 3 non-ambulatory participants with profound ID and physical impairment • aged 28–41 years • day care centre 	<ul style="list-style-type: none"> • evaluate the relative effects of using systematically assessed preferred stimuli versus staff opinion-based preferred stimuli 	<ul style="list-style-type: none"> • replication of Green & Reid, 1996 	<ul style="list-style-type: none"> • alternating treatment design with 4 conditions: <ul style="list-style-type: none"> – standard classroom program – systematically assessed preferences – staff opinion-based preferences – combination 	<ul style="list-style-type: none"> • direct observation of indices of happiness and unhappiness during leisure activities • 10-second partial interval recording during 10-minute sessions
Davis, Young, Cherry, Dahman, & Rehfeldt, 2004	<ul style="list-style-type: none"> • 3 non-ambulatory participants with profound ID and physical limitations • aged 31–45 years 	<ul style="list-style-type: none"> • compare the effects of the presentation of preferred items plus social interaction with the presentation of social interaction only 	<ul style="list-style-type: none"> • sessions 3 to 5 days per week for each individual • one 10-minute session per day 	<ul style="list-style-type: none"> • comparison of 3 conditions: <ul style="list-style-type: none"> – standard classroom program – social interaction only – social interaction plus preferred items 	<ul style="list-style-type: none"> • direct observation of indices of happiness and unhappiness • 10-second partial interval recording during 10-minute sessions
Interpersonal relations					
Schepis & Reid, 1995	<ul style="list-style-type: none"> • 1 participant with profound ID, spastic quadriplegia and visual impairments • 4 support staff 	<ul style="list-style-type: none"> • evaluate the effects of using a voice output communication aid (VOCA) on interactions with support staff 	<ul style="list-style-type: none"> • augmentative communication aid involving the production of synthesised speech 	<ul style="list-style-type: none"> • baseline • access to VOCA over several days at 2 experimental time periods and 1 control period per day, during routine morning activities • follow-up after 98 days in class and 83 days in living unit 	<ul style="list-style-type: none"> • direct observation in classroom and residence • continuous 30-second partial interval recording during 10-minute sessions
Golden & Reese, 1996	<ul style="list-style-type: none"> • 16 direct support staff of non-verbal adults with profound ID in large residential services and 8 in small community-based homes • aged 23–55 years • 1/3 non-ambulatory 	<ul style="list-style-type: none"> • improve sensitivity and responsiveness of support staff to clients' non-verbal cues 	<ul style="list-style-type: none"> • training in use of the Adapted Nursing Child Assessment Feeding Scale (NCAFS) to code interactions • 3-day instruction program 	<ul style="list-style-type: none"> • 12 staff/client pairs randomly assigned to 1 trained group ($n=6$) and 2 control (non-trained) groups ($2 \times n=3$) • multiple baseline across groups • during mealtime (training) and teaching situation (generalisation) • follow-up 6 months after completion of training 	<ul style="list-style-type: none"> • video observation of staff and client behaviour during mealtime • partial interval recording (10-second observe and 10-second record), in two to four 20-minute sessions during each phase of the study • interviews with staff

Table 1. (Continued)

Authors, date	Participants	Objectives	Intervention	Design	Evaluation methods
Dobson, Upadhyaya, & Stanley, 2002	<ul style="list-style-type: none"> 9 direct support staff who each named a client with whom they experienced difficulties in interaction 9 non-verbal adults with profound ID and physical and/or sensory impairments (aged 20–38 years) 	<ul style="list-style-type: none"> evaluate the effects of a training program on the quality of interactions of support staff with clients 	<ul style="list-style-type: none"> 6-month weekly training based on a joint problem-solving approach external multidisciplinary training team workshops and practical on-the-job training 	<ul style="list-style-type: none"> observations during baseline, after training, and at follow-up (after 6 months) 	<ul style="list-style-type: none"> video observation and analysis of staff's use of language, number of utterances, and style of interaction in naturally occurring situations (3 x 2.5 minutes) support staff's self-evaluation of their perceptions, changes in working practices and achievement of goals (Goal Attainment Scale)
Bloomberg, West, & Iacono, 2003	<ul style="list-style-type: none"> 32 direct support staff (aged 22–62 years, $M=38.75$ years) working with adults with profound and multiple disabilities and severe communication impairments residential and day services for people with PIMD 	<ul style="list-style-type: none"> evaluate the effects of the PICTURE IT training program on staff and client communicative and interactive behaviour 	<ul style="list-style-type: none"> PICTURE IT program: <ul style="list-style-type: none"> 6 monthly training days covering 6 modules work assignments and individual supervision using a collaborative problem-solving approach 	<ul style="list-style-type: none"> Experimental group ($n=16$) and control group ($n=16$) pairs consisting of 1 carer who received training and 1 carer who didn't receive training, working with the same client evaluation before, during and after implementation 	<ul style="list-style-type: none"> questionnaire on knowledge and perceptions of communication skills 1-minute interval recording during 5-minute video-samples of staff and client communicative behaviour in 1:1 interactions during routine activity and in 4 different situations early communication skills profile Goal Attainment Scale survey about communication opportunities in the physical and social environment
<i>Self-determination</i>					
Salmento & Bambara, 2000	<ul style="list-style-type: none"> 4 direct support staff (aged 23–37 years) with a minimum of 6 months' working experience, paired with 4 clients with profound ID and severe physical disabilities (aged 27–51 years) in a community-based residential home 4 additional clients for assessing generalisation 	<ul style="list-style-type: none"> evaluate the effects of a training program on support staff's provision of choice opportunities for clients during a daily dressing routine evaluate maintenance and generalisation across different routines and clients evaluate the effects of increased choice opportunities on the choice responses of clients 	<ul style="list-style-type: none"> training program consisting of: <ul style="list-style-type: none"> initial in-service consultation meeting individual in vivo training (1 week) ongoing individual feedback 	<ul style="list-style-type: none"> multiple baseline design observations during baseline, feedback, maintenance (3 weeks) and follow-up phase (1 to 3 months) 	<ul style="list-style-type: none"> analysis of number of choice opportunities provided by support staff and number of choice responses made by clients with PIMD during a dressing routine (training) and lunch (generalisation) with 4 clients (involved in training) and 4 additional clients

Table 1. (Continued)

Authors, date	Participants	Objectives	Intervention	Design	Evaluation methods
Reid, Green, & Parsons, 2003	<ul style="list-style-type: none"> 2 job coaches working with 5 supported workers with severe cognitive and physical disabilities 	<ul style="list-style-type: none"> evaluate the effects of an outcome management program on the provision of choice opportunities by job coaches, and on the choice responses made by supported workers with PIMD 	<ul style="list-style-type: none"> 6-step outcome management program 	<ul style="list-style-type: none"> observations during baseline, after training, and at follow-up (intermittent weekly visits over 1 year) 	<ul style="list-style-type: none"> continuous recording of the number of choice opportunities provided by the job coaches, and the number of choice responses made by the supported workers with PIMD during 2 work periods
<i>Activities and personal development</i>					
Mitchell & van der Gaag, 2002	<ul style="list-style-type: none"> 2 participants with severe/profound ID and physical disabilities 	<ul style="list-style-type: none"> evaluate the effects of a multi-sensory intervention program on the level of interaction and engagement 	<ul style="list-style-type: none"> Odyssey Now (ON) Program: <ul style="list-style-type: none"> – range of interactive activities – using a variety of multi-sensory techniques 	<ul style="list-style-type: none"> each session: 2 × 10 minutes of ON and 10 minutes of routine activities observations during first and fourth sessions of ON, and at the end of 8 weeks 	<ul style="list-style-type: none"> momentary time sampling 10 × 20 seconds observation checklist to record level of engagement semi-structured interviews with support staff
Vlaskamp, de Geeter, Huijsmans, & Smit, 2003	<ul style="list-style-type: none"> 19 individuals with PMID (aged 18–41 years, $M=28$ years) 5 facilities 	<ul style="list-style-type: none"> evaluate the effects of multi-sensory environments (MSE) on the level of activity 	<ul style="list-style-type: none"> at least weekly use of MSE “being active” was main goal of MSE 	<ul style="list-style-type: none"> 2 observations in MSE, 1 observation in control condition 	<ul style="list-style-type: none"> momentary time sampling every 30 seconds during 3 observation sessions of 30 minutes coding 5 levels of alertness and engagement, as well as contextual variables
Realon, Bligen, La Force, Helsel, & Goldman, 2002	<ul style="list-style-type: none"> 11 direct support staff (aged 21–40 years) working with 19 non-ambulatory clients (aged 19–44 years) with profound ID and one or more severe physical disability residential facility 	<ul style="list-style-type: none"> evaluate the effects of the Positive Environment Program (PEP) on resident and staff behaviour 	<ul style="list-style-type: none"> training in PEP consisting of: <ul style="list-style-type: none"> – training course – training sessions over 2 weeks with individual verbal feedback – awards and incentives – informal monthly monitoring system 	<ul style="list-style-type: none"> evaluation 6 months before training and 20 and 28 months after 	<ul style="list-style-type: none"> direct observation of client behaviour, staff behaviour and environmental features 15-second partial interval recording during 5-minute observations of unstructured times
Van der Putten, Vlaskamp, Reynders, & Nakken, 2005	<ul style="list-style-type: none"> 44 children with profound intellectual disabilities and severe motor limitations (aged 2–16 years, $M=9.3$ years) 7 centres for special education 	<ul style="list-style-type: none"> evaluate the effects of functional movement activities (MOVE) on the level of independence in performing movement skills 	<ul style="list-style-type: none"> MOVE (Mobility Opportunities Via Education) curriculum: training in functional movement skills integrated into daily life 	<ul style="list-style-type: none"> experimental group ($n=32$) and control group ($n=12$), no random assignment pre-test (before commencement of MOVE program) and post-test (12 months after implementation) 	<ul style="list-style-type: none"> Top Down Motor Milestone Test

emotional well-being, interpersonal relations, self-determination, personal development, community participation, and rights (Schalock et al., 2002; 2005).

Results

Physical and material well-being

Neilson, Hogg, Malek, and Rowley (2000) investigated the effects of surgical and orthotic interventions on the health status of 27 participants with PIMD. The interventions included surgical procedures, seating interventions, orthotic interventions and indoor/outdoor powered wheelchairs. The effects of these interventions were examined using the SF-36 questionnaire on health status, the time trade-off approach, video-analysis, and a measure of carers' satisfaction with the results. Results on the SF-36 questionnaire, administered prior to the intervention and after the intervention (at both 3–6 months and 6–12 months), showed that only the dimension of "role limitations owing to physical problems" approached significant improvement (from $M=46.2$ to $M=63$, $p=.05$). In the subgroup involving seating interventions, statistically significant improvements were demonstrated in "social function" ($p<.05$) and "role limitations owing to physical problems" ($p<.05$). The time trade-off approach, which implies a global measure of health-related quality of life ranging from 0 to 1.0, indicated significant improvements in clients' health-related quality of life after the intervention (from $M=0.62$ to $M=0.79$, $p=.001$). Two therapists analysed pairs of video-taped sequences, representing a "before and after" set, for each participant. They observed moderate positive change (11–50%) for 4–5 participants, and large positive change (>50%) for 3–6 participants. Although 15 of the 24 carers (62.5%) reported satisfaction with the outcome, 2 (8.3%) were borderline and 7 (29.1%) were dissatisfied with the results.

Emotional well-being

In this section, we discuss a number of intervention programs that focus on increasing emotional or subjective well-being. Favell, Realon, and Sutton (1996) implemented the Positive Environment Program and evaluated its effect on the (un)happiness index of participants with PIMD. The main components of the program include support staff making leisure materials available to clients, having frequent social interactions with clients, and distributing their attention evenly among clients. In the

first stage of their study, Favell et al. observed changes in the "happiness index" (the percentage of intervals containing a negative emotion subtracted from the percentage of intervals containing a positive emotion) before and after implementation of the program. The mean happiness index for the 20 participants with PIMD improved from 2.2 before to 6.5 after the program. Twice as many individuals showed at least some degree of happiness (from 40% to 80%). Nevertheless, the authors pointed to the wide variation between clients in individual happiness levels. In a second phase of their study, Favell et al. reported a case study of a 30-year-old man with PIMD. He was presented with short intervals during which three staff members took turns, in a fixed sequence, engaging in casual conversation with him. The mean happiness index for the two baseline conditions was 12 and for the interaction condition 79. This indicates that simple social interaction can have a significant effect on an individual's happiness.

A series of four studies (Davis, Young, Cherry, Dahman, & Rehfeldt, 2004; Green, Gardner, & Reid, 1997; Green & Reid, 1996; Ivancic, Barrett, Simonow, & Kimberley, 1997) evaluated the degree to which the presentation of preferred items or activities, in combination with social interaction, increases emotional well-being in people with PIMD. In these studies, happiness is defined as "any facial expression or vocalization typically considered to be an indicator of happiness among persons without disabilities, such as smiling, laughing and yelling when smiling". Unhappiness is defined as "any facial expression or vocalization typically considered to be an indicator of unhappiness among people without disabilities, such as frowning, grimacing and yelling without smiling".

Green and Reid (1996) developed the Fun Time Program. The main characteristics of this program are: (1) presentation of previously assessed preferred items or activities for some minutes; (2) social interaction offering the participant enjoyable experiences; and (3) planned initiation and termination of the presentation of stimuli (e.g., immediate withdrawal of an item or activity upon any indication of unhappiness; replacement of the item or activity after 1 minute during which no indication of happiness is observed). For each of the 3 participants with PIMD, an increase in the frequency of happiness indices was demonstrated during the intervention condition compared to the standard classroom condition (from $M=3\%$ to $M=10\%$; from $M=9\%$ to $M=45\%$; and from $M=0\%$ to 17%). There were no consistent changes in unhappiness levels. Follow-up observations indicated that the

frequency of observed happiness indices was maintained well above baseline levels.

Ivancic et al. (1997) replicated the study of Green and Reid (1996) by implementing the Fun Time Program for 7 participants with PIMD. They simplified the program by using staff reports rather than a formal stimulus preference assessment to identify preferred stimuli. The results of this study with an ABAB-design demonstrated large effects of the stimulation with preferred items during Fun Time sessions on happiness indices for 3 out of 4 clients who were able to move (A-condition: $M=3\%$, 9%, 13%, 0%; B-condition: $M=69\%$, 79%, 40%, 0%; A-condition: $M=8\%$, 15%, 2%, 0%; B-condition: $M=42\%$, 39%, 20%, 0%). In the minimal movement group however, there were no indications of happiness scored at all.

Green et al. (1997) replicated their original 1996 study with the specific aim of evaluating the relative effects of using systematically assessed preferred stimuli as opposed to stimuli that staff members believe to be highly preferred. Systematic preference assessment involves the presentation of at least 12 stimuli one at a time in a series of trials, with the most preferred items determined based on the client's approach responses. The results confirmed that the Fun Time Program led to noticeable increases in happiness indices for all 3 participants (A-condition: $M=5\%$, 8%, 0%; B-condition: $M=65\%$, 45%, 52%; A-condition: $M=4\%$, 0%, 10%). A component analysis showed the superiority of using high-preference stimuli identified through systematic preference assessment over stimuli identified by staff opinion. Activities that were determined to be preferred based on systematic preference assessment were accompanied by increased levels of happiness indices relative to baseline for all participants (A-condition: $M=12\%$, 1%, 15%; B-condition: $M=79\%$, 57%, 56%), whereas for staff opinion-based preferences this was only the case for 1 of the 3 participants (A-condition: $M=17\%$, 8%, 15%; B-condition: $M=17\%$, 8%, 75%). A comparison of happiness levels in both conditions indicated that the happiness indices were higher for 2 of the 3 participants when they were confronted with systematically assessed preferred items.

In the final study focusing on emotional well-being, Davis et al. (2004) compared the percentage of intervals during which happiness was observed in a group of 3 participants with PIMD across three conditions: in a standard classroom program, in a condition of social interaction only, and in a condition where preferred items were presented systematically combined with social interaction.

Each participant's preferences were identified using a systematic assessment procedure. For all participants, the percentage of intervals during which happiness was observed was substantially higher in the two experimental conditions than in the standard classroom condition, and higher in the combined condition than in the social interaction only condition.

Interpersonal relations

In this section, different studies aimed at improving the quantity and quality of interactions between staff and clients with PIMD are considered. Schepis and Reid (1995) examined the effects of using a voice output communication aid (VOCA) on the interactions of an individual with multiple disabilities with support staff. This augmentative communication aid involves the production of synthesised speech that can be readily understood by others. The client was trained to activate the VOCA by pressing a photograph of one of the items or foods that had previously been determined as highly preferred. Four staff members learned to use the VOCA in their interactions. Direct observations were carried out in a multiple probe across two experimental periods (two periods of routine morning activities during which access to VOCA was available) and one control period per day, and across settings (classroom and living unit). Results indicated that support staff increased their frequency of interactions with the client when the client had access to the communication aid (63% increase in the classroom and 86% in the living unit). This was not the case during the control period (21% and 31% respectively). The increased interactions continued at follow-up (85% and 90% respectively). The authors hypothesised that interactions might have increased because the synthesised speech provided a salient cue to staff to interact, and/or because it is much easier to understand the synthesised speech than difficult-to-interpret non-verbal vocalisations or gestures.

Three other studies (Bloomberg, West, & Iacono, 2003; Dobson, Upadhyaya, & Stanley, 2002; Golden & Reese, 1996) evaluated training programs aimed at enhancing the quality of interactions between support staff and clients. In the study by Golden and Reese (1996), 24 direct support staff of non-verbal adults with PIMD were randomly assigned to either a training group or a control group. The first group received a 3-day training program aimed at improving their sensitivity and responsiveness to clients' non-verbal cues. They learned to observe and code video-taped staff/client

interactions using the Adapted Nursing Child Assessment Feeding Scale (NCAFS), with the aim of becoming more aware of resident cues, staff responses to cues, and growth-fostering strategies. Analysis of individual staff/client interactions during mealtime (training) revealed an increase in positive verbal and non-verbal staff behaviour following training, although the effect was smaller and less consistent for non-verbal behaviour. There was a slight increase in positive verbal behaviour in the teaching (generalisation) situation following training and some maintenance of this behaviour at follow-up. However there was a possible contamination effect on the control group, which had become more positive over time. In general, there was no consistent effect of staff training on resident behaviour.

Dobson et al. (2002) developed a 6-month training package for 9 direct support staff to improve the quality of their interaction with clients. The training was based on a joint problem-solving approach and was delivered by an external multi-disciplinary consultant team through weekly experiential workshops and practical on-the-job training. Methods included presentations, role play, practical exercises, and self-analysis of working practices through video recordings. The aim of the training was to create an environment in which the support staff (i) acknowledge and value the client's communication; (ii) adopt an appropriate way of communicating that supports and extends the client's understanding of his environment; and (iii) interpret the client's communicative intent in a way that facilitates and enables communication. Video-analysis of individual staff/client interactions showed a significant increase in the total number of utterances of staff following training (from $M=14.11$ to $M=23.78$, $p<.01$) and at follow-up ($M=26.63$). More specifically, there were significant increases ($p<.05$) in the number of acknowledgements and praise used by staff, in the number of open requests for information, and in the amount of information given to clients by support staff. At follow-up, only "giving information" and "acknowledging the client's communication" had continued to increase. The percentage of requests versus other types of utterance had reduced after training and at follow-up (from 94% to 60% after training and 55% at follow-up for clients with a pre-intentional communication level, and from 85% to 71% and 53% for clients with an intentional communication level). Training also resulted in an improved (non-verbal) communication style which was maintained at follow-up: staff's "position in relation to clients" (from $M=2.87$ to $M=4.16$ after training and

$M=4.38$ at follow-up, $p<.01$) and "eye level and gaze in relation to clients" (from $M=2.56$ to $M=3.94$ and $M=4.44$, $p<.01$). The authors observed a greater responsiveness by staff and an increased expectation that the client could and would respond as an equal communication partner. Nevertheless, there was no change in the complexity of language used by staff and in their use of gestures and signs to support the meaning of their speech. However there were obvious rearrangements of the physical environment to support communication, such as furniture arrangements defining the function of areas, and symbols supporting the timetable, events and activities.

In the final study focusing on interpersonal relations, Bloomberg et al. (2003) matched 16 pairs, each consisting of one staff member who received training and another staff member without training working with the same client with PIMD. The objectives of the training for staff members were multiple: to improve their ability to interact with clients, to increase their knowledge of early and alternative communication, to increase their problem-solving skills, to increase their involvement with clients, and to create an environment that enhances communicative participation of the individual with PIMD. For clients, the training was aimed at increasing the frequency of their communicative behaviours. Training included six monthly training days, supplemented with work assignments and individual supervision. A principal characteristic of the training program was the collaborative problem-solving approach between people with different experiences and skills, using a 6-step sequence (problem description, problem explanation, prioritising problems, goal-setting, intervention, and outcome evaluation). Differences between pre- and post- scores revealed significant increases in staff's knowledge about early communication and intervention strategies ($t=3.03$, $p<.05$). Although difficulties in interpreting the function of the communicative actions remained, staff members improved their skills in recognising and responding to the (potentially) communicative behaviour of their clients. Staff initiations increased (from $M=15.6$ to $M=26.8$, $t=3.14$, $p<.01$), while their responses in interactions with clients also improved (from $M=7.9$ to $M=14.8$, $t=3.32$, $p<.01$). With regard to the clients, significant pre-test: post-test differences were found only for their responses (from $M=24.5$ to $M=30.9$, $t=3.15$, $p<.01$), but not for their initiations (from $M=11.75$ to $M=14.17$, ns). Overall, the training resulted in an environment that was more conducive to communication (e.g., the development of personal communication

dictionaries and histories), and with more communication opportunities for clients (e.g., being more involved in social and community activities).

Self-determination

The two studies identified in the domain of self-determination (Reid, Green, & Parsons, 2003; Salmento & Bambara, 2000) discuss training programs designed to increase choice opportunities for people with PIMD. Salmento and Bambara (2000) trained 4 direct support staff to increase choice opportunities for their clients during daily routines. The training began with an in-service consultation meeting, during which staff members learned to recognise choice opportunities within daily routines. A systematic sequence of steps was then introduced to present multiple single-stimulus choice opportunities during these routines and to identify and respond to choice responses of the clients. During the in vivo training (1 week) and the ongoing individual feedback phase, each staff member was offered support and feedback on their performance. Choice opportunities were analysed during a dressing routine (training) and during lunch (generalisation), with 4 clients involved in training and 4 others in a multiple baseline design. The authors found an increase in the number of choice opportunities presented by staff during daily routines following training, as well as an increase in the number of choice responses made by the clients. Staff members generalised their use of the choice-making procedure by increasing the number of choice opportunities offered across different adults for the same routine and to the same adult for different routines. There was, however, a slight decrease in choice opportunities and responses at follow-up.

Reid et al. (2003) trained 2 job coaches to provide more choice-making opportunities as part of their ongoing activities with 5 supported workers with PIMD. The training consisted of a 6-step outcome management approach: (i) determining desired worker outcomes; (ii) identifying job coach actions to assist workers in attaining these outcomes; (iii) monitoring staff performance and worker outcomes; (iv) training coaches to provide choice opportunities using a protocol that identifies different types of choices (where, with whom, how, ...) and three formats for presenting choices (open-ended questions, 2-option questions and 2-object presentations); (v) supportive vocal feedback on the number of choice opportunities provided; and (vi) corrective feedback if the number of choice opportunities decreased to baseline levels. Across job coaches

and work periods, only one choice was offered during baseline. Following the outcome management program, the number of choice opportunities offered increased, averaging 3.9 choices per work period for each coach. This increase was maintained during the follow-up observation. The authors concluded that the provision of choices became a regular part of the work routine of the job coaches involved.

Activities and personal development

Two studies (Mitchell & van der Gaag, 2002; Vlaskamp, de Geeter, Huijsmans, & Smit, 2003) focused on the effects of multi-sensory activities or environments on the level of interaction and engagement of individuals with profound multiple disabilities. Mitchell and van der Gaag (2002) implemented a multi-sensory intervention program called Odyssey Now (ON), which contains a range of interactive activities relating to the story of Odyssey, using a variety of multi-sensory techniques. They evaluated the effects of the program on the level of engagement of 2 participants with PIMD, and found significant increases in engagement level during the 8-week period of the intervention for one client ($\chi^2=8.25$, $p<.01$), but not for the other. Increased engagement was defined as a higher frequency of interactions with objects and people over time during the ON sessions. Significantly more engagement with the physical and social environment was observed during the ON sessions compared with routine activities ($p<.05$). Staff also perceived positive changes with regard to tolerance level, group integration, communication and interaction.

Vlaskamp et al. (2003) evaluated the effects of a multi-sensory environment on the level of alertness and interaction of 19 individuals with PIMD. The intervention consisted of an environment designed to stimulate the senses through light, sound, touch and smell. The authors recorded five levels of alertness and engagement based on responses directed at oneself, materials or other people. They found no significant differences between the multi-sensory condition and the standard living situation for any of the main observation categories, with the exception of a higher level of interaction with materials in the intervention condition ($t=3.13$, $p<.005$). However they did notice substantial individual differences, in that some participants were more active in the multi-sensory environment than in the standard living situation, whereas others were more passive, and for some, there seemed to be no difference at all. They also found that stimuli offered

by staff were more effective than stimuli offered by material only in increasing alertness (24% compared to 11%) or interaction (95% compared to 0%) in the multi-sensory environment.

Realon, Bligen, La Force, Helsel, and Goldman (2002) used a more general approach called the Positive Environment Program, in which the central idea is to provide a stimulating and rich physical environment (e.g., access to functional leisure materials) and social environment (e.g., establishing eye contact, providing positive comments, having positive interactions, being responsive). Eleven direct support staff working with 19 clients with PIMD were trained over 2 weeks, with additional individual verbal feedback, awards and incentives, and an informal monthly monitoring system. Improvement in resident behaviour following training was demonstrated by increased percentages of “client engagement with leisure materials” (from $M=6.3\%$ to $M=13.6\%$), “alertness” (from $M=58.4\%$ to $M=75.3\%$), and “happiness” (from $M=1.5\%$ to $M=12.9\%$). There was also improvement in the distribution of staff interactions among residents (from $M=10.3\%$ to $M=14.0\%$). However, a decrease in percentage of leisure material availability was also noticed (from $M=36.2\%$ to $M=32.3\%$).

Van der Putten, Vlaskamp, Reynders, and Nakken (2005) evaluated the effectiveness of functional movement activities using the MOVE (Mobility Opportunities Via Education) curriculum. This program integrates training in functional movement skills, such as sitting down, being seated, standing (up) and walking, into daily life and by different professions, so that the independence and participation of children with PIMD is enhanced, and they are able to exercise more control over their own lives, their environment, and the way they are addressed. The study design involved an experimental group consisting of 32 participants with PIMD (who were exposed to MOVE in addition to their regular program) and a control group of 12 participants with PIMD (who were exposed to the regular program only). Using the Top Down Motor Milestone Test, the authors found only a moderate effect for the MOVE intervention over 12 months on “level of independence when performing movement skills” (from $M=19.7$ to $M=22.8$, $z=-3.48$, $p=.001$; effect size index=0.69). There was a non-significant change in the control group. Level of independence when performing movement skills increased for 20 children in the experimental group (63%), and for 4 children in the control group (33%).

Discussion

In this paper, we have reviewed empirical research which evaluates the effectiveness of quality-enhancing strategies and interventions for individuals with PIMD. First of all, we wanted to determine which interventions and strategies have been described and implemented. Overall, we found that there are a limited number of studies available on the effectiveness of quality-enhancing strategies and interventions for this target group. Looking at the core domains of quality of life, we noted that the number of studies addressing each of these domains is quite varied. We reviewed 5 studies on enhancing the emotional well-being of individuals with PIMD, 4 on optimising staff/client interactions, and 4 on activities and personal development. We found only 1 study focusing on improving the physical and material well-being of the target group, and 2 on the provision of choice opportunities. There were no studies available evaluating quality-enhancing strategies in the domains of community participation and rights. With regard to the nature of the interventions, there are also striking differences between the studies. In the field of physical, material and emotional well-being, as well as personal development, the intervention strategies are mostly directed at the clients themselves, whereas in the field of interpersonal relations and self-determination, most interventions include a training package for direct support staff. Some interventions are applied from a behavioural-analytic approach, while others are derived from a quality of life perspective. Nevertheless, a common feature of all interventions is that they are implemented in naturally occurring everyday situations.

The second research question dealt with the effects of quality-enhancing strategies or interventions on support staff and/or clients with PIMD. This is important knowledge in order to foster evidence-based practice. The majority of studies reported positive, although moderate, effects of the interventions on staff and/or client behaviour. Surgical and orthotic interventions are cost-effective in improving the health status of clients. Providing preferred activities or items in combination with frequent social interactions with clients significantly improves the happiness indices of clients. Staff training contributes to a more person-centred approach, and results in more positive and balanced social interactions between staff and clients. Staff members become more responsive to clients' needs, have a greater appreciation of their involvement and contribution to the interaction, and focus more on the client as an individual with his or her own

interests, preferences and needs. Training results in increased opportunities for people with PIMD to participate in everyday and social activities and to make choices. Multi-sensory activities are effective in increasing clients' level of engagement and interaction. Functional movement activities enhance the level of independence of clients in performing movement skills.

We should, however, be cautious in interpreting these positive results. First of all, the studies have a number of methodological limitations. In many studies, the sample size was very small. The number of participants in the studies reviewed varied from 1 to 44 clients, and in 10 of the 16 studies was fewer than 10. Replication studies on a larger scale are necessary to draw definite conclusions about the effectiveness of the quality-enhancing strategies. In almost all studies, observation analysis of staff and client behaviour was used. We point to the importance of observational reliability. In most of the studies, inter-observer agreement scores are acceptable, but moderate and variable. The study design does not always allow conclusive demonstration of the effectiveness of interventions, excluding the impact of other factors. In some studies, there was no control group or no control condition, and alternating treatment designs were rare.

In addition to these methodological limitations, there are also some further considerations. First of all, a number of authors report a wide variation in outcomes between individual clients. Ivancic et al. (1997), for instance, found large effects for "stimulation with preferred items" on the emotional well-being of clients who were able to move, in contrast to clients in the minimal movement group, for whom no indications of happiness were observed at all. In line with these results, Salmento and Bambara (2000) found that a larger number of choice opportunities were presented to participants with the ability to point. A possible explanation might be that staff are in some way influenced by the more adaptive response mode of these clients. Future research should therefore focus on the potential differential effects of interventions, taking into account relevant client characteristics.

Secondly, some studies could not demonstrate the maintenance of effects over a longer period of time. Future evaluations should consider the long-term effects of interventions. In addition, it is not clear whether the effects may be generalised to other situations, other clients or non-trained staff. Do trained staff members actually talk about and model skills that are learnt in training? Zijlstra et al. (2001) found that staff turnover ranged from 0–73%. This raises the question of to what degree staff turnover or

absences in settings for clients with PIMD may influence the effects of training programs. We must conclude that in general, we have only limited knowledge about which strategies are most effective in improving quality of support and quality of life for individuals with PIMD. It remains a major challenge to design and implement high quality services and support for this target group.

The third question raised by our study relates to the necessary conditions for effective implementation of quality-enhancing strategies or interventions. We found that this was not an explicit focus of attention in the studies we reviewed. Nevertheless, one may assume that several critical factors influence the successful implementation of such interventions. First, the perceptions of staff about the intervention: Are the objectives clear? What do staff perceive to be the benefits and the complexity of the intervention? Are the objectives compatible with the staff's own values and vision? What are the perceived job constraints? Is the intervention attuned to the staff's priority needs? Are staff motivated to carry out the intervention? A second category of potential influencing factors relates to the implementation strategies. We may conclude from the review that a multi-component training program with practical exercises, on-the-job coaching, and ongoing support and feedback on staff performance during the process of implementation is important in obtaining positive training effects. A joint problem-solving approach across different disciplines also seems to be an effective method of fostering quality of support. The intervention may be more effective if it is integrated into the team's culture and working processes, and if it is compatible with the general vision of the service. Finally, the presence of an effective leader and an effective management structure may be relevant in acquiring and sustaining resources, guiding and clarifying organisational policies, providing staff with clear performance expectations, establishing appropriate organisational structures, and motivating staff to implement the procedures necessary to assure quality.

In conclusion, we wish to discuss some limitations of this review. First of all, we were very selective with regard to our target group of individuals with profound intellectual disabilities and severe motor or sensory limitations. This approach has the advantage that "good practices" for this target group may become clear. Support strategies that are developed as effective for people with, for example, visual and intellectual disabilities are not necessarily applicable to people with profound intellectual and severe sensory or motor disabilities. However we are not sure that the term "profound intellectual and

multiple disabilities” as used by the authors always coincides with the working definition proposed in our introduction.

Secondly, in considering quality-enhancing interventions for clients with PIMD, it is important not to ignore developments in the wider intellectual disability field. We should explore in greater depth how individuals with PIMD might benefit from recent philosophies on service delivery, such as “ordinary lives in the community” and person-centred support, and what effects these changes might have on their well-being. Emerging quality-enhancing strategies for people with intellectual disabilities should also be evaluated and implemented for this target group. We think especially of “Active Support” (Felce, Bowley et al., 2000; Jones et al., 1999, 2001; Mansell, Beadle-Brown, Macdonald, & Ashman, 2003; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; Smith, Felce, Jones, & Lowe, 2002). The basic idea of this approach is that staff practices must be changed to increase the client’s constructive engagement in social, personal, household, leisure or other typical activities of daily living. Main components of the training include: (1) proactive planning of activities on a daily basis; (2) planning of support and assistance during those activities; (3) supporting participation by adding gestural/ physical prompting, demonstration, or physical guidance to verbal instructions, and adjusting the level of assistance to each person’s needs; (4) showing interest and attention to people when they are constructively engaged in activities; and (5) monitoring the opportunities provided to each person each day. Results of several studies have shown significant increases in the level of assistance that clients receive, significant increases in their level of engagement in activities, and significant increases in the number of planned activities (Felce, Bowley et al., 2000; Jones et al., 1999, 2001; Mansell et al., 2002; Smith et al., 2002). Since these effects were more pronounced for individuals with the lowest adaptive skills, this approach looks very promising for our target group of people with profound intellectual and severe sensory or motor limitations. This would be an interesting focus for future research.

A final remark is that in this review, quality of life and quality of support characteristics are closely linked. The primary aim of each service for clients with PIMD should be to increase their quality of life outcomes. However staff assistance and support as well as staff/client interactions may be considered as necessary conditions to achieve valued quality of life outcomes for these individuals, which is why quality of life and quality of support are so inextricably linked for this group. In many of the studies

reviewed here, the results point to the importance of staff interaction and support in attaining positive quality of life outcomes for those with profound intellectual and multiple disabilities.

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