



KATHOLIEKE UNIVERSITEIT
LEUVEN

Participation of persons with profound intellectual and multiple disabilities

Prof. Dr. Bea Maes





Participation

= the action of taking part in something (Oxford dictionary)

= involvement in a life situation (ICF, 2001)

- Participation is far more than physical presence, and includes
 - active engagement (Granlund e.a., 2012)
 - social interaction (Chang e.a., 2013)
 - sense of inclusion, belonging (Hoogsteen & Woodgate, 2010)
 - fulfilling valued social rules in society (Cardol e.a., 2007)



Participation

- Participation is possible in different contexts: home, in schools, in the community
- It leads to meaningful life experiences and subjective wellbeing (enjoyment, pleasure)





Participation

- Some studies on different aspects of participation of persons with PIMD
 - Engagement and well-being during activities
 - Joint attention behaviour and episodes
 - Peer oriented behavior
- Can qualitative interactions be improved by staff training?



SOME STUDIES ON DIFFERENT ASPECTS OF PARTICIPATION OF PERSONS WITH PIMD



Engagement and well-being

Penne, Maes, & Vos, submitted

Research aims

- to evaluate the extent of active engagement and the level of well-being of persons with PIMD during an activity
- to evaluate the correlation between active engagement and well-being
- to analyse if the behavior of the DSW has an influence on the level of engagement and well-being of persons with PIMD



Engagement and well-being

Design

- 47 persons with PIMD, aged 4 – 70 years, from group homes, activity centers and schools
- Multisensory storytelling activity in a 1-1-interaction with a DSW, weekly, for a period of 10 weeks
- Evaluation of engagement and well-being (7-point Likert scale) by DSW before, during and after each activity
- For 20 dyads direct observations with video-analysis
 - continuous coding of engagement and well-being during the activity (5-point Likert scale)
 - staff interactive style using an adapted version of the Maternal Behavior Rating Scale
- Multilevel analyses (levels of client, activity, moment)



Engagement and well-being

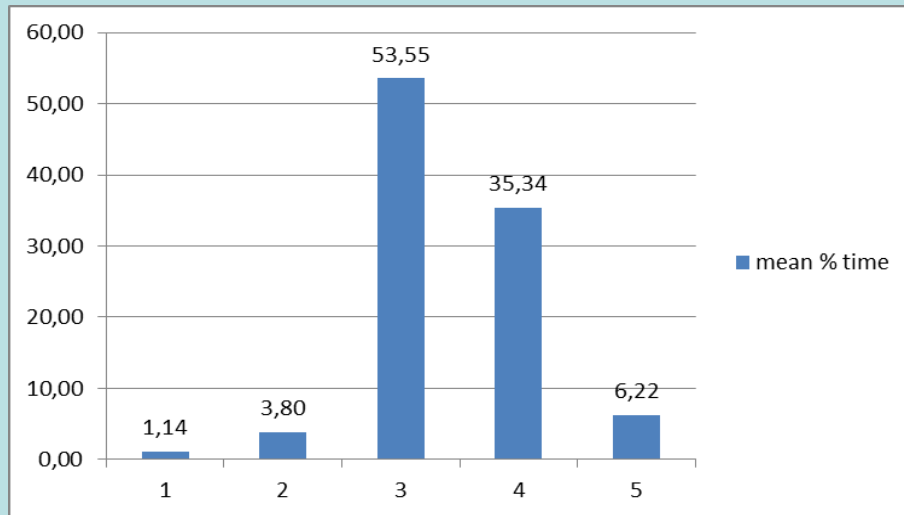


Figure 1: Mean percentage of time a well-being score is given during a session (n=20)

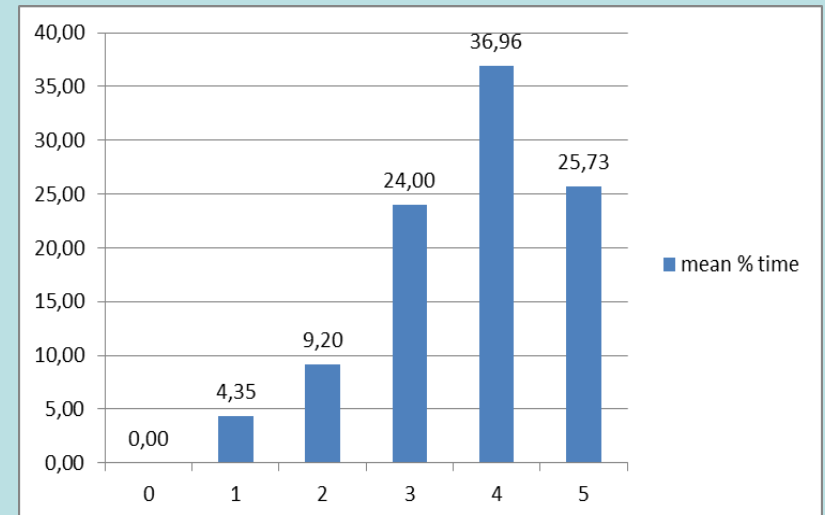


Figure 2: Mean percentage of time an engagement score is given during a session (n=20)



Engagement and well-being

Results

- Engagement and well-being were significantly higher during than before ($z=-11.79$, $p<0.0001$; $z=-10.68$, $p<0.0001$) and after the activity ($z=-6.53$, $p<0.0001$; $z=-3.68$; $p<0.0001$) ($n=47$)
- There was a significant positive relationship between engagement and well-being ($z=5.66$, $p < 0.0001$) ($n=20$)
- We found a significant relationship between engagement and the responsiveness of the DSW ($z=2.75$, $p= 0.0059$) ($n=20$)



Joint attention

Neerinckx, Vos, Van den Noortgate & Maes, 2013

Research questions

- What is the occurrence of shared and joint attention episodes in 1-1 interactions between persons with PIMD and their DSW?
- Which joint attention behaviors (JAB) are mostly used for directing and maintaining an attention episode?
- What is the association between the different initiating joint attention behaviors (IJAB) of both interaction partners and shared/joint attention episodes?



Joint attention

- joint attention (JAB)
 - a cognitive construct that assumes that two people are simultaneously focused on the same object or event in the environment, while also being aware of each other's attention and engagement towards that element of mutual attention
- initiating joint attention behaviors (IJAB)
 - behaviors used to direct the attention of the interaction partner to objects, events or themselves
- responding to joint attention behaviors (RJAB)
 - behaviors used to follow the direction of the gaze and gestures of others in order to share a common point of reference



Joint attention

Design

- 28 unique dyads of a person with PIMD (3-59 years) and his/her DSW
- Video registration of a spontaneous interaction during 10 minutes
- Interval coding (10 seconds)
 - Attention episodes: no attention, non-shared attention, shared attention, joint attention
 - Initiating joint attention behaviour of clients and DSW: visual, auditory, tactile, other
- Multilevel logistic regression for the association between IJAB (3 intervals) and attention episode

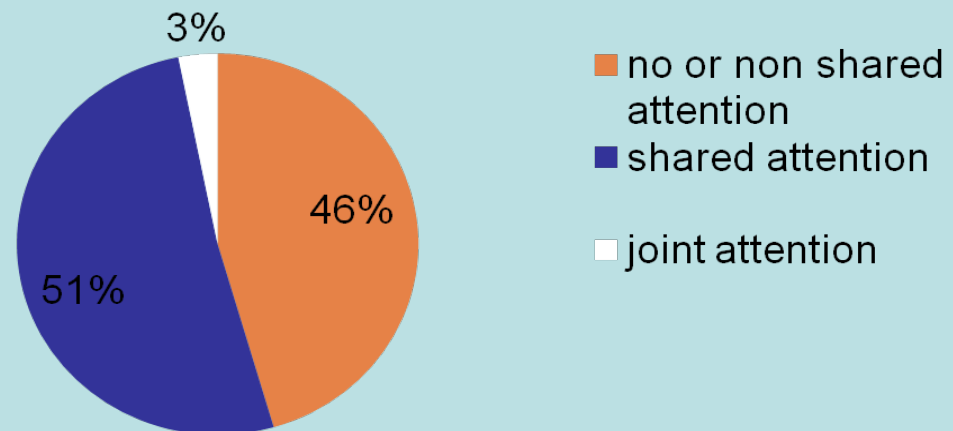


Joint attention

Results

- For 96% of the clients there were episodes of shared or joint attention
- In 54% of the time, there was shared or joint attention

percentage of intervals





Joint attention

- IJAB of the DSW
 - in 96% of the intervals
 - especially vocalisations and showing the object
 - tactile IJAB was less frequently observed
- IJAB of people with PIMD
 - in 8% of the intervals
 - by different behaviors: active eye contact, gaze shifts, vocalisations, touching the interaction partner, and making sounds with an object
- No significant association between the clients' or the DSWs' IJAB and the occurrence of the attention episodes



Peer oriented behavior

Nijs, Penne, & Maes, submitted

Research questions

- What are the frequency and nature of peer directed behavior of persons with PIMD during group activities?
- What are the frequency and nature of the DSW's peer interaction influencing behavior during group activities?
- Have the positioning of the persons with PIMD and the staff's social scaffolding behavior influence on the peer directed behavior?



Peer oriented behavior

Design

- Video-registration of 4 group activities with 3-4 children with PIMD (4-19 years) and one or more DSW
- Continuous coding of
 - Peer directed behavior of persons with PIMD
 - Peer interaction influencing behavior of DSW
 - Positioning



Peer oriented behavior

Results

- We observed peer directed behavior of the child with PIMD during only 8% of the time
- Mostly by looking at the peer; sometimes by touching the peer or grabbing the peer's object
- Most of the time the person was directed towards the DSW (68%) or the environment (17%)
- Social scaffolding behavior of the DSW is only seen in 4,4% of the time



Peer oriented behavior

- There is a significant relation between the DSW's behavior and the child's peer directed behavior
 - Higher amount of social scaffolding as well as distracting behavior during the child's peer directed behavior
- There is a significant relation between the child's peer directed behavior and his position
 - Lower amount of peer directed behavior when children can only make eye contact (and cannot touch their peers or have to do efforts to touch their peer)
 - Higher amount of peer directed behavior when children can touch their peers from rest



Conclusions

- Persons with PIMD express engagement and well-being during activities and come to shared and joint attention
- They show limited levels of initiating joint attention and peer oriented behavior in 1-1 interactions and during group activities
- Their engagement and social interactions are influenced by
 - their positioning
 - the responsiveness and scaffolding behavior of DSW



CAN INTERACTIONS BE IMPROVED BY STAFF TRAINING?

Two case-studies



Case study 1

Hostyn & Maes, 2013

Aims

- to describe in depth and systematically the quality of the interaction between a person with PIMD and her DSW
- to reflect on this with the DSW, in order to generate ideas to optimize the quality of interaction



Case study 1

Case

- C. is 16 years old, has a developmental age of 12 months, has severe motor dysfunctions and epilepsy, is tube fed
- S. is 49 years old, has a secondary education degree, knows C. for about 4 years, and has 30 years of experience in working with clients with PIMD



Case study 1

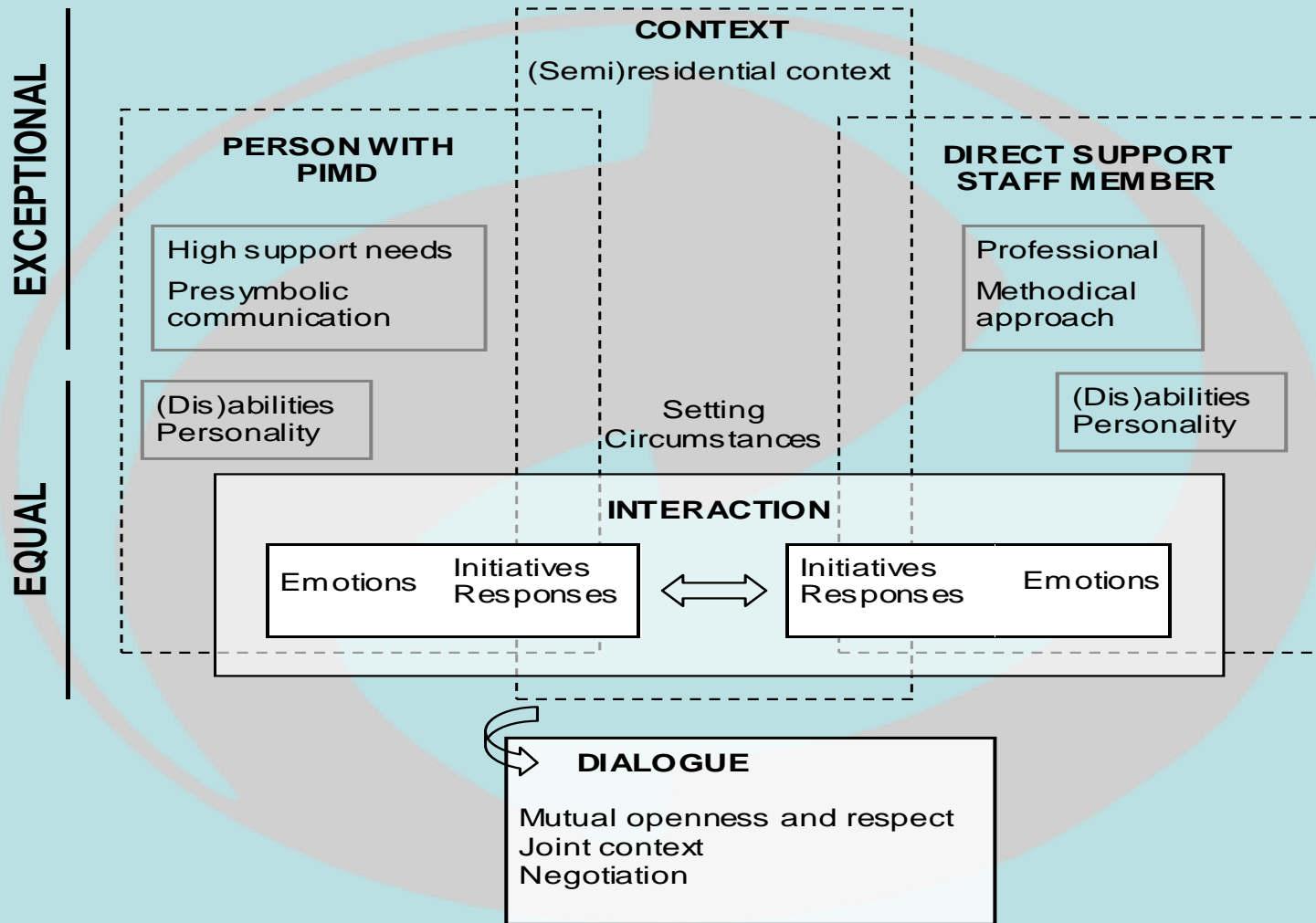
Method

- Direct observation procedure
 - an episode of a 1-1 interaction of the client-staff dyad was video-recorded during well-known and real-life activities
- Coding with observation rating scales
 - Emotional Availability Scales (EAS, Biringen et al., 1998)
 - Maternal and Child Behavior Rating Scales (M/CBRS, Mahoney, 1992, 1998)
 - Revised Erickson Scales (RES, Egeland et al., 1990)
 - Scale for Dialogical Meaning Making (S-DMM, Hostyn et al., 2009)



Case study 1

- Partial interval coding of IJAB and attention episodes
- Staff researcher dialogue
 - Multiple viewings of the recorded episode
 - 4 discussion meetings with researcher and S.
 - open questions about the different interaction dimensions



Hostyn, I. (2011). Interactions between people with profound intellectual and multiple disabilities and their direct support staff. Katholieke Universiteit Leuven, Leuven.



Case study 1

Results

- The procedure was useful to help DSW to reflect critically on the quality of the staff-client interaction
 - Value of the video-observation
 - “I am really pleasantly surprised. It is only by watching the video that I notice how he is following me when I go behind the door. In our daily work we are busy with the materials and with the group ... This helps to see the capacities of C.”*
 - Not only focusing on client, but also linking this with staff’s own interactive behaviour and strategies
 - “Now I see the effects of my behaviour on C. so clear. The video record and the discussion made me more conscious about my behaviour”*



Case study 1

- Learning to think about the interaction in a differentiated way (using the different interaction dimensions) and from a dialogical viewpoint
- “I should have offered the flute again so that he could have answered. As I immediately offered another instrument, he could not confirm here.”*



Case-study 1

- The procedure generated ideas to make future interactions better
 - give C. more chances to take own initiatives in the interaction by actively waiting
 - confirm C.'s subtle initiatives for example by imitating them
 - strive for more mutual consultation instead of individually deciding on the course of the activity
 - do not always start from available knowledge but negotiate with C.
 - use more tactile contact
 - create conditions for triadic joint attention



Case study 2

Nijs & Maes (ongoing)

Research questions

- Does staff training on social peer interactions have an influence
 - on the frequency and variation of social scaffolding behavior by the DSW?
 - on the frequency and variation of peer oriented behavior by the person with PIMD?



Case study 2

Case

- Girl, 10 years, developmental age of 6 months, auditory and motor limitations
- Girl, 14 years, developmental age of 5.5 months, motor limitations (diplegia)
- Direct support worker, 31 years, educational background, 6 years of experience with persons with PIMD



Case study 2

Intervention

- Staff training – half day (team)
 - theoretical background
 - video-illustrations of peer oriented behaviors of children with PIMD
 - discussion about influencing factors of peer interactions
 - presentation of 5 strategies to support peer interactions
 - recognizing peer oriented behavior
 - creating opportunities
 - positioning
 - offering materials and an activity that direct the children towards each other
 - social scaffolding strategies



Case study 2

Intervention

- Joint consultation to choose an activity that connects with the preferences of the duo, and may direct the attention of the peers towards each other
- Feedbackmoment
 - after the third week, the video registration of the activity was discussed together with the DSW
 - the discussion focused on the strategies used by the DSW to support peer interactions
 - adaptations to the activity were possible



Case study 2

Design

- Week 0: baseline
 - Video-observation of the duo of peers alone, and of an activity with the DSW
 - Staff training
- Week 1-10: DSW offered chosen activity to the duo of peers
 - Week 3: video-observation of the activity
 - Week 4: feedback
 - Week 10: video-observation of the activity and of the duo of peers alone
- Week 16: Follow up
 - video-observation of the activity and of the duo of peers alone



Case study 2

Method

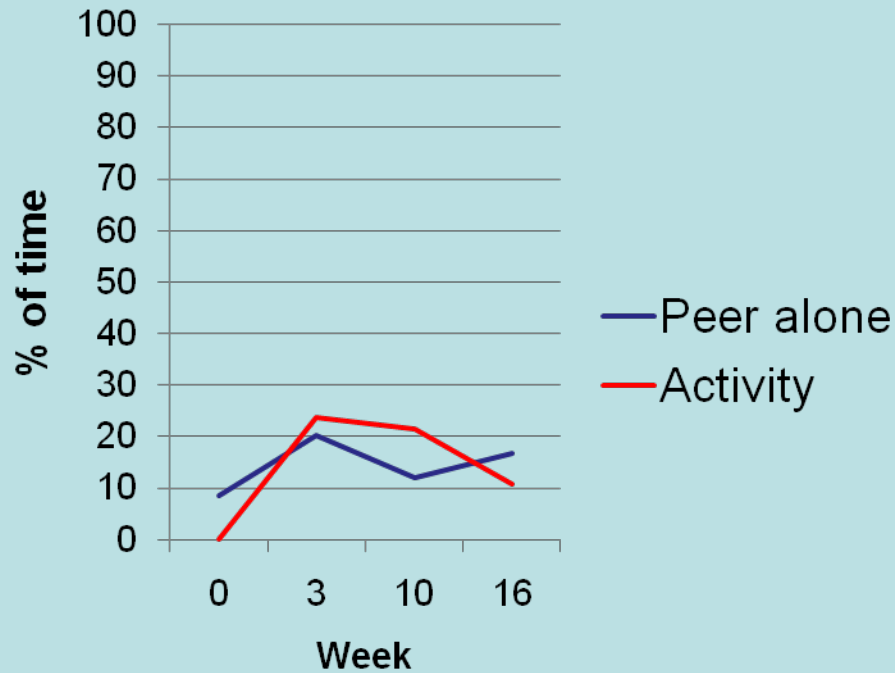
- Evaluation form after each session and at the end
- Video-registration
 - Duo of peers alone
 - Activity offered by the DSW to the duo of peers
- Continuous coding of
 - Peer directed behavior of persons with PIMD
 - Peer interaction influencing behavior of DSW



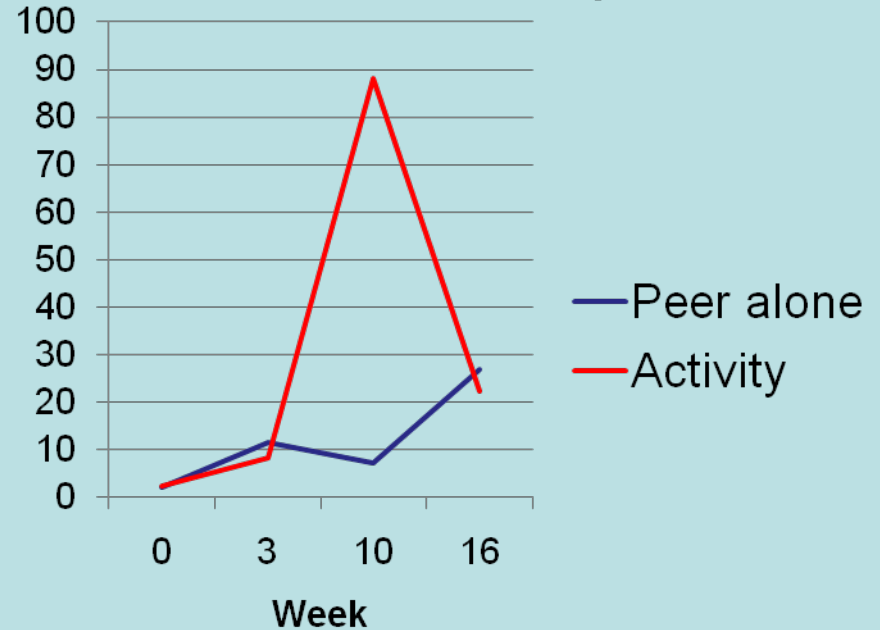
Case study 2

Results

Peer oriented behavior peer 1



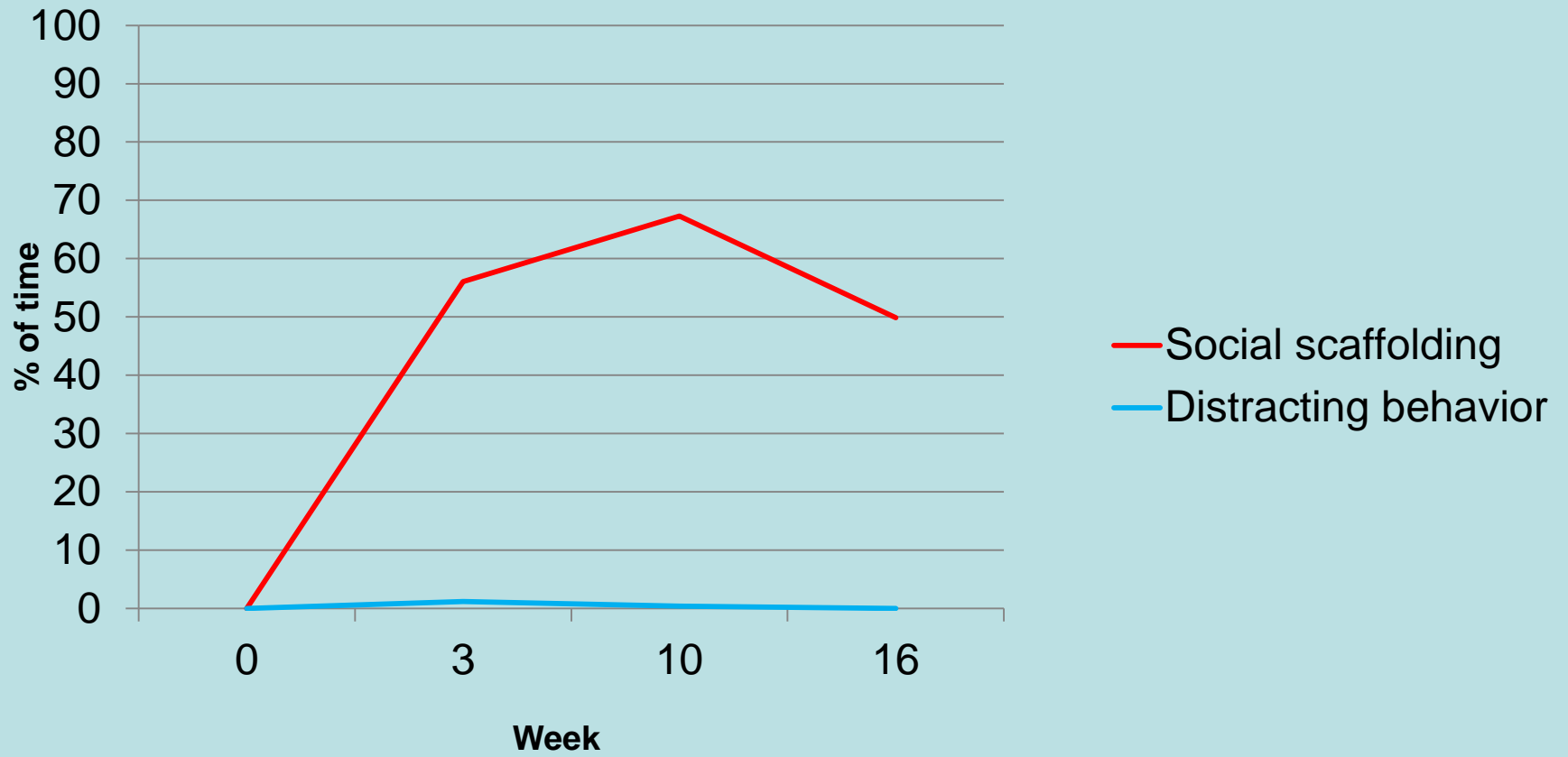
Peer oriented behavior peer 2





Case study 2

Peer interaction influencing behavior of DSW





Case study 2

- Increase in peer oriented behavior during the activity offered by the DSW, but relapse at follow up
- Gradual increase in peer oriented behavior in the peer alone condition
- More differentiation in peer oriented behavior after the intervention
 - Next to looking at the peer: object related behavior, touching peer, moving towards peer, facial expressions, vocalisations, ...
- Increase in social scaffolding behavior of DSW
 - Most frequently are creating opportunities for social peer interactions, describing or instructing social acts, describing or coaching play together, installing proximity



Conclusions

- Training and coaching may change staff behavior
 - more responsive and qualitative interactions
 - more social scaffolding behavior
- This in turn may influence engagement and (social) interactions of persons with PIMD



Conclusions

For more information:

bea.maes@ppw.kuleuven.be

Thanks for your attention !