

Description of the support needs of people with profound intellectual and 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 intellectual and multiple disabilities (PIMD), based on the five basic dimensions of the 2002 AAMR System, more specifically 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 makes clear that people with PIMD have the same needs as other people, with regard to participation, relationships, choices, resources and physical and socio-emotional well-being. However it also becomes obvious that the needs of people with PIMD require specific support. In order to meet these special needs a relational perspective and specific characteristics of the support staff and the support context are necessary.

Running title: support needs of people with PIMD

Keywords: profound intellectual and multiple disabilities, support needs, overview of literature

1. Introduction

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 persons. She expresses herself by means of her smile and facial expression. She recognizes certain persons by their voice, in particular her mother and her brother. In a few weeks Anna visits a day centre for the first time.

Anna is a person with profound intellectual and multiple disabilities (PIMD). The expression ‘profound intellectual and multiple disabilities’ refers to people with severe cognitive as well as severe sensory-motor disabilities (Nakken and 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 PIMD need specific support. In order to be able to offer this specific support, a description of their support needs is necessary.

Describing the support needs of people with PIMD is nevertheless not easy. According to Zijlstra and Penning (2004) this has to do with the fact that there is still a lack of (scientific and well-founded) assessment instruments. However a description of support needs is of great benefit for practice as well as for research. An accurate description can according to Nakken (2004, in Zijlstra & Penning, 2004): (1) prevent misinterpretations of research results and of descriptions of ‘good practices’, and result in a more effective use of e.g. support strategies,

(2) contribute to the discussion that strategies that are developed for e.g. people with visual and intellectual disabilities are not just like that applicable to people with PIMD and (3) evaluate and assess 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 PIMD. By means of a study of literature we explored what is known in international scientific research on the needs of this target group.

2. Research design

Framework

The framework that we used in the study of literature is the 2002 System's theoretical model of the AAMR (Luckasson et al., 2002). According to this model 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. 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 we agree with the plea of Nakken (2004, in Zijlstra & Penning, 2004) for a multidimensional description of (the needs of) people with PIMD.

Figure 1

For a concise description of the five dimensions, we based ourselves on Buntinx (2003, p.10-12) and Schalock & 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’ are best 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.

(4) The dimension of ‘health’ comprises a state of complete physical, mental and social well-being and the way in which it influences functioning.

(5) ‘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 socio-political influences (Bronfenbrenner, 1979, in Schalock & Luckasson, 2004).

Method

Literature was searched 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 PIMD.

Next, publications that met these criteria were categorized per dimension. If for a certain dimension the search strategy yielded very few or no hits, initially the time span was broadened and at a later stage more general publications on the application of 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.

3. Description of the support needs

3.1. Intellectual abilities

The level of cognitive functioning of the people this paper deals with is very low. Their IQ generally is under 20 to 25 or their mental age is below 24 months (Ware, 1994). In the framework of Piaget 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 (Keressies, 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. They are the foundation of single problem solving behavior.

Remington (1996) describes also the different fundamental learning processes that take place in people with PIMD. Habituation relates to the effect of repeated presenting of a stimulus (e.g. a person, who always uses a green spoon, will keep looking for it when some day it is not to be found 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 be aware of the association between 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 again display the same behavior in order to reach the same objective). Research has shown that people with PIMD are aware of or can be made aware of such contingencies (Lancioni et al., 2003; Saunders et al., 2003). Learning contingencies enables the person to have control over its environment. People with PIMD finally learn by observation and imitation.

3.2. Adaptive behavior

People with PIMD need support and stimulation in order to acquire social adaptation skills (Aird, 2001; Grove & Peacey, 1999; Haee, 2001; Porter, 2004). It concerns among other things:

- Conceptual and communicative skills such as demanding something, indicating yes or no, making eye contact, listening to stories.

- Social and emotional skills such as expressing and understanding emotions, taking turns, playing together, learning rules, making choices, taking the initiative, task orientation.
- Practical skills such as toilet-training, eating and drinking, getting dressed.

Learning and developing the above-mentioned skills is for people with PIMD only possible in an intensive relation with direct support staff and a constructive interaction with their environment (Nind & Hewett, 2001). It then is the question to organize the environment in such an adequate way and to support the people in such an active way that they reach interaction and participation (Felce, Jones, & Lowe, 2002).

The learning process has to be tackled and supported in an active and systematic manner (Choi, Meeuwssen, French, Sherrill & McCabe, 2001; Lancioni, 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. Besides that, the person's self-control and its own contribution to the learning process must be preserved. The motivation and engagement of people with PIMD 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 person'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 established 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 PIMD. 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 PIMD. 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 person (Arthur, 2003; 2004; Vlaskamp, de Geeter, Huijsmans & Smit, 2003).

Even though people with PIMD 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 PIMD, we will look into this domain of adaptive behavior more closely. People with PIMD seldom use spoken language (Vlaskamp & Oxener, 2002). They send out unconventional signals that are often difficult to interpret. They express their wishes and feeling by way of pre- or protosymbolic communication such as facial expressions, movements, sounds, body posture, and muscle tension. By means of questionnaires and systematic observation one tries to draft a profile of the communicative signals a person uses and to get an insight in the way a person expresses his or her wishes, preferences and feelings (Daelman, 2003; Granlund & Olsson, 1997). Because the communicative expressions of people with PIMD are mostly idiosyncratic and context-bound, one has to repeatedly pass through a search process in order to give an adequate and consistent meaning to the person's signals (Grove, Bunning, Porter, & Olsson, 1999). This is only possible on the basis of a thorough knowledge of the person and of the

context. 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 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 PIMD in daily living situations (Daelman, 2003; Downing, 2001; Granlund & Olsson, 1997; Nind & Hewett, 2001). Firstly, it is very important to regard the person as an active partner in communication. For instance by an analysis of video-taped interactions, support staff may get a clearer view of the person's contribution to and initiatives in the interaction and interpret it adequately. They then can better gear to the person's communicative abilities (according to nature and level) and in a responsive and contingent manner respond to the person's behavior. At first many of the person's signals have no conscious meaning but support staff attaches a meaning to them by overinterpretation. Through shared attention towards objects and familiar rituals, the partners in communication build up shared meanings to which they may refer afterwards. The person's communicative behavior e.g. may become more goal-oriented and more direct. In this way the person gets an 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.

Technical aids can support this process. These may be systems that play pre-recorded verbal messages when a button is pushed (e.g. Big Mack). Concrete objects (or parts) that refer to certain situations or activities (e.g. beaker: drink) can also be used (Jones, Pring & Grove, 2003). Finally there are graphic-visual representations in the form of communication boards or communication books (e.g. pictos, photos). When selecting communication aids the capabilities and preferences of the person in question must be taken into account. Other relevant criteria are age adequacy, availability and ease of use of the communication aids.

3.3. Participation, interaction and social roles

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

Activities play an essential role in the personal development of people with PIMD (Nilsson & Nyberg, 2003; Petry, Maes & Demuynck, 2004; Wiersma, Beumer, Koedoot & Vlaskamp, 2002). First it is important that they are able to enjoy being active, whether or not together with other people. The activities should furthermore be sufficiently stimulating and challenging. For one of the objectives is to make people with PIMD 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. Activities are also 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). They 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 PIMD in its turn gets the opportunity to participate, to enjoy interactions with others and to enlarge its social network. Recently it therefore is stressed that having people with PIMD participate in regular class and leisure time activities may develop their sense of being part of the community.

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

The positive self esteem that people with PIMD feel, is also linked to the degree of self determination they have. It is of great importance for people with PIMD to feel that they influence and control their life and environment and that they can make choices. Research has demonstrated that people with PIMD 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 advantage of 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, O'Reilly & Lancioni, 2005; Cole & Levinson, 2002; Lancioni, O'Reilly & Emerson, 1996) and problem behavior is reduced (Cannella, O'Reilly & Lancioni, 2005; Lohrmann-O'Rourke, & Yurman, 2001).

Several studies illustrate how to systematically examine the preferences of people with PIMD (Hagopian, Long & Rush, 2004; Hatton, 2004; Lancioni, O'Reilly & Emerson, 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 may be used as reinforcers in a learning process. The preferences must be repeatedly retested, for they may change over time. Reid and Green (2002) have observed that there is but little agreement between the results of a systematic investigation on the one hand and a questionnaire for support staff on the other hand about the preferences of people with PIMD.

Material aids may help the person to express certain choices (Lancioni, O'Reilly, & Basili, 2001). The person himself 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.

3.4. Health

Sensory motor functions

Regarding the motor system people with PIMD often face spastic tetra- or quadriplegia; scoliosis, deformities, malformations, fragile bones, muscular lengthening,... They therefore cannot move freely and their activities are extremely hindered. 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 (Nakken & Vlaskamp, 2002).

Measures are taken to prevent and compensate and/or treat the motor limitations. It is furthermore 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). A good posture that maximalizes movements of hand, arm and head, moreover is an important condition for learning (Smith, Gast, Logan & Jacobs, 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 through goal-orientated activities sensory motor skills can be taught such as using arms and hands to manipulate objects, eye-hand coordination, posture control, mobility and orientation.

An estimated 90% of the people with PIMD have profound, mostly cerebral, visual disorders and 25% have auditive limitations (Evenhuis & Nagtzaam, 1998; Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; van den Broek, Janssen, van Ramhorst & Deen, 2004). But other senses too, such as taste, smell and touch, are often damaged. It is obvious that these limitations affect the way these people process the stimuli they are offered. It therefore 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 PIMD 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 & Fontaine, 2004). Epilepsy occurs also frequently, with much impact on the person's alertness. Regular observation and registration of their state of health are therefore advisable. In this way 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 are avoided. Attention must also be paid to signals that indicate pain and to pain control (Zwakhalen, van Dongen, Hamers & Abu-Saad, 2001). As a consequence of sometimes complex medical problems many people with PIMD use medication. The use of medication must be carefully monitored, adjusted and if possible cut down. For medication may cause a number of side effects such as reduced alertness or habituation and resistance. Next to it, 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 special class of health problems. For research has shown that about 70% of the people with PIMD suffer from gastro-oesophageal reflux (Böhmer et al., 1999). This results in oesophageal complaints, breathing complaints and behavioral problems. Next to gastro-oesophageal reflux also phlegm, bad digestion or swallowing and chewing problems may make feeding difficult (Rouse, Herrington, Assey, Baker, & Golden, 2002). About 16% of the people with PIMD are tube fed (Inspectie voor de Gezondheidszorg, 2000). Consultation of and 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

The risk of behavioral problems seems to increase in proportion to the person's cognitive and other disabilities (Emerson, 2001). Kiernan & Kiernan (1994) find a prevalence of 22% children with problem behavior in a sample of schools for children with severe intellectual disabilities. There is question of, among other things, aggressive behavior, outbursts of anger, self injuring behavior, destructive behavior, rebellious behavior, stereotypic behavior etc. Behavioral problems may check 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). It is also possible that they are 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 PIMD (Phillip & Hogg, 2004; Ross & Oliver, 2002; Oliver, 2004). A difficulty regarding this target group remains however the interpretation of their emotional state of mind (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. Emerson (2001) therefore concludes that a clear understanding of problem behavior is only possible on the basis of a model that is directed at the interface between developmental, learning, neurobiological, psychiatric and ecologic processes.

3.5. Context

In order to be able to give people with PIMD adequate support the context too must meet certain conditions. 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 PIMD need other people who have an eye for the subtle way they express their needs and wishes, who feel its appeal and who are able and willing to somehow do something with it (Vlaskamp, & Verkerk, 2000). This relational dependence therefore is the essential core of the support process. Dependence here must not be regarded as a notion with a negative meaning, but as a means to develop one's existence and as an essential condition for quality of life. The life of people with PIMD 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 to do so.

The well-being of people with PIMD is closely connected to establishing a safe attachment relation with familiar support staff (Petry, Maes, & Demuynck, 2004; Petry, Maes, & Vlaskamp, 2005a; Vlaskamp, 1999). Such a relation is characterized by support staff making the person feel safe by his 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, 2005b). This creates a feeling of basic safety and security. It enables the person to optimally develop his/her abilities, to feel competent and active and to explore the environment. This feeling of safety is also enhanced by making the environment surveyable, recognizable and predictable. People with PIMD 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 and progress of activities is something they can hold onto. They make their environment comprehensible and predictable. This does

not alter the fact that flexibility is also a focus of attention. One day people with PIMD can manage somewhat more than other days. Support staff must adapt and gear their expectations to what the person can cope with at that moment.

Characteristics of support staff

In accordance with the relational support perspective, the importance of the relational skills of the support staff is strongly stressed (Petry, Maes & Vlaskamp, 2005b). Support staff is expected to believe in the (developmental) capabilities of people with PIMD. It is necessary that people with PIMD are approached as competent persons who are able to enter into relations and to have control over their environment (Vlaskamp, 1999).

From the perspective of ethics of care Vlaskamp en Verkerk (2001) formulate four central aspects in the attitude of support staff. In order to be able to discern the usual and special needs of people with PIMD, support staff needs to be attentive and committed. Actively supporting the person requires responsibility and competence. 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 bring his/her own contribution and actively gear their actions to his/her needs, wishes and preferences.

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

In order to be able to gear 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 PIMD (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

The support of people with PIMD is a matter of many people who must cooperate intensively (Petry, Maes & Vlaskamp, 2005b; Vlaskamp, 1993; Zijlstra, 2003). This presupposes first of all a shared responsibility and a full partnership between parents and professional support staff. Parents have a very important expertise with regard to their child. It is important that their experience and expertise is exchanged with professional support staff and that it is taken seriously. Also because of the person's limited communicative abilities, it is necessary that parents and professional support staff pass information to each other on all that is of concern to the person. Parents also want to have a voice in the support process and to join 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 gearing to one another the context of family, school and support and for enriching the parent's and professional support staff's competence in giving sensitive support to the person with PIMD (Owen, Ware, & Barfoot, 2000).

The same is required of the cooperation between professional support staff (Orelove, & Sobsey, 1996; Petry, Maes, & Vlaskamp, 2005b; Rainforth, & York-Barr, 1997; Smith et al., 2001; Vlaskamp, 1993; Zijlstra, 2003). It is essential that the work of all disciplines concerned with supporting people with PIMD, 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 also learn from other disciplines' information and skills. It may e.g. be desirable that the physiotherapist teaches the other team members how to further the child's posture. Good team work is also characterized by an open communication and consultation between disciplines.

For people with PIMD 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. Working with temporary workers and a shift system makes it more difficult to realize or carry on a relationship. People with PIMD 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.

Supporting people with PIMD finally must be goal-oriented and methodical (Petry, Maes, & Vlaskamp, 2005b; Zijlstra, 2003). This means that in an individual support plan or educational programme knowledge is systematically collected on the person's capabilities, limitations, wishes and preferences. At the same time an analysis is made of the family's resources and limitations and of other contexts that are relevant for the person. Next to it, 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. It is also regularly checked whether the objectives they planned have been realized and whether one has proceeded as agreed. Objectives and content are geared to the person's individual learning and developmental capabilities. For each person must be able to follow its own life and learning track that answers its capabilities, needs and interests.

4. Discussion

At the beginning of this paper we introduced Anna, a girl with PIMD. A description of Anna using the 2002 AAMR System (2002) would without a doubt have rendered a richer, completer 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 a person'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 PIMD 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. For people with PIMD the complex interaction between their capabilities and limitations on several domains is very decisive for their functioning. A final advantage of the 2002 AAMR System is the fact that the different dimensions are not typical for describing people with (intellectual) disabilities, but have a universal validity (WHO-FIC, 2002 in Buntinx, 2003). As such people with PIMD are not isolated as a separate group. Throughout the description it becomes clear that people with PIMD have the same needs as other people with regard to participation, relations, choices, competences and physical and socio-emotional well-being. At the same time it also becomes evident that on each of the dimensions the needs of the target group require specific support.

Using the 2002 AAMR System to describe the support needs of people with PIMD, has nevertheless 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 the model. An example of this is communication. In the 2002 AAMR System there is only space for a

description of the person's communicative skills whereas for people with PIMD communication is best looked at more broadly as a communicative process between the person with PIMD and support staff. The communicative and relational aspect takes on such a central place in people with PIMD that it influences all other aspects of functioning. As a result the theme of relation, interaction and communication repeatedly recur 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 PIMD, fits difficultly into one category of the model. Other authors also pointed out the neglect of the relational perspective in support (Reinders, 2002; Vlaskamp & Verkerk, 2000; Buntinx, 2003).

A description of the support needs of people with PIMD using the 2002 AAMR System can in several areas offer a surplus value for practice, research as well as for policy. In practice the AAMR framework is usable for the characterization of individual clients. The description that is 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. The support needs can function as a starting point for determining and evaluating the range of support that is offered to people with PIMD. In research an accurate description of the target group has the advantage that gaps in research come to light. 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. A clear delineation of the target group moreover promotes an unambiguous interpretation of research on the (needs of the) target group and on the place where and the way 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 PIMD and aids the making of

adequate policy. Also 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 PIMD. 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. A overview of literature on intervention strategies and their effectivity would be a useful addition to this overview on the support needs of children with PIMD.

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Figure 1: Theoretical model AAMR 2002

(Schalock & Luckasson, 2004, p.141)

