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## The intervention model for affective involvement and its effectiveness

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## CHAPTER 3

### **Intervening on affective involvement and expression of emotions in an adult with congenital deafblindness**

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**Abstract**

This study examined the effects of a 20-week intervention to foster affective involvement during interaction and communication between an adult with congenital deafblindness (CDB) and his caregivers in a group home and a daytime activities center. Using a single-subject design, we examined whether the intervention increased affective involvement between the participant and his caregivers, and whether the participant's positive emotions increased and his negative emotions decreased. In both settings, an increase in affective involvement and very positive emotions coincided with the onset of the intervention, with the clearest effects in the daytime activities center. Negative emotions decreased in the daytime activities center. During follow-up, affective involvement decreased in both settings but remained above baseline. The caregivers indicated that it was easier to share positive emotions than negative emotions. This study demonstrates that it is possible to foster affective involvement with an adult with CDB, both during interaction and communication.

### 3.1 Introduction

Mutual sharing of emotions or affective involvement may be crucial for persons with congenital deafblindness (CDB) because it increases positive affect and reduces negative emotions in social interactions (Diamond & Aspinwall, 2003). Communicative constraints caused by limited vision and hearing from birth makes persons with CDB vulnerable to experiencing negative emotions and tensions and hampers their ability to develop the necessary coping skills to handle complex situations and negative emotions (Martens, Janssen, Ruijsenaars, & Riksen-Walraven, 2014). Two intervention studies have addressed affective involvement between persons with CDB and their educators. In a study of 25 infants with CDB and their families, Chen, Klein, and Haney (2007) showed that educators can learn to identify the needs and emotions of infants with CDB, which is a prerequisite for building affective involvement. In a study involving 6 children and their 14 educators, Janssen, Riksen-Walraven, and Van Dijk (2003a) showed that it is possible to increase affective involvement between children with CDB and their educators. These two studies focused on increasing affective involvement during social *interaction*, which has been defined as “the process of mutually influencing each other’s behavior” (Janssen, Riksen-Walraven, & Van Dijk, 2003b, p. 198). In the present study, we went one step further and aimed to increase affective involvement during *communication*, which has been defined as “a form of interaction in which meaning is transmitted by the use of utterances that are perceived and interpreted by the partner” (Janssen et al., 2003b, p. 198).

Sharing experiences and meaning is important for persons with CDB (Janssen & Rødbroe, 2007; Martens et al., 2014). Fostering affective involvement during communication, however, may be more difficult because the majority of the persons with CDB are pre-linguistic communicators (Bruce, 2005). The caregivers of persons with CDB will therefore be more inclined to focus on the content of the person’s idiosyncratic expressions, which are hard to interpret. This may be detrimental to the quality of the underlying interactions and emotional exchanges (Martens et al., 2014).

The intervention used in the present study is based on an extended version of the Diagnostic Intervention Model (DIM; Janssen et al., 2003b) for fostering harmonious interactions between children with deafblindness and their educators. The new two-phased Intervention Model for Affective Involvement (IMAI; Figure 1) focuses first on increasing affective involvement during interaction and next on increasing affective involvement during communication (Martens et al., 2014).

In the present single-subject study, we applied the IMAI to an adult with CDB and his caregivers in a group home and daytime activities center. We examined the effects of the intervention on affective involvement between the participant and his caregivers and on the participant’s positive and negative emotions during interaction *and* communication.

## 3.2 Method

### 3.2.1 Participants and Settings

The study was conducted in the group home and daytime activities center of Royal Dutch Kentalis, an organization with extensive expertise in communication and auditory and/or visual disabilities. The study followed the tenets of the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects and was approved by the Institutional Review Board of Royal Dutch Kentalis. Informed consent was obtained from the parents of the participant (to whom we gave the pseudonym Leon) and his caregivers.

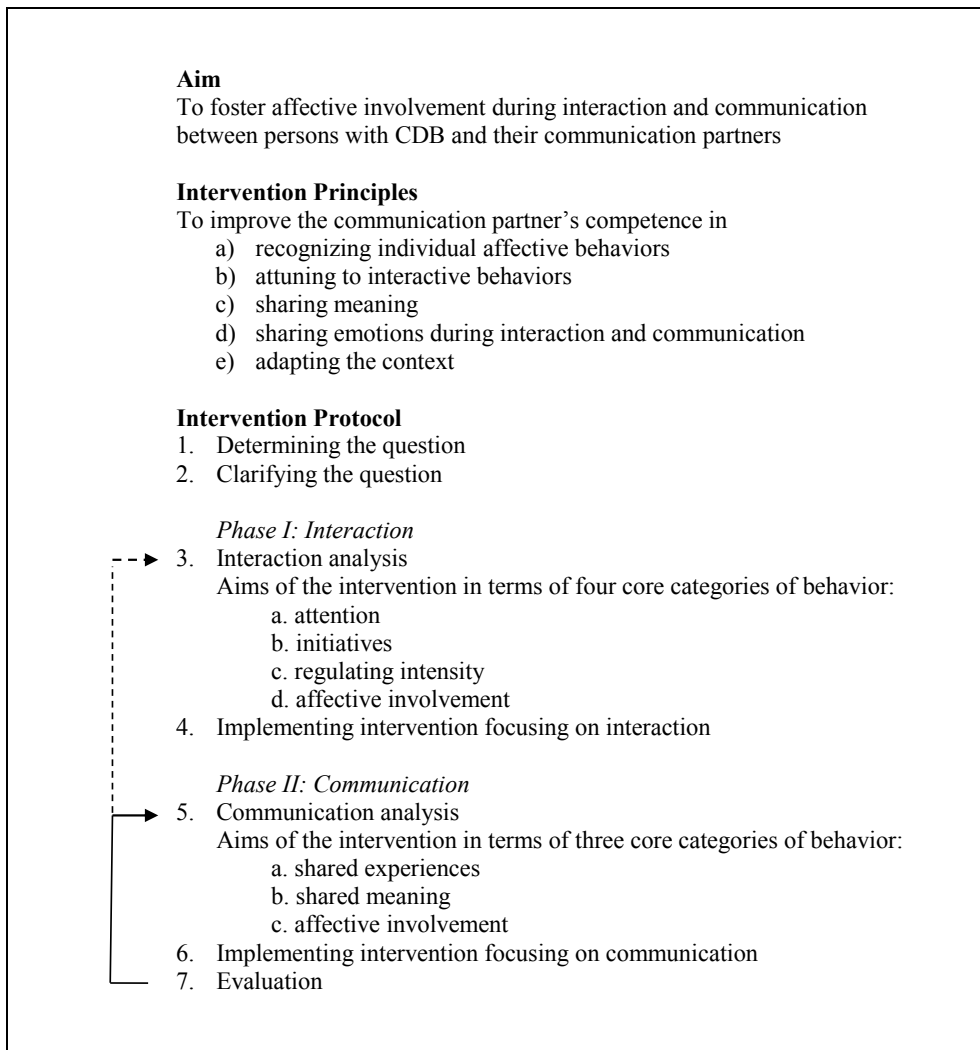


Figure 1. Intervention model for affective involvement during interaction and communication

Leon, aged 22, was born with a hearing and visual impairment caused by Rubella Syndrome. Leon has a hearing loss of about 70 dB, indicating that he is severely hard of hearing. In 2002, however, he stopped wearing hearing aids because of medical reasons (allergic reactions and recurrent ear infections) and low response to auditory stimuli during repeated hearing assessments. Leon has been legally blind since age 10 and functions at a sensorimotor level (KIDS, Reuter & Bickett, 1985; VABS, Sparrow, Balla, & Cichetti, 1984; SCOSD, Ashurst et al., 1985). Leon's communicative level is pre-linguistic, but he understands the meaning of about 50 concrete referential objects, 30 relief drawings, and 20 tactile signs when used in actual situations. Leon only uses two signs as formal means of communication, but mainly expresses his needs, wishes, and likes or dislikes by pushing the caregiver's hand or pulling the caregiver to a certain place or object. He often appears anxious and insecure and challenges educators by being aggressive, self-abusive, and compulsive, or by being very inactive.

All of Leon's caregivers in the group home (12 females ranging in age from 21–55,  $M = 31$ ) and in the daytime activities center (5 females ranging in age from 23–54,  $M = 38.6$ ) were involved in the intervention. The caregivers selected from the group home were 24, 39, and 41 years old, and had 3, 4, and 9 years of experience respectively working with persons with CDB. The two caregivers selected from the daytime activities center were 23 and 46 years old, and had 5 and 13 years of experience respectively working with persons with CDB.

Leon was selected for participation on the basis of three criteria: a) a dual sensory impairment from birth on, b) difficult emotional behaviors, and c) a request for coaching by the caregivers. The caregivers were selected based on two criteria: a) working frequently with Leon and b) having difficulties in sharing emotions with Leon.

### **3.2.2 Study Design and General Procedure**

A single-case design (Barlow, Nock, & Hersen, 2009) was used to study the functional relationship between the intervention conditions (baseline, intervention Phase I, intervention Phase II, follow-up, see Intervention section) and the occurrence of affective involvement between Leon and his caregivers and Leon's expressions of positive and negative emotions (dependent variables, see section Observation Categories). To measure the effects of the intervention, affective involvement and Leon's expressions of positive and negative emotions were observed repeatedly before, during, and after the intervention. For this purpose – and also for intervention purposes (see Intervention section) – one cameraman made weekly 20-min video recordings of Leon's interactions with his caregivers in the two settings (i.e., the group home and the daytime activities center). The situations for the video recordings were chosen based on their relevance to the intervention (i.e., *interactive leisure activities* in the group home and *cooking activities* in the daytime activities center). For the group home this meant that the caregivers had to restructure the daily program and choose interactive and motivating activities. No

such adaptations were needed at the daytime activities center. The cameraman remained silent while filming. During the video recordings, other persons in the room were asked to act as usual during their normal daytime routine.

### 3.2.3 Intervention

As shown in the intervention model in Figure 1, the intervention aimed to foster affective involvement between Leon and his caregivers by improving the caregivers' competencies in a) recognizing Leon's affective behaviors, b) attuning to his interactive behaviors, c) sharing meaning for better understanding, d) sharing emotions and evaluating the adequacy of their own affective behavior during interaction and communication, and e) adapting the context to promote affective involvement.

The intervention was carried out by a coach (the first author) who is a certified video feedback trainer and has an MSc in Educational Sciences with a specialization in Communication and CDB. At the time of the study, the coach had been working with persons with CDB and supporting their parents and caregivers for over 10 years. The coach conducted the intervention by following the subsequent steps of the intervention protocol (see Figure 1):

1. *Determining the question.* The caregivers requested coaching because they felt unsure about how to attain mutual contact, regulate Leon's negative emotions, and evoke dyadic joyful moments.

2. *Clarifying the question.* The coach discussed the request with the caregivers and formulated definite questions for coaching and relevant situations: a) How can we recognize and interpret emotions? b) How can we reduce negative emotions and evoke positive emotions? c) How can we share emotions?

The coach collected information about the characteristics of Leon's physical and social interaction context and his functioning from his personal file, live observations, and a hands-on assessment (Nelson, Van Dijk, & McDonnell, 2002). The coach also used the Severe Challenging Behavior Consensus Protocol questionnaire (Kramer, 2001) to describe and reach a consensus with the caregivers about the severity of Leon's negative emotions prior to intervention. In the Netherlands, this instrument is a commonly used and valid protocol for regularly and systematically describing and measuring challenging behavior.

3. *Interaction analysis.* The coach analyzed recent video recordings of interactive situations to formulate intervention aims for Phase I. The aims were based on the four core categories of interactive behavior depicted in Figure 1. These categories are defined as follows (Martens et al., 2014): (a) *attention*, defined as focusing on the interaction partner, the content of the interaction, and the persons and/or objects within the interaction context, (b) *initiatives*, defined as starting an interaction or raising something new as part of a reaction, (c) *regulating intensity*, defined as waiting while Leon is adapting the intensity or pace of the interaction and/or is processing new information,

(d) *affective involvement*, defined as recognition of positive and negative emotions and sharing these emotions in a positive way that is perceivable for Leon.

Examples of aims and behavior for *affective involvement* included “evoking positive emotions” by paying attention to the subject of Leon’s attention or “sharing emotions interactively” by tactilely and vocally imitating expressions.

4. *Implementing intervention focusing on interaction.* The coach used team coaching and individual coaching (see Figure 2 for an overview of the coaching sessions) mainly based on *video analysis* and *video feedback* to discuss target behaviors. Watching and commenting on video recordings of interaction situations with Leon helped the caregivers focus on Leon’s emotions and develop possible ways of sharing emotions. The coaching also included *information-transfer* to share underlying theoretical concepts and use of terminology, and *role-playing* with the coach and one of the caregivers to coactively demonstrate possible strategies for tactile communicative acting by reenacting actual communication situations (Martens et al., 2014).

Team coaching was performed during the regular team meetings and involved two 120-min group-training sessions per phase with the whole team in each setting. Team coaching was used to ensure agreement within the team about the changes in behaviors and attitudes that were needed to foster affective involvement with Leon. In team session 1, the coach related the four core categories of interactive behavior to the underlying theories of *affect attunement* (Stern, 1985) and *interpersonal communication* (Trevarthen & Aitken, 2001). During the next five weeks, the caregivers practiced the interactive behaviors. In team session 2, the coach evaluated the practicality of the intervention and the caregivers shared their experiences performing target behaviors. New videos were watched and commented on to clarify which target behaviors the caregivers should practice.

In consultation with the team of caregivers, the coach selected five team members for individual coaching: three caregivers from the group home and two from the daytime activities center. The caregiver with the highest need for coaching was given priority. Individual coaching was conducted during the caregiver’s regular overhead time (i.e., the time available for reading and studying). The coaching involved a caregiver analyzing her own behavior in three 60-min sessions per phase with enough time in between the sessions to put learning points into practice. In the first individual coaching session, individual aims were specified (e.g., *regulating intensity* by lowering the tempo and *repeating initiatives* when negative tension is too high; naming and interpreting Leon’s affective state while focusing on *affective involvement*). In the second and third individual sessions, video analysis revealed new learning points (e.g., *initiating* contact by first tapping the table and waiting for a response; increasing *attention* by changing body position; rubbing shoulder while laughing for *affective involvement*).

5. *Communication analysis.* The coach analyzed new videos made during the intervention period to formulate intervention aims for Phase II. These aims were



formulated in terms of the three core categories of behavior depicted in Figure 1. The categories are defined as follows (see Martens et al., 2014): (a) *shared experiences*, defined as elaborating on events and introducing new events so that Leon becomes motivated, feels secure, and knows what is going to happen, (b) *shared meaning*, defined as interpreting and affirming Leon’s expressions of communication and using

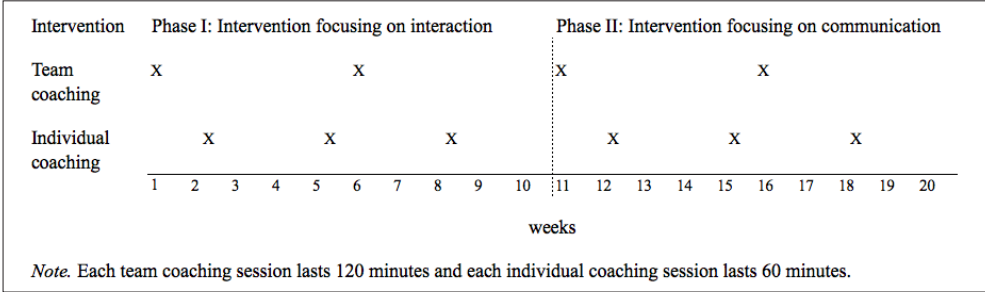


Figure 2. Coaching sessions during the two phases of intervention

different turns to negotiate about the correct meaning of the expressions, (c) *affective involvement*, defined as recognition of positive and negative emotions and sharing these emotions in a positive way that is perceivable for Leon. Aims and examples of behavior for *sharing experiences* included “creating opportunities to communicate about interests and feelings” through coactive sensory play. One example of *sharing meaning* is “using different turns to negotiate about the meaning of expressions” by introducing a Christmas ball, allowing Leon to feel it and become the actor, and then affirming his response. *Affective involvement* included “communicating more to share emotions” by shaking, rubbing, or tweaking Leon’s hand while laughing together.

6. *Implementing intervention focusing on communication.* The coach continued team and individual coaching during this step of the intervention process (Figure 2). In the first team-coaching session, the coach shared the caregivers’ experiences from Phase I and elaborated upon the three core categories of behavior with new video examples. In the second team-coaching session, the coach analyzed new videos and discussed the practicality of the second phase and the caregivers’ experiences regarding the three concepts. Target behaviors were formulated to practice with Leon during the next five weeks.

New aims and learning points were formulated in the individual coaching sessions. These included *sharing experiences* (“talking about unexpected events” by touching a fallen bottle and coactively reenacting its fall), *sharing meaning* (“using more turns and repeating initiatives” when a topic is introduced), and *affective involvement* (“sharing very positive emotions” by using vocal sounds and tickling Leon’s belly).

7. *Evaluation.* The evaluation was held in a separate team session. The coach used video fragments from the first recordings at baseline and the last recordings of

Phases I and II to support the discussion. The caregivers indicated that they had learned to foster affective involvement, to promote mutuality, and to feel more confident in interacting with Leon. Furthermore, they better understood the cause of Leon's negative emotions and had learned to regulate them, for example, by lowering tempo or by exaggerating expressions. They noted that Leon was more inclined to share intentions during intervention and that he had become much more joyful than before the intervention. The findings were recorded in a written report that was included in Leon's personal care plan.

### **3.2.4 Observation Procedure and Measures**

#### **Observation procedure.**

Videotapes were used to examine the effects of the intervention. They were randomly chosen from the weekly 20-min video recordings of Leon's interactions with his caregivers, after excluding the tapes that were used for coaching and observer training. In total, 15 videos were selected for each of the two settings: 4 from the baseline, 4 from Phase I, 4 from Phase II, and 3 from the follow-up. The first 11 minutes of interaction in each video were used for observation. Time sampling was used to record the occurrence of five observational categories on a coding form that broke the 11-min sequences into 30-sec intervals. The tapes were coded by three observers: 1) the first author, who is a qualified supervisor with over 10 years of experience in working with persons with CDB; 2) a Master's student in educational psychology; and 3) a qualified social worker with extensive work experience in youth care. To prevent observer drift, the observers were kept naïve with respect to the observation phases, and the observers read the definitions before each recording session.

#### **Observation categories.**

Observation categories were identified and operationalized by searching Leon's personal file for descriptions and examples of emotional functioning and by specifying Leon's affective states with the caregivers regarding facial expressions, body expressions, vocalization, and quality of interactive behavior. Five observation categories were described: 1) *very negative emotions*: aggressive and self-abusive behaviors, with or without vocalizations of discomfort (e.g., severely pinching, scratching, or pulling his or someone else's body, causing bruises or bleeding, with or without growling or whining sounds); 2) *negative emotions*: passive or inactive behaviors, compulsive behaviors, and refusal (e.g., repeatedly pushing objects or the caregiver away, with or without sounds of discomfort, and firmly and repeatedly pulling on objects); 3) *positive emotions*: openness to contact and exploration, and being cooperative (e.g., initiating contact or affirming the caregiver's initiatives, exploring objects or persons, sounds of comfort); 4) *very positive emotions*: laughing (from smiling to laughing out loud) or vocalizing comfort;

and 5) *affective involvement*: sharing negative and positive emotions perceivable by Leon. The observed occurrence of these five categories of behavior was used to assess the effect of the intervention on Leon's behavior.

#### **Inter-observer agreement.**

Before formal data collection, six videos were used to train the observers to reach a minimum of 80% inter-observer agreement. The percentage agreement was computed as the number of agreements divided by the number of agreements plus the number of disagreements between the observers on the occurrence of the behavior, multiplied by 100. The observers independently scored 16 tapes in which the dates and settings were unidentified. Inter-observer agreement ranged from 80% to 100%. No very negative emotions were observed.

#### **3.2.5 Social Validity**

The caregivers were involved in determining and clarifying their own coaching requests, formulating intervention aims, and selecting intervention situations to secure the program's social and clinical significance. Caregivers were repeatedly consulted about selection, analyses, and operationalization of the target behaviors. To obtain a quantitative measure of social validity, caregivers completed an adapted version of the Social Validity Scale (Martens & Janssen, 2011, following Seys, 1987). The caregivers answered questions about the practicality, acceptability, and effectiveness of the intervention by indicating their answers on a five-point Likert scale (1 = low, 5 = high), with higher ratings reflecting higher social validity.

#### **3.2.6 Data Analysis**

Given the relatively small number of observations and the serial dependencies in the data, statistical tests such as time series methods are not feasible for the present data set. Therefore, we used descriptive and visual analysis as the most important analysis method in this study. These methods are commonly used in single subject experimental research (Horner, Carr, Halle, Odom, & Wolery, 2005; Nourbakhsh & Ottenbacher, 1994).

### **3.3 Results**

#### **3.3.1 Effects on Behavior**

The frequency of the target behaviors during baseline, intervention, and follow-up are depicted in Figure 3 (daytime activities center) and Figure 4 (group home). The figures reveal an increase in affective involvement and very positive emotions from baseline to intervention in both settings and a decrease in negative emotions in the daytime

activities center.

Figure 3 shows that, in the daytime activities center, affective involvement between Leon and his caregivers, that occurred only once during baseline (session 2), increased during Phase I and Phase II of the intervention and remained above baseline during follow-up. For example, in the first session of Phase I (session 5), Leon and his caregivers displayed an improvement from 0 to 2 instances of affective involvement as compared to the last session of the baseline, and in Phase II of the intervention affective involvement was present in all sessions with a high peak of 7 instances in session 11. During follow-up, the occurrence of affective involvement dropped but still occurred more often than during baseline (twice in session 13 and once in session 15).

Improvement was also shown for very positive emotions. For example, in the first session of Phase I Leon displayed improvement as compared to the baseline (increase from 0 to 16). In Phase II of the intervention, very positive emotions further increased with a high peak of 19 instances in session 11. During follow-up, very positive emotions

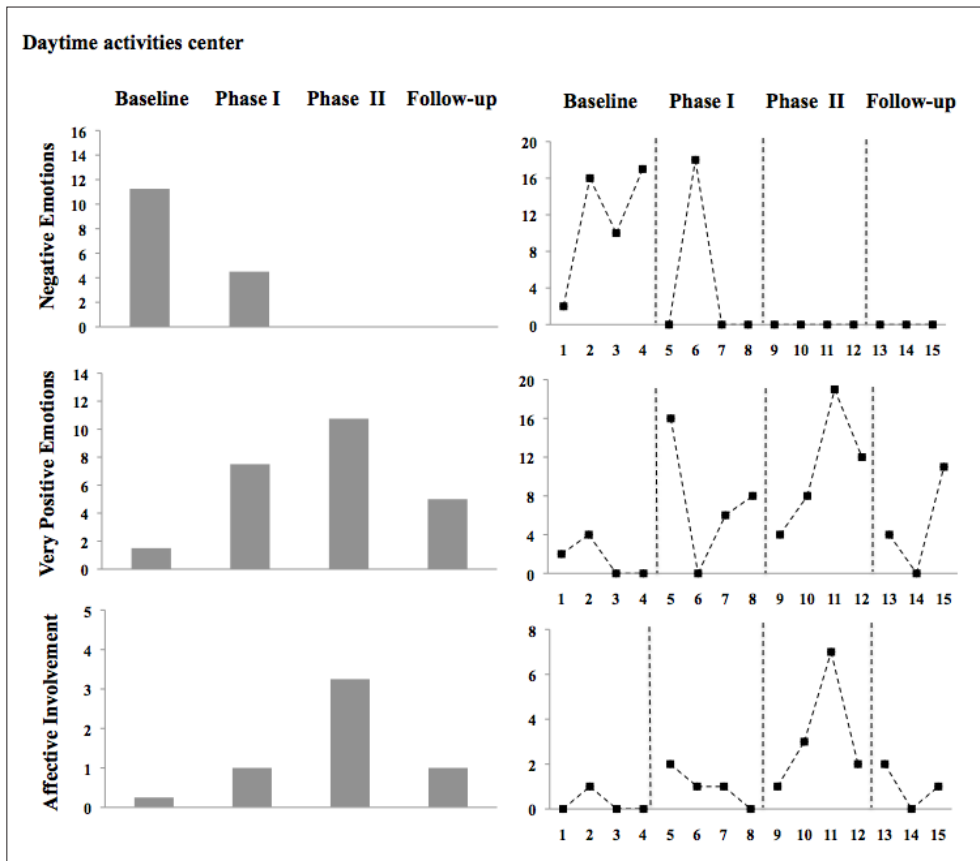
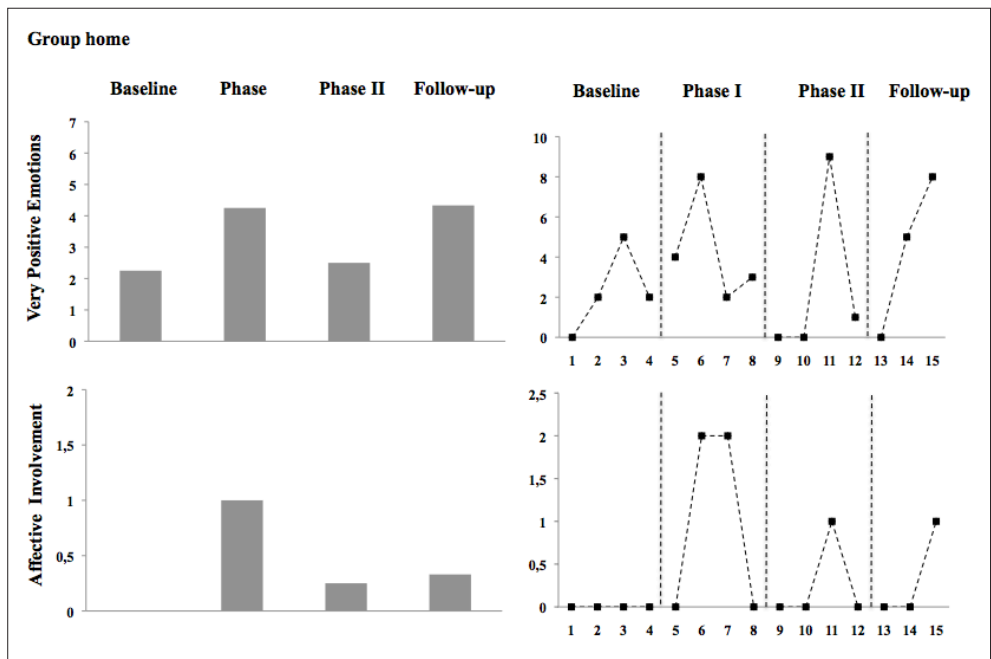


Figure 3. Mean occurrence of target behaviors during baseline, intervention, and follow-up (left), and occurrence during separate observation sessions (right) at the daytime activities center

decreased but were still more frequent than during baseline (11 times in session 15, versus 4 as the highest frequency during baseline (session 2). And with regard to negative emotions: while Leon displayed such emotions during all sessions of the baseline, they occurred only during one session after the start of the intervention (i.e., in Phase I of the intervention, during session 6, where they occurred 18 times).

*Figure 4* displays the results for the group home. Here, affective involvement was absent during baseline but appeared two times in the second and third session of Phase I (sessions 6 and 7). In Phase II, affective involvement occurred once in session 11 and during follow-up it occurred once in session 15. Very positive emotions increased in Phase I of the intervention. For example, in the first session of Phase I, Leon displayed an increase from 2 to 4 instances of very positive emotions as compared to the last session of the baseline. In Phase II of the intervention, the number of very positive emotions was in general low, with one high peak in session 11 (causing high variability in the scores during this phase). During follow-up, the number of very positive emotions increased again from 0 in the first session (session 13) to 8 in the last session. Although the average level of very positive emotions during follow-up was high, the scores also showed high variability. Negative emotions were not observed in the group home.



*Figure 4.* Mean occurrence of target behaviors during baseline, intervention, and follow-up (left), and occurrence during separate observation sessions (right) at the group home

### 3.3.2 Social Validity

The average scores of the caregivers on the Social Validity Scale indicate the following. Although individual coaching ( $M = 5.0$ ) was preferred to team coaching (4.3), both were judged to be “highly effective”. The caregivers rated their own attitude and communicative skills as “very positively changed” by both types of coaching (4.1). Leon’s behavior was rated as “positively changed” (3.5). Caregivers judged “affective involvement” to be the easiest to implement (3.9), followed by “sharing attention” (3.8), “recognizing and interpreting initiatives” (3.7), and “regulating intensity” (3.6). “Sharing experiences” (2.8) and “sharing meaning” (2.6) were judged to be “rather difficult” to implement.

### 3.4 Discussion

This study examined the effects of an intervention aimed at fostering affective involvement between an adult with CDB and his caregivers. The findings show that the onset of the intervention coincided with improvements in Leon’s affective involvement and emotional behavior. The coach successfully helped caregivers better attune their behavior to that of Leon and to foster affective involvement, not only during interaction (Phase I of the intervention) but also during communication (Phase II).

Considerable improvement in all target behaviors was observed in both settings. The intervention effects were the most compelling at the daytime activities center. Here, clear intervention effects were observed for *negative emotions*, which were present at baseline but disappeared after the intervention was introduced. Furthermore, *very positive emotions* increased considerably in this setting, and it was also possible to foster *affective involvement*, with the highest peak during the communication phase, especially in session 11. Re-observation of this session showed that Leon was remarkably alert and quick in his initiatives. The caregiver had many opportunities to be responsive, confirm Leon’s initiatives, and share experiences and emotions with him.

In the group home, positive intervention effects varied across the two intervention phases. *Very positive emotions* and *affective involvement* increased more during the interaction phase (Phase I) than during the communication phase (Phase II). During follow-up, *very positive emotions* and *affective involvement* increased compared to baseline. Variability in the occurrence of these behaviors was high during both intervention phases and follow-up. The scores for very positive emotions and affective involvement were more stable across the intervention conditions at the daytime activities center than in the group home, suggesting that the intervention worked better at the daytime activities center.

The follow-up findings (i.e., the decrease of affective involvement at the daytime activities center and the low occurrence of affective involvement in the group home) are consistent with an earlier study (Janssen et al., 2003a) in which affective involvement

decreased during follow-up in most cases compared to intervention. This suggests that individual coaching needs to be continued on a regular basis.

*Negative emotions* were not observed at all already during baseline in the group home. This is remarkable, given that the caregivers judged Leon's negative emotions to be "very severe" before the intervention (during step 2 of the intervention protocol: Clarifying the question). One reason for the absence of negative emotions during the observation sessions could be that contextual changes had already been introduced by the caregivers by the onset of the baseline: the caregivers had been asked to implement an interactive and motivating activity that would take 20 minutes or longer. Furthermore, they had learned to adapt the context during intervention by choosing the right position, adding something new to the interaction, and choosing a more relaxing activity that was suitable to Leon's mood.

During evaluation, the caregivers indicated that sharing positive emotions was easier than sharing negative emotions with Leon. This corresponds with the results of studies on engagement (Trevarthen & Aitken, 2001) and disengagement (Tronick, 1989). The practicality of the intervention was considered the most difficult during sharing meaning since it is a challenge to create meaning when you have to use movements, gestures, and touch instead of symbols to refer to people, objects, places, or events (Hart, 2010).

#### **3.4.1 Study Limitations**

This study has several limitations. First, the remarkable finding that no negative emotions were observed in the group home during baseline may have been due to contextual changes made by the caregivers during baseline. For future research, we recommend that researchers more clearly instruct the caregivers "to act as usual" during video recordings before and during baseline.

Second, we only used inter-observer agreement to estimate the reliability of the observations. Also computing intra-observer agreement would have provided a more complete reliability picture, but time limitations prevented us from doing that.

Third, the single-subject design restricts the generalizability of our findings (Barlow et al., 2009). We recommend replicating the intervention in future studies.

#### **3.4.2 Implications for Practice**

Coaching caregivers may be labor-intensive (Fukkink, Trienekens, & Kramer, 2011) and expensive. In this study, the only extra costs were related to involving a coach. In consultation with the caregivers, no extra time was spent on coaching because the coaching was performed during regular meetings and the caregiver's overhead time. This only implied that the caregivers could spend less time to other relevant topics to make coaching possible.

The decrease in affective involvement during Phase II in the group home (Figure 4) suggests that fostering affective involvement is more difficult during communication. This is because it is complex to coordinate the flow of interactions while simultaneously focusing on meanings and intentions and tactily sharing emotions (Hart, 2010). However, in the daytime activities center affective involvement increased during communication (Figure 3, Phase II). Additional case studies may further highlight the differences between fostering affective involvement during interaction and communication.

In both settings, affective involvement occurred and improved, especially in sessions where Leon's initiatives were quick and clear. At these times, his caregivers succeeded in establishing "co-authoring", in which they positioned themselves as following listeners (Nafstad, 2010) and marked topics of interest and emotions tactily. Examples of such high-quality affective involvement in a communicative context can provide opportunities to learn more about successful strategies for fostering affective involvement.



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