Description of the Support Needs of People with Profound Multiple Disabilities Using the 2002 AAMR System: An Overview of Literature

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Abstract: This paper gives a description of the support needs of people with profound multiple disabilities (PMD), based on the five basic dimensions of the 2002 AAMR System, being intellectual abilities, adaptive behavior, participation, interaction and social roles, health and context. It is based on a study of the literature concerning the target group. The overview shows that people with PMD have the same needs as other people, with regard to participation, relationships, choices, resources and physical and socio-emotional well-being. Nevertheless, it becomes apparent that the needs of people with PMD require specific support. In order to meet these special needs, a relational perspective on support as well as specific characteristics of the support staff and of the support context are necessary.

Anna is a five-year-old girl with congenital brain damage. Her diagnosis is spastic quadriplegia with epilepsy and cortical blindness. Her motor, cognitive and verbal skills are developed to a limited extent. She cannot move. Despite her limitations, Anna is a cheerful girl. She loves physical contact and individual attention from familiar people. She expresses herself by means of her smile and facial expression. She recognizes certain people by their voice, in particular her mother and her brother. In a few weeks Anna will visit a day centre for the first time.

Anna is an individual with profound multiple disabilities (PMD). The expression ‘profound multiple disabilities’ refers to people with severe cognitive as well as severe motor disabilities (Nakken & Vlaskamp, 2002). These disabilities may be the consequence of genetic defects, congenital brain damage, degenerative disorders, disorders of the metabolism or problems during pregnancy or birth. It concerns an extremely heterogeneous group in terms of functional abilities. Due to their limitations in many areas and the combination of limitations, people with PMD need specific support. In order to offer this specific support, a description of their support needs is necessary.

Nevertheless, describing the support needs of people with PMD is not easy. According to Zijlstra and Penning (2004) this has to do with the fact that there is still a lack of psychometrically sound assessment instruments for this target group. However, a description of the support needs is of great benefit for practice as well as for research. According to Nakken (2004, in Zijlstra & Penning) an accurate description can: (1) prevent misinterpretations of research results and of descriptions of ‘good practices’, and result in a more effective use of support strategies, (2) contribute to the discussion that strategies developed for people with visual and intellectual disabilities are not automatically applicable to people with PMD and (3) evaluate the consequences of new developments for the target group.

In this paper we attempt to make a contribution to the description of the support needs of people with PMD. By means of a literature review we explored what is known in international research about the needs of this target group.
Research Design

Framework

The framework that we used in this study is the 2002 System’s theoretical model of the AAMR (Luckasson et al., 2002). According to this model, which is presented in Figure 1, the functioning of people with intellectual disabilities can be understood from the interaction of factors on five dimensions. The concept ‘interaction’ implies that these dimensions are not independent, but that limitations in one dimension should always be seen in connection with other dimensions (Buntinx, 2003). This 2002 AAMR System offers a framework for categorizing and describing the capabilities, the limitations and the support needs of people with intellectual disabilities in several areas. By adopting this framework in describing the needs of people with PMD we come to meet the plea of Nakken (2004, in Zijlstra & Penning, 2004) for a multidimensional description of (the needs of) people with PMD.

For a concise description of the five dimensions, we based ourselves on Buntinx (2003, p. 10–12) and Schalock and Luckasson (2004, p. 139–142):

(1) ‘Intellectual abilities’ or ‘intelligence’ refers to “a general mental ability that includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience” (Luckasson et al., 2002, p. 51).

(2) ‘Adaptive behavior’ is the “collection of conceptual, social and practical adaptive skills that have been learned by people in order to function in their everyday lives” (Luckasson et al., 2002, p. 73).

(3) The third dimension is the dimension of ‘participation, interaction and social roles’. ‘Participation’ and ‘interaction’ must be determined by directly observing one’s engagement in everyday activities and asking whether the individual is actively engaged with (attending to, interacting with, participating in) his or her environment. ‘Social roles’ refer to a set of valued activities normal for a specific age group.
The dimension of ‘health’ comprises a state of complete physical, mental and social well-being and the way in which it influences functioning.

‘Context’ describes the interrelated conditions within which people live their everyday lives and includes the immediate social setting, including the person, family, and/or advocates; the neighbourhood, community, or organization providing education or habilitation services or supports; and the overarching patterns of culture, society, larger populations, country, or sociopolitical influences (Schalock & Luckasson).

Method

We searched literature using four bibliographical databases: ERIC, Medline, PsycINFO and Social Sciences Citation Index. The search strategy existed in combining search terms for the target group (e.g., profound multiple disabilities, profound multiple handicaps, profound mental retardation, profound learning disabilities) with search terms regarding the dimensions of the AAMR-framework (e.g., cognition, adaptive behaviour, health, participation, interaction, social roles, context). We completed the literature, which was mainly in English, with available Dutch literature on the target group. In selecting publications we laid down following criteria:

- Published between 1995 and 2005;
- Empirical research or a review of empirical studies;
- Target group is people with PMD.

Next, publications that met these criteria were categorized per dimension. If for a certain dimension the search strategy yielded very few or no hits, at first the time span was broadened and at a later stage more general publications on this dimension in relation to the target group were included. If a lot of similar studies were available on a certain topic, we only refer to the most recent publications.

Description of the Support Needs

Intellectual Abilities

The level of cognitive functioning of people with PMD is very low. Their IQ is generally under 20 to 25 or their mental age is below 24 months (Ware, 1994). In Piaget’s framework following domains of knowledge are considered to be important for this group: object permanence, (verbal and gestural) imitation, operational causality, object relations in space and cognitive schemes (Kerssies, Rensen, Oppenheimer, & Molenaar, 1989). Through an integration of sensory perceptions and physical movements and through the frequent repetition of actions that bring about certain effects, sensory-motor action schemes are developed, that are the foundation of single problem solving behavior.

Remington (1996) also describes the different fundamental learning processes that take place in people with PMD. One of these processes is habituation, which relates to the effect of repeatedly presenting a stimulus (e.g., a person, who always uses a green spoon, will keep looking for it when some day he/she cannot find it in the cutlery tray). By means of associative learning, people learn to see the association between two stimuli or situations on the basis of repeated experiences, routines and rituals in daily living conditions. This insight enables them to predict events and to anticipate them (e.g., the person has undergone painful tests in hospital, when driving into the hospital’s parking he or she already has a panic reaction). They also learn to become aware of the association between a certain behavior and its effect. When a certain behavior has a positive effect, that behavior will be displayed more often in the future (e.g., the person learns that tapping its cup on the table is followed by filling up the cup, because of this positive effect the person will display the same behavior once more in order to reach the same objective). Research has shown that people with PMD are aware of or can be made aware of such contingencies (Lancioni et al., 2003; Saunders et al., 2003). Learning contingencies enables the individual to have control over his/her environment. Finally, people with PMD learn by means of observation and imitation.

Adaptive Behavior

People with PMD need support and stimulation to acquire social adaptation skills (Aird,
These skills include:

- Conceptual and communicative skills such as demanding something, indicating yes or no, making eye contact and listening to stories.
- Social and emotional skills such as expressing and understanding emotions, taking turns, playing together, learning rules, making choices, taking initiative and task orientation.
- Practical skills such as toilet-training, eating and drinking and getting dressed.

Learning and developing these skills is only possible for people with PMD in an intensive relation with direct support staff and a constructive interaction with their environment (Nind & Hewett, 2001). Therefore, it is necessary to adequately organize the environment and to actively support people with PMD so that they can accomplish interaction and participation (Felce, Jones, & Lowe, 2002).

The learning process has to be dealt with in an active and systematic manner (Choi, Meeuwsen, French, Sherrill, & McCabe, 2001; Lancia, O’Reilly, Campodonico, & Mantini, 2002; O’Neill & Heathfield, 2004; Reid, Phillips, & Green, 1991; Remington, 1996). This regards breaking up skills into small sub-steps that are gradually taught in the person’s tempo, offering effective forms of support and systematically using reinforcers. Additionally, the person’s self-control and his/her own contribution to the learning process must be preserved. The motivation and engagement of people with PMD is furthered by relating to their initiatives and perception of the environment, by creating challenging situations and by introducing variation in the learning process. The importance of positive expectations and gaining successful experiences with this is stressed.

In the learning process technical aids can also be used (Davis, Young, Cherry, Dahman, & Rehfeldt, 2004; Murphy, Saunders, Saunders, & Olswang, 2004; Smith, Gast, Logan, & Jacobs, 2001). When selecting learning aids the individual’s cognitive and sensory-motor limitations and capabilities should be taken into account. Preferences for sensory perception of specific stimuli and materials should also be assessed in order to adequately shape the learning process.

An important focus of attention in the learning process is the alertness and attention of people with PMD. In research, these characteristics are put forward as an essential basis for learning and developing (Arthur, 2003, 2004; Foreman, Arthur-Kelly, Pascoe, & King, 2004; Guess, Roberts, & Rues, 2002). ‘Behavioral state assessment’ comprises the systematic observation of behavioral expressions of alertness in people with PMD. Research has shown that variables on the level of the individual (e.g., health status) as well on the level of the context (e.g., an active, interactive and social learning environment) influence the level of alertness of the individual (Arthur, 2003, 2004; Vlaskamp, de Geeter, Huijsmans, & Smit, 2003).

Even though people with PMD can acquire social adaptation skills, they need support in almost all daily life activities such as dressing, washing, eating, going to the toilet and so on (Nakken & Vlaskamp, 2002). Personal and intimate care therefore takes up a lot of time and it is important to pay attention to its quality (Carnaby & Cambridge, 2002).

Because communication plays a crucial part in the lives of people with PMD, we will look into this domain of adaptive behavior more closely. People with PMD rarely use spoken language, instead they express their wishes and feeling by way of pre- or protosymbolic communication such as facial expressions, movements, sounds, posture and muscle tension (Vlaskamp & Oxener, 2002). They send out unconventional and mostly idiosyncratic and context-bound signals that are often difficult to interpret. As such, a thorough knowledge of the person and the context is necessary to attach an adequate and consistent meaning to the person’s signals (Grove, Bunning, Porter, & Olsson, 1999). It is also very important that the team of professional staff and the parents confer on this matter and share experiences. For research demonstrates that direct support staff often only slightly agree with each other when it comes to interpreting affective expressions (Hogg, Reeves, Roberts, & Mudford, 2001).

Several studies deal with the question on how to support the communication of people with PMD in daily living situations (Daelman,
First, it is very important to regard the person as an active partner in communication. Analyzing videotaped interactions may offer support staff a clearer view of the person's contribution and initiatives in the interaction and may help interpreting the person's communication more adequately. As such, support staff becomes more able to attune to the person's communicative abilities and to respond in a responsive and contingent manner to the person's behavior. At first, many of the person's signals have no conscious meaning but support staff attaches meaning to them by overinterpretation. Through shared attention towards objects and familiar rituals, both partners in communication build up shared meanings to which they may refer afterwards. As such, the person's communicative behavior becomes more direct and goal-oriented and the person gets the opportunity to comment on actions and objects (protodeclaratives) or to ask something (protoimperatives). Reciprocity is encouraged by taking turns and by immediate or delayed imitation.

This process can be supported by technical aids, which include systems that play pre-recorded verbal messages when a button is pushed (e.g., Big Mack) and concrete objects (or parts) that refer to certain situations or activities (e.g., beaker: drink) (Jones, Pring, & Grove, 2003). Graphic-visual representations in the form of communication boards or communication books (e.g., pictos, photos) are also utilized. When selecting communication aids, the capabilities and preferences of the person must be taken into account. Other relevant criteria are age adequacy, availability and user-friendliness of the communication aids.

**Participation, Interaction and Social Roles**

It is important that people with PMD can participate actively in a variety of activities geared to their abilities and limitations and to their interests and preferences. Their perception of the environment is mostly orientated at their own body (Fröhlich, 1995). Therefore, sensory perception (by way of hearing, sight, taste, smell and touch) and perception of movement (by way of somatic, vestibular and vibratory stimuli) take on a central place in setting up activities.

Activities play an essential role in the personal development of people with PMD, as it is important that they enjoy being active, whether or not together with other people (Nilsson & Nyberg, 2003; Petry, Maes, & De Muynck, 2004; Wiersma, Beumer, Koedoot, & Vlaskamp, 2002). The activities should furthermore be sufficiently stimulating and challenging. For one of the objectives is to make people with PMD aware of their own capabilities and of their environment. They are encouraged to move, (re)act, manipulate and explore materials. In this way they obtain certain knowledge and insights and expand their options for action. In addition, activities are a way of building up contacts with support staff and group members.

Several authors stress the positive significance of social interactions with peers without a disability (Downing, 2001; Foreman & Arthur, 2004; Foreman et al., 2004; Logan et al., 1998). The latter turn out to be responsive partners who, when supported, interpret the person’s communicative signals adequately and use effective strategies to build up positive interactions. The person with PMD gets the opportunity to participate, to enjoy interactions with others and to enlarge its social network. Therefore, currently, it is stressed that having people with PMD participate in regular class and leisure time activities may develop their sense of being part of the community.

Every person with PMD is an individual who has his own character and temperament. The challenge therefore is to discern and to take into account each person's individuality in daily contacts and activities (Petry, Maes, & Vlaskamp, 2005). Esteem of and respect for their individuality is essential for people with PMD (Fröhlich, 1995). Moreover, it is important that support staff perceives, confirms and positively appreciates the person's capabilities. As such, a feeling of positive self esteem can grow.

The positive self esteem that people with PMD feel is also linked to the degree of self determination they have. It is of great importance for people with PMD to feel that they influence and control their life and environment and that they can make choices. Research has demonstrated that people with
PMD are able to make choices (Lancioni, O’Reilly, & Emerson, 1996; Saunders et al., 2005). Support staff is expected to adequately build in options in the daily context and to contingently take into account a person’s preferences (Browder, Cooper, & Lim, 1998; Cannella, O’Reilly, & Lancioni, 2005; Green, Middleton, & Reid, 2000). As a result of the opportunity to make choices the person takes more initiatives and is more actively involved in activities (Cannella et al.; Cole & Levinson, 2002; Lancioni et al., 1996) and problem behavior is reduced (Cannella et al.; Lohrmann-O’Rourke & Yurman, 2001).

Several studies illustrate how to systematically examine the preferences of people with PMD (Hagopian, Long, & Rush, 2004; Hatton, 2004; Lancioni et al., 1996; Logan & Gast, 2001). These preferences can be investigated in an indirect manner (e.g., interviewing proxies) as well as in a direct manner. In the latter, the person is given (one after the other or in pairs) several alternatives (e.g., food, personal things, toys, sensory stimuli) and one observes if the person turns towards the stimuli or aside and how long the person focuses on certain stimuli. It is also possible to put the person in different situations in order to determine preferences for certain postures, interactions or activities. The stimuli, objects or activities for which the person has expressed a certain preference, can subsequently be built in into the curriculum or used as reinforcers in a learning process. However, these preferences must be repeatedly retested, for they may change over time. Reid and Green (2002) have observed that there is but little agreement on the preferences of people with PMD between the results of a systematic investigation on the one hand and a questionnaire for support staff on the other hand.

Material aids may help the person to express certain choices (Lancioni, O’Reilly, & Basili, 2001). The person himself/herself may activate pleasant stimuli (light, music, toys) by using switches by hands, feet or head (Lancioni, O’Reilly, Singh, Oliva, & Groeneweg, 2002; Singh et al., 2003). Speech output systems make it possible for the person to turn a non-verbal question into a verbal message, e.g., by pushing a button or by touching on a board the photo of a favourite object or activity.

Health

*Sensory motor functions.* People with PMD often face problems with regard to their motor system such as spastic tetra- or quadriplegia, scoliosis, deformities, malformations, fragile bones and muscular lengthening. As a consequence, many people cannot sit, stand or move without support and they cannot use their hands and/or arms or only to a restricted extent. As such, they cannot move freely and their activities are extremely hindered (Nakken & Vlaskamp, 2002).

Measures need to be taken to prevent, compensate and/or treat the motor limitations. Furthermore, it is important to pay attention to a good posture. Regularly changing the person’s posture allows him/her to observe the environment from diverse angles, increases his/her bodily comfort and improves his/her social-communicative interactions (McEwan, 1992). Moreover, a good posture that maximizes movements of hand, arm and head is an important condition for learning (Smith et al., 2001). In order to make these changes of posture possible, adequate aids are used (e.g., positioning systems, supine board). Moving aids allow people with profound motor limitations to participate in activities in their immediate environment and to increase their freedom of movement (Nilsson & Nyberg, 2003). Finally, sensory-motor skills such as using arms and hands to manipulate objects, eye-hand coordination, posture control, mobility and orientation can be taught through goal-orientated activities.

An estimated 90% of people with PMD have profound, mostly cerebral, visual disorders and 25% have auditory limitations (Evenhuis & Nagtzaam, 1999; Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; van den Broek, Janssen, van Ramhorst, & Deen, 2004). Moreover, other senses, such as taste, smell and touch, are often damaged. It is obvious that these limitations affect the way people with PMD process the stimuli that are offered to them. Therefore, it is essential that sensory abilities and limitations are charted and taken into account when offering activities, making the environment recognizable and looking for adequate forms of communication.
Physical health. Physical well-being is for people with PMD no commonplace. They encounter several physical problems, e.g., regarding the bronchial tubes, the digestive system or urinary tract system (Veugelers, Benninga, Penning, & Evenhuis, 2004; Zijlstra, Vlaskamp, & Fonteine, 2004). Epilepsy also frequently occurs and has a large impact on the person’s alertness. Regular observation and registration of the person’s health status are therefore advisable. Physical problems can be registered and if possible their cause may be discerned and adequate medical treatment can be given. At the same time aggravations of existing health problems or complications can be avoided. Attention also has to be paid to signals that indicate pain and to pain control (Zwakhalen, van Dongen, Hamers, & Abu-Saad, 2001). Because of these medical problems many people with PMD take medication, which must be carefully monitored, adjusted and if possible cut down. For medication may cause a number of side effects such as reduced alertness or habitation and resistance. In addition, it is important to have an eye for the impact of health problems on the daily support of the target group (Zijlstra et al., 2004).

Feeding problems are a frequently occurring health problem. Research has shown that about 70% of the people with PMD suffer from gastro-oesophageal reflux (Böhmer et al., 1999). This results in oesophageal complaints, breathing complaints and behavioral problems. In addition to gastro-oesophageal reflux, other problems such as phlegm, bad digestion or swallowing and chewing problems make feeding difficult (Rouse, Herrington, Assey, Baker, & Golden, 2002). About 16% of people with PMD are tube fed (Inspectie voor de Gezondheidszorg, 2000). Support from nutritionists and speech therapists are necessary and meaningful in order to find adequate forms of support for people with feeding problems.

Mental health status. Behavioral problems seem to increase in proportion to the person’s cognitive and other disabilities (Emerson, 2001). Kiernan and Kiernan (1994) find a prevalence of 22% children with problem behavior (e.g., aggressive behavior, outbursts of anger, self injuring behavior, destructive behavior, rebellious behavior, stereotypic behavior) in a sample of schools for children with severe intellectual disabilities. These behavioral problems may impede the personal growth and development, relations with others and participation in the environment.

Behavioral problems are often analyzed and treated from a multimodal point of view (Emerson, 2001). Behavioral problems may be related to the person’s genetic syndromes, neurological disorders or physical state of health (e.g., pain, fatigue) or may be an expression of fear, uncertainty, traumatic experience or psychiatric disorders such as depression or psychosis (Tsiouris, 2001). As a consequence, more and more attention is paid to preventing mood disorders in people with PMD (Phillip & Hogg, 2004; Ross & Oliver, 2002; Oliver, 2004). However, interpreting the emotional state of mind of people with PMD remains a difficult matter (Ross & Oliver, 2003). Limitations in the field of learning, social relations and communication furthermore make these children especially vulnerable. Not only individual factors may elicit problem behavior, but also interactional factors (e.g., lack of positive attention, expectations that are too high or too low, lack of own contribution, lack of control, negative interactions with group members) and contextual factors (e.g., group pressure, lack of adequate activities, difficult situations of transition). In many cases problem behavior persists because of a learning process of positive or negative reinforcement. Therefore, Emerson (2001) concludes that a clear understanding of problem behavior is only possible on the basis of a model directed at the interface between developmental, learning, neurobiological, psychiatric and ecologic processes.

Context

To give people with PMD adequate support the context has to meet certain requirements. We successively go more deeply into the relational support perspective, the characteristics of support staff and the characteristics of the environment.

A relational support perspective. People with PMD need other people who have an eye for the subtle way they express their needs and wishes and who are able and willing to respond to these needs and wishes (Vlaskamp & Verkerk, 2000). This relational dependence is
the core of the support process. However, dependence must not be regarded as a notion with a negative meaning, but rather as a means to develop one’s existence and as an essential condition for quality of life. The life of people with PMD is imbedded in relations with other people that give meaning to their existence. They can have meaningful living and learning experiences only when there are other people who support them.

The well-being of people with PMD is closely connected to establishing a safe attachment relation with familiar support staff (Petry et al., 2004; Petry et al., 2005; Vlaskamp, 1999). Such a relation is characterized by support staff making the person feel safe by their availability and sensitive responsiveness. The latter implies that support staff perceives the person’s signals, accurately interprets their meaning, selects adequate answers and reacts in such a way that the person’s needs are met (Claussen & Crittenden, 2000; Petry, Maes, & Vlaskamp, in press). As such, a feeling of basic safety and security evolves which enables the person to optimally develop his/her abilities, to feel competent and to explore the environment. This feeling of safety is also enhanced by making the environment surveyable, recognizable and predictable. People with PMD can better follow and understand what is happening in the environment when support staff adapt to their pace, announce what is going to happen, avoid sudden transitions and give them time to get used to (new) situations.

Regularly recurring behavior patterns and routines, familiar support staff, permanent structures and a recognizable organization are things they can hold onto and which make their environment comprehensible and predictable. People with PMD can better follow and understand what is happening in the environment when support staff adapt to their pace, announce what is going to happen, avoid sudden transitions and give them time to get used to (new) situations.

Characteristics of support staff. In accordance with the relational support perspective, the importance of the relational skills of support staff is strongly stressed (Petry et al., in press). Support staff is expected to believe in the (developmental) capabilities of people with PMD, who need to be approached as competent persons who are able to enter into relations and to have control over their environment (Vlaskamp, 1999).

To be able to discern the needs of people with PMD, support staff needs to be attentive and committed. An attitude of receptivity is essential in order to check whether the person experiences support as it was intended to be. In a dialogue with the person support staff creates opportunities for the person to make his/her own contribution and actively gear their actions to his/her needs, wishes and preferences.

Working with people with PMD requires a great deal of motivation and commitment. Support staff is expected to critically reflect on their own beliefs, values and expectations, behavior and attitude (Maeckelberghe, 2004).

To be able to attune one’s actions to the above-mentioned support needs, support staff requires specialist knowledge and skills. High quality instruction and permanent training that is specifically oriented towards working with this target group may contribute to this. In research, a description is given of training programs that are directed at giving options to persons with PMD (Salmento & Bambara, 2000), at offering support in an well-considered and reflexive manner (Singh et al., 2003), at actively and adequately supporting them to participate in activities (Jones et al., 2001) and to improve mutual communication and interaction (Bloomberg, West, & Iacono, 2003; Dobson, Upadhyaya, & Stanley, 2002; Realon, Bligen, La Force, Helsel, & Goldman, 2002; Roemer & Van Dam, 2004).

Characteristics of the support environment. Supporting people with PMD involves many people who must cooperate intensively (Petry et al., in press; Vlaskamp, 1999; Zijlstra, 2003). This presupposes a shared responsibility and a full partnership between parents and professional support staff. Parents have acquired very important expertise with regard to their child, which is why it is important that their experience and expertise is exchanged with professional support staff. Parents have acquired very important expertise with regard to their child, which is why it is important that their experience and expertise is exchanged with professional support staff and that it is taken seriously. It is necessary that parents and professional support staff pass on information to each other because of the person’s limited communicative abilities. In addition, parents want to have a say in the support process and to participate in deciding which objectives will
be worked on and what shape and content will be given to their child’s support. Finally, sound communication between parents and professional support staff is essential for tuning the context of family, school and support in to one another and for enriching the parent’s and professional support staff’s competence in giving sensitive support to the person with PMD (Owen, Ware, & Barfoot, 2000).

The same is required of the cooperation between members of professional support staff (Orelve & Sobsey, 1996; Petry et al., in press; Rainforth & York-Barr, 1997; Smith et al., 2001; Vlaskamp, 1999; Zijlstra, 2003). It is essential that the work of all disciplines concerned with supporting people with PMD, is integrated. Together they decide which objectives they want to achieve and which approach best fits in with the person’s needs, wishes and capabilities. They are experts in their own discipline, but they can also learn from other disciplines. It may for instance be desirable that the physiotherapist teaches the other team members how to further the child’s posture. Good teamwork is characterized by an open communication and consultation between disciplines.

For people with PMD, continuity in support is essential (Zijlstra, Vlaskamp, & Buntinx, 2001). They need a stable environment with familiar people in whose company they feel safe and understood. Employing temporary workers and applying a shift system make it more difficult to build up or sustain a relationship. People with PMD not only need permanent support staff, but also a sufficient number of support as well as medico-therapeutic staff. Tøssebro (1995) demonstrated that support staff in groups of one to five people paid more attention to their individual wishes and reacted better to their communicative signals than in larger groups.

Finally, supporting people with PMD must be goal-oriented and methodical (Petry et al., in press; Zijlstra, 2003). More specifically, this implies that in an individual support plan or educational programme knowledge is systematically collected on the person’s capabilities, limitations, wishes and preferences. Concurrently, an analysis is made of the resources and limitations of the family and of other contexts that are relevant for the person. Furthermore, all parties concerned discuss how support can be optimally geared. Together they determine objectives and steps that are to be taken in order to realize them. They also regularly check whether the planned objectives have been realized and whether one has proceeded as agreed upon. Objectives and content has to be geared to the person’s individual learning and developmental capabilities. For each person must be able to follow his/her own life and learning track that answers to his/her capabilities, needs and interests.

Discussion

At the beginning of this paper we introduced Anna, a girl with PMD. A description of Anna using the 2002 AAMR System (Luckasson et al., 2002) would without a doubt have rendered a richer, more complete and more balanced picture. The multidimensionality of the model makes a broader characterization possible with the description of a person’s functioning on different dimensions. Within each of these dimensions attention is paid to the person’s capabilities, limitations and needs. It is a functional system in which the functioning of people in daily situations takes a central place with an eye for an individual’s capabilities and not only for his/her limitations (Buntinx, 2003). A description of the target group according to the 2002 AAMR System invites us to focus not only on the person with PMD but also on the context that can have an impeding or stimulating influence on the person’s functioning and offer adequate support.

Another important aspect in the 2002 AAMR System is the attention for the interaction between the dimensions. The complex interaction between the capabilities and limitations of people with PMD on several domains is very decisive for their functioning. A final advantage of the 2002 AAMR System is that the different dimensions are not typical for describing people with (intellectual) disabilities, but have a universal validity (WHO-FIC, 2002 in Buntinx). As such, people with PMD are not isolated as a separate group. Throughout the description it becomes clear that people with PMD have the same needs as other people with regard to participation, relations, choices, competences and physical and socio-emotional well-being. It also becomes appar-
ent that on each of the dimensions the needs of the target group require specific support.

Nevertheless, using the 2002 AAMR System to describe the support needs of people with PMD, has also some disadvantages. Certain aspects that are important in the functioning of the target group fit difficultly into the model or are interpreted too limited in it. An example is communication. In the 2002 AAMR System there is only room for a description of the person’s communicative skills whereas for people with PMD communication is best looked at more broadly as a communicative process between the person with PMD and support staff. The communicative and relational aspect takes on such a central place in people with PMD that it influences all other aspects of functioning. As a result, the theme of relation, interaction and communication repeatedly recurs in the description of the support needs using the 2002 AAMR System. The interdependent character of support, that forms a thread throughout all dimensions of functioning of people with PMD, fits difficultly into one dimension of the model. Other authors also pointed out this neglect of the relational perspective in support (Buntinx, 2003; Reinders, 2000; Vlaskamp & Verkerk, 2000).

A description of the support needs of people with PMD using the 2002 AAMR System can in several areas offer a surplus value for practice and research as well as for policy. In practice, the AAMR framework is usable for the characterization of individual clients. The description presented in this paper can be operationalized in concrete topics and items that give direction in assessment of this target group. The presented support needs on each dimension offer guidelines for interventions and activities and they can function as a starting point for determining and evaluating the range of support that is offered to people with PMD. In research, an accurate description of the target group has the advantage of spotting gaps in research. The overview of literature shows that the attention of researchers for this target group has increased substantially during the last years. Nevertheless, an expansion and deepening of the research on all domains remains necessary. Moreover, a clear delineation of the target group promotes an unambiguous interpretation of research on the (needs of the) target group and on the place where and the manner in which they are supported. Finally, policy benefits from an accurate description of the support needs of this target group. It offers an insight in the problems of people with PMD and aids the making of adequate policy. Additionally, evaluating and assessing the extent to which new policy developments are geared to the support needs of the target group becomes easier.

This overview of literature presents the state of the art of research on the support needs of people with PMD. Nevertheless, we do not pretend to give a complete overview. For instance, some specific intervention studies were not included although they could yield useful information on the support needs of the target group. An overview of literature on intervention strategies and their effectiveness would therefore be a useful addition to this overview on the support needs of children with PMD.

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Support Needs of People with PMD / 143