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# Supporting parents of youths with intellectual disabilities and psychopathology

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## Abstract

*Background* Parents of children and adolescents with both intellectual disabilities (ID) and psychopathology often experience high levels of parenting stress. To support these parents, information is required regarding the types of support they need and whether their needs are met.

*Method* In a sample of 745 youths (aged 10–24 years) with moderate to borderline ID, 289 parents perceived emotional and/or behavioural problems in their child. They were asked about their needs for support and whether these needs were met. Logistic regression analysis revealed the variables associated with both needing and receiving specific types of support. In addition, we asked those parents who had refrained from seeking support about their reasons.

*Results* Most parents (88.2%) needed some supports, especially a friendly ear, respite care, child mental health care and information. Parents who perceived both emotional and behavioural problems in their child needed support the most. In addition, parents whose child had any of these problems before the past year, who worried most about their child and suffered from psychopathology themselves, more often needed support. Parents of children with moderate ID or physical problems especially needed 'relief care', that is, respite care, activities for the child and practical/material help. The need for a friendly ear was met most often (75.3%), whereas the need for parental counselling was met least often (35.5%). Not receiving support despite having a need for it was primarily related to the level of need. Parents who indicated to have a stronger need for support received support more often than parents who had a relatively low need for support. The parents' main reasons for not seeking support concerned their evaluation of their child's problems (not so serious or temporary), not knowing where to find support or wanting to solve the problems themselves first.

*Conclusions* Most parents had various support needs that were frequently unmet. Service providers should especially aim at providing information, activities, child mental health care and parental counselling. Furthermore, parents need to be informed about where and how they can obtain what kind of support. A case manager can be of help in this.

**Keywords** adolescents, children, need for help, parents, psychopathology, support

## Introduction

Parents of children and adolescents (further referred to as youths) with intellectual disabilities (ID) often

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experience higher levels of parenting stress than parents both of typically developing youths (Hastings 2002; Hastings & Beck 2004) and youths without ID but with a chronic physical illness (Floyd & Gallagher 1997). Consequently, a substantial number of parents of youths with ID are in need of a variety of support, such as information, child care (e.g. respite care), family and social support (e.g. someone to talk to, leisure activities), community services (e.g. doctor), help with explaining the child's disability to others and financial support (Bailey *et al.* 1992; Petr & Barney 1993; Carr & O'Reilly 1996; Treneman *et al.* 1997; Bailey *et al.* 1999; Chadwick *et al.* 2002; Ellis *et al.* 2002).

In addition to the ID, many of these youths also have emotional or behavioural problems (Emerson 2003; Wallander *et al.* 2003). These additional problems, and especially behavioural problems (Angold *et al.* 1998), frequently lead to even higher levels of parental stress, which are likely to exceed the parents' abilities to deal with their child themselves (Hayden & Goldman 1996; Floyd & Gallagher 1997; Maes *et al.* 2003). Help to support these families seems warranted (Maes *et al.* 2003). In order to do so, information is required about their actual support needs. However, we know of only one qualitative study that investigated the support needs of parents of 17 2- to 36-year-olds with mild to severe ID, autism (in most children) and problem behaviour. Various needs were reported, such as the need for some time away or a break, a chance to relax (respite care, vacations), and helpful information regarding, for example, how to find successful child care and to take care of their own physical and mental health (Turnbull & Ruef 1996). To date, there are no quantitative data available from representative samples that describe the needs of parents whose child has ID and emotional or behavioural problems. This study is aimed at providing these data.

Additionally, understanding factors that generate the need for specific types of support is required to identify which families need what kind of support. However, we do not know any study that investigated this in parents of youths with ID, and studies in the general population are often limited to investigating variables related only to the need for child mental health care. Fortunately, results from these latter studies offer indications on variables that might also be associated with the need for other types of support by parents of youths with ID. For example, these studies showed that the type of problem a child experienced was related to parental needs. Parents whose child suffered from both emotional and behavioural problems, as opposed to one or the other, needed help the most (Wu *et al.* 1999). Furthermore, these studies revealed several other child (e.g. age, sex and ethnicity), parent (e.g. educational level and psychopathology) and family variables (e.g. social support) that were associated with needing child mental health care (Verhulst & Van der Ende 1997; Wu *et al.* 1999; Poduska 2000; Horwitz *et al.* 2003). Finally, knowledge about discrepancies between the need for and obtaining of support (i.e. met vs. unmet need) will reveal the types of support that service providers should especially focus on or improve (Treneman *et al.* 1997; Hazell *et al.* 2002).

Because the parents' subjective perception of emotional or behavioural problems in their child, rather than the assessed psychopathology, is a prerequisite for actually seeking help (Baker & Heller 1996), we focused on those parents who perceived such problems. Our aim was to gain insight into (1) the specific support needs of parents who perceive emotional and/or behavioural problems in their child with ID; (2) the extent to which these needs for support are met; (3) the variables related to both needing and receiving support; and (4) the parental role in unmet need, that is, their reasons for not seeking help.

## Method

### Subjects

This study is part of a longitudinal Dutch study on psychopathology in youths with ID that started in 1996. In the Netherlands, at that time, almost all children with moderate to mild ID attended special schools for children with mild ID (IQ range 60–80) or children with moderate ID (IQ range 30–60). Children who predominantly have behavioural problems or who have ID and additional severe physical problems (e.g. visually or hearing impaired) which require special care and/or special educational support attend other schools or day-care centres.

In 1996, 115 of all 132 schools for those with mild and moderate ID in the province of Zuid-Holland randomly selected 20% of their students, resulting in a sample of 1615 children (aged 6–18 years). Of these,

219 were excluded because they exceeded the age criteria, were not living at home or their parents had problems with the Dutch language. Of the remaining 1396 children, 231 parents could not be contacted in person. A total of 982 parents filled out at least one of the core instruments at Time 1 (T1 response = 70.3% and 84.3% of those that were personally contacted). Significantly, more parents of children from schools for children with moderate ID participated ($P < 0.01$). About 1 year later, the Time 2 assessment was conducted. A detailed description of the sampling procedure can be found elsewhere (Dekker *et al.* 2002). The present study is based on data collected at Time 3 (T3; October 2002–January 2004).

The T3 target sample consisted of 1007 children whose parent had in some way participated at T1, minus one child who had died, but including seven children who were excluded at T1 because they (slightly) exceeded the age criteria. Children were traced through consulting phonebooks and municipal registers. In only 46 cases, we were unable to locate or personally contact the parents because of, for example, emigration. Of the 961 parents we could contact, 749 participated (T3 response = 77.9%; overall study response = 53.4%).

We found no significant differences ($\chi^2$, or *t*-test, $P > 0.05$) between the 749 T3 participants and 258 non-participants on T1 measures regarding the children's average age, sex and level of additional physical problems or parental psychopathology. However, parents more often participated when their child had attended a school for children with moderate ID, and when their child's Total Problems score on the Child Behavior Checklist fell in the borderline/clinical range (Achenbach 1991). Furthermore, when the parents were of Dutch origin, not single, and had a higher socio-economic status (SES) and educational level, the parents' participation was also higher ($P < 0.05$). After adjusting for the correlation between these variables, we found that only significantly fewer non-Dutch parents had participated at T3 ($P < 0.05$).

For this study, those 289 youths were included whose parents perceived their emotional or behavioural functioning as (somewhat) problematic, which was 38.8% of all 745 parents for whom this information was obtained. Table 1 shows this sample's characteristics.

**Table 1** Sample characteristics ($n = 289$)

| Variables | % |
|---|---|
| Child | |
| Male | 60.9 |
| Age (mean, SD) | 16.5, 2.9 |
| Moderate ID | 37.0 |
| At least one negative life-event | 46.7 |
| Past psychopathology | 71.3 |
| Physical problems (higher level) | 22.4 |
| Parent | |
| Single parent | 21.2 |
| At least one parent is Dutch | 87.2 |
| Medium/high SES | 49.0 |
| Medium/high educational level | 48.8 |
| Parental psychopathology | 26.2 |
| Problematic parenting | 24.3 |
| Problematic parent–adolescent relationship | 25.3 |
| Parental worries (more) | 44.4 |
| Sufficient social support | 72.1 |
| Family | |
| More than one child in the family | 90.7 |
| Hostile family functioning | 18.7 |
| Negative involvement | 23.9 |

SD, standard deviation; ID, intellectual disabilities; SES, socio-economic status.

Compared with the 456 youths whose parents did not perceive additional problems, these 289 youths had significantly more emotional and behavioural problems, as indicated by the Child Behavior Checklist. Also, they more often had these problems before the past year, and the relationship with their parent(s) was problematic more often.

## Instruments

As no instrument was available that could adequately answer this study's questions about support needs of parents, we constructed the *Need for Help Questionnaire*. This questionnaire was based on an extensive literature study, and on semi-structured interviews with eight parents of dually diagnosed children and with seven service providers. We gathered information on these parents' various needs for support, where they went for support and their reasons for not seeking support, despite having a need for it. The questionnaire starts with two screening questions on the 'Parental perception of emotional or behavioural

problems', followed by seven questions about 'Need for support', and seven questions about the level of 'Met need' and 'Reasons for not seeking support'.

*Parental perception*

Parental perception of emotional or behavioural problems was determined through two separate questions. We asked parents how, in general, they thought their child had been doing in the past year regarding his/her (1) emotional; and (2) behavioural functioning (either 'very good', 'good', 'neither good nor bad', 'bad', or 'very bad'). When parents answered 'neither good nor bad', 'bad' or 'very bad' on either or both of these questions, we considered them to perceive (some) emotional and/or behavioural problems. For 82.0% of these 289 youths, standardized psychopathology measures confirmed the presence of emotional or behavioural problems, that is, a deviant score either on Child Behavior Checklist's Total Problems, Internalizing or Externalizing, or on a syndrome scale. Of the 289 parents, 56.7% perceived both emotional and behavioural problems, 21.3% only behavioural and 22.0% only emotional problems.

*Need for support*

To ensure that parents only reported about their needs for support because of their child's additional emotional or behavioural problems, but not about needs that were solely related to their child's ID, only those parents who perceived these problems were asked about their support needs. They were asked to what extent in the past year they had needed any of seven specific types of support because of their child's emotional or behavioural problems ('no need', 'some need', 'reasonably strong need' and 'very strong need'). The types of support were: (1) a friendly ear for the parents/someone to talk to; (2) information; (3) activities for the child; (4) respite care; (5) practical or material help; (6) child mental health care; and (7) parental counselling, specifically aimed at better handling their child's problems. Whenever parents answered with anything except 'no need', we regarded them as having had that particular need for support in the past year. For additional analyses, we dichotomized the level of need into 'low need' ('some need') and 'high need' ('reasonably strong need' and 'very strong need').

*Met need*

Next, for each type of support, we separately asked whether they had ever received that type of support. We dichotomized their answers into 'currently met need' (i.e. receiving help 'at this moment', or 'at this moment and in the past') and 'unmet need' (i.e. 'never received help' or 'only in the past').

*Reasons for not seeking support*

To study the parental role in unmet need for support, we asked parents who were with a currently unmet need for support and had not sought help, to what extent each of the 24 given reasons for not seeking help applied to them ('not at all', 'somewhat', 'very much so'). Some examples are: considering their child's problems as not so serious, or as temporary, too busy with other things, negative experiences with or no trust in professional help and not knowing where to find help.

## Child variables and instruments

*Level of intellectual disabilities.* We administered two verbal (Information, Vocabulary) and two performance subtests (Picture Completion, Block Design) of the Wechsler Intelligence Scale for Children-III that are known to be highly correlated with full IQ (Wechsler 1991; Kaufman *et al.* 1996). We distinguished between two levels of ID: moderate ID (IQ range 40–54) and mild-borderline ID (IQ ≥ 55). An estimated full IQ was obtained for 228 of the 289 included youths (78.9%), because not all parents consented to their child's participation to this study, and not all youths wanted to participate themselves. For 25 of those youths, we had reliable IQ scores from school records at T1. This meant that we did not have an IQ score for 36 youths. To reduce this number of missing cases, we analysed how well T1 school type could serve as a proxy for ID level. In this study, 79.2% of the youths originally attending a school for children with mild ID had an IQ in the mild-borderline ID range, and 77.0% of the youths originally attending a school for children with moderate ID had an IQ in the moderate ID range. An IQ was not obtained for 22 youths from schools for children with mild ID, and for 14 youths from schools for those with moderate ID. This implies that of the

289 youths, only 2.8% might be assigned to an ID group incorrectly by using T1 school type as a proxy. Therefore, whenever an IQ was unavailable, we assigned youths from schools for children with mild ID to the mild-borderline ID group and those from schools for children with moderate ID to the moderate ID group.

Using a short version of the *Life Events Questionnaire* (Berden *et al.* 1990), parents reported whether their child had experienced any of 20 major life-events in the past 2 years (e.g. one parent leaving the household, dying of a loved one, hospitalization for at least a fortnight). If so, they were asked how their child was affected by this event (positive, neutral or negative). A dichotomized variable was created for youths who experienced at least one negative life-event or none.

*Past psychopathology* was assessed by asking: 'Did your child have emotional or behavioural problems before the past year ('yes'/'no')?'

The *Wahler Physical Symptoms Inventory* (Wahler 1968) inquires about the frequency a child is affected by 42 different physical problems, for example, pains, nausea, sleeping problems (6-point scale, ranging from 'almost never' to 'almost every day'), etc. The sum of all scores was dichotomized using one standard deviation (SD) above the mean as cut-off, resulting in youths with high vs. relatively low levels of physical problems.

## Parent and family variables

*Socio-economic status* was assessed by taking the highest occupational level of either one of the parents (Central Bureau of Statistics 1993). We split these levels into 'low SES' (i.e. unemployed, unskilled work or work at a lower vocational training level) vs. 'medium/high SES' (all higher levels of work).

*Parental educational level* was assessed by taking the highest completed educational level of either parent. Lower educational level implies a degree from a lower vocational training or trade school or lower, and medium/high educational level implies a high school diploma or beyond.

The *Young Adult Self-Report* assesses psychopathology in the primary caregiver in the past 6 months (Achenbach 1997). We used the short version containing 29 of the original 110 items that discriminated best between referred and non-referred subjects (Wiznitzer 1993; Verhulst & Van der Ende 1997). One SD above the general population normative sample mean was taken to differentiate between healthy functioning caregivers and caregivers with higher levels of psychopathology (i.e. parental psychopathology).

*Problematic parenting* was assessed through the 34-item Parent Domain of the Stress Index for Parents of Adolescents (SIPA) (Sheras *et al.* 1998), which assesses four areas of functioning that relate to a parent's distress as he/she interacts with the adolescent. It contains the scales: Life Restrictions, Relationship with Spouse/Partner, Social Alienation and Incompetence/Guilt (5-point scale: 'agree' to 'disagree'). The Parent Domain score was dichotomized at the 85th percentile, resulting in problematic vs. non-problematic parenting.

The 16-item *Adolescent–Parent Relationship Domain* score of the SIPA reflects the perceived quality of the relationship the parent has with the adolescent. Elevated scores suggest the absence of a close and mutually supportive relationship. The Adolescent–Parent Relationship Domain score was dichotomized at the 85th percentile to distinguish between problematic vs. non-problematic parent–adolescent relationship.

The *Parental Worries Scale* was constructed at T1 and contains 31 items about various worries parents may have regarding their child in the past 6 months (e.g. social life, health and future independent functioning), which was answered on a 5-point scale (from 'never' to 'very often'). The sum of the item scores was dichotomized at the 75th percentile.

Perceived *social support* was determined with a single statement: 'I have enough people I can turn to when I am in need of emotional or practical help', to be answered on a 4-point scale, and then characterized as sufficient support ('fully agree', 'agree') and insufficient support ('fully disagree', 'disagree').

The *Hostility* and the *Involvement* scales of the validated Dutch questionnaire for Family Problems (VGP) were used to assess Hostile family functioning and Negative involvement in the family (Koot 1997). The Hostility scale contains 17 items about, for example, being mean to others, lying, arguing, swearing and hitting, and the Involvement scale contains 8 items about, for example, avoiding, indifference to and too little compassion with others. Both scales

were scored on a 3-point scale ('not at all', 'sometimes', 'often'). Scale scores were dichotomized consistent with the Dutch norms (95th percentile).

### Statistical analyses

Descriptive data analyses were performed to describe sample characteristics, the prevalence of support needs and level of met need. Chi-square tests and Student's *t*-tests were used to investigate significant differences between participating and non-participating parents.

To detect what factors significantly increased the likelihood of parents needing support, and of currently met need, we performed univariate logistic regression analyses for each type of support individually, which provide odds ratios (ORs) that indicate the extent of the increased likelihood. Multiple logistic regression analyses, using all significant variables from the univariate analyses, identified the variables with the strongest unique association.

## Results

Most parents (88.2%) needed some type of support because of their child's emotional or behavioural problems. Moreover, 67.4% needed at least three different types of support. Table 2 shows the proportions of parents who needed a particular type of support (column 2). The supports most often needed were 'a friendly ear', 'information' and 'child mental health care' .

Compared with parents who perceived only emotional or only behavioural problems, parents who perceived both types of problems needed support the most (Table 2, column 3–5). Table 3 shows the accompanying ORs, as well as those of other variables significantly associated with needing support. Single parenthood, perceived social support and negative involvement within the family were not significantly associated, and therefore excluded from Table 3.

In general, the type of problems parents perceived, the child's past psychopathology, parental psychopathology and having many parental worries about their child increased the odds of needing any type of support. Furthermore, higher parental educational level and SES, problematic parenting and hostile family functioning also increased the odds of needing support. More specifically, parents of youths with moderate ID or physical problems especially needed some form of relief care, that is, 'activities', 'respite care' and 'practical or material help'. Results regarding other variables are presented in Table 3.

The last column of Table 2 shows the percentages of currently met need. Need for 'a friendly ear', 'respite care' and 'information' were most often met

**Table 2** Support needs of parents who perceived emotional or behavioural problems in their ID child (overall and per type of problems separately) and the extent of currently met need (all %)

| | | Indicated need split up by type of problem perception | | | |
|---|---|---|---|---|---|
| **Type of support** | **Indicated need* (*n* = 282)** | **Emotional problems only (*n* = 63)** | **Behavioural problems only (*n* = 59)** | **Emotional and behavioural problems (*n* = 160)** | **Met need†** |
| Friendly ear | 78.1 | 63.5 | 76.3 | 84.4 | 75.3 |
| Information | 68.0 | 46.0 | 62.7 | 78.3 | 51.3 |
| Activities | 50.9 | 38.1 | 42.4 | 58.7 | 38.5 |
| Respite care | 38.9 | 15.9 | 37.3 | 48.1 | 61.1 |
| Practical/material help | 24.1 | 7.9 | 16.7 | 33.3 | 42.6 |
| Child mental health care | 56.7 | 38.1 | 49.2 | 67.3 | 40.6 |
| Parental counselling | 48.8 | 23.8 | 47.5 | 58.7 | 35.5 |

*More than one need possible.

†% of all parents who needed this type of support.

ID, intellectual disabilities.

**Table 3** Variables that are related to parents having a particular need for support because of perceived emotional and/or behavioural problems in their child: significant results from univariate and multiple (bold) logistic regression analysis (all $P < 0.05$)

| | Type of support | | | | | | |
|---|---|---|---|---|---|---|---|
| **Variables** | **Friendly ear OR, 95% CI** | **Information OR, 95% CI** | **Activities OR, 95% CI** | **Respite care OR, 95% CI** | **Practical/ material help OR, 95% CI** | **Child mental health care OR, 95% CI** | **Parental counselling OR, 95% CI** |
| Perception of problems | | | | | | | |
| Behavioural vs. emotional | | | | 3.2, 1.3–7.4<br>**3.3, 1.2–9.3** | | | 2.9, 1.3–6.3 |
| Behavioural and emotional vs. emotional | 3.1, 1.6–6.0<br>**2.6, 1.2–5.6** | 4.2, 2.3–7.9<br>**3.6, 1.7–7.6** | 2.3, 1.3–4.2 | 4.9, 2.3–10.3<br>**4.3, 1.7–11.1** | 5.8, 2.2–15.3<br>**3.2, 1.1–9.7** | 3.3, 1.8–6.1 | 4.6, 2.4–8.8<br>**3.8, 1.7–8.4** |
| Behavioural and emotional vs. behavioural | | 2.1, 1.1–4.1 | 1.9, 1.1–3.5 | | 2.5, 1.2–5.3 | 2.1, 1.2–3.9 | |
| Child | | | | | | | |
| Male | | 1.7, 1.0–2.8 | | | | | 1.7, 1.0–2.7 |
| Age* | | | | | | | 0.9, 0.8–1.0 |
| Moderate ID | | | 1.7, 1.0–2.7<br>**2.0, 1.0–3.7** | 2.8, 1.7–4.6<br>**3.4, 1.7–6.8** | 2.2, 1.2–3.8<br>**2.4, 1.2–5.0** | | |
| At least one negative life-event | | | | | 1.8, 1.0–3.2 | | |
| Past psychopathology | 2.4, 1.3–4.3 | 4.6, 2.6–7.7<br>**3.0, 1.6–5.7** | 2.8, 1.6–4.8<br>**2.0, 1.0–4.0** | 3.5, 1.9–6.4<br>**3.1, 1.4–7.1** | 3.4, 1.6–7.2 | 5.2, 2.9–9.1<br>**4.8, 2.3–9.9** | 3.6, 2.1–6.4<br>**3.5, 1.7–7.2** |
| Physical problems (higher level) | | | 2.2, 1.2–3.9 | 2.2, 1.2–3.8 | 2.0, 1.1–3.7 | | |
| Parents | | | | | | | |
| At least one parent is Dutch | | | 2.4, 1.1–5.1 | | | | |
| Medium/high SES | | | 1.8, 1.2–3.0 | 1.7, 1.0–2.7 | | 1.9, 1.1–3.0 | |
| Medium/high educational level | | 1.7, 1.0–2.8 | 2.0, 1.2–3.2 | 2.0, 1.3–3.3<br>**2.8, 1.2–6.4** | | 2.0, 1.2–3.2 | |
| Parental psychopathology | 3.0, 1.3–7.0<br>**2.6, 1.0–6.8** | 2.8, 1.4–5.6<br>**2.3, 1.0–5.1** | 2.2, 1.2–3.8 | 2.1, 1.2–3.6 | 2.4, 1.4–4.4 | 2.4, 1.3–4.3 | 2.2, 1.3–3.9 |
| Problematic parenting | | | 2.6, 1.4–5.0 | 2.1, 1.1–3.8 | 3.0, 1.6–5.7<br>**2.2, 1.0–4.8** | 2.4, 1.3–4.7 | 2.8, 1.4–5.2 |
| Problematic parent–adolescent relationship | | | | | | 1.8, 1.0–3.2 | |
| Parental worries (more) | 2.8, 1.4–5.3 | 3.3, 1.9–5.8<br>**2.1, 1.1–4.1** | 4.6, 2.7–7.7<br>**2.9, 1.4–5.7** | 4.3, 2.6–7.2<br>**3.2, 1.6–6.5** | 5.8, 3.1–10.7<br>**2.8, 1.3–5.9** | 4.3, 2.5–7.3<br>**3.1, 1.6–6.0** | 2.7, 1.6–4.4 |
| Family | | | | | | | |
| More than one child in family | | 2.5, 1.1–5.6 | | | | | |
| Hostile family functioning | 5.1, 1.5–17.0<br>**3.7, 1.1–13.0** | 2.8, 1.3–6.4 | 2.3, 1.2–4.4 | | | | 2.4, 1.3–4.7 |

*Continuous variable, for every unit increase, the odds of needing support increase by this number.
OR, odds ratio; CI, confidence interval; ID, intellectual disabilities; SES, socio-economic status.

(75.3%, 61.1% and 51.3%), whereas the other support needs were met in less than 43% of the time.

Table 4 shows the variables significantly related to parents having their need for support met. Sex of the child, past psychopathology, single parenthood, parental psychopathology, problematic parent–adolescent relationship, social support, number of children, problematic family functioning (hostility and negative involvement) and the type of problems that parents perceived in their child were not related to met need, and are therefore excluded from Table 4.

For almost all types of support, different variables were related to met need. However, of all variables, a high need for support (vs. low) most often and most strongly increased the odds of receiving 'a friendly ear', 'respite care' and 'child mental health care'. In addition, parents who worried most about their child more often received 'information'. Parents of younger children and with a moderate ID more often received 'activities'. Parents who had less problems with parenting more often received 'practical/material help', and a higher SES was related to receiving 'parental counselling'.

Finally, regardless of the type of support that was needed, the parents' main reasons for not seeking support were: wanting to solve the problems them-

**Table 4** Variables that are related to having a particular need for support met: significant results from univariate and multiple (bold) logistic regression analysis (all $P < 0.05$)

| | Type of support | | | | | | |
|---|---|---|---|---|---|---|---|
| **Variables** | **Friendly ear ($n = 219$) OR, 95% CI** | **Information ($n = 193$) OR, 95% CI** | **Activities ($n = 143$) OR, 95% CI** | **Respite care ($n = 108$) OR, 95% CI** | **Practical/ material help ($n = 68$) OR, 95% CI** | **Child mental health care ($n = 160$) OR, 95% CI** | **Parental counselling ($n = 138$) OR, 95% CI** |
| Level of indicated need | | | | | | | |
| High need (vs. low) | 2.8, 1.5–5.2<br>**2.6, 1.4–4.9** | | | 5.8, 2.5–13.4<br>**5.8, 2.5–13.4** | | 3.6, 1.8–7.1<br>**2.8, 1.4–5.9** | |
| Child | | | | | | | |
| Age* | | | 0.9, 0.8–1.0<br>**0.9, 0.8–1.0** | | | | |
| Moderate ID | 2.1, 1.0–4.1 | | 2.2, 1.1–4.4<br>**2.2, 1.1–4.4** | | | | |
| Physical problems (higher level) | | | | | 0.3, 0.1–1.0 | | |
| At least one negative life-event | | | | | | 2.0, 1.0–3.8 | |
| Parents | | | | | | | |
| Medium/high SES | | | | | 3.1, 1.1–8.5 | | 2.7, 1.3–5.6<br>**2.7, 1.3–5.6** |
| Medium/high educational level | | | | | 5.0, 1.7–14.9 | | |
| Parental worries (more) | | 2.3, 1.3–4.1<br>**2.3, 1.3–4.1** | | | | 2.0, 1.0–4.0 | |
| Problematic parenting | | | | | 0.1, 0.0–0.3<br>**0.1, 0.0–0.4** | | |

*Continuous variable, for every unit increase, the odds of receiving activities increase by this number.
OR, odds ratio; CI, confidence interval; ID, intellectual disabilities; SES, socio-economic status.

selves, considering the problems not so serious, not knowing where to find support and considering the problems as temporary.

## Discussion

We investigated needs for support in parents of youths with both ID and psychopathology as these situations often lead to high levels of parenting stress that are likely to exceed the parents' abilities to deal with the stress themselves. Because the subjective perception of emotional or behavioural problems is a prerequisite for needing and seeking help (Baker & Heller 1996), we asked parents who perceived either or both types of problems about their support needs and whether these needs were met.

### Need for support

Almost all parents needed at least one type of support, and more than two-thirds needed three or more different types. Compared with studies on parents of youths with ID but without emotional or behavioural problems (e.g. Bailey *et al.* 1992; Ellis *et al.* 2002), parents in our study had higher levels of need for support. This is consistent with these parents' higher levels of parenting stress found in other studies (Floyd & Gallagher 1997). In addition, parents who perceived both emotional and behavioural problems needed support the most, followed by parents who perceived only behavioural problems, whereas parents who only perceived emotional problems needed support the least. This trend was also found in the general population (Angold *et al.* 1998; Wu *et al.* 1999). It seems that emotional problems are less disturbing or have less impact on family life than (additional) behavioural problems (Angold *et al.* 1998) which are characterized by, for example, aggression and stubbornness.

Like parents of youths with ID but without additional psychopathology, the parents' needs for support were very diverse. Overall, the needs most often reported ('a friendly ear' and 'information') were not aimed at directly dealing with their child's problems, but rather at providing the parents informal or emotional support, or advice. In contrast, fewer parents needed formal support or professional help (such as 'child mental health care' or 'parental counselling'). This is consistent with the tendency of people to first seek informal support and to regard formal support as a last resort (Beresford 1994; Zwaanswijk *et al.* 2003).

Some types of support needs were relatively low, such as need for 'activities' and 'respite care'. This can be explained by the fact that these needs are usually more often present in parents of youths with more severe ID and younger age. In this study, these youths were a minority; 37% had a moderate ID, and 27.3% were 14 years of age or younger. Finally, the parents' unawareness of the existence of 'practical or material help' might explain why only one-quarter indicated a need for this support. It might also be that this type of support was not their highest priority.

Regarding the variables related to needing support, variables that represent increased parental stress (e.g. perceiving both emotional and behavioural problems, parental psychopathology, worries about the child and problems with parenting and within the family) especially increased the odds of needing (almost) all types of support. Of these variables, parental psychopathology might also negatively influence their feelings of competence in dealing with their child's problems themselves. Furthermore, circumstances that make it more likely to know what help is available (the child's past psychopathology, higher parental educational level and higher SES) were also related to needing support. These findings are quite similar to the ones found associated with the need for child mental health care in general population studies (Verhulst & Van der Ende 1997; Wu *et al.* 1999; Poduska 2000; Horwitz *et al.* 2003). However, our study showed that this is true not only for needing child mental health care, but also for needing other types of support.

While most variables were related to needing various types of support, our results showed that both moderate ID and additional physical problems were uniquely related to needing some kind of 'relief care', that is, 'respite care', 'activities' and 'practical/material help'. These types of support are particularly meant to relieve the burden on parents, which is likely to be higher when these stress-inducing conditions are also present.

### Met need

None of the indicated needs for support were completely met; the need for 'a friendly ear', 'respite care'

and 'information' were most often met (>50%), but the need for 'practical/material help', 'child mental health care', 'activities' and 'parental counselling' often remained unmet (<43.0%). Differences in accessibility between formal (professional) and informal sources of help are one possible explanation for these differences (Suarez & Baker 1997). Informal sources of help, such as the parents' own social network, the library or the Internet, are easier to access than formal or professional help. In order to receive 'activities', 'practical/material help', 'child mental health care' or 'parental counselling', parents must generally turn to the main providers of this kind of help – professional organizations. However, as stated before, turning to professional help is usually not the first step parents choose to take (Beresford 1994).

The variables that were found to be significantly related to receiving support did not reveal a consistent pattern across types of support, that is, the circumstances that increase met need seem to be different for the seven support types. However, a higher need for support especially increased the odds of obtaining three types of support, 'a friendly ear', 'respite care' and 'child mental health care'. It is likely that these parents are more inclined to actively seek support than parents who do not feel such a strong need. Similar reasoning might apply to the finding that parents who worried most about their child more often received information. Furthermore, parents with low SES and low educational level might be less aware of where they can find professional help, such as 'parental counselling' and 'practical/material help' than parents with higher levels of SES and education. The interpretation of the association between problematic parenting and receiving 'practical/material help', however, is not straightforward, because the wide confidence interval indicates that this result lacks precision and is not very reliable.

We also asked the parents about their main reasons for not seeking help. In general, regardless of the type of support needed, their reasons related to their evaluation of their child's problems (not so serious or as temporary), wanting to solve these problems themselves first, and not knowing where to find help. These barriers seem to apply generally, as they have also been found in general population studies regarding barriers to seeking mental health care (Pavuluri *et al.* 1996; Flisher *et al.* 1997; Freedman & Boyer 2000; Owens *et al.* 2002). The last barrier also touches on the service providers' role in unmet need, for example, through local unavailability, or lack of a central place to find information (Quinn *et al.* 1996; Freedman & Boyer 2000). However, since this study only included the perspectives of parents, no firm conclusions can be drawn about the exact role of service providers and their contribution to unmet needs for support.

Although, nonrandom sample attrition might limit the generalization of our results to non-Dutch parents, and we were not able to directly compare the support needs between parents whose child only had ID and whose child had additional emotional or behavioural problems, the present study's results point to several possibilities to reduce the level of unmet need. Service providers need to become aware of these parents' high level and diversity of needs for support, which were higher than of parents of youths with ID but without additional problems. Subsequently, service providers will have to aim at providing these types of support, and, if they are not able to provide it themselves, to help parents getting in contact with alternative service providers. In addition, it is important to provide parents with information not only about these services, but also about characteristics of these emotional and behavioural problems (in order for parents to obtain a realistic picture of their child's problems), how to handle them and where to find what types of support. Service providers can provide this information through, for example, the Internet or leaflets. Special education schools and school psychologists can also help distribute this information, but a central information source is preferable. By assigning a case manager, these issues can also be dealt with, as he or she should know the signs of psychopathology, where to find appropriate support and can mediate between the parents and those service providers (Hastings & Beck 2004).

Finally, this study underscores the importance of service providers to (continue to) address both the child's problems and the parents' and family's ability to deal with these problems, as other stressful circumstances especially increased the odds of needing help.

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