

Chapter 1

General Introduction



Parenting is among the most complex of human activities. Caregiving by parents with mild intellectual disabilities (MID; IQ 50-70) or borderline intellectual functioning (BIF; IQ 70-85 and limitations in adaptive functioning) is often challenged by multiple risk factors (Aunos & Feldman, 2002). Parents with MID or BIF (in this chapter referred to as parents with MID) adapt to those risks in various ways. In 2007, a quick-scan commissioned by the Dutch government was published about the quality of parenting by people with MID in the Netherlands (Willems, De Vries, Isarin, & Reinders, 2007). This study revealed that in 33% of the families where parents had MID, parenting quality was deemed 'good enough', meaning that parents raised their children by themselves without mandatory support or child protection service involvement and without current considerations by support professionals that mandatory services might be necessary in the near future. This study also revealed that professionals considered parental willingness to ask and accept support, effective intervention strategies, and the presence of a supportive network as important protective factors for achieving good enough parenting quality in families where parents have MID.

Protective factors in the lives of parents with MID have received little systematic research attention. Studying those protective factors may provide insight into the direction that policy and practice may take to improve support for families in which one or both parents have MID. The current study was initiated to advance the evidence base for more comprehensive, contextual models of parenting with MID as well as to advance assessment aimed at such broader models. The broader project "What Works for Parents with Intellectual Disabilities?" was initiated by a consortium of organisations supporting parents with MID (ASVZ, Gemiva-SVG and Philadelphia) and VU University Amsterdam. The project included three sub studies, corresponding with the protective factors as identified by the professionals who were surveyed by Willems and his colleagues (2007). The first sub study aimed to improve understanding of parental willingness to ask and accept support with a focus on determinants from a relationship perspective. The second sub study aimed to develop and test an intervention method to improve sensitive parenting among parents with MID. The third study focused on factors promoting or impeding support for parents with MID, from the perspective of network members of parents with MID. The current dissertation reports findings from the first sub study.

Parents with mild intellectual disabilities

Becoming a parent is a broadly desired life transition, which gives meaning to the lives of people (Baumeister, Vohs, Aaker, & Garbinsky, 2013). As a consequence of

the trend of normalisation and inclusion, this life transition has become a realistic perspective for more people with MID than in the recent past. In the Netherlands, an estimated 1.5 % of the 120,000 persons with ID have children. This figure may be growing, due to increasing autonomy of people with ID. A study in Germany found a doubling of children born to parents with MID between 1995 and 2005 (Pixa-Kettner & Sanders, 2006).

In the Netherlands, parents are referred to care organizations for people with disabilities when they show significant limitations in one or more domains of adaptive functioning. Shortcomings in social skills, communicative or daily living skills might be identified as risks to the functioning of the family and the position of the children therein, leading to referral for support from care-organizations who specialize in supporting people with disabilities. Therefore, the current study includes both parents with mild intellectual disabilities and parents with borderline intellectual functioning (IQ <85) accompanied by limitations in their adaptive functioning. Other terminology that has also been used for this group of parents is learning difficulties (e.g., Llewellyn & McConnell 2002) or intellectual disabilities, depending on journal, research tradition or country preferences. Because of journal preference, in Chapter 2, the term intellectual disabilities is used, whereas MID is used in other chapters.

If parents with MID in the Netherlands receive some form of professional support from care organizations for people with MID, additional support and supervision may be offered from the youth care or mandated through child protection systems. A disproportionate number of children of parents with MID are involved in child protection cases (Booth, Booth, & McConnell, 2005; Willems et al., 2007), and their focus is usually on the safety and development of the child. Support that is primarily aimed at the parents is provided by direct care staff, who may offer practical support a few hours per week within the family home, or who may offer more comprehensive support with daily living and child rearing in residential homes that have been set up for families with one or more parents with MID.

Within the literature on parents with MID, three generations of research can be identified (Llewellyn, Mayes, & McConnell, 2008). In the first generation, heritability of intellectual disability and the related issue regarding equal freedom of people with MID to have children were addressed. In the second generation, studies turned their focus to the topic of parenting quality of people with MID and the remediability of parenting skills of parents with MID. A disproportionate proportion of parents with MID showed doubtful parenting quality (Willems et al., 2007) and children of parents with MID faced higher risk of child abuse and neglect (Euser, Van IJzendoorn, Prinzie, & Bakermans-Kranenburg, 2010). However, these findings describe an overall perspective, with few attention for differences between parents with MID. Furthermore,

these results stem from a period wherein knowledge about tailoring interventions to individual needs of parents was less developed. A positive finding from this research phase was that parents with MID appeared to be able to benefit from parenting support when support programs fit parental needs (Feldman, 1994; Llewellyn, McConnell, Honey, Mayes, & Russo, 2003). That is, when support programs are home-based, focused on concrete skills and use behavioural teaching strategies. Given the practical and scientific insights that have been gained over the past few years on parenting support, research efforts to tailor parenting support to parents with MID still continue (Hodes, Meppelder, Schuengel, & Kef, 2014).

The third generation of research, that is also still ongoing, broadened the focus from individual characteristics of parents to contextual factors associated with parenting by persons with MID. Studies so far showed that parents with MID often face multiple risk factors while raising their children. Parents with MID have smaller supportive networks (Llewellyn & McConnell, 2002), experience more sources of stress, such as financial hardship (Booth & Booth, 1999) and (mental) health problems (Llewellyn, McConnell, & Mayes, 2003), and more often carry a history of being abused and neglected themselves (Tymchuk & Andron, 1990; Granqvist, Forslund, Fransson, Springer, & Lindberg, 2014). As a part of this shift of focus to contextual factors as important contributors to parenting quality of parents with MID, research should focus on the quality of support as a possible barrier to optimal parenting by parents with MID.

Supporting parents with MID

The rise in the number of parents with MID comes with growing challenges for organisations supporting people with MID. Although parents with MID have been shown to take advantage of parenting support programs if these are offered, the evidence comes from a limited number of often small scaled studies (Coren, Thomaes, & Hutchfield, 2011). If effects can be shown, these have been moderate in size (Coren et al., 2011) with little systematic effort to study the factors that might promote effectiveness of parenting support in individual families. In addition, the limited available evidence might mean that the range of evidence-based programs is small and might not meet all the needs that individual parents may have, and that only a fraction of parents with MID may be reached with programs that have shown to be effective. In order to be better able to tailor support to the needs of parents, the challenge for care organisations may lie prior to effective intervention and concerns the connection between support offers and the needs of parents with MID.

Heightened awareness of parents' needs as well as avenues for effective support may also help to improve the sometimes fragile relationships between parents with MID and support professionals. Child protection professionals on average voiced doubt about their ability to improve the home situations of parents with MID because of perceived parent non-cooperation or resistance to protective services (McConnell, Llewellyn, & Ferronato, 2006). Perceived parental non-cooperation was twice as frequently reported in child protection files of parents with MID than in files of non-disabled parents (McConnell, Feldman, Aunos, & Prasad, 2011). Parents themselves have reported that support services were not helpful (Pixa-Kettner, 1998) and parents and their significant others differed in their ideas about where support should focus on (Llewellyn, McConnell, & Bye, 1998). In addition, support figures for parents with MID might inhibit rather than promote parental competence by expressing negative attitudes and discouraging independence by taking over parenting tasks instead of empowering parents to grow as a parent (Tucker & Johnson, 1989). Little research has been done to address possible causes of the disturbed connection between parents with MID and the services provided to them.

Aims of the current study

The overall aim of the current thesis was to contribute to a better understanding of the way parents with MID perceive potential challenges in themselves or their families as well as the sources that may exacerbate or mitigate those challenges. Given the need for the field of practice to find better methods of working with those parents, each chapter highlights some of the factors or mechanisms that may impact on the connection between parental needs and services for parents with MID. A step-wise approach was taken, with a shift in focus from parental factors to a focus on staff and relationship factors and finally support network characteristics, and each in association with parental support seeking.

A person's decision to seek support is foremost a product of perceptions of need for support (Cohen, 1999; Fischer & Turner, 1970). When speaking of family situations and parenting quality of parents with MID, professionals or other "outsiders" do see a need for support (Llewellyn et al., 1998). However, little is known about where the needs of parents with MID themselves lie and to which needs services should attune their support. Therefore, **Chapter 2** takes the perspective of parents with MID with regard to caring for their child by focussing on parenting stress. Parenting stress includes negative expectations and perceptions by parents of their capacities and the family situation (stress in the parent domain), as well as perceptions of the child as

a challenge to their capacities and resources (stress in the child domain) (Deater-Deckard, 1998). Parenting stress has been found associated with heightened risk for child maltreatment (Slack et al., 2011), and parents with MID are more likely to experience heightened levels of parenting stress (Aunos, Feldman, & Goupil, 2008). Associations between risk factors, such as child behaviour problems, and parenting stress have been observed for parents with MID. Aunos and colleagues (2008) showed that parents of children who showed more behaviour problems experienced higher levels of parenting stress. Little is known about the role of resources in explaining individual differences among parents with MID in their levels of parenting stress. In Chapter 2, the buffering role of financial resources, social resources and parental adaptive functioning on experienced levels of parenting stress in the parent and child domain will be studied.

While parental willingness to ask and accept parenting support has been identified as a protective factor in families where parents have MID, it is not at all clear why some parents do and other parents do not ask or accept professional support in difficult child rearing situations. In **Chapter 3**, working alliance theory (Horvath & Luborksy, 1993), with its focus on goals and tasks of treatment and the bond between staff and client, is the framework to explain individual differences between parents with MID in their support seeking towards professionals. It is hypothesized that good relationship quality between a parent with MID and the professional would be positively associated with support seeking. Associations between working alliance quality and support seeking towards professionals are studied in the context of parental views of need for support and availability of informal support. If parents themselves do not feel a need for support, formal support figures might be approached less. Furthermore, support networks of parents with MID are often small, consist for a large part of professionals, and parents with MID have little family and friends to fall back on (Llewellyn & McConnell, 2002). Support seeking towards professionals of parents with MID might not only depend on the working alliance, but also on the availability of informal support. Formal support figures might be approached less when informal support figures are at hand (Marx, Miller, & Huffmon, 2011).

The quality of parenting by parents with MID is challenged by a multiplicity of risk factors (Willems et al., 2007). Besides these factors, parents with MID have to deal with negative attitudes of others towards their parenting (McConnell & IASSID, 2008). Because professionals comprise a large part of the supportive networks of parents with MID, their attitudes about parenting by people with MID are of special interest, yet have been little studied. Therefore, **Chapter 4** examines the attitudes of support workers towards parenting by persons with MID. The concept of implicit theories or mindset theory (Dweck, Chiu, & Hong, 1995) was chosen as a framework for this

chapter. Mindset theory refers to people's ideas about whether personal characteristics are static or can be changed and had been applied to intelligence or moral development. For this study, mindset theory is applied to staff ideas about parenting skills of parents with MID and whether they are remediable or static. In supportive relationships, expectations towards the other are of influence on performance. Congruent with this idea, staff mindset might be an opportunity to optimize parental benefits from parenting support for parents with MID. Therefore, associations between staff mindset and working alliance and parental support seeking are studied as well.

The final sub study accesses a relatively uncharted area in the literature on parents with MID, namely the perspectives of people in the informal social network of those parents. Given the preference that parents with MID might have for receiving support first from informal support figures, before professional support is accessed, it is surprising that the perceptions of those support figures have seldom been elicited. Important questions regard their perceptions of the need for support, perceived limiting or facilitating factors, and motivational issues. Given the limited research in this area, the questions addressed in **Chapter 5** will be exploratory.

Research design

The design of the current study was cross-sectional, with parents participating at one time point. Parents were recruited among the clients of 10 national care providers for people with disabilities in the Netherlands. Eligible were parents with an ID who acted as the primary caregiver of at least one child between 1.0 and 7.0 years old. Care organizations identified parental ID based on the parent's IQ-scores (≤ 85) and/or significant limitations in adaptive functioning. If parents had more children within the eligible age-range, the youngest child was chosen for participation. Eligible children lived at the parents' home at least 4 days a week.

Support staff asked potential participants whether they agreed to be contacted by the researchers and provided participants with written information. A total of 200 clients agreed to an informed consent visit. Of these, 156 parents (78%) agreed to participate in this study. Of the other 44 parents, 25 parents declined participation and 19 parents could not be reached. Ten parents dropped out after informed consent so the core sample for the current dissertation was a group of 146 parents.

After informed consent, parents filled out questionnaires concerning the working alliance with support staff, parenting stress and financial hardship during a 2-hour home visit. These questionnaires were the Working Alliance Inventory-Short (WAI; Tracey & Kokotovic, 1989; Vertommen & Vervaeke, 1990), a 3-minute reading test

(DMT; Verhoeven, 1995), the Parenting Stress Index – Short Form (PSI-SF; Abidin, 1983; De Brock, Vermulst, Gerris, & Abidin, 1992), and a financial hardship questionnaire based on the work of Parish, Rose, and Andrews (2009) and a national survey on basic standards for living in the Netherlands (Otten, Bos, Vrooman, & Hoff, 2008). In addition, during the home-visit, parents were interviewed regarding their tendency to ask and accept parenting support with an adapted version of the Support Interview Guide (SIG; Llewellyn & McConnell, 1999). Kindergarten or elementary school teachers filled out the Dutch version (Verhulst & Van der Ende, 1997) of the Caregiver–Teacher Report Form 1½–5 (C-TRF) or the Teacher Report Form 6-18 (TRF). If children did not visit kindergarten or school, professional staff supporting the parent filled out the (C-) TRF. An educational psychologist appointed at the care-organization which supported the parent or one of the researchers conducted the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984; Van Berckelaer-Onnes, Buysse, Dijkxhoorn, Gooyen, & Van der Ploeg, 1995) with the primary professional caregiver of the parent. Staff supporting the parent filled out the staff version of the WAI and a measure of implicit theories about the static or malleable nature of parenting capacities of parents with ID, based on the work of Levy, Stoessner, and Dweck (1998). In addition, staff was interviewed about the quality of the home environment of the parent with the Home Observation for Measurement of the Environment (HOME; Caldwell & Bradley, 1984).

Questionnaires for parents were adjusted for participants by using larger fonts and character spacing and by repeating the rating scale, numbers as well as text, after every item. The introduction texts were simplified and for each item, standardized explanations were added. Researchers read every statement out loud, after which parents could fill in the answer. If parents had difficulty finding the answer that best fitted their perception, they could ask the researcher for support. All respondents received a voucher of EUR 25. Questionnaires for support staff were mailed-out with a cover letter and a return postage paid envelope.

More detailed information about the measures, the procedure and the participants of the study can be found in Chapter 2 - 5. Sample sizes for Chapter 2 - 5 vary between $N = 134$ and $N = 15$ due to missing data and because data from the core sample were combined with data from a smaller sub study among support staff and the third study of “What Works?” among network members of participants from the current study. Because the Chapters 2 - 5 can be read as separate articles, some overlap in the description of the studies could not be avoided.

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