Chapter 6

General Discussion and Summary
The main aim of this thesis was to tailor and test a video-feedback intervention (VIPP-LD) with the focus on harmonious parent-child interaction and sensitive discipline for parents with intellectual disabilities. Supporting this group of parents in their parenting role might help them to overcome the challenges they are facing and compensate for some of the risks factors that parenting with ID brings. The attachment theory and coercion theory are important in the field of parenting, guiding a focus on enhancing sensitive responsiveness resulting in harmonious parent-child interactions, and on sensitive discipline, with benefits for the child and the parent. Intervention programs based on these two goals have already been proven to be effective for the typical population and several risk populations (Juffer, Bakermans-Kranenburg, & Van IJzendoorn, 2008; in press). The studies reported in this thesis tested if a video-feedback intervention based on these theories and tailored to the needs of parents with ID, could be effective for this group of parents and whether this effect might vary according to factors such as variation in cognitive limitation and adaptive functioning. A subsidiary goal was to investigate if VIPP-LD could alleviate experienced parenting stress of parents with ID. In this chapter we reflect on the main findings and conclusions of the previous chapters of this thesis. Moreover, the strengths and limitations of the study will be addressed and the implications for further research and practice will be considered.

Summary of main findings and conclusions

How do parents with ID respond to video-feedback intervention for positive parenting that is adapted to their needs?

It has already been established that parents with ID can benefit from parent support programs and are able to learn important parenting skills through training and instruction (Feldman, 2002, Feldman, Legér, & Walton-Allen, 1997; Feldman & Tahir 2016; Wade, Llewellyn, & Matthews, 2008). We added the VIPP-LD intervention to the intervention programs that are tested on their effectiveness for parents with ID and extended the group of studies with adapted versions of VIPP-SD for various samples of parents at risk (Juffer et al, in press). Improving sensitivity and disciplining tactics among parents with ID might help parents to improve parenting behaviour resulting in more harmonious parent-child interactions that will be to the benefit of their child. In Chapter 2 we reported on the process of tailoring the video-feedback intervention VIPP-SD. Because of their problems with executive
functions, and the more negative social information processing, consequences for memory and attention problems needed to be tackled and parents needed guidance to comprehend social information in a more positive way. By using results from earlier studies about learning needs of parents with ID (Feldman, 1994, 2004; Feldman & Tahir, 2016; Llewellyn, McConnell, Honey, Mayes, & Russo, 2003; Wade et al., 2008), for example the focus on concrete behaviour in specific settings, the Video-feedback Intervention Positive Parenting for parent with Learning Difficulties (VIPP-LD) was designed.

Involving parents themselves in the adaptation and testing of the intervention was part of the pilot study and helped to tailor this version of VIPP-SD for parents with ID. Consulting parents with ID in the preparation stage also proved useful for improving the informed consent procedure for the study. Adaptations to the intervention protocol involved separating video-recording and video-feedback sessions. In the original versions video-feedback and recording were combined and parents with ID clearly reported that they got mixed up during such a home visit. Other adaptations were: reducing the cognitive load of home visits, repeating information frequently and repeatedly training complex cognitive skills such as taking children's points of view (‘speaking for the child’), focusing on concrete parenting problems identified by the parents themselves, using visual reminders of the video-feedback sessions by composing a personal scrapbook and increasing the level of training and supervision by the professionals. An important ingredient of the VIPP-SD interventions is the use of video and the technique of video-feedback (Juffer & Steele, 2014). Especially for parents with ID, video may compensate for poorer executive functioning that might hinder their learning. By watching video recordings it was easier for parents to repeatedly review what their child was doing and what the parent-child interaction looked like. It helped the parent to take the viewpoint of the child. The benefit of this component of the intervention became very clear in the case study. The mother expressed that for the first time she understood the real intention of her daughter by watching the video recording of a play session. It guided her in the direction of changing her perception and attributions of her daughter's behaviour.

We took special care to ascertain that the VIPP-LD intervention to enhance parental sensitive behaviour was as close to the original VIPP-SD as possible. Also other studies with samples for parents at risk or children at risk made adaptations, but still with the same goal to enhance sensitive parenting tactics in a positive way. For example the VIPP-SD study with children with autism, VIPP-AUTI adapted the themes with special items concerning autism, like joint attention (Poslawsky, Naber, Bakermans-Kranenburg, De Jonge, Van Engeland, & Van IJzendoorn, 2014). The VIPP-SD study concerning Turkish Minority was adapted to cultural diversity, for example by extending the duration of a home visit to 2,5 – 3 hours due to the fact that interveners were expected to engage in social conversation about daily life topics during their visits (Yagmur, Mesman, Malda, Bakermans-Kranenburg, & Ekmekci,
The study for parents with eating disorders used a personal scrapbook for the parents to support the learning in between sessions (Woolley, Hertzmann, & Stein, 2008).

Juffer et al. (2008; in press) mentioned that a trusting relationship between parent and intervener is of paramount importance. Meppelder, Hodes, Kef, and Schuengel (2014) found that those parents who quickly approached professionals for support in difficult child-rearing situations were also the ones who successfully developed a close working alliance. This was especially so when parents had little access to informal support. In a process evaluation the experience of working with the parents during the intervention process was measured by using the logbook data of the home visitors, finding a significant increase in the evaluation scores of the home visitors. During the intervention process parents became easier to work with, more amenable to influence and more open to the intervention. The results were in line with other comparable process evaluations of the VIPP-SD programs (Juffer et al., 2008; Stolk et al., 2008), but this study was the first one to find a statistically significant increase in the evaluation scores of the home visitors. These results suggest that positive working alliances emerged between parents with home visitors.

What is the effect of VIPP-LD on two important parenting concepts: harmonious parent-child interaction and sensitive discipline in parents with ID?

After adapting the intervention it was imperative to find out if the intervention actually worked. In Chapter 3 we tested the effect of the VIPP-LD intervention on the two main outcomes harmonious parent-child interaction and sensitive discipline in a randomised controlled trial design with pre-test, post-test and 3 month follow-up measurements. A sample of 85 families was divided in an experimental group with 43 parent-child dyads receiving the VIPP-LD intervention in addition to care as usual and 42 parent-child dyads in the control group receiving care as usual only. Dependent variables were direct observations of harmonious parent-child interactions and sensitive discipline in semi-structured tasks. Additionally two moderators were taken into account. Parental IQ and parental adaptive functioning may be presumed to impact the extent to which the intervention was successful in supporting the acquisition of improved interaction between parents and their children.

The results showed that for the total group, on average, VIPP-LD did not improve harmonious parent-child interaction nor sensitive discipline of parents with ID. However, the intervention effect on harmonious parent-child interaction was conditional on parental adaptive functioning at pre-test, with parents with low adaptive functioning showing significantly more intervention benefit at post-test and at follow-up compared to care as usual.
The intervention effects did not depend on parental IQ, which was in line with other studies (Llewellyn et al., 2003; Willems et al., 2007; McGaw et al., 2010). So parents with ID whose functioning would raise the most concern, benefited the most from the VIPP-LD intervention.

Juffer et al. (in press) conducted a meta-analysis testing the effect of VIPP-SD on sensitive parenting of 12 randomised controlled trials including samples with parents at risk and children at risk. Sensitivity increased with about a half standard deviation as a result of the VIPP-SD intervention ($d = 0.47$). Effect sizes on observed sensitive parenting varied between $d = 0.25$ and $d = 0.78$. For the parent at risk group an effect size of $d = 0.54$ was reported. When the results of the recent study are compared with the other VIPP-SD results from parent at risk groups, the results for the group of parents with ID for observed parenting appeared to be weaker than for other at risk parents. It needs to be taken into account that parents with ID received the VIPP-LD intervention above care as usual, which also included elements of support. It may be the case that support in itself may benefit the quality of parenting, and that an intervention like VIPP-LD may have served as a part of a comprehensive package of support, making it difficult to discern the effects of single components in such interventions.

There are other parenting training programs for parents with ID. Reviews on parent training programs have been conducted several times. In 1994 Feldman carried out the first review of 20 parent education studies for parents with ID, resulting in the following recommendations: interventions needed to be conducted at the parents’ home, focussing on concrete skills, and using behavioural teaching strategies (task analysis, modelling, practice in vivo, positive feedback, praise and reinforcement). In 2008 Wade et al. updated Feldman’s review by adding 7 studies. Wade supported the recommendations of Feldman, but concluded that evidence on the effects of parent training interventions on child outcomes and on the generalization of parenting skills was scant. A Cochrane review was published in 2010 by Coren, Hutchfield, Thomae, and Gustafsson. Among the 1,257 studies retrieved in electronic databases on parenting interventions and ID, they only identified three studies with a randomised controlled design. These were a study of Feldman, Case, and Sparks (1992) with a sample of 22 mothers with ID on an intervention for childcare and safety issues for children at home, a study of Keltner, Finn, and Shearer (1995) with a sample of 40 mothers with ID assessing effects on sensitivity in interaction with their child in the age form 1-3, and a study of Llewellyn, McConnell, Honey, Mayes, and Russo (2003) with a sample of 45 parents with ID assessing effects on practices related to home safety and health for their children. These studies showed promising evidence on effectiveness of intervention, making the current trial with VIPP-LD look less successful. With so few studies, it is difficult to draw conclusions regarding the variation of outcomes, also given that these studied involved not only different interventions, but also different contexts. For example, the care as usual may not be directly
comparable between the samples in the Netherlands and Australia, Canada and USA, which may attenuate effect sizes of benefit. The variation in outcome does indicate that it is premature to conclude that for parents with ID no effective interventions can be developed and implemented.

In 2013 Knowles, Machalicek, and Van Norman reviewed studies from the period from 1994 – 2012 concerning parent education for adults with intellectual disability. The findings were discussed in behavioural analytic terms. They reported that the majority of the studies did not include steps to promote the generalization of skills to different stimuli or settings, although assessing the maintenance of targeted skills was tested. Due to the generalization problems of parents with ID, the VIPP-LD intervention selected real life situations for intervention rather than situations prescribed in the standard VIPP-SD protocol. The skills learned during the earlier sessions could be practised in and therefore generalized to perceived difficult parent-child interactions. The latest known review is from Wilson, McKenzie, Quale, and Murray (2014). They reviewed 7 studies from 1999 until 2012 on two types of interventions for parent with ID: those designed to strengthen social relationships and those teaching parenting skills. Concerning the first group of interventions positive changes were found, but the study designs restricted the generalizability. The second group of interventions concerning parental skill teaching suggested that behaviourally based interventions are more effective than less intensive forms like lessons, booklets and more effective than when parents got only normal services. This conclusion underscores that parents with ID need to be offered additional support and might benefit from approaches like VIPP-LD, but the level and variation in benefit are difficult to gauge and therefore difficult to predict in individual cases.

**Does VIPP-LD alleviate parenting stress in parents with ID?**

Raising a child can be challenging and many parents experience stress while executing this task. Parents with ID have been found to report high levels of parenting stress, which may influence the quality of their parenting. Meppelder, Hodes, Kef, and Schuengel (2015) investigated stress in a sample of 134 parents with ID and found that, on average, the parents reported a high level of stress (in the 75th percentile). Parents themselves reported that they want to have better relationships with their child, and would like to feel less stressed. Therefore in Chapter 4 the effect of the VIPP-LD intervention on parenting stress was tested in a randomised controlled trial with pre-test, post-test, and 3 month follow-up measurements. The VIPP-LD intervention was offered to an experimental group of parent-child dyads \( N = 43 \) above the care as usual the families already received and compared with a control group of parent-child dyads \( N = 42 \) receiving only care as usual. The dependent variable was perceived parenting stress, divided in parenting stress related to the parent's own functioning (parent domain) and parenting stress related to the child's functioning.
(child domain) measured by the Dutch version of the Parent Stress Index (short form). The division between parent related stress and child related stress was made because one consistent finding in several studies is that parenting stress in parents with and without ID is associated with child functioning and specifically child behaviour problems. The results showed that VIPP-LD may alleviate the high levels of stress associated with child rearing among parents with ID. Parents in the experimental condition showed a stronger decline in child-related parenting stress than parents in the control condition. This decline was not found in stress related to the parent's own functioning. Studies in the typical population found that parenting training (Thomas & Zimmer-Gembeck, 2007) can reduce stress. To our knowledge, intervention studies involving a RCT design concerning parenting stress have not involved parents with ID. This study demonstrated the effects of a tailored parent intervention on parenting stress in parents with ID and contributes to the body of research on parent education for parents with ID.

Predictors of the quality of interaction between parents with ID and their young children?

Concerns about parenting by parents with ID with risks for their children is still one of the main motives for parenting research in this group of parents. Feldman and Aunos (2002, 2010) pinpointed in their contextual model the different internal and external factors that influence parenting and the possible impediments to effective parenting and child outcomes. Professional services might alleviate the risk factors and parenting might improve through professional services. For parents with ID it is important to get access to the right support as soon as possible. Therefore in Chapter 5 we tested possible predictors of parent-child interaction to examine how quality of interaction may be reflected in proxy indicators of support need. We expected that parenting stress would be a major associated factor, with additional variation in parenting explained by parental adaptive functioning, quality of the home environment, informal support networks, and children’s externalizing behaviour problems as reported by professionals. Contrary to our expectations we did not find a contribution of parenting stress to the explained variance in quality of parent-child interaction. Neither did the variables home environment, social network size, child externalizing problems, and family material hardship (tested separately later on) demonstrate a link with the quality of parent-child interaction and sensitive discipline. The results showed that the only significant unique factor was parental adaptive functioning, demonstrating that lower parental adaptive functioning is associated with a lower quality of the parent-child interaction, an association not explained by other risk factors.
A study of Emerson and Brigham (2014) also indicated that parenting problems in families with a parent with ID cannot be completely explained by other risk factors. They analysed survey data on 46,025 families of young children served by primary care organizations in the UK. The health visitors who conducted the surveys also registered if the parent had learning difficulties and whether these parents were in need of support. Children of parents with ID were at increased risk for developmental delays, which could only partly be explained by the relatively more severe socioeconomic disadvantages of parents with ID. Findings suggested that parental intellectual disability was associated with increased risk of children's developmental delay and children's speech and language problems, and that part of this association was accounted for by socioeconomic and other risk factors and part by parenting problems. There were no significant associations with child behaviour problems or with the frequency of accidents and injuries. Taken together, evidence from our study as well as Emerson and Brigham's study calls attention to unique challenges that parents with ID may face in their interactions with their children.

**Strengths and limitations**

Tailored parenting intervention programs which include theory-led parental strategies like harmonious-parent child interaction and sensitive discipline, are scarce. With the development of VIPP-LD for parents with ID, a valuable intervention for this group of parents was added. In their meta-analysis ‘Less is more’, Bakermans-Kranenburg et al. (2003) reported that interaction-focused interventions appear to be most effective in a moderate number (up to 16) of sessions. With the 15 sessions of the VIPP-LD this intervention followed the recommendation of this guideline. Most studies concerning parenting by parents with ID have employed single-subject designs to evaluate parenting interventions. The current study had a randomised controlled design, with a sample size bigger than in other studies on this population, which enabled also testing of moderators of effectiveness. The current study demonstrated how important it is to differentiate the group of parents with ID. Differentiation based on IQ of parents yielded little meaningful insight. However, differentiation on the basis of adaptive functioning helped to identify families where VIPP-LD might be more likely to benefit parents and children (when adaptive functioning is low) and helped to identify families where quality of parent-child interaction is low. Concerning the concept of parenting stress, to the best of our knowledge this study is the first to test the effect of an appropriately designed parenting intervention on parenting stress in parents with ID.

Another contribution of the current thesis was to use direct observation measurements of parent-child interactions and the analyses of these observations with rating scales already reliable for the general population and used in many other studies (NICHD ECCRN, 2003). For our study also coders were extensively trained and kept blind to any information concerning condition, measurement occasion or other data concerning participants.
Furthermore a multi-informant design was used, with a combination of parent self-report, report of home visitors conducting the intervention, regular staff and direct observation of parent-child interactions. Therefore, results are not easily discounted on the basis of shared method or informant bias.

In addition to the strength of this study, several limitations need to be noted. Although a randomised control design was used, only short term effects could be tested, due to the short follow up time of three months. Now we do not know whether any effects might have come to the surface later on (sleeper effect) or whether effects will still be there after a longer term.

This study was conducted with a sample of parents known to care organisations. Parents with ID unknown to care organisations were not reached, meaning that the results of this study may not be generalizable to parents with MID who are not served by specialized care organisations. The VIPP-LD intervention is focused on the parent-child dyad, meaning that one parent and one child were involved in the intervention. Generalization of the effects of the intervention were not tested to parenting of other children in the family, nor was the effect of parenting by a parent couple tested. Although this study included the main caregiver, there was a limited amount of fathers involved meaning that generalization of the results to the group of fathers need to been done with caution.

**Directions for future research**

The VIPP-LD is a short-term video feedback intervention, based on the insights of attachment and coercion theory and tailored for the group of parents with mild intellectual disabilities and borderline functioning, who are parenting children in the age from 1 – 7. Parenting continues when the child grows up. Therefore it is desirable to develop and test intervention programs based on the same principles, that are suitable for parents with children beyond the age of 7.

It is desirable to follow the studied group of parents over a longer time and set up more longitudinal studies. VIPP-LD focusses on a limited number of parenting challenges and we do not know whether the intervention will be sufficient to offset potential later problems in parent-child relationships. The focus on harmonious parent-child interaction and sensitive discipline can potentially provide a healthy start. Additional programs are still necessary to train different specific parenting tasks more in detail. There are at least two intervention programs specially designed for parents with ID: the Step-by-Step parenting assessment and training model (Feldman & Tahir, 2016; Feldman 1998; Feldman & Case, 1998) and the Parenting Young Children program that was tested from 2003 until 2006 (Wade et al., 2008). Further research is recommended to investigate if VIPP-LD could be offered as part of a package together with one of these programs.

In the current study mainly mothers were involved as primary caregivers of their children. Further research should focus on the fathers as well. Also new research should be conducted
concerning parenting by both parents. Working with parents from different cultural backgrounds, future research attention should be paid to families with more main caregivers like grandparents or aunts/uncles. Growing up in such families might be a protective factor given the fact that parents with greater social networks appear to be less in need of professional support, because they can rely more upon informal support (Meppelder, Hodes, Kef, & Schuengel, 2014).

In this study parents with ID already known to care organisations were included. Parents with ID not served by these organisations were thus not included. Further research should attempt to identify and approach these parents as well to find out if these parents are in need of support as well or to investigate what kinds of factors make that these parents are not in care.

Although the group of parents for this research was quite large, still larger samples are necessary to test explanations for intervention effects. We recommend to set up an international based study supported by the Special Interest Research Group (SIRG) Parenting of the International Association for Scientific Study of Intellectual and Developmental Disability (IASSID).

Finally research needs to be carried out on some of the other factors mentioned in the model of Feldman and Aunos (2002, 2010) like parents’ history with professional support, the role of the working alliance with the VIPP-LD professional, and the role of social support.

Implications for practice

The findings of this study have several implications for practice. This study showed that offering parents with ID who experience parenting stress the VIPP-LD intervention may be useful for addressing parenting stress, and perhaps for those who are lowest on adaptive functioning it may also support harmonious interaction, although the moderating effect of adaptive functioning is in need of replication and thus the benefit for actual parenting is uncertain yet. Findings in Chapter 5 showed that there were no strong predictors of parenting behaviour at pre-test level except parental adaptive functioning which could explain variance in harmonious parent-child interaction and in sensitive discipline during the Don’t task. Assessment of potential support needs for families of parents with ID requires a more direct focus on parenting itself instead of using distal indicator variables that may lead to many false negative and false positives.

The first step towards implementation is to train professionals in the intervention. During the research period 19 home visitors and 13 psychologists were trained and they are prepared to offer this intervention. The opportunity to become officially certificated will be investigated. The intervention will be offered for registration in the Dutch database for effective interventions. The VIPP-LD training itself requires no big adaptations to use outside the experimental research setting. The intervention was developed, tested and executed in
everyday practice. Parents with ID piloted the intervention at the start and based on their recommendations several important adjustments were made (see Chapter 2). One important aspect may be added to the training. Meppelder, Hodes, Kef, and Schuengel, 2014 executed a study on the mindset of staff supporting parents with ID and found that around 40% of the staff held an entity (static) mindset, meaning they were not convinced that parents can learn and change. They found that parents in need of support waited for a shorter period to ask for support when staff was having a more incremental mindset (convinced about parental capacity to change). The mindset of the future VIPP-LD professional is an aspect that needs to be addressed in training.

Having an evidence based intervention available is one thing. It is also important that the local governments responsible for providing the support for parents with ID know about this intervention. Care organisations have to inform the municipalities to make it possible to provide the intervention to parents with ID.

One final implication concerns the chances parents with ID get when they are in a court case because of their parenting quality. Often the assumption is that parents with low IQ or low adaptive functioning do not benefit from parenting support (Benjet et al., 2003; McConnell et al., 2010). This research suggested that parents with low adaptive functioning benefited the most from the VIPP-LD intervention and this benefit was not associated with IQ differences. Providing this information to child protection services, judges and lawyers will be important for parents and will contribute to increasing the odds that parents and their children are offered appropriate supports.

**General conclusion**

The United Nation Convention of the rights for persons with disabilities affirms the rights of people with intellectual disabilities to start a family and calls for appropriate assistance to persons with intellectual disabilities in the performance of their child-rearing responsibilities. Several studies underpin that parents with intellectual disabilities are able to learn parenting skills and can improve parenting behaviour. An evidence based video feedback intervention for the typical population, based on attachment and coercion theory (VIPP-SD) was tailored and tested for parents with ID (VIPP-LD) in a randomised controlled trial with a sample of 85 parent-child dyads.

For the total group of parents we could not demonstrate an improvement in parenting behaviour. Harmonious parent-child interaction and sensitive discipline did not progress after the intervention. However, the group of parents with low parental adaptive functioning did improve and benefit from VIPP-LD, indicating that the group of parents professionals may be most concerned about, were most likely to stand to gain from the intervention. In addition, for the total group of parents in the experimental group, parenting stress was alleviated.

Finally, the results of this study do not support distal indicators as reliable proxy measures
for the quality of parental behaviour of parents with ID. Assessment of parenting qualities through systematic observations is therefore to be preferred, not only to gauge needs for support and the success (or lack thereof) of interventions but also to provide child and family welfare and child protection with the best possible evidence for deciding on their policy.
References


