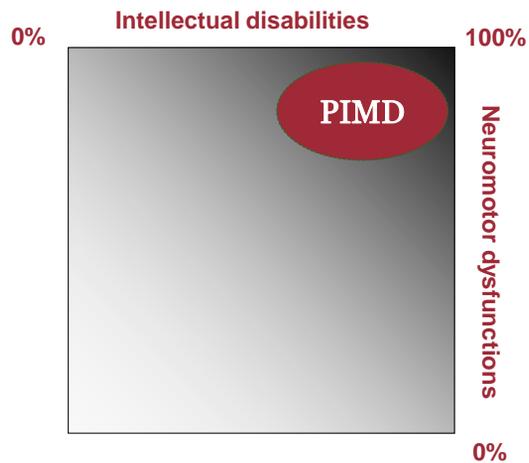


# KEY ISSUES IN SUPPORTING PERSONS WITH PIMD



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## Persons with profound intellectual and multiple disabilities



(Nakken & Vlaskamp, 2002; 2007)

## Persons with profound intellectual and multiple disabilities



### 2 key characteristics

- profound intellectual disabilities
- severe neuromotor dysfunctions

often accompanied by sensory disabilities, severe health problems and challenging behaviour

their functioning is characterized by pre- or protosymbolic communication and high daily support needs

## Key problems



- From the perspective of the person with PIMD
  - poor quality of client-staff interactions
  - limited number of and variation in activities in which persons with PIMD are engaged
  - limited opportunities for choice
  - limited social networks
  - fewer chances of living in typical community environments and of participation in community life

## Key problems



- From the perspective of the support worker
  - complexity and intensity of support
  - no clear perspective
  - high staff turnover

*(Carnaby & Cambridge, 2002; De Waele & Van Hove, 2005; Emerson, Robertson, Gregory, Kessissoglou & Hatton, 2000; Felce, Lowe, Beecham & Hallam, 2000; Felce, Lowe & Jones, 2002; Maes, Lambrechts, Hostyn & Petry, 2007; Maes, Vos, & Penne, 2010; Mansell, Beadle-Brown, Macdonald & Ashman, 2003; Seifert, Fornefeld & Koenig, 2001; Vlaskamp, Hiemstra, Wiersma & Zijlstra, 2007; Zijlstra & Vlaskamp, 2005; Zijlstra, Vlaskamp & Buntinx, 2001)*



How can support be given in a way that enhances quality of life outcomes for persons with PIMD?

## Important routes for change



- Implementing person-centred strategies
- Establishing mutual and positive interactions
- Creating an environment that fosters development and participation
- Family support and involvement
- Staff training and support



## Person-centred strategies



- Identifying needs, preferences, interests, competences of the person with PIMD
  - questionnaires and especially direct behavioural observation
  - a group of persons who are committed to the individual concerned and who search for a mutual and shared understanding of who the person is and what s/he wants and needs

*(Cannella, O'Reilly & Lancioni, 2005; Green, Middleton, & Reid, 2000; Grove, Bunning, Porter & Olsson, 1999; Porter, Ouwry, Morgan & Downs, 2001; Sanderson, 2002)*



## Person-centred strategies



- **Determining personal QOL-outcomes**
  - progress in evaluating objective QOL (e.g. QOL-PIMD) as well as subjective well-being of persons with PIMD (e.g. MIPQ, Life Satisfaction Matrix, direct behavioural observations of pleasure and happiness)
  - the basic QOL-domains are a good starting point, although the concrete indicators need to be adapted to the specific needs and characteristics of persons with PIMD

(Green & Reid, 1996; Lyons, 2003, 2005; Petry, Kuppens, Vos & Maes, 2010; Petry & Maes, 2006; Petry, Maes & Vlaskamp, 2005, 2007, 2009)



- **Examples of QOL-PIMD-items**
  - *Feeding problems have diminished during the last year* (physical well-being)
  - *The person's intimate care is taken care of by someone to whom the person gives preference* (social well-being).
  - *The person doesn't sleep during the day because of a lack of activities* (activities)
  - *The person may recognize and anticipate what happens in his environment* (communication and influence)
  - ...



## Person-centred strategies



- Housing arrangements in the community, educational opportunities, participation in community life
  - positive effects on interactions, active engagement and community participation
  - paucity of experiences in practice and research
  - doubts and uncertainty in support workers

*(Arthur-Kelly, Foreman, Bennett & Pascoe, 2008; Bigby, Clement, Mansell & Beadle-Brown, 2009; Emerson, Robertson, Gregory, Kessissoglou & Hatton, 2000; Foreman & Arthur, 2004; Foreman, Arthur-Kelly, Pascoe & Smyth-King, 2004; Spreat & Conroy, 2001)*

## Person-centred strategies



- Future research agenda
  - How do we make our interpretations of the wishes, needs, preferences of persons with PIMD more valid?
  - How do we change the negative expectations, intolerance and lack of knowledge in society in general and of professionals more specifically towards persons with PIMD?
  - How can current visions in which autonomy and community participation take a central place, be applied for persons with PIMD in ways that foster their well-being?
  - ...



## Mutual and positive interactions

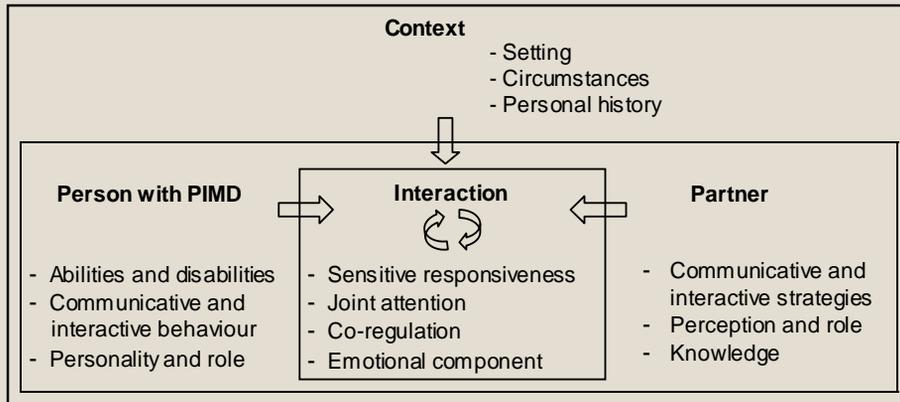


Figure 1. Model of interaction between persons with PIMD and their partners, based on Hostyn & Maes (2009)



## Mutual and positive interactions



- **Improving quality of interactions**
  - increasing knowledge about communication and interaction of persons with PIMD
  - offering tools to analyse interactions
  - training effective interactive strategies
  - joint process of looking for ways to improve dialogue by focusing on the key components of interaction

*(Bloomberg, West & Iacono, 2003; Dobson, Upadhyaya & Stanley, 2002; Firth, Elford, Leerming & Crabbe, 2008; Forster, 2008; Forster & Iacono, 2008; Hostyn, Daelman, Janssen & Maes, 2010; Hostyn, Petry, Lambrechts & Maes, 2010; Kellett, 2000; 2003; Leaning & Watson, 2006; Nind, 2009; Olsson, 2004; Roemer & van Dam, 2004; Singh et al., 2004)*



## Mutual and positive interactions



- Staff training and support
  - strategies
    - ✦ theoretical input, training, supervision, reflection and problem solving within a team
    - ✦ discussion of video-recorded interactions is frequently used
  - some evidence for positive results
    - ✦ on the ideas and knowledge of support workers about the communicative abilities of their clients
    - ✦ on their interactive strategies and style
    - ✦ on the amount and quality of mutual and positive interactions

*(Bloomberg, West & Iacono, 2003; Dobson, Upadhyaya & Stanley, 2002; Firth, Elford, Leerming & Crabbe, 2008; Kellett, 2000; 2003; Leaning & Watson, 2006; Nind, 2009; Roemer & van Dam, 2004; Singh et al., 2004)*

## Mutual and positive interactions



- Future research agenda
  - How are the different key elements in the interaction process related with each other and how do the different client, staff and context characteristics influence this?
  - Which interactive strategies are most effective in creating mutual and positive interactions?
  - What kind of strategies are most effective in changing the opinions and the interactive style and strategies of direct support workers?
  - What is the nature and the significance of social interactions between persons with PIMD mutually and between persons with PIMD and non or less disabled peers? How can meaningful relations with peers be supported?
  - ...



## Fostering development and participation



- A lot of evidence of learning potential of persons with PIMD and of their dependency on others to be able to learn and develop
- Three key principles emerge
  - systematic planning and evaluation
  - engagement in meaningful activities and interactions
  - choice and control



## Fostering development and participation



- Systematic and individualised planning and evaluation
  - more in-depth assessment of functional abilities, limitations, support needs and interests
  - determining more concrete developmental or learning goals
  - determining the right moment, the right stimuli and the right context to offer stimulating activities
  - determining the way in which the person will be supported during activities
  - evaluating the process and effects in detail and continuously

*(Emerson, Robertson, Gregory, Kessissoglou & Hatton, 2000; Felce, Lowe & Jones, 2002; Poppes, Vlaskamp, De Geeter, & Nakken, 2002; van der Putten, Vlaskamp & Poppes, 2009; Vlaskamp, Hiemstra & Wiersma, 2007; Vlaskamp & van der Putten, 2009)*



## Fostering development and participation



- **Engagement in meaningful activities**
  - stimulating, varied and age appropriate activities - at home, at school and in the community - that are geared to the capabilities, preferences and interests of the individual and that offer opportunities to experience, learn, enjoy and interact with others
  - adequate staff support such as giving individual attention during activities, using adequate support strategies and adapting support to individual needs

*(Felce & Emerson, 2004; Hogg, Cavet, Lambe & Smeddle, 2001; Mansell, Elliott, Beadle-Brown, Ashman & Macdonald, 2002; Realon, Bligen, La Force, Hesel & Goldman, 2002)*



## Fostering development and participation



- **Choice and control**
  - creating opportunities for choice and control in daily living situations and activities
  - using materials and technological aids that enable persons with PIMD to indicate a preference and to control things in their environment
  - systematic preference assessment

*(Cannella, O'Reilly & Lancioni, 2005; Lancioni et al., 2007, 2009; Salmento & Bambara, 2000; Saunders, Saunders, Mulugeta, Henderson, Kedziorsky, Hekker, & Wilson, 2005)*



## Fostering development and participation

- **Staff training and support**

- directed at the above mentioned key elements
- workshops, on the job training, supervision
- evidence for positive effects
  - on the amount of activities
  - on the ideas and expectations of support workers
  - on the level and quality of staff support
  - on the interaction, participation, engagement, choice and well-being of persons with PIMD

*(Cannella, O'Reilly & Lancioni, 2005; Felce, Bowley, Baxter, Jones, Lowe & Emerson, 2000; Jones et al., 2001; Parsons, Rollyson & Reid, 2004).*

## Fostering development and participation



- **Future research agenda**

- Lack of reliable and valid instruments to assess the functional abilities and support needs of persons with PIMD
- What about the developmental course and learning processes in persons with PIMD and which factors do influence this developmental course and learning processes?
- What are the effects of frequently used (especially sensory-motor) activities and programs for persons with PIMD?
- What are the most effective support strategies in enhancing active engagement and learning in persons with PIMD?
- ...



## Family support and involvement



- **Important service needs of parents / families**
  - more information about support
  - more practical support in daily care
  - emotional and practical support in parent support groups
  - respite care and short-break services
  - more access to support services
  - less administration and bureaucracy in obtaining support
  - more flexible, continuous and co-ordinated support services

*(Chadwick, Beecham, Piroth, Bernard & Taylor, 2002; Hastings & Beck, 2004; Hostyn & Maes, 2007; Mansell, 2010; Mencap, 2001; Mirfin-Veitch et al., 2003; Redmond & Richardson, 2003; Tadema & Vlaskamp, 2009; White & Hastings, 2004)*



## Family support and involvement



- **Involvement of parents is essential in education and support, but unfortunately still very limited !**
  - exchanging information about everything that matters for the well-being and development of the person with PIMD
  - meeting their expectations and preferences
  - determining goals and strategies of educational and support interventions in mutual consultation
  - organising self-directed services

*(Davern, 2004; de Geeter, Poppes & Vlaskamp, 2002; Fonteine, Zijlstra & Vlaskamp, 2008; Strogilos & Xanthacou, 2006)*

## Family support and involvement

### • Future research agenda



- What are the effects of different support services with regard to the child's and family's quality of life and development?
- How can adapted housing arrangements and community based support be created for adults with PIMD in close collaboration with parents?
- How can the involvement of parents in support services be increased and which factors determine different levels of involvement?
- ...

## Staff support and training

- Person-centered planning and strategies
- Building positive and mutual interactions
- Planning and evaluating systematically
- Support that fosters active engagement, participation and development
- Creating opportunities for choice and control
- Involvement of parents and other family members

## Conclusion



- Important directions have been indicated ... but there remains a lack of
  - global policy and innovative strategies
  - scientific knowledge and soundly based methods and strategies to support evidence-based practice
  - knowledge, skills and attitudes in direct support staff to implement successfully adequate principles and methods
- The only way forward is by means of a partnership between researchers, policy makers, professionals, parents and family members and the persons with PIMD themselves !



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