Prevalence and determinants of need for formal parenting support among parents raising a child with a borderline to mild intellectual disability

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Abstract
Background Raising children with borderline to mild intellectual disability (BMID) and psychosocial problems may yield a strong need for support among parents, but evidence for this is lacking. The aim of this study was to investigate the prevalence of need for parenting support in this population, and the child and parent characteristics that influence this need.

Method We obtained data from parents of 944 children aged 5–12 years with BMID (IQ 50–85) in the Netherlands: 134 (14.2%) of these parents had a need for parenting support.

Results The results of multiple regression analyses revealed that parenting stress and child psychosocial problems, adjusted for age and gender of the child, were associated with a need for parenting support.

Conclusions One in seven parents with a child with BMID has a need for parenting support. Determinants associated with a need for parenting support are parenting stress and child psychosocial problems.

Keywords: children, borderline to mild intellectual disability, parenting support, need

Introduction
Many studies show that raising children with borderline to mild intellectual disability (BMID) leads to parenting stress, especially when the child with BMID has psychosocial problems (Baker, Blacher, Crnic, & Edelbrock, 2002; Beck, Daley, Hastings, & Stevenson, 2004; Friedrich & Friedrich, 1981). Parental stress and the child’s depressive feelings affect the psychological wellbeing of the parent (Cramm & Nieboer, 2011). Moreover, child psychosocial problems contribute even more strongly to parenting stress than does the child’s ID (Baker et al., 2003; Neece, Green, & Baker, 2012). In addition, psychosocial problems in these children and parenting stress seem to exacerbate each other over time (Lecavalier, Leone, & Witz, 2006).

The combination of child psychosocial problems and parenting stress may induce a strong need for parenting support among parents of children with BMID (Einfeld, Piccinin, et al., 2006; McGillivray & McCabe, 2007). A lot of support is available to people with disability in general, and the need for support among them seems to be high too (Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2013). Where interventions for adults with disability primarily focus on the person themselves, in children a focus on the whole family system prevails (Bailey et al., 2006). Moreover, improvement of parenting skills by parenting interventions has been shown to be an effective route to reduce the psychosocial problems of the child with ID (McGillivray & McCabe, 2007).

Support for parents can be grouped into different groups of sources such as informal (family or friends), semiformal (community-based or voluntary sector), or formal support (organised or statutory

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sector; Ghate & Hazel, 2002). In this study the focus will be on parenting support as formal support for parents. Formal support generally is aimed at improving parenting skills and, as a result, often leads to a significant reduction in parenting stress and child psychosocial problems (McGillivray & McCabe, 2007). In the Netherlands, this support can consist of various interventions aimed at reducing parental stress or psychosocial problems of the child. Examples are Practical Pedagogical Family Support (PPG), Video Home Training (VHT), Intensive Pedagogical Homecare (IPT), or Intensive Orthopedagogical Family Care (IOG; Joha, Gerards, Nas, van Gendt, & Kersten, 2006; Kleefman, Jansen, & Reijneveld, 2011). To get a clearer idea of the issues parents with a child with BMID are dealing with, a vignette is described:

Patricia is an 8-year-old daughter of Jack and Mary. As a family they live in a small village in a modern house. Both parents have a job, Jack full-time and Mary part-time. In the first years of Patricia’s life, she developed at a slower pace than her older brother Jan. When she was 4 years old, Patricia went to the primary school in her hometown. From that moment on, Patricia showed delayed development and her deficits and behaviour problems increased. Her parents and the school discussed the problems several times and Patricia’s IQ was tested. The test showed an IQ of 72 and her parents rated Patricia with many psychosocial problems. They decided to move Patricia to a new school, a school for primary special education. Support from this school had a positive effect on the development of Patricia. However, her parents still experienced some problems at home. Patricia could be very angry and aggressive. Her parents experienced difficulties in adapting their parenting to the level of intelligence and the developmental stage of Patricia. The school advised the parents to seek professional support for Patricia’s problems. The parents thought about their wishes and needs and they contacted an organisation specialised in supporting parents with a child with a disability. This organisation offered home-based support in learning parenting skills and informed parents about the impairments of a child with an intellectual disability. Patricia’s parents were happy to hear that the feelings they had are common and that someone can help them.

The evidence on the prevalence of a need for formal parenting support of parents with children with BMID aged 5–12 years is insufficient. Research on parents of children aged 10–24 years with moderate to mild ID does show a high need for support related to the emotional and behavioural problems of the child (88.2%), which can vary from simply needing someone to talk to, to information on child mental health care and/or respite care (Douma, Dekker, & Koot, 2006). Other research shows that 70.6% of those parents with a child with ID and psychopathology feel a need for all kinds of professional help in order to reduce the child’s problems (Douma, Dekker, de Ruiter, Verhulst, & Koot, 2006). Furthermore, children with BMID seem to have lower risks of behavioural and emotional problems than children with moderate levels of ID and therefore probably have less need for parenting support (Chadwick, Kusel, & Cuddy, 2008; Daily, Ardinger, & Holmes, 2000; Einfeld, Piccinin, et al., 2006; Einfeld, Tonge, Gray, & Taffe, 2006; Koskentausta, Iivanainen, & Almqvist, 2007). Besides intelligence, other factors like parenting stress, coping skills, and parental resilience may influence the need of parents for support in raising a child with ID (Lloyd & Hastings, 2009; Shogren & Turnbull, 2010; Strnadová & Evans, 2007). The specific way in which these factors determine the need for support of parents with BMID is unknown.

There is insufficient evidence on the determinants of need for support in parents, particularly for those with children with BMID. When it comes to children with disability in general, it is known that they have extensive healthcare needs and high rates of health-service use compared to children without disability (Bramlett, Read, Bethell, & Blumberg, 2009; Dekker, Koot, van der Ende, & Verhulst, 2002). The need for support and/or services in parents of children without ID has been shown to be greater in cases where there are internalizing, externalizing, and academic problems with the child, and, when it comes to adolescents, when they are in lower levels of education (Verhulst & van der Ende, 1997; Zwaanswijk, van der Ende, Verhaak, Bensing, & Verhulst, 2003). Moreover, family-related factors such as family stress, parenting psychopathology, and one-parent families are associated with a greater need for help of any type (Verhulst & van der Ende, 1997; Zwaanswijk et al., 2003).

In short, evidence on the prevalence of need for parenting support among parents of children with BMID is insufficient, and it is unclear who within this group are most in need of parenting support. Therefore, the aim of this study was to determine in families with a child with BMID: (a) the prevalence of need for parenting support, and (b) the child and parent characteristics that are associated with a need for parenting support. Insight into determinants of need for support may indicate which parents especially may benefit from parenting support so
that a positive change in the behaviour of children with BMID can be reached.

**Methods**

We obtained data on parents of children with BMID in the northern parts of the Netherlands (the provinces of Groningen, Friesland, Drenthe, and a part of Overijssel). Ethical permission for the study was obtained from the Medical Ethics Committee of the University Medical Center Groningen.

**Sample and procedure**

We obtained a sample of parents of children with borderline (IQ 70–85) and mild (IQ 70–50) ID in a two-step procedure. First, schools were asked to participate in the invitation of parents of children with BMID aged 5–12 years. In the Netherlands, children aged 5–12 years with BMID mainly attend three types of schools for special educational needs, known in Dutch as “SBO,” “REC 3,” and “REC 4.” SBO (Speciaal Basis Onderwijs: special primary education) includes children with borderline intellectual disability (IQ 70–85), learning difficulties, and/or behaviour difficulties. REC 3 (Regional Expertise Center cluster 3) is a school for children with physical disability, mild to severe intellectual disability (IQ < 55 or IQ 56–70 with other severe disability), and/or chronic diseases. REC 4 (REC cluster 4) serves children with psychiatric and/or behavioural disorders without borderline ID (IQ > 85) or with borderline ID (IQ 70–85; Eurydice Network, 2013; Oeseburg, 2010). In total 49 schools (75%) agreed to participate. The main reasons for non-participation of schools were participation in other research, being under increased monitoring by the superintendent of schools, and having too little time. Nonparticipating schools did not differ from participating schools in terms of location (rural or urban) and type of school (SBO, REC 3, or REC 4).

Second, via the participating schools researchers sent out information with an informed consent form and a questionnaire to about 2,500 parents of a child with BMID. To increase the response rates of parents, we offered assistance in filling out the questionnaire. In addition, the school sent a reminder to all parents who did not respond after 4 weeks. Moreover, in cooperation with the school, the researchers published information about the study in a newsletter in order to motivate parents.

In total, 1,027 (41%) parents filled out the questionnaire. Of these, 69 parents were excluded for various reasons, such as (a) the child lived in residential care (excluding foster care), (b) the parents were unable to speak Dutch, (c) information about the child’s IQ was not available, (d) the parents lived outside the research area, or (e) an older brother or sister (with a higher Strengths and Difficulties Questionnaire [SDQ] score) was also participating in the study. Fourteen parents did not answer the outcome measurement and were not included in the analyses. A nonresponse analysis showed that there were no major differences in response in terms of gender of the child.

**Variables**

Need for parenting support was measured using the following parent-reported question (Spears, 2010): “Do you need support in bringing up your child?” This question could be answered as “yes” or “no.” “Yes” could be filled in if the parent needed any parenting support or if the parent needed more parenting support at that particular moment. If the parent did not need any parenting support or did not need additional parenting support, the parent answered “no.” We did not provide a definition of parenting support, but instead we asked the parents to keep in mind their own definition.

**Child’s psychosocial problems** were measured with the Dutch translated and validated version of the Strengths and Difficulties Questionnaire (SDQ), parent version. The SDQ consists of 25 items detailing positive and negative aspects of the child’s behaviour. These questions cover five subscales of five items each: Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Relationship Problems, and Prosocial Behaviour. Each item can be scored on a 3-point scale (0 = not true, 1 = somewhat true, and 2 = certainly true). The first four subscales together (20 items) generate a Total Difficulties Score (TDS) ranging from 0–40 (Goodman, 1997; van Widenfelt, Goedhart, Treffers, & Goodman, 2003). This total score was standardised, leading to z scores.

Parenting stress was measured with the short Dutch version of the Parenting Stress Index (PSI; de Brock, Vermulst, Gerris, & Abidin, 1992). This questionnaire consists of 25 statements about experiences related to child characteristics, parent characteristics, and situations that are directly related to the role of being a parent. Each item can be scored on a 6-point scale (1 = totally disagree to 6 = totally agree), which together generates the Total Parenting Stress Score (de Brock et al., 1992). This total score was standardised, leading to z scores.

**Background characteristics** involved family composition, parenting education, parenting employment, parenting problems, and receiving parenting support. **Family composition** was categorised as (a)
two biological parents, and (b) other: one parent, co-
parents, and adoptive and foster parents. Parental
education was categorised as (a) low education: ele-
mentary or lower levels of secondary education,
(b) middle: higher levels of secondary education or
intermediate vocational education, and (c) high: uni-
versity of applied sciences or university education.
Parental employment was categorised as (a) yes: if at
least one parent worked more than 12 hours per
week, and (b) no: if both parents together worked
less than 12 hours a week (Statistics Netherlands
[CBS], 2013). Parental problems were measured
with the question of whether there were alcohol
and/or drug problems, and/or psychiatric problems,
or no problems in the last 2 months (yes/no). Type
of school was registered after the school agreed to par-
ticipate in the study. There were three types of
schools participating: SBO, REC 3, and REC
4. Finally, current receipt of parenting support was
measured by answering the question about receipt
of parenting support with: “Yes, I receive parenting
support,” or “No, I do not receive any support.”

Data analysis
Data were analysed using IBM SPSS Statistics
Version 20. First, we described the prevalence of
need for parenting support and the characteristics
of the sample of parents with and without a need
for parenting support. Differences between these
two groups were tested using t tests and Pearson
chi-square tests. For all differences, effect sizes
according to Cohen’s d were calculated. Cohen
defines an effect size of up to 0.20 as trivial; of
\( \geq 0.20 \) to \(< 0.50\) as small; of \( \geq 0.50 \) to \(< 0.80\) as mod-
erate; and of \( \geq 0.80\) as large (Cohen, 1977). Second,
univariate logistic regression was used to select vari-
ables that were significantly associated with a need
for care, leading to crude odds ratios (OR). Third,
all variables with a \( p \) value \(< .20 \) in the univariate
model, as well as age and gender, were entered in a
multiple logistic regression model with stepwise
backward selection until all remaining variables had
a significance level of \( p < .05 \). This yielded adjusted
odds ratios. In addition, the associated Nagelkerke’s
\( R^2 \) value as an approximation of the level of explained
variance was presented.

Results
Of all 944 parents, 134 (14.2%) had a need for par-
tenting support. Table 1 shows the characteristics of
the parents with and without a need for parenting
support. The child gender ratio in this study was
similar to the ratio of boys and girls in special
education in the Netherlands (66% boys and 34%
girls; Ministry of Education, Culture, and Science,
2009). Furthermore, parents with a need for parent-
ing support had more parenting stress and experi-
enced more psychosocial problems with their child.
In addition, the ratio between receiving and not
receiving parenting support differed significantly in
parents with a need for parenting support compared
to parents without a need for parenting support:
parents with a need for support received less
support than parents without a need for support.
Table 2 shows the univariate associations between
background, parenting, and child-related variables,
and need for parenting support. The univariate
factors associated with a need for parenting support
(\( p \) value \(< .20 \)) were family composition, type of
school, parenting stress, child psychosocial
problems, and receiving parenting support.
Table 3 shows the results of the multiple logistic
regression analyses. After the backward selection pro-
cedure the best combination of determinants associ-
ated with a need for parenting support were age of the
child, gender, parenting stress, and child psychoso-
cial problems, with a total amount of explained var-
iance of 22% (Nagelkerke’s \( R^2 \)). Family
composition, type of school, and receiving parenting
support were removed from the multivariate model.
Only those variables are listed that were entered
and not removed in the stepwise regression pro-
cedure. Thus, after adjustment for gender and age,
parents with more parenting stress and children
with higher child psychosocial problems had a
higher need for parenting support.

Discussion
We found a much lower prevalence rate of need for
parenting support, 14.2%, than other studies that
reported rates of 70–80% (Douma, Dekker, de
Ruiter, et al., 2006; Douma, Dekker, & Koot,
2006). This lower prevalence rate may be due to
two factors. First, in this study we refer to parenting
support as formal support for parents that aims to
reduce problems and support parents in their role
of raising children with BMID, whereas Douma,
Dekker, de Ruiter, et al. (2006), and Douma,
Dekker, and Koot (2006) had defined the support
more broadly, namely, any support for the parent
or the child to cope with behavioural and emotional
problems of their child, including psychological ser-
vices and someone to talk to (Douma, Dekker, de
Ruiter, et al., 2006; Douma, Dekker, & Koot, 2006).
Second, this discrepancy in rates of need for
support can be partly explained due to differences
in type of problems in the population that was
Need for parenting support

Table 1. Characteristics of parents with and without a need for parenting support

<table>
<thead>
<tr>
<th></th>
<th>Need for parenting support</th>
<th>No need for parenting support</th>
<th>p value</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 134 (14.2%)</td>
<td>n = 810 (85.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of child (years), Mean (SD)</td>
<td>9.78 (1.9)</td>
<td>9.82 (2.0)</td>
<td>.83</td>
<td>.30</td>
</tr>
<tr>
<td>Gender of child, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boys</td>
<td>80 (59.7%)</td>
<td>521 (64.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Girls</td>
<td>54 (40.3%)</td>
<td>288 (35.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family composition, n (%)</td>
<td></td>
<td></td>
<td>.06</td>
<td></td>
</tr>
<tr>
<td>Two parents</td>
<td>83 (62.4%)</td>
<td>566 (70.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>50 (37.6%)</td>
<td>236 (29.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational level of mother, n (%)</td>
<td></td>
<td></td>
<td>.55</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>21 (15.9%)</td>
<td>97 (12.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle</td>
<td>52 (39.1%)</td>
<td>316 (40.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>60 (45.1%)</td>
<td>371 (47.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational level of father, n (%)</td>
<td></td>
<td></td>
<td>.51</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>20 (15.3%)</td>
<td>103 (14.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle</td>
<td>33 (24.8%)</td>
<td>239 (34.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>60 (45.1%)</td>
<td>360 (51.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental employment, n (%)</td>
<td></td>
<td></td>
<td>.32</td>
<td></td>
</tr>
<tr>
<td>At least one parent employed &gt; 12 hrs/week</td>
<td>99 (81.8%)</td>
<td>632 (85.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No parent employed &gt; 12 hrs/week</td>
<td>22 (18.1%)</td>
<td>109 (14.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental problems, n (%)</td>
<td></td>
<td></td>
<td>.78</td>
<td></td>
</tr>
<tr>
<td>No problems</td>
<td>121 (92.4%)</td>
<td>735 (93.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol and/or drugs problems and/or psychiatric problems</td>
<td>10 (7.6%)</td>
<td>55 (7.0%)</td>
<td></td>
<td></td>
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<tr>
<td>Type of schoola</td>
<td></td>
<td></td>
<td>.01</td>
<td></td>
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<tr>
<td>REC 4</td>
<td>7 (5.3%)</td>
<td>41 (5.1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>REC 3</td>
<td>43 (32.6%)</td>
<td>166 (20.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SBO</td>
<td>82 (62.1%)</td>
<td>599 (74.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parenting stress (PSI-short), Mean (SD)</td>
<td>79.0 (25.1)</td>
<td>54.9 (24.1)</td>
<td>&lt; .001</td>
<td>0.98</td>
</tr>
<tr>
<td>Child psychosocial problems (SDQ), Mean (SD)</td>
<td>19.3 (5.3)</td>
<td>13.8 (6.2)</td>
<td>&lt; .001</td>
<td>0.76</td>
</tr>
<tr>
<td>Receiving parenting support, n (%)</td>
<td></td>
<td></td>
<td>&lt; .001</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>74 (55.2%)</td>
<td>313 (38.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>60 (44.8%)</td>
<td>497 (61.4%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Sum of n is not equal to the total n due to missing data.*

included. Douma, Dekker, de Ruiter, et al. (2006), and Douma, Dekker, and Koot (2006) included only children aged 10–24 years with mild to moderate ID (IQ 30–80), and perceived emotional or behavioural functioning (Douma, Dekker, de Ruiter, et al., 2006; Douma, Dekker, & Koot, 2006). We included younger children aged 5–12 years with borderline to mild ID (IQ 50–85), independent of whether they had emotional and behavioural problems. Of course, inclusion of only those children with emotional and behavioural problems will lead to higher prevalence rates of need for support (Bramlett et al., 2009; Einfeld, Piccinin, et al., 2006, Einfeld, Tonge, et al., 2006), and restriction to that group will not provide estimates that apply to the total population. Thus our estimate is probably more valid and shows that the need for professional parenting support is relatively low in general populations of parents of children with BMID.

We found only two factors that were multivariate associated with a need for parenting support, namely, parenting stress and psychosocial problems. This confirms previous findings (Verhulst & van der Ende, 1997; Vogels, Crone, Hoekstra, & Reijneveld, 2009; Zwaanswijk et al., 2003). Nevertheless, we found no other potentially relevant factors, such as family composition, parental education, parental employment, and parental problems, to be associated with a need for parenting support. We cannot compare this finding to previous studies, as none of the studies assessed this association in a population of parents with children with BMID. However, studies among parents of children without BMID reported associations of need for parenting support with family factors such as one-parent families, parenting psychopathology, and educational level (Verhulst & van der Ende, 1997; Zwaanswijk et al., 2003). This may be interpreted as being that the determinants of a need for parenting support differ between parents of children with and without BMID.

We also found—as other studies have—that, in the univariate analysis, receiving parenting support was
negatively associated with a need for support (Bramlett et al., 2009; Dekker et al., 2002). However, when conducting multiple regression analyses with adjustment for parenting stress and the psychosocial problems of the child, receiving parenting support was no longer a determinant of a need for parenting support. An explanation may be that parents with high parenting stress and children with psychosocial problems receive more parenting support than parents with fewer problems. Therefore, they will have less need for other, additional parenting support.

**Strengths and limitations**

Important strengths of this study are its high participation rate among schools (75%), its large sample size, and its coverage of a general, unselected population of parents of children with BMID. A limitation is the relatively low response rate of 42%. This may have led to a selection bias; for example, parents with problems may participate in research less frequently than parents without problems (Olsson & Hwang, 2006, 2008). Because data on non-
respondents were limited, we checked for differences in gender between the study sample and the Dutch population of children with BMID. This showed no differences with regard to gender.

Conclusion and implications
This study shows that 14.2% of parents with a child with BMID had a need for parenting support. High parenting stress and child psychosocial problems were associated with a need for parenting support after adjustment for gender and age. Need for parenting support among parents of children with BMID in this study seems to be less prevalent than previously assumed; yet one in seven of these parents does need parenting support. Further research is needed to confirm the prevalence rate we found. Furthermore, need for parenting support is more likely when parents experience stress or when their child has psychosocial problems. Therefore, professionals working with children with BMID and their parents should monitor parenting stress and psychosocial problems and refer them for support in a timely fashion if necessary.

Our results also may indicate that the currently available parenting support does not fully meet the need of parents for parenting support. The development of interventions and use of more effective parenting support programs may partially solve this problem.

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