

# Intervening in Stress, Attachment and Challenging Behaviour

Effects in Children with Multiple Disabilities



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Deze publicatie is mogelijk gemaakt door de Vereniging Bartiméus.

ISBN 978-90-71534-57-7

Eerste druk

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**VRIJE UNIVERSITEIT**

Intervening in Stress, Attachment and Challenging Behaviour  
Effects in Children with Multiple Disabilities

**ACADEMISCH PROEFSCHRIFT**

ter verkrijging van de graad Doctor aan de Vrije Universiteit Amsterdam, op gezag  
van de rector magnificus prof.dr. L.M. Bouter, in het openbaar te verdedigen ter  
overstaan van de promotiecommissie van de faculteit der Psychologie en  
Pedagogiek op vrijdag 3 oktober 2008 om 10.45 uur in de aula van de universiteit,  
De Boelelaan 1105

door

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Voor mijn vader en moeder



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# Chapter I General Introduction

## Introduction

Attachment is regarded as a pattern of organized behaviour within a relationship (Bowlby, 1973/1998). In times of stress, anxiety or discomfort, a child's attachment behavioural system generates verbal or non-verbal behaviour in order to attain proximity to an attachment figure. This usually results in safety and care provided by this attachment figure (Bowlby, 1969/1997) and provides children with the opportunity to gradually learn to cope with stressful situations by themselves. If attachment figures react predictably in a sensitive and responsive manner, buffering children's stress levels, secure attachment relationships are likely to develop. Over time, children develop a mental representation of the relationship between the attachment figure and the self, largely based on these experiences.

However, distortions in relationships between children and their caregivers may contribute to atypical patterns of attachment (Bowlby, 1969/1997). These distortions may be the result of unfavourable caregiving (e.g. abuse or neglect) or the absence of one or a small number of caregivers with whom the child can develop a specific relationship (Bowlby, 1969/1997). Although Bowlby found evidence for early parental loss, separation, or complete absence of an early attachment figure amongst children with psychopathology, his theory concerning the link between these experiences and outcomes was not deterministic, but focused on the processes that are set in train by early attachment experiences. He proposed that early experience frames, but also is transformed by, later experience (Bowlby, 1973/1998; Sroufe, Carlson, Levy, & Egeland, 1999). Thus, although children's experience forms a critical part of the developmental context, change remains possible at numerous points in development (Sroufe et al., 1999). However, change may be more readily accomplished early in life or if there is a foundation of early support in a child's background (Sroufe et al., 1999).

While changes in atypical attachment may be possible in principle, the extent to which they can in fact take place in children without a stable attachment figure, for instance children growing up in orphanages and other institutions characterized by fragmented caregiving, is an open question. The positive outcomes experienced by many children adopted from such circumstances suggest that such a radical intervention may be successful (Rutter et al., 2007; Juffer & Van IJzendoorn, 2007). The limits of the responsiveness of the attachment behavioural system to environmental changes are largely unknown, however. Research has been mostly limited to children adopted from institutions before the age of six years. Research on attachment to foster parents has been conducted in infancy (e.g. Cole, 2005; Stovall-McClough & Dozier, 2004) or in the preschool period (e.g. Oosterman & Schuengel, 2007a, in press; Vorria et al., 2006). In addition, none of these studies have involved children with intellectual disabilities. Attachment may be as important or even more important for children with intellectual disabilities as for children without such disabilities in coping with

challenges to mental health (Janssen, Schuengel, & Stolk, 2002; Schuengel & Janssen, 2006). It is not known to what extent it is possible to stimulate attachment behaviour in deprived children of varying ages with intellectual disabilities, or to teach these children to use a specific person as a source of comfort and security during times of stress. This study was guided by these key questions, and explored the psychotherapeutic benefit of stimulating attachment in children with visual and severe intellectual disabilities who show severe challenging behaviours.

## **Disabilities and the development of attachment**

Fraiberg (1979) suggested that visual disabilities might strongly interfere with the development of an emotional attachment between infants and their parents. Clinically, she observed that in blind children the development of the ability to differentiate between oneself and an object or another person was delayed, as was object and person permanence (Fraiberg, 1977). Parents reported a lack of responsiveness in their infants, since they did not smile at them as much as other children did. In addition, their use of body language differed as the blind children used their hands, instead of facial expression, to express their emotions and reveal their wishes. Ainsworth, Blehar, Waters, & Wall (1978) and Bowlby (1969/1997) included orienting and looking among other behaviours that infants show instinctively at times of fear or distress, such as rooting and sucking, postural adjustment, listening, smiling, vocalizing, crying, and grasping. Thus, visual disabilities may interfere with the development of early attachment relationships. Nevertheless, the limited studies that have been done show little evidence that visual disabilities on their own may be predictive of the development of insecure attachment relationships in infancy (Friedman, 1988; Gerra, 1993).

Atkinson et al. (1999) examined the behavioural precursors mentioned by Ainsworth and Bowlby in children with an intellectual disability and found deficits with respect to communicative and attachment behaviours such as looking, eye contact, vocalizations, crying, smiling, turn-taking, social referencing, initiative-taking, approach and language. When affective signals are fewer and harder to interpret, caregivers may also provide less affective feedback, hindering the development of smoothly patterned emotional communication as found in secure attachment relationships. This was the conclusion drawn by Vaughn, Goldberg, Atkinson, Marcovitch, MacGregor, and Seifer (1994) from observations during the Ainsworth Strange Situation Procedure for assessing attachment security in children with Down Syndrome (DS). Children with DS gave only weak signals for contact during reunion episodes. Due to the absence of distress signals (e.g. crying, reaching, holding on) the attachment system of children with DS failed to achieve the proximity needed for arousal reduction. According to Thompson, Cicchetti, Lamb, and Malkin (1985) the children in their study with DS seemed less

distressed by the separation from their mothers, took longer to become distressed and less time to settle, and their variety of responses was smaller in comparison with a group of infants without DS. Nevertheless, the children with DS did show attachment-related behaviours. As their attachment behaviours are fewer and harder to interpret it is clear that children with an intellectual disability may need exceptionally sensitive and responsive caregiving to compensate for the risk factors they bring to the attachment relationship (Atkinson et al., 1999, Ganiban, Barnett, & Cicchetti, 2000; Schuengel & Janssen, 2006; Von Tetzchner, 2004).

Atkinson et al. (1999) found less securely attached children during the Strange Situation among the lower-functioning children. Thus, limited cognitive skills may hinder the development and use of the attachment relationship for affect-regulation during moments of stress and discomfort (Janssen et al., 2002). For example, limited cognitive skills may make it difficult for children to differentiate means from ends (Cassidy, 1999). They may therefore be unable to give attachment signals to achieve proximity to or contact with the attachment figure (Janssen et al., 2002). Furthermore, lower functioning children with deficient object permanence (Cassidy, 1999) may experience an almost permanent state of separation distress (Janssen et al., 2002).

Another risk factor for the development of an attachment relationship may be that children with disabilities more often live in group homes than children without disabilities. Research among children living away from home showed that although institutionalisation may lead to seeking out new attachment relationships (Schuengel & Van IJzendoorn, 2001; Zegers, Schuengel, Van IJzendoorn, & Janssen, 2006), the discontinuity and sheer number of professional caregivers, each with different levels of sensitivity, make it difficult for children with deficits in processing information to develop focused relationships with specific caregivers (Schuengel & Janssen, 2006). Consequently, children with an intellectual disability may be at high risk of developing insecure attachment relations.

## **Attachment deprivation and affect regulation**

Due to loss, separation, or discontinuous caregiving arrangements, some children do not have an attachment figure on whom they can rely in moments of distress (Zeanah & Boris, 2000). Children initially reared in profoundly depriving institutions in Romania and subsequently adopted in UK families, for example, show serious developmental delays and psychopathological behaviour symptoms on arrival in their adoptive homes. Although their problems tend to diminish and their growth accelerates, they do not catch up completely (O'Connor et al., 2000; Rutter et al., 2007). Children with intellectual disabilities may be even more vulnerable to the effects of disrupted, inadequate caregiving (Janssen et al., 2002). In addition, children with disabilities are at risk of maltreatment (Horner-Johnson & Drum,

2006). Thus, the developmental history of many children with intellectual disabilities may be linked to the heightened risk of mental health problems in this population and the high prevalence of challenging behaviour (Schuengel & Janssen, 2006).

Bradley (2000) stated that during infancy children need the physical proximity of their parents to help them deal with demanding and stressful situations. In this way the infant learns that distress or moments of high arousal can be modulated, giving the infant a sense of control and a sense that the environment is reasonably predictable (Bradley, 2000; Weinfield, Sroufe, Egeland, & Carlson, 1999). Psychophysiological studies have shown that the presence or absence of primary attachment figures (biological or foster parents) is associated with children's autonomic nervous system (ANS) responses in stressful situations (Oosterman & Schuengel, 2007a,b; Stevenson-Hinde & Marshall, 1999; Willemen, Goossens, Koot, & Schuengel, in press). The absence of attachment figures and thus the absence of adequately developed stress regulation is described by Bradley (2000) as being an important factor in the development of psychopathology. When there are no attachment figures to which children are able to turn in times of stress, they may experience a prolonged state of negative affective arousal, causing excessive use of a limited set of neural pathways, which may result in neural and behavioural deficits (Schore, 2001a,b).

In psychophysiological research on affect regulation, respiratory sinus arrhythmia (RSA) and pre-ejection period (PEP) are frequently used to determine changes in arousal. RSA and PEP are valid operationalizations of the activity of respectively the parasympathetic and sympathetic branches of the autonomous nervous system (ANS) (e.g. Berntson, Cacioppo, & Fieldstone, 1996; Berntson, Cacioppo, & Quigley, 1994; Cacioppo, Berntson, Binkley, Quigley, Uchino, & Fieldstone, 1994; Houtveen, Groot, & De Geus, 2005). RSA and PEP measures are both reduced under conditions of psychological stress (De Geus, Willemsen, Klaver, & Van Doornen, 1995; Riese et al., 2003). The sympathetic nervous system is a mobilizing system facilitating fight-or-flight behaviour, while the parasympathetic nervous system downregulates homeostatic processes to promote physiological flexibility and adaptability to meet environmental demands (Porges, Doussard-Roosevelt, Portales, & Greenspan, 1996). The adaptability is also reflected in behaviour, such as increased openness to new experiences, emotional expressivity, and the expression of social skills (Porges et al. 1996). According to Porges' vagal brake hypothesis (Porges, 1995; 2001), the parasympathetic nervous system responds as a brake on sympathetic activation and may sufficiently regulate arousal without activating the sympathetic nervous system.

The glucocorticoid steroid hormone cortisol is released by the adrenal glands in response to any type of physical or emotional stress and mediates in part the fight-or-flight response to stressful and dangerous situations. The hypothalamus-

pituitary-adrenal (HPA) axis mobilizes resources through the upregulation of cortisol, downregulating cortisol when challenges have been met (Blair, Granger, & Razza, 2005). As the regulating effect of the attachment relationship can also be measured through cortisol, changes in cortisol have been investigated in several attachment-related studies (Dozier, Albus, Fisher, & Sepulveda, 2002; Fisher, Gunnar, Chamberlain, & Reid, 2000; Gunnar, Morison, Chisholm, & Schuder, 2001).

## **Challenging behaviour and affect regulation**

In an attempt to understand the relationship between affect regulation and challenging behaviour among clients with an intellectual disability, Janssen et al. (2002) developed a stress-attachment model. According to this model, to the extent that persons with intellectual disabilities have fewer coping skills (e.g. a limited working memory and deficient executive verbal functions; problems in social information processing, perspective-taking, and empathy; inadequate social skills, a limited behaviour repertoire) they are more vulnerable to stress. A lack of self-control, and high impulsivity (Clark & Wilson, 2003) may indicate that in response to even minor stressors, primary appraisals (neuroception) of threat may be very common in this group (Janssen & Schuengel, 2006). Furthermore, lacking many experiences of mastery may result in low self-esteem, exacerbating the threat of any challenging situation and thus the general stress level. Frequent, and chronic stress may consequently result in the development of hardwired maladaptive responses to even low levels of stress (Perry, Pollard, Blakley, Baker, & Vigilante, 1995, Schore, 2001a, b; Van der Kolk, McFarlane, & Weisaeth, 1996). Under extreme circumstances continued stress may result in differences in baseline levels of cortisol in groups of persons with ID, indicating an association between cortisol levels and serious challenging behaviour (Neumann, Chi, & Fleming, 2000). Consequently, cumulative psychosocial stress is found to be positively associated with challenging behaviour, while adaptive competence in coping is found to be negatively associated with challenging behaviour (Eaton & Menolascino, 1982; Stack, Haldipur, & Thompson, 1987; Verhoeven & Tuinier, 1996).

## **The experimental treatment**

An integrative psychotherapeutic treatment, Integrative Therapy for Attachment and Behaviour (ITAB), was developed for children for whom other treatments (e.g. standard behaviour modification) had failed. This intensive integrative treatment is partly based on Došen's Developmental-Dynamic Relationship Therapy (1984; 1990; 2001; 2005). The attachment-based approach is combined with a behavioural intervention, in order to replace remaining maladaptive behaviour with more adaptive replacement behaviour. Furthermore, it is an integrative, individual treatment with a therapist who works directly with clients to effect intra-psychic

changes during therapy. It differs from Došen's Developmental-Dynamic Relationship Therapy in that the latter is mediated by caregivers (Došen, 1984; 1990; 2001; 2005). For the clients in this study, the social isolation and level of challenging behaviour were deemed to require a one-to-one approach from a skilled psychotherapist before caregivers could receive guidance on building positive caregiving relationships themselves and applying appropriate social rewards for adaptive replacement behaviour.

It is important to note that the attachment-based treatment must be distinguished from 're-birthing', 'holding' or 'attachment' therapies which, as Zilberstein (2006) noted, focus more broadly on a forced simulation of the birth process, and address aggression and non-compliance instead of attachment. ITAB is based on sensitive and responsive interactions, on caring and empathy, rather than coercion. The therapist positively encourages contact by letting the child become acquainted with him/her as a figure who is supportive, predictable and pleasant to be with. It also differs from other interventions in the field of care for persons with intellectual disabilities, in that the focus of the intervention is not on immediately learning new behaviour (e.g. O'Reilly, Lancioni, & Taylor, 1999). ITAB first follows the stages in the development of an attachment relationship (Bowlby, 1969/1997). Only later, in the behaviour modification phase, is attention focused on systematically placing social contingencies on adaptive replacement behaviour. In this respect, the integrative treatment is also different from approaches such as gentle teaching, which have been proposed as alternatives to behaviour modification (Jones & McCaughey, 1992). Instead of providing an alternative to behaviour modification, the integrative therapy seeks enhanced effectiveness of behaviour modification.

The focus of ITAB's first phase is on developing an attachment relationship between the client and the therapist to provide the basis for the development of adaptive affect-regulation skills. Physical contact may occur during therapy, on the initiative of the therapist or the client, but is never coerced by the therapist (AACAP, 2005). The second phase focuses on modifying challenging behaviours into new and socially acceptable behaviour. During phase 3 (generalization), the number of sessions is gradually reduced over time until therapy stops. During daily care the caregivers continue to invest in the bond with the patient through sensitive and responsive behaviour, as taught by the therapist. ITAB is described in more detail in Appendix A.

## **Aims of this study**

The overall aim of this study was to examine whether it is possible for children with a history of pathogenic care who have visual and severe intellectual disabilities to develop an attachment relationship with a psychotherapist, and to

examine the effect of ITAB on the children's behaviour. The objectives are set out below.

*To assess the attachment relationship between client and therapist. Does the client start to seek out the therapist for comfort? Does this relationship regulate stress?* As yet, no standard procedure is available for distinguishing attachment from non-attachment relationships (Schuengel & Van IJzendoorn, 2001). For the current study, a functional approach was adopted: if the relationship between client and therapist is an attachment relationship, it must fulfil the function of attachment relationships, namely regulation of stress (Bowlby, 1969/1997; Schore, 2001a). Therefore, the client should over time increasingly seek contact with or proximity to the experimental therapist and stress reactivity measured by PEP and RSA should be lower in the presence of the experimental therapist (Stevenson-Hinde & Marshall, 1999). In order to investigate whether the new attachment relationship improves stress levels, changes in the diurnal cortisol cycle were measured. In line with studies with foster children (Dozier et al., 2002; Fisher et al., 2000), at the end of the integrative treatment the cortisol levels should follow a more typical diurnal pattern.

*Examine the effect of ITAB on behaviour: Is behaviour modification given by an attachment therapist more effective than behaviour modification given by a non-attachment/control therapist? What is the effect of ITAB on the child's challenging behaviour during the daily caregiving situation?* A hypothesis to be tested is that attachment figures are more effective than non-attachment figures in the deliberate use of social cues to reinforce or extinguish behaviour. In an attachment relationship (secure or insecure), the attached person constantly monitors the whereabouts and availability of the attachment figure. Social cues emanating from attachment figures are, as a result, more salient than social cues from others. Although this may sound evident or even trivial (indeed this consideration supports the practice in behaviour modification of using parents where possible as behaviour modification agents (e.g. Golan, 2006; Sherrill & Kovacs, 2004), the enhancing effect of combining two roles (attachment figure and behaviour modifier) remains a hypothesis open to empirical testing (Friman & Altman, 1990).

## **Method**

*Research design.* In this study ITAB started with attachment therapy (phase 1) during which the experimental therapist attempted to build an attachment relationship in sessions alternating with sessions in which a control therapist provided only positive attention. In phase 2, both therapists applied the same behaviour modification protocol. The development of the attachment relationship during ITAB and the effect of ITAB on behaviour were tested by means of multiple baseline (Chapter 2 and 4) and multiple case (Chapter 3) studies. In a single-case



study (Chapter 5) the development of the attachment relationship with the psychotherapist and the effect of ITAB were described.

*Participants and selection.* The six clients in this study, between the ages of 10 and 18 years, were blind or had a serious visual disability (according to the World Health Organization criteria), had a severe intellectual disability (IQ range between 20 and 34), and persistently and severely engaged in challenging behaviour (self-injurious behaviour, aggression, or disruption). Their history included early pathogenic care leading to an attachment disorder, as diagnosed by an independent psychiatrist (DSM-IV: persistent neglect of basic emotional needs for comfort and affection, persistent neglect of physical needs, and frequent changes of regular caregivers). Their behaviour was noted as severe and persistent with a high score on the Severe Challenging Behaviour Consensus Protocol – National Institute for Health Care Management (*Consensusprotocol Ernstig Probleemgedrag - Nationaal Ziekenhuisinstituut - CEP*), a commonly used, reliable, and valid Dutch protocol for measuring challenging behaviour (Kramer, 2001). Examinations by physicians ruled out medical issues that might be associated with challenging behaviour. The independent psychiatrist had extensive experience with assessment and treatment of clients with visual and intellectual disability and could identify clients with autistic spectrum disorders; such clients were excluded from the study. Although children with autism spectrum disorders show secure attachment behaviours towards their parents (e.g. Dissanayake & Crossley, 1997, Naber et al. 2007, Rogers, Ozonoff, & Maslin-Cole, 1993) and should not actually be excluded from interventions aimed at improving their relationships, Rogers et al. (1993) and Rutgers et al. (2004, 2007) reported that children with autism and with an intellectual disability showed less secure attachment to their attachment figures than children without autism. As a result, for clients with autism spectrum disorder as well as an intellectual disability an adapted treatment protocol might have been necessary. A final criteria was that there were no contraindications to the treatment protocol, such as aversion to physical contact.

Psychologists from Bartiméus, an organization providing education, care and services for persons with visual and/or intellectual disabilities, and the Centre for Consultation and Expertise (CCE), which provides advice and support in difficult cases requiring specific know-how and experience, were asked to present clients matching the above mentioned criteria. Medical ethical approval was obtained from the VU University Medical Centre Medical-Ethical Review Board. This board is licensed to approve research by the Central Committee on Research Involving Human Subjects, which monitors compliance with Dutch legislation on medical research. The medical-ethical committee of Bartiméus, the participating care facility, also gave medical ethical approval.

## Thesis outline

The main focus of this study was to examine whether clients with a history of pathogenic care who have visual and severe intellectual disabilities and severe challenging behaviour develop an attachment relationship with a psychotherapist. Chapter 2 focuses on the following questions: *Does the client start to seek out the therapist as a source of comfort? Does this relationship regulate stress?* Proximity-seeking behaviour, RSA data, and PEP data were compared between treatments: the experimental and the control treatment. Observation-coding schedules were developed for proximity-seeking behaviour based on the observation scales for mother-child interaction in the Strange Situation Procedure (Ainsworth et al., 1978), see Appendix B. Proximity-seeking behaviour was independently scored using Noldus computer software ('The Observer', Noldus Information Technology, Wageningen, the Netherlands). The videotaped therapy and control sessions were randomly coded. RSA and PEP measurements were taken using the VU Ambulatory Monitoring System (VU-AMS) (De Geus & Van Doornen, 1996). The expectation was that during peaks of arousal, indicated by low RSA and PEP, clients would show high proximity-seeking behaviour in the experimental but not in the control treatment. Furthermore, we expected that the clients would show higher RSA and PEP (less arousal) with the experimental therapist than with the control therapist during the behaviour modification sessions. More proximity-seeking behaviour during moments of high stress may indicate the buffering effect of the therapeutic relationship.

Chapter 3 focuses on the question: *Did intervention have a regulating effect on the diurnal cortisol pattern?* Changes in the cortisol diurnal pattern were examined. Salivary samples were collected in the children's own environment four times a day on two consecutive weekend days once a month during ITAB. If the diurnal cortisol pattern at the end of the intervention were to show a more regular cycle, this might indicate that the development of an attachment relationship had a stress regulating effect.

In Chapter 4 we ask: *What is the effect of ITAB on the child's challenging behaviour? Is the behaviour modification given by an attachment therapist more effective than the behaviour modification given by the non-attachment therapist?* First, the challenging behaviour in the residential home was examined. To determine the effect of ITAB on the child's behaviour, the frequency of challenging behaviour in the daily situation, outside the therapy context, was reported on residential observation lists (Appendix C). Standardised instruments were used to assess the challenging behaviour shown by the client at the start of the intervention and after its completion. These instruments were the 'Severe Challenging Behaviour Consensus Protocol – National Institute for Health Care Management (*Consensusprotocol Ernstig Probleemgedrag – Nationaal Ziekenhuisinstituut - CEP*) (Kramer, 2001), and the 'Challenging behaviour scale for

people with an intellectual disability' (*Storend Gedragsschaal voor Zwakzinnigen*, or SGZ) (Kraijer & Kema, 1994). Next, the challenging behaviour and the use of adaptive replacement behaviour during the behaviour modification sessions (phase 2) were independently and randomly coded using Noldus computer software (The Observer). We hypothesized that ITAB would be more effective than standard behaviour modification given by the control therapist, and that it would have an overall positive effect on the child's behaviour.

The development of a therapeutic relationship and the effect of the treatment on the child's behaviour are described in a single case-study (Chapter 5). The case concerned a blind boy aged 17 with Down Syndrome, with a severe intellectual disability and persistent challenging behaviour, without an attachment figure. To examine the relationship with the therapist, observations of attachment behaviour – including proximity-seeking behaviour, resistant and avoidant behaviour, as well as contact maintenance – were made to compare these behaviours towards the experimental therapist and towards the control therapist during the first phase of ITAB. Observers independently coded these behaviours using Noldus computer software (The Observer). Observation-coding schedules were developed for these behaviours based on the observation scales for mother-child interaction in the Strange Situation (Ainsworth et al., 1978). The client's stress regulation during behaviour modification was examined using measurements of Respiratory Sinus Arrhythmia (RSA) and Pre-Ejection Period (PEP), indexing parasympathetic and sympathetic activation. To determine the effect of ITAB on the child's behaviour the frequency and intensity of the challenging behaviour in the daily situation, outside the therapy context, were reported on residential observation lists. During the behaviour therapy (phase 2), one of every two therapy sessions given by the experimental therapist and by the control therapist was videotaped each week. By independent and random coding of the client's adaptive replacement behaviours during these videotaped therapy sessions the effectiveness of the therapists, and ITAB versus standard behaviour modification, were examined, as well as the effect of ITAB on the clients' challenging behaviour during daily caregiving.

Finally, in Chapter 6 the results and conclusions of the studies described earlier are integrated and discussed. Furthermore, possible directions for further research are given and the clinical implications of the study results are discussed.

As the chapters can also be read as separate studies, some overlap in the introductory parts of the studies was inevitable.



# **Chapter 2 The therapeutic relationship supports affect regulation in children with multiple disabilities: A multiple case design study**

Sterkenburg, P.S., Janssen, C.G.C., Jeczynski, P. Jongbloed, G., & Schuengel, C. (under review). The therapeutic relationship supports affect regulation in children with multiple disabilities: A multiple case design study.

## **Abstract**

In a controlled multiple case design study, the development of a therapeutic relationship and its role in affect regulation was studied in six children with visual and severe intellectual disabilities, severe challenging behavior and prolonged social deprivation. The experimental treatment was an attachment-based intervention, which alternated with a control treatment consisting of positive attention. Clients showed, over time, more and higher levels of proximity-seeking behavior in the experimental compared to the control treatment. After behavior modification commenced with both therapists, clients showed lower psychophysiological arousal (RSA and PEP) in the experimental therapy than with the control therapist. The findings indicate plasticity in creating a therapeutic relationship with dysregulated multiple impaired clients. This therapeutic relationship facilitated affect regulation in challenging situations.

## **Acknowledgments**

This study was financially supported by ZonMw InSight, a Dutch society that fosters application-oriented scientific research that supports the needs of people with visual impairment. We are grateful for the cooperation and assistance of parents, caregivers and observers. The authors acknowledge the invaluable contributions of Francien Dekker, who together with the first author, was the experimental and control therapist. We also wish to thank our colleague Mirjam Oosterman for her comments on this article.

## Introduction

Supporting the development of adaptive affect-regulation skills is one of the primary objectives of psychotherapy, and the therapeutic relationship is an important means to that end (Bowlby, 1988/2003; Bradley, 2000). Bowlby hypothesized that clients may be better able to regulate their emotional responses to frightening situations, memories or thoughts if they have formed an attachment relationship with their therapist. Such relationships would be based on the attachment behavioral system, proposed by Bowlby (1969/1997) as a primary system for maintaining or re-establishing homeostasis in the face of stress. The absence of an attachment figure however increases stress and dysregulation.

Psychophysiological studies have confirmed that the presence or absence of primary attachment figures (biological or foster parents) is associated with children's autonomic nervous system (ANS) responses, in particular in stressful situations (Gilissen, Koolstra, Van IJzendoorn, Bakermans-Kranenburg, & Van der Veer, 2007; Oosterman & Schuengel, 2007a,b; Stevenson-Hinde & Marshall, 1999). Direct evidence for similar effects in therapeutic relationships is lacking. Relationship based support might be especially important for psychotherapy with children otherwise without attachment relationships. However, little is known about the plasticity of processes underlying the development of relationships and affect regulation within therapeutic relationships, as well as the plasticity of affect regulation systems in children developing along maladaptive pathways. To answer questions regarding the development of a therapeutic relationship and the role of therapeutic relationships in supporting affect regulation, the current study focused on affect regulation in the context of the emerging therapeutic relationship between psychotherapists and young clients who had been taken into institutionalized care due to multiple disabilities and severe behavioral problems.

### ***Attachment and affect regulation***

Sroufe (1991) theorized that caregivers, through sensitive responsiveness to infants' signals of distress, stimulate the development of affect regulation. Bradley (2000) emphasized that during infancy children need the physical proximity of their parents to help them deal with demanding and stressful situations. In this way the infant learns that distress or moments of high arousal can be modulated, giving the infant a sense of control and a sense that the environment is reasonably predictable (Weinfield, Sroufe, Egeland, & Carlson, 1999; Bradley, 2000). Consequently, as reported by Weinfield et al. (1999), the child's social competence and therefore self-confidence is positively influenced. Sroufe (1991) mentioned that external affect regulation is also supported through mirroring. The parent reflects the infant's emotional behavior and reactions to stress to such an extent that the infant receives the impression that emotions are shared and worthwhile. Furthermore, the caregiver supports affect regulation when he/she adequately attunes to the child's needs by a process of desensitization in which he/she



gradually comforts the child during stressful situations. For example, in response to an infant's gaze aversion when exposed to a stressful situation, the caregiver may help the infant by immediately seeking proximity and then by slowly lengthening the exposures (Bowlby, 1973/1998, Sroufe, 1991; Stern, 1974).

However, as a result of loss, separation, or discontinuous caregiving arrangements, some children do not have an attachment figure on whom they can rely in moments of distress (Zeanah & Boris, 2000). Children with a history of inadequate institutional upbringing, for example, show serious developmental delays and psychopathological symptoms on arrival in their adoptive home, and although their problems tend to diminish and their growth accelerates, they do not catch up completely (O'Connor et al., 2000; Rutter et al., 2007). Children with intellectual disabilities may be even more vulnerable to the effects of disrupted, inadequate caregiving, because their signals require heightened sensitivity from caregivers (Janssen, Schuengel, & Stolk, 2002). In addition, children with disabilities are at risk of maltreatment (Horner-Johnson & Drum, 2006). The developmental history of many children with intellectual disabilities may therefore be linked to the heightened risk of mental health problems in this population and the high prevalence of challenging behavior (Schuengel & Janssen, 2006).

### ***Attachment-based intervention***

For clients with a history of pathogenic care, with a visual and severe intellectual disability, and who exhibit severely challenging behavior we developed a three-phased attachment-based behavior modification treatment. This treatment was partly based on Došen's Developmental-Dynamic Relationship Therapy (1984, 1990, 2001, 2005). The focus of phase 1 was to develop an attachment relationship between the client and the therapist to provide the basis for the development of adaptive affect-regulation skills. The behavior of the therapist incorporated the principles of mirroring, adequate attuning to the child's needs, and reflections of behavior and emotion. Physical contact may occur during therapy, on the initiative of the therapist or the client, but is never coerced by the therapist (AACAP, 2005). Although behavior problems may diminish during the first phase due to more adaptive regulation of affect, the therapy included a second phase in which remaining maladaptive behaviors learned beforehand were addressed by means of behavior modification techniques. Behavior modification is usually conducted within the stressful or frustrating situations that elicit maladaptive behavior, and consists of placing social reward contingencies on adaptive replacement behavior.

### ***Affect regulation and psychophysiology***

In psychophysiological research on affect regulation, respiratory sinus arrhythmia (RSA) and pre-ejection period (PEP) are frequently used to determine changes in arousal. RSA is based on the differences in heart rate during a respiration cycle, and can be interpreted as an index of vagal control with a lower RSA an increased respiration cycle. PEP, as derived from systolic time intervals, is an index of cardiac

contractility with a lower PEP indicating more forceful contractility. RSA and PEP are valid operationalizations of the activity of respectively the parasympathetic and sympathetic branches of the autonomous nervous system (ANS) (e.g. Berntson, Cacioppo & Quigley, 1994; Berntson, Cacioppo, & Fieldstone, 1996; Cacioppo, Berntson, Binkley, Quigley, Uchino, & Fieldstone, 1994; Houtveen, Groot, & De Geus, 2005). According to Porges' vagal brake hypothesis (Porges, 1995, 2001), the parasympathetic nervous system responds as a brake on sympathetic activation. The sympathetic nervous system is a mobilizing system facilitating fight-flight behavior, while the parasympathetic nervous system down-regulates homeostatic processes to increase vagal output when environmental demands are perceived, facilitating engagement with the environment (Porges, 1995). RSA and PEP measures are therefore both reduced under conditions of psychological stress (De Geus, Willemsen, Klaver, & Van Doornen, 1995; Riese et al., 2003).

### ***Research questions***

The first question of this study concerned the developing relationship. We expected that the relationship with the experimental therapist would change over time, such that clients would increasingly show more proximity-seeking behavior towards the experimental therapist than towards the control therapist. This difference was examined during periods in which the clients showed high physiological arousal, because in an aroused state, proximity seeking might be assumed to fulfill a role in affect regulation. The second question concerned the buffering effect of the relationship with the experimental therapist on arousal during therapy, especially during the behavior modification sessions in which stress was induced by the therapist so behaviors could be modified. Our hypothesis was that the clients would show lower RSA and PEP arousal (high RSA and high PEP) during behavior modification (phase 2) conducted by the experimental therapist than when the same protocol was used by the control therapist. These hypotheses were tested in a series of six single case experiments with clients with visual and severe intellectual disabilities.

## Methods

### *Design*

A series of single case studies with alternating therapy conditions across six clients were conducted. Both the experimental and the control treatment were conducted parallel in time and consisted of two phases. Phase one in the experimental treatment involved trying to establish a therapeutic relationship, and in the control treatment involved positive attention. Phase two consisted of behavior modification and was provided to the same client by both therapists using the same protocol. Both therapists conducted the experimental treatment for three clients and the control treatment for the other three clients. Treatment sessions under both conditions alternated on the same days. After phase 2, the experimental therapists worked with caregivers in the clients' home to establish trusted relationships with these caregivers in the daily setting.

### *Participants and recruitment*

All six clients had a severe intellectual disability (IQ range between 20 and 35) and were blind or had a visual impairment (according to the World Health Organization criteria). The clients were persistently and severely engaged in challenging behavior (self-injurious behavior, aggression, or disruption). Their behavior was noted as severe and persistent with a high score on the Severely Challenging Behavior Consensus Protocol – National Institute for Health Care Management (Consensusprotocol Ernstig Probleemgedrag - Nationaal Ziekenhuisinstituut), a commonly used, reliable, and valid Dutch protocol for measuring challenging behavior (Kramer, 2001). The behavior problems were managed by providing very intensive care (VIC). Six or more caregivers provided the VIC. In addition, the history of the clients included early pathogenic care, based on the criteria for attachment disorder (DSM-IV: persistent neglect of basic emotional needs for comfort and affection, persistent neglect of physical needs, and frequent changes of regular caregivers) as assessed by an independent psychiatrist. There were no contra-indications for the treatment protocol, such as aversion to physical contact. The independent psychiatrist had extensive experience with assessment and treatment of clients with a visual and intellectual disability and was also able to identify autistic spectrum disorders; these clients were excluded from this study. Five out of the six clients lived in a residential home and one in a foster home. In the Netherlands children are placed in residential home-care only in exceptional situations, for instance if the child displays severely challenging behavior and/or in situations of dysfunctional family care. Characteristics of the participants are shown in Table 1.

**Table 1:** Participants: therapist, age, gender, visual impairment and attachment disruptions.

Client	Therapist	Gender	Age in years	Visual impairment	Attachment disruptions
A	1	M	17	Blind	Until 1 year of age in hospital & early institutionalization
B	2	F	16	Visual impairment	Persistent neglect and early institutionalization
C	1	M	17	Blind	Early institutionalization Shifts and multiple caregivers
D	2	F	14	Visual impairment	Early institutionalization
E	1	F	17	Blind	Early emotional deprivation and neglect and institutionalization
F	2	M	10	Blind	Preceding adoption early emotional deprivation and neglect

Psychologists working with children with severe intellectual and visual impairments were asked to present clients matching these criteria. Parents gave their written informed consent for the client's participation. Medical ethical approval was obtained from the VU University Medical Centre Medical-Ethical Review Board. This board is licensed by the Central Committee on Research Involving Human Subjects, which monitors compliance with Dutch legislation on medical research, to approve research.

**Intervention**

Three clients participated in the period 2002-2003 and three clients in 2003-2004, with a mean of 21.8 weeks for phase 1, a mean of 7.6 weeks for phase 2 and a mean of 8.2 weeks for phase 3. The intervention was performed in the client's residential environment. The first phase of the integrative treatment focused on the development of therapeutic relationships and addresses intra-psychic development. This phase was divided into three sub-phases:

*Phase 1.1. The start of communication-contact.* The therapist provided sensitive and encouraging responses, including touch and vocalization, depending on what was comfortable for the client. Contact starts with vocal initiatives, as clients have to get to know their therapist by voice first, due to their visual disability. Touch can be added if the client feels comfortable when touched. The therapist reacts sensitively to the positive and to the negative reactions of the client by verbally or non-verbally acknowledging the signal and adapting the interaction or the situation to suit the client.

*Phase 1.2. Symbiosis.* Mirroring and synchronizing was used to stimulate communication and control by the client over the environment. The therapist encourages the client to take the lead while attempting to achieve synchronicity in the interaction by anticipating the client's actions as closely as possible. For example, when the client and therapist rock sideways to the rhythm of music, the therapist gradually leaves the initiative to continue this activity to the client, anticipating each intended 'rock'.

*Phase 1.3. Individuation.* The therapist stimulated exploration of the environment, offering verbal or nonverbal comfort when exploration results in anger or anxiety. Seeking contact when unpleasant emotions were experienced were thus rewarded by positive attention.

The second phase focuses on modifying learned maladaptive behaviors into new and socially acceptable behavior. Antecedents-behaviors-consequences (ABC) data were collected during situations in which the challenging behavior occurred (Northup et al, 1991; Northup, Wacker, Berg, Kelly, Sasso, & De Raad, 1994; Sigafoos & Meikle, 1996), for example during free time, social encounters, or daily care. To identify the meaning of these target behaviors, separate functional analyses for each challenging behavior were conducted (Mace, Page, Ivancic, & O'Brien, 1986). According to the brief ABC assessments (e.g. Northup et al., 1991, 1994; Hanley, Iwata, & McCord, 2003) three socially acceptable adaptive replacement behaviors that served as functional alternatives were defined as target behaviors. Through systematic 'chaining' and 'fading', new appropriate behavior was taught.

In the last phase (phase 3: generalization), the number of sessions was slowly reduced over time. The regular caregivers continued to invest in the bond with the client through being sensitive and responsive towards him/her, as taught by the therapist. The intervention is described in more detail in Appendix A.

### ***Instruments***

*Psychophysiological measures.* We used the VU University Ambulatory Monitoring System (VU-AMS) to record the electrocardiogram (ECG) and changes in thoracic impedance (ICG) (De Geus & Van Doornen, 1996). This device enables a simultaneous assessment to be made of respiratory sinus arrhythmia (RSA) and

pre-ejection period (PEP). RSA is an index of activation of the parasympathetic division of the autonomic nervous system, because it is relatively uninfluenced by sympathetic activation. RSA is the difference between the lowest interbeat interval (IBI) during inspiration and the highest IBI during expiration. PEP (the interval between electric stimulation of the heart and the opening of the aorta) is an index of sympathetic activation, being relatively uninfluenced by parasympathetic activation. If the client does not move, any change in RSA and PEP can be interpreted as an indication of psychological stress. Lower PEP and lower RSA indicate greater stress. To calculate the PEP scores, coders reliably trained on 15 sample cases ( $r > .90$ ) inspected beat-by-beat data. The coders inspected the B-point, one of the 3 points automatically scored to determine the PEP scores. The B-point is the onset of left ventricular ejection of blood in the aorta (De Geus et al. 1995). Because of the limited reliability of B-point detection, due to ambiguity in the location of the B-point, each waveform was checked and corrected or deleted when automated scoring revealed B-points that were morphologically inconsistent (Riese et al., 2003). Fewer than 5% of the waveforms were discarded. Reliability checks ( $r > .90$ ) were done for each client. To edit the RSA scores for movement noise, the software package was used by the trained raters reliable on sample cases ( $r > .90$ ). Willemsen, De Geus, Klaver, Van Doornen and Carroll (1996) and De Geus and Van Doornen (1996) provided information on the VU-AMS equipment and the adequate reliability and validity of the RSA and PEP data.

*Movement.* Observers independently coded the 314-videotaped sessions (phase 1: 240 videotaped sessions; phase 2: 74 videotaped sessions), coding posture on a 3-point scale as: laying down or sitting (low activity level), standing-up or rocking (middle activity level), and walking/crawling or jumping (high activity level), using The Observer, a computer software package produced by Noldus (Wageningen, the Netherlands).

*Proximity-seeking behavior.* We developed observation-coding schedules for proximity-seeking behavior based on the observation scales for mother-child interaction in the strange situation (Ainsworth, Blehar, Waters, & Wall, 1978) (The coding schedules (in Dutch) are included in Appendix B.). The observation schedule for proximity-seeking by the client (physical or by means of an object) identified initiatives to increase proximity by the client. The coding schedules enabled recording of the intensity of the proximity-seeking behavior, with 0 representing no proximity-seeking behavior, 1 minimal, 2 moderate, 3 active and 4 very active proximity-seeking behavior. For each scoring category a clear description was given of the intensity of the proximity-seeking behavior and examples are given. Proximity-seeking behavior was only scored when the child initiated the proximity-seeking behavior towards the therapist. Three observers independently coded 240 videotapes of the treatment and control sessions during phase 1.1, 1.2 and 1.3, using Noldus' The Observer, a computer software package (Wageningen, the Netherlands). Observers were kept blind to treatment condition and phase of

therapy by offering the session recordings in random order. For mean frequency and duration of proximity-seeking behavior the interobserver agreement was 85% and Cohen's kappa was .71. We found no observer drift.

## **Analyses**

### ***Proximity-seeking behavior during psychophysiological high-arousal***

Periods of heightened arousal were identified on the basis of ANS activity. In order to remove single extreme values, considered to be outliers, the moving median algorithm with window size 3 was first applied to the data. Following Touch's (1986) method for detecting peaks in ECG signals, a baseline was introduced to represent local expected values of the score. This baseline was estimated using moving averages. Two parallel, double-sided moving averages were used one as a baseline and one as a local trend. Periods of high arousal were then identified as those times when the baseline (moving average with bigger window size) was lower than the local trend (moving average with a narrower window) minus threshold value  $c$ . In this way the focus was placed on finding the 'valleys' indicating periods of high-arousal. With both RSA and PEP scores, the window sizes for computing the moving average, which served as the baseline, were set to cover 5-6 minutes of observation. The local trend windows were set to cover 30-40 sec. This was considered small enough to be sensitive and at the same time credible in marking moments of high arousal. Another advantage is that this window size covers more or less the period over which the PEP score is recorded. Ensuring a standard period length makes further results based on the RSA data comparable with the results based on the PEP data. To eradicate short instances identified as high arousal (or non-arousal), two corrections were made. When a single time point (representing around 5 sec.) classified as high arousal was surrounded by moments of non-arousal, it was ignored. A similar adjustment was made to include the non-arousal isolated single time points into a high-arousal period. For the RSA scores, threshold  $c$  was set at 2.5. This led to 15% of the therapy sessions being classified as 'extremely aroused'. For the PEP scores the constant  $c$  was set at 4, reducing the moments of 'extreme arousal' to between 8% and 14% of the session time. Furthermore, as for the moments of arousal for the RSA and PEP scores moments of 'non' arousal were determined.

To determine whether clients did show significantly more proximity-seeking behavior towards the experimental therapist compared to the control therapist during moments of high-arousal (the high RSA and PEP arousal moments as described above) a permutation test was used. For each period of high arousal, the fraction of its total length during which the client was seeking proximity was calculated with the type of therapist as the factor. To perform the permutation test, the type of therapist (attachment or control) was shuffled randomly against the computed fractions. In this way, each observation received a new label indicating the type of therapy. Because true permutations (without 'replacement') were used, the number of observations belonging to the attachment therapy and

to the control therapy remained the same. After this random shuffling procedure had been performed many times, the  $p$  value was calculated as the proportion of permuted data sets that yielded test statistics (difference between the average time fraction for attachment and control therapist) less than the originally observed difference. Simulation was done for all six clients together. To determine the possible moderating effect of moments of non-arousal on the proximity-seeking behavior these analyses were repeated for both therapists separately. Therefore, in the permutation test the type of therapist was replaced with moments of high-arousal and non-arousal. During post hoc analyses we qualitatively examined the moments of high arousal and found the highest level of arousal when clients were given an assignment, when there was physical contact or when there was a big physical distance between the therapist and the client, and when there were environmental disturbances during the treatment (e.g. noises, another child asking for attention, or the squeaking of a door).

### ***Psychophysiological arousal during behavior modification***

To determine RSA and PEP during behavior modification and test for differences between the experimental and control treatment, the following procedure was followed. First, the sample mean of each therapy session was used for all observed values of PEP, continuously measured over every period of 30 seconds, and of RSA, continuously measured over every respiration cycle. In order to take into account the natural assumption that clients get used to situations and would therefore experience higher RSA and PEP scores (less psychophysiological arousal) in the presence of any therapist, isotonic regression was used to estimate the natural increasing trend in the computed means over the consecutive therapy phases and sub-phases (Barlow, Bartholomew, Bremner, & Brunk, 1972). Another aim in using isotonic regression was to enhance the statistical power of the analysis (Gaines & Rice, 1990). The statistics in isotonic regression are based on likelihood ratios and are related to the F statistic in ANOVA. A low  $p$  value for the test statistic indicates a significant difference between the means in so far as they were *compatible* with the assumption that the clients would show higher RSA and PEP scores (lower RSA and PEP arousal) during sessions conducted by the experimental therapist compared to the control therapist. The resulting  $p$  values based on nonparametric bootstrap experiments are reported.

## **Results**

### ***Preliminary analyses***

Our first preliminary analyses focused on dealing with the missing RSA and PEP measures. The PEP scores were taken every 30 seconds. This resulted in approximately 80 to 100 PEP measures for each of the 314 sessions. Only 2% of the data were missing for PEP and we decided not to perform imputations. RSA measurements, on the other hand, were taken for every breath cycle, resulting in



400 to 600 RSA measures for each of the 314 sessions. On average, 15% of the RSA scores were recorded as missing. Therefore, values were imputed for the missing data by extrapolation in accordance with the following three criteria. The time-series nature of RSA scores had to be preserved; the distribution of the data needed to be followed and, most crucially, the replacements had to reflect the local trend of the data scored before and after the missing data. We decided to use a Spline interpolation method to impute values for the missing data (Ibanez, Grosjean, & Etienne, 2006). The Spline interpolation uses low-degree polynomials in each interval and chooses the polynomial pieces such that they fit smoothly together (Ibanez et al., 2006). This method could also deal with blocks of missing data: the mean of RSA or PEP was placed in the middle of the missing value block (more than 4 missing values) and then the Spline method interpolated the missing values.

Our second preliminary analyses focused on the influence of the client's movement on the RSA and PEP measures. For each session, mean RSA and PEP values were calculated for low, high, and very high activity. Next, a one-way ANOVA, where the averages of PEP and RSA for each movement level were the dependent variable and level of movement served as the factor, was performed. The results indicated that higher movement levels showed lower RSA. This was more prominent in very high physical activity when the heart beats faster, causing the difference in inter-beat intervals between exhalation and inhalation to decrease. The overall p values showed that lower RSA scores were significantly associated with a higher activity level in clients A ( $F = 21.47, df = 2, 207, p < .000$ ), B ( $F = 4.23, df = 1, 170, p < .041$ ), D ( $F = 181.36, df = 2, 228, p < .000$ ), E ( $F = 28.25, df = 2, 206, p < .000$ ), and F ( $F = 18.57, df = 2, 227, p < .000$ ). Client B, who had cerebral palsy, showed no RSA scores in high levels of movement. Client C showed no significant effect of movement on the RSA scores ( $F = 2.76, df = 2, 192, p < .066$ ).

A one-way ANOVA across clients indicated that PEP scores were not significantly associated with level of activity. These findings correspond with the results reported by Cacioppo et al. (1994) and Houtveen et al. (2005). They found that changes from supine to sitting to standing led to reduced RSA values and longer pre-ejection periods, reflecting the decrease in vagal but not the increase in sympathetic activity. In this study the increase in activity level led to significantly reduced RSA values. After estimating in ANOVA the effects of 2 & 3 level of activity on RSA, the effects were subtracted from the original scores.

### ***Effect of therapy condition on proximity-seeking behavior during ANS responses***

Table 2 shows the results from the permutation tests of the proximity-seeking behavior of all the clients during moments of high-arousal (using RSA measures). The clients showed no significant difference in low levels (levels 1 and 2) of proximity-seeking behavior during moments of high-arousal. However, the clients

showed significantly more intense (in the sense of duration) proximity-seeking behavior at higher levels (levels 3 - active and 4 - very active) of proximity-seeking towards the experimental therapist compared to the control therapist. During moments of high-arousal the clients showed more and higher levels of proximity-seeking behavior towards the experimental therapist than towards the control therapist. Differences in proximity-seeking between periods of high and low parasympathetic nervous system arousal did not significantly vary among both therapists.

Table 2 also shows the results from the permutation test of the proximity-seeking behavior of all the clients during moments of high-arousal, as defined by low PEP measures. The permutation tests indicated that in the later phases of the intervention, higher levels of proximity-seeking behavior (level 3 and 4) occurred more often in the experimental therapy than in the control therapy. Again, differences in proximity-seeking between periods of high and low sympathetic nervous system arousal did not significantly vary along with type of therapist.

**Table 2:** *p* values from the permutation test for each level of proximity-seeking, during moments of high-arousal, towards the experimental and the control therapist for each phase of the treatment, for all clients together, using RSA data and PEP data.

Affect regulation	Phase	Proximity seeking 1 <i>p</i> values	Proximity seeking 2 <i>p</i> values	Proximity seeking 3 <i>p</i> values	Proximity seeking 4 <i>p</i> values
RSA	1.1	1	.22	.00	.00
	1.2	.1	.2	.00	.00
	1.3	.9	1	.00	.00
PEP	1.1	.83	.1	.05	.82
	1.2	.06	.68	.04	.00
	1.3	.08	.85	.00	.00

Effect of therapy condition on psychophysiological high-arousal during different phases of the therapy

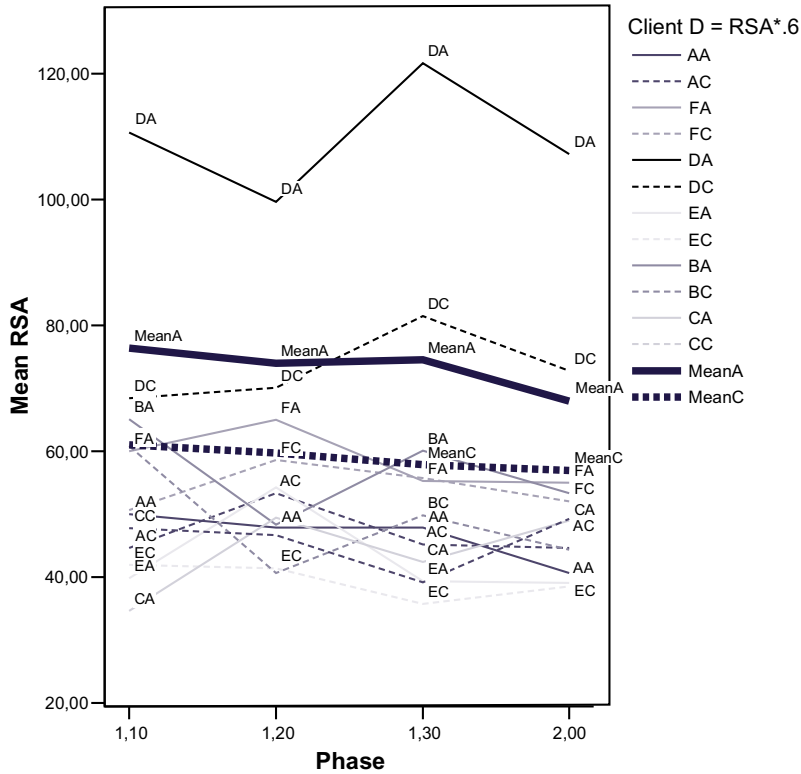
The isotonic regression analyses showed that for client D there was a significant difference in the moments of parasympathetic nervous system arousal between the two therapists in all the phases of the treatment (Table 3). Client B showed significant differences in phase 1.1 and phase 2 and client A in phase 1.2. The statistical significance of results was tested using non-parametric bootstrapping. Additionally, a parametric bootstrap was performed which showed the same results but also a significant difference between the attachment and the control therapists for client A in phase 1.1 and for client E in phase 1.2.

**Table 3:** *p* values, non-parametric bootstrapping, for RSA measures, during moments of high-arousal, for all the clients in the different phases of the intervention.

Client	Phase 1.1 <i>p</i> values	Phase 1.2 <i>p</i> values	Phase 1.3 <i>p</i> values	Phase 2 <i>p</i> values
A	.15	.04	.22	.91
B	.02	.16	.10	.01
C	.94	.68	.15	.62
D	.00	.00	.00	.00
E	.54	.21	.08	.21
F	.26	.28	.19	.26

Figure 1 shows the mean RSA scores during high-arousal for all the clients for each phase of the treatment. First, regression coefficients for each client were determined separately. With the coefficient-as-outcomes model the data from the six clients were combined. The ANOVA mixed effect model for RSA indicated that during the attachment therapy (phase 1.3) and during behavior modification (phase 2) there was a marginally significant difference between the attachment and the control therapist (phase 1.3:  $F = 6.92$ ,  $df = 1, 72$ ,  $p < .01$ , phase 2:  $F = 3.51$ ,  $df = 1, 67$ ,  $p < .06$ ), suggesting that behavior modification by the experimental therapist provoked less RSA arousal than by the control therapist, who used the same protocol.

**Figure 1:** Mean RSA score, during moments of high-arousal, per phase of the intervention for both therapists, for each client and for all the clients together.



A = Experimental therapist, C = Control therapist, Mean = all the clients together. Since for client D the magnitude of RSA is much higher than in the other cases, in order to fit it into the figure and retain the strength of the difference between the therapists we multiplied client D's RSA score by 0.6 (60%) ( $DA = RSA \cdot 0,6$  and  $DC = RSA \cdot 0,6$ ).

The isotonic regression was also used to analyze the differences in moments of sympathetic nervous system arousal PEP between the two therapists (Table 4). These were significant in phase 1.2 for client B, in phase 1.3 for client C and F and in phase 2 for four out of the six clients (client A, C, D, F). The statistical significance of results was tested using non- parametric bootstrapping. A parametric bootstrap was done, showing similar results.

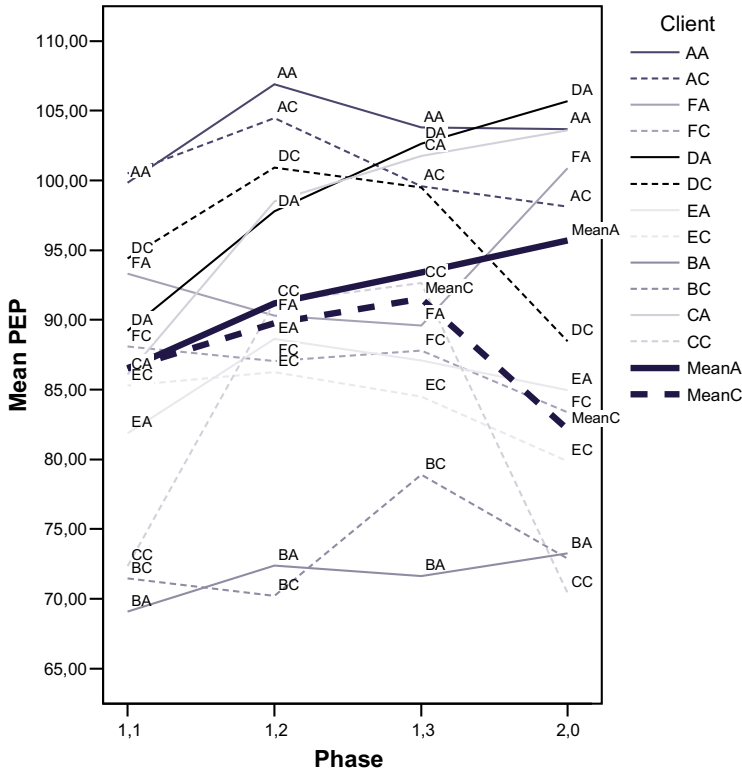
**Table 4:** *p* values, non-parametric bootstrapping, for PEP measures, during moments of high-arousal, for all the clients in the different phases of the intervention.

Client	Phase 1.1 <i>p</i> values	Phase 1.2 <i>p</i> values	Phase 1.3 <i>p</i> values	Phase 2 <i>p</i> values
A	.94	.35	.34	.02
B	.34	.02	.34	.27
C	.22	.22	.02	.01
D	.99	.97	.40	.01
E	.98	.99	.34	.10
F	.22	.23	.05	.00

Figure 2 shows the mean PEP scores during high-arousal for all the clients for each phase of the treatment. During the attachment therapy (phase 1.1 to 1.3) the level of arousal tended to decrease over time but during behavior modification (phase 2) there was a strong increase in PEP arousal (lower PEP score) only when the control therapist conducted the treatment.

First, regression coefficients for each client were determined separately. With the coefficient-as-outcomes model the data from the six clients were combined. The ANOVA mixed effect model for PEP indicated no significant difference between the attachment and the control therapist during phase 1.1, 1.2 and 1.3. During behavior modification (phase 2) when the clients were equally provoked by both therapists, the therapy condition was associated with affect regulation, indicating that the clients experienced significantly less PEP arousal (higher PEP score) when the same treatment was given by the experimental therapist than when it was given by the control therapist ( $F = 7.15$ ,  $df = 1, 69$ ,  $p < .01$ ).

**Figure 2:** Mean PEP score, during moments of high-arousal, per phase of the intervention for both therapists, for each client and for all the clients together.



A = Experimental therapist, C = Control therapist, Mean = all the clients together

## Conclusions

This study supports the plasticity of social-affective behavioral systems, even for children with multiple disabilities developing along severely maladaptive pathways, growing up without stable attachment figures. Intensive therapeutic work to stimulate the development of attachment resulted, over time, in differential behavior of these children with respect to their therapists. Having learned to seek proximity towards their sensitive and responsive therapist, these children adapted better to challenging tasks and situations. The current study demonstrates that the therapeutic relationship facilitated affect regulation during the challenging learning situations, which might explain why these children may learn more successfully (Chapter 4, 5).

### ***Development of therapeutic relationships***

Although many authors have pointed towards the importance of the quality of therapeutic relationships of working alliances, also from the perspective of attachment theory (Adshead, 1998; Goodwin, 2003; Green et al., 2001; Schuengel & Van IJzendoorn, 2001), little is known about the role of therapist behavior. Correlational studies on foster children suggest that children do develop patterns of attachment behaviors towards their new caregivers which are related to caregiver behavior (Oosterman & Schuengel, in press; Stovall-McClough & Dozier, 2004) or attachment representations of the caregiver (Dozier, Stovall, Albus, & Bates, 2001). Zegers, Schuengel, Janssens, and Van IJzendoorn (2006) showed that both the security of the attachment representations of institutionalized adolescents as well as the security of the attachment representations of their group caregiver predicted whether these adolescents would increasingly rely on their group caregiver as a source of psychological support. The current study provided a rare experimental test of the assumption that effects of therapeutic or 'parental-surrogate' relationships on outcomes are due to the behavior of the therapist or caregiver. The experimentally controlled difference between the therapist behaviors in this study was associated, over time, with discriminating proximity seeking. The same difference accounted for the extent to which these clients were able to use the relationship with the therapist to better regulate the arousal induced by situations that used to challenge them and provoked problem behavior.

The findings underscore the importance of extraordinary nurturance in the care for children experiencing disrupted attachments (Dozier, Albus, Fisher, & Sepavulda, 2002), although caution should be exercised in generalizing from the individual clients in this study to the diverse populations of children with disrupted attachments. Sustained nurturance may not only provide experiential input for the organization of the attachment behavioral system, helping children to learn to direct their attachment signals towards specific persons. Such nurturance may also help to address the difficulties these children have in behavioral, emotional, and physiological regulation. In a sample of preschool foster children, Oosterman and Schuengel (2007a, in press) demonstrated that symptoms of disordered attachment moderated the associations between foster parent sensitivity and length of placement with respectively attachment quality and autonomic nervous system response ANS reactivity to separations and reunions. Regular caregiving, even if it is family-based and stable, may not be enough for children whose attachment system is in disarray.

Questions remain regarding the nature of the therapeutic relationship that may develop as a result of the attachment-focused psychotherapy with children with multiple disabilities. Although proximity seeking behavior was identified on the basis of Ainsworth et al.'s (1978) guidelines for coding attachment behavior in the Strange Situation procedure, these guidelines also make clear that the

interpretation of proximity seeking as attachment behavior is highly situationally dependent. This was addressed by counting proximity seeking only when the children showed high physiological arousal, which might be evidence for the activity of the attachment behavioral system. However, also under conditions of low arousal, similar differences were found in proximity seeking with the experimental and control therapist. It is likely that the experimental therapist may not only become a target for attachment behavior but also a target for exploration and play, given that the capacities for independent exploration, away from the therapist as a secure base, were limited due to intellectual and visual disabilities. Future research might attempt to differentially link security seeking and exploratory proximity seeking to autonomic nervous system response. Such research may also provide more fine-grained insight in the emerging organization of the behavior of these children within the relationship, and ultimately in the nature of the relationship as an attachment relationship, and its quality.

### ***Differences between sympathetic and parasympathetic nervous system response***

Effects of the therapeutic relationship on affect regulation were found in four of the six children using the index of sympathetic nervous system activation (PEP), while on the index of parasympathetic nervous system response (RSA), an effect was only observed in two children. Furthermore, the difference in affect regulation during the sessions with the two therapists coincided with the transition from the attachment-focused therapy sessions to behavior modification sessions in which the client was prone to show problem behavior, as a response to confrontation with minor frustrations. According to Porges' (2004) polyvagal theory, activity in the sympathetic nervous system mediates evolutionary 'cruder' adaptive responses to perceived threats to homeostasis, such as fight or flight responses. Vagal regulation in the parasympathetic nervous system allows children to inhibit sympathetic arousal and mediates orientation to and communication with the (social) environment. According to Porges, however, early caregiving experiences play an important role in the development of vagal regulation. Thus, the lack of parasympathetic nervous system response in most of the clients in this study may be explained by serious attachment disruptions that these children had experienced from early on. Longer term studies are necessary to determine whether the generalization phase of the therapy was not only successful in stimulating proximity seeking to the daily caregivers but also, as an outcome of increasing social input, further organization of systems involved in vagal regulation.

Some of the findings for client D support this line of speculating. For client D there was a significant difference between the experimental therapist and the control therapist for the RSA scores during all the phases of the treatment (Table 2). Client D also had the highest verbal competencies. Thus, it is possible that in her case the vagal system was involved in engaging with her environment through verbal communication, when thus invited by the experimental therapist.



## ***Implications***

Psychophysiological measurements proved to be an effective complement to behavior observation for examining affect regulation in clients with severe intellectual disabilities. This allows for drawing conclusions of effects on psychological functioning. In the field of care for persons with intellectual disabilities, evidence based interventions are predominantly based on behavior therapy, and focused on learning adaptive skills or replacing maladaptive behavior. Psychotherapy addressing underlying cognitive and emotional processes are less well grounded in empirical evidence, due to the difficulties in acquiring data on target processes from persons with limited cognitive and communicative abilities (Sturmeijer, 2005). In the current study, the effect of the integrative therapy on proximity seeking behavior suggested that a relationship was developing with the psychotherapist, but the behavioral evidence was unspecific regarding the nature of this relationship. However, the finding that the relationship dampened arousal in a stressful situation suggested that the relationship facilitated affective homeostasis, which is the primary function ascribed to attachment relationships (Bowlby, 1969/1997). The therapist therefore had acquired a specific meaning for the clients. Although much about this meaning for the clients still needs to be explored, the study shows why integrative therapy of attachment and behavior may benefit socially deprived clients relative to standard practice focusing on behavior alone.



# **Chapter 3 Cortisol changes during psychotherapy in adolescents with a visual and intellectual disability and challenging behavior**

Sterkenburg, P.S., Janssen, C.G.C., Blankenstein, R., & Schuengel, C. (under review). Cortisol changes during psychotherapy in adolescents with a visual and intellectual disability and challenging behavior.

## Abstract

We examined changes in the diurnal cortisol pattern in patients receiving integrative psychotherapy for attachment and behavior. Five adolescents with visual disabilities and severe intellectual disabilities; severe, challenging behavior; and a background of pathogenic care were treated with integrative psychotherapy. Salivary samples were collected in the patients' residential environments four times a day on two consecutive weekend days, once a month for 9 months. Repeated measures analysis was performed to determine changes in cortisol levels and diurnal cortisol cycles. Three of five clients showed a more typical diurnal cortisol pattern at the end of the intervention. The morning cortisol level was significantly lower at the end of the intervention. Compared to a normative comparison group, the morning cortisol level was significantly lower and the evening level was significantly higher. Although cortisol samples were difficult to collect, cortisol seems to be a promising measure for evaluating the intrapsychic effects of psychotherapy for patients with multiple disabilities. Our results demonstrate the plasticity of cortisol during psychotherapy. Deviation from normative patterns of cortisol underlined the continuing vulnerability of children with multiple disabilities and challenging behavior.

## **Acknowledgments**

This study was financially supported by ZonMw InSight, a Dutch society that fosters application-oriented scientific research that supports the needs of people with visual impairment. We are grateful for the cooperation and assistance of parents and caregivers.

## Introduction

Biological systems have evolved to facilitate adaptation to environmental challenges. In humans, the hypothalamus-pituitary-adrenal (HPA) axis mobilizes resources through the upregulation of the glucocorticoid steroid hormone cortisol, downregulating cortisol when challenges have been met (Blair, Granger, & Razza, 2005). Cortisol is released by the adrenal glands in response to any type of physical or emotional stress and mediates in part the fight-or-flight response to stressful and dangerous situations. Cortisol is also important in regulating energy and has a daily circadian rhythm (Lovallo, 1997).

Individual differences in cortisol reactivity and cortisol circadian rhythm have been linked to different caregiving experiences (e.g., Dozier, Albus, Fisher, & Sepulveda, 2002; Dozier et al., 2006; Fisher, Gunnar, Chamberlain, & Reid, 2000; Gunnar & Quevedo, 2007; Gunnar & Vazquez, 2001). In general, children growing up unprotected from stressful circumstances may develop a generalized physiological hyperreactivity and elevated diurnal cortisol levels (Bradley, 2000; Halligan, Herbert, Goodyer, & Murray, 2004; Lupien, King, Meaney, & McEwen, 2000); this interferes with immune system development, physical growth, and cognitive development (e.g. De Bellis et al., 1994, Glaser, 2000, Wyatt, Simms, & Horwitz, 1997). Resilient adult survivors of physical and sexual abuse and older children chronically exposed to unmitigated stress develop a generalized physiological hyporeactivity and depressed diurnal cortisol levels (Bradley, 2000; Girdler et al., 2003; Heim, Newport, Bonsall, Miller, & Nemeroff, 2001).

Research shows that quality of care during infancy is important to developing a stress-sensitive neurobiological system and to later developing stress regulation (see Bradley, 2000 for a review). The parent-child relationship provides an environment wherein stress levels remain within certain limits; this permits the development of stress regulation. When stressed, children seek out their attachment figures; this provides children the opportunity to gradually learn how to manage stressful situations on their own. Children in secure attachment relationships, in which the parent and child flexibly balance exploration and proximity, appear to deal with stress more effectively than do children in insecure attachment relationships (Gunnar, Brodersen, Nachmias, Buss, & Rugatuso, 1996; Nachmias, Gunnar, Mangelsdorf, Parritz, & Buss, 1996; Spangler & Schieche, 1998).

Adam and Gunnar (2001) found that attachment security is associated with the functioning of the adaptive physiological stress system. Securely attached children exhibited a strong basal cortisol cycle with higher morning values and a steeper drop during the day than did insecurely attached children. In contrast, for children growing up in Romanian orphanages, an environment that makes children vulnerable to deviant attachment experiences, cortisol levels peaked in the late morning or early afternoon, rather than just after awakening (Carlson & Earls, 1997).

Hart, Gunnar, and Cicchetti (1995) suggest that the HPA axis may downregulate in response to chronic stress to avoid chronic hyperactivity. Fisher, Gunnar, Chamberlain, and Reid (2000) found that children in Early Intervention Foster Care exhibited an atypical diurnal cycle: cortisol was reduced from wake-up until mid-morning and gradually increased throughout the day. Dozier et al. (2006) also reported atypical diurnal patterns of cortisol production across the day among children in foster care. However, infants and children with traumatic childhood experiences who were placed in foster families with sensitive and responsive foster parents and developed secure attachment with the foster parents exhibited normative diurnal cycles in cortisol (Dozier et al., 2002). Fisher et al. (2000) also reported that dysregulation gave way to a more normative pattern of cortisol production upon intervention. These results indicate plasticity of the neuroendocrine cortisol system in relation to attachment and caregiving quality.

Ambulatory salivary sample collection permits the use of cortisol as an objective measure in research on stress-related treatments. In children without a mental retardation cortisol follows a circadian rhythm with high levels in the morning to prepare for necessary energy expenditure during the day, and low levels in the evening (Bartels, De Geus, Kirschbaum, Sluyter, & Boomsma, 2003). According to Terstegen et al. (2003), mean salivary cortisol levels are similar for normally developing children and children with a severe or profound intellectual disability.

Several studies have investigated changes in cortisol metabolism during psychosocial interventions (Dozier et al., 2002; Fisher et al., 2000; Gunnar, Morison, Chisholm, & Schuder, 2001). Such studies might provide clues to understanding if and how interventions affect the child's resilience (Bradley, 2000). This information might be especially important for individuals with intellectual disabilities, for whom the intrapsychic effects of psychotherapy are otherwise difficult to demonstrate.

The current study investigated the plasticity of cortisol during psychotherapy in adolescents with multiple disabilities and extremely challenging behavior. We compared cortisol levels in institution-reared adolescents with severe visual and intellectual disabilities and typical adolescents before and after a psychotherapy intervention. Based on the former adolescents' probable atypical attachment experiences and their limited capacities to resolve environmental stressors on their own, we expected that diurnal cortisol cycles would exhibit dysregulation at the start of therapy. However, we also expected that this pattern might change over the course of psychotherapy. Thus, we anticipated a change in diurnal cortisol, because the psychotherapist, as an attachment figure, might become an important regulator of adolescents' stress.

## Methods

### ***Design***

A within-group, repeated measures design was used. Repeated measurements of cortisol were obtained in adolescents at the beginning and end of psychotherapy to assess changes in diurnal cortisol patterns.

### ***Patients and recruitment***

Psychologists working in three different centers for patients with intellectual impairment cooperated in patient selection. Information letters were sent to parents, all of whom provided written informed consent.

The experimental group consisted of five patients between the ages of 10 and 18 years (One patient, a blind boy aged 18 years, was resistant to saliva collection and was therefore excluded from this study. The full sample comprised five patients.). The patients were blind or had a serious visual impairment (according to the World Health Organization criteria), had a severe intellectual disability, and persistently and severely engaged in challenging behavior (self-injurious behavior, aggression, or disruption). Their behavior was noted as severe and persistent with a high score on the Severely Challenging Behavior Consensus Protocol – National Institute for Health Care Management (Consensusprotocol Ernstig Probleemgedrag - Nationaal Ziekenhuisinstituut), a commonly used, reliable, and valid Dutch protocol for measuring challenging behavior (Kramer, 2001). The patients' history also included early pathogenic care for attachment disorder, as diagnosed by an independent psychiatrist (DSM-IV: persistent neglect of basic emotional needs for comfort and affection, persistent neglect of physical needs, and frequent changes of regular caregivers). Examinations by physicians ruled out medical issues that might be associated with challenging behavior. The independent psychiatrist had extensive experience with assessment and treatment of patients with visual and intellectual disability and could identify patients with autistic spectrum disorders; such patients were excluded from the study. There were no contraindications to the treatment protocol, such as aversion to physical contact. Patient characteristics are shown in Table 1.



**Table 1:** Participant age, gender, and vision.

Participant	Age in years	Gender	Vision
Patient 1	10	M	Blind
Patient 2	14	F	Visually impaired
Patient 3	17	F	Blind
Patient 4	17	M	Blind
Patient 5	16	F	Visually impaired

Medical ethics approval was obtained from the VU University Medical Centre Medical- Ethical Review Board. This board is licensed by the Central Committee on Research Involving Human Subjects, which monitors compliance with Dutch legislation on medical research, to approve research. The medical-ethical committee of Bartiméus, the participating care facility, also gave medical ethical approval.

### ***Intervention***

The patients participated during the period of 2002 to 2004, with a mean 37.6 weeks of each treatment. Therapy was administered in the patients' residential environments. The first phase of the integrative treatment (Appendix A) focused on the development of attachment relationships and intrapsychic development. This phase was subdivided into three subphases.

*Phase 1.1. Initiation of communication.* The therapist provided sensitive and inciting responses, including touch and vocalization, depending on what was comfortable for the patient. Contact began with vocal initiatives, as patients needed to acquaint themselves with the therapist by voice, due to their visual disability. Touch was added if the patient felt comfortable. The therapist reacted sensitively to the positive and negative reactions of the patient by verbally or nonverbally acknowledging the signal and adapting the interaction or situation to suit the patient.

*Phase 1.2. Symbiosis.* Mirroring and synchronizing was used to stimulate communication and patient control of the environment. The therapist encouraged the patient to take the lead and attempted synchronicity in the interaction by closely anticipating the patient's actions. For example, when the patient and therapist rocked sideways to the rhythm of music, the therapist gradually yielded the control over continuing the activity to the patient, anticipating each intended rock.

*Phase 1.3. Individuation.* The therapist stimulated exploration of the environment, offering verbal or nonverbal comfort when exploration stimulated anger or anxiety. Thus, patients' requests for contact in response to unpleasant emotions were rewarded with positive attention.

The second phase of the treatment focused on modifying learned maladaptive behaviors into new and socially acceptable behavior. Antecedents-behaviors-consequences (ABC) data were collected during situations in which challenging behavior occurred (Northup, Wacker, Berg, Kelly, Sasso, & De Raad, 1994; Northup et al., 1991; Sigafos, & Meikle, 1996), for example during free time, social encounters, or daily care. Separate functional analyses of each challenging behavior were performed to identify their meaning (Mace, Page, Ivancic, & O'Brien, 1986). According to the brief ABC assessments (Hanley, Iwata, & McCord, 2003; Northup, Wacker, Berg, et al., 1994, Northup, Wacker, Sasso, et al., 1991), three socially acceptable adaptive replacement behaviors that serve as functional alternatives were defined as target behaviors. Appropriate behavior was taught through systematic 'chaining' and 'fading'.

During phase 3, generalization, the number of sessions was gradually reduced until discontinuation of the therapy. During daily care the caregivers continue to invest in the bond with the patient through sensitive and responsive behavior, as taught by the therapist.

### **Measures**

Noninvasive saliva samples were collected four times a day on 2 consecutive days once a month for 9 months. Samples were collected on weekends by familiar caregivers to increase standardization and to enable more precise timing. Over the weekend, no therapeutic sessions occurred. Written instructions were given urging the parents or caregivers to collect the samples at the indicated times. The schedule was the same as that used by Bartels, De Geus, Kirschbaum, Sluyter, and Boomsma (2003) in their research involving 12-year-old twins ( $N = 180$  pairs) and by Weitzman et al. (1971) in their research into the characteristic diurnal rhythm of plasma cortisol levels. The first sample was taken in the morning at 07:30 hr, just before rising, while the child was lying in bed. The second sample was obtained one half hour after waking but before tooth brushing, between 08:15 hr and 08:30 hr. The third sample was obtained at 12:30 hr, before lunch. The fourth sample was obtained 2 hours after dinner at 20:30 hr. The salivette sampling device (Starstedt, Rommelsdorf, Germany) or a thin plastic pipette and a 2-mL microtube with cap were used. Parents and caregivers used the method that they found least upsetting to the patients. Samples were stored in the refrigerator, picked up by the test administrator, and taken to the laboratory. The samples were analyzed at the VU University laboratory using radio immunoassays with coated tubes (Spectra Orion Diagnostics, Espoo Finland). If the adolescent was resistant to providing a saliva sample, the sample was scored as missing data.

## Data Analyses

The feasibility of reliably obtaining cortisol samples was determined by assessing the valid and missing samples. The results reported by Bartels et al. (2003) were used as normative data (see Table 2). We used the 95% confidence intervals based on the standard error to compare cortisol levels in the normative and patient samples. We used the 95% confidence intervals based on the standard deviations to compare the normative cortisol levels to cortisol levels from individual patients.

**Table 2:** Mean cortisol levels (nmol/L) (over 2 consecutive days) in a normative sample of 180 twins aged 12 years (Bartels et al., 2003).

Time of day	Mean cortisol level (nmol/L)	N	Standard deviation	95% confidence interval
07:30 hr	14.51	313	4.60	>14.00 and <15.02
08:30 hr	15.2	309	6.07	>14.51 and <15.89
12:30 hr	5.67	312	1.80	>5.47 and <5.89
20:30 hr	1.84	295	0.78	>1.74 and <1.94

The Wilcoxon test for two related samples was used to analyze the effect of the attachment- based treatment on the diurnal cortisol pattern. The analyses were performed using the means for each of the four daily samples, and the cortisol level at the start (phase 1.1.) and end (phase 2) of the intervention were taken as pairs.

## Results

### Feasibility of Approach

The start (phase 1.1) and end (phase 2) of the treatment were separated by an average of 16 weeks (phase 1.2 and phase 1.3). On average, phase 1.1 lasted 5 weeks and phase 2 lasted 8 weeks. Saliva samples were collected four times a day on two consecutive days once a month for 9 months (4 samples × 9 months × 2 days). For patient 1, saliva was collected on 13 of 18 days, for patient 2 on 9 of 18 days, for patients 3 and 4 on 12 of 18 days, and for patient 5 on all the selected days. Thus, data was collected on a total of 64 of 90 days (71%). Samples for patient 2 were obtained during home visits and therefore depended on the frequency of these visits. For the other patients, missed collections occurred due to illness and temporary absence of well known caregivers. For patient 4, extra samples were obtained after completion of the intervention to compensate for missing end-of-intervention values.

Table 3 reports the number of missing samples for all patients during the data collection on the 64 days at 07:30 hr, 08:30 hr, 12:30 hr, and 20:30 hr. The percentage of missing values ranged between 20% and 41%. For phase 1.1., 25% of the values were missing; for phase 1.2., 40% of the values were missing; for phase 1.3., 44% of the values were missing; and for phase 2.0, 18% of the values were missing. The percentage of missing values was 31% for patient 1, 22% for patient 2, 12% for patient 3, 55% for patient 4, and 32% for patient 5. In most cases, too little saliva was collected due to difficulties instructing adolescents with visual disabilities and severe intellectual disabilities to open their mouth or keep their head turned towards the caregiver. Dry mouth or restlessness also interfered with sampling.

**Table 3:** Mean cortisol levels (nmol/L), standard deviation, number of samples, and number of missing samples.

Time of day	Mean cortisol level (nmol/L)	Standard deviation	Number of samples	Number of missing samples
07:30 hr	10.68	6.8	64	22
08:30 hr	10.71	8.43	64	13
12:30 hr	6.23	5.32	64	22
20:30 hr	4.57	4.78	64	26

### ***Changes in diurnal Cortisol during treatment***

Table 4 shows the mean cortisol levels and standard deviations at the start (phase 1.1) and end (phase 2) of the intervention. The Wilcoxon test for two related samples indicated a significantly lower cortisol level at 08:30 hr at the end of the intervention ( $z = -2.023$ ,  $p_{2-sided} < .043$ ). No other significant differences were found (Table 4).

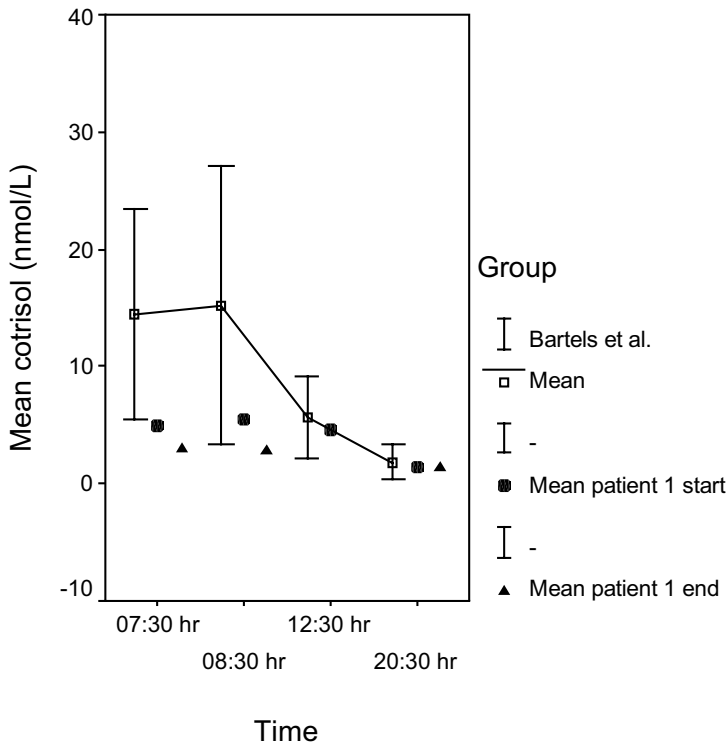
**Table 4:** Mean cortisol levels (nmol/L), standard deviation, and standard deviation error at the start and end of the intervention.

Time	Number of patients with start and end score	Mean cortisol level (nmol/L) SD at start of intervention	Mean cortisol level (nmol/L) SD at end of intervention	Z	<i>P</i> <sub>2-sided</sub>
07:30 hr	4	12.89 (6.96)	7.74 (4.88)	-1.095	.273
08:30 hr	4	15.68 (10.21)	7.37 (3.43)	-2.023	.043
12:30 hr	4	4.56 (1.07)	6.25 (2.41)	-1.095	.273
20:30 hr	4	4.49 (5.04)	3.99 (2.72)	-.365	.715

Figures 1 through 5 show the diurnal cortisol pattern for each patient at the start and end of treatment. For comparison, the means and 95% confidence intervals for normative adolescents (age 12 years) are shown.

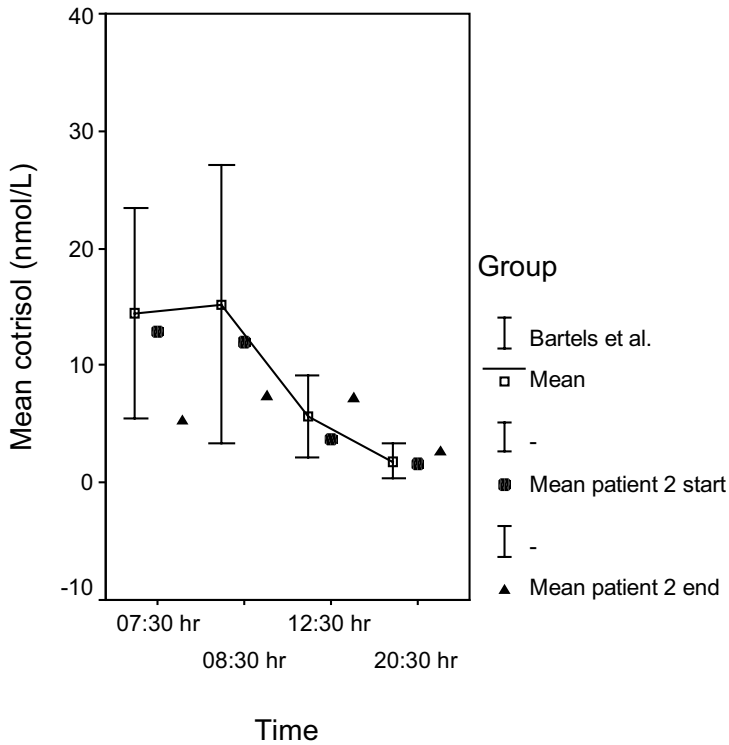
*Patient 1: Blind and intellectually impaired boy, age 10.* For patient 1, the diurnal cortisol cycles were quite similar at the start and end of the intervention. The morning cortisol level at 07:30 hr at the start and end of the intervention and the morning cortisol level at 08:30 hr at the end of the intervention were significantly lower compared to the normative group (Fig. 1).

**Figure 1.** Mean cortisol levels (nmol/L) and 95% confidence intervals for the normative group (Bartels et al., 2003) and mean cortisol levels for patient 1 at the start and end of the intervention.



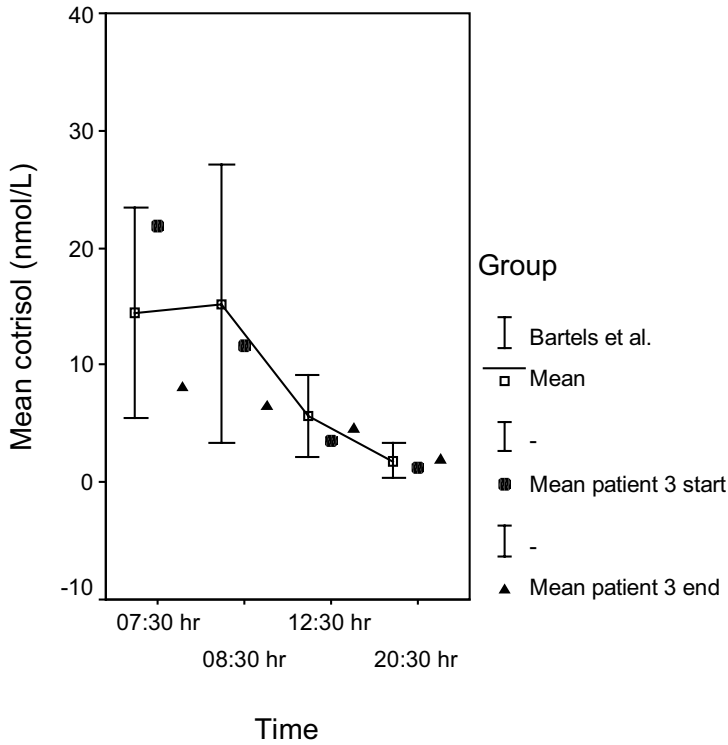
*Patient 2: Visually and intellectually impaired girl, age 14.* The circadian cortisol pattern for patient 2 is shown in Fig. 2. There were no atypical values at the start or end of the intervention. The levels were within the 95% confidence interval for the normative sample.

**Figure 2.** Mean cortisol levels (nmol/L) and 95% confidence intervals for the normative group (Bartels et al., 2003) and mean cortisol level for patient 2 at the start and end of the intervention.



*Patient 3: Blind and intellectually impaired boy, age 17.* Fig. 3 shows the cortisol levels for patient 3. At the start of the intervention, patient 3 exhibited an atypical cortisol cycle; the cortisol level at 07:30 hr was higher than that at 08:30 hr. At the end of the intervention the diurnal cycle showed a more typical pattern with a smaller difference between the 07:30 hr and 08:30 hr measures. At the end of the intervention all the values were below the means for the normative sample but within the 95% confidence intervals.

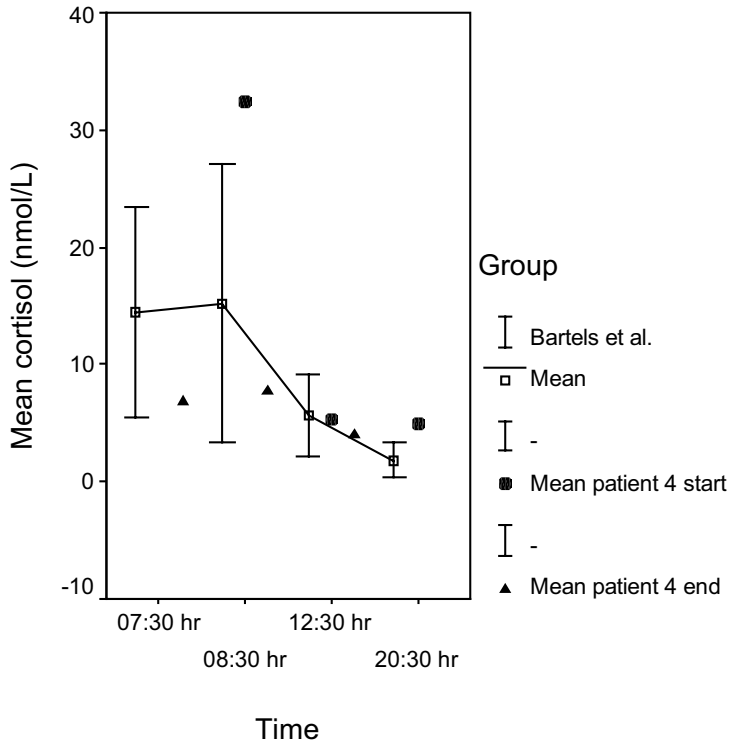
**Figure 3.** Mean cortisol levels (nmol/L) and 95% confidence intervals for the normative comparison group (Bartels et al., 2003) and mean cortisol levels for patient 3 at the start and end of the intervention.



*Patient 4: Blind and intellectually impaired girl, age 17.* Fig. 4 shows patient 4's cortisol levels. At the start of the intervention, the cortisol cycle was atypical, with a very high morning measure (08:30 hr) that was significantly higher than that for the normative comparison sample. The pattern at the end of the intervention was more typical, at which point all cortisol levels were within the 95% confidence interval for the normative sample.

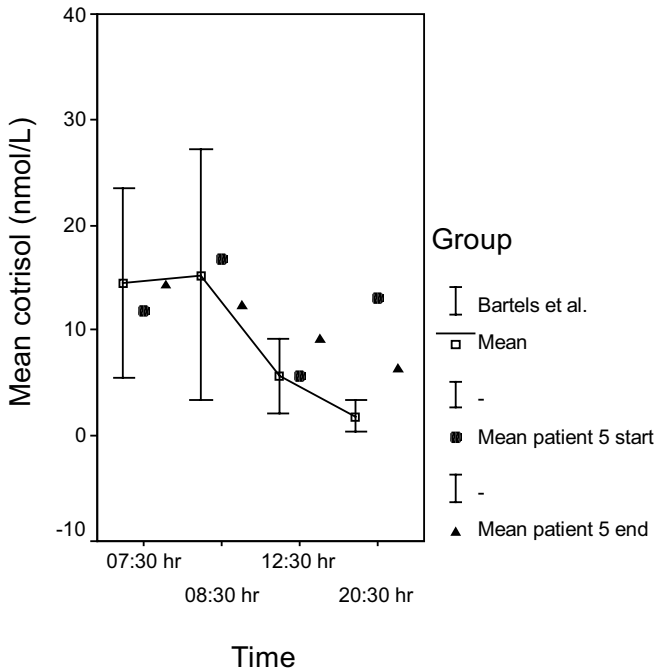


**Figure 4.** Mean cortisol levels (nmol/L) and 95% confidence intervals for the normative comparison group (Bartels et al., 2003) and mean cortisol levels for patient 4 at the start and end of the intervention.



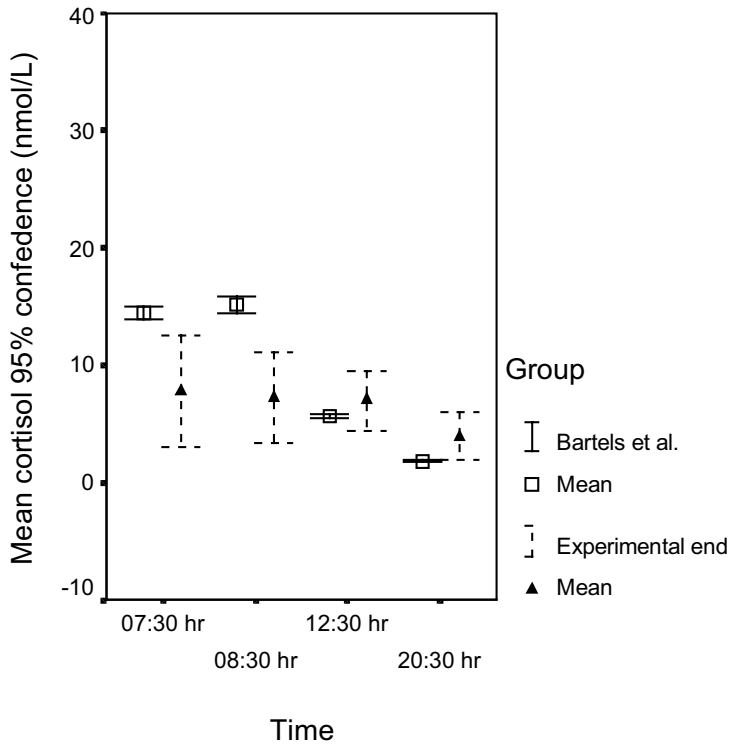
*Patient 5: Visually and intellectually impaired girl, age 16.* Patient 5's cortisol levels are shown in Fig. 5. At the start of the intervention, the cortisol pattern was atypical, with levels increasing from 12:30 hr to 20:30 hr. At the end of the intervention, the diurnal cortisol cycle was more typical, with downregulation in the evening. Although the cortisol levels at the end of the intervention were significantly higher than for the normative sample, the difference was less extreme than at the start of the intervention.

**Figure 5.** Mean cortisol levels (nmol/L) and 95% confidence intervals for the normative comparison group (Bartels et al., 2003) and mean cortisol levels for patient 5 at the start and end of the intervention.



In summary, three patients (patients 3, 4, and 5) exhibited an atypical cortisol cycle at the start of the intervention, which evolved to a more typical diurnal cycle with less extreme levels at the end of the intervention. Overall, compared to the normative sample, patients' morning cortisol levels (07:30 and 08:30 hr) were significantly lower and their evening cortisol levels (20:30 hr) were significantly higher (Fig. 5).

**Figure 6.** Mean cortisol levels (nmol/L) and 95% confidence intervals for the normative comparison group (Bartels et al., 2003) and for all patients at the end of the intervention.



## Discussion

In this multiple case study, we investigated the plasticity of cortisol during psychotherapy in five adolescents with multiple disabilities and extremely challenging behavior. We compared diurnal cortisol cycles at the start and end of the intervention and between our patient sample and the sample reported by Bartels et al. (2003). For three of five patients, the cortisol cycle was more normative at the end of the intervention, at which point all patients exhibited a regular diurnal cortisol pattern with downregulation in the evening. These results are consistent with the results of other investigations into the effects of attachment interventions on cortisol measures (Dozier et al., 2002; Fisher et al., 2000).

The morning cortisol value at 08:30 hr was significantly lower at the end of the intervention. Lower morning measures may indicate reduced stress and thus more regulated behavior; high cortisol levels can be associated with dysregulated behavior and psychiatric illness (Essex, Klein, Cho, & Karin, 2002). However, when cortisol values were compared with the normative sample from Bartels et al. (2003), they were significantly lower in the morning (07:30 and 08:30 hr) and significantly higher in the evening (20:30 hr). Similarly, low early-morning levels were reported for young children in foster care (Dozier et al., 2006; Gunnar, et al., 2006), for maltreated children with a mean clinically significant internalization of problems (Cicchetti & Rogosch, 2001), and resilient adult survivors and older children chronically exposed to unmitigated stress (Bradley, 2000; Girdler et al., 2003; Heim et al., 2001; Gunnar et al., 2006). It is therefore possible that the problematic circumstances preceding the intervention may have affected development of the corticolimbic circuits involved in emotion and stress responses (Dozier et al., 2006, Glaser, 2000).

For all patients, the diurnal cortisol rhythm was quite flat. Studies have demonstrated disordered melatonin (Lewy & Newsome, 1983; Lockley, Skene, Arendt, Tabandeh, Bird, & DeFrance, 1997) and flatter diurnal cortisol variation among individuals who are blind (Sack, Lewy, Blood, Keith, & Nakagawa, 1992). Further research using larger groups is needed to verify whether this pattern is more common among patients who are visually impaired or blind and intellectually disabled.

The percentage of missing values ranged between 20% and 41%. There were comparable numbers of missing values at the beginning (25%) and end of the treatment (18%). Looking at each patient separately, for patient 4, 55% of the values were missing, whereas for other patients the value ranged between 12% and 32%. These values indicate that cortisol collection was difficult. However, the missing sampling points were quite equally distributed over the time points and patients, indicating the feasibility of using the data for this study.

In conclusion, our results suggest that a systematic intervention for severe, challenging behavior in patients with visual and severe intellectual disabilities might not only reduce the challenging behavior (Chapter 4) but may also help to normalize the diurnal cortisol cycle. However, in interpreting the results it is important to consider that it was difficult to collect saliva samples from these adolescents, such that there was a high percentage of missing values. Furthermore, we did not compare the change with a no-intervention condition. Frequent cortisol measurement seems to be a viable alternative means to evaluate the effect of psychotherapy for clients with multiple disabilities, for whom the intrapsychic effects of psychotherapy are otherwise generally determined using observational instruments.

# **Chapter 4 The effect of an attachment-based behaviour therapy for children with visual and severe intellectual disabilities**

Sterkenburg, P.S., Janssen, C.G.C., & Schuengel, C. (2008). The effect of an attachmentbased behaviour therapy for children with visual and severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21(2): 126-135.

## Abstract

**Background:** A combination of an attachment-based therapy and behaviour modification was investigated for children with persistent challenging behaviour.

**Method:** Six clients with visual and severe intellectual disabilities, severe challenging behaviour, and with a background of pathogenic care were treated. Challenging behaviour was recorded continuously in the residential home and during therapy sessions. Alternating treatments were given by two therapists. In phase 1, the experimental therapist attempted to build an attachment relationship in sessions alternating with sessions in which a control therapist provided positive attention only. In phase 2, both therapists applied the same behaviour modification protocol.

**Results:** Across clients, challenging behaviour in the residential home decreased during the attachment therapy phase. The behaviour modification sessions conducted by the experimental therapist resulted in significantly more adaptive target behaviour than the sessions with the control therapist.

**Conclusion:** For these clients with a background of attachment problems, attachment-based behaviour modification treatment may have important advantages over standard behaviour modification.

## **Acknowledgments**

This study was received funding from ZonMw InSight, a Dutch association promoting application-oriented research to support the needs of people with a visual impairment. We are grateful for the cooperation and assistance of parents, caregivers and observers. The authors acknowledge the invaluable contributions of Francien Dekker, psychotherapist, as co-attachment and control therapist.

## Introduction

Some children with serious intellectual and visual disabilities appear insensitive to social contingencies to their behaviour, impeding the therapeutic use of social reinforcers to treat challenging behaviour and shape adaptive behaviour (e.g. O'Reilly et al., 2003). Insensitivity to social rewards may result from disrupted or atypical attachment relationships, for which children with intellectual and multiple disabilities are at risk (Schuengel & Janssen, 2006). Intensive social contact found in attachment relationships is necessary for the development of social regulatory systems (Porges, 2004), allowing social contact to become rewarding. The study sought to test the hypothesis that addressing the attachment needs of children with severe intellectual and visual disabilities would subsequently increase the effectiveness of social contingencies in the treatment of challenging behaviour.

Enabling children to build attachment relationships with caregivers or therapists may not only provide a scaffolding for the development of children's social behaviour systems, but may also have beneficial effects on affect regulation in these children. Attachment theory and recent theories of affect regulation point to the important homeostatic affect-regulating function of attachment relationships (Bowlby, 1969/1994; Bradley, 2000). Children without attachment relationships are more likely to develop maladaptive ways of regulating stress in their daily lives (Janssen et al. 2002; Schuengel & Janssen, 2006). Using medication, it has been shown that decreasing the level of arousal is associated with a decrease in challenging behaviour in people with intellectual disabilities (Verhoeven & Tuinier, 1996). Developing a therapeutic attachment relationship with children who are currently not involved in stable and/or organized attachment relationships may in itself have beneficial effects on challenging behaviour through its effect on affect regulation. Indeed, this may even precede its effects on sensitivity to social reinforcements (Bradley, 2000; Fisher et al., 2000).

Many studies on the effectiveness of treatment for challenging behaviours in clients with intellectual disabilities has shown strong evidence that behavioural interventions can be effective and efficient (e.g. Sturney, 2005, Prout & Nowak-Drabik, 2003, Didden et al., 1997, Scotti et al., 1991). But for some clients, as mentioned above, behavioural interventions have shown little effect: for example, in clients who show no sensitivity to reinforcement (e.g. O'Reilly et al., 2003), and in clients with histories suggesting that they may have had little opportunity to develop selective attachment, because of pathogenic care in the past (early disruptions in caregiving relationships, abuse, neglect).

An integrative psychotherapeutic treatment, the Attachment-based Behaviour Modification Therapy, was developed for children for whom other treatments (e.g. standard behaviour modification) had failed. These children exhibited severe challenging behaviour and had visual and severe intellectual disabilities. This



intensive integrative treatment is partly based on Došen's (1984, 1990, 2001, 2005) Developmental-Dynamic Relationship Therapy. The attachment-based approach is combined with a behavioural intervention, in order to replace remaining maladaptive behaviour with more adaptive behaviour. Furthermore, it is an integrative, individual treatment with a therapist who works directly with clients to effect intra-psychic changes during therapy. It differs from Došen's Developmental-Dynamic Relationship Therapy in that the latter is mediated by caregivers (Došen, 1984, 1990, 2001, 2005). For the clients in this study, however, the social isolation and level of challenging behaviour were deemed to require a one-to-one approach from a skilled psychotherapist before caregivers could receive guidance on building positive caregiving relationships themselves and applying appropriate social rewards for adaptive behaviour.

It is important to note that the attachment-based treatment must be distinguished from 're-birthing', 'holding' or 'attachment' therapies which, as Zilberstein (2006) mentioned, focus more broadly on a forced simulation of the birth process, and address aggression and non-compliance instead of attachment. Attachment-based treatment as described in this paper is based on sensitive and responsive interactions, on caring and empathy, instead of coercion. The therapist positively encourages contact by letting the child become acquainted with him or her as a figure that is supportive, predictable and comfortable to be with. In addition, the integrative treatment also does not mainly focus on developing new behaviour (O'Reilly et al. 1999). The attachment-based behaviour therapy first follows the stages in the development of an attachment relationship (Bowlby, 1969/1997). Only later, in the behaviour modification phase, the attention is focused on systematically placing social contingencies on adaptive replacement behaviour. In this respect, the integrative treatment is also different from approaches such as gentle teaching, which have been proposed as alternatives to behaviour modification (Jones & McCaughey, 1992); this integrative treatment seeks to complement behaviour modification. Audiovisual and written materials describing the intervention in detail are available through the authors.

In this study, the effect of attachment-based behaviour modification treatment on children with visual and severe intellectual disabilities was tested. First of all, changes in challenging behaviour in the residential home during the period in which the children were in therapy were examined. The main aim of the study was, however, to test whether the attachment therapist was more effective than the non-attachment or control therapist in modifying challenging into adaptive behaviour, with both therapists using the same behaviour modification protocol.

## Methods

### *Design*

A series of single case studies with alternating therapy conditions across clients was conducted. Both conditions (attachment therapy and the control treatment) were conducted concurrently and consisted of two phases, attachment-based therapy (phase 1) and behaviour modification (phase 2), followed by a generalization phase (phase 3). The attachment therapist conducted the phase 1 attachment therapy sessions (the intervention is described later in this article) and the control therapist merely positively engaged with that same client during the control sessions. During behaviour modification (phase 2), both therapists used the same behaviour modification protocol. The alternating treatment design meant that therapist 1 was the attachment therapist and therapist 2 the control therapist for three clients, the situation being reversed for the other three clients. In this study it was not possible to add a baseline in a non-treatment phase preceding behaviour modification, as is usually done in single case studies. The reason was that the attachment-based intervention preceded behaviour modification. A baseline before the attachment-based intervention would not accurately represent the frequency of challenging behaviour approximately 5 months later at the start of behaviour modification, due to the expected positive effect of the attachment-based treatment. The manifestation of challenging behaviour might thus be different at the start of the attachment-based intervention from what it was at the start of behaviour modification. Furthermore, adding a no-treatment baseline after the attachment-based intervention might disrupt the child's fragile security of attachment to the therapist and was therefore not considered to be an option.

### *Participants*

All six clients had a severe intellectual disability and were blind or had a visual impairment (in accordance with the WHO criteria). Five clients lived in a residential home, one in a foster home. In the Netherlands children are placed in residential homes only in exceptional situations, for instance if the child displays severe challenging behaviour and/or in situations of dysfunctional family care. Characteristics of the participants are shown in Table 1.

**Table 1:** Characteristics of participants.

Therapist	Client	Gender	Age in years	Motor development	Medical information
1	A	M	17	Normal	Blind, Down Syndrome
1	C	M	17	Normal	Blind
1	E	F	17	Delayed	Blind
2	B	F	16	Cerebral palsy delayed	Visual impairment
2	D	F	14	Normal	Visual impairment
2	F	M	10	Normal	Blind

All the clients persistently engaged in severe self-injurious behaviour, aggression and disruption. Their behaviour was noted as severe and persistent with a high score on the 'Severe Challenging Behaviour Consensus Protocol – National Institute for Health Care Management'(Consensusprotocol *Ernstig Probleemgedrag - Nationaal Ziekenhuis- instituut*), a commonly used Dutch protocol for measuring challenging behaviour which is reliable and valid (Kramer, 2001). Table 2, column 2 describes the challenging behaviour noted at the start of the intervention for each client.

**Table 2:** All challenging behaviour noted at the start of the intervention, and the target challenging behaviour and appropriate behaviour which were the focus of treatment during phase 2 (behaviour modification).

**Therapist 1**

Client	All challenging behaviour noted at the start of the intervention	Target challenging behaviour focused on during phase 2 (behaviour modification)	Functional alternative appropriate behaviour focused on during phase 2 (behaviour modification)
A	Pinching/scratching Hitting/kicking Spitting Screaming Other challenging behaviour	Scratching (himself and others)	Using his hand to ask for music Turning away or putting his hand under his legs Using his hand to ask for sweets
C	Pinching/scratching Hitting/kicking Biting Hair pulling Screaming Other challenging behaviour	Pinching/scratching Hitting/kicking Biting Screaming Other challenging behaviour	Getting up from his chair without showing challenging behaviour Sighing Using his hands to play with toys
E	Pinching/scratching Hitting/kicking Biting Screaming Other challenging behaviour	Pinching/scratching Hitting/kicking Screaming	Using her hand to ask for music Turning away or pushing the therapist away Walking to another chair without challenging behaviour

## Therapist 2

Client	All challenging behaviour noted at the start of the intervention	Target challenging behaviour focused on during phase 2 (behaviour modification)	Functional alternative appropriate behaviour focused on during phase 2 (behaviour modification)
B	Pinching/scratching Hitting/kicking Biting Screaming loudly Other challenging behaviour	Pinching/scratching Screaming loudly	Using her hand to ask for fruit Using her hands to play with toys Making low noises
D	Hitting/kicking Hair pulling Screaming Other challenging behaviour	Hitting/kicking	Using her hands to hold a handkerchief Stroking her ears or turning her head towards shoulder Using her hands to play with toys
F	Pinching/scratching Hitting/kicking Screaming Crying Other challenging behaviour	Hitting/kicking Screaming	Using his voice to stay 'no' Putting the toys on the table when finished Using his hands to play with toys

The history of the clients included early pathogenic care, as defined by the criteria for attachment disorder (DSM-IV: persistent neglect of basic emotional needs for comfort and affection; persistent neglect of physical needs; frequent changes of regular caregivers), as assessed by an independent psychiatrist. Examinations by physicians ruled out medical aspects that might be associated with self-injury. There were no contra-indications for the treatment protocol, such as aversion to physical contact. The independent psychiatrist had extensive experience with assessment and treatment of clients with a visual and intellectual disability and was also able to identify clients with autistic spectrum disorders; these clients were then excluded from this study. Psychologists working with children with severe intellectual and visual disabilities were asked to present clients matching these criteria. Medical ethical approval was obtained from the Vrije Universiteit Medical Centre Medical-Ethical Review Board. This board is licensed to approve research by the Central Committee on Research Involving Human Subjects (CCMO), which monitors compliance with Dutch legislation on medical research. Parents gave their informed consent in writing. Three clients participated during 2002-2003 and three clients during 2003-2004 with a mean of 21.8 weeks for phase 1, a mean of 7.6 weeks for phase 2 and a mean of 8.2 weeks for phase 3. The intervention took place in the residential environment of the client.

## ***Intervention***

The integrative treatment (Appendix A) consists of three phases. Phase 1 is aimed at creating the conditions under which attachment may develop. First (phase 1.1), the therapist provides sensitive and encouraging responses with the aim of making contact with the client. Contact starts with vocal initiatives, as clients have to get to know their therapist by voice first, due to their visual disability. Touch can be added if the client feels comfortable when touched. The therapist reacts sensitively to the positive and to the negative reactions of the client by verbally or non-verbally acknowledging the signal and adapting the interaction or the situation to suit the client. The therapist positively engages with the client by singing, telling stories and talking to the client. The next step is taken when the client shows signs of recognition of the therapist, when the therapist can predict the client's behaviour, when the client experiences positive and enjoyable contact which can easily be restored after contact is broken, and when the client initiates proximity-seeking in relation to the therapist.

During the next, 'symbiotic', phase (1.2), communication in close contact is central. The therapist stimulates the client to take the lead while the therapist attempts to achieve synchronicity in the interaction by anticipating the client's actions as closely as possible.

For example, when the client and therapist rock sideways to the rhythm of music, the therapist gradually leaves the initiative to continue this activity to the client, anticipating each intended 'rock'. The therapist may start with phase 1.3 when the therapist and the client can easily establish synchronous interaction, when the client takes the initiative to indicate that he/she wants to have pleasurable contact with the therapist, and when the client focuses not only on him or herself but also on the contact with the therapist.

Subsequently (phase 1.3), the therapist stimulates exploration of the environment, offering verbal or nonverbal comfort when exploration results in anger or anxiety. Seeking contact when unpleasant emotions are experienced, is thus rewarded by giving positive attention. When the client (i) actively explores the environment, (ii) not only enjoys the closeness of the therapist but also enjoys playing together and playing next to the therapist, and (iii) when the client continues exploration when the therapist leaves the room, then phase 2 of the intervention may be introduced.

Phase 2 is aimed at replacing remaining maladaptive behaviours by teaching socially acceptable alternative behaviour. Using functional behaviour analysis (e.g. Northup et al., 1991, 1994; Sigafos & Meikle, 1996), socially acceptable behaviour is identified, and through systematic 'chaining' and 'fading' new appropriate behaviour is taught. Verbal and nonverbal social reinforcements such as affectionate pats, hugs, approval and praise are given. More information on the

behaviour modification therapy is provided later on in this article under the section Procedure.

The last phase (phase 3: generalization) starts when challenging behaviour has diminished and the client uses socially acceptable, appropriate behaviour instead. The therapist facilitates contact between the client and the regular caregivers by giving feedback on the caregivers' sensitive responses to the client during video-training and team discussions. Over time, the number of sessions is slowly reduced until the therapy stops. The caregivers continue to invest in the bond with the client through being sensitive and responsive towards him or her, as taught by the therapist. The therapy ends when the transfer of the principles of sensitivity and responsivity to the caregivers is completed, when the caregivers can sooth the child when distressed and when the caregivers appropriately stimulate the client's exploration of objects and the environment.

### ***Instruments***

*Challenging behaviour in the residential home.* Standardised instruments were used to assess the challenging behaviour shown by the client at the start of the intervention as well as after its completion. These instruments were the 'Severe Challenging Behaviour Consensus Protocol – National Institute for Health Care Management (CEP) with a Cohen's kappa of .91 and with a demonstrated high external validity (Kramer, 2001), and the 'Challenging behaviour scale for people with an intellectual disability' (Storend Gedragsschaal voor Zwakzinnigen or SGZ) with a Cohen's kappa of between  $r = .75$  and  $.79$  and adequate validity (Kraijer & Kema, 1994). Two caregivers under the supervision of a psychologist scored the instruments independently.

*Residential observation lists for challenging behaviour.* The professional caregivers in the clients' residential homes were instructed to record the frequency of the challenging behaviours listed in Table 2. The observation lists (Appendix C) were easy to score and fitted into the caregiver's daily reporting routine. Because these clients had severe challenging behaviour, they received individual care or participated in a small group, giving caregivers the opportunity to complete the observation lists. Observation results were reported and evaluated every month, ensuring the subsequent continuation of their use. Challenging behaviour was recorded every waking hour of each day during the intervention over a 12-month period. Frequency was rated by the number of times the challenging behaviour had occurred during the past hour. These frequencies were summed to provide a total frequency for the data. The day totals were combined into weekly average scores, which were used in the data analysis. Intraclass correlation coefficients were computed for each client to gauge the reliability of the weekly averages. Because the weekly averages were determined on the basis of scores from different days from different raters (caregivers), the criterion for reliability should be based on the product of acceptable interrater reliability and short-term stability. Taking .80

as a criterion for both, we therefore examined whether the intraclass coefficients for the weekly averages were .64 (.80 x .80) or above. This was the case for four out of the six clients (range .64 - .81). Apparently, challenging behaviour either occurred and/or was reported in highly inconsistent patterns in the remaining two cases. These cases were therefore dropped from the analyses of challenging behaviour in the residential setting.

*Challenging and adaptive behaviour in the therapy sessions.* During the behaviour therapy, one of the two therapy sessions given by the attachment therapist and by the control therapist was videotaped each week. A weekly frequency for video analysis was chosen in the expectation that change would occur over weeks, not days. Observers who were blind to therapist status and phase of therapy independently coded the sessions in random order using Noldus computer software (Noldus Information Technology, Wageningen, The Netherlands). The observers recorded the occurrence of the challenging behaviour and the adaptive replacement behaviour. The mean duration of these behaviours was calculated for each session. Interrater reliability was analysed in 15 randomly selected sessions. Twenty-minute checks were done for each of the 15 videotapes evenly divided over the two therapists and over different clients. For the frequency of target challenging behaviour, interobserver agreement was 78% and Cohen's kappa was .74; for duration it was 93% and .92, respectively. For the frequency of adaptive replacement behaviour interobserver agreement was 81% and Cohen's kappa was .78; for duration it was 91% and .90, respectively.

### **Procedure**

During the attachment-based therapy (phase 1), the attachment therapist conducted three systematic 1-h sessions every week. During phase 1 the control therapist, who only positively engaged with that same client by for example reading aloud, singing or sitting next to the child listening to music, visited the client weekly for one one-hour session. The main goal for the control therapist was to become a familiar figure with whom the client experienced positive engagement. It was expected that one 1-h weekly session would be sufficient to achieve this goal.

After having completed the attachment-based intervention (phase 1), the remaining challenging behaviours were screened and the behaviours the caregivers considered to be the most disturbing were selected as target behaviours. Staff members who routinely worked with the clients were interviewed and asked about the situations that typically evoked challenging behaviour. Antecedents-behaviours-consequences (ABC) data were collected during the selected situations within which the challenging behaviour occurred (e.g. Northup et al., 1991, 1994; Sigafos & Meikle, 1996), for example during free time, social interaction or daily care. The identification of appropriate replacement behaviours was aided by separate functional analyses for each challenging behaviour (Mace et al., 1986). For



each client, three socially acceptable adaptive replacement behaviours that could serve as functional alternatives were defined. The target challenging behaviour and the adaptive replacement behaviour that were focused on during behaviour modification (phase 2 of the treatment) are shown in Table 2, columns 3 and 4. During behaviour modification (phase 2), both therapists conducted two 1-h therapy sessions every week, using the same behaviour modification protocol. The treatment was completed with the last phase of the intervention (phase 3 – generalization) being conducted by the attachment therapist.

### **Data analysis**

*Visual inspection.* The effect of the intervention on the client's challenging behaviour in the residential setting were studied using the weekly mean frequency of all challenging behaviour scored on the residential lists. We expected a decrease in challenging behaviour to occur as early as the attachment-based treatment phase. The visual inspection of effects was performed in accordance with Nugent's (2000) method of visual data analysis using the weighted mean trend line for the intervention. In addition, Nugent's weighted average trend across the sessions, an index of the average rate of change in challenging behaviour, was used.

*Meta-analytic combination of treatment effects across single-case studies.* The results of the six single cases were meta-analytically combined into an overall average effect size, using the P-values. For every P-value a natural logarithm was determined. The sum of the natural logarithms was then multiplied by  $-2$ . The result was a chi-squared deviation, with twice the number of P-values as the degree of freedom. In cases in which the client had P-values of  $< .005$ , the possibility that significance was based solely on that one client was excluded by replacing this value with  $.01$ . If the change was in a non-expected direction, a P-value of  $.5$  was used, irrespective of the actual P-value (De Weerth & Van Geert, 2002).

## Results

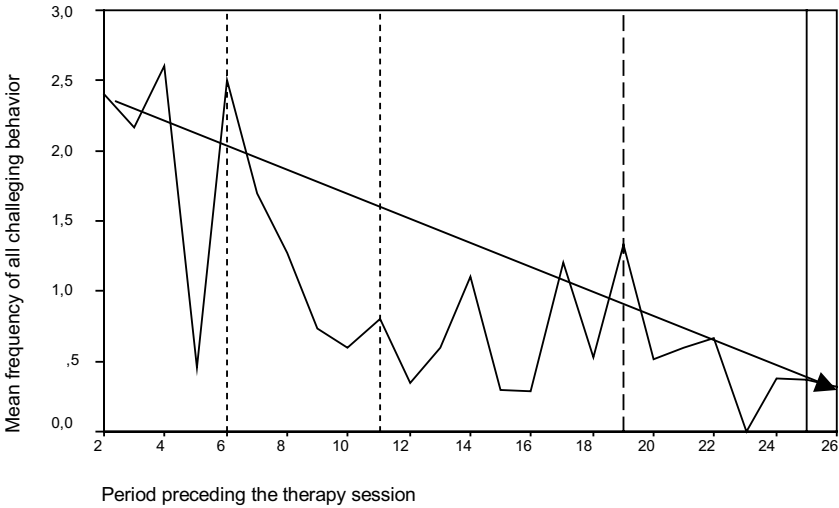
### ***Changes in challenging behaviour during the integrative therapy***

The non-parametric sign test for two related samples showed that for the six clients the CEP score was significantly lower at the end compared to the start of the intervention (mean before = 3.17, mean after = 2.17,  $p_{\text{one-sided}} < .034$ ). All the clients except client B dropped from clinical to sub-clinical levels. The increase in the total SGZ-score failed to reach significance (mean before = 5.29, mean after = 5.75,  $p_{\text{one-sided}} < .059$ ). All except clients B and C showed a higher score.

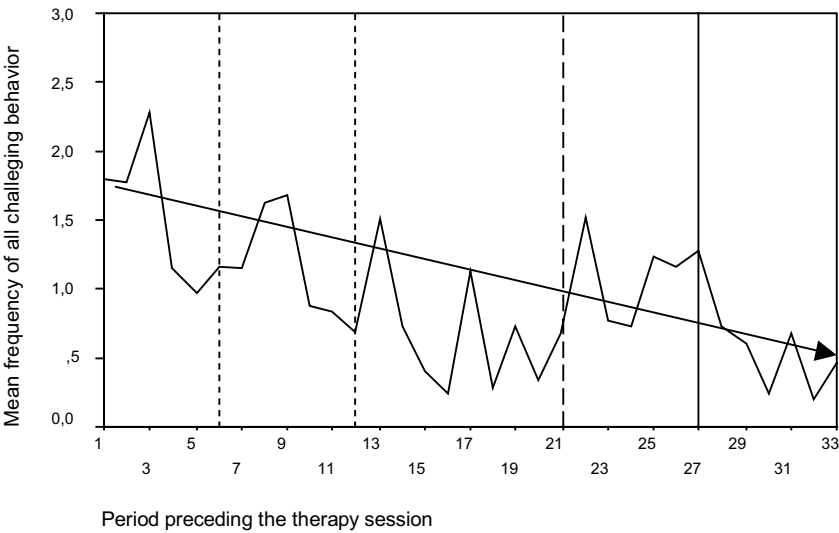
Figure 1 shows the weekly aggregated frequencies of the challenging behaviour that were recorded by the caregivers in the residential home, in all phases and sub-phases for the four clients with sufficiently reliable scores. Visual inspection aided by trend lines (Nugent, 2000) showed a decrease in challenging behaviour from phase 1.1 onwards, with a slight increase in phase 2 when behaviour therapy commenced and a further decrease in phase 3 after completion of the therapy and generalization of its effects. The weighted mean trend statistics were for client A -0.090, client B -0.014, client C -0.050, and for client F -0.048. These values show the smallest change for client B. This client also had most of her scores above the weighted mean trend line. Overall, these results indicate that challenging behaviour in the residential home decreased from the start to the end, and for the four clients studied in detail we consistently found a downward trend line.

**Figure 1:** Frequency of all challenging behaviour scored on the residential observation lists and mean trend lines (solid arrows).

**Therapist 1**

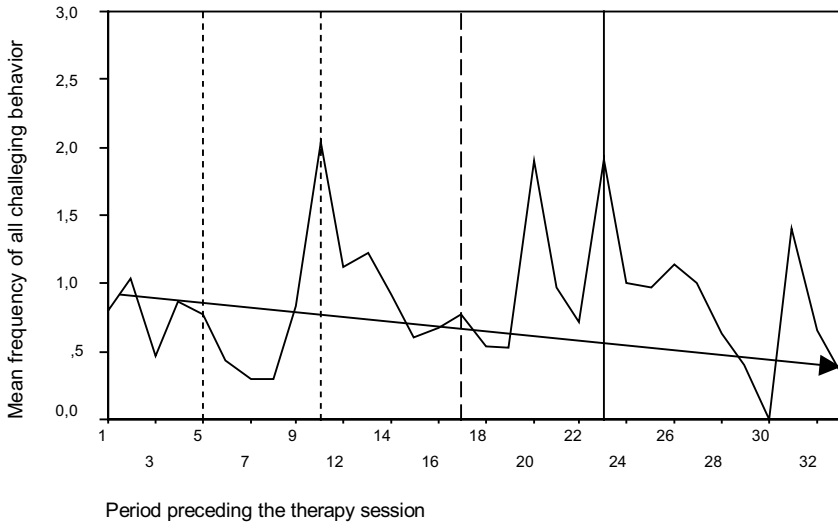


**Client A**

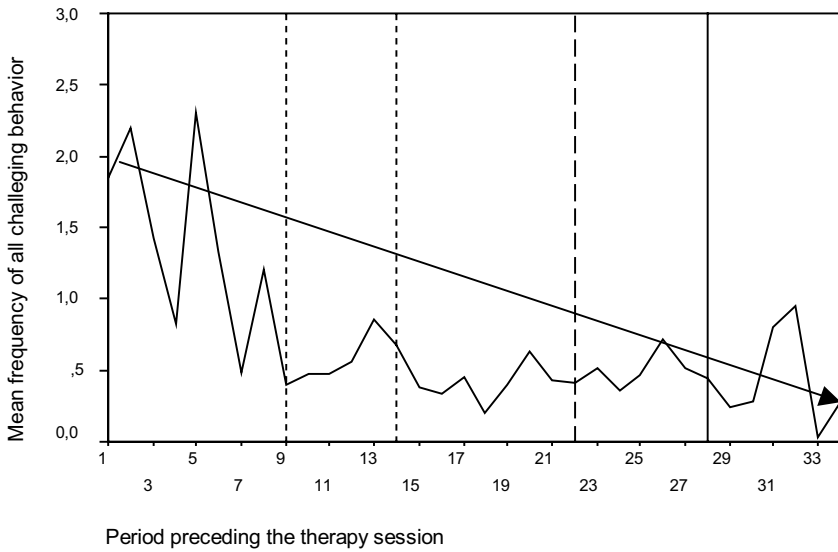


**Client C**

### Therapist 2



### Client B



### Client F

### **Differences in effect of behaviour modification between attachment and control therapist**

Observations of behaviour modification sessions conducted by the control therapist were compared with the sessions conducted by the attachment therapist to test the hypothesis that the experimental therapist, having stimulated an attachment relationship, would be more effective in applying behaviour modification than a familiar control therapist. The duration of the shaped adaptive behaviour and the target challenging behaviour in this phase were analysed. Table 3 shows the mean duration of the shaped adaptive behaviour. A longer duration of adaptive behaviour was found in the sessions conducted by the attachment therapist except for client C. The Fisher's combination of the  $p$  values for the one-way ANOVA for the six clients indicated a significant overall longer duration of adaptive behaviour during behaviour modification given by the attachment therapist (combined  $\chi^2$  deviation = 25.34,  $p < .025$ ).

**Table 3:** Mean and standard deviation (SD) of the duration of the appropriate behaviour during behaviour modification (phase 2).

Client	Attachment therapist mean (SD) [n]	Control therapist mean (SD) [n]	F (d.f. 1, d.f. 2)
A	8.98 (12.06) [7]	1.61 (0.89) [7]	2.60 (1,12)
B	36.14 (6.03)* [7]	26.44 (10.76) [7]	4.33 (1,12)
C	11.96 (6.8) [7]	16.00 (10.63) [7]	0.72 (1,12)
D	41.00 (4.65)*** [7]	26.90 (10.38) [7]	10.76 (1,12)
E	3.15 (2.16) [7]	2.67 (0.58) [7]	0.99 (1,12)
F	1.10 (0.92) [8]	0.92 (0.96) [7]	0.14 (1,13)

n = number of videotaped behaviour modification sessions. \* $p < .06$ , \*\* $p < .05$ , \*\*\* $p < .01$

Table 4 shows the mean duration of the target challenging behaviour, the focus of behaviour modification. For all clients, except for client A, Table 4 shows less target challenging behaviour during behaviour modification in the sessions conducted by the attachment therapist compared to those given by the control therapist, but the absolute values were very low. Probably as a result, we found no significant difference.

**Table 4:** Mean and standard deviation (SD) of the duration of target challenging behaviour that was the focus of the behaviour modification (phase 2).

Client	Attachment therapist mean (SD) [n]	Control therapist mean (SD) [n]	F (d.f. 1, d.f. 2)
A	0.42 (0.18) [7]	0.40 (.08) [7]	0.05 (1,12)
B	0.09 (0.23)* [7]	0.10 (0.18) [7]	0.01 (1,12)
C	0.05 (0.06) [7]	0.08 (0.05) [7]	0.81 (1,12)
D	0.34 (0.41) [7]	2.87 (7.08) [7]	0.90 (1,12)
E	2.28 (1.72) [7]	4.18 (3.40) [7]	1.74 (1,12)
F	0.09 (0.14) [8]	0.60 (0.98) [7]	2.09 (1,13)

n = number of videotaped behaviour modification sessions

In conclusion, the effects for the six clients combined showed that during behaviour modification the attachment therapist was significantly more effective in stimulating adaptive behaviour. No significant differences were found between the therapists in their effectiveness with respect to reducing the fairly low levels that had remained of target challenging behaviour during the behaviour therapy sessions.

## Conclusion

The clients in this study appeared to learn replacement behaviours more easily from therapists who had previously attempted to build a therapeutic relationship based on attachment principles, compared to therapists who were just familiar. By the time the therapists had concluded the phase of building attachment relationships, the severe levels of challenging behaviour had already dropped drastically. All in all, the integrative attachment-based behaviour modification therapy showed promise as a therapeutic method to treat children with severe intellectual and visual disabilities who exhibit severe behaviour problems and are withdrawn and unresponsive to social stimulation.

Our visual analyses of the daily scored residential observation lists and results from standardized ratings suggested that the integrative psychotherapeutic intervention, a combination of an attachment-based treatment and behaviour modification, was effective in reducing challenging behaviour. It is important to note that these results were found in clients for whom in the past no other therapies and interventions had proven successful.

No significant difference was found between the attachment and the control therapists in the duration of the target challenging behaviour during behaviour modification. Testing for differences was difficult because the frequency and duration of the challenging behaviour during these sessions were already quite low at this point in the therapy. Future experimental studies are needed to establish whether attachment-based therapy by itself reduces challenging behaviour in clients with severe multiple disabilities.

The results of the part of the therapy aimed at establishing a relationship with the client were generalized to the caregivers in phase 3. By adding a generalization phase, during which contact between caregivers and client was stimulated and the therapeutic sessions were gradually reduced, clients were protected from experiencing the end of the intervention as a loss. In this phase the clients had the opportunity to build new, promising and long-lasting relationships with their caregivers.

The results indicated that for client B the effect of the integrative treatment was limited. She was the client with the lowest cognitive and physical skills (she had cerebral palsy and was confined to a wheelchair). Due to her severe disabilities there was limited scope for teaching this client alternative behaviour. For example, the focus of behaviour modification was on making low noises instead of screaming loudly, because no other alternative could be found for her target challenging behaviour. It is however important to note that even for this client the attachment therapist was more effective than the control therapist in modifying her behaviour. She did show longer-lasting appropriate behaviour (although it was

a statistical trend;  $p < .060$ ) and over all the challenging behaviour significantly less challenging behaviour during the behaviour modification ( $F = 8.14$ ,  $d.f. = 1, 12$ ,  $p < .015$ ) conducted by the attachment therapist (mean = 1.66,  $SD = 2.10$ ,  $n = 7$ ) compared to that given by the control therapist (mean = 5.91,  $SD = 3.34$ ,  $n = 7$ ). Despite the gains during the treatment sessions, the scores on the standardized instruments, the CEP and the SGZ, remained unchanged. It is possible that in the case of such a dependent client with multi-impairments an extra intervention is needed for the transference of the newly learnt behaviour as shown during the therapy sessions to the residential setting. Client D displayed considerable fluctuations in her behaviour, with many outliers and extremes, revealing a highly unreliable pattern on the residential observation lists. However, the standardized instruments did show lower post-test scores.

The integrative treatment was developed for clients for whom social contingencies failed to reinforce adaptive behaviour. Our hypothesis was that if it is possible for clients to develop a certain sensitivity to social rewards, this would not only have a therapeutic effect, that is a reduction in challenging behaviour but they would also be able to learn new, appropriate behaviour, at least from the therapists for whom they developed this sensitivity. This hypothesis was confirmed by the study results. This might be explained by the higher reward value of positive social contingencies on behaviour, as well as by better affect regulation during the presence of the attachment therapists, allowing clients to concentrate better on learning.

### ***Study limitations and directions for further research***

In this study we focused on the effect of an integrative intervention. The quality and characteristics of the therapeutic relationship as attachment relationship were not examined in this report, nor was the actual affect-regulating function of the attachment relationship in these children analysed. Such data will be important to further explain the effects of the therapy. Another limitation was that the design did not allow for examination of the independent effect of the attachment-based therapy phase. A reversal design (ABAB) was deemed undesirable, because that would have disrupted the developing relationship. Finally, the number of sessions in the behaviour modification phase limited statistical power in testing treatment effects.

Further research is needed to examine the effect of the generalization component of the intervention protocol, in order to find out whether children and caregivers are able to capitalize on a newly established sensitivity to social rewards and interactions to develop trusting relationships within the context of residential care, given the challenges of staff turnover and workloads. Ultimately, the most important effect of the therapy may be the increased reactivity of children with severe disabilities to their social environment. The therapy may have long-term effects if the caregiving environment sustains this social reactivity and continues to stimulate the development of adaptive behaviour using positive and social means of communication.



# **Chapter 5 Developing a therapeutic relationship with a blind client with a severe intellectual disability and persistent challenging behaviour**

Sterkenburg, P.S., Schuengel, C., & Janssen, C.G.C. (in press). Developing a therapeutic relationship with a blind client with a severe intellectual disability and persistent challenging behaviour. *Disability and Rehabilitation*.

## **Abstract**

### ***Purpose***

A blind, severely intellectually impaired boy aged 17 with Down Syndrome and persistent serious challenging behavior received attachment-based behavior modification treatment. The aim was to study the effect of the treatment and the development of the therapeutic attachment relationship.

### ***Method***

In a single case study, attachment therapy sessions alternated with control sessions. Treatment started with attachment therapy (phase 1), followed by behavior modification (phase 2). The instruments used were: residential observation lists for challenging behavior, video analyses of attachment behavior in therapy sessions and physiological indicators of affect regulation measuring the pre-ejection period (PEP) and respiratory sinus arrhythmia (RSA) as indices of cardiac sympatho-vagal activity.

### ***Results***

The client exhibited less frequent and less intensely challenging behavior. The data indicated more appropriate replacement behavior and less PEP arousal during the behavior modification treatment given by the attachment therapist compared to the control therapist who used the same protocol. The client showed more active and longer-lasting attachment behavior, especially proximity seeking, towards the attachment therapist than towards the control therapist.

***Conclusions*** Attachment-based psychotherapy proved successful in eliciting attachment behavior in a severely intellectually disabled, socially deprived, behaviorally and affectively dysregulated adolescent. The resulting relationship proved to be a therapeutic platform conducive to behavior change.

## **Acknowledgments**

This study was financially supported by ZonMw InSight, a Dutch association promoting application-oriented research to support the needs of people with a visual impairment. The authors acknowledge the invaluable contributions of Francien Dekker as attachment therapist and wish to thank Pawel Jeczynski for his statistical support.

## Introduction

In an attempt to understand the challenging behavior shown by clients with a severe or profound intellectual disability (ID), Janssen, Schuengel and Stolk (2002) developed a stress-attachment model. According to this model, persons with intellectual disabilities have fewer coping skills and are therefore more vulnerable to stress. Stress may be buffered by support from significant others, especially from attachment figures (Bowlby, 1988; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). In essence attachment is primarily characterized as the tendency to seek comfort in times of stress and to use the attachment figure to achieve a state of emotional homeostasis, allowing exploration of the environment (Bradley, 2000; Cassidy, 1999). Children with ID, however, are at risk of developing insecure attachment relationships, in particular disorganized attachment (see Schuengel & Janssen (2006) for a review). An additional risk factor is present when children with ID also have a visual disability. Eye contact is thought to play an important facilitating role in the development of attachment between infants and their parents. Fraiberg (1977, 1979) found that the development of attachment between parents and infants was delayed in blind children.

In order to directly influence children's severe and persistent challenging behavior, pharmacotherapy or behavior modification are usually indicated as treatment options (Didden, Duker, & Korzilius, 1997; Sturmey, 2005). Pharmacotherapy may have unwanted side effects, especially in children (Tuinier & Verhoeven, 1993). Indicated behavior modification approaches are (differential) reinforcement of alternative or incompatible behaviors (e.g. Vollmer, Roane, Ringdahl, & Marcus, 1999) as well as 'Functional Communication Training' (FCT) (Carr & Durand, 1985). FCT is a method to train communicative behaviors that allow the client more control over his or her environment. Several authors have reported that FCT on its own may not be sufficiently effective for clients with severe challenging behavior (Fisher, Piazza, Cataldo, Harrell, Jefferson, & Conner, 1993; Wacker et al., 1990). To effect a clinically significant reduction in destructive behaviors for these clients, they added mild punishment to FCT. Furthermore, behavior modification is not always effective as some children with serious intellectual and visual impairments appear insensitive to social contingencies on their behavior, impeding the therapeutic use of social reinforcers to treat challenging behavior and shape adaptive behavior (e.g. O'Reilly, Murray, Lancioni, Sigafos, & Lacey, 2003).

Are there alternatives to adding punishment to increase the effectiveness of interventions such as differential reinforcement or FCT? Attachment-based interventions have been developed aimed at improving the parent's or caregiver's sensitive responsivity towards children with intellectual and/or sensory disabilities. Positive results have been reported for these interventions (Došen, 2001; Janssen, Riksen-Walraven, & Van Dijk, 2003; Janssen, Riksen-Walraven, & Van Dijk, 2003). However, attachment-based interventions and behavior modification may also be

combined in order to obtain even stronger treatment effects. As an example with non-disabled children, Fisher, Gunnar, Chamberlain and Reid (2000) developed an integrative treatment program for maltreated children who had been placed in foster care which combined behavior modification methods with techniques to enhance sensitive responsiveness in the foster parents. Their experimental study indicated that the treatment was effective in improving the children's behavior, but also that hypothalamic-pituitary-adrenal (HPA) hyperactivation was reduced, as measured by the concentration of salivary cortisol (a 'stress hormone'), resulting in a long-term positive effect. Synergy between attachment-based and behavior-based treatment may be the result of the increased salience of social rewards by the attachment figure, and of improved affect regulation, which is conducive to learning new behavior. Behavior modification may therefore be more effective when conducted by a therapist who has been building on an attachment relationship with a client than by a therapist who has no special relationship with the client, especially when clients have been showing low responsivity to social contact previously. In the current study it was tested whether an attachment-based intervention would enhance the effectiveness of behavior modification in clients who have been shown to be difficult to treat, and whether this might be explained by more effective stress regulation by the child in the presence of the attachment therapist. Thus, this integrative treatment was expected both to positively influence the behavior of the client and positively affect the underlying intra-psychic processes of stress-regulation.

The effect of the integrative approach, an attachment-based behavior modification treatment, was tested in this case study. Because of the particular importance of the therapeutic relationship, attachment behavior and stress-buffering was studied intensively within that relationship. The objectives of our study were as follows. First, we wanted to verify if challenging behavior in the group home was reduced during therapy, and during what phase of therapy this change in behavior occurred. Second, behavior modification aimed to replace challenging behavior by alternative appropriate behavior was expected to be more effective when conducted by a therapist who had been building an attachment relationship compared to behavior modification conducted by a therapist who was familiar, but had no special relationship. Third, we investigated the therapeutic relationship for evidence of a developing attachment between the client and the therapist. We expected that the client would display more attachment behavior towards the attachment therapist than to the control therapist and that this behavior would increase in the course of the attachment therapy. Finally, less activation of the autonomic nervous system was expected when the attachment therapist engaged in the stressful part of the treatment, during behavior modification, than when the control therapist did so. These electrophysiological measures were used as an important additional window to gauge the regulation of stress and wellbeing in clients with communicative problems, as well as to measure effects of

interventions aimed at these outcomes (Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005).

## Method

*Participant:* Roy was a blind, 17-year-old boy with a diagnosis of Down syndrome. Although no formal IQ scores were available, he was considered to be severely intellectually impaired. Roy was not toilet trained and was unable to feed and dress himself. He was completely isolated from the world. He persistently engaged in severe self-injurious behavior, aggression and disruption. The behavior was noted as severe and persistent with the highest score on the 'Consensusprotocol Ernstig Probleemgedrag - Nationaal Ziekenhuisinstituut', a widely used Dutch protocol for measuring challenging behavior, with a reliability Cohen's kappa of .91 and high external validity (Kramer, 2001). Roy had been mechanically restrained because he scratched himself to such an extent that he seriously injured his arms and chin. He also scratched and spat at his caregivers, resulting in limited contact with them.

Roy lived in a group home for children with severe intellectual impairments. Because of the need for special medical care and his complex home environment, his parents were not able to provide adequate care. He spent the first year of his life in hospital and then moved to a 24-hour care facility. He frequently had to move from one group home to the next and encountered numerous caregivers. His challenging behavior started very early. Roy's history included early pathogenic care, based on the criteria for attachment disorder (DSM-IV: persistent neglect of basic emotional needs for comfort and affection; persistent neglect of physical needs; frequent changes of regular caregiver). None of the medical interventions, medication for allergies and special diets, and the frequent behavior modification treatments he received were successful. An independent psychiatrist with extensive experience with clients with a visual and intellectual impairment was consulted.

This assessment did not reveal any contraindications for the treatment protocol, such as aversion to physical contact, and did not indicate disorders in the autistic spectrum.

Roy's parents gave their written informed consent for his participation in this study and medical ethical approval was obtained from the Vrije University Medical Centre Medical-Ethical Review Board. This board is licensed to approve research by the Central Committee on Research Involving Human Subjects (CCMO), which is responsible for monitoring compliance with Dutch legislation governing medical research. In the protocol it was noted that if the client showed continued resistance to the use of the electrocardiogram, the treatment would continue

without obtaining these physiological measures. Roy showed no resistance to the placement of the electrodes.

### ***Intervention***

An intensive integrative psychotherapeutic treatment was developed for highly challenging behavior in visually and severely intellectually impaired clients. The therapy is aimed at children for whom other treatments (e.g. standard behavior modification) have failed, and at children whose histories suggest that they may have had little opportunity to develop selective attachment, due to pathogenic care in the past (early disruptions in caregiving relationships, abuse, neglect). A therapist works with clients to induce intra-psychic changes during therapy. This integrative treatment consists of three phases (Appendix A). Phase 1 is aimed at creating the conditions, following Bowlby (1969/1997), under which attachment may develop. First (phase 1.1), the therapist provides sensitive and inciting responses with the aim of making contact with the client. Contact-seeking starts with vocalization, as the blind or visually impaired client has to get to know the voice of the therapist. Touch can be added if the client feels comfortable when touched. The therapist reacts to the positive and negative reactions of the client by verbally reflecting the client's behavior and emotions. The next step follows once the therapist and the client have got to know each other and experience positive and enjoyable interaction and contact, which can easily be restored after contact is broken, and when the client initiates contact-seeking with the therapist. The therapist and client know each other when the therapist can anticipate the behavior of the client and when the client gives a sign, any behavioral or verbal indication, that he recognizes the therapist. The client shows that he enjoys the interaction and contact with the therapist by laughing, having fun and making pleasurable sounds. The therapist stimulates this by playing enjoyable games for instance giving a hug or rocking together.

Next (phase 1.2), mirroring and synchronizing are added to stimulate communication. During this symbiotic phase the therapist imitates the client's movements and behaviors, and provides anticipatory responses to the client's reactions in order to create a sameness in behavior. The therapist stimulates the client to take initiatives to start new cycles of interaction, but gradually introduces pauses and restarts. The therapist can begin phase 1.3 when synchronous cycles of behavior can be broken but easily restored, and when the client shows initiatives for interaction with the therapist.

Subsequently (phase 1.3), the therapist stimulates exploration of the environment, offering comfort when exploration results in anger or anxiety. The result may be an increased propensity to seek contact with or proximity to the therapist when the client exhibits distress or fear. When the client is comfortable to such an extent that he actively explores the environment, when the client enjoys the closeness of the therapist but also enjoys playing together and playing next to the therapist and

when the client continues exploration when the therapist leaves the room, then phase 2 of the intervention may be introduced.

Phase 2 focuses on behavior modification to teach the client new and socially acceptable behavior as an alternative to challenging behavior. By means of a functional behavior analysis (ABC analysis) socially acceptable behavior is specified, and through systematic 'chaining' and 'fading' new appropriate behavior is taught. Verbal and nonverbal social reinforcements like affectionate pats, hugs, approval and praise are given.

The last phase (phase 3: generalization) starts when challenging behavior has diminished and the client exhibits socially acceptable appropriate behavior instead. The therapist facilitates contact between the client and regular caregivers by giving feedback on the caregivers' sensitivity and responsiveness towards the client during video-training and team discussions. Over time, the number of sessions is slowly reduced until the therapy stops. The caregivers should continue to invest in the bond with the client through being sensitive and responsive towards the client, as taught by the therapist. The therapy ends when the transference of the principles of sensitivity and responsibility to the caregivers, the principles of providing a *secure base* and a *safe haven* for the client (Ainsworth, Blehar, Waters, & Wall, 1978) is completed. This is evident when the caregivers can soothe the child when distressed and when the caregivers appropriately stimulate the client's exploration of objects and the environment.

**Procedure:**

During phase 1, attachment-based therapy as described above was given by the attachment therapist (therapist A). The control therapist (therapist B) provided only positive attention. Sessions systematically alternated over mornings and afternoons. After having completed the attachment-based intervention (phase 1 of the treatment), remaining challenging behaviors were screened and the challenging behaviors indicated by the caregivers as being the most disturbing were selected as target behaviors. A basic ABC analysis was conducted, based on observation and an interview with the caregivers, to identify the contingencies of these target behaviors. Subsequently, socially acceptable replacement behaviors that would serve as functional alternatives were defined for these target behaviors. Several challenging behaviors already appeared to have been extinguished after the attachment therapy (phase 1) (spitting, head banging and scratching himself). Roy's remaining target challenging behavior was scratching his caregivers. The ABC analyses showed that this scratching occurred in the following situations: (i) during free time, if he wanted to listen to some specific music; (ii) during social interaction, if he wanted to be left alone for a while; and (iii) during daily care, if he became impatient during meals. It is important to note that both therapists used the same intervention protocol during the behavior modification therapy (phase 2).



Scratching behavior was ignored. The protocol included the following replacement behaviors:

*Using his hand to ask for music.* At the start of the session the therapist entered the room and turned on the radio (music he did not like). If Roy showed a reaction, such as a groaning sound, a frown or restlessness, it was interpreted as an indication that he wanted a different kind of music. By taking and shaking his hand the therapist enforced the use of his hand to show that he wanted another kind of music. Then the therapist praised Roy by giving him a pat on his shoulder, followed by changing the music. This was repeated at the end of the session.

*Turning away or putting his hand under his legs.* Roy did not like to be disturbed while listening to his favorite music. However, both the attachment therapist and control therapist sat next to him on his couch during their respective sessions. When Roy wanted to scratch the therapist, the therapist would sooth him verbally and verbally encourage him to turn around and put his hands under his legs. Positive verbal praise and a pat on his shoulder reinforced this self-controlling behavior.

*Using his hand to ask for sweets.* During every session the therapist put approximately 10 small soft sweets on a plate. The therapist announced that there were sweets on the plate and if Roy wanted a sweet he could put his hand on the therapist's leg and she would let him take one sweet. The therapist encouraged positive behavior by giving compliments and a shoulder pat. She encouraged him verbally to put his hand on her leg when he wanted another sweet. Whenever he accomplished this, he could take a sweet from the plate.

During phase 1 there were 18 videotaped 40 to 45 minute sessions for each therapist; during the second phase there were 7 videotaped 40 to 45 minute sessions for each therapist.

### ***Instruments***

*Residential observation lists.* Roy's professional caregivers recorded challenging behavior on the observation lists (Appendix C). They were instructed to score the frequency and intensity of this behavior. The behavior was scored every hour of each day during the intervention. Intensity was rated on a 10 point Likert-type scale with 1 as low and 10 as high; frequency was rated by the number of times the challenging behavior occurred during the past hour. Observation results were monthly reported and evaluated ensuring the subsequent continuation of the use of the observation lists.

*Target challenging and target appropriate behavior.* Each week one of the three therapy sessions given by the attachment therapist and one session given by the control therapist was videotaped. A weekly frequency of video analysis was chosen

on the basis of the expectation that change would occur over weeks, not days. Observers independently coded challenging and appropriate replacement behavior during the behavior therapy (phase 2) using Noldus computer software, The Observer (Noldus Information Technology, Wageningen, The Netherlands). The mean duration of these behaviors was calculated for each session. Inter-rater reliability was analyzed in 15 randomly selected sessions. Twenty-minute checks were done for 15 videotapes. For the frequency of target challenging behavior the interobserver agreement was 78% and Cohen's kappa was .74; for duration it was 93% and .92. For the frequency of appropriate replacement behavior the interobserver agreement was 81% and the Cohen's kappa was .78; for duration it was 91% and .90.

*Attachment behavior.* We developed observation coding schedules for the four types of attachment behavior: proximity seeking, attachment resistance, attachment avoidance and contact maintenance, based on the observation scales for mother-child interaction in the Strange Situation (Ainsworth et al., 1978), see Appendix B. The coding schedules enabled recording of the intensity of these behaviors.

*Proximity seeking by the client (physical or by means of an object).* The observation schedule for proximity seeking identified initiatives by the client to seek proximity. Intensity of proximity seeking could vary from signaling (minimal) to locomotion (very active) on a 4-point scale.

*Resistance by the client.* The observation schedule for resistance identified the child's behaviors signaling resistance to the therapist while in contact. Resistance could vary from negative vocalizations (mild) to active squirming and/or pushing to get away from the therapist on a three-point scale.

*Avoidance by the client.* The observation schedule for avoidance was used to identify behaviors resulting in avoidance of contact with the therapist. Behaviors could vary from being slow to respond to overtures by the therapist and looking away briefly (mild) to being unresponsive for long periods while the therapist was trying to make contact (strong). 'Mild' avoidance was scored as showing 'no' avoidance because some behaviors indicative of mild avoidance were indistinguishable from typical behavior of people with a visual and intellectual disability, for example turning the head away during contact, thus using a three-point scale.

*Contact maintenance by the client.* Contact maintenance was coded as the active effort on the part of the client to hold on to the therapist after the therapist had signaled that s/he was about to leave. A three-point rating scale allowed for the distinction between mild, active or very active proximity seeking within the period

from the therapist's signal that the session was over until the therapist really left the room.

Attachment behaviors were scored on the basis of videotapes of the treatment and control sessions, as described above. Observers independently coded the attachment behaviors during phase 1, using Noldus computer software, The Observer (Noldus Information Technology, Wageningen, The Netherlands). Observers were kept blind to therapist status and phase of therapy by offering the session recordings in random order. For mean frequency and duration of proximity seeking and contact maintenance behavior the interobserver agreement was 85% and Cohen's kappa was .71, for resistance the interobserver agreement was 94% and the Cohen's kappa was .77 and for avoidance the interobserver agreement was 83% and the Cohen's kappa was .64.

For the analyses, the total duration of each of the four attachment behaviors in each of the categories of intensity of the attachment behaviors was computed for each session. A weighted score was developed for each attachment behavior using the scale values (minimal attachment behavior + 2\*mild attachment behavior + 3\*active attachment behavior + 4\*very active attachment behavior). We expected that all four forms of attachment behavior would be shown more in the presence of the attachment therapist compared to the control therapist.

*Physiological indicators of autonomic arousal.* The Vrije University-Ambulatory Monitoring System (VU-AMS) was used to record the electrocardiogram (ECG) and changes in thoracic impedance (ICG) (De Geus & Van Doornen, 1996). With this device simultaneous and continuous assessment can be made of the Respiratory Sinus Arrhythmia (RSA) and Pre-Ejection Period (PEP). RSA is an index of activation of the parasympathetic division of the autonomic nervous system, and is relatively uninfluenced by sympathetic activation. RSA is the difference between the lowest interbeat interval (IBI) during inspiration and the highest IBI (in milliseconds) during expiration. PEP is an index of sympathetic activation, relatively uninfluenced by parasympathetic activation. PEP is a measure of cardiac sympathetic activity representing the time between the onset of left ventricular depolarization and the ejection of blood into the aorta (in milliseconds), a measure of contractility of the heart. When the client's movement does not change, any change in RSA and PEP can be interpreted as the result of stress. Lower PEP and lower RSA indicate more stress. To create the PEP scores, coders reliably trained using sample cases ( $r > .90$ ) inspected beat-by-beat data and removed movement artifact using custom software. To edit the RSA scores for movement noise, the software package was used by the trained raters reliable on sample cases ( $r > .90$ ). Willemsen, De Geus, Klaver., Van Doornen, & Carroll (1996) and De Geus, Willemsen, Klaver, & Van Doornen (1995) provide information on the VU-AMS equipment and the adequate reliability and validity of the PEP and RSA data.

### ***Data analysis***

The sample mean of each therapy session was used for all analysis of PEP, continuously measured over every period of 30 seconds and for RSA, continuously measured over every respiration cycle. The hypothesis ( $H_0$ ) of no difference in stress between both therapists during the behavior modification was tested. The natural assumption that people get used to situations and would therefore experience less stress in the presence of both therapists was taken into account. In this set of data with a natural increasing trend, isotonic regression could be used to find values that best fit the observations in the consecutive sessions of the four successive (sub-)phases (Barlow, Bartholomew, Bremner, & Brunk, 1972). Another reason to use isotonic regression was to enhance statistical power for testing the direction of the hypothesis (Gaines & Rice, 1990). The statistics in isotonic regression are based on likelihood ratios and are related to the F statistic in ANOVA. The probability of the F statistic indicated whether there were significant differences between the means in so far as they were compatible with the hypothesized order. The resulting  $p$  values of nonparametric bootstraps are reported.

## **Results**

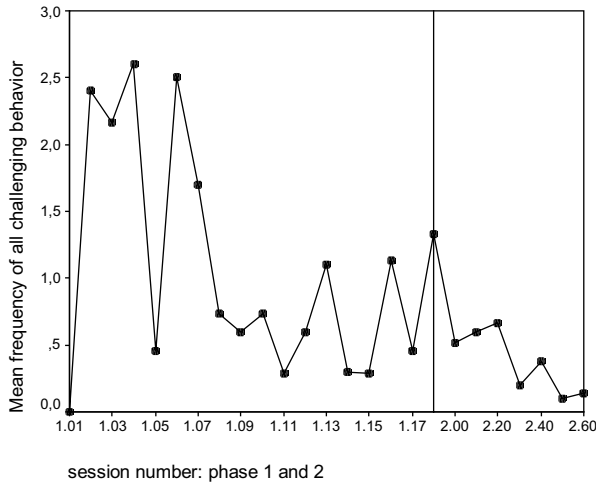
### ***Challenging and appropriate behavior***

Roy received the integrative treatment over a 12-month period. After completing the treatment a remarkably positive change was found in Roy's challenging behavior in his daily situation. The arm restraints he wore during the nine years preceding this intervention were no longer necessary and Roy even went to the kitchen to ask his caregivers to change the music instead of relapsing into his extreme self-injuring behavior. Daily observations of Roy's problem behavior during the course of treatment and on follow-up by the caregivers (in his home apart from the therapy situation) confirmed these large effects on behavior problems during treatment, effects that were for the largest part accomplished during the attachment therapy phase. Table 1 and Figure 1 show the decrease in the mean frequency of challenging behavior scored by caregivers on the residential observation lists during the week preceding the sessions. The mean intensity rated by the caregivers followed the same pattern (Table 1). ANOVAs for the frequency as well as for the intensity of all challenging behavior showed significant phase effects (frequency:  $F = 11.68$ ,  $df = 1, 134$ ,  $p < .01$ ; intensity:  $F = 13.56$ ,  $df = 1, 134$ ,  $p < .00$ ), indicating that positive effects generalized to daily situations outside the therapy.

**Table 1:** Means and standard deviations for frequency and intensity of all challenging behavior scored on the residential observation lists.

Challenging behavior	Therapy type	Mean	SD	N
Frequency	Attachment therapy	.95	1.13	87
	Behavior modification	.36	.52	49
Intensity	Attachment therapy	2.31	2.54	87
	Behavior modification	.88	1.25	49

**Figure 1:** Mean frequency for all challenging behavior scored on the residential observation lists during the days preceding the sessions.

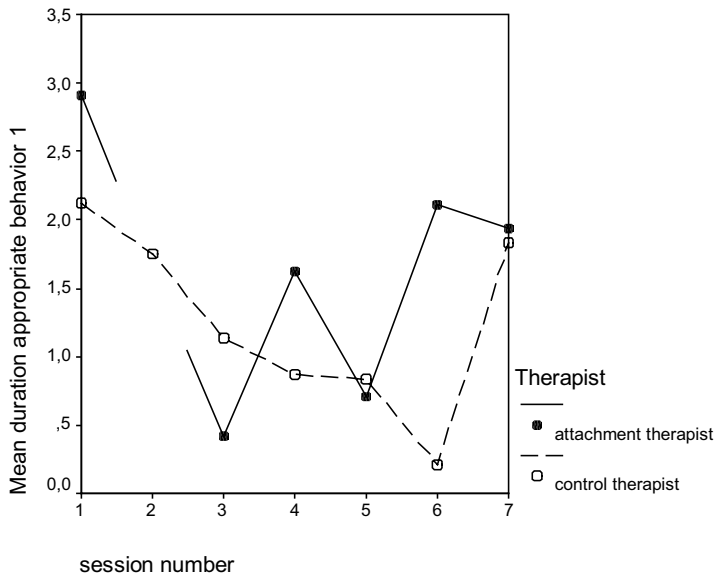


To determine if the attachment therapist was more effective in behavior modification (phase 2) than the control therapist - both used the same protocol in this phase - we compared their videotaped sessions. The target challenging behavior rarely occurred during the behavior modification sessions and there was little difference between the attachment therapist (total duration of session:  $M = .42$ ;  $SD = .18$ ) and the control therapist (total duration of session:  $M = .40$ ;  $SD = .08$ ).

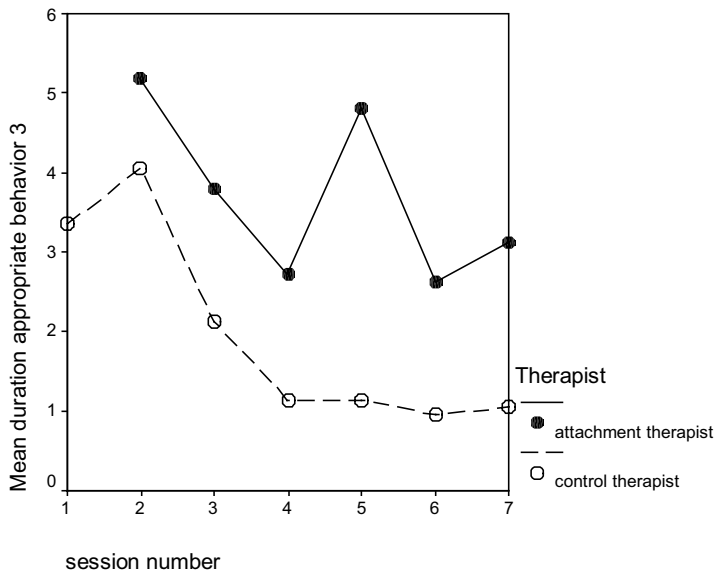
Figures 2 and 3 show the effectiveness, of both therapists in teaching appropriate behaviors 1 and 3 (the mean percentage of the total duration): asking for music (Figure 2) and using his hand to ask for sweets (Figure 3). The sessions with outlying values were removed. The attachment therapist showed a higher effectiveness (appropriate behavior 1:  $M = 1.6$ ;  $SD = .92$ ; appropriate behavior 3:  $M = 3.71$ ;  $SD = 1.08$ ) compared to the control therapist (appropriate behavior 1:

$M = 1.2$ ;  $SD = .68$ ; appropriate behavior 3:  $M = 2.0$ ;  $SD = 1.26$ ). The independent samples t-test indicated that this difference was significant for the mean of appropriate behaviors 1 and 3 ( $t = 2.38$ ,  $df = 12$ ,  $p < .04$ ). This significant difference was due to the significant difference in 'appropriately asking for music' ( $t = 2.64$ ,  $df = 11$ ,  $p < .02$ ). Roy did not show significantly more self-restraint (appropriate behavior 2) when the control therapist conducted the therapy ( $M = 9.4$ ;  $SD = 7.85$ ) than when it was conducted by the attachment therapist ( $M = 6.1$ ;  $SD = 3.94$ ).

**Figure 2:** Mean duration for appropriate behavior 1 during the behavior modification (phase 2).



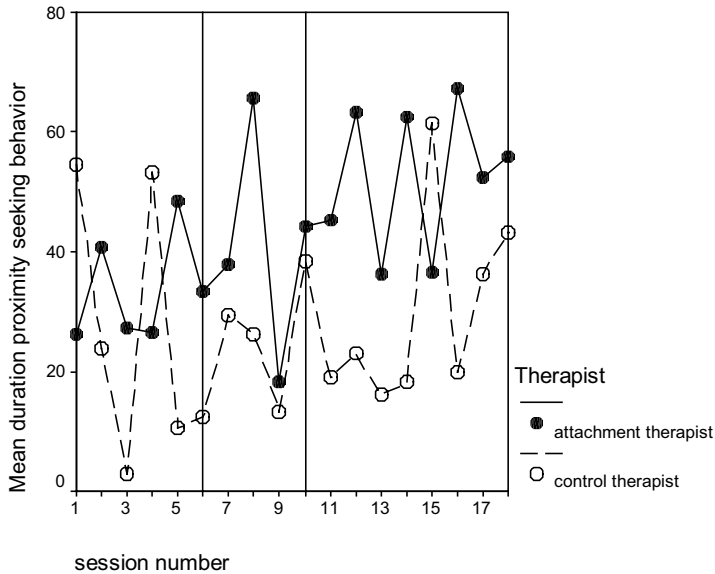
**Figure 3:** Mean duration for appropriate behavior 3 during the behavior modification (phase 2).



### **Attachment behavior**

*Proximity seeking by the client:* Figure 4 shows the weighted score for proximity-seeking behavior, the mean percentage of the total duration of each session, during the attachment therapy phase of both therapists. The Figure shows more proximity-seeking behavior towards the attachment therapist ( $M = 43.83$ ;  $SD = 14.92$ ) than towards the control therapist ( $M = 27.89$ ,  $SD = 16.6$ ). The one-way ANOVA indicated that this difference was significant ( $F = 9.18$ ,  $df = 1,34$ ,  $p < .005$ ). The proximity-seeking behavior towards the attachment therapist increased over time (start of the intervention:  $M = 26.21$ , end of the intervention  $M = 56.00$ ).

**Figure 4:** Mean duration for proximity-seeking behavior (weighted) during the attachment therapy (session 1-6 = phase 1.1, session 7-10 = phase 1.2 and session 11-18 = phase 1.3).



*Resistant attachment behavior by the client:* Resistant attachment behavior was rare in the presence of either therapist. No significant difference was found in resistant attachment behavior (weighted) towards the attachment therapist ( $M = .93, SD = .58$ ) compared to the control therapist ( $M = .93, SD = 1.1$ ).

*Avoidant attachment behavior by the client:* Likewise, avoidant attachment behavior directed at the therapist was rarely scored in either kind of therapy and in all phases. Roy showed significantly more avoidant attachment behavior towards the attachment therapist ( $M = .42; SD = .57$ ) than towards the control therapist ( $M = .13; SD = .15$ ): ANOVA  $F = 4.32, df = 1, 34, p < 0.05$ .

*Contact maintenance by the client:* Contact maintenance indicated Roy’s proximity seeking behavior in the period after the therapist’s signal that the session was over until the therapist left the room. He did not show significantly more contact maintenance towards the control therapist ( $M = 32.56; SD = 37.59$ ) than towards the attachment therapist ( $M = 16.41; SD = 19.39$ ).



### Physiological indicators of stress

The mean PEP for each session is shown in Figure 5 (a lower PEP indicates more stress). During behavior modification (phase 2), when the client was provoked the attachment therapist seemed to be a buffer for stress as Roy showed less stress when this treatment was given by the attachment therapist ( $M = 103.69$ ;  $SD = 3.88$ ) than when it was given by the control therapist ( $M = 98.12$ ;  $SD = 3.03$ ). The isotonic regression analyses of the PEP difference in the stress level between the two therapists showed that the stress reaction was significantly stronger with the control therapist than with the attachment therapist ( $p < .02$ ; the statistical significance of results was tested using non-parametric bootstrapping, which is why only the p-values are given).

**Figure 5:** Mean PEP for the attachment therapy (session 1-17) and the behavior modification (session 18-24).

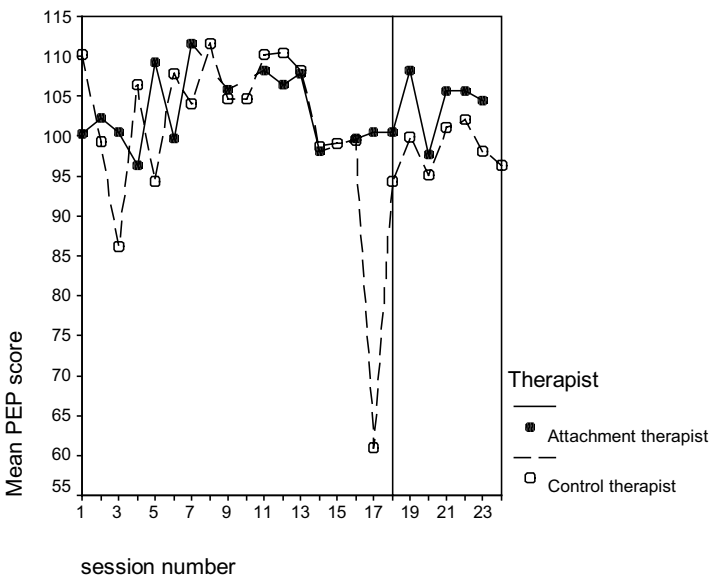
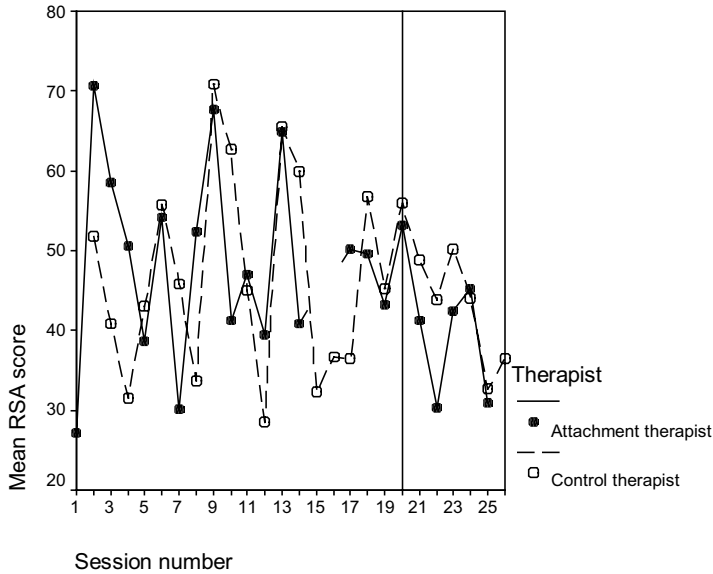


Figure 6 shows the mean RSA (a lower RSA indicates more stress) per session during the integrative treatment (phase 1 and phase 2). The isotonic regression analysis and a non-parametric bootstrap with mean RSA per session on the data of the behavior modification treatment (phase 2) showed no significant difference between RSA arousal when the attachment therapist conducted the treatment ( $M = 40.59$ ;  $SD = 8.69$ ) and when the control therapist conducted the treatment ( $M = 44.61$ ;  $SD = 8.02$ ).

**Figure 6:** Mean RSA for the attachment therapy (session 1-17) and the behavior modification (session 18-24).



## Discussion

In this case study we focused on the effect of an integrative psychotherapeutic intervention and on the components that may be responsible for positive therapy effects. Firstly, we determined changes during treatment in Roy’s challenging behavior. Second, behavior modification by an attachment therapist and a control therapist were compared. Third, the therapeutic relationship was examined to determine if the attachment therapy gave more way to attachment behavior by the client than the sessions with the control therapist and whether autonomic reactivity provided evidence for more effective affect regulation during contact with the attachment therapist than with the control therapist.

The results suggested that the treatment was beneficial as Roy, over time, showed significantly less frequent and less intensely challenging behavior even outside the therapy situation. His formerly very resistant challenging behavior decreased markedly during the attachment therapy (phase 1) and continued decreasing during behavior modification (phase 2). The results also indicated that the attachment therapist was significantly more effective in teaching Roy new appropriate behavior in the behavior modification phase of the integrative therapy. It should be noted that both therapists were compared using social contingencies of similar quality and strength. The difference may be that the client *experienced* social contingencies from the attachment therapist as stronger or qualitatively more salient than the same contingencies coming from the control therapist. Therefore the attachment phase might be a positive augmentation to enhance the

effectiveness of behavioral interventions, such as differential reinforcement and Functional Communication Training. Furthermore, the decrease in challenging behavior was so rapid and extensive during the attachment therapy that the target challenging behavior rarely occurred during the behavior modification sessions, such that behavior modification could mainly focus on teaching new appropriate and functionally communicative behaviors.

Observations during the sessions revealed that Roy showed significantly more proximity-seeking behavior towards the attachment therapist than towards the control therapist. The intensity of this behavior increased over time. The client rarely exhibited resistant and avoidant attachment behaviors, but when he did it, was more towards the attachment therapist than towards the control therapist. It should be noted that before the therapy, proximity to caregivers resulted in aggressive behavior and spitting.

In addition to behavioral changes as evidence for the development of attachment, we also inferred intra-psychic changes. Although little is known about the association between measures of autonomic arousal and subjective affective experience in persons with severe or profound ID, on the basis of research on people without an intellectual impairment the decrease found in autonomic activity during contact with the attachment therapist may be interpreted as an increase in regulation of affect and an increase in wellbeing (Bradley, 2000). Additional evidence for the effect of the therapy on affect regulation was found during phase 2, when sessions were conducted under conditions that before the therapy would have provoked challenging behavior. Roy showed less PEP arousal when the attachment therapist rather than the control therapist conducted the behavior modification therapy. One interpretation could be that the attachment therapist had become more sensitive to Roy's distress signals, which made the intervention less stressful. However, the behavior modification protocol was highly structured and explicit in order to safeguard comparability of the intervention as conducted by the two therapists. It is more likely that the lower level of arousal can be explained by Roy having learned to derive stress relief from having the attachment therapist in close proximity.

Although a reaction was expected on PEP *as well as* RSA, the results indicated that the parasympathetic system (RSA) was not differentially activated. According to Porges' model of a social engagement system (Porges, 2004), the parasympathetic system is activated when situations involve non-threatening challenges of homeostasis (e.g. focused attention or social interactions). Consequently, the result of parasympathetic activation is, without activating the sympathetic nervous system, a down-regulation of the vagal system due to the rapid increase of cardiac output (decrease in RSA) (Porges, 2004). Roy used the sympathetic system (PEP) to react to the therapists' provocative behavior. The sympathetic nervous system mediates fight-flight reactions, which are usually shown in cases where

homeostasis is more severely under threat than during normal social interactions. This might indicate that the sweets and the music he preferred were highly important items. Food and auditory stimulations may be essential elements in the lives of blind and severely impaired children.

During the generalization phase of the intervention special attention was given to enhance the relationship with the client. Furthermore, an important aspect was to provide a setting, which supports the expression of preferences and stimulates making choices. Therefore, this intervention may be an important step towards giving the client the possibility of attaining some degree of self-determination. More self-determination is important to give the client a feeling of control in their life and thus to improve the quality of life (Wehmeyer & Schwartz, 1998).

The results indicated that the integrative treatment was effective, and that this effect may be due to the fact that the client was allowed to develop an attachment relationship with a therapist and learned to use this therapist as an external regulator of stress. As with the treatment described by Fisher et al. (2000), this integrative treatment starting with an attachment-based intervention also led to changes in the individual-level processes, which might have been carried into other situations as well. The expectation is, therefore, that the treatment will have a long-term effect.

The attachment therapist proved to be more effective than the control therapist in teaching the client new appropriate behavior. This finding supports the importance of the use of an integrative treatment and is consistent with the stress-attachment model developed by Janssen et al. (2002). Whether these findings may be generalized to children other than Roy awaits further research.

# Chapter 6 General Discussion

## Introduction

The central question underlying this thesis was whether children with a history of pathogenic care, visual and severe intellectual disabilities, and severe challenging behaviour can develop an attachment relationship with a therapist. Furthermore, from an intervention point of view, the effect of Integrative Therapy for Attachment and Behaviour (ITAB, see Appendix A) on children's behaviour was studied.

The development of an attachment relationship was studied by testing the stress-regulating function of the therapeutic relationship using physiological (PEP, RSA, cortisol), and behavioural measures. The effect of ITAB was studied by comparing the behaviour modification given by an attachment therapist with behaviour modification given by a non-attachment/control therapist, and by examining behavioural changes in daily life.

In this chapter, the findings of the studies presented in Chapter 2 to 5 are summarized and discussed. Limitations and strengths of the study are addressed. Finally, its clinical implications are discussed.

## Summary and conclusions

Chapter 2 describes a multiple baseline study whose central question was whether the clients could develop an attachment relationship with the therapist. Because attachment relationships are supposed to facilitate affect regulation (Bradley, 2000) in challenging situations, the autonomic nervous system responses of six clients were examined. Respiratory sinus arrhythmia (RSA) and pre-ejection period (PEP) were recorded using the VU-AMS (De Geus & Van Doornen, 1996). First, the RSA data were corrected for level of activity. Because no association was found between PEP and level of activity, no corrections were necessary for PEP. Proximity-seeking behaviour (Appendix B) was independently coded using Noldus computer software (The Observer), during peaks of arousal indicated by low RSA and PEP, and was compared between the experimental and control treatments. The clients showed significantly longer periods of proximity-seeking behaviour at higher levels (levels 3 – active – and 4 – very active –) towards the experimental therapist compared to the control therapist. In addition, during moments of high RSA and PEP arousal the clients showed more and higher levels of proximity-seeking behaviour towards the experimental therapist than towards the control therapist. Differences in proximity-seeking between periods of high and low parasympathetic nervous system arousal did not significantly vary between therapists. During behaviour modification, a phase in ITAB in which the clients are confronted with stressful situations, the clients showed marginally significantly less RSA and significantly less PEP arousal in the presence of the experimental compared to the control therapist. Consequently, as this intensive therapeutic

intervention over time resulted in more proximity-seeking behaviour towards the experimental therapist compared to the control therapist and in particular more proximity-seeking during peaks of arousal, the therapeutic relationship fulfilled a function similar to that of an attachment relationship. In addition, this therapeutic relationship had an affect-regulating effect similar to that of an attachment relationship.

Psychophysiological studies have confirmed that the presence or absence of primary attachment figures (biological or foster parents) is associated with children's autonomic nervous system (ANS) responses, in particular in stressful situations (Gilissen, Koolstra, Van IJzendoorn, Bakermans-Kranenburg, & Van der Veer, 2007; Oosterman & Schuengel, 2007a,b; Stevenson-Hinde & Marshall, 1999; Willemsen et al., in press). Our study may be the first study showing similar effects in therapeutic relationships. Relationship-based support might be especially important in psychotherapy involving children without attachment relationships. Our results support the plasticity of developing an attachment relationship, even for children with multiple disabilities developing along severe maladaptive pathways, and growing up without stable attachment figures.

Adam and Gunnar (2001) found that security of attachment between mothers and their 2-year-old children is associated with more adaptive functioning of the physiological stress system. A similar mechanism may perhaps be at work in the therapeutic relationship established during integrative therapy. Through better affect-regulation attained by developing an attachment relationship with the therapist, the client might experience lower levels of less continuous stress. Because cortisol is important for stress regulation (Blair et al., 2005), and cortisol reactivity and cortisol circadian rhythm have been linked to caregiving experiences (Dozier et al. 2002, Dozier et al. 2006, Fisher et al. 2000, Gunnar & Quevedo, 2007, Gunnar & Vazquez, 2001), the expectation was that clients who develop an attachment relationship with the therapist will show a more typical circadian rhythm at the end compared to the start of the intervention. This was the focus of the study described in Chapter 3. Salivary samples were collected in the clients' residential environments four times a day on two consecutive weekend days once a month during ITAB. One client, a blind boy aged 17 years, resisted saliva collection and was therefore excluded from the study. In interpreting the results it is important to keep in mind that collecting saliva samples from children with serious visual and severe intellectual disabilities proved to be difficult, and resulted in a high percentage of missing values. Nevertheless, the results showed that three clients exhibited an atypical cortisol cycle at the start of the intervention, which evolved to a more typical diurnal cycle with less extreme levels at the end of the intervention. However, compared to a community comparison group involving 12-year-old twins (N = 180 pairs: Bartels et al., 2003), morning cortisol levels were still significantly lower and evening levels were significantly higher at the end of the intervention. Concerning the overall aim of this study, the results

indicate that the diurnal cycle of cortisol might indeed change in response to changes in the environment. The lower morning cortisol levels at the end of the intervention period in particular may indicate, like the autonomous nervous system (PEP and RSA) findings reported in Chapter 2, that the development of the therapeutic relationship supports better stress regulation in the clients of this study.

The effect of ITAB on behaviour was tested in a series of single case studies with alternating therapy conditions (Chapter 4) for the six clients, described in Chapter 2 and 3. Standardized instruments were used to assess the challenging behaviour shown by the clients at the start of the intervention and after its completion. For the six clients the 'Severe Challenging Behaviour Consensus Protocol – National Institute for Health Care Management' (CEP) (Kramer, 2001) score was significantly lower at the end compared with the start of the intervention. On the 'Challenging Behaviour Scale for People with an Intellectual Disability' (Storend Gedragschaal voor Zwakzinnigen or SGZ) (Kraijer & Kema, 1994) four out of the six clients showed a higher score, which indicates less challenging behaviour.

Professional caregivers in the clients' residential homes were instructed to record the frequency of challenging behaviour. Challenging behaviour was then recorded continuously (every waking hour of each day during the intervention) in the residential home using observation lists (Appendix C). Due to low intraclass reliability coefficients for the weekly averages of the scored observation lists, two cases were dropped from the analyses of challenging behaviour in the residential setting. For the four remaining cases the results indicated that challenging behaviour in the residential home, outside the therapeutic intervention, decreased during the attachment relationship building phase and continued decreasing during behaviour modification (phase 2).

The weekly videotaped sessions conducted by both therapists were randomly and independently coded using Noldus computer software (The Observer) by observers who were blind to the therapeutic condition. The challenging behaviour and adaptive replacement behaviours were coded during behaviour modification (phase 2). For the six clients the behaviour modification sessions conducted by the experimental therapist resulted in significantly more adaptive replacement behaviour than the behaviour modification sessions conducted by the control therapist. No significant differences were found between the therapists in their effectiveness with respect to reducing the already fairly low levels that had remained of target challenging behaviour during the behaviour therapy sessions.

These positive effects of ITAB were found in clients for whom in the past no other therapies and interventions had proven successful. We found that clients learned adaptive replacement behaviours more easily from therapists who had previously



attempted to build a therapeutic relationship based on attachment principles, compared with therapists who were merely familiar (control therapists).

In the single case study (Chapter 5) we integrated the two research aspects, the development of a therapeutic relationship and the effect of ITAB. Roy, a 17-year-old blind boy with Down Syndrome and a severe intellectual disability, received this treatment over a 12-month period. At the start of the intervention he was completely isolated from the world, exhibiting challenging behaviour noted as severe and persistent. His history included early pathogenic care, based on the DSM-IV criteria for an attachment disorder. No earlier interventions had been successful.

Observation-coding schedules were developed for the four types of attachment behaviour used for mother-child interaction in the Strange Situation (Ainsworth et al., 1978; Appendix B) to determine the attachment behaviour during attachment therapy (phase 1). Independent observers blind to condition coded the therapy sessions in random order. The results indicated that Roy, over time, sought more proximity to the experimental therapist than towards the control therapist. Additional evidence for the development of an attachment relationship was found in phase 2. Roy showed less PEP arousal when the experimental therapist rather than the control therapist conducted behaviour modification therapy, indicating that during the sessions with the experimental therapist systems underlying fight-or-flight responses were less activated. Furthermore, the experimental therapist was significantly more effective than the control therapist in teaching Roy new adaptive replacement behaviour during behaviour modification (phase 2).

Challenging behaviour was coded on the basis of videotaped therapy sessions, by coders who were blind to the experimental condition and treatment phase. The frequency and intensity of the challenging behaviour decreased over time. Furthermore, the intensity and frequency of the challenging behaviour in the week after the therapy sessions followed the same pattern, with significant phase effects indicating that positive effects had generalized to daily situations outside the therapy. Challenging behaviour in the residential setting was scored on the observation lists every hour of each day during the intervention by the professional caregivers.

These results are consistent with the theory that when clients such as Roy are able to develop an attachment relationship with another person, in this case a psychotherapist, stress regulation may improve and learning new behaviors may become easier.

## Study limitations and implications for future research

Although proximity-seeking behaviour was identified on the basis of the guidelines developed by Ainsworth et al. (1978) for coding attachment behaviour in the Strange Situation Procedure, these guidelines also make it clear that proximity-seeking is related to moments of stress. Therefore, highly stressful moments were selected which then give evidence for the activity of the attachment behavioural system. However, also under conditions of low arousal, similar differences were found in proximity-seeking between the experimental and control therapist. One possible explanation is that the experimental therapist not only became a target for attachment behaviour but also a target for exploration and play, given that the capacity for independent exploration away from the therapist as a secure base was limited due to intellectual and visual disabilities. Further research might attempt to differentially link security-seeking and exploratory proximity-seeking to autonomic nervous system response. Nevertheless, the combined results (Chapter 2-5) would seem to indicate that an attachment relationship developed between clients and the therapist administering ITAB. As might be expected, proximity-seeking behaviour towards the experimental therapist increased over time, whereas it remained stable in the sessions with the control therapist. Furthermore, the experimental therapist was more effective in supporting affect regulation during behaviour modification (phase 2). This therapist was also more effective in modifying adaptive replacement behaviour (phase 2).

Behaviour modification (phase 2) started when challenging behaviour had already dropped to fairly low levels during the therapy and control sessions. Combined with the limited number of sessions during phase 2, this may explain the result that no significant differences were found between the therapists in their effectiveness in reducing the target challenging behaviour. However, we can state that the experimental therapist was significantly more effective in shaping selected adaptive replacement behaviour.

A limitation of the design used in this study to examine the effect of ITAB was that the independent effect of the attachment-based therapy phase (phase 1) was not examined. However, a reversal design (ABAB) was deemed undesirable, because that would have disrupted the developing relationship. The results showed that the control therapist's positive presence alone did not result in the clients showing more attachment behaviour towards the control therapist. Therefore, without an ABAB design it is plausible that the increase of attachment behaviour shown towards the experimental therapist may be ascribed to ITAB.

In the multiple baseline study (Chapter 4) and in the single-case study (Chapter 5), the frequency of challenging behaviour diminished during the phase of the therapy in which an attachment relationship was stimulated. After having completed phase 1.3 (see Appendix A) behaviour modification (phase 2) was initiated. However, the

question remains of whether over time the challenging behaviour would have diminished even without behaviour modification (phase 2), by extending phase 1.3, skipping phase 2 and continuing with phase 3. In other words, it is not clear whether behaviour modification is necessary for an intervention based on attachment to treat challenging behaviour. Nevertheless, behaviour modification may certainly be needed in order to teach clients adaptive replacement behaviour.

Further research is needed to examine the effect of the generalization component of the intervention protocol, in order to find out whether clients and caregivers are able to capitalize on a newly established sensitivity to social rewards and interactions in order to develop trusting relationships within the context of residential care, given the challenges of staff turnover and workloads. Ultimately, the most important effect of the therapy may be the increased responsiveness of children with severe disabilities to their social environment. The therapy may have long-term effects if the caregiving environment sustains this social responsiveness and continues to stimulate the development of adaptive replacement behaviour using positive and social means of communication. Replication of this study may give insight into situations where ITAB is found to be effective but also into situations where the treatment seems to lack the expected effect.

Further research is also needed to determine whether the buffering effect of the relationship-based treatment on affect regulation as reported in this study is found among other clients, for example children or adults with an intellectual disability but no visual disability or adults with a visual and intellectual disability, and in other settings, for instance among young children without a visual or intellectual disability, deaf-blind clients or clients with an ASS diagnosis.

ITAB was given by two different therapists, each working with three clients, showing the same treatment effects. However, the question remains of whether different therapists would achieve the same results after using the ITAB protocol.

## **Clinical implications**

This study indicates that it was possible for the multiply disabled clients in this study, who had a history of pathogenic care, to develop an attachment relationship. A psychotherapist became a source of comfort and security during times of stress. These results show the plasticity even for clients with a prolonged and severe background of social deprivation. Caregivers may be important as stress regulators, and may indirectly reduce the likelihood of developing challenging behaviour. In this thesis we found that during the intervention, over time, challenging behaviour reduced significantly in the daily caregiving environment with significantly less challenging behaviour reported on observation lists and on the standardized tests, e.g. from a CEP 3 and 4 to 1 and 2. Thus, a

caring relationship, which provides comfort and safety, may support the client in coping with life stresses, such as the loss of a loved one, moving to a new home or care-centre, or during changes in day-care facilities.

The experimental therapist was found to be more effective in teaching the clients new adaptive replacement behaviour in the behaviour modification phase of ITAB than the control therapist (Chapter 3 and 5), presumably because the experimental therapist functioned as a stress regulator (Chapter 2 and 5). For this reason, building a therapeutic attachment relationship may be considered as an adjunctive treatment to enhance the effectiveness of behavioural interventions. These findings thus support the practice in behaviour modification of using parents or attachment figures, where possible, as behaviour modification agents. But these results may also emphasize the importance of focusing on the therapeutic relationship prior to using behaviour modification for therapists using behaviour modification as a therapeutic intervention.

Looking at the effect of the ITAB we not only found a decrease in challenging behaviour, but also, over time, more possibilities for social interaction. On this basis, maybe with more effect than in previous treatments, the interaction between the client and caregiver can be guided, stimulating the development of a network of secure relations in the daily caregiving environment.

## **General conclusions**

This thesis is of importance to the care of persons with disabilities. First, the study confirmed the plasticity of the development of an attachment relationship even in adolescence, indicating also that it was possible to develop an affect-regulating relationship with clients with visual and severe intellectual disabilities who had not had the opportunity to develop an attachment relationship with specific attachment figures earlier in life. Second, an attachment-based intervention can help children with multiple disabilities and unfavourable past experiences to cope with challenges to mental health. This was found in clients for whom, in the past, no other therapies and interventions had proven successful.

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# Appendix A Protocol for 'Integrative Therapy for Attachment and Behaviour' (ITAB)

Translated protocol published in: Sterkenburg, P.S. & Schuengel, C. (in press). Behandelprotocol 'Integratieve Therapie voor Gehechtheid en Gedrag' (ITGG). In C. Braet & S. Bögels (Eds.), *Protocollaire behandelingen voor kinderen en adolescenten*. Meppel: Boom.

Permission for translation and reproduction of the text included in this thesis was given by the publisher. The complete text of the above mentioned chapter gives extended information and illustrations.

Word of Thanks

The sketches were made by artist Lida de Zeeuw [www.lidaline.com](http://www.lidaline.com)

## Introduction

Prior to treatment, all parents/caregivers are informed about ITAB by means of the DVD 'Attachment: A Psychotherapeutic Treatment' ([www.bartimeus.nl](http://www.bartimeus.nl)). Subsequently, appointments are made regarding the offering of the treatment: three hours a week in the location where the child spends his/her day (= at home or the day care centre). Finally, appointments are made regarding monthly consultations to discuss the progress of the treatment.

ITAB is a phased treatment in which each phase has a specific function and depends on the success of the previous phase. Initially the psychotherapist/healthcare psychologist tries, by means of intensive contact, to build up an (renewed or first-time) attachment relation with the child. This first phase of the treatment consists of three sub-phases, namely 'bonding and making contact', 'symbiosis' and 'stimulation to individuation'. Because it is not to be expected that attachment alone will make the challenging behaviour disappear, the first phase is followed by behavioural therapy in phase 2. During the third and final phase, 'generalization and completion', the network of relations gets expanded and the therapist gradually assumes a place in the background. The treatment is offered three hours a week, on different days, in the daily environment of the child. It is important, however, to find a location where the child feels safe and comfortable, with little noise in the vicinity. The total time the treatment can be up to one year.

## Phase 1. ATTACHMENT THERAPY

### ***Phase 1.1: BONDING – ESTABLISHING CONTACT***

During the first phase of treatment the two most important aspects are: *sensitive response* and *inciting response*. Initially the child rejects and/or offers resistance to or avoids contact. The therapist responds to this by being very sensitive and following the child's pace. The therapist follows the behaviours of the child and adjusts his/her own behaviour accordingly - if the child is quiet, the therapist responds quietly; if the child is agitated, the therapist will also react in an agitated way. For example, the therapist will mirror the rhythm in which the child moves in order to reach the same wavelength as the child. The repetition of sounds the child makes can also put the child at ease.

Tactile contact begins with respecting the distance at which the child feels comfortable. That is to say: initially the child will determine the physical distance to the therapist. If the child wants to sit in the therapist's lap, he/she will take the child in his/her lap; if the child wants distance, the therapist will maintain distance (as represented in Sketch 1). The distance between therapist and child is a distance at which the child feels comfortable.

### **Sketch 1. phase 1.1: Bonding – establishing contact**



The therapist then starts to slowly build up physical contact, beginning with lightly touching where the child accepts it, for example a pat on the shoulder, a stroke on the hand or foot. This can be done first with the tips of the fingers, then with the entire hand, first for just a few seconds, then building up to a minute, then to several minutes. The touching is in tune with the child's movements; that is to say, if the child moves, the therapist moves along. The therapist moves along to the rhythm of the child.

The therapist is alert to his/her own signals of feelings and limits. It is important to name and process these limits experienced during the therapeutic contact at the time of intervention. During therapy the focus is on the child. The child is offered what he/ she needs. For example, if the child wants to sit on the therapist's lap, the latter should observe his/her own feelings as a therapist (how does the therapist feel in this situation), and proceed to offer the child what is necessary in order to make contact; that is to say, for example by taking the child into his/her lap. Limits are to be set with respect to any sexual contact initiated by the client. The therapy is always given in a room where other persons can observe the therapist and can enter freely.

The therapist names and articulates what he/she sees, what happens and what is about to happen. He/she talks softly, in a repetitive, melodious and questioning manner (just like when talking to a baby). The therapist is very alert, not only while talking but also while listening and waiting for the child's reactions. The therapist articulates feelings the child may have.

Gradually the therapist begins to take more initiatives. The therapist enlarges the movements the child makes, so that eventually the entire body is being used during movements. Rhythmic movements and use of language increase. Attention is paid to playfulness in the relation, for example by variations in tone of voice (hard-soft, high-low, fast-slow).

Behavioural problems are not reprimanded. If the child scratches or bites, the therapist responds in a comforting and reassuring voice, for example by saying: 'there there', 'easy', 'it's all right', 'hush hush'. If the child walks away, he/she is taken back to the room where the therapy sessions take place. This is done in a calm voice, clearly and concretely stating what is expected.

Enjoyable moments are looked for and utilized for as long as possible, making due allowance for moments of rest. Daily activities such as eating and drinking do not take place during these sessions.

**Signals that indicate the beginning of the next phase of treatment:**

- There is contact. Contact can be broken off and initiated again, and this is a contact between 'me' and 'you'. Moving 'together' and playing 'together' take place with increasing frequency and duration. Over time it is no longer a question of playing 'alongside' each other, playing takes place 'together'.
- During observation it is clear that the therapist and the child move and play together. It is almost as if a single person is being observed.
- When the symbiosis is broken off, the child seeks contact with the therapist on his/her own account.
- During the sessions the child's pace is being followed.
- The therapy sessions are enjoyable.

***Phase 1.2: SYMBIOSIS – SECURE ATTACHMENT***

The therapist stimulates the building up of a symbiotic relation by imitating the child's sounds/words. Complete synchronicity is reached when the therapist has learned to anticipate the child's behaviour. That is to say: the therapist moves along with the child in the direction in which the child is expected to move (see Sketch 2). During therapy the therapist articulates what the child is doing, but also what the child may be feeling and thinking.

### **Sketch 2. phase 1.2: symbiosis – secure attachment**



The therapist sees to it that certain rituals originate during the therapy. This may be a ritual during an interactive game such as 'Itsy Bitsy Spider'. The games become predictable. Initially the therapist is the initiator, later on the therapist responds when the child indicates himself/herself what games he/she wants to play. The therapist holds back and waits. The symbiosis (mirroring/being one) appears to be broken. This provokes the child into taking initiative and making it even clearer what his/her desires are. For example, if the ritual that has been established is a game of movement, the therapist can at some point assess what the child wants, namely to hold the therapist's hand in a certain way. The therapist begins the game but pretends not to understand what the child wants.

This somewhat breaks the symbiosis, which creates tension. The therapist asks the child what he/she wants. This stimulates the child into making an extra effort to indicate what he/she wants. The therapist then sees to it that symbiosis is re-established by doing what the child wants. This releases the tension.

This way a game of 'in tune/out of tune' develops, which always ends with 'in tune'. The symbiotic point of departure contributes to the confidence that will allow the child to take initiatives on his/her own. The therapist's positive reaction aims to contribute to a feeling of acceptance.

During this phase the child may feel such a bond with the therapist that he/she will resent the end of the therapy session. The child may show this by holding on to the therapist. If such behaviour occurs, the therapist names the behaviour and the feelings the child may have. The therapist subsequently states clearly when the next therapy session will take place and when the child will therefore have contact with the therapist again.

Aggression may also occur when the child is reunited with the therapist. The therapist's behaviour can easily be experienced by the child as ambivalent, which may lead to rejection and holding on to the therapist. This aggression can therefore be seen as a 'call' for contact. At such moments it is particularly important to be very sensitive to the child's feelings. Again, the child's feelings are named and the therapist stays very close to the child: the therapist offers the child contact.

**Signals that indicate the beginning of the next phase of treatment:**

- There is symbiosis. This symbiosis can be broken off and re-established. There is a 'we' situation.
- The physical distance between the child and the therapist is short and they play in unison. During observation it is as if 'one' person is being observed (two people who together look as one).
- There is predictability in the therapy.
- The child takes initiatives himself/herself to begin moments of playing together.
- The games move from being inwardly directed to being outwardly directed – towards the surroundings. The child begins to respond to the therapist's initiatives, for example by accepting toys and playing with them for a bit.

***Phase 1.3: STIMULATION TO INDIVIDUATION***

Breaking off and re-establishing contact without this causing anxiety is only possible if the child is aware of the continuity of the relationship in spite of interruptions. Person permanence (the realization that specific individuals do exist even if they can't be perceived temporarily) is an important cognitive precondition for this. In some cases acquiring person permanence goes hand in hand with acquiring object permanence. The child has to learn that toys can be found again (the use of tactile sense), because toys don't disappear when they fall or have been put somewhere else. When the child picks up toys on his/her own initiative *more frequently* (not always and usually still after a lot of encouragement), this means that there is a development in the direction of object permanence. In people with moderate to serious intellectual disabilities, acquiring object permanence requires continuous repetition and creativity within the therapy. During this phase the child will dare to do more, explore more and investigate more from within a secure relationship (as represented in Sketch 3). There is a moving back and forth: away from the therapist to play on his/her own and subsequently moving back towards the therapist.

### **Sketch 3. phase 1.3: stimulation to individuation**



The therapist encourages the child to express his/her own desires and feelings. The therapist does this by encouraging the child's initiatives and by giving in to his/her desires. The goal of stimulating the expression of the child's own desires and feelings is aimed at developing an 'I' or 'ego'. It is important to respond to desires like, for example, the desire to listen to specific music or sit in a specific spot.

Expressing desires and feelings indicates that the child is gradually developing an internal representation of the surroundings and of the therapist. Once the child develops this internal representation, he/she will be better able to support short separations. The child learns to look for attachment figures when he/she feels anxious. The child's greater sense of security may become apparent, for example, from a lessening of the desire to have prolonged contact, for example when sitting in the therapist's lap.

#### **Signals that indicate the beginning of the next phase of treatment:**

- The child regularly takes the initiative to play with toys/objects.
- Symbiosis has ended, but playing together continues. Playing material is used to play together.
- The child explores the surroundings and the playing material.
- The child enjoys both proximity and playing together with the therapist and next to the therapist.
- If the therapist leaves the room, the child plays alone for a while and re-establishes the contact easily when the therapist returns.

## Phase 2: BEHAVIOURAL THERAPY

The relation the psychotherapist has built up with the child can be used to realize the treatment objectives. After all, stimulating attachment development does not necessarily cause the child to replace his/her challenging behaviour by more adaptive behaviour.

Phase 2 aims at acquiring new, desirable behaviour as a substitute for undesirable behaviours (as represented in Sketch 4), such as pinching, banging, hitting, kicking, screaming, that still stand in the way of functioning in a group and building up relationships with the daily caregivers. Together with the educators/caregivers the situations in which challenging behaviour occurs are mapped by analysing what precedes the challenging behaviour and what consequences the behaviour has for the child (Antecedent-Behaviour-Consequent [ABC] Analysis; Northup et al. 1991, 1994; Sigafoos & Meikle, 1996). This analysis focuses on daily situations in the living environment of the child, for example during leisure time, during moments of social interaction or during daily care situations. This analysis results in a hypothesis regarding the function or significance of the undesirable behaviour and the consequences that reinforce and maintain that behaviour. This function analysis is repeated for all challenging behaviours (Mace et al., 1986). Once the function/significance of the challenging behaviour is known, alternative/ desirable behaviours with the same function/significance for the child are looked for in consultation with the daily caregivers. The therapist subsequently tries to get the child to acquire these alternative behaviours. In order to reinforce the desirable behaviour, the therapist uses social rewards through affective touching (pats and hugs), nodding/smiling and compliments (with special attention to intonation). The way in which the desirable behaviour will be taught is worked out in a behavioural therapy protocol. Undesirable behaviour is ignored, or, if the child threatens to harm himself/herself or the therapist, interrupted.

### ***Sketch 4. phase 2: Behavioural therapy***





**Signals that indicate the beginning of the next phase of treatment:**

- New, positive behaviour is being learned.
- Challenging behaviour dies out – disappears.

### **Phase 3: GENERALIZATION AND COMPLETION**

The treatment aims to increase the social interaction between the child and his/her caregivers, and other people in his/her surroundings (as represented in Sketch 5). The chances of social interaction already increase because encouragement of the exploration of materials and playful interactions during the therapy sessions may stimulate the child to explore outside of these sessions. Discovery by the child of the world surrounding him/ her, and his/her own possibilities within that world takes place in phase 1 primarily by means of the therapist's support. This also offers learning opportunities for behaviour that the child can apply outside the sessions as well.

***Sketch 5. fase 3: Generalization and completion***



The daily educators/caregivers play an important role in the generalization, because the way they offer materials, activities and contact opportunities has to tie in with the child's development during therapy. The gradual reduction of psychotherapy is therefore accompanied by the supervision of the interaction between the educators/caregivers and the child in his/her daily environment. In this context the following guidelines are followed:

- Therapist – Child: There is a gradual reduction from three times a week, to first once a week, then twice a month and then once a month. This reduction depends on the way the child reacts. It is important that the reduction of therapy sessions and length of treatment take place gradually.
- Educators/Caregivers – Child: The psychotherapist uses his/her knowledge about the child to support the daily caregivers/supervisors in communication, in offering clarity, predictability and stimulation. Toys, music and other materials that tie in with the new development of playing are selected together with the caregivers/supervisors, in order to keep stimulating this development.
- Therapist – Educators/Caregivers: The therapist gradually passes the responsibility for the reinforcement of the therapeutic effect over to the daily educators/caregivers. The therapist also makes it clear that he/she is available for support and advice.

**Completion of treatment:**

- A transfer has taken place from the therapist to the parents and educators/caregivers.
- The caregivers encourage the child to continue developing.

***Role of the surroundings***

The therapy is offered for about 1 year in the child's home. The child's caregivers are expected to give the child food and drink in advance and to 'take care' of the child after treatment; that is to say, eat or undertake some other relaxing activity, because the therapy is very intensive (no food or drink is offered during the therapy).

During the last phase of treatment the therapist gives supervision to the educators/ caregivers in order to support them in developing their relationship with the child. This is possible at this point in the therapy because the child accepts contact (it is usually not possible at the beginning of treatment). This investment involves engaging in enjoyable activities with the child in order to get better acquainted with the child. In case of a relapse it is important to first look at the way the relationship between caregivers and the child is being developed.

# Appendix A Protocol 'Integratieve Therapie voor Gehechtheid en Gedrag' (ITGG)

uit: Sterkenburg, P.S. & Schuengel, C. (in druk). Behandelprotocol 'Integratieve Therapie voor Gehechtheid en Gedrag' (ITGG). In: C. Braet & S. Bögels (red.), *Protocollaire behandelingen voor kinderen en adolescenten*. Meppel: Boom. Met toestemming van de uitgever deels opgenomen in dit werk. De volledige tekst van bovengenoemd hoofdstuk biedt uitgebreide informatie en illustraties.

Dankwoord

De schetsen zijn gemaakt door kunstenaar Lida de Zeeuw [www.lidaline.com](http://www.lidaline.com)

## Inleiding

Voorafgaand aan de behandeling worden alle ouders/begeleiders aan de hand van de DVD 'Gehechtheid: een psychotherapeutische behandeling' ([www.bartimeus.nl](http://www.bartimeus.nl)) geïnformeerd over ITGG. Vervolgens worden afspraken gemaakt over het aanbieden van de behandeling: drie uur per week op de plaats waar het kind zijn/haar dag doorbrengt (= op de woning of binnen dagbesteding). Tenslotte worden afspraken gemaakt met betrekking tot een maandelijks overleg om het verloop van de behandeling te bespreken.

ITGG is een gefaseerde behandeling, waarbij elke fase een specifieke functie heeft, en afhankelijk is van succes in de voorgaande fase. Aanvankelijk tracht een psychotherapeut/ gz-psycholoog door middel van intensief contact (opnieuw of voor het eerst) een gehechtheidsrelatie op te bouwen met het kind. Deze eerste fase van de behandeling is opgebouwd uit drie subfasen namelijk: 'bonding en contact maken', 'symbiose' en 'stimulatie tot individuatie'. Omdat het niet te verwachten is dat alleen gehechtheid de probleemgedragingen doen verdwijnen volgt fase 2 met gedragstherapie. Tijdens de derde fase, generalisatie en afronding, wordt het netwerk van relaties uitgebreid en neemt de therapeut steeds meer een plek op de achtergrond in. De behandeling wordt drie uur per week, uren verspreid over de week, in de dagelijkse leefomgeving van het kind aangeboden. Wel wordt gezocht naar een plaats waar het veilig en prettig voelt voor het kind, met weinig omgevingsgeluiden. De totale duur van de behandeling kan tot een jaar zijn.

## Fase 1. GEHECHTHEIDSTHERAPIE

### Fase 1.1: BONDING – CONTACT MAKEN

In de eerste fase van de behandeling zijn de twee belangrijkste aspecten: *sensitieve respons* en *'inciting' respons*. Aanvankelijk is het kind afwijzend en/of biedt weerstand tegen of vermijdt het contact. De therapeut reageert hierop door heel sensitief te zijn en het tempo van het kind te volgen. De therapeut volgt de gedragingen van het kind en past zich daarbij aan (is het kind rustig – reageert de therapeut op een rustige wijze, is het kind druk – reageert de therapeut ook druk). De therapeut gaat bijvoorbeeld het ritme waarin het kind beweegt spiegelen om als het ware op dezelfde golflengte te komen als waarop het kind is. Ook het herhalen van de geluiden die het kind maakt kan het kind geruststellen.

Het tactiele contact begint bij het respecteren van de afstand waarbij het kind zich gemakkelijk voelt. Dat wil zeggen: aanvankelijk wordt de fysieke afstand tot het kind bepaald door het kind. Indien het kind op schoot wil dan wordt het kind op schoot genomen indien het kind afstand wil, dan houdt de therapeut afstand (zoals te zien in Schets 1). De afstand tussen therapeut en kind is een afstand waarbij het kind zich comfortabel voelt.

### **Schets 1. fase 1.1: Bonding – Contact maken**



De therapeut gaat vervolgens het lichamelijke contact langzaam opbouwen. Beginnend bij heel licht aanraken op een plaats waar het kind dat accepteert, bijvoorbeeld een schouderklopje, een aai over een hand of een voet. Eerst de puntjes van de vingers en vervolgens met de hele hand. Eerst alleen een paar seconden opbouwend naar een minuut tot een aantal minuten. De aanraking sluit aan bij de bewegingen van het kind, dat wil zeggen: indien het kind beweegt, beweegt de therapeut zijn/haar hand mee. De therapeut beweegt mee met het ritme van het kind.

De therapeut is alert op het signalen van eigen gevoelens en grenzen. Belangrijk is om deze grenzen na het therapeutische contact tijdens intervisie te benoemen en te verwerken. Tijdens therapie staat het kind centraal. Het kind wordt geboden wat hij/ zij nodig heeft. Bijvoorbeeld indien het kind op schoot wil, dient hij/zij zijn/haar eigen gevoelens als therapeut te signaleren (hoe voelt de therapeut zich in deze situatie) om vervolgens het kind wel te bieden wat nodig is om contact te maken, dat wil zeggen wel het kind op schoot nemen. Grenzen zijn er ten aanzien van doelbewust seksueel gedrag.

De therapeut benoemt en verwoordt wat hij/zij ziet, wat er gebeurt en wat er gaat gebeuren. Er wordt zacht gesproken op een herhalende, melodieuze en vragende wijze (net als het praten met een baby). De therapeut is heel alert, niet alleen pratend maar ook luisterend en wachtend op reacties van het kind. De therapeut verwoordt de mogelijke gevoelens van het kind.

Langzaam gaat de therapeut meer initiatieven nemen. De therapeut vergroot de bewegingen die het kind maakt zodat uiteindelijk het gehele lichaam wordt gebruikt tijdens bewegingen. Ritmische bewegingen en taalgebruik nemen toe. Er wordt aandacht besteed aan speelsheid in de relatie bijvoorbeeld door variatie in stemgebruik (hard - zacht, hoog - laag, snel - langzaam).

Gedragsproblemen worden niet afgestraft. Krabt of bijt het kind, dan reageert de therapeut met een troostende en geruststellende stem door bijvoorbeeld te zeggen: “stil maar”, “rustig”, “het is goed”, “shu- shu- shu”. Indien het kind wegloopt wordt hij teruggebracht naar de ruimte waarin de therapie sessies plaatsvinden. Dit gebeurt met een rustige stem, duidelijk en concreet zeggend wat de bedoeling is.

Er wordt gezocht naar plezierige momenten en die worden zo lang mogelijk benut met inachtneming van rustmomenten. Tijdens deze sessies vinden de alledaagse activiteiten zoals eten of drinken niet plaats.

**Signalen die duiden op het ingaan van de volgende fase van behandeling:**

- Er is contact. Contact kan worden verbroken en heropend en dit contact is een contact van “ik” en “jij”. Tijdens de sessies wordt steeds vaker en langer ‘samen’ bewogen en ‘samen’ gespeeld. Er is niet langer sprake van spelen ‘naast’ elkaar maar er is sprake van ‘samen’ spel.
- Bij observatie is duidelijk dat de therapeut en het kind samen bewegen en samen spelen, het is als het ware alsof één persoon wordt geobserveerd.
- Wanneer de symbiose wordt verbroken zoekt het kind uit zichzelf weer contact met de therapeut.
- Tijdens de sessies wordt het tempo van het kind gevolgd.
- De therapie sessies zijn plezierig.

**Fase 1.2: SYMBIOSE - VEILIGE GEHECHTHEID**

De therapeut stimuleert het opbouwen van een symbiotische relatie door het gedrag en de geluiden/woorden van het kind te imiteren. Complete synchroniciteit wordt bereikt als de therapeut het gedrag van het kind heeft leren anticiperen. Dit wil zeggen: de therapeut beweegt mee met het kind in de richting waarin het kind, naar verwachting, zal bewegen (zie Schets 2). Tijdens de therapie verwoordt de therapeut wat het kind doet, maar ook wat het kind mogelijk voelt en denkt.

## **Schets 2. fase 1.2: symbiose – veilige Gehechtheid**



De therapeut zorgt ervoor dat er bepaalde rituelen tijdens de therapie tot stand worden gebracht. Dit kan zijn een ritueel tijdens een interactief spel zoals “er komt een muisje aangelopen...”. De spelletjes worden voorspelbaar. Aanvankelijk is de therapeut de initiator en later reageert de therapeut op het kind die zelf aangeeft bepaalde spelletjes te willen doen. De therapeut is afwachtend en het lijkt dan net alsof de symbiose (het spiegelen/één zijn) wordt doorbroken. Hierdoor wordt het kind uitgelokt om initiatief te nemen en nog duidelijker aan te geven wat zijn/haar wensen zijn. Bijvoorbeeld als het ontstane ritueel een bewegingsspel is, kan de therapeut op een gegeven moment inschatten wat het kind wil, namelijk de hand van de therapeut op een bepaalde wijze vasthouden. De therapeut begint het spel maar doet net alsof ze niet begrijpt wat het kind wil. De symbiose wordt hierdoor iets verbroken (dit roept spanning op). De therapeut vraagt aan het kind wat hij/zij wil. Dit stimuleert het kind om extra moeite te doen om aan te geven wat hij/zij wil. De therapeut zorgt vervolgens weer voor het tot stand komen van een symbiose door te doen wat het kind prettig vindt (dit roept dan weer ontspanning op).

Er ontstaat nu een spel – “in tune / out of tune” -- dat iedere keer eindigt met “in tune”. De symbiotische uitgangssituatie draagt bij het vertrouwen waarmee het kind eigen initiatieven kan gaan nemen. De positieve reactie hierop van de therapeut beoogt bij te dragen aan een gevoel van acceptatie.

Tijdens deze fase kan het kind zich zo verbonden voelen met de therapeut dat hij/zij het vervelend vindt als de therapie sessie is afgelopen. Het kind kan dit laten merken door de therapeut vast te houden. Wanneer dit gedrag zich voordoet, benoemt de therapeut het gedrag en de mogelijke gevoelens van het kind. Vervolgens geeft de therapeut duidelijk aan wanneer de volgende therapie sessie

zal plaatsvinden en wanneer dus het kind weer contact met de therapeut zal hebben.

Er kan ook agressie zijn bij hereniging. Het gedrag van de therapeut kan door het kind immers makkelijk ervaren worden als ambivalent, wat leidt tot afstoten en vasthouden. De agressie kan daarom worden gezien als een 'roep' om contact en het is juist belangrijk om op zo een moment heel sensitief te zijn voor de gevoelens van het kind. Ook hier worden de gevoelens van het kind benoemd en de therapeut blijft heel dicht bij het kind; de therapeut biedt het kind contact aan.

**Signalen die duiden op het ingaan van de volgende fase van behandeling:**

- Er is een symbiose en deze symbiose kan worden verbroken en weer worden hersteld. Er is een "wij" situatie.
- De lichamelijke afstand tussen het kind en de therapeut is klein en er is samenspel. Tijdens de observatie wordt als het ware 'één' persoon geobserveerd (twee personen die samen één zijn).
- Er is voorspelbaarheid in de therapie.
- Het kind neemt zelf initiatief voor het starten van momenten van samenspel.
- Het spel verplaatst zich van een gerichtheid naar binnen naar een gerichtheid naar buiten – naar de omgeving. Het kind begint op de initiatieven van de therapeut te reageren door bijvoorbeeld het aangeboden speelgoed aan te nemen en even met de speelgoed te spelen.

## **Fase 1.3: STIMULATIE TOT INDIVIDUATIE**

Het zonder angst kunnen verbreken en herstellen van het contact is alleen mogelijk wanneer het kind besef heeft van continuïteit van de relatie, ongeacht de onderbrekingen in het contact. Persoonspermanentie (het besef dat specifieke personen ook bestaan als ze tijdelijk niet kunnen worden waargenomen) is hiervoor een belangrijke cognitieve voorwaarde. In sommige gevallen gaat het leren van persoonspermanentie hand in hand met het leren van objectpermanentie. Het kind moet leren dat speelgoed kan worden teruggevonden (gebruik van tastzin), omdat speelgoed niet weg is als het valt of ergens anders ligt. Wanneer het kind *meer* (niet altijd en meestal nog met veel aanmoediging) uit zichzelf het speelgoed pakt, betekent dit dat er een ontwikkeling is in de richting van objectpermanentie. Bij mensen met een matige tot ernstige verstandelijke beperking vraagt het leren van objectpermanentie continue herhaling en creativiteit binnen de therapie. In deze fase zal het kind vanuit een veilige relatie meer durven doen, meer durven exploreren en verkennen (zoals te zien in Schets 3). Er is een heen en weer bewegen: weg van de therapeut en zelf met spel/speelgoed bezig zijn en vervolgens weer terug bewegen naar de therapeut.



### **Schets 3. fase 1.3: stimulatie tot individualie**



De therapeut stimuleert het kind om eigen verlangens en gevoelens te gaan uiten. De therapeut doet dit door de initiatieven van het kind aan te moedigen en door tegemoet te komen aan deze wensen. Het doel van het stimuleren van het uiten van eigen verlangens en gevoelens is gericht op het ontwikkelen van een 'ik' of 'ego'. Het is belangrijk om te reageren op wensen zoals bijvoorbeeld dat het kind naar bepaalde muziek wil luisteren of aangeeft op een bepaalde plaats te willen zitten.

Het uiten van verlangens en gevoelens is een teken dat het kind langzaam een interne representatie van de omgeving en de therapeut ontwikkelt. Wanneer het kind deze interne representatie ontwikkelt kan het kind kortdurende scheiding beter verdragen. Het kind kan leren om gehechtheidsfiguren op te zoeken wanneer hij/zij zich angstig voelt. Dat het kind zich daardoor zekerder gaat voelen, kan onder andere blijken uit vermindering van de wens om langdurig contact te hebben, zoals bij het op schoot zitten.

#### **Signalen die duiden op het ingaan van de volgende fase van behandeling:**

- Het kind neemt regelmatig initiatieven tot spel met speelgoed/objecten.
- Er is geen symbiose meer maar wel samenspel, er wordt samen gespeeld met spelmaterialen.
- Het kind exploreert de omgeving en spelmateriaal.
- Het kind geniet van nabijheid maar geniet ook van spel samen en naast de therapeut.
- Indien de therapeut de kamer verlaat speelt het kind even alleen en herstelt vervolgens het contact gemakkelijk wanneer de therapeut terug keert.

## Fase 2: GEDRAGSTHERAPIE

De relatie die de psychotherapeut heeft opgebouwd met het kind kan worden ingezet om de behandeldoelen te halen. Het stimuleren van de gehechtheidsontwikkeling hoeft immers niet te betekenen dat het kind als vanzelf zijn probleemgedrag verruilt voor meer adaptief gedrag.

Fase 2 is gericht op het aanleren van nieuw gewenst gedrag als vervanging voor de ongewenste gedragingen die het functioneren in groepsverband en het opbouwen van relaties met de dagelijkse opvoeders nog in de weg staan, zoals knijpen, bonken, slaan, schoppen, schreeuwen. Met de opvoeders/begeleiders worden de situaties in kaart gebracht waarin het probleemgedrag zich voordoet, door te analyseren wat aan het probleemgedrag vooraf gaat en welke gevolgen het gedrag heeft voor het kind (Antecedent-Behavior-Consequent [ABC] analysis; Northup et al. 1991, 1994; Sigafos & Meikle, 1996). Deze analyse richt zich op dagelijkse situaties in de leefomgeving van het kind, bijvoorbeeld tijdens vrije tijd, tijdens sociale interactie momenten of tijdens dagelijkse verzorging. Deze analyse leidt tot een hypothese omtrent de functie of betekenis van het ongewenste gedrag en de gevolgen die het gedrag bekrachtigen en in stand houden. Voor alle probleemgedragingen wordt de functieanalyse herhaald (Mace et al., 1986). Wanneer de functie/betekenis van het probleemgedrag bekend is worden alternatieve/gewenste gedragingen met dezelfde functie/betekenis voor het kind gezocht, in overleg met de dagelijkse opvoeders. Vervolgens richt de therapeut zich op het aanleren van deze alternatieve gedragingen (zoals te zien in Schets 4). Voor de bekrachtiging van het gewenste gedrag gebruikt de therapeut sociale beloning door middel van affectieve aanrakingen (klopjes en knuffels), knikken/glimlachen en complimenten (met speciale aandacht voor intonatie). Hoe het gewenste gedrag zal worden aangeleerd wordt in een gedragstherapieplan uitgewerkt. Ongewenst gedrag wordt genegeerd, of als het kind zichzelf of de therapeut dreigt te beschadigen, tegengehouden.

### Schets 4. fase 2: Gedragstherapie



**Signalen die duiden op het ingaan van de volgende fase van behandeling:**

- Nieuw positief gedrag is aangeleerd.
- Probleemgedrag dooft uit – verdwijnt.

### **Fase 3: GENERALISATIE EN AFRONDING**

De behandeling beoogt een toename van sociale interactie tussen het kind en zijn/haar opvoeders, en andere mensen in zijn/haar omgeving (zoals te zien in Schets 5). De kansen op sociale interactie nemen al toe, doordat het ondersteunen van exploratie van materialen en speelse interacties tijdens de therapiesessies stimulerend kan werken op exploratie buiten deze sessies. Het ontdekken van de wereld om het kind heen en van de eigen mogelijkheden in die wereld gebeurt in fase 1 primair door ondersteuning van de therapeut, en biedt leermogelijkheden voor gedrag dat het kind ook buiten de sessies kan toepassen.

**Schets 5. fase 3: Generalisatie en afronding**



De dagelijkse begeleiders/opvoeders spelen een belangrijke rol in de generalisatie, omdat zij met het aanbieden van materialen, activiteiten en contactmogelijkheden moeten aansluiten bij de ontwikkeling van het kind tijdens de therapie. Het afbouwen van de psychotherapie gaat daarom gepaard met het begeleiden van de interactie tussen de opvoeders/begeleiders en het kind in zijn of haar dagelijkse omgeving. Hierbij worden de volgende richtlijnen aangehouden:

- Behandelaar – Kind: Er is een geleidelijke afbouw van 3 keer per week naar eerst 1 keer per week, vervolgens 2 keer per maand en daarna 1 keer per maand. De afbouw is afhankelijk van hoe het kind reageert. Voorop staat een geleidelijke afbouw.

- Opvoeders/begeleiders – Kind: De psychotherapeut gebruikt zijn of haar kennis van het kind om de dagelijkse opvoeders/begeleiders te ondersteunen in communicatie, in het bieden van duidelijkheid, voorspelbaarheid en stimulatie. Samen met opvoeders/begeleiders wordt gezocht naar speelgoed, muziek en materialen die aansluiten bij de nieuwe ‘spel’ontwikkeling, om deze te blijven stimuleren.
- Behandelaar – Opvoeders/begeleiders: De behandelaar draagt de verantwoordelijkheid voor het bestendigen van het therapie-effect geleidelijk aan over aan de dagelijkse opvoeders/begeleiders. De behandelaar maakt daarnaast duidelijk dat hij of zij beschikbaar is voor ondersteuning en advies.

#### **Afsluiting van de behandeling:**

- Er heeft overdracht plaatsgevonden van de behandelaar naar de ouders en begeleiders.
- De begeleiders stimuleren het kind tot verdere ontwikkeling.

#### ***Rol van omgeving***

De therapie wordt over een periode van ongeveer 1 jaar op de woning van het kind aangeboden. Van de omgeving wordt verwacht om het kind van te voren eten/drinken te geven en na afloop van de behandeling ‘op te vangen’. Met andere woorden om dan te gaan eten of een andere ontspannende activiteit te doen, juist omdat de therapie zo intensief is (tijdens de therapie wordt geen eten/drinken aangeboden).

Bij de laatste fase van de behandeling geeft de therapeut interactiebegeleiding aan de opvoeders/begeleiders om hen te ondersteunen bij het verdiepen van de relatie met het kind. Op dit moment in de therapie is dit mogelijk omdat het kind open staat voor contact (dit is bij de start van de behandeling meestal niet mogelijk). Deze investering houdt in dat zij plezierige activiteiten met het kind ondernemen om het kind beter te leren kennen. Mocht er sprake zijn van een terugval, dan is het belangrijk dat er eerst wordt gekeken naar de wijze waarop er invulling wordt gegeven aan de relatie die begeleiders met het kind hebben.

# **Appendix B Observatie-instrument voor gehechtheidsgedrag (OIG)**

(OBSERVATION INSTRUMENT FOR ATTACHMENT BEHAVIOUR IN DUTCH)

Authors: Sterkenburg, P.S., Janssen, C.G.C., Vlek, L., Peeters, S., Molenaar, M.,  
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## Introduction

This observation instrument aims to measure the frequency, duration and intensity of attachment behaviour of clients during the ITAB. Independent observers score attachment behaviour based on the Strange Situation Procedure (Ainsworth et al., 1978) and use the Noldus computer software ('The Observer', Noldus Information Technology, Wageningen, the Netherlands). The instrument will be described in Dutch.

## Doel

Het doel van het observatie-instrument is het meten van frequentie, duur en intensiteit van gehechtheidsgedrag van cliënten tijdens de ITGG met behulp van video en met gebruikmaking van het Noldus computerprogramma ('The Observer', Noldus Information Technology, Wageningen, Nederland).

## Ontwikkeling

Het observatie-instrument is gebaseerd op de beoordelingsschalen voor interactief gedrag van baby's tijdens de Vreemde Situatie Procedure (Ainsworth et al., 1978).

Om de volgende redenen waren aanpassingen noodzakelijk:

- De schalen van Ainsworth betreffen gedrag van baby's.
- De schalen van Ainsworth betreffen gedrag tijdens de Vreemde Situatie Procedure.
- Globale beoordelingsschalen zijn als regel minder gevoelig voor het meten van intra-persoonsveranderingen over de tijd.

Er zijn vier schalen van gehechtheidsgedrag deze zijn: nabijheid en contact zoeken, afwerend gedrag, vermijdingsgedrag en contact handhaven (Ainsworth et al., 1978).

Het gedrag kan aanwezig (score 1) of afwezig (score 0) zijn. Ainsworth et al. (1978) onderscheiden vier dimensies waarop gehechtheidsgedragingen kunnen variëren:

(1) mate van activiteit en initiatief van het gedrag, (2) promptheid van het gedrag, (3) frequentie van het gedrag, (4) duur van het gedrag.

De categorieën 2, 3 en 4 worden gemeten door de aanwezigheid of afwezigheid van het gedrag te registreren door middel van event coding, waarbij het start- en stopmoment van elk gedrag wordt vastgelegd en de tijdsduur wordt geregistreerd.

Activiteit en initiatief worden door de observator beoordeeld. In het observatie-instrument wordt met uitzondering van 'Contact handhaven van de cliënt naar de therapeut' voor iedere categorie een uitgebreide beschrijving van gedragingen gegeven. 'Contact handhaven van de cliënt naar de therapeut' wordt als volgt

gescoord: het tijdsinterval van de score op schaal 1 (Nabijheid en contact zoeken) vanaf het moment dat de therapeut aangeeft dat zij de sessie gaat beëindigen tot wanneer de therapeut niet langer op de video te zien is.

## Schaal 1: Nabijheid en contact zoeken door de cliënt naar de therapeut.

### Algemene informatie

- De gedragingen die voor de schaal 'Nabijheid en contact zoeken door de cliënt naar de therapeut' gescoord worden zijn gedragingen die niet neutraal van aard zijn. Bij het gedrag van de cliënt wordt gekeken naar de actie die de cliënt onderneemt en er wordt gescoord op het moment van actie. Het initiatief ligt bij de cliënt en mag volgen op een actie van de therapeut. Wanneer deze actie ondernomen blijft worden, blijft de score aanhouden. Een actie eindigt wanneer de cliënt zich terugtrekt uit een actie of wanneer de cliënt zijn lichaam laat rusten (geen actie onderneemt). Een actie blijft een actie wanneer de cliënt aan een stuk doorbeweegt.

#### Voorbeelden

- |  |
|--|
| <ul style="list-style-type: none"><li>• De cliënt beweegt de armen van de therapeut heen en weer, dit wordt als een doorlopende actie gezien en doorgescoord.</li><li>• De therapeut gaat naast de cliënt zitten en de cliënt onderneemt hierbij geen enkele actie, de score blijft 0.</li><li>• De cliënt gaat op schoot of in spreidzit bij de therapeut zitten en blijft hier zitten. Er wordt gescoord op het moment dat de cliënt gaat zitten, er wordt teruggescoord op het moment dat de cliënt zijn lichaam laat rusten.</li></ul> |
|--|
- 'Spreidzit van de therapeut'. Hieronder wordt verstaan: de cliënt gaat tussen de benen van de therapeut zitten, waarbij een aanzienlijk deel van het lichaam van de cliënt (tenminste de romp) zich tussen het bekken en de voeten van de therapeut bevindt.
  - Als aan gedrag geen duidelijke score verbonden kan worden of bij twijfel wordt een score 0 toegekend. Ook stereotiep gedrag van de cliënt krijgt de score 0.
  - Onder 'heen en weer bewegen' wordt verstaan: van de ene naar de andere kant bewegen door de cliënt en weer terugkomen naar het beginpunt. Wanneer de cliënt opnieuw vertrekt van dit beginpunt wordt er gescoord. Wanneer de cliënt 'heen en weer' blijft bewegen, dus de actie niet onderbreekt, wordt er doorgescoord.
  - Wanneer naar 'spel' wordt verwezen in score 4 gaat het alleen om 'samenspel'. Wanneer de cliënt in zijn eentje aan het spelen is, wordt dit niet gescoord (score 0).
  - Wanneer er tijdens het intypen van een lage score een hogere score toegekend kan worden, wordt de lagere score vervangen door de hogere score.

**Voorbeelden:**

- De cliënt richt zijn aandacht op de therapeut en pakt direct hierna een voorwerp uit de handen van de therapeut. De score 1 wordt vervangen door score 3.
- De cliënt pakt een voorwerp uit de handen van de therapeut en pakt direct hierna opnieuw een voorwerp uit de handen van de therapeut. De score 3 wordt vervangen door score 4.

- Een ‘rustmoment’ is een moment waarbij de cliënt niet beweegt. Zodra er een rustmoment plaatsvindt wordt er teruggescoord. In de scores wordt gesproken over ‘meer dan eenmaal’. Hieronder wordt verstaan: de cliënt onderneemt herhaaldelijk een actie (dit mogen ook verschillende acties zijn) richting de therapeut, waarbij tussen de acties geen rustmoment plaatsvindt.
- Bij spel (score 4) gaat men er vanuit dat de therapeut het spel start en de cliënt hierin mee gaat of dat de cliënt de therapeut overduidelijk uitnodigt tot spel. We verstaan hieronder het duidelijk aanbieden van een spel door de cliënt in de richting van de therapeut.

**Voorbeelden:**

- De cliënt is aan het spelen en de therapeut gaat hieraan meedoen, is score 0.
- De therapeut is aan het spelen en de cliënt gaat meespelen, is score 4. Bij eenmalige ‘aanraking’ van het spel scoort men score 3.

- In de scores wordt gesproken over ‘oriënteren op’. Hiermee wordt bedoeld dat de cliënt zijn gezicht richting de therapeut draait. Hierbij hoeft de cliënt met een visuele beperking niet precies gericht te zijn op het gezicht van de therapeut.
- Duidelijk grijpen, knijpen en slaan door de cliënt worden gescoord in schaal 3 ‘Afwerend gedrag van de cliënt naar de therapeut’.

**Score 0: Geen nabijheid en contact zoeken door de cliënt naar de therapeut.**

Activiteit: De cliënt zoekt geen nabijheid en geen lichamelijk contact, ook niet via een voorwerp. De cliënt neemt geen initiatief om dit contact of deze nabijheid te zoeken.

**Voorbeelden:**

- De cliënt zit naast de therapeut en richt zich hierbij niet op de therapeut.
- De cliënt raakt de therapeut aan, terwijl de cliënt zich verplaatst.



**Score 1: Minimaal lichamelijk of via een voorwerp nabijheid en contact zoeken door de cliënt naar de therapeut.**

Activiteit: De cliënt oriënteert zich op de therapeut. De cliënt doet minimale moeite om lichamelijk of via een voorwerp nabijheid of contact te zoeken. De cliënt maakt geen beweging om de afstand naar de therapeut te verkleinen of om de therapeut aan te raken.

**Voorbeelden:**

- De cliënt richt zijn aandacht op de therapeut door in de richting van de therapeut te 'kijken'.
- De score wordt doorgescoord zolang de cliënt de therapeut 'aan blijft kijken'/ gericht is op de therapeut.

**Score 2: Zwak lichamelijk of via een voorwerp nabijheid en contact zoeken door de cliënt naar de therapeut.**

Activiteit: De cliënt maakt voorzichtig lichamelijk of via een voorwerp contact of verkleint de afstand tot de therapeut. De cliënt onderneemt voorzichtige pogingen om de afstand naar de therapeut te verkleinen.

**Voorbeelden:**

- De cliënt raakt de therapeut kort (tikje) aan met de handen, voeten, andere lichaamsdelen of via een voorwerp.
- De cliënt gaat naast de therapeut zitten zonder dat er daadwerkelijk lichamelijk contact is.
- De cliënt reikt zijn hand in de richting van de therapeut.

**Score 3: Actief lichamelijk of via een voorwerp nabijheid en contact zoeken door de cliënt naar de therapeut.**

Activiteit: De cliënt maakt duidelijk lichamelijk of via een voorwerp contact. De cliënt onderneemt actief actie om daadwerkelijk lichamelijk of via een voorwerp contact te maken.

**Voorbeelden:**

- De cliënt gaat op schoot zitten bij de therapeut. Alleen de actie wordt gescoord, wanneer de cliënt vervolgens blijft zitten wordt er teruggescoord.
- De cliënt gaat tegen de therapeut aanzitten/ liggen/ hangen (ook in spreadzit), waarbij er daadwerkelijk lichamelijk contact is. Alleen de actie wordt gescoord, wanneer de cliënt vervolgens blijft zitten/ liggen/ hangen wordt er teruggescoord.

**Score 4: Zeer actief lichamelijk of via een voorwerp nabijheid en contact zoeken door de cliënt naar de therapeut.**

Activiteit: De cliënt maakt overduidelijk lichamelijk of via een voorwerp contact. De cliënt onderneemt actief actie om de afstand naar de therapeut te overbruggen.

<b>Voorbeelden:</b>
<ul style="list-style-type: none"><li>• De cliënt speelt actief met de therapeut.</li><li>• De cliënt doet uit zichzelf mee met spel.</li></ul>



**Score 3 of score 4**

Bij de volgende voorbeelden blijft de score drie, of gaat over in score 4 zolang de actie aanhoudt:

- De cliënt raak éénmaal of meer dan éénmaal het lichaam van de therapeut aan met de handen of voeten (handje, kusje).
- De cliënt tikt meer dan eenmaal het lichaam van de therapeut aan.\*
- De cliënt raakt éénmaal het lichaam van de therapeut aan met een voorwerp.\*
- De cliënt beweegt/ legt éénmaal de hand van de therapeut richting of op het voorwerp.
- De cliënt biedt éénmaal de therapeut een voorwerp aan.\*
- De cliënt klapt éénmaal tegen of frunnikt éénmaal met de handen van de therapeut.\*
- De cliënt pakt een voorwerp uit de handen van de therapeut.\*
- De cliënt aait/ tikt/ raakt éénmaal een voorwerp terwijl de therapeut dit aanbiedt/ vast heeft/ omheeft.\*

Het (meer dan) twee maal scoren van de score 3 met \* (zoals hierboven aangegeven) volgt score 4.

## Schaal 2: Vermijdingsgedrag door de cliënt naar de therapeut.

### *Algemene informatie*

- Het vermijdingsgedrag betreft het bewust niet reageren op de therapeut (score 1) of het op neutrale wijze verbreken van contact (score 2 en 3). Het vermijdingsgedrag van de cliënt kan zich bijvoorbeeld uiten in totaal passief gedrag of geheel opgaan in eigen activiteiten.
- Er is geen sprake van vermijdingsgedrag (score 0) als de cliënt reageert op initiatieven tot contact door de therapeut of als de cliënt zelf initiatief neemt tot contact.

<b>Voorbeelden:</b>
<ul style="list-style-type: none"><li>• Als de cliënt zich toewendt naar de therapeut (score 0).</li><li>• Wanneer de cliënt de therapeut aankijkt of aanraakt (score 0).</li><li>• Als de cliënt het materiaal dat de therapeut aanbiedt accepteert of er naar kijkt (score 0).</li></ul>



- Vermijdingsgedrag is de reactie van de cliënt op initiatief tot (meer) contact door de therapeut. (Initiatieven door de therapeut worden daarom ook gescoord. Vervolgens worden het SPSS-computerprogramma de gedragingen van de therapeut gekoppeld aan het vermijdingsgedrag van de cliënt. Vermijdingsgedrag dat geen reactie op gedrag van de therapeut is, wordt door middel van deze koppeling verwijderd.)
- Wanneer de cliënt niet in beeld is wordt een score 0 toegekend. Indien de therapeut niet in beeld is wordt ook een score 0 toegekend, tenzij de therapeut op verbale/ vocale wijze of via een geluidsvoorwerp contact maakt en de cliënt geen reactie laat zien (vermijdingsgedrag).
- Als aan bepaald gedrag niet duidelijk een score vermijdingsgedrag gegeven kan worden of bij twijfel wordt een score 0 toegekend.

<b>Voorbeelden:</b>
<ul style="list-style-type: none"><li>• Als op de video niet duidelijk zichtbaar is of de cliënt non-verbaal contact zoekt met de therapeut (score 0).</li><li>• Als niet goed zichtbaar is of er sprake is van 'oogcontact' / gericht zijn op de therapeut (score 0).</li></ul>



- Lachen en praten zijn uitingen van contact indien de cliënt gericht is op de therapeut, dit wil zeggen: als de cliënt de therapeut aankijkt of naar de therapeut toegewend is.

- Wanneer de cliënt met de therapeut meeloopt of meespeelt, speelgoed in de richting van de therapeut gooit of aanwijzingen van de therapeut uitvoert, wordt een score 0 toegekend.
- Het kan voorkomen dat wel duidelijk is dat er sprake is van vermijdingsgedrag, maar dat niet duidelijk is welke score toegekend moet worden. Bij twijfel wordt de hoogste score toegekend.

**Voorbeeld:**

- De cliënt zit met zijn handen bij z'n ogen, maar het is niet duidelijk of dit wrijven in zijn ogen (stereotiep gedrag, score 1) of zijn handen voor zijn ogen houden (terugtrekken uit contact, score 2) is. Hierbij wordt een score 2 toegekend.

- Wanneer de cliënt het initiatief tot contact neemt, wordt een score 0 toegekend. De score 0 blijft geldig totdat het contact verminderd of verbroken wordt.

**Voorbeeld:**

- De cliënt biedt zijn hand aan of legt zijn voet bij de therapeut op schoot. De cliënt gaat op schoot zitten bij de therapeut (score 0), blijft hier even zitten (score 0 doorscoren), de therapeut neemt initiatief tot samen bewegen, maar de cliënt gaat van schootaf (score 3).

- Wanneer tegelijkertijd vermijdingsgedrag (bijvoorbeeld stereotiep gedrag) en geen vermijdingsgedrag (bijvoorbeeld hand pakken / vasthouden) vertoond wordt, wordt dat gedrag gescoord dat het meest aanwezig is.

**Voorbeelden:**

- De cliënt pakt de hand van de therapeut en toont stereotiep gedrag (score 0).
- De cliënt laat stereotiep gedrag zien en houdt passief de hand van de therapeut vast (score 1).

- Als de therapeut initiatief neemt tot contact en de cliënt hierop in gaat, wordt een score 0 toegekend. Indien de cliënt hier niet op ingaat, volgt een score 1, 2 of 3.

**Voorbeelden:**

- De therapeut biedt speelgoed aan en de cliënt pakt het speelgoed aan (score 0).
- De therapeut beweegt de armen van de cliënt, waarbij de cliënt niet meewerkt (score 1, 2 of 3).

- Het gaat bij vermijding om gedrag dat neutraal en niet uitdagend is. De cliënt laat geen tekenen van boosheid zien. Wanneer de cliënt boos reageert is het gedrag niet neutraal en krijgt het gedrag een score 0. In zo 'n situatie wordt 'Schaal 3: Afwerend gedrag van de cliënt naar de therapeut' gescoord.

**Score 0: Geen vermijdingsgedrag van de cliënt naar de therapeut.**

Activiteit: De cliënt toont geen vermijdingsgedrag en/of geen negerend gedrag ten opzichte van de therapeut. Het contact is positief, afwerend of er is geen sprake van initiatief door de therapeut. De cliënt neemt initiatief tot contact met de therapeut.

**Voorbeelden:**

- De cliënt gaat op schoot zitten bij de therapeut (score 0).
- De therapeut neemt de cliënt mee aan haar hand en de cliënt loopt mee (score 0).

**Score 1: Matig vermijdingsgedrag van de cliënt naar de therapeut.**

Activiteit: De cliënt laat passief gedrag zien, negeert de therapeut of gaat door met zijn eigen activiteit. De cliënt doet bijvoorbeeld niet wat de therapeut van hem vraagt, staart naar de grond of kijkt uitdrukkelijk de andere kant op. In tegenstelling tot afwerend gedrag is de toon van het gedrag neutraal. Er wordt niet direct gereageerd en er is geen reactie op een initiatief van de therapeut.

**Voorbeeld:**

- De therapeut biedt verbaal en non-verbaal speelgoed aan, maar de cliënt reageert niet en blijft wiegen, spelen of gaat door met stereotiep gedrag.

**Score 2: Duidelijk vermijdingsgedrag van de cliënt naar de therapeut.**

Activiteit: De cliënt draait zijn lichaam weg van de therapeut of schuift de andere kant op. Het kan ook zijn dat de cliënt zich wegbuigt, rechtop gaat zitten of overeind komt. Het gaat om kleine verplaatsingen, terugtrekken uit contact of zich afsluiten. Het wegbewegen is kort en het gedrag is neutraal. De cliënt laat door het vergroten van de afstand duidelijk blijken dat hij het contact met de therapeut niet wil aangaan of wil vergroten/versterken. Het gaat hierbij om gedrag dat neutraal en niet uitdagend is en geen tekenen van boosheid laat zien. De acties zijn niet nadrukkelijk, maar subtiel en onopvallend. Na het toekennen van score 2 wordt weer een score 0 toegekend, ongeacht de duur van de actie. Eventueel kan daarna doorgescoord worden met score 1, als de actie overgaat in passiviteit/ niet reageren (zie score 1).

### **Score 3: Ernstig vermijdingsgedrag van de cliënt naar de therapeut.**

Activiteit: De cliënt loopt weg, kruipt de andere kant op of staat op. Het betreft dus vrij grote bewegingen waarbij duidelijk de afstand met de therapeut vergroot wordt en er vrijwel geen mogelijkheden zijn voor contact. De cliënt verplaatst zich weg van de therapeut en gaat met een eigen activiteit beginnen. Het gedrag van de cliënt is neutraal. Na het toekennen van een score 3 moet weer een score 0 toegekend worden, ongeacht de duur van de actie. Eventueel kan daarna doorgescoord worden met score 1, als de actie overgaat in passiviteit/ niet reageren (zie score 1).

#### **Voorbeeld:**

- Wanneer de cliënt de therapeut meeneemt of diens hand blijft vasthouden wanneer hij weg beweegt, vermijdt de cliënt het contact met de therapeut niet. De afstand met de therapeut wordt dan niet vergroot en score 0 wordt daarom toegekend.

## **Schaal 3: Afwerend gedrag van de cliënt naar de therapeut.**

### **Algemene informatie**

- Afwerend gedrag naar de therapeut is een reactie op contact met of initiatief tot contact door de therapeut.
- Als aan bepaald gedrag niet duidelijk een afwerend gedrag score gegeven kan worden wordt een score 0 toegekend. Bij twijfel wordt een score 0 toegekend.

#### **Voorbeelden:**

- Als niet duidelijk is of de cliënt de therapeut wegduwt (score 0).
  - Indien het gedrag een reactie is op geluiden of gebeurtenissen in de omgeving (score 0).
- 
- Wanneer een score 2 wordt toegekend en er volgen meerdere acties uit score 2, dan wordt score 3 toegekend, gevolgd door een score 0 wanneer het gedrag stopt. Indien het bij één actie uit score 2 blijft, wordt 2 doorgescoord totdat het gedrag stopt, dan volgt score 0. Ook als tegelijkertijd verschillende acties beginnen wordt eerst een score 2 toegekend, gevolgd door een score 3.

**Voorbeelden:**

- Meerdere keren slaan, schoppen en gillen (scores 2, 3, 0).
- Een schop gevolgd door slaan en slaan gevolgd door een gil/gillen (scores 2, 3, 0).
- Een schop gevolgd door een rustmoment (scores 2, 0).
- Slaan en gillen begint tegelijk (scores 2, 3, 0).

- Wanneer er sprake is van een rustmoment wordt van score 3 of 2 teruggescored naar 0. Een rustmoment vindt plaats als er drie seconden of langer geen actie heeft plaatsgevonden. Kortere momenten van rust worden dus doorgescored (dit kan ook achteraf in Noldus 'The Observer' nog worden gecorrigeerd).

**Score 0: Geen afwerend gedrag van de cliënt naar de therapeut.**

Activiteit: Er is geen afwerend gedrag van de cliënt naar de therapeut. Er is geen contact tussen de cliënt en de therapeut of het contact is positief of neutraal.

**Score 1: Matig afwerend gedrag van de cliënt naar de therapeut.**

Activiteit: De cliënt maakt zich los van de omarming of het lichamenlijk contact met de therapeut door het maken van een wegduwende beweging. Er is sprake van lichte tekenen van boosheid en licht ongenoegen. Het afwerend gedrag is duidelijk gericht op de therapeut en is niet neutraal maar negatief of boos bedoeld. Bij twijfel wordt een score 0 toegekend. Na het toekennen van een score 1 wordt direct weer een score 0 toegekend, ongeacht de lengte van de actie.

**Voorbeelden:**

- De cliënt slaat de therapeut.
- De cliënt zet zich af tegen de therapeut.
- De cliënt duwt de arm van de therapeut weg (bij vermijdingsgedrag van de cliënt naar de therapeut -score 2- is er bijvoorbeeld sprake van weg bewegen zonder wegduwen).
- Bewegingen die deel uitmaken van chaotisch gedrag waarbij de cliënt verschillende bewegingen door elkaar laat zien en de intentie niet duidelijk is, krijgt score 0.
- Wegduwen van de therapeut kan enige minuten duren, maar wordt slechts éénmaal gescored.

**Score 2: duidelijk afwerend gedrag van de cliënt naar de therapeut.**

Activiteit: De cliënt laat het volgende naar de therapeut gericht gedrag zien: één keer schoppen, slaan, krabben, aan diens haren trekken, gooien, knijpen, één keer gillen (niet huilen), schreeuwen, schelden/vloeken, één keer duwen van de therapeut, één keer wegduwen van door de therapeut aangeboden materiaal. Er is een korte uiting van boosheid door middel van één van de beschreven gedragingen of een poging hiertoe. Er zijn duidelijke tekenen van ongenoegen maar het gedrag is nog wel beheerst.

**Voorbeelden:**

- Druk gedrag (heftig bewegen met de armen en benen) volgend op initiatief tot contact door de therapeut, het gedrag is gericht op de therapeut.

**Score 3: ernstig afwerend gedrag van de cliënt naar de therapeut.**

Activiteit: De cliënt laat de volgende gedragingen zien: schoppen, slaan, krabben, haren trekken, gooien, knijpen, gillen, schreeuwen, schelden/vloeken, wegduwen van de therapeut, wegduwen van door de therapeut aangeboden materiaal. Het betreft hier uitingen van boosheid door middel van een combinatie van een actie en geluid bij de beschreven gedragingen, of meer den één actie zonder tussenpozen. De cliënt is zeer boos en het gedrag kan soms uitmonden in een escalatie.

**Voorbeelden:**

- Twee keer of meer slaan zonder rustmoment (score 3).
- Langdurige geluiden (gillen in plaats van één gil) (score 3).



# **Appendix C Observatielijsten voor het scoren van gedragsproblemen in de dagelijkse woon / leef situatie**

(RESIDENTAL OBSERVATION LISTS FOR CHALLENGING BEHAVIOUR IN DUTCH)

**Observatielijst: A****Datum: ..... Begeleider (dag): ..... Begeleider (avond): .....**

	Schreeuwen. Frequentie	Schreeuwen. Intensiteit 1 (bijna niet te horen) - 10 (heel hard)	Zich slaan. Frequentie	Zich slaan. Intens- iteit 1 (voelde het bijna niet) - 10 (beschadiging van huid)	Begeleiders krabben/ knijpen/ haar trekken. Frequentie	Begeleiders krab- ben/ knijpen/ haar trekken. Intensiteit 1 (voelde het bijna niet) - 10 (bloed)	Fixatie. Frequentie	Onrust. Intensiteit 1 (ontspannen) - 10 (zeer onrustig)
07:30 – 08:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
08:30 – 09:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
09:30 – 10:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
10:30 – 11:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
11:30 – 12:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
12:30 – 13:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
13:30 – 14:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
14:30 – 15:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
15:30 – 16:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
16:30 – 17:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
17:30 – 18:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
18:30 – 19:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
19:30 – 20:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
20:30 – 21:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10

**Observatielijst: B****Datum: ..... Begeleider (dag): ..... Begeleider (avond): .....**

	Huilen. Fre- quentie	Huilen. intensiteit 1 (zacht en even hуilen) - 10 (heel hard en langer dan 30 minuten)	Schreeu- wen / gillen. Frequentie	Schreeuwen / gillen. Intensiteit 1 (bijna niet te horen) - 10 (heel hard)	Zich slaan/ bonken. Fre- quentie	Zich slaan / bonken. Intensiteit 1 (voelde het bijna niet) - 10 (bescha- diging van huid)	Onrust. Fre- quentie	Onrust: intensiteit 1 (paar minuten) 10 (meer dan een 30 uur)	In zichzelf gekeerd. Fre- quentie	In zichzelf gekeerd. Intens- iteit 1 (klein beetje) - 10 (vraagt continu aandacht)
08:00 – 09:00		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
09:00 – 09:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
09:30 – 10:00		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
10:00 – 10:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
10:30 – 11:00		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
11:00 – 11:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
11:30 – 12:00		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
12:00 – 12:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
12:30 – 13:00		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
13:00 – 13:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
13:30 – 14:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
14:30 – 15:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
15:30 – 16:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
16:30 – 17:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
17:30 – 18:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
18:30 – 19:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
19:30 – 20:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
20:30 – 21:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10



**Observatielijst: D**

**Datum:** ..... **Begeleider (dag):** ..... **Begeleider (avond):** .....

	Schreeuwen. Frequentie	Schreeuwen. Intensiteit 1 (bijna niet te horen) - 10 (heel hard)	Zich slaan. Frequentie	Zich slaan. Intens- iteit 1 (voelde het bijna niet) - 10 (beschadiging van huid)	Begeleiders krabben/ knijpen/ haar trekken. Frequentie	Begeleiders krab- ben/ knijpen/ haar trekken. Intensiteit 1 (voelde het bijna niet) - 10 (bloed)	Fixatie. Frequentie	Onrust. Intensiteit 1 (ontspannen) - 10 (zeer onrustig)
07:30 – 08:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
08:30 – 09:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
09:30 – 10:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
10:30 – 11:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
11:30 – 12:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
12:30 – 13:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
13:30 – 14:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
14:30 – 15:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
15:30 – 16:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
16:30 – 17:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
17:30 – 18:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
18:30 – 19:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
19:30 – 20:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10
20:30 – 21:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10

**Observatielijst: E****Datum: ..... Begeleider (dag): ..... Begeleider (avond) .....**

	Schreeuwen Frequentie	Schreeuwen: intensiteit 1 (zacht en even) - 10 (heel hard en langer dan 30 minuten)	Zich krabben en knijpen. Frequentie	Zich krabben en knijpen. Intensiteit 1 (bijna niet te horen) - 10 (heel hard)	Zich slaan/ bonken. Frequentie	Zich slaan / bonken. Intensiteit 1 (voelde het bijna niet) - 10 (bescha- diging van huid)	Onrust. Frequentie	Onrust. Intensiteit 1 (paar minuten) 10 (meer dan een 30 uur)v	Vastklampen. Frequentie	Vastklampen. Intensiteit 1 (klein beetje) - 10 (vraagt continu aandacht)	Oogboren. Frequentie
07:00 – 08:00		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
08:00 – 09:00		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
09:00 – 09:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
09:30 – 10:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
10:30 – 11:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
11:30 – 12:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
12:30 – 13:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
13:30 – 14:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
14:30 – 15:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
15:30 – 16:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
16:30 – 17:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
17:30 – 18:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
18:30 – 19:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
19:30 – 20:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	
20:30 – 21:30		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	

**Observatielijst: F**

Datum: .....

Naam:.....

	Vloeken. Fre- quentie	Huilen. Fre- quentie	Schreeu- wen / gillen. Fre- quentie	Schreeuwen / gillen. Intensiteit 1 (bijna niet te horen) - 10 (heel hard)	Begeleiders slaan/ schoppen. Frequentie	Begeleiders slaan /schoppen. Intensiteit 1 (voelde het bijna niet) - 10 (bescha- diging van huid)	Onrust (time-out). Frequentie	Onrust. Intensiteit 1 (ontspannen) - 10 (zeer onrustig)	Aandacht vragen (bijvoor- beeld aan je hangen). Frequentie	Uitdagend gedrag (Voeten op tafel, natte duim in jouw mond enz). Intensiteit 1 (ontspannen) - 10 (zeer onrustig)
06:30 – 07:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
07:30 – 09:00*				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
09:00 – 09:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
09:30 – 10:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
10:30 – 11:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
11:30 – 12:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
12:30 – 13:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
13:30 – 14:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
14:30 – 15:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
15:30 – 16:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
16:30 – 17:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
17:30 – 18:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
18:30 – 19:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
19:30 – 20:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10
20:30 – 21:30				1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10		1 2 3 4 5 6 7 8 9 10	Ja / nee	1 2 3 4 5 6 7 8 9 10

\* deze tijd kon niet worden gescoord.





# Samenvatting

(SUMMARY IN DUTCH)

Interveniëren bij stress, gehechtheid en gedragsproblemen: effecten voor kinderen met meervoudige beperkingen

Sommige kinderen met ernstige beperkingen groeien op met zoveel wisselende opvoeders, communicatieve beperkingen, en soms inadequate zorg, dat ze geen gelegenheid krijgen om gehechtheidsrelaties te ontwikkelen. Deze kinderen worden naarmate ze ouder worden steeds moeilijker te bereiken. In hun sociale isolement doet de goed- of afkeuring van hun opvoeders en verzorgers hen nog maar weinig, wat het moeilijk maakt hun gedrag bij te sturen. Hun isolement en achterstand worden daardoor alleen nog maar vergroot. De vraag is wat een wending teweeg kan brengen in de ontwikkeling van deze kinderen. In dit onderzoek stond psychotherapie centraal, meer in het bijzonder een 'Integratieve Therapie voor Gehechtheid en Gedrag (ITGG)', als middel om aan te tonen dat ondanks de slechte start van deze kinderen, het opbouwen van een gehechtheidsrelatie een positief verschil kan maken. Eerst is onderzocht of kinderen met een geschiedenis van pathogene zorg, met een visuele en ernstig verstandelijke beperking en ernstige gedragsproblemen een gehechtheidsrelatie met de therapeut kunnen opbouwen. Vervolgens is onderzocht wat het effect is van ITGG op het gedrag van het kind.

De ontwikkeling van een gehechtheidsrelatie is onderzocht met behulp van fysiologische (PEP, RSA en cortisol) en gedragsmaten, om zodoende de functie van de therapeutische relatie voor stressregulatie te toetsen. Het effect van ITGG is onderzocht door de gedragstherapie gegeven door de experimentele therapeut te vergelijken met de gedragstherapie gegeven door de controletherapeut. Verder is het effect onderzocht door te kijken naar gedragsveranderingen van de cliënt in het dagelijkse leven.

### ***Integratieve therapie voor Gehechtheid en Gedrag (ITGG)***

ITGG is een gefaseerde behandeling, waarbij elke fase een specifieke functie heeft en succes in de volgende fase afhankelijk is van het succes in de voorgaande. In de eerste fase tracht een psychotherapeut/gz-psycholoog door middel van intensief contact (opnieuw of voor het eerst) een gehechtheidsrelatie op te bouwen met de cliënt. Deze eerste fase van de behandeling is opgebouwd uit drie subfasen: 'bonding en contact maken', 'symbiose' en 'stimulatie tot individuatie', de fasen van de ontwikkeling van een gehechtheidsrelatie zoals beschreven door Bowlby (1969/1984). De focus van deze eerste fase is gericht op de ontwikkeling van een gehechtheidsrelatie tussen de cliënt en de therapeut. De gehechtheidsrelatie vormt de basis voor de ontwikkeling van adaptieve affectregulerende vaardigheden. Op initiatief van zowel de cliënt als de therapeut kan fysiek contact voorkomen. Fysiek contact wordt nimmer afgedwongen of opgedrongen (AACAP, 2005). De tweede fase van de integratieve therapie is gericht op gedragsmodificatie, het aanleren van nieuw- en sociaal gewenst gedrag. Tijdens de derde fase, generalisatie, wordt het netwerk van relaties uitgebreid en neemt de therapeut steeds meer een plek op de achtergrond in. Gedurende de dagelijkse zorg wordt tijdens en na deze derde fase door opvoeders/begeleiders steeds geïnvesteerd in de band met de cliënt door gebruik te maken van sensitieve en responsieve

interventies. ITGG wordt in meer detail beschreven in Sterkenburg en Schuengel (in druk); zie voor een korte beschrijving Bijlage 1.

### **Methodes**

*Onderzoeksdesign.* Tijdens fase 1 van de ITGG was de experimentele therapeut erop gericht om een gehechtheidsrelatie met de cliënt op te bouwen. De sessies met de experimentele therapeut alterneerden met de sessies waarin een controletherapeut alleen positieve aandacht gaf. In fase 2 werd door beide therapeuten dezelfde geprotocolleerde gedragstherapie aangeboden. De ontwikkeling van de gehechtheidsrelatie tijdens de ITGG en het effect van de ITGG op het gedrag van de cliënt werden getoetst met behulp van multiple baseline (Hoofdstuk 2 en 4) en multiple case (Hoofdstuk 3) studies. In de single- case studie (Hoofdstuk 5) werden zowel de ontwikkeling van de gehechtheidsrelatie met de experimentele therapeut als het effect van de ITGG beschreven.

*Onderzoeksgroep en selectie.* De zes cliënten die betrokken waren bij dit onderzoek, waren tussen 10 en 18 jaar oud, waren blind of hadden een visuele beperking (volgens de normen van de World Health Organization), hadden een ernstig verstandelijke beperking (IQ tussen 20 en 34) en hadden ernstige hardnekkige gedragsproblemen (zelfverwondend gedrag, agressie of ernstig verstoringend gedrag) blijkend uit een hoge score op het Consensusprotocol Ernstig Probleemgedrag – CEP, Nationaal Ziekenhuisinstituut (Kramer, 2001). In de dossiers moest sprake zijn van gedocumenteerde vroege pathogene zorg, zoals omschreven in de DSM-IV criteria voor reactieve hechtingsstoornis, te weten ernstige lichamelijke of emotionele verwaarlozing, misbruik of mishandeling, of meerdere verbrekingen van primaire opvoedingsrelaties. Medische problematiek werd uitgesloten. Kinderen met de diagnose autisme spectrum stoornis werden uitgesloten, op basis van onderzoek door een onafhankelijke psychiater met ruime ervaring in het diagnosticeren en behandelen van cliënten met visuele en verstandelijke beperkingen. Een contra-indicatie voor de ITGG was tactiele afweer.

Psychologen/(ortho)pedagogen van Bartiméus, een organisatie die zich inzet om de kwaliteit van leven van mensen die slechtziend of blind zijn te verbeteren met persoonlijk advies, ondersteuning en kennisoverdracht, en van het Centrum voor Consultatie en Expertise (CCE) dat advies en ondersteuning biedt aan cliënten met een bijzondere hulpvraag, werden gevraagd om cliënten aan te melden die aan bovengenoemde criteria voldeden. Medisch-ethische goedkeuring werd gevraagd en ontvangen van de Commissie voor Medisch-Ethische Zaken van het VU Medisch Centrum alsook van de Medisch- Ethische Commissie van Bartiméus.

### **De ontwikkeling van de gehechtheidsrelatie tussen cliënt en therapeut**

Zoekt de cliënt, tijdens momenten van stress, troost of steun bij de therapeut? Draagt de relatie bij tot stressregulatie? Om de vraag te beantwoorden of zich tussen therapeut en cliënt een gehechtheidsrelatie ontwikkelt (Hoofdstuk 2) is een

functionele benadering gebruikt: als de relatie tussen de cliënt en de therapeut een gehechtheidsrelatie is, zal de functie ervan zijn dat dan sprake is van stressregulatie (Bowlby, 1969/1997, Schore, 2001a), en zal de cliënt in tijden van stress contact zoeken met de therapeut. De verwachting was daarom dat de cliënten naarmate de therapie vorderde in toenemende mate bij de experimentele therapeut troost of steun zouden zoeken. Verwacht werd dat de cliënten tijdens momenten van stress meer nabijheidzoekend gedrag zouden laten zien naar de experimentele therapeut dan naar de controletherapeut. Voor het scoren van dit nabijheidzoekend gedrag werden observatieschalen ontwikkeld, gebaseerd op de moeder-kind interactie schalen in de Vreemde Situatie Procedure (Ainsworth et al. 1978). Nabijheidzoekend gedrag werd door onafhankelijke beoordelaars, zonder voorkennis voor therapeut en fase van behandeling, gecodeerd met behulp van het Noldus computerprogramma (The Observer, Noldus Information Technology, Wageningen). De videobanden van experimentele en controlesessies werden gescoord en vervolgens werden de momenten van hoge RSA- en PEP-arousal gecombineerd met de scores voor nabijheidzoekend gedrag. De data van de experimentele therapeut werden met de data van de controle therapeut vergeleken.

Tijdens de aanwezigheid van de experimentele therapeut zouden de cliënten tijdens stressvolle situaties ook een betere stressregulatie, en derhalve minder arousal, moeten laten zien (Stevenson-Hinde & Marshall, 1999) dan tijdens de aanwezigheid van de controletherapeut. Met behulp van het VU Ambulatory Monitoring System (VU-AMS: De Geus & Doornen, 1996) werden de parasympathische (Respiratory Sinus Arrhythmia - RSA) en de sympathische (Pre-Ejection Periode - PEP) activiteit geregistreerd. De RSA-data werden gecorrigeerd voor beweging, dit bleek niet nodig te zijn voor de PEP-data.

De resultaten toonden aan dat de cliënten inderdaad significant langere periodes van actief en zeer actief nabijheidzoekend gedrag lieten zien. Ook lieten de cliënten gedurende momenten van hoge RSA- en PEP-arousal meer (zeer) actief nabijheidzoekend gedrag zien naar de experimentele therapeut dan naar de controletherapeut.

Gedurende de gedragstherapie in fase 2 van de ITGG werd er meer van de cliënten geëist hetgeen stressvol was voor de cliënten. Het maakte echter verschil of de experimentele therapeut de gedragstherapie uitvoerde of dat de controletherapeut het deed. Arousal in het sympathische deel van het autonome zenuwstelsel (PEP) nam toe, maar alleen voor de sessies met de controletherapeut. Sympathische arousal was significant lager bij de experimentele therapeut, hetgeen suggereert dat cliënten bij deze therapeut minder de neiging hadden om te vechten of te vluchten. Ook de arousal in het parasympathische deel van het autonome zenuwstelsel was lager, maar dit verschil was net niet significant ( $p = .06$ ).

Deze resultaten laten zien dat de nieuwe therapeutische relatie dezelfde stressregulerende functie had als gehechtheidsrelaties blijken te hebben, bijvoorbeeld tussen ouders en kinderen. Psychofysiologische studies hebben bevestigd dat de aan- of afwezigheid van een primaire gehechtheidsfiguur (biologische of pleegouders) geassocieerd kan worden met de autonome zenuwstelsel (ANS) response, voornamelijk tijdens stressvolle situaties (Gilissen, Koolstra, Van IJzendoorn, Bakermans-Kranenburg, & Van der Veer, 2007; Oosterman & Schuengel, 2007a, b; Stevenson-Hinde & Marshall, 1999; Willemsen, Goossens, Koot, & Schuengel, in druk). Deze studie lijkt de eerste te zijn die soortgelijke resultaten laat zien voor een therapeutische relatie. De therapeutische relatie lijkt daarmee van groot belang voor de behandeling van cliënten zonder een relatie met een gehechtheidsfiguur. Deze onderzoeksresultaten tonen aan dat het ook voor deze kinderen, met meervoudige beperkingen en ernstige gedragsproblemen en zonder gehechtheidsfiguren, mogelijk is om een gehechtheidsrelatie op te bouwen.

Om te onderzoeken of de nieuwe gehechtheidsrelatie vermindering van stress tot gevolg had, is ook de cortisol-dagcurve onderzocht (Hoofdstuk 3). De cortisol-dagcurve werd onderzocht omdat de aanmaak en afbraak van cortisol onderdeel uitmaakt van stressregulatie (Blair, Granger, & Razza, 2005). Immers, onderzoek naar het effect van een integratieve behandeling bij pleegkinderen heeft aangetoond dat deze kinderen aan het eind van de behandeling een meer 'normale' cortisol-dagcurve hadden (Dozier et al. 2002; Fisher et al. 2000). De verwachting was daarom dat aan het eind van de ITGG de cliënten een meer 'normale' cortisol-dagcurve zouden hebben. Hiertoe werden gedurende de hele ITGG eenmaal per maand -vier keer per dag op twee achtereenvolgende dagen gedurende het weekend- speekselmonsters genomen bij alle cliënten in dit onderzoek. Bij de resultaten moet worden aangetekend dat er een hoog percentage 'missing-values' was, omdat het verzamelen van speekselmonsters bij deze cliënten met een visuele en ernstig verstandelijke beperking moeilijk bleek. Zo bood één cliënt zoveel weerstand dat het verzamelen van speeksel moest worden gestaakt. Ondanks deze praktische problemen lieten de resultaten zien dat drie cliënten die bij de start van de ITGG een a-typische dagcurve lieten zien, vervolgens een meer typische/normale dagcurve ontwikkelden met minder extreme maten aan het eind van de ITGG. Wanneer deze maten echter werden vergeleken met tweelingen van 12 jaar (N=180 paren: Bartels et al. 2003), waren de ochtendwaarden significant lager en de avondwaarden significant hoger aan het eind van de interventie. De resultaten suggereren dat de cortisol-dagcurve kan veranderen in reactie op de veranderingen in de omgeving en het functioneren van de cliënt. De lagere cortisolwaarden aan het eind van de interventie bevestigen de eerdere resultaten met betrekking tot RSA en PEP, namelijk dat de ontwikkeling van een therapeutische relatie bijdroeg aan een betere stressregulatie bij de cliënten in deze studie.

### ***Het effect van ItGG op gedrag***

Had gedragsmodificatie door de experimentele therapeut een sterker effect dan gedragsmodificatie door de controletherapeut? En wat was het effect van ITGG op het gedrag van de cliënt tijdens dagelijkse zorgsituaties buiten de therapie? In een serie van single-case studies met alternerende behandelingen voor de cliënten (Hoofdstuk 4) werden deze onderzoeksvragen beantwoord. Gestandaardiseerde instrumenten werden gebruikt om voorafgaand aan de ITGG de gedragsproblemen van de cliënten te bepalen: het Consensusprotocol Ernstig Probleemgedrag (CEP: Kramer, 2001) en de Storend Gedragsschaal voor Zwakzinnigen (SGZ: Kraijer & Kema, 1994). De (pleeg) ouders/ begeleiders van de cliënten registreerden daarnaast dagelijks ieder uur op overzichtelijke en makkelijk beschikbare scoringsformulieren de frequentie van gedragsproblemen op een observatielijst. De wekelijks op video opgenomen sessies voor de experimentele en controle therapeut werden in willekeurige volgorde gecodeerd door onafhankelijke beoordelaars, zonder voorkennis voor therapeut conditie, met behulp van het Noldus computerprogramma (The Observer). Zowel gedragsproblemen (agressie en zelfverwondend gedrag) als adaptief gewenst gedrag werden voor de gedragstherapie sessies (fase 2) gescoord.

De verwachting was dat cliënten aan het eind van de behandeling minder gedragsproblemen zouden laten zien. Verder werd verwacht dat de cliënten tijdens de gedragstherapie gevoeliger zouden zijn voor de sociale beloning door de experimentele therapeut dan door de controletherapeut.

Aan het eind van de behandeling was er inderdaad sprake van minder gedragsproblemen: een significant lagere score op de CEP en voor vier van de zes cliënten een hogere score op de SGZ. Bij niet alle cliënten konden de dagelijkse rapportage van de verzorgers gebruikt worden voor het meten van het beloop van gedragsproblemen. De betrouwbaarheid van de scores was niet altijd voldoende, wat bleek uit lage intraclass correlatiecoëfficiënten tussen de weekgemiddelden voor gedragsproblemen bij twee van de zes cliënten. Voor de vier andere cliënten, zo bleek uit de observatielijsten, was er buiten de therapiesessies met de experimentele therapeut (dus in de zorgsituatie) zelfs al een vermindering van gedragsproblemen gedurende het opbouwen van een gehechtheidsrelatie met de cliënt (fase 1) en vervolgens een verdere vermindering gedurende de gedragstherapie (fase 2). Een belangrijke test was, of de experimentele therapeut effectiever was in het gebruiken van sociale beloningen voor gewenst gedrag dan de controletherapeut. Dat bleek het geval te zijn. Gedurende de gedragstherapie (fase 2) lieten de cliënten significant meer nieuw gewenst gedrag zien gedurende de sessies met de experimentele therapeut dan tijdens de sessies met de controle therapeut. Er was geen significant verschil tussen de experimentele- en de controletherapeut met betrekking tot de al weinig voorkomende vormen van ongewenst gedrag / gedragsproblemen.

Voor deze cliënten, bij wie andere vormen van behandeling niet effectief waren gebleken, liet ITGG dus wel positieve effecten zien. De resultaten tonen aan dat de cliënten meer gewenst nieuw gedrag leerden bij een therapeut die gericht was geweest op het opbouwen van een gehechtheidrelatie dan bij de therapeut die voordien alleen positief aanwezig was geweest (controgetherapeut).

### ***Effect van ITGG op de ontwikkeling van een kind bij wie sprake was van een vastgelopen situatie***

In de single case-study (Hoofdstuk 5) werden de twee onderzoeksvragen, de ontwikkeling van een gehechtheidsrelatie en het effect van ITGG, geïntegreerd om zo antwoord te geven op de vraag of ITGG een wending teweeg kan brengen in de ontwikkeling van een kind bij wie sprake was van een vastgelopen situatie. ITGG werd over een periode van één jaar geboden aan Roy, een 17 jarige blinde jongen met een ernstige verstandelijke beperking (Down Syndroom). Zijn voorgeschiedenis toonde een serie van verbrekings van primaire opvoedingsrelaties in de eerste jaren van zijn leven en daarna, waarmee hij voldeed aan de DSM-IV omschrijving van pathogene omgevingsfactoren voor de ontwikkeling van een reactieve hechtingsstoornis. Eerdere medische en gedragsgerichte interventies hadden hem niet van zijn ernstige en hardnekkige gedragsproblemen af kunnen helpen.

De vier typen gehechtheidsgedrag (nabijheid zoekend -, nabijheid handhavend -, vermijdend - en afwerend gedrag) voor het scoren van moeder-kind interactie in de Vreemde Situatie Procedure (Ainsworth et al., 1978) werden aangepast voor het coderen van gehechtheidsgedrag van de cliënt naar de experimentele therapeut en de controgetherapeut gedurende fase 1 van de ITGG. In willekeurige volgorde werden de experimentele en controle sessies gecodeerd door onafhankelijke beoordelaars, zonder voorkennis voor fase van therapie en behandelconditie. De resultaten toonden aan dat Roy, over de tijd heen, meer nabijheidzoekend gedrag liet zien naar de experimentele dan naar de controle therapeut. Deze resultaten werden ondersteund door de lagere arousal wanneer de gedragstherapie (fase 2) werd aangeboden door de experimentele therapeut, in vergelijking met de controgetherapeut. Gedurende fase 2 werd tijdens de aanwezigheid van de experimentele therapeut het systeem dat betrokken is bij vechten of vluchten (het sympathische deel van het autonome zenuwstelsel) minder geactiveerd. Arousal in het sympathische deel van het zenuwstelsel werd gemeten met behulp van de VU-AMS (De Geus & Doornen, 1996). Verder bleek de experimentele therapeut vergeleken met de controgetherapeut significant meer effect te hebben bij het aanleren van nieuw gewenst gedrag (fase 2). Onafhankelijke beoordelaars, zonder voorkennis voor therapieconditie en fase, codeerden de gedragsproblemen met behulp van het Noldus computerprogramma (The Observer). Over de tijd heen was er een afname van de frequentie en intensiteit van de gedragsproblemen. De frequentie en intensiteit van de gedragsproblemen in de dagelijkse zorgsituatie, zoals iedere uur gescoord door de begeleiders van Roy, volgden dezelfde afname van gedragsproblemen met significante fase-effecten. Dit is een aanwijzing dat

tijdens de therapie sessies bereikte veranderingen tijdens de daaropvolgende week doorwerkten in de dagelijkse zorgsituatie.

Deze resultaten zijn consistent met de theorie dat een gehechtheidsrelatie stress-regulerend is voor cliënten zoals Roy. Indien zij een gehechtheidsrelatie kunnen ontwikkelen met een andere persoon, in deze situatie met een therapeut, is het vervolgens makkelijker om met steun van deze persoon (als 'veilige basis') nieuw gewenst gedrag te leren.

### **Conclusie**

Voor de zorg voor mensen met beperkingen hebben de resultaten van dit onderzoek een aantal belangrijke consequenties. Deze studie bevestigt de plasticiteit van de ontwikkeling van een gehechtheidsrelatie, zelfs bij adolescenten. Het was mogelijk om een affectieregulerende relatie op te bouwen met cliënten met een visuele en ernstig verstandelijke beperking zonder een gehechtheidsrelatie. Verder bleek de op de gehechtheid gebaseerde interventie cliënten met meervoudige beperkingen, met een geschiedenis van pathogene zorg, te helpen om effectief om te gaan met dagelijkse stressvolle situaties. Deze bevindingen werden vastgesteld bij cliënten voor wie in het verleden geen andere therapie of interventie effectief bleek te zijn. Dit wil zeggen dat een relatie die voor de cliënt troost, steun en veiligheid biedt, de cliënt kan ondersteunen in de omgang met stressvolle levensgebeurtenissen. Het is natuurlijk het meest gewenst, als alle kinderen, ook al hebben ze meervoudige beperkingen, van jongs af aan een veilige gehechtheidsrelatie kunnen opbouwen met hun verzorgers en opvoeders. Daar waar nodig, kunnen potentiële gehechtheidsfiguren daarin ondersteund worden. Interventies ten behoeve van gehechtheid komen nooit te vroeg. De resultaten van deze studie geven echter ook aan, dat dergelijke interventies ook op latere leeftijd nog zeer wel mogelijk zijn - en dus als behandelingsalternatief te overwegen.

Een klinische implicatie van deze resultaten is dat, voor het aanleren van nieuw gewenst gedrag, het zinvol kan zijn om te investeren in de relatie met de cliënt voorafgaand aan gedragsmodificatie. Een verdere implicatie is dat een relatie die troost, steun en veiligheid biedt, ook zal helpen bij het omgaan met dagelijkse stresssituaties. Juist voor mensen met meervoudige beperkingen kunnen verhuizingen of andere veranderingen in de dagelijkse leef- of woonsituatie erg stressvol zijn. De reactie op dergelijke stress is vaak probleemgedrag. Het bieden van troost, steun en veiligheid kan dus probleemgedrag voorkomen.

Alleen al het ontwikkelen van een therapeutische relatie die lijkt op een gehechtheidsrelatie deed erg veel probleemgedrag afnemen, dat voorheen resistent was; dit, terwijl nog geen sprake was van de systematische behandeling ervan. Dit is een interessant onderzoeksgegeven. Wellicht kan de hoge prevalentie van gedragsproblemen in de zorg voor mensen met beperkingen ten minste voor een deel afnemen door te investeren in de mogelijkheid tot het aangaan van



vertrouwensrelaties tussen cliënten en hun directe hulpverleners. Het opvoeden en verzorgen van kinderen en volwassenen met meervoudige beperkingen binnen een netwerk van veilige gehechtheidsrelaties, zou daarom een grote bijdrage kunnen leveren aan de geestelijke gezondheid en de kwaliteit van bestaan van deze kwetsbare groep cliënten.



# Dankwoord

(ACKNOWLEDGEMENTS)

‘Ek wil graag vir almal baie, baie dankie sê vir alles wat jul vir mij gedoen en beteken het’...Maar als ik het hierbij zou laten zou ik de mensen die mij hebben begeleid en gesteund, met wie ik een speciale band heb, tekort doen. Daarom onderstaande toevoeging.

Eerst een hartelijk woord van dank aan de cliënten, hun ouders en begeleiders met wie we een korte en veelal intensieve band hadden. Er werd veel van u als ouders en jullie als begeleiders gevraagd: onder andere het bijhouden van de observatielijsten en verzamelen van spreekselmonsters. Bedankt voor de inzet voor en deelname aan dit onderzoek.

Twee gedreven en zeer bekwame wetenschappers, mijn promotor Carlo Schuengel en co-promotor Cees Janssen, hebben mij geïnspireerd tot verdere theoretische verdieping en wetenschappelijke onderbouwing van mijn werk. Ik bedank jullie voor de prettige begeleiding en kritische opmerkingen, ook al betekende dit weer opnieuw beginnen als ik dacht dat ik al klaar was.... Graag neem ik jullie nieuwsgierigheid naar de meest recente wetenschappelijke inzichten en jullie gedrevenheid tot het onderzoeken van eigen inzichten mee in mijn verdere werk als onderzoeker.

Francien Dekker, zowel therapeut als controletherapeut tijdens dit onderzoek. Francien, jou bedank ik hier graag uitdrukkelijk voor jouw inzet, interesse en betrokkenheid. En met Hans Giltaij, hoofd van de afdeling Psychotherapie van Bartiméus, voerden we twee- wekelijks intervisiegesprekken tijdens de behandelingen en was hij ook voorzitter bij een viertal bijeenkomsten met de klankbordgroep. Ik heb me zeer gesteund gevoeld door jullie betrokkenheid en die van onze andere collega's en door de collegialiteit van jullie allen. Leden van de klankbordgroep waren: dr. Clerkx, prof. dr. Došen, drs. Gosenshuis, drs. Gunther, dr. Niezen, en prof. dr. Riksen-Walraven. De kritische opmerkingen vanuit deze vergaderingen waren zeer waardevol. Thera Koopmans, bedankt voor alle secretariële ondersteuning voor deze bijeenkomsten.

Verder hartelijk dank aan Johanna Plug en Hanneke Dirkwager (student-assistenten) en alle studenten, onder andere Pawel Jeczynski, die de afgelopen jaren hebben meegewerkt aan het coderen en verwerken van de gegevens. Ook de betrokkenheid van mijn collega's van de afdeling (Ortho)pedagogiek aan de VU Amsterdam was zeer motiverend. Van harte bedankt voor alle aanmoediging en ondersteuning.

Prof. dr. Cuijpers, prof. dr. Fearon, prof. dr. Juffer, prof. dr. Meininger, prof. dr. Riksen- Walraven, ben ik erkentelijk voor het plaatsnemen in de leescommissie ter beoordeling van mijn proefschrift.

Zonder financiële steun was dit project niet mogelijk geweest. Naast de subsidie van ZonMw-InZicht voor twee jaar van het onderzoek heb ik financiële steun ontvangen van de Vereniging Bartiméus en ZonMw-InZicht voor het implementeren ervan. Daarmee heb ik op een zeer plezierige wijze samen met Jan IJzerman, programmamaker Audiovisuele Dienst van Bartiméus, een DVD met handleiding en e-learningpakket kunnen ontwikkelen met betrekking tot de ITGG (ITAB).

Mijn studentenjaren aan de Noord-Wes Universiteit te Potchefstroom Zuid-Afrika (Potchefstroomse Universiteit vir Christelike Hoër Onderwys) waren de basis voor mijn vorming als 'sielkundige'. 'Baie dankie aan al die docente wat hieraan bijgedra het'.

Dan zijn er nog vele andere belangrijke mensen in mijn leven. Deze relaties kleuren en verrijken mijn leven. Familie en vrienden, bedankt voor jullie belangstelling en betrokkenheid. Mariëlle en Pim, Lennart en Rianne: bedankt voor de vele telefoontjes en kaartjes. Harry, je hebt de nodige vakanties, weekends en avonden 'moeten' lezen en computeren of ging alleen naar ons moeder in het zuiden terwijl ik mijn aandacht op mijn dissertatie richtte. Bedankt voor je liefde en steun.

De voor mij dierbare relaties die ik het langst heb, zijn die met mijn al overleden broer Frits, mijn broer Jaap Jan en mijn zus Elizabeth. Ook al wonen we in andere continenten, jullie voelen steeds heel dichtbij. En omdat niet alle familieleden uit Zuid-Afrika op 3 oktober aanwezig kunnen zijn, noem ik graag jullie namen... zo zijn jullie er toch een beetje bij.. Mathilde, Renier, Louis, Emma, Christo, Christiaan, Gerrit, Marita en Frits.

Het fundament voor het aangaan van relaties is door mijn ouders gelegd en zij hebben mij alle gelegenheid geboden om mij te ontwikkelen. Daarom draag ik deze dissertatie op aan u, Moeks en aan Papa: wat zou hij hebben genoten van dit moment. Bedankt voor uw liefde.



# Curriculum Vitae

Paula Sterkenburg completed her MA in clinical psychology in 1991 at North-West University in Potchefstroom, South Africa. From 1992 to 1993 the focus of her MA study at Utrecht University in the Netherlands was on developmental psychology. Since 1991 she has been working, first as care-giver and later as health-care psychologist and therapist, at Bartiméus, an organization that aims to improve quality of life for blind and visually impaired persons by providing personal advice, guidance and knowhow. Since 2001 she has been lecturing at the VU University of Amsterdam, The Netherlands. In 2002, the VU University and Bartiméus launched a joint project with ZonMW InSight funding. InSight is a Dutch organization which fosters application-oriented research supporting the needs of persons with a visual impairment. This project was the basis for her thesis: An Integrative Therapy for Attachment and Behaviour (ITAB). For her applied research she received the first Award of the Dutch Association of Health Care Providers for People with Disabilities in 2007. She will continue her work at the VU and Bartiméus as researcher, lecturer, health-care psychologist and therapist in the field of care for persons with visual and intellectual disabilities.

Paula Sterkenburg studeerde in 1991 af als 'klinische sielkundige / clinical psychologist' aan de Noord-Wes Universiteit te Potchefstroom in Zuid-Afrika. De focus van haar studie aan de Rijksuniversiteit Utrecht van 1992 tot 1993 was ontwikkelingspsychologie. Zij werkt sinds 1991 eerst als begeleider en later als gz-psycholoog en therapeut bij Bartiméus, een instelling die onderwijs, zorg en dienstverlening biedt aan mensen die slechtziend of blind zijn. Sinds 2001 werkt zij als docent aan de Vrije Universiteit te Amsterdam. Met ZonMW- InZicht subsidie is in 2002 gestart met een Bartiméus-VU project dat de basis vormde voor deze thesis: een 'Integratieve Therapie voor Gehechtheid en Gedrag' (ITGG). Voor haar toegepast onderzoek ontving zij de eerste VGN-Gehandicaptenzorgprijs in 2007. Zij zal haar werk aan de VU en Bartiméus voortzetten als onderzoeker, docent, gz-psycholoog en therapeut in de zorg voor mensen met een visuele en verstandelijke beperking.