Chapter 1

General Introduction
Becoming a parent is one of the most intense transitions in a person's life and seen as a highly regarded social role, adding meaning to someone's life (Baumeister, Vohs, Aaker, & Garbinsky, 2013). Persons with intellectual disabilities make this important transition as well, although it is unclear how many and whether that number increases or decreases over the years (Schuengel, Kef, Hodes, & Meppelder, in press). The parties to the United Nations Convention on the Rights of Persons with Disabilities (2006) have seen it as pertinent to affirm the right of persons with disabilities to marry and start a family in, formulating article 23, paragraph 1 as follows: “States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.” This article also points out in paragraph 2 that states are bound to “render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.” A separate article indicates the importance to equip professional staff: “States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services” (article 26). Thus it is highly important to develop knowledge on the challenges facing parents with intellectual disability and on the ways in which these parents can be effectively supported.

The challenges for parents with ID are numerous (Aunos & Feldman, 2002). This may explain the reports that these parents are overrepresented as clients of child welfare and child protection services (Booth, Booth, & McConnell, 2005; McConnell, Feldman, Aunos, & Prasad, 2011; McGaw, Scully, & Pritchard, 2010; Willems, De Vries, Isarin, & Reinders, 2007). Related to the question of overrepresentation of parents with ID in child welfare and protection is the question whether parental intellectual disability in itself leads to inept parenting. In their research around court cases concerning parenting, Booth et al. (2005) found that family court involvement with children of parents with ID led far more often to authorization of adoption than with children of parents without intellectual disability. Later studies reported however, that the intellectual disability might not have a direct effect on attributions of child protection workers. Proctor and Azar (2012) presented child protection workers with vignettes (hypothetical scenarios with and without the description of the parental ID status) and asked them to make ratings of emotional reactions, attributions and decisions concerning risk and support. They found that these child protection workers responded with heightened willingness to help when the parent in the vignette was identified with ID. Although parental IQ status did not have a direct effect on attributions of the workers or on the decision whether to remove the child, some of the responses, such as pity, reflected
stereotypes associated with people with ID. Another recent study (Trefe, 2016) executed in three countries (Norway, England – UK, California – USA) offered child welfare workers a vignette with a combined case of a parent with an intellectual disability and infant neglect of a two month old baby. The workers agreed about the high risk of the case presented, but they varied in their justifications for the risk assessments. Risk factors were grouped in three categories: (1) risk factors associated with mother’s parenting, (2) risk factors associated with the child’s age, safety and health and (3) risk factors concerning support network and environment. The professionals differed in their reasoning about the most important concern. The Californian workers showed a greater concern about the mother’s cognitive functioning and the child’s age and health. The English and Norwegian workers differed on attention to social and environmental factors. This study demonstrated that assessment of risk associated with parents’ intellectual disability varies across contexts, and that there is room for more research based guidance for professionals to assess cases and develop intervention plans.

Parents with ID are also much more likely to face a multiplicity of risk factors for inadequate parenting, including health problems, stress, depression, and histories of institutional or non-parental upbringing (Emerson & Brigham, 2014; Hatton & Emerson, 2003; Hindmarsh, Llewellyn, & Emerson, 2015; Willems et al., 2007), which partly explains why parents with ID and their children show more negative developmental and behavioural outcomes. A Swedish study using a matched comparison design (N = 48) reported that mothers with ID were significantly lower in sensitivity than the comparison group mothers without ID. Maternal experiences of maltreatment were related to low sensitivity, indicating that mother’s history of receiving care is important to take into account (Lindberg, Fransson, Forslund, Springer, & Granqvist, 2016).

More than 600 refereed journal papers in the field of parenting by parents with intellectual disabilities (abstracts available at http://www.healthystart.net.au) were published (at least as counted up to 2015), indicating that parenting by parents with intellectual disabilities has captured the attention of a growing number of researchers. Still, evidence-based support and interventions that might help these parents in the upbringing of their children are rather scarce (see Coren, Hutchfield, Thomae, & Gustafsson, 2010; Knowles, Machalicek, & Van Norman, 2015; Wade, Llewellyn, & Matthews, 2008; Wilson, McKenzie, Quayle, & Murray, 2014 for reviews).

In 2004 the Dutch government commissioned a national survey on parenting by people with intellectual disabilities. Willems et al. (2007) reported that 33 % of the parents with ID offered ‘good enough’ parenting as defined by the lack of involvement of child protection services and the absence of concerns about abuse or neglect. Also three important protective factors were detected as associated with this ‘good enough’ parenting: asking and accepting support, effective intervention strategies, and the presence of a supportive social network. The results informed the societal debate about parenting capacity and learnability of parents
with intellectual disabilities, and the professional discourse on ways in which these parents could be supported, and professionals working with these parents could be equipped with suitable methods and skills.

The research presented in the following chapters contributes to insight into the extent to which interventions may successfully address the parenting needs of parents and professionals, taking into account the learning difficulties of parents with ID. The intervention in question is a tailored video-feedback protocol based on two important theories, attachment and coercion theory (Juffer, Bakermans-Kranenburg, & Van IJzendoorn, 2008). This study was part of a larger project “What works for parents with intellectual disabilities?”, conducted by three care organisations (ASVZ, Gemiva-SVG, Philadelphia) and the Vrije Universiteit Amsterdam, and further supported by seven other care organisations and the self-advocacy group for people with intellectual disabilities (Landelijke Federatie van Belangenverenigingen Onderling Sterk [National Federation of self-advocacy groups “Strong together”]; LFB). The two aims of this larger project were to produce and provide knowledge useful to the public debate around parenting by parents with intellectual disabilities and to supply educational and training resources for the professionals working with these parents.

Parents with intellectual disabilities: Definition, characteristics and prevalence

The American Association on Intellectual and Developmental Disabilities (AAIDD, 2010) defines intellectual disability as “characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive behaviour”. Across countries and across time the specific criteria for intellectual disability differ. Parents with intellectual disabilities are mainly represented in the group of persons with an IQ from 50/55 – 70 (mild intellectual disability) and the group with borderline intellectual functioning (IQ 71–85), both in combination with significant limitations in adaptive behaviour. In this thesis we used the term ID as well as the term MID for the total group of persons with intellectual disabilities.

Llewellyn, Traustadóttir, McConnell, and Sigurjonsdóttir (2010) proposed in their introduction to the book ‘Parents with Intellectual Disabilities: Past, Present and Future’ to distinguish three groups of parents. First, there is the group of parents who previously lived in the institutions and now moved into the community as a result of the normalization and inclusion vision. Second, there is the group of parents with a permanent label of intellectual disabilities; these parents were never institutionalised, and are receiving special services for persons with intellectual disabilities. Finally, there is the group of parents who were not in touch with services until they made the transition to parenthood and started facing difficulties because of their new parenting role. The last group is called the hidden majority (Edgerton, 2001). While many studies, including the present one, have been conducted with samples
overlapping with the second and third group, the larger literature on parenting and ID moves more towards population based research that investigates the role of parental ID without services being necessarily involved (Schuengel et al., in press).

In the Netherlands there is no registration of persons having intellectual disabilities and no registration of marriages of persons with intellectual disabilities. Therefore, only a rough estimate of the possible number of parents with intellectual disabilities can be given. From around 142,000 persons with intellectual disabilities (Sociaal Cultureel Planbureau, 2013) an estimated 1.5% have children. The percentage of 1.5 was based on the study of Willems et al. (2007). For this study, questionnaires were sent all over the country to organizations and professionals providing help and support to persons with intellectual disabilities. Respondents were asked to indicate how many people with ID they knew of were parents. On a total of 110,000 people served by these professionals and organizations, 1,549 were identified to be parents. Findings from a German study suggest that the prevalence may be growing. Pixa-Kettner (2008) reported a doubling of children born to parents with MID between 1995 and 2005. Weiber (2011) reported that out of 1000 children born per year, 2.12 were born to women with intellectual disabilities in Sweden. A large representative Australian national disability household survey (N = 61,900, aged 15-64) found that 0.41% of the population were parents with an intellectual disability (Man, Wade, & Llewellyn, 2016). A national representative household survey in the UK (N = 14,373) reported that among adults in the age between 16-49 years old, 66% of adults with intellectual disability had biological children, which was quite similar to the 57% of the adults without intellectual disability (Emerson, Llewellyn, Hatton, Hindmarsh, Robertson, Man, & Baines, 2015), which means that it might become more common for persons with ID to have children. The prevalence estimates of parents with ID are highly dependent on methods and criteria. It is therefore difficult to know whether parenthood with ID is more or less prevalent than among people without ID and whether prevalence varies across countries and time.

Several authors have expressed caution at the assumption that intellectual disability may cause inept or maladaptive parenting. An interplay of different child, parent, family and environmental factors influence parenting and the well-being of the child, and this may also be the case for families with a parent with an intellectual disability (Aunos & Feldman, 2002; Feldman, 2002; Feldman & Aunos, 2010; Feldman & Tahir, 2016; Knowles et al., 2015; Wade et al., 2015; Willems et al., 2007). Characteristics that have been found to be present more often among persons with mild intellectual disabilities are poorer executive functioning and negative social information processing (Van der Molen, Van Luit, Van der Molen, & Jongmans, 2010; Van Nieuwenhuijzen & Vriens, 2012). Executive functioning has to do with inhibition (preventing impulsive reactions), cognitive flexibility (ability to adapt to different environments or tasks by changing mental sets) and working memory (Miyake, Friedman, Emerson, Witzki, Howarter, & Wager, 2000). Social information processing concerns the way someone is able
to encode and interpret social stimuli and is able to come up with appropriate actions (Crick & Dodge, 1994). Deater-Deckard and colleagues found that maladaptive parenting behaviours were linked to poor executive functions in combination with hardship, household chaos, and child conduct problems (Deater-Deckard, Sewell, Petrill, & Thompson, 2010; Deater-Deckard, Wang, Chen, & Bell, 2012). Negative social information processing (i.e., hostile attributions) was also found to be associated with insensitive and harsh parenting (Caselles & Milner, 2000; Strassberg, 1995). This knowledge is important to take into account when parents with ID are in need of support and are offered intervention programs.

Wade et al. (2015) reported on the basis of an Australian sample of 120 parents with intellectual disabilities on the associations between socioeconomic disadvantage, social support, parent mental health, parenting practices, and child well-being. They found that parents’ access to social support and parent mental health had a direct positive effect on self-reported parenting practices. Although the limitations of self-reported parenting practices should be kept in mind, this is still an encouraging result, indicating that supporting parents with ID is potentially useful. They also found in their study that mental health in parents with intellectual disabilities had an indirect effect via parenting warmth and efficacy at child care tasks and suggest that intervention programs should focus on improving parenting warmth and responsivity to influence child outcomes.

Compared to the general population, parents with ID are found more often in vulnerable positions and are more likely to have low incomes, live in deprived neighbourhoods and report low levels of social support (Aunos, Feldman, & Goupil, 2008; Braveman, Marchi, Egerter, Kim, Metzler, Stancil, & Libet, 2010; Emerson & Brigham, 2014; Emerson et al., 2015; Gillmore & Cuskelley, 2014; McConnell, Breitkreuz, & Savage, 2010; Parish, Rose, & Andrews, 2009). In addition, parents with ID have to deal with stigma and discrimination based on the label ‘intellectual disabilities’ which brings them in an unequal position compared to typical parents without intellectual disabilities (Fraser & Llewellyn, 2015; McConnell et al., 2011). In short, people with ID (including parents) are in a difficult situation because of their own limitations and because of a range of social and environmental risks.

**A contextual model for parenting**

Based on the work of Belsky (1993) and Bronfenbrenner (1989), and on empirical data available from studies concerning parenting by parents with intellectual disabilities, Feldman (Feldman, 2002; Feldman & Aunos, 2010) developed a contextual model, with the different internal and external factors affecting parenting by parents with ID. The model presents the relationships between these variables and parenting by parents with ID, and the possible impediments to effective parenting and optimal child outcomes. This model is useful for guiding studies, like the current one, that focus on parenting behaviour, the interaction between parent and child, and the impact of the parent's psychological wellbeing, in particular
perceived parental stress. Parental stress is associated in the general population with a more coercive parenting behaviour style and a higher risk for neglect and abuse (Deater-Deckard, 1998). Potential impact of support and services on parenting stress is therefore highly relevant as well.

**Effectiveness of support for parents with ID**

The AAIDD emphasize the level of support intensity needed (Schalock, Borthwick-Duffy, Bradley, Buntinx, Coulter, & Craig, 2010) when persons with intellectual disabilities need to execute normative activities. For parents with ID, parenting would be a normative activity of major importance. Assessing their need for support on this activity and effective ways to provide this support are therefore highly important. It should be kept in mind, however, that parents with ID are a very diverse group. The support they need will vary by family, the characteristics of the family members and the living circumstances.

A number of studies have demonstrated that parents with intellectual disabilities can improve child-care skills and parent-child interactions. As a rule, such studies employed behavioural skills training with individual cases; these studies tend to result in

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corresponding benefits to their children (Feldman, 1994; Wade et al., 2008). Feldman (1994, 2004) observed that parenting education programs that have proven to be effective for parents with ID in single case experiments share a number of characteristics. Effective programs are home-based, focused on concrete skills rather than abstract ideas, and incorporate behavioural teaching strategies, including modelling and positive reinforcement. The extent to which the findings from these experiments are generalizable across different settings and situations remains unclear, however.

Furthermore, the parent education programs that have been investigated with parents with ID have focused on concrete caregiving tasks that can be improved through behavioural teaching and evaluated through behavioural learning paradigms. Knowles et al. (2015) claim that there is still room for improvement, especially concerning generalization of skills to different stimuli and settings and direct observation of child outcomes. Little is known about the effectiveness of training parents with ID to be sensitive and responsive in interaction with their children, and how effects generalize across families.

Studies focusing on parenting of parents with ID with a randomised controlled design are rather scarce. Coren and colleagues (2010) conducted a Cochrane review and identified three studies using randomised controlled designs. The first study (Feldman, Case, Garrick, MacIntyre-Grande, Carnwell, & Sparks, 1992) concentrated on the improvement of daily care and safety promoting skills and found that giving verbal instruction, booklets, modelling and feedback on the parenting at home led to an improvement in the intervention group compared to the control group. The second study with 40 participating mothers with intellectual disabilities (Keltner, Finn, & Shearer, 1995) showed that mothers could improve parent-child interaction when provided with small-group psycho education. In the third study Llewellyn, McConnell, Honey, Mayes, and Russo (2003) demonstrated that mothers (N = 45) in the intervention group were improving significantly more in their knowledge regarding health and danger issues than mothers in the control group. All these studies suggest that parenting support is helpful and reduces the risks concerning caregiving by this group of parents. Although all these results are promising, the group sizes were still relatively small and only the study of Keltner used observation of parent-child interaction outcomes as a method. Therefore, the current study was aimed to contribute to the body of RCT trials with a larger sample of parents with ID and included observational measures of parent-child interactions.

Parental sensitivity, the ability to respond accurately and promptly to the affective signals of a child in a sensitive way, is seen as a key factor fostering secure child-parent relationships (Ainsworth, Blehar, Waters, & Wall, 1978; Bowlby, 1982, 1988; De Wolff & Van IJzendoorn, 1997), resulting in more harmonious parent-child interactions. When children grow older an increasing need for autonomy emerges. Dealing with this increasing autonomy is not an easy task and might result in a circle of ineffective parental discipline with increasing difficult and challenging child behaviour (Patterson, 1982). Teaching parents to use positive ways to
discipline their child sensitively and to refrain from power and coercive responses will be to the benefit of the development and wellbeing of the child, especially given indications that intellectual disability makes it more difficult to be sensitive, even when other background risks are held constant (Lindberg et al., 2016).

For parents without intellectual disabilities evidence based intervention programs focusing on positive parenting and integrating the concepts of attachment and coercion theory are available and have been tested on their effectiveness. One of these programs is the ‘Video-feedback Intervention to promote Positive Parenting with the focus on Sensitive Discipline’ (VIPP-SD; Juffer et al., 2008). This intervention program stimulates harmonious parent-child interactions and sensitive discipline, helps parents to focus their attention on children’s signals, improves awareness of children’s emotional needs and aims to prevent coercive cycles of parent-child conflicts. The intervention has been found to be effective in multiple trials, including samples of parents in severely deprived conditions (e.g., Negraõ, Pereira, Soares, & Mesman, 2014), parents of children with externalizing behaviour problems (Mesman et al., 2008), and parents with children with an Autism Spectrum Disorder (Poslawsky, Naber, Bakermans-Kranenburg, Van Daalen, Van Engeland, & Van IJzendoorn, 2015). Juffer, Bakermans-Kranenburg, and Van IJzendoorn (in press) meta-analysed the results of randomised controlled trials testing the effectiveness of VIPP-SD. They found that the six studies focusing on parents at risk showed an effect size of $d = 0.54$ and drew the conclusion that the VIPP-SD program is effective for at risk groups. The question is whether this intervention, already qualified as evidence based for the typical population and found to be effective for populations at risk, may also be successfully tailored for parents with intellectual disabilities and help these parents to improve their parenting behaviour.

Parenting stress, asking and accepting support, and developing a working alliance

One of the protective factors associated with ‘good enough’ parenting is asking and accepting support (Willems et al., 2007). Intervention programs can only be helpful when parents feel a need for it and are able to accept the support offered. Parenting stress might be a reason for parents to seek support. Meppelder, Hodes, Kef, and Schuengel (2015) found in a sample of 134 Dutch parents with ID that parents especially experienced stress concerning their child related behaviour problems. When parents experienced a higher level of stress, they tended to ask for support. The quality of the relationship between the professional and the parent seemed to be important as well. Especially, parents with small support networks of their own appealed to their regular support worker with a request for additional help, but only if they had already developed a good working alliance with that support worker. The findings help to understand how parent support can be effective. These results are also encouraging for professionals executing intervention programs, indicating
that investing in building up a good relationship with the parents will prepare them to accept support.

High parenting stress is associated with child-related problems and influences the well-being of child and parent (Aunos et al., 2008; Feldman, 2002; Feldman, Legér, & WaltonAllen, 1997; Meppelder et al., 2015). Reducing parenting stress through parenting intervention is to the benefit of the development of the child and the parents’ quality of life. Therefore, the current study paid attention to the effect of parenting support on parenting stress, in addition to the effect on actual parenting behaviours. The problems parents with ID are facing might decrease through support from professional services. Parenting stress is often seen as an important indicator for the need of support, although mixed results are reported. In a sample of mothers participating in a substance abuse program, Espinet, Jeong, Motz, Racine, Major, and Pepler (2013) did not find an association between parenting stress and parenting behaviour, while in our larger study parenting stress was associated with looking for professional support (Meppelder, Hodes, Kef, & Schuengel, 2014). This raises the question how parents may benefit from support when it is offered. This is a question we address in our study.

**Aims of the current study**

The overall aim of the current study was to test to what extent a parenting intervention tailored to parents with ID leads to actual improvements in parenting, with a focus on harmonious parent-child interaction and sensitive discipline. Answering this question has important implications for assumptions regarding the potential of people with ID to become ‘good enough’ parents. Furthermore, this question also would address the lack of evidence-based interventions that parents with ID might access or be offered from services that are tasked with the responsibility to provide support. In order to investigate the role of intellectual disability as a factor potentially limiting the effectiveness of intervention, our sample included parents with ID (IQ < 70) as well as parents with borderline intellectual functioning (85 > IQ > 70) and significant limitations in social adaptive functioning. Parenting support was provided to both groups through the same care organizations.

In Chapter 2 we described the tailoring of the Video-feedback Intervention to promote Positive Parenting with the additional focus on Sensitive Discipline (VIPP-SD) into the VIPP-LD. The tailored version for parents with ID is called Video-feedback Intervention on Positive Parenting for parents with Learning Difficulties (VIPP-LD). The term Learning Difficulties was chosen in order not to offend or disempower parents with ID who are not identifying themselves with the label intellectual disability, while learning difficulties refer to the core reason why support is offered with learning how to adapt to the challenges of parenting. A case sample illustrates the perceptions and attributions of a mother with ID working with this intervention as well as the experiences of the professional working with this mother.
Adaptation of an intervention is one thing, but finding out whether it actually works is another thing. Therefore, in Chapter 3 the effect of VIPP-LD was tested in a randomised controlled trial to find out if harmonious parent-child interactions and sensitive discipline of parents with ID would increase after the intervention and whether such effects still held at follow up. VIPP-LD may also alleviate the high levels of stress associated with child rearing among parents with ID. Therefore, in Chapter 4 the effect of VIPP-LD on parenting stress was tested in a randomised controlled trial. In Chapter 5 attention was paid to the possible indicators for parent-child interaction to more quickly determine when parents are in need of support. It is for professionals important to know these indicators, so parents can be referred in a correct way. In Chapter 6 conclusions are drawn from the various findings. Besides, their potential implications for further research and practice are discussed.

**Research design**

To test if parenting support is effective for parents with ID, the design of this intervention study was a randomised controlled trial with an experimental group receiving the VIPP-LD intervention above the care as usual and a control group receiving care as usual only. These control group parents were put on the waiting list with the promise of receiving the intervention, after the last follow up measurement. Parents were recruited from 10 care organizations in the Netherlands supporting parents with ID. Parents needed to be identified who met the inclusion criteria: an IQ score between 50 – 85 and or significant limitations in adaptive functioning. Other conditions for eligibility were: parents had to have at least one child in the age range from 1 up to 7 years, they had to be the primary caregiver (mother or father) of the child, and they had to live with their child for at least four days a week. The VIPP-LD intervention focused on the parent-child dyad. Therefore, if parents had more than one child, the youngest one in the age-range of 1 to 7 was chosen for participation. Children diagnosed with an autism spectrum disorder were excluded because additional adaptations to the VIPP-SD intervention are indicated (see Poslawsky et al., 2015) when children have an autistic spectrum disorder. Parents who had received a video-based intervention in the six months preceding the VIPP-LD intervention were excluded as well. Finally, a total of 146 parents participated in the study. Parents who got a total score above the 62th percentile (subclinical level) on the Dutch version of the Parental Stress Index – short form (NOSIK) were recruited for the intervention study (76 parents). Parents who received residential family support and parents whose children were placed under custody of the child protection services were also included if their NOSIK score was below the 62th percentile (9 parents), which made a total of 85 parents for the intervention study. Three measurements were repeated at both pre-test, post-test and follow-up: harmonious parent-child interaction, sensitive discipline and parenting stress.
More detailed information about the measures, procedures and participants can be found in Chapters 2 – 5. For the effect studies (Chapter 3 and 4) data were collected and used during pre-test, post-test and follow-up. For Chapter 5 data were taken from pre-test assessment only. Data were collected during a period of 3 years. Parents in the intervention group and in the control group received gift vouchers at pre-test, post-test and follow-up, and a bonus once they had completed the whole trajectory (total €125,-). Ethical approval was obtained from the Medical Ethical Committee of VU University Medical Center, Amsterdam (ref. no. NL 31934.029.10).
References


