

# Parenting of children with a visual impairment



Chair: Paula Sterkenburg

Co-chair: to be appointed.

Dr. Paula Sterkenburg is a licensed psychologist/therapist with Bartiméus' Psychotherapy department in Doorn and Assistant Professor at the Department of Clinical child and Family Studies of the Faculty of Behavioural and Movement Sciences and the EMGO+ Institute for health and care research of the VU University of Amsterdam. The theme of her doctoral research was 'Integrative Therapy for Attachment and Behaviour'. In 2007 she was the recipient of the Award of the Dutch Association of Healthcare Providers for People with Disabilities (*VGN Gehandicaptenzorgprijs*) for the way in which she has succeeded in building a bridge between research and practice. In 2012 the University of Groningen granted her the Han Nakken Award for most remarkable practical accomplishment with the workbook titled 'Developing Attachment'. In 2013 NutsOhra Fund and Vilans Centre she received subsidy for her winning proposal for an APP for parents and caregivers of persons with profound intellectual and multiple disabilities' and in 2015 she was in the top 3 for the VU EMGO+ Societal Impact Award. In 2015 she collaborated in a team from Stichting Nieuwzorg, Vrije Universiteit Amsterdam and Bartiméus, that development of an APP to facilitate the communication between clients and professionals called WhatsUpp. The project won the expert jury award given by ONVZ Care-provider. In 2016 the serious game 'Stop bullying now!' was on the shortlist for the 2016 Award of the Dutch Association of Healthcare Providers for People with Disabilities (*VGN Gehandicaptenzorgprijs*).

## Symposium outline

In this symposium we will focus on recent research in the field of parenting of young children with a visual impairment. First, we will focus on results from a systematic review in which the important aspects of parenting of children with a visual impairment were examined. Most research focused on the themes interaction, intersubjectivity and joint attention, although the themes exploration, play and specific behavior were also covered well. It indicates the importance of evolving interaction as the most important aspect of parenting. Second, the

effects of an intervention study VIPP-V will be presented. In this RCT study 77 parents and children participated. The first effect results will be presented. Third, important aspects in early intervention will be presented with the focus on important aspects in parental support given by professionals for example aspects of being supportive but not intrusive will be discussed. Fourth, parenting of adolescents with visual impairments will be presented. Results showed that parents reported rather positive parenting behavior in adolescence. Eight years later, parents were positive in retrospective reflection on their parenting behavior. The parenting behavior during adolescence had a modest significant positive relation with the level of social functioning of their children in young adulthood.

### **1. Parenting of young children with a visual impairment. Results of a systematic literature review**

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**Introduction:** Secure parent-child attachment may help children to overcome the challenges of growing up with a visual or visual-and-intellectual impairment (VI). Many studies have been conducted on interventions that promote parental sensitivity and secure attachment. The Video-feedback Intervention to promote Positive Parenting (VIPP) has been found to be effective. While it has been adapted to several specific at risk populations, interventions for children with VI may require additional adjustments. This study aimed to identify the themes that should be addressed in adapting VIPP.

**Method:** A Delphi-consultation was conducted with 13 professionals in the field of visual impairment to select the themes for a relationship focused intervention. Interaction, intersubjectivity, joint attention, exploration, play and specific behavior were the themes mentioned in the Delphi-group. These themes were used in the systematic literature search.

Paired with the keywords visual impairment or vision disorders, infants or young children (and their parents) the search yielded 74 articles.

**Results:** Although the themes ‘exploration’, ‘play’ and ‘specific behavior’ were covered well, the main focus was on the themes ‘interaction’, ‘intersubjectivity’ and ‘joint attention’. Accurate perception of and response to the child’s signals is a prerequisite for both parent and child to experience pleasure and meaning in interaction.

**Conclusion:** The focus on these themes indicated the importance of evolving communication between children with visual impairments and their parents and the evolving interaction between these children and their surrounding world. Strong support was found in the literature for the choice of interventions such as VIPP, which focuses on parental sensitivity. Not only are these themes important to incorporate in a version of VIPP for children with visual impairments, they can also be applied more widely to inform effective interventions in parent-child relationships.

## **2. The effectiveness of Video-feedback Intervention to promote Positive Parenting for parents of children with a visual or visual-and-intellectual disability (VIPP-V)**

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**Introduction:** Video-feedback Intervention to promote Positive Parenting - Visual or visual-and-intellectual disability (VIPP-V) is based on Video-feedback Intervention to promote Positive Parenting - Sensitive Discipline (VIPP-SD). It is an attachment-based intervention aimed at enhancing sensitive parenting and adequate discipline strategies of parents. The aim VIPP-V is to promote positive parent-child relationships. VIPP-SD has shown to be quite effective in enhancing parental sensitivity. The aim of this study is to examine the effect of VIPP-V on the parental sensitivity.

**Method:** A randomized controlled trial was conducted to assess the effectiveness of VIPP-V for parents of children aged 1-5 with visual or visual-and-intellectual disabilities. In total 77 parents and their child participated in a pre-, post- and follow-up test. Parental sensitivity and quality of

parent-child interaction was assessed using The National Institute of Child Health and Human Development Scales (NICHD-scales) scored by trained and independent researchers.

**Results:** We will present the results from our study and control the data on parental sensitivity.

**Conclusions:** For parents with a child with a visual-and-intellectual disability parental sensitivity may be challenging. Therefore, the level of intellectual disability of the child may be an important factor in parent-child interaction, and needs be examined.

### **3. Supporting Parents: Early intervention in families with a child with blindness**

*Irma Uijen de Kleijn, Marloes van Oort*

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**Introduction:** Having a child with blindness places parents in an exceptional position. In most cases, they have no frame of reference, which can cause them to be unsure of the future. Parents often receive home-based early intervention from an organization with knowledge and expertise concerning care for children with visual impairments. With the knowledge, parents not only gain information but also a parenting perspective regarding possibilities for their child. However, at the same time parents can perceive the intervention as an invasion of their privacy. The goal of parental support is to create a situation in which, on the one hand, parents maintain control of their lives, while on the other hand professionals share their expertise on parenting of children with visual impairments. This is an admirable goal, however, hard to achieve in practice.

**Method:** In a practical based study, information about early intervention is gathered in three fields. First, interviews with parents from children with blindness have been conducted. Second, meetings were arranged with professionals from centers with expertise in blindness. Finally, an exploratory literature search was conducted.

**Results:** With the information, seven themes were collected in a practical book for professionals. The themes mentioned by parents and professionals are: respectful family support, adequate advising, maintaining professional engagement, coping with mourning, using parents' personal qualities, arranging assessment and the use of video images during early intervention. Another revenue from the study, is a website for parents, which is currently

developed. The website will provide parents access to knowledge available on children with blindness, and will enable them to use the expertise.

**Conclusion:** With this book and website we could realize discussion among professionals and achieve qualitative improvement of the early intervention for families with a child with blindness.

#### **4. A retrospective perspective on parenting behavior and stress: parents and adolescents with visual impairments**

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**Introduction:** In two studies, several factors related to parenting of youth with visual impairment were studied, for example parenting behavior, parenting stress and well-being. Little is known on parenting of adolescents, and studies with multiple datameasurements in time are scarce.

**Method:** In study 1 conducted in 2004, 161 parents of 106 adolescents with visual impairments completed a questionnaire on their parenting experiences. In study 2 in 2012, a group of these parents participated in a retrospective study, looking back at their parenting during their child's puberty. Furthermore, their children also reported during puberty and young adulthood on their psychosocial development using standardized questionnaires.

**Results:** The outcome of these studies showed that parents reported rather positive parenting behavior in adolescence. Their level of parenting stress was not alarming. Some differences between mothers and fathers were found, for example: mothers scored significantly higher on responsiveness, higher on monitoring/knowledge on their child and lower on overprotectiveness than fathers. Few significant differences were found between the parenting behavior (reported by parents) and parenting experienced by their adolescent children. Eight years later, parents were positive in retrospective reflection on their parenting behavior during adolescence. The parenting behavior during adolescence had a modest significant positive relation with the level of social functioning of their children in young adulthood. For example, a strong significant correlation was found between parenting behavior stimulating autonomy during puberty (t1) and higher self-esteem and acceptance of impairment of their young adult child (t2).

**Conclusion:** This study provides new insights into parenting stress and parenting behavior in parents of adolescents with visual impairments, and the determinants that are involved in this. Furthermore, it's one of the first studies to include multiple measurements in time and multiple informants (parents and their (young adult) children).