Mental Health Problems in Youths with Intellectual Disability: Need for help and help-seeking

Emotionele problemen en gedragsproblemen bij jongeren met verstandelijke beperkingen:
Hulpbehoefte en hulp zoeken

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Rotterdam, 2006

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Chapter 1
General introduction

In this thesis, the results are presented of a follow-up study of the one that started in 1996 (Dekker, 2003). That study was focused on psychopathology in children and adolescents with intellectual disabilities (ID), i.e., on the assessment of psychopathology (Dekker, Nunn, & Koot, 2002; Dekker, Nunn, Einfeld, Tonge, & Koot, 2002), the prevalence and impact of these emotional and behavioural problems and psychiatric disorders (Dekker & Koot, 2003a; Dekker, Koot, Van der Ende, & Verhulst, 2002), and on the child and family predictors of psychiatric disorders (Dekker & Koot, 2003b).

Results from that study, but also from other studies, showed that many children and adolescents with ID have emotional or behavioural problems or a psychiatric disorder, i.e., psychopathology (Dekker & Koot, 2003a; Einfeld & Tonge, 1996). Moreover, compared with typically developing peers, children and adolescents with ID have a three to four times increased risk for developing these problems (Bregman, 1991; Dekker, Koot et al., 2002; Dykens, 2000; Emerson, 2003b; Linna et al., 1999; Wallander, Dekker, & Koot, 2003). Furthermore, the sparsely available longitudinal studies show that psychopathology in youths with ID is quite persistent. Follow-up studies showed that about 70% of youths with ID and psychopathology still suffered from these problems one to four years after first assessment (Wallander et al., 2003), and more than 50% still did up to nine years later (Tonge & Einfeld, 2003).

While the ID itself is a serious handicap, the additional presence of psychopathology has been found associated with even more critical circumstances for both the child/adolescent, and his/her parents and family. For example, these youths are at increased risk for injuries (Sherrard, Tonge, & Ozanne-Smith, 2002), and out-of-home placement (Hayden & Goldman, 1996; McIntyre, Blacher, & Baker, 2002). These emotional and/or behavioural problems can also lead to restrictions in family activities, but also to embarrassment and shame, higher levels of parental psychopathology, and family dysfunction (Emerson, 2003a). Furthermore, their families are more often socially and materially disadvantaged (Emerson, 2003b), and the levels of parenting stress are also higher than of parents of typically developing youths (Dyson, 1997; Hastings & Beck, 2004; Maes, Broekman, Dosen, & Nauts, 2003; Orr, Cameron, Dobson, & Day, 1993), but also of parents of non-ID children with a chronic illness (Floyd & Gallagher, 1997).

Evidently, professional help for these youths with ID and additional problems, and/or their families is crucial. However, despite the high prevalence and stability of these problems and the negative consequences, just about one third of youths with ID and psychopathology receive help from mental health services, such as from psychiatrists or psychologists (Dekker & Koot, 2003a; McCarthy & Boyd, 2002). It is yet not exactly clear what causes this discrepancy between the high prevalence of psychopathology and low treatment rates in these youths with ID. The same is true for typically developing youths, for whom this discrepancy has also been detected (Zwaanswijk, Verhaak, Bensing, Van der Ende, & Verhulst, 2003). Previous research has shown that parents in general, but especially parents of youths with ID, have an important role in the initiation of the help-seeking process (Borthwick-Duffy, 1994; Edelstein & Glenwick, 1997; Moss, Bouras, & Holt, 2000). How these parents fulfil this role, and why some parents seek help and obtain help, where other parents do not, has not been thoroughly studied. In this thesis, these issues will be addressed.

The key objectives of this study are to:
1. determine the objective and subjective need for mental health services of youths with ID and their parents,
2. identify determinants of objective and subjective need for help and help-seeking for mental health problems,
3. predict objective and subjective need from earlier adjustment of the youths, and
4. identify discrepancies between need for help and help obtained, and to identify determinants of these discrepancies.

In the remainder of this first chapter, we will clarify these objectives by discussing the definitions and assessment of 'need for help', and the help-seeking process or pathway to obtaining help.

Need for help

There are several definitions of the concept 'need'. For example, back in 1972 Bradshaw described the concept of social need and distinguished four types: normative need, felt need, expressed need and comparative need (Aoun, Pennebaker, & Wood, 2004; Bradshaw, 1972).

A *normative need* is defined in objective terms and is determined by experts, such as psychiatrists or general practitioners, on the basis of research and professional opinion, or a 'standard'. If an individual fails to meet a desirable standard, he/she is identified as being in need. When someone meets the criteria of a psychiatric disorder as defined by, for example, the Diagnostic and Statistical Manual of mental disorders-DSM-IV (American Psychiatric Association, 2000), he/she can be considered as being in need of mental health services. A problem with this definition of normative need, however, is that there may be different criteria of these standards, or that these criteria change in time.

A *felt need* is defined as 'a wanting need'. This type of need is a subjective need for help, and involves what people say they want or need. This can be assessed by directly asking people about their needs in a survey, or interview. Bradshaw argues that felt need by itself also is an inadequate measure of real need, because it is limited by the perception of the individual. When someone is not aware of the existence of specific services, they might not express a need for it. On the other hand, there are also people who ask for help, but not really need it.

Expressed need can be regarded as 'demand', i.e., it is a felt need changed into action, which is demonstrated by people's use of services or demand of new or more services. Under this definition, in health services, waiting lists are an indication of unmet need. However, this is a poor definition, as it does not take into account the needs of those who are not currently in contact with services, or who are pre-symptomatic.

A *comparative need* can relate to both geographical areas and individuals. The first one is determined by comparing the services available in one geographical area with those in other areas, i.e., a need is the gap between the services that exist in one area compared with those in another area. The second one is determined by comparing the relative access to psychiatric services of persons with a similar psychiatric disorder. If persons with similar disorders do not receive services, whereas others do, they are said to be in need.

The difficulty with this definition is how to exactly define the similarity in psychiatric disorders.

Costello and colleagues also give an overview of definitions of need for mental health services. They differentiate between needs defined as: service use, diagnosis, functional impairment, and exposure to risk (Costello, Burns, Angold, & Leaf, 1993).

Need defined as *service use* relates to how many individuals receive mental health services during a particular time period. Counting the number of service users can assess this need. This is a very restrictive definition and it implies that there is no such thing as 'unmet need', as all people who need these services also receive them.

The definition of need as the presence of a *diagnosed* disorder is comparable to Bradshaw's definition of normative need. The determination of who is in need and who is not depends on various factors, such as who is interviewed, what tools are used to assess a diagnosis, and how the results are interpreted. However, Costello et al. conclude that, despite these potential weaknesses, the prevalence rates of psychiatric disorders are quite consistent across studies. Hence, under this definition a population's level of need for mental health services also seems to be quite consistent.

A *functional impairment* as a consequence of the diagnosis is a stricter definition than meeting the criteria of a diagnosis per se. An individual is only regarded as needing help when he/she also experiences significant problems in everyday life as a result of the diagnosed disorder. It is not clear when someone really needs services; is someone in need when he/she is impaired in one aspect of life, and is there hierarchy in the various aspects of life?

The fourth definition regards need as *exposure to risk*. This implies that a person needs mental health services when he/she is exposed to circumstances that are known to increase the risk of becoming mentally ill. Risks can be assessed at various levels (e.g., biological, psychological, or social) and in different developmental periods in life. A difficulty with this definition might be that of the various circumstances, or specific combinations of circumstances that are related to becoming ill, only a few, or even none, are known. This makes it hard to accurately assess this need for help.

While the definitions of Bradshaw (1972) contain both objective and subjective needs for help, those described by Costello et al. (1993) can all be regarded as objective needs for help. Of these objective needs for help, most commonly, mental health need has been defined and studied as meeting the criteria of a diagnosis with or without impairment. This definition also seems the most robust one; despite different criteria or standards, it has been concluded that prevalence rates of psychiatric disorders, and thus objective need for help, are quite consistent across studies. This also seems to be true for youths with ID. As mentioned before, several studies have found a three to four times increased risk for developing these problems in youths with ID compared with peers without ID. This definition of objective need has already been comprehensively studied in Phase 1 of this study, and will also receive attention in another Phase 3 study that has been conducted parallel to this thesis' study. However, two specific aspects of objective need for help have received little attention in the literature on youths with ID, namely the assessment of an objective need for help defined as meeting the criteria of emotional or behavioural problems, through self-reports, and information on a specific objective need for help, i.e., antisocial and delinquent behaviours and its determinants. In this thesis, we first studied the extent to which youths with ID are able to contribute to the assessment of emotional or behavioural problems. It is very likely that, as in the general population, parents are not fully aware or informed about their child's emotional and behavioural functioning. In the general population, the youths' own contribution to the diagnostic process of assessing psychopathology is considered to be very important (Van der Ende, 1999), but this has received relatively little attention in studies on youths with ID. Second, we studied the prevalence and predictors of antisocial and delinquent behaviours. Despite the fact that (1) these behaviours bring about a heavy burden and major costs to society (Scott, Knapp, Henderson, & Maughan, 2001), and (2) several studies showed that individuals with ID are more often engaged in these undesirable behaviours than persons without ID (Hall, 2000; Hodgins, 1992; Simpson & Hogg, 2001a), little is known about the prevalence and predictors of these behaviours in youths and young adults with ID.

With respect to the aforementioned definitions of need for help, by studying these two types of 'objective need for help', we studied an objective need for help as a diagnosis or a normative need, but also as exposure to risk. Regarding the latter, by studying the predictors of antisocial and delinquent behaviours, our aim was to identify the specific circumstances that increase the odds of engaging in these undesirable behaviours.

The subjective need for help (a felt need) has received little attention in studies. In addition, little is known about the relation between the objective need and the subjective perception of need (Srebnik, Cauce, & Baydar, 1996). The presence of an objective need for help does not inevitably lead to having a subjective need for help (Andrews, 2000). Conversely, a subjective need for help does not automatically imply that someone meets the criteria of a disorder (objective need). Therefore, in this study, we explored both the objective and subjective need for help and its interrelation.

Help-seeking process or pathway

For youths with and without ID, the level of unmet need appears to be high. As mentioned before, a considerable gap has been found between the number of children and adolescents who have mental health needs or who have a disorder and those who actually receive help for these problems. In order to bridge this gap, we need to know more about the nature of this gap (Srebnik et al., 1996). The framework of the help-seeking pathway, or the help-seeking process, contributes to gaining insight into the origins of this gap, and how to bridge it. It provides the critical link between psychiatric, or emotional and behavioural problems, and the provision of mental health care (Rogler & Cortes, 1993).

In the past years, several pathways to mental health care have been suggested. For the adult population, the framework of Goldberg and Huxley (1980) has received a lot of attention. Their pathway consists of levels and filters and represents the steps that have to be taken in order for individuals with a psychiatric disorder to receive mental health care. For this study, the model of the *referral pathway* by Verhulst and Koot (1992) is more relevant as it deals with receiving psychiatric care for children and adolescents. Their model is an adaptation of the framework of Goldberg and Huxley and is transformed to the field of child and adolescent psychiatry (Goldberg & Huxley, 1980; Verhulst & Koot, 1992). The main difference between the two models lies in the persons that have to take action. In the model of Goldberg and Huxley the individuals seek help for themselves, while in the model of Verhulst and Koot the parents or caregivers seek help for their child.

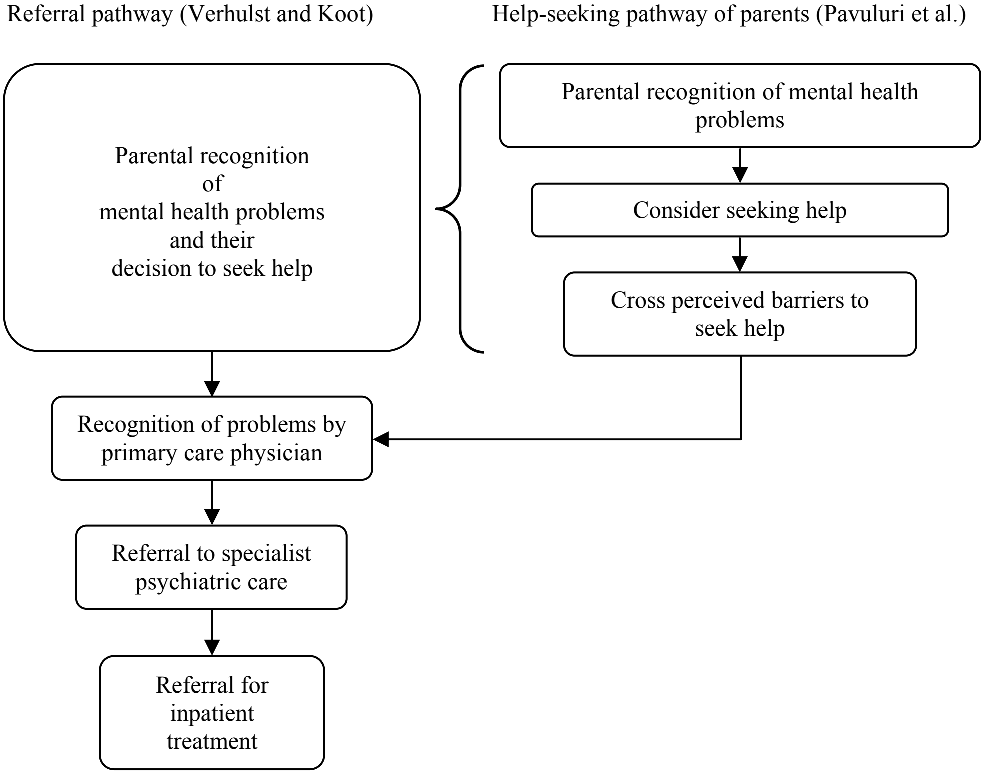
In brief, this framework of Verhulst and Koot consists of levels and filters. Each level indicates a specific setting in which mental health problems can be manifested (e.g., in the community, and among attenders of primary care). In order to go to the next level in the pathway to receiving mental health services, one has to pass through a filter (see Figure 1.1). The filters describe the selection processes, or the actions, that determine who of the children and adolescents go on to the next level to eventually receiving help, and who of them remain stuck at a certain level. At *level 1*, at the community level, a child or adolescent has emotional or behavioural problems or a psychiatric disorder; the child/adolescent has an objective need for help. To go to level 2 (to become an attender of primary care), parents will have to recognise these problems and make the decision to consult a primary care physician. Both these activities are part of the *first filter* and can be considered to entail the parents' subjective need for mental health care for their child. At *level 2*, the referred child/adolescent gets examined by the primary care physician. The activity of *filter 2* is for the primary care physician to recognise the child's psychopathology. At the *third level*, the primary care physician has assessed the psychopathology and recognised the problems. Subsequently, at *filter 3* he has to refer the child to specialist psychiatric care. Finally, when the child has entered the specialist psychiatric care (*level 4*), some may be referred to inpatient treatment (*filter 4*).

At each filter, several factors and circumstances can have an effect on whether or not a child passes on to the next level. For example, the type and severity of the child's problems is not only related to whether the parents recognise the problems and decide to consult a primary care physician (filter 1), but also to the recognition of these problems by the primary care physician (filter 2), and the referral to specialist psychiatric care (filter 3). Furthermore, the parents' educational level, distress threshold, and social support from family and friends affect the activities and outcomes of the filters (Farmer, Stangl, Burns, Costello, & Angold, 1999; Foets, Cuperus, Spreeuwenberg, Verhaak, & Van Engeland, 1996; Garralda & Bailey, 1988; Pavuluri, Luk, & McGee, 1996; Sourander et al., 2001; Verhulst & Van der Ende, 1997; Wu et al., 2001). Specific characteristics of the primary care physician, such as his expertise, interview techniques, and availability of screening measures are associated with passing through filter 2 (Dulcan et al., 1990; Stiffman, Chen, Elze, Dore, & Cheng, 1997; Stiffman et al., 2000; Zwaanswijk et al., 2003). His attitude towards psychiatrists and his confidence in his own ability to manage the child's problems himself are related to passing through filter 3 (Verhulst & Koot, 1992). Finally, whether a child gets admitted to inpatient treatment (filter 4) has been found to depend on the availability of both beds and primary caretakers, and of financial circumstances (Flisher et al., 1997; Verhulst & Koot, 1992).

A complement to the Verhulst and Koot model is the model of the *help-seeking pathway* as proposed by Pavuluri, Luk and McGee (1996). While the Verhulst and Koot model postulates the first filter as one unit, Pavuluri et al. state that, to comprehensively study the parental role, this first filter should not be considered as one activity. They suggest refining this filter and splitting it up into three different filters (see Figure 1.1). Just as in the model of Verhulst and Koot, at the *first level* a child has emotional or behavioural problems, but the *first filter* of Pavuluri's model only includes the parents' recognition of psychopathology in their child. At *level 2*, the parents have recognised the problems, but they subsequently have to consider getting help for these problems. This is their activity of *filter 2*, which can be regarded as an indication of their subjective need for help. However, considering getting help is not the same as actually seeking help. Parents have to cross perceived barriers in getting help, which is the activity of the *third filter* (Pavuluri et al., 1996). After this third filter, parents have actually sought help.

Then, basically, the help-seeking pathway continues at level and filter 2 of the pathway of Verhulst and Koot as described above (see also Figure 1.1).

Figure 1.1
Filters of the referral pathway and of the help-seeking pathway of parents



In order to study the levels and filters, and the factors associated with passing through the filters of the entire pathway to eventually receiving specialist psychiatric help, information from all actors is indispensable. Unfortunately, it was not feasible in our study to investigate the role and perspectives of the primary care physician and specialist psychiatric services. However, since parents have an important role in this process, and they usually are the ones to initiate the help-seeking process, and are sometimes even regarded as the main gatekeepers for access to specialist services (Dulcan et al., 1990; Sayal, Taylor, Beecham, & Byrne, 2002), it is important to unravel their role in seeking and obtaining help.

Not just children, but also adolescents rely on their parents or caregivers to initiate the help seeking process (Logan & King, 2001). This is even more true for youths with ID, because they are often, more or less, limited in their verbal expression of their psychological wellbeing (Borthwick-Duffy, 1994; Edelstein & Glenwick, 1997; Moss et al., 2000). Therefore, the pathway proposed by Pavuluri et al., although developed for parents of pre-school children with behavioural problems, was selected as a framework for our study to comprehensively investigate the parental role in seeking help for psychopathology in their child with ID.

The fact that the level of unmet need is high implies that not all parents and children passed through all filters of the pathway. The majority remains stuck at a level, because they fail at carrying out the activities of the next filter. In the study of Pavuluri et al. that explored this model, not recognising the psychiatric problems in their child, and not overcoming perceived barriers in seeking help were both major blocks in the help-seeking process.

Studying this refined model of Pavuluri et al. may provide insight into the number of parents and youths that pass through these filters, or fail at doing so, and studying the variables that are related to passing through may provide a clearer and more detailed picture of the actual pathway to seeking and receiving help; where exactly does the dropping out take place and what forces, decisions and actions are involved (Logan & King, 2001)?

Although the importance of studying these various steps has been acknowledged (Baker & Heller, 1996; Costello & Janiszewski, 1990; Offord et al., 1987; Stiffman et al., 1997), many studies in the general population focused primarily on the outcome of the process, i.e., child mental health service use (Angold et al., 2002; Angold et al., 1998; P. Cohen & Hesselbart, 1993; Costello & Janiszewski, 1990; Gunther, Slavenburg, Feron, & Van Os, 2003; Jensen, Bloedau, & Davis, 1990; Offord et al., 1987; Sayal, 2004). Moreover, we are not aware of any study that examined the role in the help-seeking process of parents whose child not only has psychopathology, but also has ID.

Even though the pathway itself and the individual steps are similar irrespective of the population that is being studied, the adolescent's ID might hamper the help-seeking process and its outcome (Borthwick-Duffy, 1994; Moss et al., 2000). Recognition of psychopathology can be more difficult, because, especially those with a more severe ID are not or are less capable of verbally describing their feelings. Consequently, especially the parents are the ones to recognise their child's problems and interpret them as being psychiatric problems. This interpretation has been found to be a problem, not only for parents, but also for professionals. This has been referred to as 'diagnostic overshadowing', i.e., ascribing the symptoms of mental illness/disorder to the ID and not to a psychiatric disorder (Reiss, Levitan, & Szyskzo, 1982). Furthermore, higher parental educational level has been found to increase parental recognition (Verhulst & Koot, 1992), but parents of youths with ID generally have lower educational levels (Dekker, Nunn, & Koot, 2002). This might also impede these parents' recognition of their child's psychopathology and their subsequent help-seeking. These issues underscore the importance of studying the help-seeking pathway of parents of youths with ID even more, but also of investigating the possibility of using self-reports of youths with ID on their own emotional and behavioural functioning.

Studying the help-seeking process of parents of youths with ID, and the factors that are related to passing through the filters and to receiving help will give more precise directions about the measures that can be taken to avoid dropping out of the help-seeking process, and to reduce the level of unmet need in this at-risk population.

This thesis

The main focus of this thesis is to provide insight into the parents' objective and subjective need for help/support, their help-seeking process to actually seeking and receiving (professional) help for their child's emotional or behavioural problems over and above the ID.

After thoroughly studying the literature, we concluded that there was no instrument available that would enable us to answer the questions of this study (key objectives). We therefore constructed this instrument ourselves. This instrument and the sampling procedure and sample characteristics are presented in *Chapter 2* (Method).

The next three chapters are devoted to disentangling these parents' subjective needs for help, the help-seeking process, and level of met need (key objectives 1, 2, and 4). More specifically, in *Chapter 3*, we thoroughly study the first step/filter of the help-seeking pathway. When either the Child Behavior Checklist (Achenbach, 1991a; Verhulst, Van der Ende, & Koot, 1996) or the Diagnostic Interview Schedule for Children – Parent version (Shaffer, Fisher, Lucas, & Comer, 2000; Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000) indicated the presence of emotional and/or behavioural problems or a psychiatric disorder in a child/adolescent, defined in this study as an objective need for help, we investigated the extent to which their parents also subjectively perceived these problems, i.e., the extent to which they recognised or were aware of their child's psychopathology, and the factors associated with awareness. We distinguished between parental awareness of their child's (1) emotional problems, (2) behavioural problems, and (3) unspecified (emotional or behavioural) problems.

In *Chapter 4*, we unravel the help-seeking process of those parents who subjectively perceived emotional and/or behavioural problems in their child on top of the ID. Because not the assessed psychopathology, but rather the subjective perception of parents of emotional or behavioural problems is a prerequisite for actually seeking help (Baker & Heller, 1996), in this chapter we focus on those parents who subjectively perceived these problems. We examined their subjective need for professional help (child mental health care or parental counselling). Whenever this particular need for professional help was present, we studied these parents' actual help-seeking. We also studied the factors that were associated with taking each of these three steps, among which the child's psychopathology or their objective need for help. When parents had refrained from seeking professional help, we asked them about their reasons for doing so.

As stated before, additional emotional or behavioural problems in a child with ID frequently lead to high levels of parental stress (Floyd & Gallagher, 1997; Hayden & Goldman, 1996; Maes et al., 2003). Even though providing help is likely to reduce these stress levels, this does not necessarily imply that mental health care is required. Reducing these parents' stress levels can also be achieved by offering other types of help, for example respite care, in order for the parents to regain their strengths to deal with their child's problems themselves. To gain insight into how these parents are best supported, in *Chapter 5* we explore the specific subjective needs for support of parents who perceived emotional and/or behavioural problems in their child with ID (e.g., getting information, respite care, child mental health care, or practical/material help), and the extent to which these needs were currently met. We also investigated the factors associated with needing support and met need.

The next two chapters (*Chapter 6 and 7*) are concentrated on ascertaining the youths' objective need for help. While the Phase 1 study provided extensive information about the prevalence of psychopathology in youths with ID (Dekker & Koot, 2003a; Dekker, Koot et al., 2002), we examined two other ways of assessing these youths' objective need for help. First of all, in *Chapter 6*, we study whether the Youth Self-Report (YSR) can be used to obtain reliable self reports of emotional and behavioural problems from adolescents with ID (normative need/diagnosis; key objective 1). Until recently information from self-reports has only seldom been used to assess psychopathology in youths with ID (Emerson, 2005), while this type of information may be highly valuable in the diagnostic process.

Secondly, in *Chapter 7*, we determine whether a specific objective need for help can be predicted from earlier adjustment (key objective 3). More precisely, we studied the prevalence, five-year persistence, and child, parent and family predictors of different types of antisocial and delinquent behaviours (e.g., truancy and running away from home, physical aggression, theft, and setting fires) in youths with mild to borderline ID. To ascertain whether these behaviours have different predictors for boys and girls, and for younger and older youths, we tested for moderating effects of sex and age. To determine whether more youths with ID engaged in antisocial and delinquent behaviours (ADBs) than youths without ID, we compared the prevalence rates of these two groups of youths. Finally, we investigated whether specific types of ADBs tended to co-occur, i.e., whether profiles of ADBs can be distinguished in youths with ID.

Finally, in *Chapter 8*, we discuss this study's main finding and conclusions, and give recommendations for future studies and clinical implications.

Chapters 3 to 7 contain individual studies that are presented in the regular lay-out of scientific journals. Hence, there is considerable overlap between some of these chapters regarding the method section on the sample and the instruments used in this study.

2 | Method

Chapter 2
Method

In this chapter, we will first discuss the study's sampling procedure and provide the main characteristics of the Phase 3 (or Time 3) sample. In the second part of this chapter, we will describe how the two core instruments of this study, the 'Need for Help Questionnaire', and the 'Help-seeking Interview' were developed. Most of the other instruments and variables that were used in this study are similar to the ones used at Phase 1 and Phase 2 (or Time 1 and Time 2). The instruments that were used in this study are displayed in Table 2.3 on page 31. Detailed information on these instruments and variables can be found in *Chapters 3 to 7*.

Sample

Phase 1 and Phase 2

As mentioned in *Chapter 1*, this study is the second follow-up (Phase 3) of a longitudinal Dutch study on psychopathology in children and adolescents (i.e., youths) with ID that started in 1996 (Phase 1). Children and adolescents (aged between 6 and 18 years) were sampled through schools and day-care centres for youths with ID. Then, in the Netherlands, almost all children with a moderate to borderline ID attended special schools for the 'educable' or children with mild learning problems or mild ID (School voor Moeilijk Lerende Kinderen: IQ range 60-80), schools for the 'trainable' or children with moderate ID or severe learning problems (School voor Zeer Moeilijk Lerende Kinderen: IQ range 30-60), or day-care centres for children with ID (IQs below 50 and additional physical problems or sensory handicaps).

As in the first follow-up study that was carried out in 1999 (Phase 2), parents of children who visited a day-care centre were excluded from this Phase 3 study, because of the small number of children that were included at Phase 1, and because of the heterogeneity of these children regarding level of ID and additional problems. In this chapter, we will therefore only discuss the sampling procedure of the children and adolescents from special schools for the 'educable' and 'trainable'.

In 1996, all schools for the 'educable' and 'trainable' in the province of Zuid-Holland were approached and informed about this study. About 20% of all Dutch citizens live in this province, and it comprises urban, rural, and semi-rural areas. A total of 115 of all 132 schools for the 'educable' and 'trainable' children agreed to participate, but significantly more schools for the 'trainable' than for the 'educable' participated (97.8% versus 81.6%). These schools randomly selected 20% of their students, resulting in a sample of 1,615 children (aged 6-18 years). Of these, 219 were excluded because they exceeded the age range, were not living at home, or their parents had problems with the Dutch language. Of the remaining 1,396 children, 231 parents could not be contacted in person. A total of 982 parents filled out at least one of the core instruments at Phase 1 (response = 70.3% and 84.3% of those that were personally contacted). Significantly more parents of children from schools for the 'trainable' than for the 'educable' participated ($p < .01$).

About one year later, in 1999, Phase 2 assessments were conducted in a random sample of 58% of the parents that were included in the first study, except parents of youths from day-care centres. More detailed information on the sampling procedure and the sample characteristics of both Phase 1 and Phase 2 can be found in Table 2.2 and elsewhere (Dekker, 2003; Dekker, Koot et al., 2002).

Phase 3

Parents

The present study is considered to be the third phase of the study, even though for about half of the sample it was the second time they were requested to participate. Data was collected between October 2002 and January 2004. The target sample consisted of 1,001 children whose parent(s) had in some way participated at Phase 1. Of these, in the in between years, one child had died, resulting in 1,000 children. However, we decided to include seven children who were excluded at Phase 1 because they (slightly) exceeded the age range. Therefore, in this Phase 3 study, the target sample consisted of 1,007 children and their parents.

About half of the children and parents were traced by comparing the addresses and phone numbers from Phase 1 and Phase 2 with the information in the phonebook. The other half was tracked down through different ways. We first sent letters and information about this study out to the remaining addresses of Phase 1, not knowing if these parents/caregivers still lived there, and asked them to inform us about their address and phone number. About a quarter provided us with the requested information. Second, we approached the municipal registers to inform us about the whereabouts of the children on the basis of their full names, dates of birth, and last known addresses. Almost all municipal registers co-operated. With the new gained addresses, we again consulted the phonebook and sent letters to these new addresses to receive their (new) phone number, so we could speak to them about this study in person. If no phone number was available, we instructed the interviewers to pay these addresses a visit, at least three times, and on different days, and at different hours.

Table 2.1
Reasons for not being able to locate or personally speak to parents/caregivers in Phase 3

Reasons	N
Emigration, or temporarily living abroad	9
Moved to a too faraway part of the Netherlands, phone number was unknown	4
Child/adolescent resided in institutions through which we were not able to contact the parents	3
Municipal register could not or did not provide the requested address	12
House looked uninhabited	2
Adolescent did not have any contact with her parents	1
The parents did not have any contact with their child	2
Door was not opened when we paid them a visit, nor did they respond to our requests to send us their phone numbers, and no name plate was on the door to affirm the name of the inhabitants	13
Total number	46

Eventually, we were able to personally speak to 961 parents or caregivers about this study, but in 46 cases we were not due to a number of reasons (see Table 2.1). Of the 961 parents or caregivers, eventually 749 either fully participated by filling out a booklet of questionnaires and doing an interview, or partly by filling out at least one questionnaire or doing at least one part of the interview. The Phase 3 response rate of those we could contact was 77.9%, and the overall study response rate counted from the Phase 1 target sample of 1,403 (1,396 + 7 excluded children) was 53.4%.

We found no significant differences (χ^2, or t-test, $p > .05$) between the 749 Phase 3 participants and 258 non-participants (including those we were not able to locate or contact) on Phase 1 measures regarding the children's average age (although the children of the participating parents tended to be somewhat younger, $p = .052$), sex, and level of additional physical problems, or parental psychopathology. However, parents more often participated when their child had attended a school for the 'trainable' ($\chi^2 = 9.7$, df = 1), had a deviant CBCL Total Problems score ($\chi^2 = 4.1$, df = 1), and both parents were of Dutch origin ($\chi^2 = 35.0$, df = 1), less often single ($\chi^2 = 11.0$, df = 1), and had a higher socio-economic status (SES: $\chi^2 = 19.0$, df = 1) and educational level ($\chi^2 = 13.6$, df = 1). Table 2.2 presents the Phase 3 sample characteristics. More specific details are provided in the next chapters.

Table 2.2
Sample characteristics of Phase 1, Phase 2 and Phase 3 (%)

Variables	Phase 1 N=982	Phase 2 N=474	Phase 3 N=749
Child			
Male sex	60.0	61.8	59.4
Mean age (SD)	11.6 (3.1)	12.8 (2.8)	16.8 (3.0)
Mild-borderline ID (versus moderate)	-	-	59.0
Phase 1 school for the 'educable'	69.2	77.4	66.6
Parent			
Single parent	15.8	15.2	21.2
≥ 1 parent is Dutch	77.3	88.2	85.3
Low SES (versus medium/high)	54.3	49.9	52.0
Low educational level (versus medium/high)	69.0	66.7	54.5

Children and adolescents

As the children and adolescents were between 10 and 24 years old at the time of Phase 3, we also wanted to gain information from the children/adolescents themselves. In order to locate and contact them, we followed the same procedure as we did to locate the parents. However, because at Phase 1 and Phase 2 only parents (and teachers) were asked to participate, and because it was likely that not all adolescents knew about this study, we first contacted their parents. Only after we got their permission to contact their child, we asked the adolescents themselves to participate. In 48 cases we were unable to locate or personally contact them. Besides not being able to contact their parents, there were two other adolescents we could not personally contact. One had run away from home shortly before we contacted the parents, and the mother of the other one was unable the give accurate information on her child's whereabouts. Furthermore, 140 parents did not give permission to contact their child. Of the remaining 819 eligible adolescents, 638 participated either fully, by taking an IQ-test – short form, and by doing a complete interview, or partially, by either taking the IQ-test, or completing at least one questionnaire (response rate = 77.9%).

Teachers - job coaches - supervisors

Teachers or job coaches were only asked to participate after we got permission of the parents and the youths themselves, when they were at least 18 years of age. In 48 cases, we could not trace the youths and/or their parents and therefore we could not ask their permission, resulting in 959 youths and/or parents we could ask their permission. This was refused in 299 cases. Another 16 did not supply us with the right or sufficient information, and 34 did not go to school nor had a job. A total of 610 teachers/job coaches were sent questionnaires of which 515 were completed and returned (response rate = 84.4%).

In *Chapters 3 to 7*, further information is presented about the Phase 3 sample characteristics.

Need for Help Questionnaire and Help-seeking Interview

As mentioned in *Chapter 1*, the primary aims of this study, among others, were to gain insight into the parents' objective and subjective need for help and the process of their help-seeking for their child's additional emotional or behavioural problems.

An objective need for mental health care generally refers to and has been determined as the presence of psychopathology, as indicated by, for example, a deviant score on a standardised instrument, such as the Child Behavior Checklist (Achenbach, 1991a) or Developmental Behaviour Checklist (Einfeld & Tonge, 2002), or meeting the criteria of a psychiatric disorder. The assessment of this objective need for help in youths with ID has received a fair deal of attention in recent years, among which in the Phase 1 study (Dekker, Nunn, & Koot, 2002; Dekker, Nunn, Einfeld et al., 2002). The opposite is true for the assessment of a subjective need for help, which refers to the parents' felt need for help as a consequence of their child's emotional or behavioural problems. This need for help might not only imply needing mental health care, but also needing other types of help for the parents to deal with these additional problems in their child with ID. However, regarding how to assess these subjective needs for help, we did not come across a suitable instrument in the literature. Therefore, the first object of this study was to construct an instrument to assess these subjective needs and to further inform us about the parents' help-seeking process.

Literature study

Through PubMed and PsychInfo, we searched and studied the literature on parental need for help, and on help-seeking for emotional and/or behavioural problems in young people with ID, but only with limited results (Petr & Barney, 1993; Turnbull & Ruef, 1996). Consequently, we broadened our search criteria and also studied literature on needs due to having an ID alone and not solely as a result of additional psychopathology. This resulted in an array of possible needs for help these parents can have (Bailey, Blasco, & Simeonsson, 1992; Bailey et al., 1999; Carr & O'Reilly, 1996; Ellis et al., 2002; Freedman & Boyer, 2000; Hollingsworth, 1992; Nadler, Lewinstein, & Rahav, 1991). Regarding the help-seeking process, we also studied publications on parental help-seeking for emotional and/or behavioural problems in young people without ID (Bussing, Zima, Gary, & Garvan, 2003; Hanley, Tasse, Aman, & Pace, 2003; Hazell, Tarren-Sweeney, Vimpani, Keatinge, & Callan, 2002; Quinn, Epstein, Cumblad, & Holderness, 1996; Zima, Bussing, Yang, & Belin, 2000).

We came across several models or conceptual frameworks of the help-seeking process (Goldberg & Huxley, 1980; Pavuluri et al., 1996; Verhulst & Koot, 1992), barriers to seeking help, and variables influencing this process. Of these, the framework provided by Pavuluri, Luk, and McGee (1996) appeared to be most useful for this study, because, compared with the models of Goldberg and Huxley, and Verhulst and Koot, they put most emphasis on the parental role in the help-seeking process, which is the focus of this follow-up study (see also *Chapter 1*).

The levels and filters in their model reflect the consecutive steps parents have to take before seeking and receiving (specialist) help for their child's emotional and/or behavioural problems (see also *Chapter 1*). For the purpose of this study, we made some alterations to their model and studied the following filters or steps for the parents to take:

1. *Perception of child psychopathology.* Since frequently the parents have to initiate the help-seeking, they first have to perceive problems in their child's emotional or behavioural functioning before they will actually seek help for their child (Baker & Heller, 1996). When the subjective perception of parents is compared with the assessed presence of psychopathology in their child, this can be viewed as the parents' recognition or awareness of their child's psychopathology (see *Chapter 3*).
2. *Need for professional help.* This is our definition of the original second filter of Pavuluri et al. 'consider getting help'. Perceiving problems in their child is necessary, but most probably not sufficient for parents to seek professional help. Perceiving a need for professional help has been found to be an important condition for seeking and using professional help (Wu et al., 1999). We presumed that parents will only consider getting help when they feel a certain need for it.
3. *Crossing perceived barriers in seeking help.* Still, not all parents who perceive a need for professional help actually seek help. Studies on parents of typically developing youths revealed several potential barriers to seeking help, e.g., barriers related to perception of mental health problems or mental health services, and structural barriers, such as financial and geographical barriers (Aoun et al., 2004; Bussing et al., 2003; Flisher et al., 1997; Owens et al., 2002; Yeh, McCabe, Hough, Dupuis, & Hazen, 2003). These might also apply to parents of youths with ID.

Interviews with parents and mental health care providers

The adapted model of Pavuluri and colleagues served as the structure for the instrument that was to be constructed. We then had to explore what variables and circumstances have an effect on passing through these filters: Why do some parents pass through all these filters, while others do not? Because the literature did not supply us with sufficient and relevant information, we decided to consult those persons who know best, i.e., parents of children with both ID and psychopathology. We contacted the Dutch Federation of Parents Associations (Federatie van Ouderverenigingen) and through them we came in contact with parents of five children and adolescents with ID and emotional and/or behavioural problems. All parents that were approached agreed to be interviewed. A major advantage of these parents was that they all were actively involved in the Parents Association. They were therefore able to not only speak for themselves, but also for other parents of that association. A disadvantage lay in the fact that for all children, the intellectual disability and the additional emotional and/or behavioural problems were a consequence of a syndrome or a chromosomatic disorder, such as Prader-Willi-syndrome, Sotos syndrome, and Velocardiofacial syndrome. Also, most of these children were younger than the average age of our study's population. We therefore recruited two other parents of children who visited schools for special education, and whose ID and psychopathology were not a result of chromosomal defects.

We conducted semi-structured interviews with six mothers and one married couple. All seven interviews were recorded and later fully transcribed. An average interview lasted for about 1.5 hours. The first 15-20 minutes were spent on getting some background information about the child and his/her development over the past years and their families. Next, we spoke with them about the emotional and behavioural problems of their child, the impact that these problems had on the development of the child, on family life, and what specific needs they had felt as a result of these problems. We also asked them if they had sought help for these problems and their specific needs for help. If they had, we inquired about where they had gone for help, whether or not they had received help, reasons for not getting help, and whether the help received was satisfactory to their needs. When parents had not sought help, even though they had felt a need for it, we asked them about their reasons for not seeking help. Because most parents were active members of Parents Associations, we spoke with them about the situation of other parents as well.

Besides speaking with parents, we also wanted to get information from the mental health service provider's perspective about this population of youths with moderate to borderline ID and mental health problems. We interviewed seven people who were active in this field of work, of whom two were researchers, and the other five were social workers, psychologists, and psychiatrists. These interviews were also recorded and transcribed. We spoke with them about the characteristics of these youths and their parents, their specific needs of help, what help is provided to these youths and parents/family, the pathway that leads to specialised mental health services, and the obstacles these parents may encounter on their way to obtaining help.

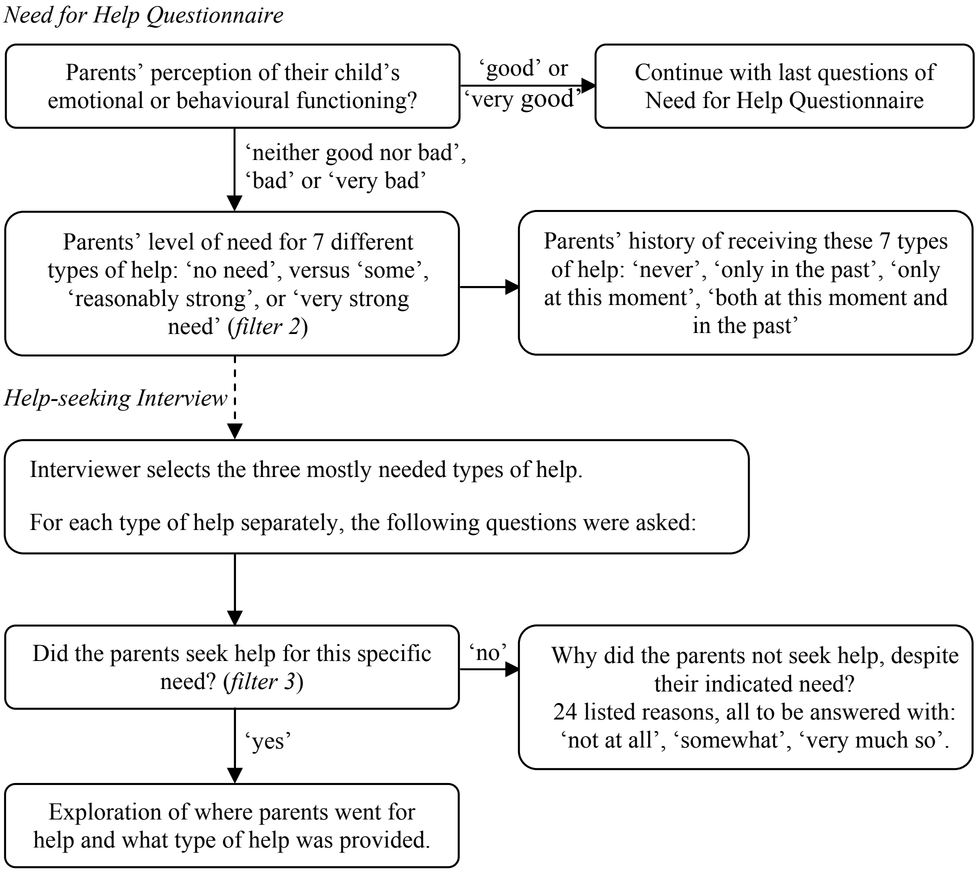
Both sets of interviews supplied us with very useful information about the various needs these parents can have, the different perspectives on the mental health problems, and variables that can influence taking the steps in the help-seeking process as distinguished by Pavuluri et al. (1996).

Construction of the Need for Help Questionnaire and Help-seeking Interview

Besides the basic structure that was offered by the model of Pavuluri et al., on the basis of these interviews and the literature study, we were able to construct our instrument. Our primary aim was to get a good impression of the various needs these parents can have as a direct consequence of the emotional and behavioural problems in their child and the subsequent help-seeking process. To optimise the reliability of the parents' information, we decided to construct two instruments: the Need for Help Questionnaire and the Help-seeking Interview. Figure 2.1 shows the basic structure of these two instruments and the incorporation of the filters of the Pavuluri model.

We assumed that parents would be perfectly capable of answering questions about how they perceived their child's emotional and behavioural functioning, and reporting about their needs for support when they perceived problems. On the other hand, answering questions about their help-seeking could be too complicated for some of the parents without the help of an interviewer.

Figure 2.1
Structure of the Need for Help Questionnaire and the Help-seeking Interview



Need for Help Questionnaire

Because the ID itself can bring about many different needs for help, we had to make sure that the parents would only report about their needs that were a direct consequence of their child's emotional and/or behavioural problems. Moreover, not all youths with borderline to moderate ID suffer from mental health problems, and for this part of the study we were only interested in the ones who did. To resolve that issue, we included two questions that would discriminate between parents who did and who did not perceive emotional and/or behavioural problems in their child.

To not start out with asking the parents how they perceived their child's emotional functioning and behaviour, we first asked them about how, in the past year, their child had been doing in general, at school, at home, and with friends. Then, also in a neutral way, we asked them about how they thought their child had been doing in the past year regarding his/her emotional functioning. A similar question followed about how they had perceived their child's behaviour. These questions were to be answered on a 5-point scale ('very good', 'good', 'neither good nor bad', 'bad', 'very bad'; in Dutch: 'zeer goed', 'goed', 'redelijk', 'slecht', 'zeer slecht'). When at least one of these two questions about emotional functioning and behaviour was answered with either 'neither good nor bad', 'bad', or 'very bad', we considered these parents as perceiving emotional and/or behavioural problems in their child. Only these parents were subsequently asked about their needs for help. The parents who did not perceive these problems could skip these questions about need for help for these problems and proceed with the last questions of this questionnaire. As already mentioned, these two questions on 'perception of emotional or behavioural problems' would also enable us to examine the first filter of the Pavuluri model, i.e., whether parents recognised these problems that were assessed in other, standardised ways.

The next questions were about the needs for help parents had felt because of their child's additional problems, i.e., need for help defined as a felt need. To tackle the problem that is associated with the definition of felt need, i.e., that it depends on the awareness of the existence of services (see *Chapter 1*), instead of asking parents to instantly name all their needs for support, we listed seven specific types of help they might have needed and we asked them to what extent they had felt these particular needs for help in the past year. We inquired about the following needs for help: 'information', 'activities for the child', 'respite care', 'treatment/therapy for the child', 'someone to talk to', 'parental counselling' aimed at better handling their child's problems, and 'practical or material help'. These needs were mainly derived from the interviews we had with the parents in the prestudy, but also from the literature study. If parents had had any other need than the seven that were listed, they could write down one other need they had had. For each type of help, we asked two questions:

1. "In the past year, to what extent did you, as a consequence of possible emotional and/or behavioural problems of your child, feel a need for …… (type of help)?" Parents had to indicate whether they had had 'no need', 'some need', 'reasonably strong need' or a 'very strong need'. When parents answered with anything but 'no need', we considered them to have had that particular need for help. Their answers would give us insight into these parents' subjective needs and the extent to which these needs were felt. We were also interested if they had ever received that specific type of help, irrespective of whether they had felt a need for it. For that reason, we next asked them:
2. "Have you ever received either informal (from family/friends) or professional help for this need for …… (type of help)?" This question could be answered with 'no', 'yes, in the past, but also at this moment', 'yes, but only at this moment', or 'yes, but only in the past'. If they answered with anything but 'no', they were asked from whom they had received that type of help.

The last questions of this questionnaire were about their child's emotional and behavioural functioning prior to the past year, and the pathway to professional help, i.e., perception of problems, need for professional help, seeking professional help, and receiving professional help. These were answered by all parents in the study.

The first two filters of the framework of Pavuluri et al. were incorporated in the Need for Help Questionnaire; recognition of psychopathology, and consider getting help, which was converted into having a need for help.

Help-seeking Interview

When parents reported to have perceived emotional and/or behavioural problems *and* to have felt at least one of the seven needs for help, they were asked another set of questions about their help-seeking for those needs in the Help-seeking Interview.

One assumption of this study was that parents can have various needs for help, and that the pathway to obtaining help, and where parents go for help (professional or informal help) can differ across needs and is, at least partly, determined by the nature of that need. For example, when parents need information, they can search the Internet, or go to a library. On the other hand, if parents feel a need for therapy or treatment for their child, they will most likely go to their primary care physician first and will eventually obtain help from mental health services. In order to learn more about the different ways to help for different needs, we asked the same questions for each type of help separately.

To avoid lengthening the interview too much (it would already last at least 1,5 hours without these questions), the maximum number of needs to ask the questions about was set at three. We expected that, even with this restriction, we would get enough data to study the help-seeking process for different needs. This meant that, since parents could report about eight different needs for help, very often choices had to be made about the types of help to ask these questions about. This is also a reason why these questions had to be asked in an interview.

Furthermore, we also expected that many parents would need help to stay focused on the object of this interview: help-seeking as a consequence of their child's emotional and/or behavioural problems, and on the specific type of help the questions related to. The ID itself often brings about different needs for help. It was up to the interviewer to verify that parents were only talking about their needs and help-seeking because of their child's additional psychopathology. They were allowed to ask for clarifications if they had any doubts about this.

Also, parents who have different needs for help can seek this help from one and the same service provider or person. However, the effect of and the satisfaction with the provided help may be different. Therefore, it was also the responsibility of the interviewer to make sure that the evaluation of the provided help was only about that specific type of help and not about the other types. Whenever necessary, the interviewers were also allowed to bring up information from the Need for Help Questionnaire if that would help to get a complete and truthful account of the help-seeking process in the past year.

The reported needs for help in the Need for Help Questionnaire were the basis of this interview. The interviewer had to examine this questionnaire to determine which were the three most urgent needs of parents in the past year. This implied that, when parents had indicated to have needed at least four types of help, the interviewer had to narrow them down to three. Clear guidelines were given to the interviewers on how to do that. Basically, they selected the types of help that the parents needed the most. If there was a tie, the interviewer consulted the parents to decide on which of these types of help they had needed the most.

The interviewer started asking the questions with the need most felt. After finishing these questions for that first need, if applicable, the interviewer continued with the same questions for the second, and subsequently the third need for help.

The first question asked about whether or not the parents had sought help for that specific need for help (‘yes’ or ‘no’). If they had sought help, the next questions were to inform us about where they had gone for help, and about the evaluation of the obtained help. If they had not sought help, they were asked about their reasons for not seeking help.

When parent reported to have sought help, we asked them where, in the past year, they had gone for help. We had already listed 20 potential ‘help providers’, both informal and professional. The interviewer could easily mark the source of help that was reported by the parents. We also added a ‘something else, ……..’ category to this list. We distinguished between parents who had only sought informal help and parents who had (also) sought professional help.

The next set of questions inquired about the service provider or person they had addressed themselves to most recently. We asked the parents about the help they had received, the effect of the provided help, but also about their subjective evaluation of the service provider (e.g., had they been treated kindly and with respect). These questions were asked irrespectively of whom had provided the help and the type of help that was provided.

Parents who had answered on the first question of the Help-seeking Interview that they had not sought help were obviously not asked about their help-seeking. Instead, they were asked about their reasons for not seeking help, despite the fact that they had felt a need for it. From the interviews of the prestudy and literature, we were able to compile a list of 24 potential reasons. For every reason, these parents were asked to indicate on a 3-point scale (‘not at all’, ‘somewhat’, ‘very much so’) to what extent these specific reasons applied to them. If there were other reasons than on the list, they could give two other reasons. This information would enable us to gain insight into these parents’ barriers to seeking help (filter 3 of the ‘Pavuluri-framework’).

Other measures and instruments

Besides the Need for Help Questionnaire and Help-seeking Interview, several other instruments were used at this Phase 3 study to gather information on various variables that might be related to needing, seeking and obtaining help. Because we also used data from Phase 1 of this study, these measures and instruments are also listed in Table 2.3.

Table 2.3
Variables and instruments used in this thesis and collected in Phase 1 and/or Phase 3 of the study

Variable	Instrument	Phase 1	Phase 3
Parent report	*Questionnaire*		
Demographic variables	Demographic questionnaire	X	X
Emotional and behavioural problems	Child Behavior Checklist/4-18	X	X
Past psychopathology of the child	Single question, self constructed		X
Life-events	Short version of Life Events Questionnaire	X	X
Physical problems	Wahler Physical Symptoms Inventory	X	X
Drug use of the child	Single question, self constructed		X
Parental psychopathology	29-item version of the Young Adult Self-Report	X	X
Need for help of the parents	Need for Help Questionnaire		X
Past help-seeking for the child's problems	Single question of Developmental Behaviour Checklist-Primary Caregiver	X	X
Problematic parenting & Problematic parent-adolescent relationship	Stress Index for Parents of Adolescents		X
Parental worries about their child	Parental Worries Scale		X
Parental monitoring over their child	Parental Monitoring Scale		X
Family dysfunction	Family Assessment Device-General Functioning	X	X
	Questionnaire for Family Problems		X
Social support	Single question, self constructed		X
	Interview		
Psychiatric disorders of the child	Diagnostic Interview Schedule for Children – IV (Parent version)		X
Adaptive functioning of the child	Vineland Screener	X	X
Help-seeking for their child's emotional/behavioural problems	Help-seeking Interview		X
Teacher report	*Questionnaire*		
Emotional and behavioural problems	Teacher's Report Form	X	X
Youth report	*Interview*		
Emotional and behavioural problems	Youth Self-Report		X
IQ	Wechsler Intelligence Scale for Children-III, short form		X
Drug use	Two questions, self constructed		X

3 | Parental awareness of psychopathology in youths with intellectual disabilities

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Chapter 3
Parental awareness of psychopathology in youths with intellectual disabilities

Abstract

Objective: To study parental awareness of psychopathology in their moderate to borderline intellectually disabled child, and the factors associated with awareness.

Method: Parents of 708 youths (aged 10-24 years) filled out the Child Behavior Checklist (CBCL), and the Diagnostic Interview Schedule for Children (DISC-IV) was administered to assess emotional or behavioural problems. Whenever these problems were found present (n=402), we investigated the parents' subjective perception of these problems, and the factors potentially affecting parental awareness.

Results: When parents subjectively perceived (some) emotional or behavioural problems in their child, for about 70% CBCL or DISC-IV indicated these problems to be present. Overall, 63.6% of the parents were aware of their child's psychopathology, but they were significantly more often aware of behavioural than of emotional problems. Parental awareness was most strongly correlated with prior experience with psychopathology, worrying about, and additional problems in and with the child, in the parents themselves, and in the family.

Conclusions: Even relatively small parental concerns about their child's emotional or behavioural functioning should be taken seriously. Measures to increase parental awareness should especially be aimed at (1) parents of youths who do not draw much attention from their parents, and at (2) increasing parental awareness of emotional problems.

Introduction

Many youths with intellectual disabilities (ID) have additional emotional or behavioural problems, or psychiatric disorders, i.e., psychopathology. Compared with typically developing peers, they have a 3 to 4 times increased risk for developing these problems (Emerson, 2003b; Wallander et al., 2003). Furthermore, the sparsely available longitudinal studies show that psychopathology in ID youths is quite persistent; at least 70% still had these problems after one to four years (Wallander et al., 2003). Hence, professional help seems warranted, but unfortunately, there is a large gap between the occurrence of psychopathology, as assessed with standardised measures, and the actual treatment of these problems (Dekker & Koot, 2003a; McCarthy & Boyd, 2002).

Parents are generally regarded as the ones to initiate the help-seeking process that leads to eventually obtaining professional help for their child's additional emotional or behavioural problems (Dulcan et al., 1990; Logan & King, 2001). But, before parents will seek help, they first have to perceive their child's emotional or behavioural functioning as problematic (Baker & Heller, 1996). However, it is not known to what extent these parents' subjective perception coincides with the actual presence of psychopathology as assessed with standardised measures.

In the past decade, numerous studies have examined help-seeking of parents of typically developing youths (Logan & King, 2001; Zwaanswijk et al., 2003), but only few have investigated the first prerequisite of help-seeking namely, parental awareness of psychopathology. Moreover, these studies differed in definitions used, sample size, age range, and type of psychopathology studied. Overall, 13% to 88% of parents were aware of their child's additional problems (Bussing et al., 2003; Dulcan et al., 1990; Logan & King, 2002; Pavuluri et al., 1996; Sayal, Taylor, & Beecham, 2003; Teagle, 2002; Verhulst & Van der Ende, 1997), but only Verhulst and Van der Ende (1997) and Teagle (2002) investigated parental awareness of a broad range of emotional or behavioural problems in large representative population-based samples, using standardised assessment methods. In both studies, less than half of the parents were aware of their child's psychopathology, i.e., 39% in case of a psychiatric diagnosis (Teagle, 2002), and 45% of the parents whose child's Total Problems score fell in the borderline/clinical range of the Child Behavior Checklist (CBCL) (Verhulst & Van der Ende, 1997). Thus, in the general population, parental awareness of child psychopathology seems limited. It is unknown whether this is also true for parents of ID youths.

In addition, it is important to gain insight into the factors that are associated with parental awareness. When standardised measures indicate psychopathology, what distinguishes parents who perceive these problems in their child from those who do not? This might pinpoint specific measures that might help to increase awareness of these problems, and consequently seeking and obtaining professional help. While not studied in ID samples, we only found general population studies that investigated variables associated with parental awareness of *specific* child psychiatric disorders. For example, awareness of depression was associated with parental perception of family burden (Logan & King, 2002), and the child's age and problem severity were related to parental awareness of their child being at risk for Attention Deficit Hyperactivity Disorder (Bussing et al., 2003). However, although not the same as parental awareness, we found some large representative population-based studies that examined factors associated with *parental perception* of emotional or behavioural problems, irrespective of its objectively assessed presence (Dulcan et al., 1990; Horwitz, Gary, Briggs-Gowan, & Carter, 2003; Teagle, 2002; Verhulst & Van der Ende, 1997). These studies revealed several child-related (age, ethnicity, life-events, physical handicap), parent-related (educational level, psychopathology, problematic parent-child relationship, worrying about the child's behaviour), and family-related factors (composition, a family member in mental health care, and family functioning) associated, although not always consistently across studies. These factors might also be related to awareness of psychopathology in parents of ID youths.

The aims of the present study were to gain insight into: (1) the extent to which the parents' subjective perception of emotional or behavioural problems in their ID child coincide with the presence of these problems as assessed with standardised measures (parental awareness of child psychopathology), and (2) the factors that are related to this parental awareness. We distinguished between parental awareness of emotional problems and of behavioural problems, because behavioural problems have been found to cause higher levels of parental burden than emotional problems (Angold et al., 1998). It is therefore likely that parents will be more aware of their child's behavioural than of emotional problems.

Method

Procedure and participants

This study is part of a longitudinal Dutch study on psychopathology in ID youths that started in 1996. Then, in the Netherlands, almost all children with a moderate to mild ID attended special schools for the educable (IQ range 60-80) or trainable (IQ range 30-60). In 1996, 115 of all 132 schools for the educable and trainable in the province of Zuid-Holland (school response = 87.1%) randomly selected 20% of their students, resulting in a sample of 1,615 children (aged 6-18 years). Of these, 219 were excluded because they exceeded the age range, were not living at home, or their parents had problems with the Dutch language. Of the remaining 1,396 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 (response = 70.3%, and 84.3% of those that were personally contacted). Significantly more parents of children from schools for the trainable than for the educable participated ($p < .01$). About one year later, Time 2 assessment was conducted. A detailed description of the sampling procedure can be found elsewhere (Dekker, Koot et al., 2002). This present study was based on data collected at Time 3 (October 2002 until January 2004).

The Time 3 target sample consisted of 1,007 youths whose parent had at least partially participated at Time 1 (minus 1 child who was deceased). Children were traced through consulting phonebooks and municipal registers. In only 46 cases we were unable to locate or personally contact the parents, for example because of emigration. Of the 961 parents we could contact, 749 participated (Time 3 response = 77.9%; overall study response = 53.7%).

In this part of the study parents of 708 youths were included for whom an awareness rate could be derived. We found no significant differences (χ^2, or t-test, all $p > .05$) between the 708 participants and 299 non-participants on Time 1 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 the trainable, had a deviant CBCL Total Problems score, and their parents were both of Dutch origin, not single, and had a higher SES and educational level ($p < .05$). After adjusting for the correlation between these variables, we found that significantly fewer parents of children from schools for the educable, and of children with a non-deviant CBCL Total Problems Score, and non-Dutch parents had participated at Time 3 ($p < .05$). Time 3 sample characteristics are presented in column 4 of Table 3.1.

Instruments

The variables and instruments used are described in Table 3.1, those needing more clarification are also described below.

Child psychopathology. The Dutch version of the CBCL (Achenbach, 1991a; Verhulst et al., 1996) was used to assess emotional and behavioural problems in youths during the past 6 months. The CBCL has shown to have good reliability and validity for both typically developing and ID youths (Dekker, Koot et al., 2002). The sum of scores of Total Problems, Internalizing (subscales Withdrawn, Anxious/Depressed, Somatic Complaints), and Externalizing (Aggressive, and Delinquent Behavior) were dichotomised using the borderline/clinical cut-off criteria.

Table 3.1
Description of measures and sample characteristics, Time 3, N=708

Variable	Instrument	Cut-off criteria/ variable specification	%	Cron-bach's α
Child				
Psychopathology	CBCL	T-scores ≥ 60:		
		Total Problems	39.8	0.94
		Internalizing	33.7	0.88
		Externalizing	32.4	0.90
	DISC-IV	Any Disorder	28.4	
		Any Mood/Anxiety Disorder	19.5	
		Any Disruptive Disorder	14.7	
Age	Age in years: mean (sd)		16.8 (3.0)	
Sex		Male	58.3	
Only child		Only child	8.5	
IQ	Estimated full IQ determined by two verbal (Information, Vocabulary) and two performance subtests (Picture Completion, Block Design) of the Wechsler Intelligence Scale for Children-III (Kaufman, Kaufman, Balgopal, & McLean, 1996; Wechsler, 1991).	Mild-borderline ID	58.3	
Past psychopathology	Presence of psychopathology before the previous year according to the parents; single question.	Yes	41.2	
Life-events	Adapted version of Life Events Questionnaire (Berden, Althaus, & Verhulst, 1990) containing 20 life-events (e.g., parent leaving the household, death of a loved one) and their (positive, neutral or negative) impact on the child in the past two years.	≥ 1 negative life-event	29.3	
Physical problems	Wahler Physical Symptoms Inventory (Wahler, 1968); 42 items about physical and somatic complaints (e.g., headache, feeling tired, tense muscles); 6-point scale (almost never to almost every day).	1 SD > mean	13.2	0.83
Parent				
Ethnicity		≥ 1 parent is not Dutch	13.7	
Number of parents		Two parents	79.0	
Educational level	Highest completed parental education of parent(s): none to secondary low versus secondary medium to high education.	Secondary medium/high	44.4	
Socio-economic status	Highest occupational status of parent(s), indicated by the Standard Classification of Professions (Central Bureau of Statistics, 1993); unemployed, work requiring no skills, or lower vocational training (low) versus higher levels (medium/high).	SES medium/high	48.4	

Table 3.1 *continued*

Variable	Instrument	Cut-off criteria/ variable specification	%	Cronbach's α
Parental psychopathology	Total score on Young Adult Self Report (Achenbach, 1997), 29 of the 110 items that discriminated best between referred and non-referred adults (Wiznitzer, 1993). 83% were mothers.	1 SD > mean	16.2	0.90
Parental worries	Parental Worries Scale (constructed at Time 1) containing 29 items about various aspects parents may worry about regarding their child in the past 6 months (their social life, health, and future independent functioning), to be scored on 5-point scale (never to very often). Total score was dichotomised.	≥ 75th percentile	25.2	0.96
Parental monitoring	6-item questionnaire based on the Parental Monitoring Scale (Brown, Mounts, Lamborn, & Steinberg, 1993; Dekovic, 1996). How much do parents know about their child regarding his/her whereabouts after school and at night, free time spending, money spending, friends, and school marks (4-point scale: nothing to everything). Total score was dichotomised into more vs. less monitoring.	≥ 75th percentile	16.3	0.89
Problematic parent-child relationship	16-item Adolescent-Parent Relationship domain of the Stress Index for Parents of Adolescents (Sheras, Abidin, & Konold, 1998) with 5-point answering scale. Total score was divided in problematic vs. non-problematic in accordance with the original cut-off criteria.	≥ 85th percentile	15.7	0.78
Past help-seeking	One question (yes/no) of the Developmental Behaviour Checklist-Primary Caregiver, Dutch version (Einfeld & Tonge, 2002; Koot & Dekker, 2001) on past help seeking for child mental health problems.	Yes	41.2	
Family				
Hostile family functioning	17-Item Hostility-subscale of Dutch Questionnaire for Family Problems (VGP), 3-point answering scale (Koot, 1997). Total score was dichotomised in accordance with the original Dutch norms.	≥ 95th percentile	10.9	0.92
Negative involvement	8-Item Involvement-subscale of VGP (Koot, 1997).	≥ 95th percentile	15.1	0.86

The Anxiety, Mood, and Disruptive Disorder modules of the Dutch Diagnostic Interview Schedule for Children-Parent version (DISC-IV) were administered by trained lay interviewers to assess DSM-IV psychiatric disorders in the past year (Ferdinand & Van der Ende, 1998; Shaffer, Fisher, Lucas, Dulcan et al., 2000). In line with the CBCL, we distinguished between any psychiatric disorder, any internalising disorder (Anxiety or Mood disorder), and any externalising disorder (Disruptive disorder).

To measure a broad concept of psychopathology, we combined the measures of CBCL and DISC-IV into three measures of psychopathology: (1) any psychopathology (deviant CBCL Total Problems score or any psychiatric disorder); (2) emotional problems (deviant CBCL Internalizing score or any Mood/Anxiety disorder); and (3) behavioural problems (deviant CBCL Externalizing score or any Disruptive disorder).

Parental subjective perception of their child's emotional and behavioural functioning. While both parents and interviewers were blind to the criteria of CBCL and DISC-IV to assess psychopathology, to determine the parents' subjective perception of their child's emotional and behavioural functioning we asked them two questions. These were: "How, in general, do you think your child has been doing in the past year regarding his/her (1) emotional, and (2) behavioural functioning?" They could answer with either 'very good', 'good', 'neither good nor bad', 'bad', or 'very bad'.

Intelligence. An estimated full *IQ* was obtained for 621 youths. We distinguished two ID groups: moderate ID (IQ 40-54), and mild-borderline ID (IQ > 54). In this study, 76.6% of the youths who attended a school for the educable at Time 1 had a mild-borderline ID, and 84.4% of those who attended a school for the trainable had a moderate ID. Whenever an IQ was unavailable (educable, n=78; trainable, n=39), we assigned these cases to an ID-group corresponding best with the school type they attended at Time 1.

Statistical analyses

Differences between proportions of parental awareness were tested with χ^2 (significance level $p < .05$, two-tailed). Univariate logistic regression analyses were conducted to test the contribution of each independent variable to parental awareness of any psychopathology, emotional problems, and of behavioural problems. Parents who were aware of their child's psychopathology were compared with those who were not. Multiple logistic regression analyses, adjusting for all significant variables from the previous univariate analyses, revealed the variables with the strongest unique contribution to parental awareness.

Results

Of all parents, 68.1% subjectively perceived their child's emotional functioning as 'very good'/'good', 27.5% as 'neither good nor bad', and 4.4% as 'bad'/'very bad'. Regarding their child's behavioural functioning, these percentages were 68.1%, 27.2%, and 4.7% respectively.

While parents' report of their child's functioning as 'bad' or 'very bad' suggests that they perceive problems, and 'very good' or 'good' suggests that they do not perceive problems, parents' indication of their child's functioning as 'neither good nor bad' could be regarded as both. To decide how parental perception of problems was defined best, i.e., using a broad definition (including 'neither good nor bad') or a strict definition (not including 'neither good nor bad'), we compared each of these judgements with the presence (sensitivity) and absence (specificity) of emotional and behavioural problems as indicated by CBCL or DISC-IV (Table 3.2).

As can be seen from Table 3.2, levels of parental awareness of the *presence* of both emotional and behavioural problems dropped dramatically when the strict instead of the broad definition was applied. This drop was 40.8% for awareness of emotional problems and 52.5% for awareness of behavioural problems. On the other hand, the change in level of parental awareness of the *absence* of emotional or behavioural problems was less striking between both definitions of problem perception. The broad definition of problem perception was therefore considered most suitable and applied in further analyses. In addition, in case of this broad definition, whenever parents perceived problems in their child's emotional or behavioural functioning, for the vast majority of these children these problems were present according either CBCL or DISC-IV (66.7% for emotional, and 73.4% for behavioural problems).

Table 3.2
Percentage of parents who perceived emotional or behavioural problems when present, and of parents who did not perceive emotional or behavioural problems when absent, using two definitions of problem perception

	CBCL or DISC-IV indication of			
	Emotional problems		Behavioural problems	
Definition of problem perception	Present (n=292)	Absent (n=396)	Present (n=251)	Absent (n=432)
Broad definition[*]				
Perceiving problems	50.0%		63.7%	
Not perceiving problems		81.6%		86.4%
Strict definition[**]				
Perceiving problems	9.2%		11.2%	
Not perceiving problems		99.2%		99.1%

[*] 'neither good nor bad' is considered as perceiving problems together with 'bad' and 'very bad'
[**] 'neither good nor bad' is considered as not perceiving problems together with 'good' and 'very good

When any psychopathology was found present in a child (deviant CBCL Total Problems or any psychiatric disorder, n=346), 63.6% of their parents were aware of these problems. Regarding parental awareness of emotional versus behavioural problems, parents were significantly more aware of behavioural than of emotional problems (63.7% vs. 50.0%; $\chi^2 = 10.37$, $p < .01$).

Even though many parents were aware of their child's psychopathology, 36.4%, 36.3%, and 50% respectively were not. Univariate logistic regression analyses showed that several factors discriminated between these two groups of parents (Table 3.3), but the parents' ethnicity, the child's age, and parental educational level and SES were not among them.

Five, predominantly child-related variables were associated with parental awareness across all types of psychopathology, i.e., the child being an only child, physical problems, and past psychopathology in the child, more parental worrying about their child, and negative involvement within the family. Next to male sex of the child and living in a 2-parent household, especially additional problems in or with the child or family increased the odds of parental awareness of specific problems, i.e., negative life-events, problematic parent-child relationship, less parental monitoring, past help-seeking for their child's problems, and hostile family functioning. Finally, parents of a child with mild-borderline ID, and parents with psychopathology of their own were more often aware of any psychopathology in their child than parents of children with moderate ID, and parents without psychopathology.

Multiple logistic regression analyses indicated that, besides enhanced parental worrying about the child, and a problematic parent-child relationship, mainly child variables remained associated with parental awareness, including past psychopathology, negative life-events, male sex, and mild-borderline ID (bold figures Table 3.3).

Table 3.3
Variables related to parental awareness of any psychopathology, emotional problems, and behavioural problems in their child, when present according to either CBCL or DISC-IV

	Any psychopathology (n=346)		Emotional problems (n=292)		Behavioural problems (n=251)	
Variables	OR	95% CI	OR	95% CI	OR	95% CI
Child						
Sex (male)					1.7	1.0-2.9
					2.0	**1.0-3.8**
Mild-borderline ID	2.3	1.5-3.6				
	2.0	**1.1-3.5**				
Only child	3.4	1.1-10.1	3.2	1.1-8.9	4.5	1.0-20.4
Physical problems	1.8	1.1-3.3	2.3	1.3-4.1	2.3	1.1-4.6
≥ 1 negative life-event	3.1	1.9-5.1	2.6	1.6-4.2		
	2.6	**1.4-4.8**				
Past psychopathology	6.2	3.8-10.2	5.4	3.2-9.1	3.7	2.1-6.4
	3.9	**2.0-7.8**	**2.6**	**1.3-5.2**	**2.3**	**1.1-5.0**
Parents						
Two parents			1.9	1.1-3.3		
Parental psychopathology	2.2	1.3-3.9				
Parental worries	3.3	2.0-5.5	4.6	2.8-7.6	3.3	1.8-5.8
			2.9	**1.6-5.3**		
Less parental monitoring	2.3	1.1-4.5			2.8	1.3-6.0
Problematic parent-child relationship	3.0	1.5-5.7			3.9	1.8-8.5
					2.5	**1.0-6.3**
Past help-seeking	4.2	2.6-6.7	3.8	2.3-6.2		
Family						
Hostile family functioning	2.9	1.4-6.1	2.3	1.1-4.5		
Negative involvement	2.7	1.4-5.3	2.2	1.2-4.1	2.1	1.1-4.3

OR = Odds Ratio; CI = Confidence interval
Results were obtained from univariate and multiple (**bold** figures) logistic regression analysis; all $p < .05$

Discussion

While standardised measures are commonly used to determine the presence of psychopathology in youths for which professional help is considered warranted, it is especially the parents' subjective perception of their child's functioning as being deviant or problematic that will encourage them to seek help (Baker & Heller, 1996). We examined the extent to which parents' subjective perception of their child's emotional or behavioural problems corresponds with the presence of these problems as assessed with CBCL or DISC-IV, in other words the level of parental awareness of their child's psychopathology. Although many parents seem not aware of their child’s psychopathology (Pavuluri et al., 1996; Teagle, 2002; Verhulst & Van der Ende, 1997), its accuracy has hardly been studied, and, as far as we know, not at all in youths with ID.

Our results showed that parents’ subjective perception of their child’s functioning as (somewhat) problematic was a fairly good indicator of the actual presence of problems, as in the majority of cases these problems were indeed present according to CBCL or DISC-IV. On the other hand, parents were not always *aware* of their child’s problems; when CBCL or DISC-IV indicated a child having emotional problems, only 50% of their parents were aware of these problems. Parents were significantly more often aware of their child’s behavioural problems than of emotional problems. This is in line with studies that found externalising, as opposed to internalising problems to increase the level of perceived parental burden (Angold et al., 1998).

Compared to large population-based studies on parents of typically developing youths (Teagle, 2002; Verhulst & Van der Ende, 1997), we found higher rates of parental awareness of child psychopathology. This might be explained by our definition of problem perception. Instead of directly asking about problems in a ’yes-or-no’ format, we used neutral wordings and a 5-point answering scale to determine parents’ perception of their child’s emotional and behavioural functioning. It could very well be that a substantial number of parents would have answered ‘no’, instead of ‘neither good nor bad’, when directly being asked about problems in a ‘yes-or-no’ format. The ‘neither good nor bad’ category might enable parents to express concerns without directly labelling their child’s situation as really problematic.

Another explanation for our higher awareness rates might be related to the special schools and work settings many ID youths attend. Compared with regular schools or jobs, in these settings more attention is likely to be paid to the overall development of the youths and not solely to the learning or working process. Parents might get more information about their child’s functioning, and consequently be more aware of these problems.

Univariate analyses revealed several child, parent, and family factors associated with awareness of child psychopathology. To some extent, these factors correspond with those found in studies on parental perception in typically developing youths, such as life-events, physical handicap, parental psychopathology, problems in the parent-child relationship, and problematic family functioning (Dulcan et al, 1990; Horwitz et al., 2003; Teagle, 2002; Verhulst & Van der Ende, 1997). Other comparisons are hard to make because of differences in definition, sample composition, and used measures.

Of the factors that we found to be related with awareness, four broad categories of factors can be distinguished, namely, (1) parental familiarity with child psychopathology, (2) specific child-related features, (3) problems in the parent-child interaction, and (4) deviant parental and familial functioning.

First, regarding parental familiarity with child psychopathology, our results suggest that when a child suffered from psychopathology before, or when parents had previously sought help for these problems, parents seem more likely to know the signs, or are more sensitive to signs of recurrence of these problems.

Second, when specific child-related features enabled (being an only child) or caused parents to pay closer attention to their child’s functioning, or to spend more time with him/her (e.g., due to physical problems, life-events, worrying about their child), they were more likely to be aware of their child’s psychopathology. Parents of an only child have also been found to be more over-protective than parents who have more children (Thomasgard & Metz, 1997), which might make them extra sensitive to any problems in their child. Additional problems in the child, such as the experience of a negative life-event, and physical problems may increase parental concern and lower the threshold for perceiving psychopathology (Verhulst & Van der Ende, 1997). In contrast, our results showed that not a more severe ID (moderate ID), but a less severe ID (mild-borderline ID) increased the likelihood of parental awareness. Parents of children with moderate ID may be more inclined to attribute mental health problems to the ID and not to an underlying psychiatric problem or disorder (Borthwick-Duffy, 1994). Also, awareness will most likely be increased when the youths can inform their parents about what is bothering them, for which the ability of recognising their own feelings and putting them into words is essential. Youths with moderate ID more often lack these skills. Finally, male sex of the child was uniquely related to recognition of behavioural problems. This corresponds with the higher prevalence rates for these problems in boys in non-ID populations (Verhulst & Koot, 1992). It seems to be ‘common knowledge’ that boys engage in these kinds of behaviour more often. Parents may be more likely to overlook these problems in girls (Thompson, 2005).

Third, problems within the parent-child interaction, including lack of parental monitoring or supervision, and a problematic parent-child relationship also increased the odds of parental awareness of any psychopathology and of behavioural problems. It seems understandable that parents are more concerned about their children when these do not inform them about their whereabouts, do not listen, and show a lack of mutual love and understanding. Consequently, they might more often perceive and be aware of problems in their child.

Fourth, deviant parental functioning (psychopathology), and deviant family functioning (hostile and negative involvement) increased parental awareness of child psychopathology. Verhulst and Van der Ende (1997) indicated that these parental problems might lower the threshold for perceiving these problems. This might also be true for problematic family functioning.

Limitations

In our analyses, we only used cross-sectional data, which cannot inform us about causal relationships between the independent variables and parental awareness and underlying processes. Furthermore, non-random sample attrition at both Time 1 and Time 3 has led to the participation of relatively fewer parents of children who attended a school for the educable (higher IQ range). Since a higher IQ of the child was found to increase the likelihood of awareness of any psychopathology, these awareness rates might be an underestimation of the actual rates. Because parents who had problems with the Dutch language were excluded at Time 1, and significantly less non-Dutch parents participated at Time 3, this limits the generalisation of our results to these parents and children.

To assess child psychopathology, we used CBCL and DISC-IV, which are validated for children until 18 years of age. Almost 30% of our sample was older than 18. We assumed both instruments could be used, because, compared with peers of the same age, their conceptual, social, and practical skills are less developed (American Psychiatric Association, 2000). Despite these limitations, we consider our results to provide valuable information about parental awareness of child psychopathology in this population.

Clinical implications and future research

Parents in our study were more often aware of their child's psychopathology than parents of non-ID children in other studies. It seems that our definition of perception of problems was crucial in this. In either clinical settings or future research, we therefore suggest using neutral wordings and at least a 3-point answering scale to determine problem perception. Furthermore, when parents perceive their child's emotional or behavioural functioning as 'neither good nor bad', this ought to be taken seriously and warrants further examination of the child.

Even though many parents in our study were aware of their child's psychopathology, especially taking measures to increase awareness of emotional problems is important. Informing and educating parents about these problems (their children's increased risk, verbal and non-verbal signs, and prognosis) is crucial. This information should particularly be provided to parents who are not familiar with these problems, who seem to have no specific reasons to pay extra attention to their child (e.g., no or less physical problems, negative life-events, worries, and problems between parent and child), and whose child has more severe ID.

In addition, personnel in schools and sheltered work settings can also contribute to detecting these problems and informing the parents (Leaf et al., 1996; McCarthy & Boyd, 2002). Moreover, screening routinely for psychopathology in all youths with ID by schools (Wallander et al., 2003) and systems serving these children, seems not in vain.

This study has several implications for future research. There is a shortage of studies on parental awareness in large and representative population-based samples of youths with and without ID. Furthermore, these studies should distinguish between awareness of emotional and behavioural problems, since our study revealed differences in awareness rates and the factors associated. In addition, future studies are needed to determine to what extent the parents' subjective perception of emotional or behavioural problems is the first step to eventually seek professional help, and, more specifically, to what extent the level of problem perception, i.e., 'neither good nor bad' versus 'bad'/'very bad' is associated. Longitudinal studies might shed a light on predictors of parental awareness, which allow policy makers to take accurate measures to increase the number of parents that perceive problems, and eventually seek professional help.

4 | Help-seeking process of parents for psychopathology in youths with moderate to borderline intellectual disabilities

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Submitted for publication

Chapter 4

Help-seeking process of parents for psychopathology in youths with moderate to borderline intellectual disabilities

Abstract

Objective: To study the help-seeking process of parents for emotional or behavioural problems in their child with borderline to moderate intellectual disabilities.
Method: In a special education-based sample of parents of 745 youths (aged 10-24 years), we studied the parents' (1) perception of emotional or behavioural problems in their child, (2) subsequent felt need for professional help, and (3) actual help-seeking. Factors possibly related to these steps in help-seeking and reasons for not seeking help were investigated.
Results: Of all parents, 38.8% perceived additional problems in their child. Consequently, two-thirds felt a need for professional help, of whom 57.9% subsequently sought professional help. Parents were most likely to seek help when their child had problems of anxiety and depression, had experienced negative life-events, and had psychopathology before the past year. Reported reasons for not seeking help predominantly related to their subjective evaluation of these problems (not so big, temporary) and not knowing where to find help.
Conclusions: Perceiving problems and feeling a need for professional help does not imply actual help-seeking. The reported barriers to help-seeking provide us with useful indications about how to increase actual help-seeking.

Introduction

Compared with peers without intellectual disabilities (ID), youths with ID have at least a 3 to 4 times increased risk for developing emotional and behavioural problems, i.e., psychopathology (Dekker, Koot et al., 2002; Emerson, 2003b). Furthermore, the sparsely available longitudinal studies show that these problems are quite persistent (Wallander et al., 2003). Professional help for these youths or their families seems warranted. However, just about one third of youths with ID and additional psychopathology receive professional help (Dekker & Koot, 2003a; McCarthy & Boyd, 2002), which is comparable to non-ID youths (Zwaanswijk et al., 2003). It is not clear why the majority do not get professional help. We do know that parents, and especially of ID youths, have an important role in initiating the help-seeking process for their children (Borthwick-Duffy, 1994). However, why some parents seek help, while others do not, is not known. It is therefore important to learn more about these parents' characteristics and motives.

The parental help-seeking process comprises several consecutive steps that lead to actual help-seeking (Pavuluri et al., 1996). First, parents have to *perceive problems* in their child's emotional or behavioural functioning (Baker & Heller, 1996). After perceiving problems, feeling a *need for professional help* is a second important condition for seeking and using professional help (Wu et al., 1999). Still, not all parents who perceive problems *and* subsequently feel a need for professional help actually seek help. Parents may conceive several barriers that keep them from seeking help (Logan & King, 2001). Overcoming these barriers and *actually seek professional help* therefore is the third and final step. For each step, parents consciously or unconsciously decide to follow through with the help-seeking process or not.

As far as we know, this process and the parental role have not been studied in parents of youths with ID. In case of typically developing youths, even though the importance of studying these separate steps has been acknowledged (Costello & Janiszewski, 1990), most studies focused on the outcome of the process, i.e., use of mental health services (Angold et al., 2002; Sayal, 2004). Only few population-based studies examined one or more of these individual steps (Flisher et al., 1997; Horwitz et al., 2003; Pavuluri et al., 1996; Pihlakoski et al., 2004; Verhulst & Van der Ende, 1997). Even though these studies provide valuable information, none of them were aimed at unravelling the whole pathway from perceiving emotional or behavioural problems to seeking professional help. In addition, it is not known what characteristics and circumstances are related to taking the next step. Insight into this process and associated factors and reasons should give more precise indications about possible measures to increase parental help-seeking for their child's additional problems (Logan & King, 2001).

We studied each consecutive step in the help-seeking process of parents who perceived emotional or behavioural problems in their child with ID. For all three steps separately our aim was to (1) determine how many parents proceeded to the next step, and to (2) gain insight into the factors that increase the likelihood of parents' proceeding in the help-seeking process. Regarding the third step, seeking help, we also wanted to learn from the parents themselves about their reasons for not seeking professional help despite the fact that they had felt a need for it.

Method

Procedure and participants

This study is part of a longitudinal Dutch study on psychopathology in ID youths that started in 1996. Then, in the Netherlands, almost all children with a moderate to mild ID attended special schools for the educable (IQ range 60-80) or trainable (IQ range 30-60). In 1996, 115 of all 132 schools for the educable and trainable in the province of Zuid-Holland randomly selected 20% of their students, resulting in a sample of 1,615 children (aged 6-18 years). Of these, 219 were excluded because they exceeded the age range, were not living at home, or their parents had problems with the Dutch language. Of the remaining 1,396 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 (response = 70.3% and 84.3% of those that were personally contacted). Significantly more parents of children from schools for the trainable than for the educable participated ($p < .01$). About one year later, Time 2 assessment was conducted. A detailed description of the sampling procedure can be found elsewhere (Dekker, Koot et al., 2002). This present study was based on data collected at Time 3 (October 2002 until January 2004).

The Time 3 target sample consisted of 1,007 children whose parent had in some way participated at Time 1 (minus 1 child who was deceased), including seven children who were excluded at Time 1 because they (slightly) exceeded the age range. Children were traced through consulting phonebooks and municipal registers. In only 46 cases we were unable to locate or personally contact the parents, for example because of emigration. Of the 961 parents we could contact, 749 participated (Time 3 response = 77.9%; overall study response = 53.7%).

We found no significant differences (χ^2, or t-test, $p > .05$) between the 749 Time 3 participants and 258 non-participants on Time 1 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 the trainable, had a deviant Child Behavior Checklist (CBCL) Total Problems score (Achenbach, 1991a), and their parents were both of Dutch origin, less often single, and had a higher SES and educational level. After adjusting for the correlation between these variables, we found that significantly fewer non-Dutch parents had participated at Time 3 ($p < .05$).

Measures

Outcome variables

Parental perception of child psychopathology. In two questions, we asked parents in neutral wordings about their child's emotional (1) and behavioural (2) functioning in the past year (either 'very good', 'good', 'neither good nor bad', 'bad', or 'very bad'). When parents answered 'neither good nor bad', 'bad', or 'very bad' on at least one of these two questions, we considered them to perceive child psychopathology. For 745 parents a valid answer was obtained.

Need for professional help. Only parents who perceived child psychopathology filled out the, for this study constructed, Need for Help questionnaire. For seven types of help separately (e.g., information, respite care, child mental health care, and parental counselling), we asked to what extent parents had needed that particular type of help in the past year due to their child's psychopathology (either 'no need', 'some need', 'reasonably strong need', or 'very strong need'). Here, we focus on two types of professional help, namely (1) child mental health care, and (2) parental counselling (to learn how to deal with their child's problems). When for at least one of these types of professional help at least 'some need' was indicated, we regarded parents as having had a 'need for professional help'.

Actual help-seeking. When parents needed some type of support, in an interview we asked whether they had sought help in the past year. Due to time restrictions, we only asked about their three strongest needs (out of a maximum of seven needs). Consequently, 138 of the 189 parents who had reported a *need for professional help* were questioned about their help-seeking behaviour, and 51 were not. These 138 did not significantly differ from the 51 parents regarding any of the independent variables used in this study, nor the extent of felt need (χ^2 or t-test, all $p > .05$).

Only those parents who reported that they had not sought professional help were asked to what extent each of the 24 given reasons applied to them for not seeking professional help ('not at all', 'somewhat', or 'very much so').

All *independent variables* and instruments are presented in Table 4.1. In addition to the information in Table 4.1, an estimated *IQ* score was obtained for 621 youths. We distinguished two groups: moderate ID (IQ 40-54), and mild-borderline ID (IQ > 54). In this study, 76.6% of the youths who attended a school for the educable at Time 1 had a mild-borderline ID, and 84.4% of those who attended a school for the trainable had a moderate ID. When an IQ was unavailable, children were assigned to the ID-group corresponding best with their school type at Time 1 (educable, n=93; trainable, n=44).

Table 4.1
Description of independent variables and sample characteristics (N=745)

Variable	Instrument description	Dichotomization	%	Cron-bach's α
Child				
Psychopathology	Subscales of the Dutch CBCL (Verhulst et al., 1996) were used to assess emotional and behavioural problems during the past 6 months. The CBCL has shown to have good reliability and validity for both typically developing and ID youths (Dekker, Koot et al., 2002). Subscale scores were dichotomised using the borderline/clinical cut-off score (T-scores ≥ 67).	Withdrawn	13.0	0.76
		Somatic Complaints	10.6	0.66
		Anxious/Depressed	12.0	0.85
		Social Problems	33.8	0.71
		Thought Problems	12.5	0.66
		Attention Problems	25.7	0.79
		Delinquent Behavior	11.8	0.73
		Aggressive Behavior	12.6	0.88
Age	Age in years: mean (sd); range; 10-24 years		16.8 (3.0)	
Sex		Male	59.4	
Only child		Only child	8.3	
IQ	Estimated full IQ: two verbal (Information, Vocabulary) and two performance subtests (Picture Completion, Block Design) of the Wechsler Intelligence Scale for Children-III (Kaufman et al., 1996; Wechsler, 1991).	Mild-borderline ID	59.0	
Past psychopathology	Presence of psychopathology before the previous year according to the parents; single question.	Yes	40.0	
Life-events	Adapted version of Life Events Questionnaire (Berden et al., 1990) containing 20 life-events (e.g., parent leaving the household, death of a loved one) and their impact on the child in the past two years.	≥ 1 negative life-event	28.8	
Physical problems	Wahler Physical Symptoms Inventory (Wahler, 1968); 42 items about physical and somatic complaints (e.g., headache, feeling tired, tense muscles); 6-point scale (almost never to almost every day).	1 SD > mean	12.9	0.83
Parent				
Ethnicity		≥ 1 parent is not Dutch	14.7	
Number of parents		Single parent	21.2	
Educational level	Highest completed parental education: none to secondary low versus higher education.	Higher education	43.8	
Socio-economic status	Highest occupational status of parent(s), indicated by the Standard Classification of Professions (Central Bureau of Statistics, 1993); unemployed, work requiring no skills, or lower vocational training (low) versus higher levels (medium/high).	SES medium/high	47.9	

Table 4.1 *continued*

Variable	Instrument description	Dichotomization	%	Cronbach's α
Problematic parenting	Total score on 34-item Parent Domain of the Stress Index for Parents of Adolescents (SIPA) (Sheras et al., 1998). Problematic parenting related to being the parent of an adolescent (including subscales Life Restrictions, Incompetence/Guilt, Social Alienation, Relationship with Spouse). Total score was divided in problematic vs. non-problematic parenting in accordance with original cut-off criteria.	≥ 85th percentile	15.1	0.91
Parental psychopathology	Total score on the Young Adult Self Report (Achenbach, 1997), 29 of the 110 items that discriminated best between referred and non-referred adults (Wiznitzer, 1993). 83% were mothers.	1 SD > mean	16.0	0.90
Parental worries	Parental Worries Scale (constructed in Phase 1) containing 31 items about various aspects parents may worry about regarding their child in the past 6 months (social life, health, and future independent functioning), to be scored on 5-point scale (never to very often). Total score was dichotomised.	≥ 75th percentile	24.5	0.96
Parental monitoring	Total score on a 6-item questionnaire based on the Parental Monitoring Scale (Brown et al., 1993). How much do they know about their child regarding his/her whereabouts after school and at night, free time spending, money spending, friends, and school marks (4-point scale: nothing to everything). Total score was dichotomised into more vs. less monitoring.	≥ 75th percentile	16.0	0.89
Problematic parent-child relationship	16-item Adolescent-Parent Relationship domain of the SIPA (Sheras et al., 1998). Total score was divided in problematic vs. non-problematic using original cut-off criteria.	≥ 85th percentile	15.5	0.78
Social support	Perceived social support by parents, single question; sufficient vs. not sufficient	Not sufficient	21.1	
Family				
Hostile family functioning	17-Item Hostility-subscale of Dutch Questionnaire for Family Problems (VGP) (Koot, 1997). Total score was dichotomised in accordance with the Dutch norms.	≥ 95th percentile	10.6	0.92
Negative involvement	8-Item Involvement-subscale of VGP (Koot, 1997)	≥ 95th percentile	14.7	0.86

Table 4.2
Variables related to perceiving child psychopathology, needing professional help, and seeking professional help: Results from univariate logistic regression analysis

	Perception[a] (n=745)		Need[b] (n=282)		Seek[c] (n=133)	
Variables	OR	95% CI	OR	95% CI	OR	95% CI
Child						
CBCL						
Withdrawn	5.5	3.4-8.9	2.5	1.3-4.9		
Somatic Complaints	3.3	2.0-5.4				
Anxious/Depressed	8.2	4.7-14.3	5.1	2.3-11.2	2.5	1.2-5.5
Social Problems	3.9	2.8-5.4	2.2	1.3-3.7		
Thought Problems	7.6	4.5-12.9	3.0	1.5-5.9		
Attention Problems	5.5	3.9-8.0	2.4	1.4-4.0		
Delinquent Behavior	8.1	4.6-14.0				
Aggressive Behavior	7.7	4.6-13.2	2.3	1.2-4.2		
Age*	0.9	0.9-1.0	0.9	0.8-1.0		
≥ 1 negative life-event	4.2	3.0-5.9			2.9	1.4-6.1
Physical problems	3.4	2.2-5.2				
Past psychopathology	9.8	7.0-13.9	4.8	2.7-8.3	2.7	1.1-6.8
Parents						
Single parent	1.7	1.2-2.4				
Educational level (higher)	1.4	1.0-1.9	1.8	1.1-2.9		
SES medium/high			1.7	1.0-2.8		
Parental psychopathology	3.8	2.2-5.2	3.1	1.6-6.1		
Problematic parenting	3.0	1.9-4.8	2.8	1.3-5.8		
Problematic parent-child relationship	3.3	2.2-5.1				
Parental worries	6.0	4.1-8.8	4.2	2.4-7.5		
Parental monitoring (less)	2.1	1.4-3.1				
Social support (not sufficient)	1.9	1.3-2.8				
Family						
Hostile family functioning	4.0	2.4-6.7	2.6	1.2-5.7		
Negative involvement	3.2	2.0-4.9				

OR = Odds Ratio; CI = Confidence interval; $p < .05$
*Continuous variable, for every unit increase, the odds increase by this number.
[a] Parents who perceived emotional or behavioural problems vs. who did not
[b] Parents who indicated a need for professional help vs. who did not
[c] Parents who actually sought professional help vs. who did not

Data analysis

Through univariate logistic regression analyses the contribution of each independent variable to respectively perceiving problems, needing professional help, and actual help-seeking was tested. We first compared parents who had perceived psychopathology in their child with those who had not. Then, of those perceiving problems, we compared parents who subsequently indicated a need for professional help with those who had not. Finally, within those who needed professional help, we compared parents who sought professional help with those who had not. Multiple logistic regression analyses, adjusting for all significant variables from the previous univariate analyses, revealed the variables with the strongest unique contribution.

Results

Table 4.2 shows the results from univariate logistic regression analyses for all three steps in the help-seeking process separately and Table 4.3 shows the adjusted results. Sex and ID of the child, being an only child, and ethnicity of the parents were not significantly related to any outcome variable.

Of all parents, 38.8% (n=289/745) had *perceived psychopathology* in their child during the past year (of which 82.7% perceived their child's emotional or behavioural functioning as 'neither good nor bad'). Of these children, 74.7% had a deviant score on a CBCL subscale.

Of the variables associated with perceiving psychopathology (Table 4.2), besides a deviant score on CBCL Anxious/Depressed, the strongest variables were related to the child (younger age, life-events, physical problems, past psychopathology), to problems between parent and child, and to the parents' educational level (Table 4.3).

Of the parents who perceived child psychopathology, 67.0% (189/282) had also felt a *need for professional help*. Needing professional help was more likely when a child had a deviant CBCL subscale score, was younger, and had these problems before the past year. Furthermore, their parents were higher educated, more often suffered from psychopathology themselves, had problems with parenting, more worries about their child, and the family functioning was hostile (Table 4.2). Of these, past psychopathology in the child and more parental worrying had the strongest unique contribution (Table 4.3).

Table 4.3
Variables uniquely related to perceiving child psychopathology, needing professional help, and seeking professional help (multiple logistic regression analysis)

	Perception [a]		Need [b]		Seek [c]	
Variables	OR	95% CI	OR	95% CI	OR	95% CI
CBCL Anxious/Depressed	2.6	1.1-6.3			2.2	1.0-5.0
Age*	0.9	0.8-1.0				
≥ 1 negative life-event	2.9	1.7-5.0			2.5	1.2-5.3
Physical problems	2.5	1.1-5.3				
Past psychopathology	5.3	3.2-8.8	4.2	2.0-8.9		
Educational level (higher)	1.8	1.1-2.9				
Problematic parent-child relationship	2.3	1.1-4.9				
Parental worries			2.6	1.2-5.8		

OR = Odds Ratio; CI = Confidence interval; $p < .05$
* Continuous variable, for every unit increase, the odds increase by this number.
[a] Parents who perceived emotional or behavioural problems vs. who did not
[b] Parents who indicated a need for professional help vs. who did not
[c] Parents who actually sought professional help vs. who did not

Of parents who both perceived psychopathology and needed professional help, 57.9% (77/133) *actually sought professional help*. Five parents had not sought professional help because they were already receiving professional help before the past year. They were therefore excluded from further analyses. Parents were more likely to seek professional help when their child had a deviant CBCL Anxious/Depressed scale score, negatively experienced at least one life-event, and had psychopathology before the past year (Table 4.2). Only the latter did not remain significant (p = 0.1) in multiple logistic regression analysis (Table 4.3).

The most often reported reasons for not seeking professional help are presented in Table 4.4. Noteworthy is that for 75.0% of the parents who 'considered the problems not so big', at least one of the CBCL subscale scores was deviant. Financial, religious, language, and practical reasons (parking space, public transport, fear of waiting lists) were least common (< 5.6%).

Table 4.4
Most often reported reasons for not seeking professional help (n=55)

Reason [a]	%
Considered problems not so big	63.6
Wanted to handle problems themselves	54.5
Considered problems temporary	49.1
Not knowing where to find help	30.9
Fear of too big a burden for family/child	27.3
Negative experiences with professional help	27.3
Having difficulties in describing the problems and needs	23.6
Too busy/other priorities	21.8
Step to seek help is too big	20.0
Other people did not want the parent to seek help	16.4
No trust in professional help	12.7
Fear of labelling or stigma	10.9
Knowing other people with negative experiences with professional help	10.9
Child did not want to	10.2
Finding it hard to let go of the child	9.1
Fear of the child being taken from the family	9.1
Distance too long	9.1

[a] more than one reason could be indicated

Discussion

Although many youths with ID have additional emotional or behavioural problems, like youths in the general population only a minority receives professional help. Irrespective of the child's intellectual functioning, it is important to recognise the parental role in this (Baker & Heller, 1996; Costello & Janiszewski, 1990). However, our study was the first that aimed to unravel the parental role in the help-seeking process.

Based on a model that was constructed to study the help-seeking process of parents of non-ID pre-school children (Pavuluri et al., 1996), we distinguished three consecutive steps, namely 'perceiving child psychopathology', 'needing professional help', and 'actually seeking professional help'. In retrospect, we followed the parents on their way to seeking help in the past year.

Comparable to the study of Pavuluri and colleagues, our results showed that when parents perceived psychopathology in their child, this did not automatically imply seeking professional help. Moreover, even when parents indicated a need for professional help for their child's problems, just little over half actually sought professional help. Taking this last step turned out to be the biggest hurdle in the help-seeking process.

When looking at the process step by step, we found that 38.8% of the parents in this study *perceived psychopathology* in their child. This was about 2 to 4 four times more than reported by parents of non-ID youths who perceived these problems between 10.7% to 19.8% of their children (Flisher et al., 1997; Teagle, 2002; Verhulst & Van der Ende, 1997). However, this is in accordance with the reported 3- to 4-fold increase in psychopathology in ID youths (Dekker, Koot et al., 2002; Emerson, 2003b), which is likely to cause these higher perception rates.

As expected, parents were most likely to perceive problems when a CBCL subscale score was deviant, especially in case of Anxious/Depressed. Verhulst and Van der Ende (1997) also found these problems associated with problem perception in non-ID youths. In addition, most of the other variables we found to be related to perception were also found in non-ID studies (Horwitz et al., 2003; Teagle, 2002; Verhulst & Van der Ende, 1997). They predominantly seem to represent elevated parental stress caused by additional problems in or with their child (e.g., life-events, physical problems, past psychopathology, problems between parents and child), parental characteristics (e.g., single parent, parental psychopathology, less social support), or deviant family functioning (hostile and negative functioning). These stressors might not only lower the threshold to perceiving problems in their child (Kinsman, 2001; Verhulst & Van der Ende, 1997), they may also lead to parents being more sensitive and alert for these problems to (re)appear. Two other variables represent circumstances that put parents in a better position to observe their child's functioning (child's younger age), and to know and recognise the signs of psychopathology (higher educational level).

Regarding the second step, of those parents who perceived problems of psychopathology in their child, two-thirds reported to have felt a *need for professional help*. This is comparable with the 76% of Pihlakoski et al. (2004) who used a more stringent definition of problem perception, but higher than was found in studies that asked all parents and not only those who perceived child psychopathology, i.e., between 4% and 20% (Owens et al., 2002; Teagle, 2002; Wu et al., 1999; Zahner, Pawelkiewicz, DeFrancesco, & Adnopoz, 1992).

The elevated need for professional help found in this study might be related to the child's ID, which in itself often brings about parental stress (Hastings & Beck, 2004). Additional emotional or behavioural problems frequently lead to even higher stress levels which increase their need for professional help (Maes et al., 2003).

Results from univariate logistic regression analyses showed that parents more often needed professional help when the CBCL indicated emotional or behavioural problems in their child. However, when other significant child, parent, and family factors, of which many seem to be stress-related (e.g., parental psychopathology, problems with parenting, increased worrying about the child, and family problems), were included in the model, deviant CBCL scale scores were no longer associated with needing professional help. Of these stress-related factors, increased parental worrying about the child remained a major factor in needing professional help. This is in line with studies in which the amount of distress or burden parents experience in raising a child was found to be more important for seeking professional help than the level of child psychopathology itself (cf. Zwaanswijk et al, 2003).

Finally, parents more often needed (and sought) professional help when their child still had, or also had these problems before the past year. This might reflect the tendency of parents to wait some time before needing and seeking help, perhaps hoping that these problems will pass or finding it difficult to determine when the problems are severe enough to seek help (Laitinen-Krispijn, Van der Ende, Wierdsma, & Verhulst, 1999).

As stated before, both perceiving problems and needing professional help apparently does not guarantee *actual help-seeking*, since this was done by only half of the parents who indicated a need for professional help. Studies in the general population found similar results, although they studied help-seeking as a single step, and not as one step in a process, and in different samples (Feehan, Stanton, McGee, & Silva, 1990; Pihlakoski et al., 2004). The perceived barriers to seeking help, as reported by the parents themselves, enable us to also draw conclusions about their motives, which goes beyond drawing conclusions about the associated factors. Reported reasons for not seeking help primarily related to the parents' perception of the problems (not so big, or temporary), and to the professional help itself (not knowing where to go, and previous negative experiences). These reasons are comparable to those given by parents of typically developing youths (Flisher et al., 1997; Owens et al., 2002; Pavuluri et al., 1996), and by those who refrained from seeking help for themselves (Wells, Robins, Bushnell, Jarosz, & Oakley-Browne, 1994). They seem to generally apply, irrespective for whom help is needed. In contrast, while in our study financial reasons were uncommon, in other studies they were frequently reported (Flisher et al., 1997; Pavuluri et al., 1996). The reason might be that in the Netherlands there are less financial constraints to receiving this kind of professional help (Zwaanswijk et al., 2003).

It is remarkable that within this selective group of parents (who all perceived emotional or behavioural problems in their child, *and* indicated a need for professional help), three factors were found associated with actual help-seeking, namely a deviant score on CBCL Anxious/Depressed, negative life-events, and past psychopathology. The relation with life-events was also found for parents of infants (Horwitz et al., 2003). However, in contrast with general population studies (Zwaanswijk et al., 2003), not behavioural problems but problems of anxiety and depression increased help-seeking. It might be that parents of ID children are more inclined to consider deviant behavioural functioning as part of the general behavioural repertoire of their child (Rush, Bowman, Eidman, Toole, & Mortenson, 2004), and not as a reason to seek help.

Limitations

Non-random sample attrition might somewhat limit the generalisation of our results to parents of youths from schools for the educable, and non-Dutch parents. Furthermore, although not specifically designed for ID youths, to assess child psychopathology we used the CBCL, because specific measures are still being developed and validated, and because it is generally believed that the problems as assessed with the CBCL also apply to youths with moderate to borderline ID (Wallander et al., 2003).

For our definition of parental perception of child psychopathology, we considered those parents who indicated their child's emotional or behavioural functioning as 'neither good nor bad' to perceive these problems. One might question whether this is an indication of problem perception, but this seems justified since almost 75% of these parents' children had a deviant CBCL subscale score.

We relied on parents' reports only to gain insight into their help-seeking process. To reduce the odds of parents reporting about another time period or about their help-seeking for problems due to the ID alone, and for emotional or behavioural problems, interviewers repeatedly stressed these limitations.

Finally, one has to keep in mind that, especially in this population, besides parents, other persons can also initiate the help-seeking process, for example teachers or school psychologists, but they were not included in this study.

Clinical implications and future research

Overcoming perceived barriers in actually seeking professional help was a major obstacle in the help-seeking process. Parents' reasons for not seeking help were based on their (mis)perception of the problems ('not so big' or 'temporary', despite a frequently present deviant CBCL subscale score), and to not knowing where to go for help. Since many ID youths have psychopathology which appears to be quite persistent, it is important to inform all parents, including those who are not faced with stressful situations, about these problems (signs, and potential negative prospects when untreated), but also about where to find what type of help. Especially schools, sheltered work settings, and service providers for the ID can provide this information, but also contribute in detecting these problems (Leaf et al., 1996). Routine screening for psychopathology in all youths with ID can be a first step to increase the number of youths that eventually obtain help when needed (Wallander et al., 2003). This can also be encouraged by assigning a case manager. He should know the signs of psychopathology, helps to obtain professional help when needed, knows where what kind of help is provided, and can mediate between parents and service providers or professional help (Hastings & Beck, 2004).

To better understand the parental role and motives in the help-seeking process, and the relation with stressors and resources, more research is needed that examines the process, and not a single step or outcome, in large representative samples of both ID and non-ID populations. In addition, future research is needed to shed a light on the outcome of this help-seeking process, i.e., the extent to which the need for help is being met.

5 | Supporting parents of youths with intellectual disabilities and psychopathology

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Chapter 5

Supporting parents of youths with intellectual disabilities and psychopathology

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 support, 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’, i.e., 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.

Introduction

Parents of children and adolescents (further referred to as youths) with intellectual disabilities (ID) often 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; Bailey et al., 1999; Carr & O'Reilly, 1996; Chadwick, Beecham, Piroth, Bernard, & Taylor, 2002; Ellis et al., 2002; Petr & Barney, 1993; Treneman, Corkery, Dowdney, & Hammond, 1997).

In addition to the ID, many of these youths also have emotional or behavioural problems (Emerson, 2003b; 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 (Floyd & Gallagher, 1997; Hayden & Goldman, 1996; 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 seventeen 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 is 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 this 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 of 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 (Horwitz et al., 2003; Poduska, 2000; Verhulst & Van der Ende, 1997; Wu et al., 1999). Finally, knowledge about discrepancies between the need for and obtaining of support (i.e., met versus unmet need) will reveal the types of support service providers should especially focus on or improve (Hazell et al., 2002; Treneman et al., 1997).

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, i.e., 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 1,615 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 1,396 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 ($p < .01$). About one year later, the Time 2 assessment was conducted. A detailed description of the sampling procedure can be found elsewhere (Dekker, Koot et al., 2002). The present study is based on data collected at Time 3 (T3; October 2002 until January 2004).

The T3 target sample consisted of 1,007 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, for example because of emigration. Of the 961 parents we could contact, 749 participated (T3 response = 77.9%; overall study response = 53.4%).

We found no significant differences (χ^2, or t-test, $p > .05$) 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 (CBCL) fell in the borderline/clinical range (Achenbach, 1991a). 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 ($p < .05$). After adjusting for the correlation between these variables, we found that only significantly fewer non-Dutch parents had participated at T3 ($p < .05$).

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 5.1 shows this sample's characteristics.

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 CBCL. 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 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, standardised psychopathology measures confirmed the presence of emotional or behavioural problems, i.e., a deviant score on either CBCL'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 due to their child's additional emotional or behavioural problems, and not about needs that were solely related to their child's ID, only those parents who perceived these additional 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 due to 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 dichotomised 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 dichotomised 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 with a currently unmet need for support and who had not sought help, to what extent each of 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 ID. 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 (Kaufman et al., 1996; Wechsler, 1991). We distinguished between two levels of ID: moderate ID (IQ 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 two years (e.g., one parent leaving the household, dying of a loved one, hospitalisation for at least a fortnight). If so, they were asked how their child was affected by this event (positive, neutral, or negative). A dichotomised 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, WPSI* (Wahler, 1968) inquires about the frequency a child is affected by 42 different physical problems, e.g., pains, nausea, sleeping problems (6-point scale, ranging from ‘almost never’ to ‘almost every day’). The sum of all scores was dichotomised using one standard deviation (SD) above the mean as cut-off, resulting in youths with high versus relatively low levels of physical problems.

Parent and family variables

SES 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) versus ‘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 (YASR)* assesses psychopathology in the primary caregiver in the past six months (Achenbach, 1997). We used the short version containing 29 of the original 110 items that discriminated best between referred and non-referred subjects (Verhulst & Van der Ende, 1997; Wiznitzer, 1993). 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 dichotomised 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 dichotomised 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 six months (e.g., social life, health, and future independent functioning), which was answered on 5-point scale (from ‘never’ to ‘very often’). The sum of the item scores was dichotomised 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 characterised 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 dichotomised consistent with the Dutch norms (95th percentile).

Table 5.1
Sample characteristics (n=289)

Variables	%	Variables	%
Child		*Parent(s)*	
Male sex	60.9	Single parent	21.2
Age (mean, SD)	16.5, 2.9	≥ 1 parent is Dutch	87.2
Moderate ID	37.0	Medium/high SES	49.0
≥ 1 negative life-event	46.7	Medium/high educational level	48.8
Past psychopathology	71.3	Parental psychopathology	26.2
Physical problems (higher level)	22.4	Problematic parenting	24.3
		Problematic parent-adolescent relationship	25.3
Family		Parental worries (more)	44.4
> 1 child in the family	90.7	Sufficient social support	72.1
Hostile family functioning	18.7		
Negative involvement	23.9		

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 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 due to their child's emotional or behavioural problems. Moreover, 67.4% needed at least three different types of support. Table 5.2 shows the proportions of parents who needed a particular type of support (column 2). Most often needed were 'a friendly ear', 'information', and 'child mental health care'.

Table 5.2
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 [a] (n=282)	Indicated need split up by type of problem perception			Met need [b]
Type of support		emotional problems only (n=63)	behavioural problems only (n=59)	emotional *and* behavioural problems (n=160)	
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

[a] = More than one need possible
[b] = % of all parents who needed this type support

Compared with parents who perceived only emotional or only behavioural problems, parents who perceived both types of problems needed support the most (Table 5.2, columns 3-5). Table 5.3 shows the accompanying Odds Ratios (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 5.3.

Table 5.3

Variables that are related to parents having a particular need for support due to perceived emotional and/or behavioural problems in their child: Significant results from univariate and multiple **(bold)** logistic regression analysis (all $p < .05$)

Type of support	Friendly ear		Information		Activities		Respite care		Practical/ material help		Child mental health care		Parental counselling	
Variables	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Perception of problems														
Behavioural vs. emotional							3.2	1.3-7.4					2.9	1.3-6.3
							3.3	**1.2-9.3**						
Behavioural and emotional vs. emotional	3.1	1.6-6.0	4.2	2.3-7.9	2.3	1.3-4.2	4.9	2.3-10.3	5.8	2.2-15.3	3.3	1.8-6.1	4.6	2.4-8.8
	2.6	**1.2-5.6**	**3.6**	**1.7-7.6**			**4.3**	**1.7-11.1**	**3.2**	**1.1-9.7**			**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	2.8	1.7-4.6	2.2	1.2-3.8				
					2.0	**1.0-3.7**	**3.4**	**1.7-6.8**	**2.4**	**1.2-5.0**				
≥ 1 negative life-event									1.8	1.0-3.2				
Past psychopathology	2.4	1.3-4.3	4.6	2.6-7.7	2.8	1.6-4.8	3.5	1.9-6.4	3.4	1.6-7.2	5.2	2.9-9.1	3.6	2.1-6.4
			3.0	**1.6-5.7**	**2.0**	**1.0-4.0**	**3.1**	**1.4-7.1**			**4.8**	**2.3-9.9**	**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														
≥ 1 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			2.0	1.2-3.2		
							2.8	**1.2-6.4**						
Parental psychopathology	3.0	1.3-7.0	2.8	1.4-5.6	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
	2.6	**1.0-6.8**	**2.3**	**1.0-5.1**										
Problematic parenting					2.6	1.4-5.0	2.1	1.1-3.8	3.0	1.6-5.7	2.4	1.3-4.7	2.8	1.4-5.2
									2.2	**1.0-4.8**				
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	4.6	2.7-7.7	4.3	2.6-7.2	5.8	3.1-10.7	4.3	2.5-7.3	2.7	1.6-4.4
			2.1	**1.1-4.1**	**2.9**	**1.4-5.7**	**3.2**	**1.6-6.5**	**2.8**	**1.3-5.9**	**3.1**	**1.6-6.0**		
Family														
> 1 child in family			2.5	1.1-5.6										
Hostile family functioning	5.1	1.5-17.0	2.8	1.3-6.4	2.3	1.2-4.4							2.4	1.3-4.7
	3.7	**1.1-13.0**												

OR = Odds Ratio; CI = Confidence interval, * Continuous variable, for every unit increase, the odds of needing support increases by this number

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, i.e., 'activities', 'respite care' and 'practical or material help'. Results regarding other variables are presented in Table 5.3.

Table 5.4
Variables that are related to having a particular need for support met: Significant results from univariate and multiple **(bold)** logistic regression analysis (all p < .05)

Type of support	Friendly ear (n=219)		Information (n=193)		Activities (n=143)		Respite care (n=108)	
Variables	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Level of indicated need								
High need (versus low)	2.8	1.5-5.2					5.8	2.5-13.4
	2.6	**1.4-4.9**					**5.8**	**2.5-13.4**
Child								
Age*					0.9	0.8-1.0		
					0.9	**0.8-1.0**		
Moderate ID	2.1	1.0-4.1			2.2	1.1-4.4		
					2.2	**1.1-4.4**		
Parents								
Parental worries (more)			2.3	1.3-4.1				
			2.3	**1.3-4.1**				

OR = Odds Ratio; CI = Confidence interval
* Continuous variable, for every unit increase, the odds of receiving activities increases by this number

Table 5.4 *continued*

Type of support	Practical/ material help (n=68)		Child mental health care (n=160)		Parental counselling (n=138)	
Variables	OR	95% CI	OR	95% CI	OR	95% CI
Level of indicated need						
High need (versus low)			3.6	1.8-7.1		
			2.8	**1.4-5.9**		
Child						
Physical problems (higher level)	0.3	0.1-1.0				
≥ 1 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
					2.7	**1.3-5.6**
Medium/high educational level	5.0	1.7-14.9				
Parental worries (more)			2.0	1.0-4.0		
Problematic parenting	0.1	0.0-0.3				
	0.1	**0.0-0.4**				

OR = Odds Ratio; CI = Confidence interval

The last column of Table 5.2 shows the percentages of currently met need. Need for ‘a friendly ear’, ‘respite care’ and ‘information’ were most often met (75.3%, 61.1%, and 51.3%), whereas the other support needs were met in less than 43% of the time.

Table 5.4 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 5.4.

For almost all types of support, different variables were related to met need. However, of all variables, a high need for support (versus 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 themselves, 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 characterised 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 (Horwitz et al., 2003; Poduska, 2000; Verhulst & Van der Ende, 1997; Wu et al., 1999). However, our study showed that this is not only true 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', i.e., '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, but also 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 organisations. 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, i.e., 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 (Flisher et al., 1997; Freedman & Boyer, 2000; Owens et al., 2002; Pavuluri et al., 1996). 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 (Freedman & Boyer, 2000; Quinn et al., 1996). 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, non-random sample attrition might limit the generalisation 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 also 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 about not only 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.

6 | Self-reports on mental health problems of youths with moderate to borderline intellectual disabilities

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Chapter 6

Self-reports on mental health problems of youths with moderate to borderline intellectual disabilities

Abstract

Objective: To determine the extent to which the Youth Self-Report (YSR) can also be used to assess emotional and behavioural problems in adolescents with intellectual disabilities (ID).

Method: In 2003, 281 11 to 18-year-olds with ID (IQ ≥ 48), and in 1993, 1,047 non-ID adolescents completed the YSR. Parents completed the Child Behavior Checklist (CBCL). The ID sample was split into a lower (IQ 48-69) and higher IQ group (IQ ≥ 70). Cronbach's alphas of the YSR scales, and (intraclass) correlation coefficients between and within YSR and CBCL scale scores were calculated to determine parent-adolescent agreement, and YSR construct validity, which were compared between samples. Mean YSR scale scores were compared between ID adolescents with and without a psychiatric disorder.

Results: Cronbach's alphas, parent-adolescent agreement, and indications of construct validity were about similar in all samples, although the latter to a somewhat lesser extent in the lower IQ group. Mean scale scores were 1.5-2.0 times higher for ID adolescents with a psychiatric disorder.

Conclusions: The YSR seems applicable in youths with an IQ ≥ 48. Further research is needed to refine and confirm these findings and the factor structure of the YSR in ID adolescents, and to differentiate between adolescents with a moderate and mild ID.

Introduction

Until recently, to assess psychopathology and challenging behaviour in children and adolescents with intellectual disabilities (ID), most studies based their results on reports from parents and teachers, whereas only few used information from self-reports (Emerson, 2005). In the past decade, and in line with the trend of stimulating participatory research in ID people, there seems to be an increase in studies that (also) use self-reports. While lower-functioning children and adolescents may not be fully capable of reflecting on their own emotional and behavioural functioning (Wallander et al., 2003), several studies showed that individuals with mild and moderate ID are capable of reporting about their own functioning and feelings (Beck, Carlson, Russell, & Brownfield, 1987; Benavidez & Matson, 1993; Bramston & Fogarty, 2000; Deb, Thomas, & Bright, 2001; Demb, Brier, Huron, & Tomor, 1994; Emerson, 2005; Gullone, Cummins, & King, 1996; Heiman, 2001; Lindsay, Michie, Baty, Smith, & Miller, 1994; Manikam, Matson, Coe, & Hillman, 1995; Moss, Prosser, Ibbotson, & Goldberg, 1996).

In the general population (GP), including the views of children and adolescents is imperative to obtain a complete picture of their emotional and behavioural functioning (Van der Ende, 1999). This perspective is also gaining ground in the field of ID (Emerson, 2005).

To study psychopathology in children and adolescents in the GP, the validated Child Behavior Checklist (CBCL), Teacher's Report Form (TRF) and Youth Self-report (YSR) are frequently used (Achenbach, 1991a, 1991b, 1991c). Both CBCL and TRF are not only considered (Wallander et al., 2003), but also proven to be useful in adolescents with mild to moderate ID (Borthwick-Duffy, Lane, & Widaman, 1997; Dekker, Koot et al., 2002) who, on the whole, function and display similar behaviours as non-ID peers. Even though the YSR contains the same constructs as the CBCL and TRF, it has not yet been comprehensively studied in adolescents with ID.

The aim of this study was to determine whether the YSR could also be used to assess emotional and behavioural problems in adolescents who have moderate to borderline ID. Because these adolescents can be considered as a heterogeneous group, and in order to detect differences within the ID sample, and between the ID samples and the GP, we distinguished between those with a lower IQ (< 70) and higher IQ (≥ 70). More specifically, we compared the psychometric properties of the YSR between the ID and GP samples regarding levels of:

1. internal consistency,
2. parent-adolescent agreement on similar subscales,
3. construct validity, and
4. criterion-related validity (in ID samples only).

Regarding 1-3, since we considered ID adolescents to be capable of understanding and answering questions about their own emotional and behavioural functioning, we expected not to find differences in psychometric properties between the ID and GP samples. Regarding aim 4, we expected the mean YSR scale scores of ID youths with a psychiatric disorder to be higher than of those without a psychiatric disorder. However, several studies showed that acquiescence (the tendency to say yes to questions irrespective of the content), as well as suggestibility, and problems with question content, phrasing and answering format can especially be a problem in persons with a more severe ID (Finlay & Lyons, 2001). Therefore, if differences in psychometric properties of the YSR would appear between samples, we expected them to mostly be between the lower IQ group and the GP.

Method

Participants and procedure

ID Sample. This study is part of a Dutch study on psychopathology in ID youths that started in 1996. Then, in the Netherlands, most children and adolescents with a moderate to borderline ID went to special schools for the educable (IQ range 60-80) or trainable (IQ range 30-60). In the original sample, 1,615 children (age range 6-18 years) were randomly selected from all 132 schools for the educable and trainable in the province of Zuid-Holland (school response = 87.1%). Of these, 219 children were excluded because they exceeded the age range, were not living at home, or had parents having problems with the Dutch language. Of the remaining 1,396 children, 231 parents could not be contacted in person, but 982 filled out at least one of the core instruments (response = 70.3% and 84.3% of those that were personally contacted). Significantly more parents of children from schools for the trainable than for the educable participated ($p < .01$).

The present study was based on data collected at Time 3 (October 2002 until January 2004). The target sample consisted of 1,001 adolescents whose parent(s) had in any way participated at Time 1, minus 1 adolescent who had died, but plus 7 adolescents who were excluded at Time 1 because they (slightly) exceeded the age range (N=1,007). Adolescents were traced through consulting phonebooks and municipal registers, but their parents were contacted first, because this was the first time the adolescents themselves were asked to participate, and it was likely that not all knew about this study. Only after we got the parents' permission, we approached the adolescents. This was refused for 140 adolescents, and in 48 cases we were unable to personally contact the adolescents (e.g., due to emigration, or no valid address). Of the 819 eligible adolescents, 638 participated (response = 77.9%).

We found no significant differences (χ^2, or t-test, $p < .05$) between the 638 Time 3 participating and 369 non-participating adolescents on Time 1 measures regarding sex, school type attended, and mean CBCL scores (Total Problems, Internalizing, or Externalizing). However, adolescents more often participated when they were younger, and when there were two parents in the household, the parents were of Dutch origin, and had higher SES and educational level. After adjusting for the correlation between these family variables, only fewer adolescents of non-Dutch parents had participated at Time 3 ($p < .05$).

Because many children and adolescents with autism are impaired in answering questions about their own functioning (Hill, Berthoz, & Frith, 2004), we excluded 56 adolescents who had some form of an autistic disorder. Furthermore, since the YSR has been constructed and validated for 11 to 18-year-olds, we only included those 416 within this age range. Of these, 10 had filled out the YSR by themselves. For the sake of standardisation they were also excluded, because all adolescents were interviewed and had taken the IQ test. Eventually, 406 adolescents participated, but 67 were not able of answering the questions of the YSR, most often because of their ID. This inability was first determined through an inability to answer any of the questions of the verbal subtests of the IQ test. Second, the researchers (who are experienced in the field of ID) trained the interviewers to detect an adolescents' lack of comprehension of the questions, answering format, time period, and consequently to detect inconsistencies in the answers. Interviewers were trained to explain the item content, when necessary, without being suggestive, and the response categories were written on a paper. An interviewer was allowed to end the interview when an adolescent was not able to answer any of the first questions. The interviewer reported to the researchers about their detection of any inconsistencies, and about the questions they had explained. In case of any indication of an adolescent's inability, or when the number of missing values exceeded 10%, the researchers regarded an adolescent as unable to reliably answer the questions of the YSR.

To ensure that only those were included who were really capable answering the questions, we determined through ROC-curves whether IQ could be taken as a measure to distinguish between adolescents who were and who were not capable of doing this. The area under the curve was 0.916, which implied that the IQ score is a very accurate measure to distinguish between these two groups of adolescents. At an IQ of 48 both sensitivity and specificity were the highest (.826 and .896 respectively) and this was therefore taken as a cut-off point.

The final sample thus consisted of 281 adolescents with an IQ ≥ 48 (mean IQ = 66.8, *SD* = 12.1), which was split into a lower IQ group (n=173, IQ 48-69, mean IQ = 58.9, *SD* = 6.2), and a higher IQ group (n=108, IQ ≥ 70, mean IQ = 79.3, *SD* = 7.7).

General population sample. In 1993, 2,916 children and adolescents (4-18 years old, Dutch nationality, and living in the Netherlands) were selected by a stratified multistage cluster and random sampling design (Verhulst, Van der Ende, Ferdinand, & Kasius, 1997). Exclusion criteria were an ID, severe physical handicap, and the parents' limited comprehension of the Dutch language (n=57). Another 62 were not traceable, and 88 could not be personally contacted. Of the remaining 2,709 eligible adolescents, 2,227 parents (82.2%) answered the questions of the CBCL. Non-response analysis showed that significantly more parents of an adolescent in the lower age group (4-10 years) participated.

Only 11 to 18-year-olds were asked to fill out the YSR themselves (n=1,124). Of these, 51 who visited a school for special education, 10 10-year-olds, and 16 19-year-olds were excluded. Consequently, the GP sample consisted of 1,047 adolescents.

Measures

The *YSR* is used to assess emotional and behavioural functioning in the preceding six months through self-report by 11 to 18-year-olds. It was modelled after the CBCL (see below). It contains 119 items, of which 16 socially desirable items and 103 problem items. All items are short sentences worded in the first person, using active wordings, to be answered on a 3-point scale, ranging from '0 = not true', '1 = somewhat or sometimes true', to '2 = very true or often true'. Eight syndrome scales, 2 broad-band scales (Internalizing, containing the items of Withdrawn, Anxious/Depressed and Somatic Complaints, and Externalizing, containing the items of Delinquent Behavior and Aggressive Behavior), and a Total Problems score (containing 101 problem items) can be derived. Higher scores represent higher levels of problems. Good validity and test-retest reliability has been established (Achenbach, 1991c) and was confirmed for the Dutch version (Verhulst, Van der Ende, & Koot, 1997b).

Adolescents from the GP filled out the YSR by themselves. To control for lack of reading ability in ID adolescents, and to determine an inability to answer the questions, the YSR was administered in an interview. Before the start of the interview adolescents were told that their answers would not be shared with their parents, caregivers, or anyone else, and that there were no wrong answers.

The *CBCL* is completed by parents of 4 to 18-year-olds and consists of 120 statements about emotional and behavioural problems. Parents are asked to what extent (3-point scale, same as the YSR) these statements applied to their child in the preceding six months. Similar to the YSR, 8 syndrome scales, 2 broad-band scales, and a Total Problems score (containing 118 problem items) can be derived. The Dutch version of the CBCL has shown to have good reliability and validity (Verhulst et al., 1996). Results from our Time 1 study in ID youths revealed similar internal consistency of the CBCL scales as in the GP, high one-year stability, relatively high inter-informant agreement, and high correlation coefficients between CBCL scales and similar scales from another instrument (Dekker, Koot et al., 2002). Most parents of the ID adolescents filled out the CBCL themselves. In the GP the CBCL was administered in an interview.

IQ (ID sample only). Estimation of the full IQ was obtained by administering 2 verbal (Information and Vocabulary) and 2 performance subtests (Picture Completion and Block Design) of the Dutch version of the Wechsler Intelligence Scale for Children-III (WISC-III) (Wechsler, 1991). We were not able to administer the whole WISC-III, but the average correlation coefficient of the subtest dyad Information-Vocabulary with the Verbal scale was .93, and .88 between the subtest dyad Picture Completion-Block Design with the Performance scale (Dumont & Faro, 1993; Kaufman et al., 1996). Hence, these subtests provide a reliable estimation of the full IQ.

Socio-economic Status (SES) was assessed by taking the highest occupational level of either one of the parents (Central Bureau of Statistics, 1993; Van Westerlaak, Kropman, & Collaris, 1975). We split these levels up into two categories 'low' (i.e., unemployed, or work that requires no skills or lower vocational training) versus 'medium/high' (i.e., higher levels of work).

The Dutch version of the *Diagnostic Interview Schedule for Children*-Parent version (DISC-IV) was administered by trained lay interviewers to assess the presence of any DSM-IV Anxiety, Mood, or Disruptive (including Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder and Conduct Disorder) Disorder, without impairment, in the past year (American Psychiatric Association, 2000; Ferdinand & Van der Ende, 1998; Shaffer, Fisher, Lucas, Dulcan et al., 2000).

Data analysis

Differences between GP and ID sample characteristics were tested with t-tests and chi-square tests (χ^2). Internal consistency of the YSR scales was determined through Cronbach's alphas. Parent-adolescent agreement was assessed through calculating two-way mixed Intraclass Correlation Coefficients (ICCs) between scores on similar subscales of YSR and CBCL. Fisher's Z-transformations were used to test for differences in the ICCs between samples.

ANOVAs were used to determine the level of criterion-related validity in the ID samples by comparing the mean YSR scale scores between adolescents with and without a psychiatric disorder. We calculated the Percentage Explained Variance (PEV) for significant differences, adjusting for the adolescents' sex, age, IQ, and family SES.

Multitrait-multimethod (MTMM) matrices were inspected to determine the level of construct validity of the YSR in all samples. MTMM matrices contain correlation coefficients between (1) different scale scores within one instrument (i.e., multitrait-monomethod correlation triangle), and (2) between scale scores of different instruments that measure both different and the same constructs, i.e., multitrait-multimethod correlation triangles and monotrait-multimethod (comparable to parent-adolescent agreement) respectively. We inspected these matrices consistent with five criteria of Campbell and Fiske (1959). Kendall's tau correlation coefficients (τ) were calculated to compare the ordering of correlation coefficients across the multitrait-monomethod and multitrait-multimethod triangles, each containing 28 multitrait correlation coefficients, within and between samples (Fisher's Z-transformations).

Results

The GP sample composition significantly differed from the ID sample with respect to sex, average age, and SES. In the GP sample, adolescents were less often of the male sex (49.0% vs. 61.9%, $\chi^2 = 14.8$, $p < .00$), were of a younger age (14.4 vs. 15.3, df = 1326, t = 7.3, $p < .00$), and they more often came from medium/high SES families, as opposed to low (71.9% vs. 41.6%, $\chi^2 = 88.1$, $p < .00$). Table 6.1 (columns 2-4) shows the means and *SDs* of the YSR scales in the GP and ID samples.

Table 6.1
Means, standard deviations (SD), and Cronbach's alphas of YSR scales in the GP and ID samples, and Intraclass Correlation Coefficients (ICCs) between parent report (CBCL) and self report (YSR) on similar scales

	Mean (SD)			Cronbach's α			ICC [a]		
Scales	GP	HIQ	LIQ	GP	HIQ	LIQ	GP	HIQ	LIQ
Withdrawn	2.5	2.6	2.4	.61	.68	.52	.33	.31	.25
	(2.1)	(2.3)	(2.0)						
Somatic Complaints	2.5	2.6	2.6	.65	.75	.70	.32	.42	.32
	(2.4)	(2.7)	(2.5)						
Anxious Depressed	4.8	4.3	4.0	.79	.88	.83	.34	.50	.49[b]
	(4.0)	(4.7)	(4.2)						
Social Problems	2.5	2.7	2.7	.56	.72	.56	.29	.31	.25
	(2.1)	(2.6)	(2.2)						
Thought Problems	1.2	1.5	1.0	.48	.66	.52	.12	.16	.16
	(1.6)	(1.9)	(1.4)						
Attention Problems	4.8	4.5	3.9	.65	.69	.65	.36	.32	.29
	(2.8)	(2.8)	(2.7)						
Delinquent Behavior	3.4	3.5	3.0	.61	.47	.46	.39	.34	.44
	(2.4)	(2.2)	(2.2)						
Aggressive Behavior	7.3	6.5	6.2	.80	.85	.85	.36	.53[b]	.35
	(4.6)	(5.2)	(5.3)						
Internalizing	9.7	9.2	8.8	.83	.90	.85	.37	.43	.41
	(6.5)	(8.2)	(6.9)						
Externalizing	10.7	10.0	9.2	.83	.85	.85	.40	.49	.39
	(6.3)	(6.8)	(6.8)						
Total Problems	33.8	31.6	29.3	.92	.95	.93	.34	.40	.36
	(17.1)	(21.1)	(18.5)						

GP = General population, HIQ = Higher IQ group, LIQ = Lower IQ group
[a] All ICCs at $p < .05$, except Thought Problems (HIQ) $p = .05$; [b] ICC is higher than in the GP sample ($p < .05$)

Internal consistency

Cronbach's alphas were about similar in both the GP and ID samples, but with overall higher alphas in the ID samples, except for Delinquent Behavior. The alphas in the lower IQ group were smaller than in the higher IQ group, but mostly still somewhat higher than in the GP (Table 6.1, columns 5-7).

Parent-adolescent agreement

Columns 8-10 of Table 6.1 show the ICCs between similar YSR and CBCL scale scores. Overall, ICCs were not significantly different between samples, except for Anxious/Depressed (higher ICC in the lower IQ group than in the GP; ICC = .49 vs. ICC = .34, $z = 2.26$, $p = .02$), and for Aggressive Behavior (higher ICC in the higher IQ group than in the GP; ICC = .53 vs. ICC = .36, $z = 2.00$, $p = .05$).

Table 6.2
The extent of meeting the MTMM criteria in the GP, higher IQ, and lower IQ samples

Criteria for construct validity	GP	higher IQ	lower IQ
Convergent validity			
Monotrait-multimethod correlations [a] are (1) significantly different from zero and (2) sufficiently large	(1) met (2) lowest is 0.13 (Thought Problems)	(1) met (2) lowest is 0.20 (Thought Problems)	(1) met (2) lowest is 0.16 (Thought Problems)
Discriminant validity			
Monotrait-multimethod correlations [a] are higher than their corresponding multitrait-multimethod correlations (i.e., correlations between both different subscales and different instruments)	4x not met: all for Thought Problems	3x not met: 1x Withdrawn, 2x Thought Problems	6x not met: 1x Withdrawn, 3x Social Problems, 1x Thought Problems, 1x Attention Problems
Monotrait-multimethod correlations [a] are higher than multitrait-monomethod correlations (i.e., correlations between different subscales in one instrument)	68.3% not met	74.1% not met	78.6% not met
Patterns of correlations are the same among the multitrait-monomethod and multitrait-multimethod correlation triangles [b]	Kendall's τ from .60 to .70	Kendall's τ from .21 to .59	Kendall's τ from .28 to .66
Within YSR: the correlations between different subscales are lower than the Cronbach's alphas of the subscales (Table 6.1, columns 5-7)	met	1x not met	5x not met

[a] These correlations were about similar to the ICCs in Table 6.1, columns 8-10.
[b] No significant differences between the GP and ID samples were detected.

Construct validity

Table 6.2 shows the extent to which five criteria of both convergent and discriminant validity were met in all three samples (Campbell & Fiske, 1959). The criterion of convergent validity was met in all samples (averaging .33, .39, and .34, for the GP, higher IQ, and lower IQ samples respectively), and in all samples, the lowest monotrait-multimethod correlation coefficient was found for Thought Problems. Compared with the GP, most criteria of discriminant validity were met to a similar degree in the higher, but to a lesser degree in the lower IQ group. However, in all samples, the second criterion, i.e., monotrait-multimethod correlations are higher than the correlations between different subscales in one instrument, was not met, ranging from 68.3% in the GP to 78.6% in the lower IQ group. The range of Kendall's τ was smaller in the GP than in the ID samples, but the correlation coefficients were not significantly different between samples (all z > 1.96, p > .05).

Criterion-related validity

In both ID groups all mean YSR scale scores were higher for adolescents with than without a psychiatric disorder, although for the higher IQ group these differences were not significant for Withdrawn and Social Problems (Table 6.3). According to Cohen's criteria (J. Cohen, 1988), most effect sizes of significant differences can be considered medium (PEV between 5.9-13.8), or large (PEV > 13.8). Small effect sizes (PEV < 5.9) were found for Somatic Complaints and Thought Problems (lower IQ group), and Anxious/Depressed (higher IQ group).

Table 6.3
Comparing mean YSR scale scores between ID adolescents with (present) and without a psychiatric disorder (absent) in two ID samples

	Higher IQ			Lower IQ		
YSR Scales	Absent (n=78)	Present (n=18)	PEV	Absent (n=116)	Present (n=43)	PEV
Withdrawn	2.3	3.5	-	2.1	3.4	9.9
Somatic Complaints	2.2	4.8	14.5	2.2	3.2	2.4
Anxious Depressed	3.6	6.2	4.9	3.1	6.6	14.2
Social Problems	2.4	3.6	-	2.4	3.6	6.7
Thought Problems	1.3	2.7	9.1	0.9	1.6	5.1
Attention Problems	3.9	7.2	24.2	3.4	5.4	11.2
Delinquent Behavior	3.2	4.7	6.3	2.6	4.1	10.1
Aggressive Behavior	5.3	11.5	18.3	4.9	9.5	14.9
Internalizing	7.8	14.2	9.0	7.2	12.7	13.9
Externalizing	8.5	16.2	16.8	7.5	13.6	16.1
Total Problems	27.0	49.9	15.9	24.4	42.4	19.3

PEV = Percentage Explained Variance, ANOVAs corrected for age, sex, IQ, and SES differences.
Only PEVs for significant ($p < .05$) differences are presented.

Discussion

To determine whether the YSR can also be used by youths with moderate to borderline ID, we compared the psychometric properties of the YSR of two groups of ID adolescents with GP adolescents. Overall, the results from this study support the use of the YSR to assess emotional and behavioural problems through self-reports in an interview in 11 to 18-year-olds with an IQ ≥ 48, without autism. This is especially true for adolescents with an IQ ≥ 70. While other studies draw similar conclusions for other self-report instruments on overall or specific types of psychopathology (Emerson, 2005; Heiman, 2001; Lindsay et al., 1994; Manikam et al., 1995), this study is the first to provide a more precise indication of the intellectual requirements for completing the YSR, instead of referring to an ID level (e.g., mild or moderate). The only exception is the study of Beck et al. (1987), in which a verbal IQ ≥ 55 was found to be sufficient for adolescents (N=26, 11-23 years old) to reliably complete two depression rating instruments. That cut-off, however, was based on the fact that of the 4 adolescents who were unable to complete a questionnaire 3 had IQs below 50. We based our conclusion on ROC-curve analysis, which revealed that the adolescents' IQ was a very accurate measure to differentiate between adolescents who were and were not capable of successfully participating.

Internal consistency

Levels of internal consistency give an indication of how well a set of items measure a defined construct. Cronbach's alphas of .70 or higher suggest good reliability (Nunnally & Bernstein, 1994). In both ID samples, except for Delinquent Behavior, alphas were about the same or higher than in the GP, and more often indicated good reliability, especially in the higher IQ group. In the lower IQ group alphas were lower than in the higher IQ group. The constructs as measured in the individual subscales seem to also apply to ID adolescents, but to a lesser degree for Withdrawn (lower IQ group), and Delinquent Behavior.

Parent-adolescent agreement

As in GP studies where parent-adolescent agreement averages at 0.25 (Achenbach, McConaughy, & Howell, 1987; Van der Ende, 1999), levels of parent-adolescent agreement were relatively low in all three samples. They were lowest for Thought Problems (ICCs < .16), but most ICCs ranged from .30 to .40, which stands for moderate agreement (J. Cohen, 1988). Between both ID samples, ICCs did not significantly differ. This was also true for differences between the GP and both ID groups, except for Anxious/Depressed (higher in the ID groups) and Aggressive Behavior (higher in higher IQ group).

Regarding Anxious/Depressed, it might be that because ID adolescents are usually more dependent on their parents than GP adolescents, and perhaps spend less time outside the house, their parents can more closely watch them, hence are more able to observe these behaviours (e.g., loneliness, fears, getting embarrassed easily). It might also be that these adolescents themselves are less capable of concealing emotional problems from their parents than GP adolescents. Nonetheless, this does not explain why this higher level of agreement was only found for this specific type of problems and not for the other types of internalising problems. In addition, it is not clear why in the higher IQ group parents and adolescents more often agreed on Aggressive Behavior than in the GP. Possibly, when they display these kinds of behaviours, such as screaming, teasing, and acting hot tempered, parents of higher IQ adolescents more often confront their child with their behaviours than parents of lower IQ adolescents, who may be more likely to view these behaviours as part of their child's ID. Furthermore, parents of GP adolescents may be less aware of their child's behaviour, since their children usually spend more time outside the house than ID youths do.

Construct validity

We assessed construct validity through inspecting MTMM matrices according to five criteria. Although statistical approaches such as confirmatory factor analysis are preferred in analysing the MTMM matrix (Kenny & Kashy, 1992), due to relatively small sample sizes of the two ID groups, this was not feasible in our study.

The level of convergent validity was about similar in all samples, but with respect to discriminant validity, the results were less outspoken. These criteria were not perfectly met in any sample, but were most met in the GP, and least in the lower IQ group. Not surprisingly, the higher IQ group resembled the GP more than the lower IQ group. Of all discriminant validity criteria, the second criterion (monotrait-multimethod correlation coefficients are higher than correlation coefficients between different subscales of one method/instrument, i.e., multitrait-monomethod) was not met in any sample. This suggests problems with discriminant validity as different constructs being measured with one instrument are higher correlated than two independent measures of one construct. However, this was true for both the ID samples and, although to a lesser degree, for the GP sample. Since relatively high levels of comorbidity of internalising and externalising problems are frequently found, also in ID youths (Dekker & Koot, 2003a), this might explain the relatively high correlation coefficients between subscales.

Even though the patterns of trait interrelationships were not significantly different between and within samples (criterion 3 of discriminant validity), the pattern was most consistent in the GP, i.e., smaller range Kendall's τ. In the ID samples, correlation of measures of traits or types of behaviour seems more dependent of informants than in the GP.

One should keep in mind, though, that the MTMM method is originally meant to compare different methods, such as an observation and a questionnaire, that measure the same constructs or traits, and not to compare multiple informants.

Criterion-related validity

Criterion-related validity was supported in both IQ groups. All adolescents with an unspecified psychiatric disorder had about 1.5-2.0 times higher scores on all YSR scales, although not significantly higher on Withdrawn and Social Problems in the higher IQ group. Since most effect sizes of these differences can be considered medium or large, these results provide strong indications that the YSR assesses emotional and behavioural problems in ID adolescents.

Limitations

Non-random sample attrition with somewhat less participation of educable children and children from non-Dutch parents at Time 1 and Time 3 might limit the generalisation of these results to non-Dutch youths with ID. Furthermore, the IQ was based on 4 subscales, which provides a marginally less accurate IQ than a whole IQ test. Also, since individual differences occur frequently, the IQ ≥ 48-criterion for successfully completing the YSR should be taken as an indication and not as a strict criterion to determine whether the YSR can be administered.

Even though the YSR can be administered orally, and adolescents with ID were told that their answers would be treated confidential, it might be that were more reluctant to report about displaying some behaviours than youths without ID who filled out the YSR themselves.

Finally, as an indication of criterion-related validity, we compared the mean scores of youths with and without a psychiatric disorder (assessed with DISC-IV). It is preferable to use a more solid measure indicating the presence of mental health problems, such as mental health care status.

Clinical implications and future research

This study has demonstrated that adolescents with ID are capable of providing information about their own emotional and behavioural functioning that is not similar, and thus adds to the information given by their parents. Therefore, in either clinical or research settings, to obtain a more comprehensive picture of these adolescents' emotional and behavioural functioning, they should also be consulted as informants. Secondly, compared with results from the GP, we have no reason to reject the YSR as a valuable tool to serve the purpose of obtaining this information through self-reports especially in higher functioning ID adolescents without autism. In addition to CBCL (and TRF), the YSR can also be used in this population.

Since this study is the first to examine the YSR in a large population-based sample of ID adolescents, more research is needed to confirm the results from this study, but also to statistically examine the construct validity of the YSR in this population, and to better determine the criterion-related validity in this population. In addition, longitudinal studies are needed to examine the test-retest reliability and predictive validity.

Finally, in this study, moderate and mild ID adolescents were studied as one group. As especially adolescents with moderate ID were found to have the most trouble in completing self-reports, future research is needed to refine the findings and conclusions from this study by investigating moderate and mild ID adolescents separately in larger population-based samples.

7 | Predicting antisocial and delinquent behaviours in youths with mild to borderline intellectual disabilities

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Chapter 7

Predicting antisocial and delinquent behaviours in youths with mild to borderline intellectual disabilities

Abstract

Six types of antisocial and delinquent behaviours (ADBs, e.g., ‘mean’, ‘property destruction’, ‘theft/arson’, and ‘authority avoidance’) were assessed in 526 youths (11-24 years) with mild to borderline intellectual disabilities (ID) and in 1,030 11 to 18-year-olds without ID. Overall, 10-20% of youths with ID exhibited some type of ADB, which were quite persistent over a five-year period. Youths who exhibited one type of ADB were likely to also exhibit other types of ADBs. Being a male, being younger and having behavioural problems particularly predicted ADBs, and higher levels of overall ADB. Overall, boys but not girls with ID exhibited ADBs more often than peers without ID. Clinical implications and implications for future research are discussed.

Introduction

Several studies have suggested that individuals with mild intellectual disabilities (ID) show higher rates of offending behaviours, such as theft, arson, and vandalism than both typically developing persons, and people with more severe ID (Hall, 2000; Hodgins, 1992; Simpson & Hogg, 2001a). In addition, in prisons and penal institutions many individuals have relatively low IQ scores (Holland, Clare, & Mukhopadhyay, 2002). However, methodological inconsistencies in definitions of ID, type of studied offences, and studied populations limit drawing firm conclusions about the prevalence and nature of antisocial and delinquent behaviours (ADBs) in persons with ID (Simpson & Hogg, 2001a).

Even less is known about the characteristics of persons with ID who exhibit ADBs. The only conclusion so far is that, as in the general population (GP), particularly youths up to the age of 18 are considered to show these behaviours (Hall, 2000). Hence, studies focussing on ADBs in adolescents and young adults (further referred to as youths) with ID are needed. These studies might show a considerably elevated level of ADBs in these individuals, since several factors that were found to be predictive of future ADBs in typically developing youths, e.g., emotional and behavioural problems and low socio-economic status (SES) (Burke, Loeber, & Birmaher, 2002; Farrington, 1995; Hawkins et al., 1998; Lipsey & Derzon, 1998), are more prevalent in youths with ID (Dekker, Koot et al., 2002; Emerson, 2003b). Furthermore, specific characteristics related to the ID, e.g., impulsivity, exploitability, and a desire to please might also increase the risk for ADBs (Cockram, 2005; Winter, Holland, & Collins, 1997).

Information is needed about which youths with mild to borderline ID are most likely to engage in these undesirable behaviours. In the general population, particularly boys exhibit ADBs (Lipsey & Derzon, 1998; Loeber & Hay, 1997). Besides age, sex, emotional and behavioural problems and low SES, minority race, involvement with antisocial peers, poverty, antisocial parents, poor family management and child-rearing practices, family and marital conflict were found associated with ADBs (Burke et al., 2002; Farrington, 1995; Hawkins et al., 1998; Lipsey & Derzon, 1998). These factors might also predict ADBs in youths with ID. Studies on the predictors of conduct problems and disruptive disorders in youths with ID can, of course, also offer directions on potential predictors of ADBs. These studies revealed the following factors: physical problems, inadequate socialisation, and life-events of the child, low parental educational level, single parenthood, parental psychopathology, frequent use of punitive strategies, and family dysfunction (Dekker & Koot, 2003a, 2003b; Emerson, 2003b).

The overall aim of this study was to explore ADBs in youths with ID. Since it is considered fruitful to distinguish between different kinds of conduct problems and antisocial behaviours when investigating the prevalence and the associated risk factors (Frick et al., 1993; Simpson & Hogg, 2001b), we differentiated between various types of ADBs. In addition, whereas many GP studies are limited by using a single informant to assess ADBs (Bor, McGee, & Fagan, 2004; Lahey et al., 2000), we used information from three informants: parents, teachers/job coaches, and the youths themselves. In this study, we examined the prevalence, five-year persistence, and child, parent and family predictors of ADBs in youths with mild to borderline ID. Because different predictors have been found and suggested for boys versus girls, and younger versus older adolescents (Burke et al., 2002; Lipsey & Derzon, 1998; Pakiz, Reinherz, & Giaconia, 1997), we tested for moderating effects of sex and age. Additionally, we compared the prevalence rates of ADBs between youths with ID and without ID. Finally, we investigated whether specific types of ADBs tend to co-occur, or whether specific profiles of ADBs can be distinguished in youths with ID, and what factors are associated with these profiles.

Method

Participants

ID sample. This study is part of a longitudinal Dutch study on psychopathology in youths from schools for children with mild ID (IQ range 60-80) and with moderate ID (IQ range 30-60) that started in 1996. Then, in the Netherlands, almost all children with a moderate to mild ID attended one of these special schools. In this study, we focused on youths with mild ID, and therefore we only included youths from schools for children with mild ID. In 1996, 71 of all 87 schools for the mild ID in the province of Zuid-Holland randomly selected 20% of their students, resulting in a sample of 1,199 children (school response = 81.6%). Of these, 171 were excluded because they exceeded the age range (6-18 years), were not living at home, or their parents had problems with the Dutch language. Of the remaining 1,028 eligible children, 198 of their parents could not be contacted in person, but 695 participated at Time 1 (T1 response = 67.6%, and 83.7% of those who were personally contacted). Children of participating parents were significantly younger than of non-participating parents ($p < .05$), but no significant sex differences were found ($p > .05$).

In this study, we only used data from T1 (1998) and Time 3 (T3, 2003), because only then data was collected for the entire sample. The T3 target sample consisted of 695 youths whose parent had participated at T1. Parents were traced through consulting phonebooks and municipal registers. In 40 cases we could not locate or personally contact the parents again, for example because of emigration, but 498 participated (76.0%).

To include youth self-reported information, parents were asked consent to contact their child. Seventy-three parents refused and 41 youths could not be traced, but 428 of the 581 eligible youths participated (73.7%). Finally, regarding teacher/job coach information, 239 youths and/or their parents refused consent to send questionnaires to these informants, 39 youths could not be traced, 13 supplied insufficient information, and 29 did not go to school nor had a job. We sent questionnaires to 375 teachers/job coaches of which 303 were filled out and returned (80.8%).

For 526 youths (75.7% of 695) information on ADBs could be derived. We found no significant differences regarding sex, age group, or T1 deviant score on the Child Behavior Checklist (CBCL) syndrome scales Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, and Thought Problems between the 526 youths for whom these measures could be derived and those 169 for whom this could not be done ($p > .05$). However, youths for whom ADBs could be derived more often had a deviant score on the CBCL syndrome scales Attention Problems, Delinquent Behavior, and Aggressive Behavior, and their parents were more often of Dutch origin, not single, and had a higher SES, and educational level (all $p < .05$). After adjusting for the possible interrelation between these variables, we found that youths for whom ADB measures could be derived significantly more often had Dutch parents, and parents with higher SES, and more youths had a deviant T1 score on CBCL Attention Problems ($p < .05$). The T1 characteristics of the 526 youths are presented in Table 7.2 (column 2).

General population sample. We used data from a general population (GP) study to compare ADB frequencies between youths with and without ID. In 2003, 1,593 11 to 18-year-old youths were randomly drawn from municipal registers of the province of Zuid-Holland. Of these, 153 were excluded because they had ID or a major physical disability, their parents had problems with the Dutch language, or because they moved outside this province, resulting into 1,440 eligible youths. Of these, 1,033 of their parents participated (71.7%). Only youths whose parents participated were requested to participate, of which 860 (83.3%) responded positively. Regarding teacher information, 104 youths did not go to school, and of the remaining 929 parents who participated, 253 refused consent to contact their child's teacher. Consequently questionnaires were sent to 676 teachers, of which 463 were filled out and returned (68.5%). We found no sex differences between the youths who participated in this study versus those who did not or who were excluded from this study ($p = .83$).

Measures

Antisocial and Delinquent Behaviours (ADBs). Items from the *CBCL,* the *Youth Self-Report (YSR)*, and the *Teacher's Report Form (TRF)* (Achenbach, 1991a, 1991b, 1991c) were selected to assess ADBs. The YSR and TRF are modelled after the CBCL, and all questionnaires contain statements about a child's emotional and behavioural problems in the preceding six months (TRF: two months), to be answered on a 3-point scale (0 = 'not true', 1 = 'somewhat or sometimes true', 2 ='very true or often true'). All participants filled out the relevant questionnaires themselves. In youths with ID, the YSR was administered in an interview. To establish the youths' *drug use*, we asked the parents one question about their child's non-medical use of soft drugs and/or hard drugs in the past six months ('yes'/'no'). The youths themselves were asked about their use of soft drugs and hard drugs in the past year (two questions, yes/no, ID sample only).

We assessed the following types of ADBs (CBCL/TRF/YSR items in brackets): 'mean to others' (16. 'mean to others'), 'physical aggression' (57. 'attacking others', 97. 'threaten to hurt others'), 'property destruction' (21. 'destroying things of others', 106. 'vandalism'), 'theft/arson' (72. 'arson', 82. 'stealing outside the home'), 'authority avoidance (67. 'running away from home', 101. 'truancy'), and 'substance (ab)use' (2.

‘drinking alcohol without parents’ permission’, and the three drug use questions). An adolescent was regarded to have engaged in ADB, when either of three informants had scored at least 1 (‘sometimes true’) on an ADB item, or ‘yes’ on a question on drug use.

Predictors

Parents and teachers completed the Dutch *CBCL* and *TRF* respectively to assess emotional and behavioural problems. Both instruments have shown to have satisfactory to good reliability and validity not only for youths from the GP (Verhulst et al., 1996; Verhulst, Van der Ende, & Koot, 1997a), but also for youths with ID (Dekker, Koot et al., 2002). Of both instruments, we used the Total Problems score, the scores on the two broad-band scales Internalizing and Externalizing, and on the eight syndrome scales (Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Behavior, and Aggressive Behavior). We differentiated between youths scoring in the borderline/clinical range on either CBCL or TRF versus ‘normal functioning’ youths, according to the Dutch cut-off scores (Verhulst et al., 1996; Verhulst, Van der Ende et al., 1997a).

The *Vineland Screener* is a 45-item short form of the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984). It assesses the extent to which adaptive behaviours regarding Communication, Daily Living Skills, and Socialisation are performed (0 = ’not/seldom’, 1 = ’sometimes’, 2 = ’usually’). A standard score below 85 represented inadequate adaptive functioning.

The *Wahler Physical Symptoms Inventory* (Wahler, 1968) inquires after the frequency (6-point scale, ranging from ‘almost never’ to ‘almost every day’) of which a child is affected by 42 different physical problems (e.g., pains, nausea, sleeping problems). The total score was dichotomised at one standard deviation (SD) above the mean, resulting in children with low versus high physical symptoms (i.e., physical problems).

On a short version of the *Life Events Questionnaire* (Berden et al., 1990), parents reported whether their child had experienced either of 16 listed life-events in the past two years (e.g., one parent leaving the household, dying of a loved one, hospitalisation for at least a fortnight). If so, they were asked if their child was negatively affected by it. The sample was split up in children who experienced none versus at least one negative life-event.

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

Family functioning was determined through the General Functioning subscale of the McMaster *Family Assessment Device* (Byles, Byrne, Boyle, & Offord, 1988). Parents indicated whether they agreed or disagreed (4-point scale) with each of the 12 statements about their family functioning. A mean item score of 2.17 discriminated between ‘healthy’ and ‘dysfunctional’ families.

Family *SES* 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) versus ‘medium/high SES’ (all higher levels of work).

Taking the highest completed educational level of either parent assessed *parental educational level*. Lower educational level implied a degree at a lower vocational training level or lower, and medium/high educational level implied at least a high school degree.

The demographic questionnaire provided information on the parents' *ethnical background* (both parents are Dutch versus at least one non-Dutch parent), and the *number of parents* in the household (single parent versus two parents).

Table 7.1
T3 prevalence and T1 to T3 persistence of ADBs in youths with ID, and comparing prevalence rates of ADBs between 11 to 18-year-old boys and girls with ID and without ID (GP)

	T3 (%)	Youths with ID (%)			Boys (%)			Girls (%)		
		T1→T3[e]			ID	GP		ID	GP	
Type of ADB	N=526	N=506	OR	95% CI	N=239	N=511	p	N=153	N=522	p
Mean to others	31.0	39.3	5.9	3.7-9.4	37.4	30.1	<.05	28.1	31.6	.41
Physical aggression	17.7	21.8	5.7	3.0-10.7	25.2	16.2	<.01	10.5	9.4	.69
Theft / arson [a]	10.6	17.6	3.7	1.8-7.8	16.7	8.6	<.01	4.6	4.0	.76
Property destruction [b]	13.1	27.8	5.8	3.1-10.6	18.0	11.2	.01	5.2	4.6	.75
Authority avoidance [c]	19.0	30.2	2.9	1.5-5.6	21.8	18.4	.27	17.0	22.2	.16
Substance (ab)use [d]	17.5									

[a] Not included TRF item 72; [b] Only CBCL was used for item 106; [c] Not included TRF item 67; [d] Not included TRF item 2; [e] % Of youths who displayed this behaviour at T1 and also at T3, these rates are based on parent and teacher reports only

Data analysis

For each type of ADB separately, we calculated the percentage of youths who displayed ADB at T1 and also at T3. Through logistic regression analysis we assessed the increased risk for ADBs at T3 in youths who displayed these behaviours at T1, indicated by Odds Ratios (ORs) and corresponding 95% Confidence Intervals (95% CIs). Chi-square tests were used to detect differences in the prevalence rates of ADBs between the ID and GP sample. Due to differences in definitions of 'substance (ab)use' at T1 and T3 and in the GP sample, we could not compare these prevalence rates, nor the extent of persistence in the ID sample. Logistic regression analyses were also applied to detect the predictors of youths with ID engaging in a certain type of ADB, adjusted for sex and age differences. We tested for moderating effects of age group and sex by adding either age or sex and its interaction term with each main predictor into the model. In case of a significant interaction, post-hoc probing provided the ORs of the predictor for each sex or age group (Holmbeck, 2002). In a multiple logistic regression analysis, besides sex and age group, we used all significant main predictor variables from the univariate analysis to identify the strongest unique predictors of ADBs. Nagelkerke R^2 was calculated to provide an approximation of the percentage explained variance (PEV) of these full models (R^2 * 100). We performed three separate analyses for each ADB outcome, including the dichotomised T1 CBCL/TRF scores on (1) Total Problems, (2) Externalizing and Internalizing, and (3) the eight syndrome scales as predictors.

Table 7.2
Prevalence of T1 predictors, and significant predictors of six types and higher levels of overall ADBs [*]

	Prevalence T3	Type of antisocial and delinquent behaviour		
		Mean to others	Physical aggression	Property destruction
T1 predictors	%	OR (95% CI)	OR (95% CI)	OR (95% CI)
Child characteristics				
Male sex	59.7		2.2 (1.3-3.7)	2.7 (1.5-5.0)
6-11 years (vs. 12-18)	52.5	2.0 (1.4-3.0)	1.7 (1.1-2.8)	1.7 (1.0-2.9)
≥ 1 negative life-event	23.0			
Physical problems				
Emotional / behavioural problems				
Total Problems	62.6	1.8 (1.2-2.7)	3.1 (1.8-5.5)	2.3 (1.3-4.2)
Internalizing	53.3	1.8 (1.2-2.6)	2.5 (1.5-4.1)	
Externalizing	52.5	2.2 (1.5-3.2)	2.4 (1.4-3.8)	2.3 (1.3-4.1)
Withdrawn	23.0			B=ns; G=5.3 (1.8-15.9)[**]
Somatic Complaints	18.0		2.0 (1.1-3.4)	
Anxious/Depressed	23.6	1.8 (1.2-2.9)	2.2 (1.3-3.7)	
Social Problems	43.1	2.3 (1.6-3.5)	3.2 (2.0-5.3)	1.9 (1.1-3.2)
Thought Problems	16.7		2.3 (1.3-3.9)	
Attention Problems	40.4	2.5 (1.7-3.6)	2.4 (1.5-3.8)	3.0 (1.7-5.1)
Delinquent Behavior	25.1	2.6 (1.7-4.0)	3.1 (1.9-5.0)	3.2 (1.9-5.5)
Aggressive Behavior	30.1	2.7 (1.8-4.1)	2.7 (1.7-4.4)	2.6 (1.5-4.4)
Inadequate adaptive functioning				
Communication	82.5			
Socialisation	67.9		2.1 (1.2-3.5)	
Daily living skills	61.7			
Parent and family predictors				
Single parent	14.9			2.2 (1.2-4.0)
≥ 1 parent non-Dutch	23.1			
Low SES	57.2			1.8 (1.0-3.1)
Low educational level	72.2			
Parental psychopathology	15.3			B=ns; G=7.0 (2.2-22.6)
Family dysfunction	14.7			Y=ns; O=2.8 (1.0-7.5)[**]

[*] Results from univariate logistic regression analysis, adjusted for sex and age group (all $p < .05$)
[**] Significant interaction effect, no main effect;
OR = Odds Ratio, CI = Confidence Interval; Y = 6-11 years, O = 12-18 years; B = boys, G = girls, ns = not significant

Table 7.2 *continued*

	Type of antisocial and delinquent behaviour			Higher levels overall ADB
	Theft/arson	Substance (ab)use	Authority avoidance	
T1 predictors	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Child characteristics				
Male sex	4.1 (2.0-8.6)	2.5 (1.5-4.2)		2.3 (1.4-3.8)
6-11 years (vs. 12-18)	3.5 (1.8-6.7)			1.8 (1.1-2.9)
≥ 1 negative life-event				
Physical problems	Y=ns; O=5.9 (1.8-19.1)**	Y=ns; O=ns**		
Emotional / behavioural problems				
Total Problems				
Internalizing			1.6 (1.0-2.6)	
Externalizing	2.1 (1.1-3.9)			1.6 (1.0-2.6)
Withdrawn			1.9 (1.2-3.1)	
Somatic Complaints				
Anxious/Depressed			1.7 (1.1-2.8)	
Social Problems	2.5 (1.4-4.6)		Y=ns; O=3.1 (1.5-6.4)	2.8 (1.7-4.6)
Thought Problems				B=ns; G=3.3 (1.2-9.0)**
Attention Problems	2.2 (1.2-3.9)		Y=ns; O=2.7 (1.3-5.3)**	2.0 (1.3-3.3)
Delinquent Behavior	2.0 (1.1-3.6)			2.6 (1.6-4.3)
Aggressive Behavior	2.1 (1.2-3.9)		1.6 (1.0-2.6)	2.4 (1.5-3.9)
Inadequate adaptive functioning				
Communication				
Socialisation			1.7 (1.0-2.9)	
Daily living skills	2.0 (1.1-3.9)		1.6 (1.0-2.6)	B=ns; G=6.2 (1.4-27.6)**
Parent and family predictors				
Single parent				
≥ 1 parent non-Dutch		1.8 (1.0–3.0)	Y=ns; O=ns**	
Low SES	B=2.4 (1.2-4.9); G=0.17 (0.03-0.85)**			B=ns; G=ns**
Low educational level	B=ns; G=0.18 (0.04-0.76)**			
Parental psychopathology				
Family dysfunction			2.0 (1.2-3.5)	

* Results from univariate logistic regression analysis, adjusted for sex and age group (all $p < .05$)

** Significant interaction effect, no main effect

OR = Odds Ratio, CI = Confidence Interval; Y = 6-11 years, O = 12-18 years; B = boys, G = girls, ns = not significant

Finally, for CBCL, TRF and YSR separately, Latent Class Analyses (LCA) were performed on the ADB items to test whether specific types of ADB tended to co-occur. LCA aims to find the smallest number of classes of individuals with similar patterns of, in this study, ADBs. Classes are added stepwise until the model optimally fits the data. The Vuong-Lo-Mendell-Rubin Likelihood ratio test determines the number of classes that fit the data best (Lo, Mendell, & Rubin, 2001). Class sensitivity indicates how well youths are classified to a particular class (ranging from 0.0-1.0).

Results

Column 2 of Table 7.1 shows that 'mean to others' had the highest prevalence rate (31.0%), while most types of ADB were displayed by about 10 to 20% of youths with mild to borderline ID. The results presented in the columns 3-5 of Table 7.1 show that the persistence of ADBs was highest for 'mean to others' (39.3%), whereas 'theft/arson' (17.6%) and 'physical aggression' (21.8%) were least persistent. Furthermore, youths who engaged in a specific type of ADB at T1 were at a significantly increased risk for displaying the same type of ADB five years later. The extent of increased risk (OR) ranged from 2.9 for 'authority avoidance' to 5.9 for 'mean to others'.

We next compared the prevalence rates of ADBs in 11 to 18-year-old boys and girls with and without ID (right half of Table 7.1). Whereas girls with ID did not engage in ADBs more often than girls without ID (all $p > .05$), prevalence rates of all ADBs were higher in boys with ID than boys without ID, except for 'authority avoidance' ($p = .27$). Compared with boys without ID, boys with ID were between 1.4 ('mean to others') and 2.1 ('theft/arson') times more likely to engage in ADBs.

The results from LCA indicated that for CBCL, YSR, and TRF separately, two classes fitted the data better than a three-class solution ($p < .05$). For all instruments, the first class consisted of youths with low levels of ADB, whereas the second class represented high levels of overall ADB. Eighty-seven youths (16.6%) fell into the high levels of overall ADB-group on at least one instrument. For all three instruments, class sensitivity was high (CBCL: .98-.98; YSR: .84-.97; TRF: .91-.99).

Next, we studied the five year-predictors of the ADBs and high levels of overall ADB. Table 7.2 shows that, except for 'authority avoidance', especially a younger age and male sex predicted all types of ADBs and high levels of overall ADB. Additionally, emotional and/or behavioural problems also predicted both all types and high overall ADB level, although not 'substance (ab)use'. Besides Social Problems, mainly Attention Problems, Delinquent Behavior, Aggressive Behavior, and Externalizing predicted ADBs. Most of the other child, parent and family factors predicted only one or two types of ADB, but not high levels of overall ADB. Moreover, results from multiple logistic regression analyses show that most of these other child, parent, and family factors did not uniquely predict ADBs (Table 7.3). Except for 'substance (ab)use' and 'authority avoidance', different types of ADB and a high level of overall ADB were mainly predicted by a child's younger age and male sex, and by T1 behavioural problems (Externalizing, and Delinquent Behavior), but high levels of overall ADB were uniquely predicted by Externalizing and Social Problems. The PEV of the full models (Nagelkerke R^2) ranged from 5.5% for 'substance (ab)use' to 17.3% for 'theft/arson'.

Table 7.2 also shows that few specific moderating effects for age and sex were found. Withdrawn and Parental psychopathology (in girls) and Family dysfunction (in older youths) predicted 'Property destruction'. Physical problems (in older youths), low SES (in boys), and higher SES and higher parental educational level (in girls) predicted 'theft/arson'. Social Problems and Attention Problems (in older youths) predicted 'authority avoidance', and Thought Problems and inadequate Daily living skills predicted high levels of overall ADB (in girls).

Discussion

Even though youths with ID seem at increased risk for exhibiting ADBs, this study was the first to thoroughly explore ADBs in a population-based sample of 11 to 24-year-olds with mild to borderline ID, using information from multiple informants. Our results showed that, roughly, each type of ADB was exhibited by 10% to 20% of the youths with ID. Least prevalent were the behaviours that might be perceived as the most serious, namely 'theft/arson' and 'property destruction'. Additionally, most prevalent was the type of ADB that might be considered as least serious, i.e., 'mean to others', which was also the most persistent type of ADB. Moreover, the odds of engaging in all types of ADB at T3 were significantly increased for those who showed that type of ADB at T1. Similar to GP studies (Storvoll & Wichstrom, 2003), this points to reasonable five-year stability of ADBs.

Whereas other studies indicated that individuals with ID more often offend than peers without ID (Hall, 2000; Hodgins, 1992; Simpson & Hogg, 2001a), our study only confirmed this for boys (except for 'authority avoidance'), but not for girls. The latter is contrary to the study of Hodgins (1992), who found that women with ID were more likely to offend and to commit a violent offence (and be convicted for it) than women without a handicap. One has to keep in mind, though, that the age of the subjects in Hodgins' study (1992) was higher than in our study (up to 30 years), and that criminal records were examined to collect data on mainly serious offences. Regarding the differences between boys and girls with ID, it might be that parents are more protective towards their daughters than towards their sons with ID, and keep their daughters closer to home. It might also be that especially boys with ID are prone to being impulsive and to being lured into engaging in undesirable behaviours.

Next, regardless of the informant, two classes of ADBs fitted the data best. These two classes included youths with low and with high levels of overall ADB. Apparently, when youths with ID engage in a certain type of ADB, they are also likely to exhibit other types of ADB. Our results suggest that studying an overall measure of ADB in youths with ID is at least as important as studying different types or profiles of ADBs. Additionally, except for 'substance (ab)use' and 'authority avoidance', the main predictors of ADBs were also about similar across each type of ADB, and they were comparable to the predictors of displaying high levels of overall ADB.

With respect to the predictors of ADBs, similar to GP studies and to studies in youths with ID on psychopathology and offences, especially boys and 11 to 18-year olds (i.e., the 6 to 11-year-olds at T1) exhibited ADBs (Lipsey & Derzon, 1998; Loeber & Hay, 1997; Loeber & Stouthamer-Loeber, 1998). In addition, problem behaviour in childhood, but also inadequate adaptive functioning, single parenthood, low family SES, parental psychopathology, and family dysfunction predicted ADBs (Burke et al., 2002; Dekker, Koot et al., 2002; Hawkins et al., 1998; Simpson & Hogg, 2001b).

Table 7.3
Strongest predictors of ADBs and high levels of overall ADB: Results from multiple logistic regression analysis, adjusted for sex and age, and all significant main predictors from univariate analysis (all $p < .05$)

	Type of antisocial and delinquent behaviour			
T1 predictors	Mean to others OR (95% CI)	Physical aggression OR (95% CI)	Property destruction OR (95% CI)	Theft/arson OR (95% CI)
I. Total Problems				
Total Problems	1.8 (1.2-2.7)	2.9 (1.6-5.1)	1.9 (1.0-3.6)	
Male sex		2.2 (1.3-3.7)	3.3 (1.7-6.3)	
6-11 years (vs. 12-18)	2.2 (1.5-3.2)	2.0 (1.2-3.2)	1.8 (1.1-3.2)	
Inadequate socialisation		1.8 (1.0-3.1)		
≥ 1 parent non-Dutch				
Nagelkerke R^2 (full model)	.063	.117	.122	-
II. Internalizing/Externalizing				
Internalizing		1.9 (1.1-3.2)		
Externalizing	2.0 (1.3-2.9)	1.8 (1.1-3.1)	1.9 (1.1-3.3)	2.0 (1.1-3.7)
Male sex		2.3 (1.4-3.9)	3.3 (1.7-6.3)	4.2 (2.0-8.8)
6-11 years (vs. 12-18)	2.1 (1.4-3.1)	1.9 (1.2-3.0)	1.8 (1.0-3.1)	3.5 (1.8-6.8)
Inadequate daily living skills				1.9 (1.0-3.7)
Nagelkerke R^2 (full model)	.089	.122	.124	.161
III. Syndrome scales				
Social Problems				
Attention Problems			2.3 (1.2-4.6)	
Delinquent Behavior		1.9 (1.0-3.4)	2.0 (1.0-4.0)	
Male sex		2.7 (1.6-4.6)	3.4 (1.8-6.7)	4.7 (2.2-10.2)
6-11 years (vs. 12-18)	2.3 (1.5-3.5)	2.0 (1.2-3.3)		3.8 (1.9-7.5)
Nagelkerke R^2 (full model)	.130	.155	.169	.173

OR = Odds Ratio, CI = Confidence Interval

Furthermore, with a few exceptions and comparable to a GP study (Storvoll & Wichstrom, 2002), about similar variables predicted ADBs in both boys and girls, and in younger and older youths. Thus, predictors of ADBs in youths with mild to borderline ID are highly comparable to those in typically developing peers.

Multiple logistic regression analyses showed that, besides age and gender, primarily Attention Problems, Delinquent Behavior, and Externalizing were the strongest unique predictors of ADBs, although this was not true for ‘substance (ab)use’ and ‘authority avoidance’. Moreover, regarding the latter, multiple logistic regression analysis did not reveal any unique predictor, and all significant factors from univariate analysis explained about 5% of the variance in these types of ADB five years later. ‘Authority avoidance’ and ‘substance (ab)use’, apparently, can not be accurately predicted by the child, parent and family variables that were investigated in this study. For the other types of ADB, the significant predictors of univariate analysis explained between 6.3% (‘mean to others’, including the Total Problems score) and 17.3% (‘theft/arson’, including the syndrome scales) of variance. The PEV for displaying high levels of overall ADB ranged from 6.5% to 12.4%. Although significant predictors were found, they could only partially explain

Table 7.3 *continued*

	Type of antisocial and delinquent behaviour		High levels of overall ADB
T1 predictors	Substance (ab)use OR (95% CI)	Authority avoidance OR (95% CI)	OR (95% CI)
I. Total Problems			
Total Problems			
Male sex	2.5 (1.5-4.2)		
6-11 years (vs. 12-18)			
Inadequate socialisation			
≥1 parent non-Dutch	1.8 (1.0-3.0)		
Nagelkerke R^2 (full model)	.055	-	-
II. Internalizing/Externalizing			
Internalizing			
Externalizing			1.6 (1.0-2.6)
Male sex			2.3 (1.4-3.9)
6-11 years (vs. 12-18)			1.8 (1.1-3.0)
Inadequate daily living skills			
Nagelkerke R^2 (full model)		.046	.065
III. Syndrome scales			
Social Problems			2.0 (1.1-3.7)
Attention Problems			
Delinquent Behavior			
Male sex			2.7 (1.6-4.7)
6-11 years (vs. 12-18)			2.0 (1.2-3.4)
Nagelkerke R^2 (full model)		.053	.124

OR = Odds Ratio, CI = Confidence Interval

engaging in ADBs at T3. This might be due to the length of time between T1 and T3, or to the studied predictor variables. A five-year interval might be too long a period to predict ADBs. Indeed, a longitudinal study in the GP showed that antisocial behaviour at age 21 could be better predicted at the age of 18 than at the ages of 15, nine and five (Pakiz et al., 1997). It might also be that the specific type of ADB, e.g., ‘mean to others’, is a stronger predictor for exhibiting that same behaviour later on in life than more generic measures of problem behaviour as the Total Problems score, or even Delinquent Behavior. Furthermore, other factors than were included in this study seem likely to (also) predict engaging in ADBs. For example, in GP studies child-rearing practices and family management both were strongly associated with ADB (Hawkins et al., 1998). Because we were not able to examine these factors, to better comprehend ADBs in youths with ID, future studies need to address these circumstances.

Non-random sample attrition is a limitation of this study. This might have resulted in a slight overestimation of the prevalence rates of ADBs (except ‘substance (ab)use’) since more youths with deviant T1 scores on CBCL Attention Problems, Delinquent Behavior and Aggressive Behavior were included in this study, and these problem behaviours increased the odds of displaying ADBs and having a high level of overall ADB. At the same time, because especially fewer youths from non-Dutch parents were included in this study, and having a non-Dutch parent increased the risk for ‘substance (ab)use’, the found prevalence of ‘substance (ab)use’ might be a slight underestimation. Moreover, the findings from this study are less applicable to youths whose parents had problems with the Dutch language (T1 exclusion criterion).

Furthermore, the CBCL, TRF and YSR items that were used to construct ADBs did not explicitly include serious and violent offences such as armed robbery and sexual assault. Future studies are also needed to determine the prevalence and predictors of these offences. In addition, youths were considered to have engaged in a type of ADB when either of the informants indicated that this type of behaviour was displayed at least ‘sometimes’. However, even with these lenient criteria, the majority of the adolescents had not engaged in ADBs.

Despite these limitations, this study offers some suggestions for clinical implications. As primarily adolescent boys (as opposed to girls and older boys) exhibited ADBs, and more often than peers without ID, preventive measures should at least be targeted at 6 to 11-year-old boys who have higher levels of emotional and behavioural problems, and already display ADBs. General instruments, like the CBCL, TRF, and YSR can help to improve early detection of these problems and behaviours.

Obviously, treatment of emotional and behavioural problems at an early age is recommended, as it might also prevent future ADB. GP studies have indicated that treatment needs to address multiple risk factors, of which especially the parenting domain (Burke et al., 2002). Since low SES has been associated with less preferable parenting styles (Patterson, DeBaryshe, & Ramsey, 1989), and relatively many families of youths with ID have low SES, the parent domain also needs to be considered when treating youths who have emotional and behavioural problems, or participate in ADB, in order to prevent future ADB or worse.

8

General discussion and conclusions

Chapter 8
General discussion and conclusions

Mental health problems in children and adolescents (i.e., youths) with intellectual disabilities (ID) frequently bring about a heavy burden to not only the youths themselves, but also to their parents and family. Despite the fact that relatively many youths with ID have mental health problems or psychopathology, these problems frequently remain untreated, or their needs for help frequently remain unmet. The overall aim of this study was to contribute to eventually reducing the level of unmet need for help and consequently to reducing the heavy burden of these youths and their parents by elucidating their needs for help, the parental role in obtaining help for their child's problems, and to ascertain the level of unmet need for help. In this thesis, we addressed these issues for parents of adolescent children (10-24 years old) with moderate to borderline ID. More precisely, we studied the determinants and predictors of both the objective and subjective need for help, the discrepancies between need for help and help obtained, and the process of help-seeking for these youth's emotional or behavioural problems.

In this chapter, we first consider 'need for help' and the 'help-seeking pathway' and then continue with discussing the main findings, conclusions, and limitations of this study. Because, as far as we know, these issues have not been studied in parents of children and adolescents with moderate to borderline ID, we mostly compared our results with those found in studies in parents of typically developing children and adolescents. We end this chapter with discussing clinical implications and with giving suggestions for future research.

Exploring 'need for help'

The key objectives of this study contained the following phrases: "to determine the objective and subjective need for mental health services", and "to identify determinants of objective and subjective need for help (…)." Even though these aims seem clear, in *Chapter 1* we demonstrated that both objective and subjective need for help can be defined and studied in different ways. Objective need for help (due to mental health problems) commonly has been studied as 'meeting the criteria of a psychiatric disorder, or of emotional or behavioural problems'. In Phase 1 of this study this objective need has already been explored by studying the prevalence and determinants of psychopathology in youths with ID (Dekker & Koot, 2003a, 2003b; Dekker, Koot et al., 2002), and in another Phase 3 study parallel to this thesis' study, the developmental course of these problems, or of the objective need for help is being investigated (De Ruiter et al., in preparation). Therefore, in this study our emphasis was on the parents' subjective need for help, i.e., their felt need or 'want' and their subsequent help-seeking, and studied two aspects of objective need for help (see *Chapter 2*).

Based on the sparsely available literature, our assumption was that parents of youths with both ID and psychopathology can have various needs for help due to their child's problems (Floyd & Gallagher, 1997; Turnbull & Ruef, 1996), that can include a need for mental health services, which is usually the objective of studies on needs for help. We assumed that it can also comprise needing other types of help instead of, or in addition to mental health services (Chadwick et al., 2002; Hoare, Harris, Jackson, & Kerley, 1998;

Treneman et al., 1997; Van den Borne et al., 1999). This assumption was supported by the semi-structured interviews that were conducted with parents of dually diagnosed children. Based on these interviews and on the literature, we constructed the Need for Help Questionnaire in which we inquired about the parents' diversity in and level of need for help.

An objective need for help can be studied in different ways. In addition to the Phase 1 study and the companion Phase 3 study on objective need for help, we investigated two specific aspects of objective need for help that have received little attention in the literature but are of great importance. First of all, we investigated the extent to which youths with ID are capable of contributing to the assessment of an objective need for help, i.e., their own psychopathology by using the Youth Self-Report (YSR). In the general population, including the views of children and adolescents in the diagnostic process to assess psychopathology is considered imperative to obtain a more complete picture of their functioning and problems. However, youths with ID are frequently omitted in this process, even though it is likely that many of them are capable of providing information about their emotional and behavioural functioning that adds to the information given by their parents. Secondly, we investigated the prevalence and predictors of antisocial and delinquent behaviours (ADBs) in youths with mild to borderline ID. These behaviours can not only be regarded as an objective need for help of the parents, but also of society, because these problems bring about a heavy burden and major costs to society as well (Scott et al., 2001). Despite these negative and critical consequences, and that youths with ID are regarded as being more likely to engage in these behaviours than youths without ID (Hall, 2000), these behaviours have not yet been thoroughly studied in youths with ID. Hence, information is needed about the magnitude of these behaviours and to identify the youths with ID who are at increased risk for engaging in these behaviours, and thus need help the most.

Studying the help-seeking pathway

Whereas many studies employ the framework of Verhulst and Koot (1992) to explore the pathway to obtaining child mental health care, we employed the help-seeking pathway as suggested by Pavuluri and colleagues (1996) to study the distinctive phases that lead to eventually seeking help. This pathway pays more attention to the parental role in help-seeking, which was a major objective of this study. By studying the process that leads to seeking help, instead of only studying the outcome, this will provide us with a clearer and more detailed picture of the actual pathway to seeking help, and it will tell us where especially the dropping out of this pathway takes place (Logan & King, 2001). Consequently, it should give more precise indications about the phase(s) in the pathway intervention measures that are especially needed to increase the number of parents who seek help for their children with ID and mental health problems.

The model of Pavuluri et al. consists of three steps to actual help-seeking of parents whose child has psychopathology: (1) recognition of psychopathology, (2) consider getting help, and (3) cross perceived barriers in getting help. For each step, parents consciously or unconsciously decide to follow through with the help-seeking process or not. To investigate the parents' recognition of psychopathology, we asked them how they had subjectively perceived their child's (1) emotional and (2) behavioural functioning. When parents answered either of these two questions with 'neither good nor bad', 'bad', or 'very bad' (as opposed to 'good' or 'very good'), we considered them to perceive emotional and/or behavioural problems in their child. When a child or adolescent with ID had psychopathology, as assessed with standardised instruments, *and* their parents had subjectively perceived emotional or behavioural problems in their child, we regarded these parents as recognising their child's psychopathology, and taking the first step.

The second step 'consider getting help' was converted into asking parents whether they had felt a need for …. (a specific type of help) due to their child's emotional and/or behavioural problems. We assumed that parents only consider getting help when they have a need for it. When parents reported to have had at least some need for a specific type of help, they were regarded as having taken the second step for that specific type of help.

The third step 'crossing perceived barriers in getting help' was investigated by only asking the parents who had had a need for a certain type of help whether or not they had actually sought help. Those who had sought help were considered to have crossed the barriers, and those who had not sought help did not take this third step. To identify the barriers from taking this step, we asked the parents who had refrained from seeking help about their reasons for not seeking help, despite having had a need for it.

Steps towards seeking and obtaining of help

In the following paragraphs, the main findings regarding three key objectives of this study are discussed (see *Chapter 1*): we investigated the parents' subjective needs for help (key objective 1) and the determinants of these needs (first part of key objective 2), we explored the parents' help-seeking for their child's emotional or behavioural problems (second part of key objective 2) by distinguishing between several steps that lead to actual help-seeking, and we identified the discrepancies between the need for and obtaining of help and the determinants of these discrepancies (key objective 4). In this paragraph, we use the consecutive steps of the help-seeking process to discuss these issues. We first discuss the main findings regarding parental perception and parental recognition of their child's psychopathology, then continue with the parents' needs for help, their crossing of perceived barriers to seeking help, and end with discussing these parents' level of met need for help.

Parental perception and parental recognition of their child's psychopathology

Even though parental perception and parental recognition of child psychopathology are closely related, and both rely on the subjective judgements of parents about their child's functioning, they have different prerequisites. Whereas for parental recognition the actual (assessed) presence of psychopathology is required, this is not the case for parental perception, which solely consists of the parents' judgements regardless of the actual presence of psychopathology.

In *Chapter 3* we thoroughly investigated parental recognition (or parental awareness) and in *Chapter 4* we focused on parental perception of their child's psychopathology. By studying both approaches, the interrelation between the objective need for help (i.e., assessed psychopathology) and the subjective parental perception of emotional or behavioural problems has been unravelled in this population of youths with ID and their parents. Whereas the assessed psychopathology is frequently taken as a starting point to study the help-seeking process and/or its outcome, which is for example the case for the pathways of Pavuluri et al. (1996), and Verhulst and Koot (1992), the parents' subjective perception of problems has found to be a requirement for actual help-seeking. Hence, it is important to study the extent to which this perception of problems is associated with the actual presence of these problems, or whether other factors are (also) at play. We studied the extent to which subjective perception of emotional or behavioural problems is associated with the actual assessed presence of these problems and/or other factors. In addition, we studied the extent to which a child's assessed psychopathology is subjectively perceived as a problem by the parents and the factors that are related to parental recognition of child psychopathology.

Parental perception

As previously mentioned, to study parental perception, in neutral wordings we asked parents two questions about their child's emotional and behavioural functioning. Beforehand, we had decided on our definition of problem perception: When parents answered 'neither good nor bad', 'bad', or 'very bad', instead of 'good' or 'very good', on either of these questions, they were regarded as perceiving problems in their child's functioning. It turned out that of all parents who were regarded as such, about 85% of them had labelled their child's functioning as 'neither good nor bad', and only 15% as 'bad' or 'very bad'.

Because this cut-off of defining 'neither good nor bad' as perceiving problems might raise some eyebrows, we first examined whether this decision was justified. Our results in *Chapter 3* indicated that this was indeed the case as for the vast majority of children whose parents perceived problems in their functioning (using this definition), these problems were confirmed by either CBCL or DISC-IV (66.7% for emotional, and 73.4% for behavioural problems). Thus, even when parents indicate their child's emotional or behavioural functioning as 'neither good nor bad', this frequently implies that these problems are indeed present in their child with ID.

Of all parents in this study, 38.8% perceived emotional and/or behavioural problems in their adolescent child with ID, which is about 2 to 4 times more often than parents of youths without ID (Flisher et al., 1997; Teagle, 2002; Verhulst & Van der Ende, 1997), and in line with the 3 to 4 fold increase in psychopathology in youths with ID (Wallander et al., 2003). More specifically, of the parents who perceived problems, more than half (56.7%) perceived both emotional and behavioural problems, whereas just over 20% perceived only emotional problems, or only behavioural problems. This is comparable with the trend in comorbidity that was also found in Phase 1 of this study (Dekker & Koot, 2003a), and in Phase 3 as well. Of all youths who had a deviant Phase 3 CBCL scale score on Internalizing or Externalizing, 44.4% of the youths had deviant scores on both scales, 27.6% only on Externalizing, and 30.3% only on Internalizing.

The odds of parents perceiving emotional and/or behavioural problems in their child were increased when the child/adolescent had a deviant score on either of the eight syndrome scales of the CBCL, but especially on Anxious/Depressed which was also found in the general population study of Verhulst and Van der Ende (1997). Most of the other variables that we found to be related with perception were also found in studies in youths without ID, i.e., experiencing (negative) life-events, the child's (younger) age and presence of physical problems, problems between parents and child, single parenthood, parental psychopathology, higher parental educational level, less social support, and problematic family functioning (Horwitz et al., 2003; Teagle, 2002; Verhulst & Van der Ende, 1997). Most of these variables predominantly seem to represent elevated parental stress caused by additional problems in or with their child, by parental characteristics, or by deviant family functioning. This stress might not only lower the threshold to perceiving problems in their child (Kinsman, 2001; Verhulst & Van der Ende, 1997), but may also lead to parents being more sensitive and alert for these problems to (re)appear. Three other variables represent circumstances that increase the chance of parents to perceive problems in their child, because they put parents in a better position to observe their child's functioning, i.e., child's younger age, or to know the signs of psychopathology, i.e., higher educational level, and past psychopathology of the child.

Parental recognition

We combined the measures of CBCL and DISC-IV to determine the presence of psychopathology in youths with ID, that is to determine the objective need for help. When either CBCL or DISC-IV indicated the presence of emotional problems, 50.0% of the parents recognised these problems of their child. In addition, 63.7% of the parents recognised their child's behavioural problems. When the DISC-IV indicated the presence of any psychiatric disorder, or the Total Problems score of the CBCL fell in the borderline/clinical range, 63.6% of the parents also perceived emotional and/or behavioural problems.

Behavioural problems were more often recognised than emotional problems. This is in line with the study of Angold et al. (1998) who found that especially externalising problems increased the level of perceived parental burden. Emotional problems seem to be less disturbing and seem to have less impact on the parents than behavioural problems that are characterised by, for example, aggression and stubbornness (Angold et al., 1998).

Results from other analyses (not previously presented in this thesis) indicated that this trend of behavioural problems being more often recognised than emotional problems was also found when the analyses were carried out for the CBCL and the DISC-IV separately. Moreover, the recognition rates of the same type of problems did not differ between these two instruments, even though the assessment procedure for these instruments differs; the CBCL is a questionnaire that the parents fill out themselves, and the DISC-IV is administered in a structured interview with the parents. In case of behavioural problems, 69.2% of the parents recognised these problems as defined by a deviant score on CBCL Externalizing, and 70.4% when the DISC-IV indicated a Disruptive disorder. Emotional problems were recognised by 54.3% of the parents when their child's CBCL Internalizing score fell in the borderline/clinical range, and by 54.6% when the DISC-IV pointed to the presence of an Anxiety or a Mood disorder. When the CBCL Total Problems score fell in the borderline/clinical range, 69.2% of the parents recognised these emotional and/or behavioural problems in their child. This was 63.7% of the parents when the DISC-IV pointed to the presence of any psychiatric disorder.

Besides differences in assessment procedure, the subscales of the CBCL and the corresponding DISC-IV disorders have been found to only moderately converge (Kasius, Ferdinand, Van den Berg, & Verhulst, 1997). In our study, this was also true for the overlap between CBCL Internalizing and any Mood or Anxiety disorder (DISC-IV), and CBCL Externalizing and any Disruptive disorder (DISC-IV). When the DISC-IV indicated a Mood or Anxiety Disorder, 55.6% of these youths also scored in the borderline range of the CBCL Internalizing scale. In addition, of those youths who had a deviant score on CBCL Internalizing, 34.8% were also ‘diagnosed’ by the DISC-IV as having a Mood or Anxiety Disorder. Regarding behavioural problems, when the DISC-IV indicated a Disruptive Disorder, 73.7% of these youths also scored in the borderline range of the CBCL Externalizing scale, and of those youths who had a deviant score on CBCL Externalizing, 35.0% were also considered to have a Disruptive Disorder by the DISC-IV. Therefore, the similarities in the recognition rates of the same type of problems, but assessed with different instruments, strengthen the findings and the trend in parental recognition that were found in this study (*Chapter 3*).

Compared with the two general population studies that (also) investigated parental recognition of a broad range of emotional or behavioural problems, and not of specific problems or disorders, in large representative population-based samples also using standardised assessment methods, parents of youths with ID more often recognised their child’s psychopathology. Teagle (2002) found that of the parents whose typically developing child had at least one psychiatric diagnosis, 39% recognised it as being a problem for the child. In our study, 63.7% of the parents recognised any psychiatric disorder. Verhulst and Van der Ende (1997) showed that 45% of the parents whose child scored in the borderline/clinical range of the CBCL Total Problem thought their child had a behavioural or emotional problem. In our study, this was 69.2%. These discrepancies can be explained by both our broader definition of parental perception of emotional and/or behavioural problems, and the fact that most youths with ID attended special schools and sheltered work settings where more attention might be paid to their overall functioning. However, actually comparing these studies with our study is questionable because these studies differ in sample size and sample composition, definition of recognition, and in assessment of psychopathology.

Even though in the previous section on parental *perception* we concluded that even when the parents indicate their child’s emotional or behavioural functioning as somewhat problematic, this often indicates the actual presence of these problems, the results in this section call for nuancing. Because not all parents recognised their child’s psychopathology, and especially did not recognise emotional problems, this means that the parents’ subjective judgement about their child’s emotional and behavioural functioning can not replace the more objective assessment of psychopathology with standardised measures.

We also studied the factors associated with parental recognition of emotional problems, behavioural problems, and of emotional and/or behavioural problems. We found some differences in associated factors between recognition of specific types of problems, but overall, four broad categories of factors that were related to parental recognition or awareness could be distinguished. These were (1) parental familiarity with child psychopathology, e.g., their child had suffered from psychopathology before, or the parents had previously sought help for these problems, (2) specific child-related features that enabled the parents to focus on their child (e.g., the child being an only child), or led to the parents spending more time with their child, such as physical problems of their child, and more worries about their child, (3) problems in the parent-child interaction, such as less supervision of the child, and a lack of mutual love and understanding between parent and child, and (4) deviant parental and familial functioning, which might lower the threshold for perceiving emotional and/or behavioural problems in their child. The child, parent, and family factors that were found associated with parental recognition were generally comparable to those found related to parental *perception* of child psychopathology both in general population (GP) studies and in our study; while the actual assessed presence of child psychopathology is a prerequisite for studying parental recognition, in the multiple logistic regression analyses on parental perception we adjusted for these problems.

One finding that could strike a bit odd is that parents' more often recognised behavioural problems, while their subjective perception of emotional *and/or* behavioural problems was especially related to their child's Anxious/Depressed problems. However, univariate analyses on parental perception showed that all syndrome scales were related to perception, including Delinquent and Aggressive Behaviors. In multiple logistic regression analyses, we adjusted not only for all these problems, but also for all other factors that were significant in the univariate analyses.

All in all, besides the assessed emotional or behavioural problems, both parental perception and parental recognition of their child's psychopathology were increased when the parents had dealt with these problems in their child before, and when there were additional problems in the child, the parents themselves, or in family functioning.

Need(s) for help

We next explored the parents' subjective or felt needs for help as a consequence of their child's psychopathology (*Chapter 5*). To ensure that parents only reported about their needs for support due to their child's additional emotional or behavioural problems, and not about needs that were solely related to their child's ID, only those parents who perceived these emotional or behavioural problems were asked about their support needs. This implied that we were not able to compare the needs for help of parents whose child had emotional or behavioural problems with the needs of parents whose child did not have these problems. However, it did allow us to more accurately answer this study's questions of determining these parents' support needs associated specifically with child psychopathology as defined and perceived by themselves.

Because the parents' subjective perception of emotional or behavioural problems in their child, rather than the assessed psychopathology, is a requirement for actually seeking help (Baker & Heller, 1996; Morrissey-Kane & Prinz, 1999), we focused on those parents who *perceived* these problems, and not on parents who *recognised* their child's problems. Consequently, we did not study the second step as proposed by Pavuluri and colleagues, i.e., following those parents on their way to seeking help whose child has psychopathology, as assessed with standardised measures. Furthermore, by only including the parents who perceived their child's functioning as (somewhat) problematic, also those parents were included whose child had fewer or less severe emotional and/or behavioural problems according to standardised assessment. Conversely, parents of youths with relatively high levels of psychopathology that were not subjectively perceived as 'problematic' were not included.

These parents who subjectively perceived problems in their child's emotional or behavioural functioning were asked to what extent in the past year they had needed any of seven specific types of support due to their child's emotional and/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. To study the parents’ need for professional help, we combined the needs for ‘child mental health care’ and ‘parental counselling’ into a need for ‘professional help’ (*Chapter 4*).

Almost all parents (88.2%) had needed some type of support. Their needs were quite diverse (see Table 8.1 – column 2), and 67.4% needed at least three different types of support. 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 parents of youths in the general population (Angold et al., 1998; Wu et al., 1999). Thus, emotional problems are not only less often recognised by parents than behavioural problems, they also lead to having fewer needs for support.

Table 8.1
Taking each consecutive step to obtaining help

	Consecutive steps % of parents who took that step		
Type of support	Need help	Seek help [a]	Obtain help [b]
Friendly ear	78.1	77.6	95.6
Information	68.0	62.0	92.5
Activities	50.9	48.2	90.2
Respite care	38.9	70.9	87.2
Practical/material help	24.1	56.0	78.6
Child mental health care	56.7	63.3	84.1
Parental counselling	48.8	55.6	80.0

[a] % of the parents who needed this particular type of help
[b] % of the parents who needed this particular type of help *and* sought help

Parents more often needed informal support (such as ‘a friendly ear’ and ‘information’) than formal support (such as ‘child mental health care’ or ‘parental counselling’), which is in line with the overall tendency of people to first seek informal support and to regard formal support as a last resort (Beresford, 1994; Zwaanswijk et al., 2003). The need for support reported by the parents in this study is higher than of parents of youths with ID but without assessed emotional or behavioural problems in other studies (e.g., Bailey *et al.* 1992, Ellis *et al.* 2002).

Variables that seem to 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 need for (almost) all types of support. 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 in general. These associated factors are quite similar to the ones found associated with the need for child mental health care in GP studies (Horwitz et al., 2003; Poduska, 2000; Verhulst & Van der Ende, 1997; Wu et al., 1999) and in our own study on needing professional help (*Chapter 4*). However, this is not only true for needing child mental health care, but also for needing other types of support, hence with needing help in general. Moreover, about the same variables were also found related to *parental perception* of their child's emotional and/or behavioural problems in this study. Thus, parents who are confronted with more stress-inducing circumstances not only more often perceive or recognise their child's problems, these circumstances are also related to more often needing support *after* perceiving these problems.

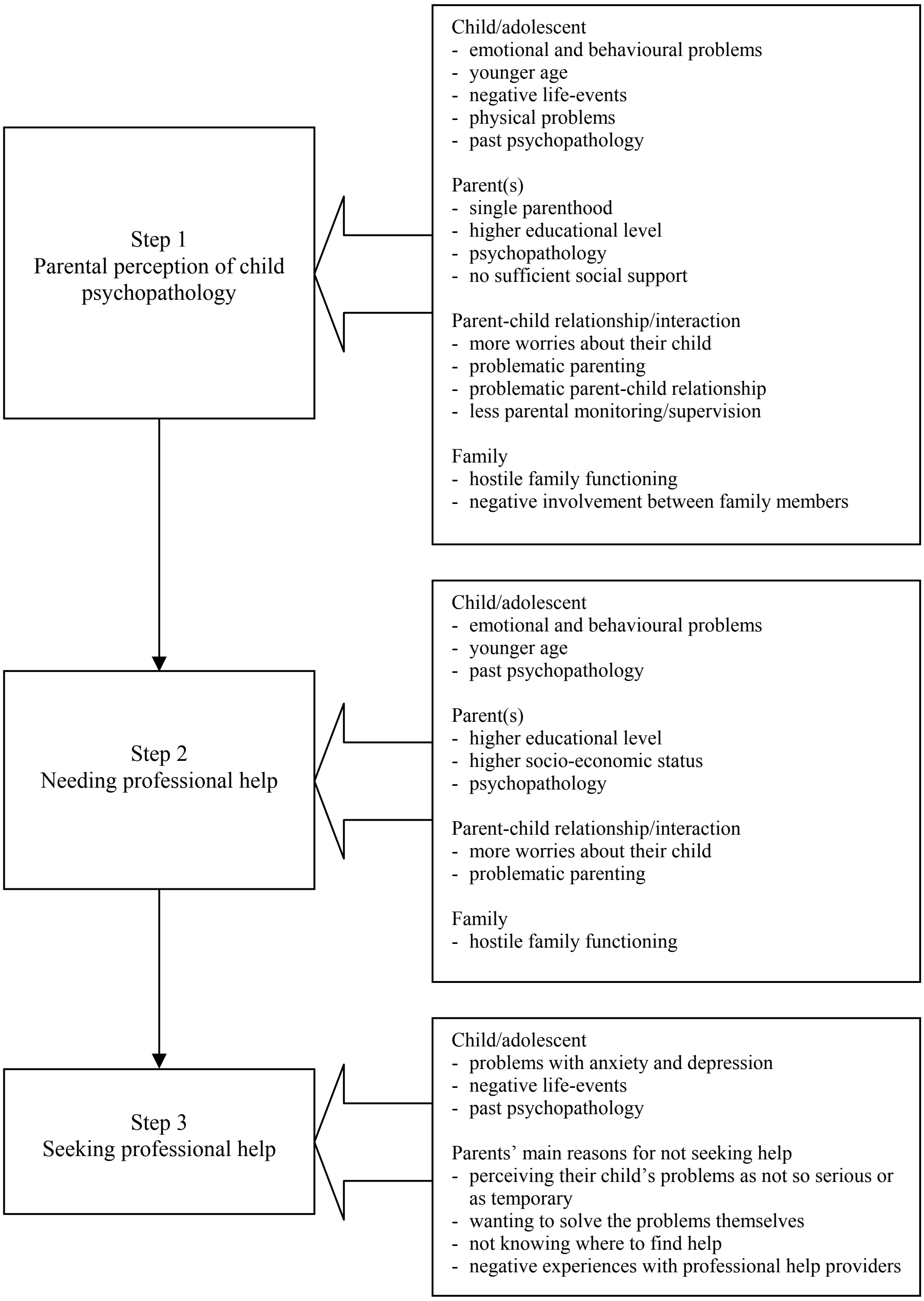
Crossing perceived barriers to actual help-seeking

When parents had indicated a need for some type of support, in an interview we asked them whether they had actually sought help for that support need. However, because we only asked parents about their help-seeking for their three most needed types of support (out of a maximum of seven), the actual rates of help-seeking might be lower than our results indicated, as a stronger need for help is likely to increase actual help-seeking (*Chapter 5*).

In *Chapter 4* we focused on the parents' help-seeking for their need for professional help for either their child or for themselves to learn how to better handle their child's problems. We found that only 57.9% of the parents who had both perceived emotional and/or behavioural problems in their child's functioning *and* had felt a need for professional help, had actually sought professional help. With respect to the other types of support needs, 77.6% of the parents had sought 'a friendly ear', 62.0% 'information', 48.2% 'activities for their child', 70.9% 'respite care for their child', 63.3% child mental health services', 55.6% 'parental counselling', and 56.0% had actually sought 'practical or material help' (see Table 8.1 – column 3). Overall, when parents had a support need, 64.3% of them had actually sought help from either informal (e.g., from family or friends) or professional sources of help. Apparently, perceiving emotional or behavioural problems in their child *and* needing help does not guarantee *actual help-seeking*, especially not in case of 'activities', 'parental counselling' and 'practical or material help'.

As with parental perception and need for help, we studied the factors potentially related to actually seeking professional help (*Chapter 4*). Despite the fact that the parents in this group were quite homogeneous, as they all perceived problems *and* subsequently felt a need for professional help, we still found some differences between parents who had and had not sought professional help. Of these parents in relatively stressful circumstances, the child's deviant score on CBCL Anxious/Depressed, the child having experienced at least one negative life-event in the past two years, and the child's past psychopathology increased the odds of seeking professional help when in need for it, of which only the latter did not have a unique contribution. This relation between life-events and help-seeking was also found for parents of infants (Horwitz et al., 2003). Contrary to results from GP studies (Zwaanswijk et al., 2003), not behavioural problems but problems of anxiety and depression increased help-seeking. Again, one has to keep in mind that comparing results from other studies with ours is questionable, since we studied help-seeking as a process and that in our study parents who had to decide on seeking help were a select group with specific features. However, it might be that parents of youths with ID are more inclined to consider deviant behavioural functioning as part of the general behavioural repertoire of their child (Rush et al., 2004) and not as a reason to seek help.

Figure 8.1
Factors related to taking each step in the help-seeking pathway to seeking professional help



Whereas many studies did not go beyond exploring variables associated with seeking or using help (Gunther et al., 2003; Redmond, Spoth, & Trudeau, 2002; Witt, Kasper, & Riley, 2003; Zahner & Daskalakis, 1997), we also investigated the parents' subjectively perceived barriers to seeking help. This enabled us to also draw conclusions about their motives for not seeking professional help. Reported reasons for not seeking professional help primarily related to the parents' perception of the problems (e.g., as not so serious, or as temporary, wanting to handle their child's problems themselves), and to the professional help itself (not knowing where to find help, and previous negative experiences). These reasons are comparable to those given by parents of typically developing youths (Flisher et al., 1997; Owens et al., 2002; Pavuluri et al., 1996), and by those who refrained from seeking professional help for their own mental health problems (Mojtabai, Olfson, & Mechanic, 2002; Wells et al., 1994). Moreover, in our study these barriers were also reported as most important reasons for not seeking either informal or formal/professional help for the parents' other support needs. Hence, irrespective of the question for whom help is required, and of the type of support that is needed, above all, people do not seek help because they perceive the problems as not serious or as temporary, they do not know where help is provided, or they want to solve the problems themselves.

Figure 8.1 provides a summary of the factors that were found related to the parents' taking each step of the pathway to seeking professional help for their child's emotional or behavioural problems (perception of problems, needing professional help, crossing perceived barriers to seeking professional help), including the parents' self-reported reasons for not seeking help.

Obtaining help

We investigated the levels of currently met need, i.e., whether parents were receiving the types of help they had indicated to need in the past year. However, one has to keep in mind that in *Chapter 5* we did not study met need as the outcome of the help-seeking process, but as a single question that was asked right after parents were inquired about their needs for help. Our results showed that the need for 'a friendly ear', 'respite care' and 'information' were most often met (75.3%, 61.1%, and 51.3%). Except for 'child mental health care', this trend is comparable to the trend in parental help-seeking, i.e., parents most often sought help when they were in need for these types of help. To complete the picture of the help-seeking pathway, we computed the extent of obtained help of parents who had actually sought help (Table 8.1 – column 4).

When we compare the levels of met need of parents who had actually sought help (Table 8.1 – columns 3 and 4) with the levels of currently met need as displayed in Table 5.2 in *Chapter 5*, most percentages of met need are about similar. For example, 75.3% of the parents reported to receive 'a friendly ear' in *Chapter 5*, and the results in Table 8.1 indicate that 73.6% of the parents received this type of help (77.6 * 95.6%). This was true to a somewhat lesser extent for parents' receiving 'child mental health care', i.e., 40.6% versus 53.2%, 'parental counselling', i.e., 35.5% versus 44.5%, and 'activities', i.e., 38.5% versus 43.5%. These types of help are mainly provided by professional organisations, but turning to professional help is usually not the first step parents choose to take (Beresford, 1994). Because we only asked parents about their help-seeking for their three most felt support needs, parents with a less strong need for these types of help were not asked about their help-seeking. It might be that more parents would have reported to have not sought help for these particular types of support needs than parents who were not asked about their help-seeking for their needs for more informal types of help (e.g., ‘a friendly ear’, ‘information’, and ‘respite care’). The true help-seeking rates for especially these types of help might therefore actually be lower than presented in column 3 of Table 8.1.

Finally, we also studied the variables potentially related to met need. Our results did not reveal a consistent pattern of associated variables across the various types of support, i.e., the circumstances that increase met need seem to be different for the seven support types. This keeps us from drawing conclusions about variables that are related to obtaining help in general. However, having a stronger need for support was found to significantly increase the odds of receiving ‘a friendly ear’, ‘respite care’, and ‘child mental health care’. This trend was also found for obtaining ‘information’, although not significant (p = .08). It seems likely that parents who have a stronger need are more inclined to actively seek support than parents who do not feel such a strong need.

Moreover, in this study unmet need seems largely due to the parents’ not seeking of help (Table 8.1 – column 2), which in turn seems to be caused by their unrealistic perceptions of the severity and future prospects of their child’s problems, and by their lack of knowledge on where to find help. Since the Dutch policy is to let ‘Bureau Jeugdzorg’ become the central gate to obtaining professional help for mental health problems in youths with mild to borderline ID (in addition to non-ID youths), hopefully more parents will know where to go when in need for child mental health care.

The previous paragraphs incorporated several key objectives of this study. We investigated the parents’ subjective needs for help and the determinants of these needs, we explored the parents’ help-seeking for their child’s emotional or behavioural problems by distinguishing between several steps that lead to actual help-seeking, and we identified the discrepancies between the need for and obtaining of help and the determinants of these discrepancies. We studied these issues through thoroughly investigating the individual steps to seeking and obtaining help.

We found that, regarding the first step to help-seeking, parents more often recognised behavioural problems than emotional problems in their child. Furthermore, compared with parents of youths without ID, parents of youths with ID more often recognised their child’s psychopathology. This discrepancy might be due to our definition of parental perception of problems. Instead of asking parents about their child’s problems in a ‘yes-or-no-format’, we inquired about their child’s emotional and behavioural functioning in a neutral way, using a 5-point answering scale. Even when parents answered ‘neither good nor bad’, emotional or behavioural problems were frequently indicated by standardised measures as the CBCL and the DISC-IV. Parents’ subjective perception of emotional or behavioural problems seems fairly indicative of the actual presence of these problems. However, since behavioural problems, but especially emotional problems were not always recognised by the parents, parental perception can not replace standardised measures of assessment. Parental recognition was found associated with about similar variables as those that were found associated with parental perception of problems, which mainly consisted of stress-inducing circumstances, such as their child’s problems, but also problems within themselves or within the family.

As a consequence of perceiving emotional or behavioural problems in their adolescent child with ID, most parents indicated to have needed more than one type of support, of which especially informal support such as ‘a friendly ear’ or ‘information’. Most factors that were found to be related to taking this second step of needing a type of help were comparable to the ones found associated with the first step of parental perception and recognition, namely stress-inducing circumstances.

Despite perceiving problems in their child and having a need for help, we found that this did not guarantee taking the third step of actual help-seeking. Regarding the need for professional help, this was sought by only somewhat more than half of the parents. Not taking this step was an important obstacle to obtaining help. Especially the parents’ reported reasons for not seeking help provided important information on the content of this obstacle. Primarily reasons that related to the parents’ perception of their child’s problems (not so serious, or considering them to be temporary, wanting to solve the problems themselves), not knowing where to go for help, or having negative experiences with professional help kept them from seeking professional help.

Finally, our results showed that a need for help frequently remained unmet, of which especially a need for professional help. We did not find a clear pattern of factors that were related to met or unmet need for help. However, frequently a stronger need for help was associated with a higher level of met need for help. In addition, unmet need for help seemed largely due to the parents’ not seeking of help.

Objective need for help

In the following paragraphs, we discuss the main findings regarding two key objectives of this study (see *Chapter 1*): we investigated the extent to which youths with ID can contribute to determining an objective need for help, i.e., their emotional or behavioural problems (key objective 1), and we aimed at predicting a specific objective need for help of not only the parents, but also of society; the prediction of antisocial and delinquent behaviours in youths with mild to borderline ID (key objective 3).

Using self-reports to assess mental health problems in youths with ID

To assess an objective need for support, defined as meeting the criteria of psychopathology, most studies that investigated this in youths with ID based their results on reports from parents and/or teachers, whereas only few used information from self-reports (Emerson, 2005). However, including the perspectives of youths without ID themselves, in addition to their parents’ and teachers’ contribution, is regarded as vital to obtain a comprehensive picture of their emotional and behavioural functioning (Ferdinand, Van der Ende, & Verhulst, 2004). Self-reports of individuals with ID are also important, because the ID itself can make it difficult for others to recognise psychopathology, which can also be regarded as diagnostic overshadowing (Van Minnen, Savelsberg, & Hoogduin, 1994). Youths’ self-reports may reveal symptoms that otherwise would not be recognised in these individuals, or reveal symptoms that are recognised, but incorrectly attributed to the ID.

While lower-functioning youths may not be fully capable of reflecting on their own emotional and behavioural functioning (Wallander et al., 2003), youths and adults with mild and moderate ID were found capable of reporting about their own functioning and feelings (Beck et al., 1987; Benavidez & Matson, 1993; Bramston & Fogarty, 2000; Deb et al., 2001; Demb et al., 1994; Emerson, 2005; Gullone et al., 1996; Heiman, 2001; Lindsay et al., 1994; Manikam et al., 1995; Moss et al., 1996). In *Chapter 6*, we studied whether youths with moderate to borderline ID are able to contribute to the diagnostic process of assessing their objective need for help (emotional and behavioural problems) by using the self-report version of the CBCL; the Youth Self-Report (YSR). This instrument is often used to assess these problems in youths without ID, but had not yet been thoroughly studied in an ID sample. Because in this study all youths took an IQ test, but not all could complete the YSR, through ROC-curve analysis we found that an IQ score of 48 reliably distinguished between 11 to 18-year-old youths who were and who were not capable of completing the YSR in an interview. While other studies particularly draw conclusions regarding the youths' level of ID that still allows successful completion of self-reports, this study was the first to provide a more precise indication of the intellectual requirements for completing the YSR.

To determine whether the YSR is a suitable instrument for assessing emotional and behavioural problems in youths with ID, we compared the Cronbach's alphas, levels of cross-informant agreement, and levels of construct validity by inspecting the multitrait-multimethod (MTMM) matrices in a lower (IQ 48-69) and higher IQ group (IQ ≥ 70) and a GP sample of typically developing peers. Overall, our results indicated that psychometric properties were comparable across the ID and GP samples, although this was especially the case for youths with an IQ ≥ 70, and to a somewhat lesser extent for those with an IQ between 48 and 69. Within the two ID groups only, we assessed the criterion-related validity by comparing the mean scale scores of youths who had a psychiatric disorder according the DISC-IV with those who had not. Youths with a psychiatric disorder had significantly higher scores on almost all YSR scales than those without a disorder.

All in all, these results suggest that adolescents with ID are capable of providing information about their objective need for help that adds to the information given by their parents and/or teachers. Therefore, in order to obtain a more comprehensive picture of these adolescents' emotional and behavioural functioning and problems, they should also be consulted as informants besides parents and teachers. Furthermore, we have no reason to reject the YSR as a valuable tool to serve this purpose of obtaining information through self-reports especially in 11 to 18-year-olds with mild to borderline ID. Future studies are, however, needed to refine and confirm the results from this study as this was a first to systematically study the YSR in youths with ID.

Antisocial and delinquent behaviours in youths with mild to borderline ID

Several studies have pointed to higher rates of, and an increased risk for engaging in antisocial and delinquent behaviours (ADBs) in individuals with mild intellectual disabilities (ID) than in both typically developing persons and in people with more severe ID (Cockram, 2005; Hall, 2000; Hodgins, 1992; Simpson & Hogg, 2001a; Winter et al., 1997). Accordingly, their objective need for help is also likely to be higher. However, due to differences between studies regarding definitions of ID, type of studied offences, and between studied populations, firm conclusions can not be drawn (Simpson & Hogg, 2001a).

Similar to the general population (GP), particularly youths up to the age of 18 are expected to show these behaviours (Hall, 2000). Therefore, in *Chapter 7* we compared the prevalence rates of various types of ADBs, such as being ‘mean to others’, ‘property destruction’, ‘physically attacking others’, and ‘authority avoidance’ (truancy and running away from home) between 11 to 18-year-old youths with mild to borderline ID and youths without ID. Only for boys, our study confirmed that more boys with ID than boys without ID engaged in ADBs, although this was not true for ‘authority avoidance’. On the other hand, prevalence rates of ADBs did not differ between girls with ID and girls without ID. Parents might be more protective towards their daughters with ID than towards their sons with ID, and keep their daughters closer to home. Another explanation for the differences between boys and girls might be that especially boys with ID are prone to being impulsive and to being lured into engaging in undesirable behaviours.

All ADBs turned out to be quite persistent over a five-year period in youths with ID, and displaying a certain type of ADB at Phase 1 increased the odds of also displaying this behaviour five years later. Still, additional results (not presented in *Chapter 7*) showed that, overall, the prevalence rates of ADBs decreased over time between 6.3% (‘theft/arson’) and 18.6% (‘physical aggression’). The only exception was ‘authority avoidance’ which showed an increase of 4.1% that was mainly caused by an increase in the younger age group (11-17 years in Phase 3). For the older youths the prevalence of ‘authority avoidance’ decreased over time, although not significantly. Regarding the other types of ADBs, the decrease in prevalence rates was also stronger for the older youths (18-24 years in Phase 3) than for the younger ones, although this difference was only significant for ‘theft/arson’ and ‘authority avoidance’. These results also underline that, as in the GP, ADBs in youths with ID seem fairly age-related; engaging in ADBs in childhood or adolescence does not imply that this behaviour will continue in adulthood. However, it does increase the risk for future ADBs, and at least reasonable stability of ADBs in youths with ID was found, which was also found for the GP (Storvoll & Wichstrom, 2003).

We also investigated whether ADBs can be predicted five years beforehand. By studying these predictors, our aim was to gain insight into the specific circumstances that are related to exhibiting these behaviours five years later. In other words, we studied need for help defined as ‘exposure to risk’ (see *Chapter 1*). Moreover, we investigated whether ADBs have different predictors for boys than for girls, and for older than for younger youths. Regarding the latter, although such differences have been indicated and suggested by other studies (Burke et al., 2002; Lipsey & Derzon, 1998; Pakiz et al., 1997), this was not supported by our results, which revealed about similar predictors for both sexes and age groups. Several child, parent and family characteristics at Phase 1 predicted ADBs at Phase 3, but multiple logistic regression analyses showed that child characteristics were the strongest unique predictors of ADBs, i.e., the child’s younger age, male sex, and the presence of behavioural problems. Apart from the child’s male sex, these predictors were not associated with ‘substance (ab)use’ and ‘authority avoidance’, which can both be considered as covert (less visible for outsiders) and as non-destructive behaviours (Bongers, Koot, Van der Ende, & Verhulst, 2004; Frick et al., 1993). Moreover, these behaviours (‘substance (ab)use’ and ‘authority avoidance’) could not be accurately predicted by the studied factors as all significant factors from univariate analysis explained only about 5% of the variance in these types of ADBs five years later. The destructive types of ADBs (‘theft/arson’, ‘property destruction’, and to a somewhat lesser extent ‘physical aggression’) could be predicted most accurately, but the percentage of explained variance did not exceed 17.3%. These relatively low percentages might be due to the length of time between Phase 1 and Phase 3, i.e., five years might be too long to predict ADBs, but it might also be that other factors also or better predict engaging in ADBs. For example, GP studies revealed that child-rearing practices and family management both were strongly associated with ADB (Hawkins et al., 1998). Because this kind of information was not collected at Phase 1, we were not able to examine the influence of these factors.

Finally, since it is considered fruitful to distinguish between different types of ADBs (Bongers et al., 2004; Frick et al., 1993; Simpson & Hogg, 2001b), we differentiated between six types of ADBs. The results from latent class analysis, however, revealed that not different profiles of ADBs, but two groups of youths could be distinguished: one group with relatively low levels of overall ADBs and another group of youths with relatively high levels of overall ADBs. Apparently, when youths with ID engage in a certain type of ADB, they are also likely to exhibit other types of ADBs. Additionally, except for ‘substance (ab)use’ and ‘authority avoidance’, the main predictors of different types of ADBs were also about similar to the predictors of displaying high levels of overall ADBs. All this suggests that studying an overall measure of ADB is at least as important as studying different types or profiles of ADBs.

In the previous paragraphs we discussed two key objectives of this study. We studied the youths’ contribution to determining their objective need for help defined as the presence of emotional or behavioural problems (key objective 1), and we studied the predictors of antisocial and delinquent behaviours (key objective 3) in which need was investigated as an exposure to risk. Our results showed that 11 to 18-year-old youths with an IQ higher than 48 are capable of providing information on their emotional and behavioural functioning. By comparing the psychometric properties of the YSR between youths without ID and youths with ID, we found that the YSR can also be used in youths with ID to gather this kind of information through self-reports. This was especially true for youths with an IQ higher than 70.

Regarding the specific objective need for help that we explored, our results showed that youths with mild to borderline ID engaged in various types of antisocial and delinquent behaviours (ADBs), such as ‘mean to others’, ‘theft/arson’, ‘property destruction’, and ‘authority avoidance’. When an individual displayed one of these behaviours, it was likely that he or she also displayed other types of ADBs. Compared with peers without ID, boys with ID more often exhibited these behaviours. This was not the case for girls with ID versus girls without ID. The strongest five-year predictors of ADBs were the youths’ male sex, a younger age (11 to 17 years of age versus 18 to 24 years of age), and past behavioural problems and past ADBs. Youths with these characteristics are at increased risk for exhibiting these behaviours later on in life, and thus need help the most. However, relatively low percentages of explained variance in the predictors of types of ADBs five years later, suggest that other factors should be considered, such as parenting style, when studying the predictors of these objective needs for help.

Strengths and limitations of this study

This study is a follow-up of a large study on psychopathology in youths with ID that started in 1996. Youths were randomly selected through almost all schools for children with mild (MLK) and moderate ID (ZMLK) in the province of Zuid-Holland. As then most children and adolescents with moderate to mild/borderline ID attended schools for children with mild and moderate ID, the Phase 1 sample was regarded to be representative of Dutch school-aged children with ID who were living at home. About five to six years later, all parents who had participated at Phase 1 were contacted again and asked to participate in the Phase 3 study. Of all 961 eligible parents 749 participated again (77.9%), and 84.4% of all teachers or job coaches we could contact returned the questionnaires (N=515). In addition, we also included the youths themselves in this study. Of all 819 youths we were allowed to approach, 638 participated (77.9%). Thus, this Phase 3 study encompassed a large sample of youths with moderate to borderline ID in a broad age-range (10-24 years) about whom data was collected from multiple informants about various aspects potentially related to psychopathology and help-seeking.

Another strength of our study is that we studied the help-seeking process of parents of youths with ID and psychopathology and not just the outcome or one specific step or filter of the help-seeking pathway or process. Also, we not only studied the variables related to taking each consecutive step to seeking help, when parents had not sought help, we also asked them about their reasons for not seeking help. This provided a clear and rather detailed picture of the actual pathway to seeking and receiving help. It also informed us where the dropping out took place and what forces, decisions and actions were involved.

In addition, we inquired about these parents' full range of need for help and not only about the need for mental health services for their child. To assess these needs and the parents' help-seeking, we constructed the Need for Help Questionnaire and Help-seeking Interview. The content of these instruments were based on both a literature study and on semi-structured interviews that were conducted with parents of dually diagnosed children and with mental health care providers. Therefore, these instruments are likely to capture information on their actual needs and help-seeking.

To ensure that parents reported about their needs for support solely due to their child's additional emotional or behavioural problems, only those parents who perceived these additional problems were asked about their support needs. This allowed us to more accurately answer this study's questions about their support needs.

Regarding the two studies on the 'objective need for help', because all youths took the IQ-test, but not all were able to complete the YSR, through ROC-curve analysis, we were able to give a fairly precise indication on the youths' intellectual requirements for completing the YSR.

In the study on ADBs, whereas many GP studies are limited by using a single informant to assess ADBs (Bor et al., 2004; Lahey et al., 2000), we had information from three informants at our disposal, from parents, teachers/job coaches, and the youths themselves. Finally, we were able to directly compare prevalence rates of five different types of ADBs between youths with and without ID, within the same age range, who all lived in the same province, and who all participated in 2003.

Besides these strengths, this study has some limitations that need to be addressed to put our results into perspective. First, this study suffered from non-random sample attrition.

Parents more often participated in Phase 3 when their child had attended a school for children with moderate ID, had a deviant CBCL Total Problems score, and when both parents were of Dutch origin, not single, and had a higher socio-economic status, and educational level. Additionally, parents who had problems with the Dutch language were excluded at Phase 1. This limits the generalisation of our results to all youths with moderate to borderline ID, and especially to those with non-Dutch parents. In *Chapter 3 to 7* the specific implications of these limitations were discussed.

Second, to assess these youths' psychopathology, we used CBCL and DISC-IV which are validated for children until 18 years of age, while almost 30% of our sample was older than 18. However, we assumed that both instruments could be used, because, compared with peers of the same age, their conceptual, social, and practical skills are less developed (American Psychiatric Association, 2000). Furthermore, these instruments were constructed and validated for youths without ID, but it was shown that the CBCL and TRF can be used in youths with moderate to mild ID (Borthwick-Duffy et al., 1997; Dekker, Koot et al., 2002). However, even though the DISC-IV is frequently used in ID samples, no information is yet available on the psychometric properties of the DISC-IV in youths with ID. As in our previous study (Dekker & Koot, 2003a), we stress that it is generally assumed that people with moderate to mild/borderline ID show psychiatric disorders in about similar manners as peers without ID (Borthwick-Duffy, 1994).

Third, in *Chapter 3 to 5*, we only used cross-sectional data, which cannot inform us about causal relationships between the independent variables and the consecutive steps of the help-seeking pathway and the outcomes of help-seeking, and about the underlying processes.

Fourth, when parents had needed some type of support, in an interview we only asked them about their help-seeking behaviours for their three most strongly needed types of support (out of a maximum of seven). The rates of help-seeking might thus actually be lower than our results indicated, as a stronger need for help was found to increase actual help-seeking.

Fifth, even though this study provides valuable information on the parental role to seeking and obtaining help, one has to keep in mind that other persons, such as teachers or school psychologists, can also initiate the help-seeking process. Furthermore, in *Chapter 1* we showed that after the parents have sought help a whole range of other factors can influence the actual obtaining of help. Since we were not able to study the entire process to obtaining help after the parents' help-seeking, we can not draw conclusions about the exact role in and contribution of other actors to met and unmet need for support, such as of service providers. In addition, we acknowledge that parents' help-seeking can be directed by different social processes, such as out of 'free choice', 'coercion of others', an by 'muddling through', i.e., lacking a clear agent (Pescosolido, Gardner, & Lubell, 1998). Even though the parents' reasons for not seeking help primarily related to their subjective perception of their child's problems, we did not study the parents' reasons for their decision to *do* seek help. We can therefore not infer about the social processes that were at play in their decision to seek help.

Finally, in our study on ADBs, the CBCL, TRF, and YSR items that were used to construct ADBs did not explicitly include serious and violent offences such as armed robbery and sexual assault. This prohibited the study of the prevalence and predictors of these forms of ADBs that cause even more damage to society. In addition, youths were considered to have engaged in a type of ADB when either of the informants indicated that this type of behaviour was displayed at least ‘sometimes’, which can not always qualify someone as being ‘delinquent’. However, even with these lenient criteria, the majority of the adolescents had not engaged in these types of ADB. Furthermore, because we had no information from the youths themselves available of Phase 1, we based our results regarding the persistence of these behaviours on the reports of parents and the teachers only. Due to differences in questions on ‘substance (ab)use’ between Phase 1 and Phase 3 and the GP sample, we were not able to compare these prevalence rates.

Clinical implications and future research

This study provides several clinical implications and offers suggestions for future research that have already been discussed in *Chapters 3 to 7*. This paragraph gives an overview of these implications.

Clinical implications

1. Even when parents indicate their child’s emotional or behavioural functioning as ‘neither good nor bad’, next to ‘bad’ or ‘very bad’, this frequently implies that these problems are indeed present in youths with ID according to standardised measures. Hence, the parents’ subjective perceptions need to be taken seriously and warrant further examination of the child. However, we also found that not all parents recognised their child’s psychopathology, and they especially did not recognise emotional problems. This implies that the parents’ subjective perception about their child’s emotional and behavioural functioning can not be a replacement of the standardised assessment of psychopathology.
2. Informing and educating parents about the characteristics of emotional and behavioural problems in youths with ID (e.g., about their increased risk for these problems, verbal and non-verbal signs, prognosis, and potential negative prospects when untreated), how to handle these problems, and where they can go for what type of support is important for a number of reasons. First of all, it is likely to increase parental recognition of their child’s additional problems. This should especially be aimed at increasing recognition of emotional problems, as these were least often recognised. Information should particularly be provided to those parents who seem to be most vulnerable to under-recognition, i.e., parents who are not already familiar with these problems, who seem to have no specific reasons to pay extra attention to their child, or who worry less about their child, and whose child has more severe ID. Primarily these characteristics interfered with parental recognition of child psychopathology. Secondly, informing parents is important for them to obtain a realistic picture of their child’s problems. Not seeking help was a major obstacle to eventually obtaining help and parents’ reasons for not seeking help were often based on their (mis)perceptions of their child’s problems (‘not so big’ or ‘temporary’, despite a frequently present deviant CBCL subscale score). Thirdly, another reported reason for not seeking help concerned them not knowing where to go for help. Thus, providing information to parents is likely to increase parental recognition of their child’s emotional and/or behavioural problems, and to reduce the level of unmet need. Especially schools, sheltered work settings, and service providers for the ID

can provide this information through, for example, the Internet or leaflets, but a central information source is preferable.

3. Besides informing the parents, screening routinely for psychopathology in all youths with ID seems not in vain, as many youths with ID have emotional or behavioural problems that frequently remain undetected. Schools, sheltered work settings and systems serving these youths with ID can also contribute to detecting these problems (Leaf et al., 1996; McCarthy & Boyd, 2002).
4. Assigning a case manager to an individual with ID and/or his or her parents can also be of help in reducing the level of unmet need for help by assisting in every step of the help-seeking process. He should know the signs of psychopathology, helps to obtain professional help when needed, knows where what kind of help is provided, and can mediate between parents and service providers or professional help to obtain help (Hastings & Beck, 2004).
5. Service providers need to become aware of the parents' high level and diversity of needs for support due to their child's additional problems, which were higher than of parents of youths with ID but without additional problems. Subsequently, they 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.
6. 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 several sources of stress apart from the child's emotional or behavioural problems especially increased the odds of needing help.
7. Since most parents had various needs for support, giving them a personal budget (e.g., Persoonsgebonden Budget, PGB) might enable them to set their own priorities in what type of support to purchase from what organisations or persons. Moreover, financial funding was found to improve flexibility and continuity in receiving help (Caldwell & Heller, 2003; Freedman & Boyer, 2000). However, for this to succeed, the amount of money needs to be sufficient, people or services for hiring to be available, parents need to know where what help can be purchased, and they will have to be capable of making these choices and controlling these finances.
8. This study has demonstrated that, just like GP adolescents, adolescents with an IQ ≥ 48, without autism, are capable of providing information about their own emotional and behavioural functioning that adds to the information of parents and/or teachers. Therefore, in either clinical or research settings, to obtain a comprehensive picture of these adolescents' emotional and behavioural functioning, they should also be consulted as informants.
9. The YSR appears to be a valuable tool to serve the purpose of assessing emotional and/or behavioural problems through self-reports in especially higher functioning 11 to-18-year-olds (IQ ≥ 70).
10. As primarily adolescent boys exhibited ADBs, and more often than peers without ID, preventive measures should at least be targeted at 6 to 11-year-old boys who have higher levels of emotional and behavioural problems, and already display ADBs. General instruments, like the CBCL, TRF, and YSR can help to improve early detection of these problems and behaviours.
11. Treatment of emotional problems and especially of behavioural problems at an early age is recommended, as it might also prevent future ADB or worse. GP studies have indicated that treatment needs to address multiple risk factors, including especially

the parenting domain (Burke et al., 2002). Since low SES has been associated with less preferable parenting styles (Patterson et al., 1989), and relatively many families of youths with ID have low SES, the parent domain also needs to be considered in the treatment of youths with ID.

Implications for future research

Whereas relatively many studies investigated the variables related to a distinct step or the outcome of the help-seeking process, i.e., receiving services, they do not provide insight into the process to seeking and obtaining help. There is a shortage of studies in large and representative population-based samples on the help-seeking process of parents for psychopathology of their child both with and without ID. These studies are needed to better understand the parental role in the help-seeking process, the circumstances and underlying mechanisms that are related to taking each subsequent step to seeking and obtaining help. More specifically, future studies on parental recognition of child psychopathology should distinguish between recognition of emotional problems and recognition of behavioural problems, since our study revealed differences in recognition rates and the factors associated. Making this distinction might also be relevant in studying the entire help-seeking process and its outcome.

To obtain a complete understanding of the pathway to seeking and obtaining help, insight into the role of other actors is also required. While we focused on the parental role, other persons, such as teachers or school psychologists, may also initiate the help-seeking for a child's emotional or behavioural problems. It is important to learn more about who these other actors are and the extent of their contribution to seeking and obtaining help. In addition, when help has been sought, this does not always result in help being provided. Several circumstances may impede obtaining help, for example waiting lists, or because first-line service providers do not recognise the problems. Future studies are needed to fully comprehend the pathway to obtaining help for a child's or adolescent's emotional and/or behavioural problems.

In the previous paragraph, we provided several clinical implications that are aimed at reducing the level of unmet need for help. Future studies are needed to ascertain the effects of these implications by determining whether emotional and behavioural problems of youths with ID are detected more often (e.g., through recognition by their parents), whether more parents seek help when in need, and whether their needs for help are met more often.

Since this study was the first to examine whether the YSR can be used for the assessment of emotional and/or behavioural problems in youths with ID, more research is needed to confirm and extend the results from this study. While we inspected the MTMM matrices, statistical analyses are needed to examine the construct validity of the YSR more accurately in this population (Bagozzi, 1993; Cole, 1987; Kenny & Kashy, 1992; Schmitt & Stults, 1986). Also, to get an indication of criterion-related validity, we compared the mean scores of those with and without a psychiatric disorder (assessed with DISC-IV-Parent version). It would have been preferable to use a more solid independent measure to indicate the actual presence of mental health problems, such as mental health care status. In addition, longitudinal studies are needed to examine the test-retest reliability and predictive validity of the YSR. Finally, in this study, moderate and mild ID adolescents were studied as one group. As especially adolescents with moderate ID were found to have the most trouble in completing self-reports, future research is needed to refine the findings and conclusions from this study by investigating moderate and mild ID adolescents separately in larger population-based samples.

Regarding future studies on ADBs, other factors than in this study need to be investigated, of which especially child-rearing practices and family management, as they both were strongly associated with ADBs (Hawkins et al., 1998). Also, future studies are needed to determine the prevalence and predictors of the more serious and violent types of ADBs.

Conclusion

This study aimed to contribute to eventually increasing the level of met need for help of parents of youths with mild to borderline ID and emotional or behavioural problems. In the previous chapters, we first unravelled the parental role in met and unmet need for help by studying three consecutive steps that parents have to take to eventually seek help for their child's problems. Our results showed that only a minority of the parents took all three steps and actually sought help. We offered several suggestions to increase the number of parents who take all consecutive steps. Next, we focused on the assessment of these youths' emotional and behavioural problems, i.e., their objective need for help. To more accurately determine the extent to which this objective need for help is being met, careful assessment of these problems is needed first. For youths without ID, their contribution to the diagnostic process of assessing these problems is considered vital. However, this study was a first to show that youths with ID can also contribute to the assessment of their emotional or behavioural problems, and that their information adds to the information given by their parents. Finally, we revealed which youths with ID are at increased risk for engaging in antisocial and delinquent behaviours later on in life, and thus which youths need help the most in this respect. This offered more specific directions for measures to both reduce the level of this objective need for help, and to increase the numbers of youths who receive help.

References

References

Achenbach, T. M. (1991a). *Manual for the Child Behavior Checklist/4-18 and 1991 Profiles*. Burlington, VT: Department of Psychiatry, University of Vermont.

Achenbach, T. M. (1991b). *Manual for the Teacher's Report Form and 1991 Profiles*. Burlington, VT: Department of Psychiatry, University of Vermont.

Achenbach, T. M. (1991c). *Manual for the Youth Self-Report and 1991 Profiles*. Burlington, VT: Department of Psychiatry, University of Vermont.

Achenbach, T. M. (1997). *Manual for the Young Adult Self-Report and Young Adult Behavior Checklist*. Burlington, VT: Department of Psychiatry, University of Vermont.

Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychological Bulletin, 101*, 213-232.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of mental disorders: DSM-IV, 4th edition, text revision*. Washington, DC: American Psychiatric Association.

Andrews, G. (2000). Meeting the unmet need with disease management. In G. Andrews & S. Henderson (Eds.), *Unmet need in psychiatry: Problems, resources, responses* (pp. 11-36). Cambridge: University Press.

Angold, A., Erkanli, A., Farmer, E. M., Fairbank, J. A., Burns, B. J., Keeler, G., et al. (2002). Psychiatric disorder, impairment, and service use in rural African American and white youth. *Archives of General Psychiatry, 59*, 893-901.

Angold, A., Messer, S. C., Stangl, D., Farmer, E. M., Costello, E. J., & Burns, B. J. (1998). Perceived parental burden and service use for child and adolescent psychiatric disorders. *American Journal of Public Health, 88*, 75-80.

Aoun, S., Pennebaker, D., & Wood, C. (2004). Assessing population need for mental health care: A review of approaches and predictors. *Mental Health Services Research, 6*, 33-46.

Bagozzi, R. P. (1993). Assessing construct validity in personality research: Applications to measures of self-esteem. *Journal of Research in Personality, 27*, 49-87.

Bailey, D. B., Blasco, P. M., & Simeonsson, R. J. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal on Mental Retardation, 97*, 1-10.

Bailey, D. B., Skinner, D., Correa, V., Arcia, E., Reyes Blanes, M. E., Rodriguez, P., et al. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation, 104*, 437-451.

Baker, B. L., & Heller, T. L. (1996). Preschool children with externalizing behaviors: Experience of fathers and mothers. *Journal of Abnormal Child Psychology, 24*, 513-532.

Beck, D. C., Carlson, G. A., Russell, A. T., & Brownfield, F. E. (1987). Use of depression rating instruments in developmentally and educationally delayed adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 26*, 97-100.

Benavidez, D. A., & Matson, J. L. (1993). Assessment of depression in mentally retarded adolescents. *Research in Developmental Disabilities, 14*, 179-188.

Berden, G. F., Althaus, M., & Verhulst, F. C. (1990). Major life events and changes in the behavioural functioning of children. *Journal of Child Psychology and Psychiatry, 31*, 949-959.

Beresford, B. A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry, 35*, 171-209.

Bongers, I. L., Koot, H. M., Van der Ende, J., & Verhulst, F. C. (2004). Developmental trajectories of externalizing behaviors in childhood and adolescence. *Child Development, 75*, 1523-1537.

Bor, W., McGee, T. R., & Fagan, A. A. (2004). Early risk factors for adolescent antisocial behaviour: An Australian longitudinal study. *Australian and New Zealand Journal of Psychiatry, 38*, 365-372.

Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology, 62*, 17-27.

Borthwick-Duffy, S. A., Lane, K. L., & Widaman, K. F. (1997). Measuring problem behaviors in children with mental retardation: Dimensions and predictors. *Research in Developmental Disabilities, 18*, 415-433.

Bradshaw, J. (1972). The concept of social need. *New Society, 30*, 640-643.

Bramston, P., & Fogarty, G. (2000). The assessment of emotional distress experienced by people with an intellectual disability: A study of different methodologies. *Research in Developmental Disabilities, 21*, 487-500.

Bregman, J. D. (1991). Current developments in the understanding of mental retardation. Part II: Psychopathology. *Journal of the American Academy of Child and Adolescent Psychiatry, 30*, 861-872.

Brown, B. B., Mounts, N., Lamborn, S. D., & Steinberg, L. (1993). Parenting practices and peer group affiliation in adolescence. *Child Development, 64*, 467-482.

Burke, J. D., Loeber, R., & Birmaher, B. (2002). Oppositional defiant disorder and conduct disorder: A review of the past 10 years, part II. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*, 1275-1293.

Bussing, R., Zima, B. T., Gary, F. A., & Garvan, C. W. (2003). Barriers to detection, help-seeking and service use for children with ADHD symptoms. *Journal of Behavioral Health Services & Research, 30*, 176-189.

Byles, J. A., Byrne, C., Boyle, M. H., & Offord, D. R. (1988). Ontario Child Health Study: Reliability and validity of the general functioning subscale of the McMaster Family Assessment Device. *Family Process, 27*, 97-104.

Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research, 47*, 352-366.

Campbell, D. T., & Fiske, D. W. (1959). Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychological Bulletin, 56*, 81-105.

Carr, A., & O'Reilly, M. (1996). Service needs of carers for people with intellectual disabilities: Profiles of high-need and low-need groups. *Irish Journal of Psychology, 17*, 48-59.

Central Bureau of Statistics. (1993). *Standaard beroepen classificatie 1992 [Standard classification of professions 1992]*. Den Haag: SDU.

Chadwick, O., Beecham, J., Piroth, N., Bernard, S., & Taylor, E. (2002). Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it? *Child and Adolescent Mental Health, 7*, 66-72.

Cockram, J. (2005). Careers of offenders with an intellectual disability: The probabilities of rearrest. *Journal of Intellectual Disability Research, 49*, 525-536.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed. ed.). Hillsdale, NJ: Erlbaum.

Cohen, P., & Hesselbart, C. S. (1993). Demographic factors in the use of children's mental health services. *American Journal of Public Health, 83*, 49-52.

Cole, D. A. (1987). Utility of confirmatory factor analysis in test validation research. *Journal of Consulting and Clinical Psychology, 55*, 584-594.

Costello, E. J., Burns, B. J., Angold, A., & Leaf, P. J. (1993). How can epidemiology improve mental health services for children and adolescents? *Journal of the American Academy of Child and Adolescent Psychiatry, 32*, 1106-1114.

Costello, E. J., & Janiszewski, S. (1990). Who gets treated? Factors associated with referral in children with psychiatric disorders. *Acta Psychiatrica Scandinavica, 81*, 523-529.

Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research, 45*, 495-505.

Dekker, M. C. (2003). *Psychopathology in children with intellectual disability: Assessment, prevalence and predictive factors.* Erasmus MC - Sophia Children's Hospital, Rotterdam.

Dekker, M. C., & Koot, H. M. (2003a). DSM-IV disorders in children with borderline to moderate intellectual disability. I: Prevalence and impact. *Journal of the American Academy of Child and Adolescent Psychiatry, 42*, 915-922.

Dekker, M. C., & Koot, H. M. (2003b). DSM-IV disorders in children with borderline to moderate intellectual disability. II: Child and family predictors. *Journal of the American Academy of Child and Adolescent Psychiatry, 42*, 923-931.

Dekker, M. C., Koot, H. M., Van der Ende, J., & Verhulst, F. C. (2002). Emotional and behavioral problems in children and adolescents with and without intellectual disability. *Journal of Child Psychology and Psychiatry, 43*, 1087-1098.

Dekker, M. C., Nunn, R., & Koot, H. M. (2002). Psychometric properties of the revised Developmental Behaviour Checklist scales in Dutch children with intellectual disability. *Journal of Intellectual Disability Research, 46*, 61-75.

Dekker, M. C., Nunn, R. J., Einfeld, S. E., Tonge, B. J., & Koot, H. M. (2002). Assessing emotional and behavioral problems in children with intellectual disability: Revisiting the factor structure of the developmental behavior checklist. *Journal of Autism and Developmental Disorders, 32*, 601-610.

Dekovic, M. (1996). *Vragenlijst Toezicht Houden (VTH) [Parental Monitoring Questionnaire]*. Utrecht: University of Utrecht (Internal report).

Demb, H. B., Brier, N., Huron, R., & Tomor, E. (1994). The Adolescent Behavior Checklist: Normative data and sensitivity and specificity of a screening tool for diagnosable psychiatric disorders in adolescents with mental retardation and other development disabilities. *Research in Developmental Disabilities, 15*, 151-165.

Dulcan, M. K., Costello, E. J., Costello, A. J., Edelbrock, C., Brent, D., & Janiszewski, S. (1990). The pediatrician as gatekeeper to mental health care for children: Do parents' concerns open the gate? *Journal of the American Academy of Child and Adolescent Psychiatry, 29*, 453-458.

Dumont, R., & Faro, C. (1993). A WISC-III short form for learning-disabled students. *Psychology in the Schools, 30*, 212-219.

Dykens, E. M. (2000). Psychopathology in children with intellectual disability. *Journal of Child Psychology and Psychiatry, 41*, 407-417.

Dyson, L. L. (1997). Fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning, and social support. *American Journal on Mental Retardation, 102*, 267-279.

Edelstein, T. M., & Glenwick, D. S. (1997). Referral reasons for psychological services for adults with mental retardation. *Research in Developmental Disabilities, 18*, 45-59.

Einfeld, S. L., & Tonge, B. J. (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: II. Epidemiological findings. *Journal of Intellectual Disability Research, 40*, 99-109.

Einfeld, S. L., & Tonge, B. J. (2002). *Manual for the Developmental Behaviour Checklist. Primary Carer Version (DBC-P & Teacher Version (DBC-T)* (2nd ed.). Clayton, Victoria / Sydney: Monash University, Centre for Developmental Psychiatry & Psychology / University of New South Wales, School of Psychiatry.

Ellis, J. T., Luiselli, J. K., Amirault, D., Byrne, S., O'Malley Cannon, B., Taras, M., et al. (2002). Families of children with developmental disabilities: Assessment and comparison of self-reported needs in relation to situational variables. *Journal of Developmental and Physical Disabilities, 14*, 191-202.

Emerson, E. (2003a). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research, 47*, 385-399.

Emerson, E. (2003b). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research, 47*, 51-58.

Emerson, E. (2005). Use of the Strengths and Difficulties Questionnaire to assess the mental health needs of children and adolescents with intellectual disabilities. *Journal of Intellectual and Developmental Disability, 30*, 1-10.

Farmer, E. M., Stangl, D. K., Burns, B. J., Costello, E. J., & Angold, A. (1999). Use, persistence, and intensity: patterns of care for children's mental health across one year. *Community Mental Health Journal, 35*, 31-46.

Farrington, D. P. (1995). The twelfth Jack Tizard memorial lecture. The development of offending and antisocial behaviour from childhood: Key findings from the Cambridge Study in Delinquent Development. *Journal of Child Psychology and Psychiatry, 36*, 929-964.

Feehan, M., Stanton, W., McGee, R., & Silva, P. A. (1990). Parental help-seeking for behavioural and emotional problems in childhood and adolescence. *Community Health Studies, 14*, 303-309.

Ferdinand, R. F., & Van der Ende, J. (1998). *DISC-IV: Diagnostic Interview Schedule for Children; informatie ouder (Interview over kind of jeugdige) [DISC-IV:*

Diagnostic Interview Schedule for Children; information parent (Interview about child or adolescent)]. Rotterdam: Department of Child and Adolescent Psychiatry, Erasmus MC.

Ferdinand, R. F., Van der Ende, J., & Verhulst, F. C. (2004). Parent-adolescent disagreement regarding psychopathology in adolescents from the general population as a risk factor for adverse outcome. *Journal of Abnormal Psychology, 113*, 198-206.

Finlay, W. M., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment, 13*, 319-335.

Flisher, A. J., Kramer, R. A., Grosser, R. C., Alegria, M., Bird, H. R., Bourdon, K. H., et al. (1997). Correlates of unmet need for mental health services by children and adolescents. *Psychological Medicine, 27*, 1145-1154.

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations, 46*, 359-371.

Foets, M., Cuperus, J., Spreeuwenberg, P., Verhaak, P., & Van Engeland, H. (1996). Weinig herkenning van psychische problemen bij kinderen door ouders en huisartsen [Little recognition of mental problems in children by parents and family physicians]. *Nederlands Tijdschrift voor Geneeskunde, 140*, 1907-1912.

Freedman, R. I., & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health and Social Work, 25*, 59-68.

Frick, P. J., Lahey, B. B., Loeber, R., Tannenbaum, L., Van Horn, Y., Christ, M. A. G., et al. (1993). Oppositional defiant disorder and conduct disorder: A meta-analytic review of factor analyses and cross-validation in a clinic sample. *Clinical Psychology Review, 13*, 319-340.

Garralda, M. E., & Bailey, D. (1988). Child and family factors associated with referral to child psychiatrists. *British Journal of Psychiatry, 153*, 81-89.

Goldberg, D., & Huxley, P. (1980). *Mental illness in the community: The pathway to psychiatric care*. London: Tavistock Publications.

Gullone, E., Cummins, R. A., & King, N. J. (1996). Self-reported fears: A comparison study of youths with and without an intellectual disability. *Journal of Intellectual Disability Research, 40*, 227-240.

Gunther, N., Slavenburg, B., Feron, F., & Van Os, J. (2003). Childhood social and early developmental factors associated with mental health service use. *Social Psychiatry and Psychiatric Epidemiology, 38*, 101-108.

Hall, I. (2000). Young offenders with a learning disability. *Advances in Psychiatric Treatment, 6*, 278-286.

Hanley, B., Tasse, M. J., Aman, M. G., & Pace, P. (2003). Psychometric properties and norms of the Family Needs Scale. *Journal of Child and Family Studies, 12*, 41-48.

Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability, 27*, 149-160.

Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry, 45*, 1338-1349.

Hawkins, J. D., Herrenkohl, T., Farrington, D. P., Brewer, D., Catalano, R. F., & Harachi, T. W. (1998). A review of predictors of youth violence. In R. Loeber & D. P. Farrington (Eds.), *Serious & violent juvenile offenders: Risk factors and successful interventions* (pp. 106-146). Thousand Oaks, CA: Sage Publications, Inc.

Hayden, M. F., & Goldman, J. (1996). Families of adults with mental retardation: Stress levels and need for services. *Social Work, 41*, 657-667.

Hazell, P. L., Tarren-Sweeney, M., Vimpani, G. V., Keatinge, D., & Callan, K. (2002). Children with disruptive behaviours II: Clinical and community service needs. *Journal of Paediatrics and Child Health, 38*, 32-40.

Heiman, T. (2001). Depressive mood in students with mild intellectual disability: Students' reports and teachers' evaluations. *Journal of Intellectual Disability Research, 45*, 526-534.

Hill, E., Berthoz, S., & Frith, U. (2004). Brief report: cognitive processing of own emotions in individuals with autistic spectrum disorder and in their relatives. *Journal of Autism and Developmental Disorders, 34*, 229-235.

Hoare, P., Harris, M., Jackson, P., & Kerley, S. (1998). A community survey of children with severe intellectual disability and their families: Psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research, 42*, 218-227.

Hodgins, S. (1992). Mental disorder, intellectual deficiency, and crime: Evidence from a birth cohort. *Archives of General Psychiatry, 49*, 476-483.

Holland, T., Clare, I. C., & Mukhopadhyay, T. (2002). Prevalence of criminal offending by men and women with intellectual disability and the characteristics of offenders: Implications for research and service development. *Journal of Intellectual Disability Research, 46 Suppl 1*, 6-20.

Hollingsworth, J. (1992). Service needs of children with disabilities and their families. *Journal of Paediatrics and Child Health, 28*, 283-285.

Holmbeck, G. N. (2002). Post-hoc probing of significant moderational and mediational effects in studies of pediatric populations. *Journal of Pediatric Psychology, 27*, 87-96.

Horwitz, S. M., Gary, L. C., Briggs-Gowan, M. J., & Carter, A. S. (2003). Do needs drive services use in young children? *Pediatrics, 112*, 1373-1378.

Jensen, P. S., Bloedau, L., & Davis, H. (1990). Children at risk: II. Risk factors and clinic utilization. *Journal of the American Academy of Child and Adolescent Psychiatry, 29*, 804-812.

Kasius, M. C., Ferdinand, R. F., Van den Berg, H., & Verhulst, F. C. (1997). Associations between different diagnostic approaches for child and adolescent psychopathology. *Journal of Child Psychology and Psychiatry, 38*, 625-632.

Kaufman, A. S., Kaufman, J. C., Balgopal, R., & McLean, J. E. (1996). Comparison of three WISC-III short forms: Weighing psychometric, clinical, and practical factors. *Journal of Clinical Child Psychology, 25*, 97-105.

Kenny, D. A., & Kashy, D. A. (1992). Analysis of the multitrait-multimethod matrix by confirmatory factor analysis. *Psychological Bulletin, 112*, 165-172.

Kinsman, A. M. (2001). Mother and child perceptions of child functioning: Relationship to maternal distress. *Family Process, 40*, 163-172.

Koot, H. M. (1997). *Handleiding bij de Vragenlijst voor Gezinsproblemen [Manual Questionnaire on Family Problems]*. Rotterdam: Department of Child and Adolescent Psychiatry, Sophia Children's Hospital, Erasmus University Rotterdam.

Koot, H. M., & Dekker, M. C. (2001). *Handleiding voor de VOG: Ouder- en leerkrachtversie [Manual VOG: Parent and Teacher version]*. Rotterdam: Department of Child and Adolescent Psychiatry, Sophia Children's Hospital, ErasmusMC.

Lahey, B. B., Schwab-Stone, M., Goodman, S. H., Waldman, I. D., Canino, G., Rathouz, P. J., et al. (2000). Age and gender differences in oppositional behavior and conduct problems: A cross-sectional household study of middle childhood and adolescence. *Journal of Abnormal Psychology, 109*, 488-503.

Laitinen-Krispijn, S., Van der Ende, J., Wierdsma, A. I., & Verhulst, F. C. (1999). Predicting adolescent mental health service use in a prospective record-linkage study. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*, 1073-1080.

Leaf, P. J., Alegria, M., Cohen, P., Goodman, S. H., Horwitz, S. M., Hoven, C. W., et al. (1996). Mental health service use in the community and schools: Results from the four-community MECA Study. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 889-897.

Lindsay, W. R., Michie, A. M., Baty, F. J., Smith, A. H., & Miller, S. (1994). The consistency of reports about feelings and emotions from people with intellectual disability. *Journal of Intellectual Disability Research, 38*, 61-66.

Linna, S. L., Moilanen, I., Ebeling, H., Piha, J., Kumpulainen, K., Tamminen, T., et al. (1999). Psychiatric symptoms in children with intellectual disability. *European Child and Adolescent Psychiatry, 8*, 77-82.

Lipsey, M. W., & Derzon, J. H. (1998). Predictors of violent or serious delinquency in adolescence and early adulthood: A synthesis of longitudinal research. In R. Loeber & D. P. Farrington (Eds.), *Serious & violent juvenile offenders: Risk factors and successful interventions* (pp. 86-105). Thousand Oaks, CA: Sage Publications, Inc.

Lo, Y., Mendell, N. R., & Rubin, D. B. (2001). Testing the number of components in a normal mixture. *Biometrika: a journal for the statistical study of biological problems, 88*, 767-778.

Loeber, R., & Hay, D. (1997). Key issues in the development of aggression and violence from childhood to early adulthood. *Annual Review of Psychology, 48*, 371-410.

Loeber, R., & Stouthamer-Loeber, M. (1998). Development of juvenile aggression and violence: Some common misconceptions and controversies. *American Psychologist, 53*, 242-259.

Logan, D. E., & King, C. A. (2001). Parental facilitation of adolescent mental health service utilization: A conceptual and empirical review. *Clinical Psychology, 8*, 319-333.

Logan, D. E., & King, C. A. (2002). Parental identification of depression and mental health service use among depressed adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*, 296-304.

Maes, B., Broekman, T. G., Dosen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research, 47*, 447-455.

Manikam, R., Matson, J. L., Coe, D. A., & Hillman, N. (1995). Adolescent depression: Relationships of self-report to intellectual and adaptive functioning. *Research in Developmental Disabilities, 16*, 349-364.

McCarthy, J., & Boyd, J. (2002). Mental health services and young people with intellectual disability: Is it time to do better? *Journal of Intellectual Disability Research, 46*, 250-256.

McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: The impact on families. *Journal of Intellectual Disability Research, 46*, 239-249.

Mojtabai, R., Olfson, M., & Mechanic, D. (2002). Perceived need and help-seeking in adults with mood, anxiety, or substance use disorders. *Archives of General Psychiatry, 59*, 77-84.

Morrissey-Kane, E., & Prinz, R. J. (1999). Engagement in child and adolescent treatment: The role of parental cognitions and attributions. *Clinical Child and Family Psychology Review, 2*, 183-198.

Moss, S., Bouras, N., & Holt, G. (2000). Mental health services for people with intellectual disability: A conceptual framework. *Journal of Intellectual Disability Research, 44*, 97-107.

Moss, S., Prosser, H., Ibbotson, B., & Goldberg, D. (1996). Respondent and informant accounts of psychiatric symptoms in a sample of patients with learning disability. *Journal of Intellectual Disability Research, 40*, 457-465.

Nadler, A., Lewinstein, E., & Rahav, G. (1991). Acceptance of mental retardation and help-seeking by mothers and fathers of children with mental retardation. *Mental Retardation, 29*, 17-23.

Nunnally, J. C., & Bernstein, I. R. (1994). *Psychometric theory 3rd ed*. New York: McGraw-Hill.

Offord, D. R., Boyle, M. H., Szatmari, P., Rae-Grant, N. I., Links, P. S., Cadman, D. T., et al. (1987). Ontario Child Health Study. II. Six-month prevalence of disorder and rates of service utilization. *Archives of General Psychiatry, 44*, 832-836.

Orr, R. R., Cameron, S. J., Dobson, L. A., & Day, D. M. (1993). Age-related changes in stress experienced by families with a child who has developmental delays. *Mental Retardation, 31*, 171-176.

Owens, P. L., Hoagwood, K., Horwitz, S. M., Leaf, P. J., Poduska, J. M., Kellam, S. G., et al. (2002). Barriers to children's mental health services. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*, 731-738.

Pakiz, B., Reinherz, H. Z., & Giaconia, R. M. (1997). Early risk factors for serious antisocial behavior at age 21: A longitudinal community study. *American Journal of Orthopsychiatry, 67*, 92-101.

Patterson, G. R., DeBaryshe, B. D., & Ramsey, E. (1989). A developmental perspective on antisocial behavior. *American Psychologist, 44*, 329-335.

Pavuluri, M. N., Luk, S. L., & McGee, R. (1996). Help-seeking for behavior problems by parents of preschool children: A community study. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 215-222.

Pescosolido, B. A., Gardner, C. B., & Lubell, K. M. (1998). How people get into mental health services: Stories of choice, coercion and "muddling through" from "first-timers". *Social Science & Medicine, 46*, 275-286.

Petr, C. G., & Barney, D. D. (1993). Reasonable efforts for children with disabilities: The parents' perspective. *Social Work, 38*, 247-254.

Pihlakoski, L., Aromaa, M., Sourander, A., Rautava, P., Helenius, H., & Sillanpaa, M. (2004). Use of and need for professional help for emotional and behavioral problems among preadolescents: A prospective cohort study of 3- to 12-year-old children. *Journal of the American Academy of Child and Adolescent Psychiatry, 43*, 974-983.

Poduska, J. M. (2000). Parent's perceptions of their first graders' need for mental health and educational services. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*, 584-591.

Quinn, K., Epstein, M. H., Cumblad, C., & Holderness, D. (1996). Needs assessment of community-based services for children and youth with emotional or behavioral disorders and their families: Part 2. Implementation in a local system of care. *Journal of Mental Health Administration, 23*, 432-446.

Redmond, C., Spoth, R., & Trudeau, L. (2002). Family- and community-level predictors of parent support seeking. *Journal of Community Psychology, 30*, 153-171.

Reiss, S., Levitan, G. W., & Szyskzo, J. (1982). Emotional disturbances and mental retardation: Diagnostic overshadowing. *American Journal on Mental Retardation, 86*, 567-574.

Rogler, L. H., & Cortes, D. E. (1993). Help-seeking pathways: A unifying concept in mental health care. *American Journal of Psychiatry, 150*, 554-561.

Rush, K. S., Bowman, L. G., Eidman, S. L., Toole, L. M., & Mortenson, B. P. (2004). Assessing psychopathology in individuals with developmental disabilities. *Behavior Modification, 28*, 621-637.

Sayal, K. (2004). The role of parental burden in child mental health service use: Longitudinal study. *Journal of the American Academy of Child and Adolescent Psychiatry, 43*, 1328-1333.

Sayal, K., Taylor, E., & Beecham, J. (2003). Parental perception of problems and mental health service use for hyperactivity. *Journal of the American Academy of Child and Adolescent Psychiatry, 42*, 1410-1414.

Sayal, K., Taylor, E., Beecham, J., & Byrne, P. (2002). Pathways to care in children at risk of attention-deficit hyperactivity disorder. *British Journal of Psychiatry, 181*, 43-48.

Schmitt, N., & Stults, D. M. (1986). Methodology review: Analysis of multitrait-multimethod matrices. *Applied Psychological Measurement, 10*, 1-22.

Scott, S., Knapp, M., Henderson, J., & Maughan, B. (2001). Financial cost of social exclusion: Follow up study of antisocial children into adulthood. *British Medical Journal, 323*, 191-193.

Shaffer, D., Fisher, P., Lucas, C. P., & Comer, J. (2000). *Scoring manual Diagnostic Interview Schedule for Children (DISC-IV)*. New York: Columbia University, New York State Psychiatric Institute.

Shaffer, D., Fisher, P., Lucas, C. P., Dulcan, M. K., & Schwab-Stone, M. E. (2000). NIMH Diagnostic Interview Schedule for Children Version IV (NIMH DISC-IV): Description, differences from previous versions, and reliability of some common diagnoses. *Journal of the American Academy of Child and Adolescent Psychiatry, 39*, 28-38.

Sheras, P. L., Abidin, R. R., & Konold, T. R. (1998). *Stress Index for Parents of Adolescents: Professional Manual*. Odessa, FL: Psychological Assessment Resources, Inc.

Sherrard, J., Tonge, B. J., & Ozanne-Smith, J. (2002). Injury risk in young people with intellectual disability. *Journal of Intellectual Disability Research, 46*, 6-16.

Simpson, M. K., & Hogg, J. (2001a). Patterns of offending among people with intellectual disability: A systematic review. Part I: Methodology and prevalence data. *Journal of Intellectual Disability Research, 45*, 384-396.

Simpson, M. K., & Hogg, J. (2001b). Patterns of offending among people with intellectual disability: A systematic review. Part II: Predisposing factors. *Journal of Intellectual Disability Research, 45*, 397-406.

Sourander, A., Helstela, L., Ristkari, T., Ikaheimo, K., Helenius, H., & Piha, J. (2001). Child and adolescent mental health service use in Finland. *Social Psychiatry and Psychiatric Epidemiology, 36*, 294-298.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Manual Vineland Adaptive Behavior Scales: Interview edition, survey form*. Circle Pines, MN: American Guidance Service.

Srebnik, D., Cauce, A. M., & Baydar, N. (1996). Help-seeking pathways for children and adolescents. *Journal of Emotional and Behavioral Disorders, 4*, 210-220.

Stiffman, A. R., Chen, Y. W., Elze, D., Dore, P., & Cheng, L. C. (1997). Adolescents' and providers' perspectives on the need for and use of mental health services. *Journal of Adolescent Health, 21*, 335-342.

Stiffman, A. R., Hadley Ives, E., Dore, P., Polgar, M., Horvath, V. E., Striley, C., et al. (2000). Youths' access to mental health services: The role of providers' training, resource connectivity and assessment of need. *Mental Health Services Research, 2*, 141-154.

Storvoll, E. E., & Wichstrom, L. (2002). Do the risk factors associated with conduct problems in adolescents vary according to gender? *Journal of Adolescence, 25*, 183-202.

Storvoll, E. E., & Wichstrom, L. (2003). Gender differences in changes in and stability of conduct problems from early adolescence to early adulthood. *Journal of Adolescence, 26*, 413-429.

Suarez, L. M., & Baker, B. L. (1997). Child externalizing behavior and parents' stress: The role of social support. *Family Relations, 46*, 373-381.

Teagle, S. E. (2002). Parental problem recognition and child mental health service use. *Mental Health Services Research, 4*, 257-266.

Thomasgard, M., & Metz, W. P. (1997). Parental overprotection and its relation to perceived child vulnerability. *American Journal of Orthopsychiatry, 67*, 330-335.

Thompson, R. (2005). The course and correlates of mental health care received by young children: Descriptive data from a longitudinal urban high-risk sample. *Children and Youth Services Review, 27*, 39-50.

Tonge, B. J., & Einfeld, S. E. (2003). Psychopathology and intellectual disability: The Australian child to adult longitudinal study. In L. M. Glidden (Ed.), *International*

Review of Research in Mental Retardation (Vol. 26, pp. 61-91). San Diego, CA: Academic Press.

Treneman, M., Corkery, A., Dowdney, L., & Hammond, J. (1997). Respite-care needs--met and unmet: Assessment of needs for children with disability. *Developmental Medicine & Child Neurology, 39*, 548-553.

Turnbull, A. P., & Ruef, M. (1996). Family perspectives on problem behavior. *Mental Retardation, 34*, 280-293.

Van den Borne, H. W., Van Hooren, R. H., Van Gestel, M., Rienmeijer, P., Fryns, J. P., & Curfs, L. M. G. (1999). Psychosocial problems, coping strategies, and the need for information of parents of children with Prader-Willi syndrome and Angelman syndrome. *Patient Education and Counseling, 38*, 205-216.

Van der Ende, J. (1999). Multiple informants: Multiple views. In H. M. Koot, A. A. M. Crijnen & R. F. Ferdinand (Eds.), *Child psychiatric epidemiology: Accomplishments and future direction* (pp. 39-52). Assen: Van Gorcum.

Van Minnen, A., Savelsberg, P. M., & Hoogduin, K. A. (1994). A Dutch version of the Psychopathology Inventory for Mentally Retarded Adults (PIMRA). *Research in Developmental Disabilities, 15*, 269-278.

Van Westerlaak, J. H., Kropman, J. A., & Collaris, J. W. M. (1975). *Beroepenklapper (Manual for occupational level)*. Nijmegen: Instituut voor Sociologie.

Verhulst, F. C., & Koot, H. M. (1992). *Child psychiatric epidemiology: Concepts, methods, and findings*. Thousand Oaks, CA, US: Sage Publications, Inc.

Verhulst, F. C., & Van der Ende, J. (1997). Factors associated with child mental health service use in the community. *Journal of the American Academy of Child and Adolescent Psychiatry, 36*, 901-909.

Verhulst, F. C., Van der Ende, J., Ferdinand, R. F., & Kasius, M. C. (1997). The prevalence of DSM-III-R diagnoses in a national sample of Dutch adolescents. *Archives of General Psychiatry, 54*, 329-336.

Verhulst, F. C., Van der Ende, J., & Koot, H. M. (1996). *Handleiding voor de CBCL/4-18 [Manual for the CBCL/4-18]*. Rotterdam: Department of Child and Adolescent Psychiatry, Sophia Children's Hospital, Erasmus University Rotterdam.

Verhulst, F. C., Van der Ende, J., & Koot, H. M. (1997a). *Handleiding voor de Teacher's Report Form (TRF) [Manual for the TRF]*. Rotterdam: Department of Child and Adolescent Psychiatry, Sophia Children's Hospital, Erasmus University Rotterdam.

Verhulst, F. C., Van der Ende, J., & Koot, H. M. (1997b). *Handleiding voor de Youth Self-Report (YSR) [Manual for the YSR]*. Rotterdam: Department of Child and Adolescent Psychiatry, Sophia Children's Hospital, Erasmus University Rotterdam.

Wahler, H. J. (1968). The Physical Symptoms Inventory: Measuring levels of somatic complaining behavior. *Journal of Clinical Psychology, 24*, 207-211.

Wallander, J. L., Dekker, M. C., & Koot, H. M. (2003). Psychopathology in children and adolescents with intellectual disability: Measurement, prevalence, course and risk. In L. M. Glidden (Ed.), *International Review of Research in Mental Retardation* (Vol. 26, pp. 93-134). San Diego, CA: Academic Press.

Wechsler, D. (1991). *Wechsler Intelligence Scale for Children- Revised.* San Antonio, TX: The Psychological Corporation.

Wells, J. E., Robins, L. N., Bushnell, J. A., Jarosz, D., & Oakley-Browne, M. A. (1994). Perceived barriers to care in St. Louis (USA) and Christchurch (NZ): Reasons for not seeking professional help for psychological distress. *Social Psychiatry and Psychiatric Epidemiology, 29*, 155-164.

Winter, N., Holland, A. J., & Collins, S. (1997). Factors predisposing to suspected offending by adults with self-reported learning disabilities. *Psychological Medicine, 27*, 595-607.

Witt, W. P., Kasper, J. D., & Riley, A. W. (2003). Mental health services use among school-aged children with disabilities: The role of sociodemographics, functional limitations, family burdens, and care coordination. *Health Services Research, 38*, 1441-1466.

Wiznitzer, M. (1993). *Het Young Adult Self Report project: De validiteit van een vragenlijst voor de herkenning en de beschrijving van psychopathologie bij jong volwassenen [The Young Adult Self Report Project. Phd. Thesis]*. University of Groningen, Groningen, the Netherlands.

Wu, P., Hoven, C. W., Bird, H. R., Moore, R. E., Cohen, P., Alegria, M., et al. (1999). Depressive and disruptive disorders and mental health service utilization in children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*, 1081-1190.

Wu, P., Hoven, C. W., Cohen, P., Liu, X., Moore, R. E., Tiet, Q., et al. (2001). Factors associated with use of mental health services for depression by children and adolescents. *Psychiatric Services, 52*, 189-195.

Yeh, M., McCabe, K., Hough, R. L., Dupuis, D., & Hazen, A. (2003). Racial/ethnic differences in parental endorsement of barriers to mental health services for youth. *Mental Health Services Research, 5*, 65-77.

Zahner, G. E., & Daskalakis, C. (1997). Factors associated with mental health, general health, and school-based service use for child psychopathology. *American Journal of Public Health, 87*, 1440-1448.

Zahner, G. E., Pawelkiewicz, W., DeFrancesco, J. J., & Adnopoz, J. (1992). Children's mental health service needs and utilization patterns in an urban community: an epidemiological assessment. *Journal of the American Academy of Child and Adolescent Psychiatry, 31*, 951-960.

Zima, B. T., Bussing, R., Yang, X., & Belin, T. R. (2000). Help-seeking steps and service use for children in foster care. *Journal of Behavioral Health Services & Research, 27*, 271-285.

Zwaanswijk, M., Verhaak, P. F., Bensing, J. M., Van der Ende, J., & Verhulst, F. C. (2003). Help seeking for emotional and behavioural problems in children and adolescents: A review of recent literature. *European Child and Adolescent Psychiatry, 12*, 153-161.

Summary
Samenvatting

Summary

In this thesis, the results are presented of a follow-up study on psychopathology in children with intellectual disabilities (ID) that started in 1996. That study, but also other studies showed that children and adolescents (i.e., youths) with moderate to borderline ID have a three to four fold increased risk for developing emotional and/or behavioural problems, or a psychiatric disorder (psychopathology). In addition, the sparsely available longitudinal studies showed that psychopathology in these youths with ID is quite persistent. Moreover, whilst the ID in itself is a serious handicap, when psychopathology is also present, this has even more critical consequences, not only for the youths themselves, but also for their parents and family. Professional help from mental health care services for these youths and their parents and family, therefore, seems imperative. However, only a minority of these youths receives mental health care. Several reasons might explain why these youths (and their parents and family) do not receive professional help. The main aim of this study was to explore the discrepancies between need for help and obtained help, and the role of the parents in this discrepancy, as they are often the ones that have to initiate the help-seeking process. More specifically, the key objectives of this study were to:

1. determine the objective and subjective need for mental health services,
2. identify determinants of objective and subjective need for help and help-seeking for mental health problems,
3. predict objective and subjective need from earlier adjustment, and
4. identify discrepancies between need for help and help obtained, and identify determinants of these discrepancies.

In 1996, a population-based sample of 1,615 children and adolescents (6-18 years old) was recruited through special education schools for children with mild ID (Moeilijk Lerende Kinderen) and children with moderate ID (Zeer Moeilijk Lerende Kinderen) in the province of Zuid-Holland. Of these children, 1,165 met the inclusion criteria and could be contacted in person, of which 982 parents filled out one of the two core instruments. More parents of children who attended a school for the moderate ID participated in this Phase 1 study than parents of children who attended a school for the mild ID. In 1999, 58% of the parents were requested to participate in Phase 2 of the study. Between October 2002 and January 2004 all parents who had in any way participated in Phase 1 (N=1,007) were located and asked to participate in Phase 3 of this study. Of these, 46 could not be located or personally contacted, but 749 agreed to participate (response rate = 77.9%). Significantly more parents participated whose child had attended a school for children with moderate ID, and had a deviant Child Behavior Checklist (CBCL) Total Problems score. Also, when the parents were of Dutch origin, not single, and had a higher socio-economic status and educational level, they more often participated.

Besides the parents, we also asked the youths themselves to participate since they were now old enough to participate, i.e., between 10-24 years (after their parents consented to contacting their child), and we asked the teacher or job coach/supervisor to fill out some questionnaires (only when both the parents and the 18^+-child gave their consent). Finally

638 of 819 eligible youths participated (response = 77.9%) and 515 teachers or job coaches (84.4% of 615).

In *Chapter 3,* we studied the first crucial step that parents have to 'take' to eventually seeking and obtaining help for their child's emotional and/or behavioural problems; recognising or being aware of their child's additional problems. When a child had emotional and/or behavioural problems, as indicated by the CBCL, or a psychiatric disorder, as indicated by the Diagnostic Interview Schedule for Children (DISC), we investigated the parents' subjective perception of these problems in their child. In addition, we studied the extent to which the parents' subjective perception of their child's emotional and behavioural problems coincided with the assessed or actual presence of these problems. Our results showed that when parents subjectively perceived (some) emotional or behavioural problems in their child, for about 70% the CBCL or the DISC-IV indicated these problems to be present, which implies that even relatively small parental concerns about their child's emotional or behavioural functioning should be taken seriously. On the other hand, when either CBCL or DISC indicated the actual presence of emotional and/or behavioural problems, 63.6% of the parents were *aware* of their child's psychopathology, but they were more often aware of behavioural than of emotional problems. Parental awareness of their child's psychopathology was most strongly correlated with prior experience with psychopathology in their child, worrying about and additional problems in and with their child, in themselves, and in the family. Measures to increase parental awareness should especially be aimed at parents of youths who do not draw much attention from their parents, i.e., youths who have not suffered from psychopathology before, whose parents have less worries about them, and who do not have additional problems. In addition, measures are especially needed to increase parental awareness of emotional problems.

In *Chapter 4*, we further explored the individual steps of the help-seeking process of parents for their child's emotional and/or behavioural problems besides the ID. More specifically, we studied the parents' (1) perception of emotional and/or behavioural problems in their child, (2) subsequent felt need for professional help, and (3) actual seeking of professional help. We found that 38.8% of the parents perceived these additional emotional and/or behavioural problems in their child. Subsequently, of those who perceived these problems, about two-thirds indicated a need for professional help, of whom 57.9% subsequently crossed the perceived barriers and sought professional help. The crossing of barriers was the biggest obstacle to eventually seeking professional help after the parents had perceived these additional problems. Parents were most likely to seek help when their child had problems of anxiety and depression, had experienced at least one negative life-event in the past two years, and when their child had psychopathology before the past year. Next to these factors, we also inquired about the parents' reasons for not seeking professional help, despite the fact that they had felt a need for it. Those parents' reasons predominantly related to their subjective evaluation of these problems (considering them not so serious, or as temporary), and not knowing where to find professional help. Apparently, perceiving problems and feeling a need for professional help does not imply actual help-seeking. Especially, the reasons for not seeking professional help provided valuable indications on how to increase actual help-seeking. It is important to inform these parents about the signs and symptoms of emotional and behavioural problems in a child or adolescent with ID and the negative prospects when these remain untreated. Furthermore, informing them about where what type of help is provided is also imperative.

Even though emotional and/or behavioural problems in a child or adolescent with ID frequently lead to high levels of parental stress and providing professional help is likely to reduce these stress levels, other types of help can (also) be needed the parents to regain their strengths. Therefore, in *Chapter 5* we explored the parents' subjective needs for support in the past year due to their child's emotional and/or behavioural problems, and the extent to which these needs were currently met. The vast majority of parents had needed some type of support, especially a friendly ear, respite care, child mental health care, and information. Parents who perceived both emotional and behavioural problems in their child, whose child had any of these problems before the past year, who worried most about their child, and who suffered from psychopathology themselves, more often needed support. The support needs of parents frequently remained unmet, especially the need for child mental health care, parental counselling, practical or material help, and activities. Service providers should therefore especially aim at providing these types of support.

Whereas the previous chapters concentrated on the parents' subjective need for help and the help-seeking pathway, *Chapter 6 and 7* were devoted to the assessment and predictors of the youths' objective need for help, respectively. In *Chapter 6*, we studied whether the Youth Self-Report (YSR) could be used to assess emotional and behavioural problems in 11 to 18-year-olds with ID. We compared the psychometric properties of the YSR in our sample with those in a sample of peers without ID. Our results showed that most youths with an IQ of 48 or higher were capable of answering the questions of the YSR in an interview. Overall, psychometric properties were similar across the samples, although to a somewhat lesser extent in the lower IQ group (IQ between 48 and 69). Thus, the YSR appears especially applicable for youths with mild to borderline ID, which allows them to contribute in the assessment of their emotional or behavioural problems.

In *Chapter 7*, we studied the prevalence, persistence, and five-year predictors of different types of antisocial and delinquent behaviours (ADBs) in youths with mild to borderline ID. Generally, each type of ADB was exhibited by 10% to 20%, with least prevalent the behaviours that might be perceived as the most serious, namely 'theft/arson' and 'property destruction'. Most prevalent was the type of ADB that might be considered as least serious, i.e., 'mean to others' (31.0%). All types of ADBs turned out to be fairly persistent over a five-year period of time. Compared with 11 to 18-year-old peers without ID, more boys with ID exhibited ADBs, but this was not found for girls.

Regarding the predictors of ADBs, above all, being a male, being between 6 and 11 years of age, and having behavioural problems predicted engaging in ADBs five years later. In addition, we found that those who exhibited one type of ADB were likely to also engage in other types of ADBs. Preventive measures should at least be targeted at 6 to 11-year-old boys who have higher levels of emotional and behavioural problems, and already display ADBs. General instruments, like the CBCL, Teacher's Report Form, and YSR can help to improve early detection of these problems and behaviours. Treatment of emotional and behavioural problems at an early age is recommended, as it might also prevent future ADBs or worse.

Finally, in Chapter 8, we discussed how we operationalised and investigated the key objectives of this study, discussed this study's main findings, strengths and limitations, we provided clinical implication and we gave suggestions for future research.

Samenvatting

In dit proefschrift staan de resultaten beschreven van een onderzoek dat een vervolg is op het onderzoek naar psychopathologie in kinderen en adolescenten (jongeren) met verstandelijke beperkingen (VB) dat gestart is in 1996. Dat onderzoek, maar ook andere onderzoeken lieten zien dat zwakbegaafde jongeren of jongeren met matige of lichte VB een drie tot vier keer verhoogd risico hebben op het ontwikkelen van emotionele en/of gedragsproblemen of een psychiatrische stoornis (psychopathologie). Daarnaast laten de weinige longitudinale onderzoeken op dit gebied zien dat psychopathologie in deze jongeren van redelijk blijvende aard is. Alhoewel de VB op zich al een serieuze handicap is, is dit nog ernstiger wanneer een jongere ook nog psychopathologie heeft. Dit heeft niet alleen negatieve gevolgen voor de jongere zelf, maar ook voor zijn ouders en het gezin. Professionele hulp voor deze jongeren en hun ouders en het gezin lijkt geboden. Echter, slechts een minderheid van deze jongeren krijgt professionele hulp. Verschillende redenen kunnen ten grondslag liggen aan het niet krijgen van professionele hulp door deze jongeren (en hun ouders en gezin). Het hoofddoel van dit onderzoek was om de discrepantie tussen de hulpbehoefte en het werkelijk krijgen van hulp te onderzoeken. Daarnaast is ook gekeken naar de rol van de ouders hierin, omdat zij vaak degenen zijn die het initiatief moeten nemen in het zoeken van hulp voor hun kind. De afzonderlijke doelen van deze studie waren:

1. het bepalen van de objectieve en subjectieve behoefte aan professionele hulp,
2. vaststellen van de determinanten van de objectieve en subjectieve behoefte aan hulp, en het feitelijk zoeken van hulp voor geestelijke gezondheidsproblemen,
3. het voorspellen van de objectieve en subjectieve hulpbehoefte, en
4. het vaststellen van de discrepanties tussen een hulpbehoefte en het krijgen van hulp, en het bepalen van de determinanten van deze discrepanties.

In 1996 is er een willekeurige steekproef getrokken van 1.615 kinderen en jongeren tussen de 6 en 18 jaar uit scholen voor Moeilijk Lerende Kinderen (MLK) en Zeer Moeilijk Lerende Kinderen (ZMLK) in Zuid-Holland. Van hen voldeden er 1.165 aan de inclusiecriteria en konden persoonlijk gecontacteerd worden, waarvan 982 ouders één van de twee hoofdinstrumenten hadden ingevuld. Meer ouders van kinderen van een ZMLK-school participeerden in Fase 1 van dit onderzoek dan ouders van kinderen van een MLK-school. In 1999 is 58% van de ouders gevraagd om mee te doen aan Fase 2. Tussen oktober 2002 en januari 2004 zijn alle ouders die op enigerlei wijze hadden meegedaan in Fase 1 (N=1.007) opgespoord en gevraagd om mee te doen aan Fase 3 van dit onderzoek. Het is uiteindelijk niet gelukt om 46 van de ouders te traceren of hen persoonlijk te spreken. In totaal deden 749 ouders mee (respons = 77,9%), waarvan significant meer ouders van ZMLK-jongeren, en van jongeren die een deviante Totale Probleem score hadden op de Child Behavior Checklist (CBCL). Ook Nederlandse, niet-alleenstaande ouders met een hoger opleidingsniveau en met een hogere socio-economische status participeerden vaker.

Behalve de ouders hebben we ook aan de jongeren zelf gevraagd of ze mee wilden doen (na toestemming van de ouders), omdat ze daar toen oud genoeg voor waren (tussen de 10-24 jaar), en we hebben de leerkracht of werkbegeleider gevraagd om een aantal

vragenlijsten in te vullen (na toestemming van zowel de ouders als de 18^+ jongeren). Uiteindelijk deden 638 van de 819 jongeren mee (respons = 77,9%) en 515 leerkrachten of werkbegeleiders (84,4% van 615).

In *Hoofdstuk 3* hebben we de eerste belangrijke stap onderzocht die ouders moeten 'nemen' om uiteindelijk hulp te zoeken en te krijgen voor de emotionele en/of gedragsproblemen van hun kind; het herkennen of zich bewust zijn van de bijkomende problemen in hun kind. Wanneer een kind emotionele en/of gedragsproblemen had volgens de CBCL of een psychiatrische stoornis volgens het Diagnostic Interview Schedule for Children (DISC), hebben we de subjectieve perceptie door ouders van deze problemen in hun kind onderzocht. Daarnaast hebben we onderzocht in hoeverre deze subjectieve perceptie van emotionele en/of gedragsproblemen in hun kind overeenkwam met de vastgestelde feitelijke aanwezigheid van deze problemen. Onze resultaten toonden aan dat wanneer ouders subjectief (enige) emotionele of gedragsproblemen waarnamen in hun kind, in ongeveer 70% de CBCL of de DISC de aanwezigheid van deze problemen ook aangaf. Dit betekent dat zelfs relatief kleine zorgen van ouders over het emotionele of gedragsmatige functioneren van hun kind serieus moet worden genomen. Andersom, als emotionele en/of gedragsproblemen waren vastgesteld door CBCL of DISC, waren 63,6% van de ouders zich bewust van de psychopathologie van hun kind, maar ze waren zich vaker bewust van gedragsproblemen dan van emotionele problemen. Het bewust zijn of herkennen van problemen door ouders hing vooral samen met eerdere ervaringen met psychopathologie in hun kind, het zorgen maken over hun kind, en bijkomende problemen in en met hun kind, in henzelf en in het gezin. Maatregelen om de bewustwording of herkenning van ouders te verbeteren, moeten vooral gericht zijn op ouders van jongeren die niet veel aandacht vragen van de ouders, d.w.z. jongeren die niet eerder psychopathologie hebben gehad, wiens ouders zich minder zorgen over hen maken, en die geen bijkomende problemen hebben. Daarnaast zijn er vooral maatregelen nodig die gericht zijn op het bevorderen van het herkennen van emotionele problemen door ouders.

In *Hoofdstuk 4* zijn we verder gegaan met het onderzoeken van de stappen of fasen van het hulpzoekproces van ouders voor de emotionele en/of gedragsproblemen van hun kind naast de VB. Meer specifiek, we hebben (1) de ouderlijke perceptie van emotionele en/of gedragsproblemen in hun kind, (2) de daaruit volgende behoefte aan professionele hulp, en (3) het werkelijk zoeken van professionele hulp onderzocht. We vonden dat 38,8% van de ouders deze bijkomende problemen in hun kind waarnamen. Vervolgens gaf ongeveer tweederde van deze ouders aan een behoefte aan professionele hulp te hebben, waarvan 57,9% vervolgens ook werkelijk professionele hulp had gezocht. Deze laatste stap bleek de grootste hindernis op de weg naar het uiteindelijk zoeken van professionele hulp nadat de ouders psychopathologie in hun kind hadden waargenomen. Ouders waren het meest geneigd om hulp te zoeken wanneer hun kind angst- of depressieve problemen had, minimaal één negatieve levensgebeurtenis had meegemaakt in de afgelopen twee jaar, en wanneer hun kind psychopathologie had vòòr het afgelopen jaar. Behalve deze factoren hebben we de ouders ook nog gevraagd naar hun redenen voor het niet zoeken van professionele hulp, terwijl ze daar wel een behoefte aan hadden. Hun redenen waren met name gerelateerd aan hun visie op deze problemen (niet zo groot, of tijdelijk), en aan het niet weten waar ze professionele hulp konden vinden. Blijkbaar betekent het waarnemen van problemen en het hebben van een behoefte aan professionele hulp niet dat ouders daadwerkelijk hulp gaan zoeken. Met name de redenen voor het niet zoeken van professionele hulp leveren belangrijke aanwijzingen op hoe het hulp zoeken verbeterd kan worden. Het is belangrijk dat ouders geïnformeerd worden over de signalen van emotionele of gedragsproblemen in een kind of jongere met een VB en de negatieve vooruitzichten als deze niet behandeld worden. Ook is het belangrijk om ouders te informeren over waar welke hulp geboden wordt.

Ondanks het feit dat emotionele en/of gedragsproblemen in een jongere met een VB vaak tot veel ouderlijke stress leiden en dat professionele hulp deze stress waarschijnlijk zal verminderen, kunnen andere vormen van hulp (ook) noodzakelijk zijn om de ouders weer op adem te laten komen of hen bij te laten tanken. Daarom hebben we in *Hoofdstuk 5* de subjectieve hulpbehoeften van ouders als gevolg van de emotionele en/of gedragsproblemen van hun kind onderzocht, en de mate waarin de ouders ook die hulp kregen. De overgrote meerderheid van de ouders had in het afgelopen jaar behoefte gehad aan een vorm van hulp, met name een luisterend oor, opvang, hulpverlening voor het kind, en informatie. Ouders die zowel emotionele als gedragsproblemen waarnamen in hun kind, wiens kind deze problemen vòòr het afgelopen jaar had, die de meeste zorgen over hun kind hadden, en die zelf psychopathologie hadden, hadden vaker hulp nodig. Deze hulpbehoeften van ouders bleven vaak onbeantwoord, met name in het geval van de behoefte aan hulpverlening voor het kind, hulpverlening/begeleiding voor de ouders, praktische of materiële hulp en activiteiten. Hulpverleningsinstanties moeten zich met name richten op het aanbieden van deze vormen van hulp.

Waar de vorige hoofdstukken zich richtten op de subjectieve hulpbehoefte van ouders en het hulpzoekproces, zijn Hoofdstuk 6 en 7 respectievelijk gewijd aan de vaststelling en voorspellers van de objectieve hulpbehoefte van jongeren. In *Hoofdstuk 6* hebben we onderzocht of de jongerenversie van de Gedragsvragenlijst voor kinderen (Youth Self-Report, YSR) gebruikt kon worden om emotionele en gedragsproblemen vast te stellen in 11 tot 18-jarigen met een VB. We hebben de psychometrische kwaliteiten van de YSR in onze onderzoeksgroep vergeleken met die van leeftijdsgenoten zonder VB. Onze resultaten toonden aan dat de meeste jongeren met een IQ van 48 of hoger in staat waren om de vragen van de YSR te beantwoorden in een interview. Over het algemeen waren de psychometrische kwaliteiten vergelijkbaar in de onderzoeksgroepen, zij het in iets mindere mate voor de jongeren met een lager IQ (IQ tussen 48 en 69). De YSR lijkt dus met name bruikbaar te zijn voor zwakbegaafde jongeren of met een lichte VB, wat hen in staat stelt om een bijdrage te leveren in de vaststelling van hun emotionele en/of gedragsproblemen.

In *Hoofdstuk 7* hebben we de prevalentie, persistentie en de 5-jaars-voorspellers van verschillende vormen van antisociaal en delinquent gedrag (ADG) onderzocht in zwakbegaafde jongeren en jongeren met lichte VB. Over het algemeen werd iedere vorm van ADG door 10 tot 20% vertoond, waarvan het minst die gedragingen die als meest serieus kunnen worden beschouwd, namelijk ‘diefstal/brandstichting’ en ‘vernielen van eigendommen’. Het meest vertoond werd de vorm van ADG die als minst ernstig zou kunnen worden beschouwd, namelijk ‘gemeen naar anderen’ (31,0%). Alle vormen van ADG bleken van tamelijk blijvende aard te zijn in een periode van zes jaar. Vergeleken met 11 tot 18-jarige leeftijdsgenoten zonder VB vertoonden meer jongens met VB ADGs, maar dit was niet het geval voor meisjes.

Wat betreft de voorspellers van ADGs, vooral het zijn van het mannelijke geslacht, tussen de 6 en 11 jaar, en het hebben van gedragsproblemen voorspelden ADG vijf jaar later. Daarnaast bleek dat degenen die een bepaalde vorm van ADG vertoonden, ook het meest geneigd waren om andere vormen van ADG te laten zien. Preventieve maatregelen zouden op z'n minst gericht moeten zijn op 6 tot 11-jarige jongens die meer of een hoger niveau van emotionele en gedragsproblemen hebben, en al ADGs vertonen. Instrumenten zoals de CBCL, Teacher's Report Form en YSR kunnen bijdragen aan de vroegtijdige onderkenning van deze problemen en gedragingen. Behandeling van emotionele en gedragsproblemen op een vroege leeftijd is aanbevolen, omdat het ook toekomstige ADGs of nog ernstigere gedragingen kan voorkomen.

Tot slot, in *Hoofdstuk 8* hebben we aandacht besteed aan de wijze waarop we de afzonderlijke doelen van dit onderzoek hebben geoperationaliseerd en onderzocht en hebben we de belangrijkste resultaten, de kracht en beperkingen van dit onderzoek besproken en hebben we aanbevelingen gedaan ten behoeve van de klinische praktijk en hebben we suggesties gedaan voor toekomstig onderzoek.

Dankwoord
Curriculum Vitae

Dankwoord

Er zijn verschillende mensen die direct of indirect een belangrijke bijdrage hebben geleverd aan het onderzoek en de totstandkoming van dit proefschrift die ik hiervoor graag zou willen bedanken.

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En nu verheug ik me enorm op de komende tijd. Genoeg leuke dingen in het verschiet!

Curriculum Vitae

Jolanda Cornelia Helena Douma werd geboren op 3 september 1970 te De Lier. In 1988 behaalde zij haar VWO-diploma aan het Interconfessioneel Westland College te Naaldwijk. Tussen augustus 1988 en december 1991 volgde en voltooide zij de inservice-opleiding tot Z-verpleegkundige op Het Westerhonk te Monster. Tussen 1992 en 1998 is zij zowel fulltime als parttime werkzaam geweest als Z-verpleegkundige (Eerste Verantwoordelijke Groepsbegeleider) op verschillende woongroepen voor mensen met een verstandelijke beperking op Het Westerhonk. Vanaf september 1992 studeerde zij Orthopedagogiek aan de (Rijks)Universiteit Leiden, waar zij in oktober 1996 het doctoraal examen behaalde. Haar afstudeerscriptie had als onderwerp ‘De gevolgen van het ouder worden van mensen met een verstandelijke handicap’, en werd begeleid door Dr. J. Hoekman (UL / Gemiva-SVG Groep).

Tussen februari en november 1997 was zij aangesteld als junior-onderzoeker aan de afdeling Orthopedagogiek van de Universiteit Leiden waar zij een literatuurstudie verrichtte naar seksueel misbruik en verstandelijke handicap. Dit resulteerde in 1998 in de publicatie van een boek met dezelfde titel in de Orthoreeks, uitgegeven door Lemniscaat te Rotterdam. In 1998 verrichtte zij binnen hetzelfde project een deelstudie naar de afhandeling van zedenzaken, waarin mensen met een verstandelijke handicap als slachtoffer of als dader betrokken waren, door politie en justitie. Dit resulteerde in 1999 in de publicatie ‘Zedenzaken en verstandelijk gehandicapten’ uitgegeven door DSWO Press te Leiden (P.M. van den Bergh als eerste auteur). Beide onderzoeken werden begeleid door Dr. P.M. van den Bergh en Dr. J. Hoekman.

Vanaf januari 1999 tot oktober 2001 werkte zij als wetenschappelijk functionaris op het Bisschop Bekkers Instituut te Utrecht (thans LKNG/NIZW) alwaar zij onderzoek verrichtte naar uiteenlopende onderwerpen rondom de zorgverlening aan mensen met een verstandelijke beperking. Tussen maart 2000 en oktober 2001 werkte zij één dag in de week als coördinator van het Expertisecentrum Seksueel Misbruik Zorgsector Zuid-Holland (thans ondergebracht bij het Consulententeam te Gouda).

Vanaf oktober 2001 tot december 2005 was ze als assistent in opleiding (AIO/promovenda) verbonden aan de Erasmus Universiteit Rotterdam en deed zij binnen de afdeling Kinder- en Jeugdpsychiatrie van het Erasmus MC-Sophia (Hoofd: Prof.dr. F.C. Verhulst) onderzoek naar de hulpbehoefte en het hulpzoekproces van ouders van jongeren met een verstandelijke beperking en psychopathologie (projectleiders: Prof. Dr. F.C. Verhulst en Prof. Dr. J.M. Koot, en onder (dagelijkse) begeleiding van Dr. M.C. Dekker). De resultaten van dit onderzoek staan beschreven in dit proefschrift.

Vanaf januari 2006 is zij werkzaam als wetenschappelijk onderzoeker binnen het Parnassia Addiction Research Centre (PARC) te Den Haag.