Psychopathology in Children with Intellectual Disability:

Assessment, prevalence and predictive factors

Psychopathologie bij Kinderen met Verstandelijke Beperkingen:

Vaststelling, prevalentie en voorspellende factoren

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Promotiecommissie:

Promotor: Prof.dr. J.M. Koot

Overige leden: Prof.dr. H. Evenhuis
                  Prof.dr. M.W. Hengeveld
                  Prof.dr. F.C. Verhulst

Paranimfen:

Annette de Gast
Peggy Kalkhoven

Man did not weave the web of life;
he is merely a strand in it.
Whatever he does to the web,
he does to himself.

Attributed to Seattle, chief of the Suquamish (1854).

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Introduction

This study's main focus is psychopathology in children and adolescents with intellectual disability (ID). The main topics addressed in this study are the assessment of psychopathology in children (also including adolescents) with ID, the prevalence and impact of psychopathology in children with ID, and associated risk factors.

The present study is an epidemiological study. In short, epidemiological studies are concerned with the study of patterns of disease occurrence in human populations, and with the factors that influence those patterns. Epidemiological research is empirical by nature, involves quantification of relevant factors, is probabilistic, and uses the method of comparison as a basic tool (Verhulst, 1995).

The number of studies addressing the epidemiology of psychopathology in children with ID is limited, though it has increased in the last decade. Few systematic studies on the relationship between ID and psychopathology in children exist. Theoretical considerations and empirical findings suggest that children with ID are at higher risk than children without ID for developing psychopathology. Further, several other issues hamper our understanding of the subject, such as the use of different definitions for both ID and psychopathology, the lack of standardized assessment procedures, and the use of not so representative samples.

In this chapter we will discuss some of the major issues in this research-field. Further, we will account for the choices made in this study in an effort to provide good quality data on the epidemiology of psychopathology in children with ID. First, we will discuss some issues concerning the definition of ID, the prevalence of ID, and its possible causes. Second, different approaches to define psychopathology are addressed, instruments are reviewed, and this study's approach is described. Thirdly, the prevalence of psychopathology, and previous empirical findings on the increased risk of psychopathology in children with ID compared to non-ID children will be discussed. Fourth, we will discuss previous findings on important correlates and risk factors of psychopathology in children with and without ID. We will end this chapter with the formulation of the major aims of this study.

Intellectual disability

In this part, we will discuss some issues concerning the definition of ID and borderline intellectual functioning, and problems related to the estimation of the prevalence of ID. We will end with a short description of possible causes of ID.

Defining ID

The terminology used to describe people with deficits in intellectual functioning has varied over time. Terms like 'idiot', 'imbecile', 'mentally retarded', 'learning disabled', and 'intellectually disabled' were or are used to characterize people with cognitive impairments. It seems to be an ongoing challenge to find labels that are less stigmatizing. In the past 10 years more and more the term 'intellectually disabled' is being used in the international community, and so this is the phrase we will use in the present study.

In the field of ID, there is a controversy about whether a sub-average IQ should be the cornerstone of the definition of ID or whether adaptive functioning should be the main focus (King, State, Shah, Davanzo, & Dykens, 1997). Since there is no uniform and defined etiology, or course, underlying the deficits in intellectual functioning in this heterogeneous group, the definition of ID is based on an arbitrary IQ cut-off point below which people are

considered to have ID. In most epidemiological studies, ID is defined as having a sub-average IQ of two standard deviations below the mean (IQ<70) with an standard error of ±5 points, and with an onset before age 18 (Einfeld & Tonge, 1996a; Koller, Richardson, Katz, & McLaren, 1982; Linna et al., 1999; Rutter, Tizard, & Whitmore, 1970). The generally accepted sub-classifications of ID are defined such that about 85% of those with ID are estimated to have mild ID (IQ between 50 and 70), about 10% to have moderate ID (IQ between 35 and 50), about 4% to have severe ID (IQ between 20-35), and less than 1% to have profound ID (IQ below 20) (American Psychiatric Association, 1994; Scott, 1994).

The definition of ID proposed by the American Association on Mental Retardation (AAMR; American Association on Mental Retardation, 1992) includes the presence of a sub-average IQ in combination with concurrent deficits or impairments in adaptive functioning in at least two out of ten areas of functioning (e.g. social functioning, communication, self-care, leisure, functional academic skills, use of community resources). The definition of ID by the American Psychiatric Association (APA), as stated in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994), also includes both IQ and adaptive functioning.

We agree that adaptive skills are important indicators of present and future success in life. However, deviant adaptive functioning can be a result of ID, as well as of physical disability or psychopathology, and therefore including deviant adaptive functioning in the definition of ID while studying psychopathology is somewhat problematic. Furthermore, there is no empirical basis for the selection of the ten areas of adaptive functioning, and instruments assessing all these areas are lacking. Therefore, to learn more about all people with ID, this study assesses adaptive functioning as an independent factor, rather than a defining characteristic, and uses low intellectual functioning to define ID. This definition also ensures that we are consistent with the majority of the research that we cite. Whether ID, mental retardation, or some other term has been used, most of the studies on psychopathology in this population have not assessed or otherwise documented deficits in adaptive functioning in their samples. Rather, most samples were defined solely by an IQ criterion.

Borderline intellectual functioning

Another issue is whether or not to include children with borderline intellectual functioning (defined as having an IQ between 71 and 84) in studies on psychopathology in children with ID. Although these children are not intellectually disabled according to the IQ criterion, they are also a vulnerable group with limited cognitive and social functioning skills, who are likely to be needing special support during their lives (e.g. special education, social work to assist with finances).

In general population studies on the psychopathology of children in the Netherlands, children receiving special education, including those who attend schools for the educable (IQ between 60 and 80), are often excluded (Verhulst, Berden, & Sanders-Woudstra, 1985). Furthermore, when we started the present study in 1996, many children with borderline intellectual functioning and mild ID in the Netherlands both attended the same type of school, i.e. a school for the educable.

Even though an IQ between 60 and 80 is used as a selection criterion to enter a Dutch school for the educable, only for a small majority of the children in the present study could reliable, well-administered, and recent (less than 5 years old) IQ scores be retrieved. Furthermore, practical and financial limitations prevented us from administering IQ tests ourselves.

In the Netherlands, children with an IQ score between 30 and 60 attend a school for the trainable. In the case of lower IQ scores or severe additional physical or sensory disabilities, children are likely to visit a day-care center for the ID (see also page 6 of this Chapter). Children with an IQ between 60 and 80, as previously mentioned, attend a school for the educable. The Dutch educational and day-care system gave us the opportunity to access a large majority of our target sample within a broad definition of ID, including children with borderline intellectual functioning. We decided to use educational level as proxy for intellectual functioning in the present study. In Chapter 2 we will further describe the present study's sample composition.

Estimating the prevalence of ID

Estimates of the prevalence of ID from international studies range from 1% to 3% in developed countries (Hodapp & Dykens, 1996). If we translate these results to the Netherlands, this would mean that about 40,000 to 120,000 0- to 19 year-olds are ID.

This wide range of prevalence of ID is not only caused by definition problems (e.g. including adaptive skills will lower prevalence estimates), but also by identification problems. For example, in the USA the number of people receiving special services often determines the prevalence of ID. Regulations regarding these special services vary, however, from state to state (King et al., 1997). In addition, it is hard to make an accurate estimation of the number of pre-school children with mild ID and borderline intellectual functioning, because their sub-average functioning often goes undetected until they start school.

In this study we selected the participants through schools for the educable and trainable, and through day-care centers for the ID, regardless of whether the children received any other specialized services for the ID (see Chapter 2 for further description of sampling frame and study design). When we started this study in 1996, about 40,000 6- to18-year-olds attended a school for the educable, about 10,500 a school for the trainable, about 4,500 of the 0- 19-year-olds visited a daycare center for the ID in the Netherlands. About 3,800 children attended a school for the multiple handicapped (Central Bureau for Statistics, 2001). Though no exact numbers are available, few children with ID were expected to attend a school for the sensory or physically disabled or for the chronically ill. In addition, few children with ID (about 500) were expected to attend regular schools in the Netherlands in those days (Scheepstra, Pijl, & Nakken, 1992). Almost 5,000 0- to 19-year-olds resided away from home in special houses and institutions for the ID (Central Bureau of Statistics, 2001). Assuming that at least 1% of the 0- to 4-year-olds who live at home have ID, and that about 50% of the educable children have an IQ below 70, we can cautiously conclude that *at least* about 45,800 of all 3,772,000 0– to 19-year-olds in 1996 were ID in the Netherlands (1,2%).

Possible causes of ID

In general two groups of ID are specified: children with familial ID and children with organic ID. In more recent years, further differentiation of organic ID into many different etiological groups (e.g. Down's syndrome, Fragile-X syndrome, Prader-Willi syndrome) has been advocated in various research studies (Dykens, 2000; Flint & Yule, 1994; Hodapp & Zigler, 1995).

Children with familial ID show no clear organic cause for their ID, and constitute the lower tail of the Gaussian distribution of intelligence. Their ID is likely due to both polygenic and environmental factors. Children with familial ID are more likely to come from families with lower socio-economic status, and to have parents with relatively lower IQ or educational

level (e.g. Hodapp, Burack, & Zigler, 1998). These children function for the most part in the mild to moderate ID range and account for somewhat over 50% of all children with ID. In general, children with familial ID are more similar in characteristics, behaviors, and personality patterns to children without ID than they are to children with severe or profound ID.

Children with organic ID, show at least one of many possible causes of ID. In 1992, the AAMR offered a listing of more than 350 causes, while others count over 500 genetic causes alone (King et al., 1997). Influences can be prenatal, perinatal, and postnatal, but are not necessarily known to the parents or caregivers. The range of functioning varies greatly in this group, although the majority will have severe to profound ID. Three basic etiological categories can help to describe groupings of possible causes of ID (Szymanski & Kaplan, 1997, p. 187):

1. Prenatal errors in morphogenesis of the central nervous system (CNS), including malformations (e.g. Down's syndrome, Fragile X syndrome, neural tube defects, Prader-Willi syndrome), and disruptions to the developing CNS (e.g. fetal alcohol syndrome, toxoplasmosis, rubella)
2. Alterations in the intrinsic biological environment of an individual such that the function of the CNS is also altered (e.g. enzyme deficiencies like phenylketonuria)
3. Extraordinary extrinsic influences, resulting in a drastic change in mental functioning (e.g. hypoxia, trauma, poisoning, meningitis)

As a large majority of the children in the present study were expected to function in the mild to moderate ID range, and to have familial ID or ID without known organic cause, we did not differentiate according to etiology of ID, although in our study several causes of ID (e.g. Down's syndrome, Fragile-X syndrome) were identified (see Chapter 2, and Chapters 4 to 7).

Psychopathology in children with ID

Psychopathology in children with ID may have a major effect on their personal well-being, academic functioning, social functioning, and on their personal independence, as well as on their family and on other caregivers. The co-occurence of ID and psychopathology can also give rise to further stigmatization, prejudices, and misunderstandings over and above the presence of ID alone, which may decrease the likelihood of full integration in society.

In the next paragraphs we will consider evidence on the association between general ID and overall psychopathology. We will discuss in turn, issues concerning the definition and assessment of psychopathology in children with ID, the instruments available for the assessment and diagnosis, findings regarding prevalence of psychopathology in children with ID, and their increased risks compared to non-ID children. We refer to Dykens (2000) and Flint and Yule (1994) for discussions of the emerging literature on specific psychopathologies associated with specific syndromes or diagnoses.

Defining psychopathology

As is the case with the definition of ID, the terminology used to describe psychopathology varies. Terms such as psychiatric or behavior disorder, mental illness or mental health problems, and emotional and behavior problems are used. Regardless of terminology, these problems need to be operationally defined to make interpretation of study results possible and allow comparisons between studies.

To achieve an operational definition of psychopathology we need to distinguish between two elements of the diagnostic process: assessment and taxonomy (Achenbach, 1995; Verhulst & Koot, 1992). Assessment involves the instruments and procedures for measuring distinguishing features of individual cases, such as children's manifest behavioral and emotional functioning. The results of assessment may be expressed in different ways, such as with continuous scales or discrete categories.

Taxonomy is the grouping of cases meeting some criteria according to their distinguishing features, such as specific symptoms or problems, symptom aggregates, syndromes, functional disorders, or etiological factors. Using reliable and valid assessment tools and valid taxonomic constructs, cases may be grouped or classified according to their common features. Diagnosis in the narrow sense can be regarded as the medical term for classification into a specific taxonomy. However, diagnosis in the broader sense involves a formulation of the nature and possible etiology of an individual's problems.

Two main approaches to assessment and taxonomy have dominated the theory and practice in psychopathology: the clinical-medical and the psychometric-empirical approach.

Clinical-medical approach to psychopathology

The clinical-medical assessment tradition seeks syndromes of signs and symptoms to distinguish between disorders expected to have distinctive organic etiologies and course. The principles of this approach have shaped nosological systems covering the majority of child psychiatric conditions such as the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) and the International Classification of Diseases (ICD-10; World Health Organization, 1992). These classification systems are characterized by diagnostic categories that include listings of symptoms that are scored as "present" versus "absent" for each child. A child is assigned a formal diagnosis if he/she meets its criteria, including a required number of symptoms present during a certain amount of time, and excluding certain confounding conditions.

The application of these classification systems in the general population of children has some difficulties, including lack of empirical evidence for their distinctive categories, rather loosely defined criteria, and lack of specification of assessment procedures to obtain the required diagnostic information (Verhulst & Koot, 1992). In addition, although most childhood onset disorders contain the criterion that only behaviors inappropriate for the child's age should be regarded as symptoms, no guidelines are given for how to account for age, let alone for differences in development among children. This problem is accentuated in children with ID, who follow a slower or different developmental course that varies considerably among individuals with ID.

The application of the DSM and ICD systems is further complicated in children with ID in several manners. First, these children are less likely to be able to report on their own experiences and feelings, making it desirable to use parents and teachers as important sources of information (Dykens, 2000). However, the proxy procedure has its own set of issues (Achenbach, 1995; Cummins, 2002). Second, confounding factors associated with both psychopathology and ID can make it difficult to decide whether certain behaviors are due to one or the other, referred to as diagnostic overshadowing (Borthwick-Duffy, 1994; Lovell & Reiss, 1993). Furthermore, children with ID may show deviant behaviors that are seldom reported for children without ID, such as self-absorbed behaviors (e.g. stereotypic behavior, self-injurious behavior), communication disturbances (e.g. echolalia, confusing pronouns), and social relating problems (e.g. avoiding eye contact, not showing affection) (Einfeld &

Aman, 1995; Einfeld & Tonge, 1995). Because of these qualitative symptom differences, there is an added value in using instruments specifically designed for children with ID rather than instruments designed for children in general. However, direct comparisons with children from the general population are then no longer possible, eliminating a valuable point of reference, particularly when studying children with mild ID.

Although several standardized DSM-based (semi-)structured interviews have been developed for use with children and adolescents (e.g. Angold & Costello, 2000; Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000), their applicability to children even with mild ID may be complicated. People with ID have limited ability to express abstract thoughts and feelings, and to answer questions about the onset, duration, frequency, and severity of symptoms, and in addition they show acquiescence bias to interview questions (Heal & Sigelman, 1995). These difficulties have led some to adapt the standard DSM and ICD criteria for use with ID (King, DeAntonio, McCracken, Forness, & Ackerland, 1994; Szymanski & King, 1999). Others have designed interview schedules specifically for this population, including the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD or Mini-PAS-ADD; Moss et al., 1997; Moss, Prosser, & Goldberg, 1996). Moss et al. (1996) showed that direct interviews with both adults with ID and their caregiver informants using these schedules ID reduced missed diagnoses. However, we are not aware of an adapted interview schedule for children with ID.

In this study we chose to only assess the presence of a DSM-IV disorder through an interview with the parent or caregiver. Although this study has a sample where the majority of children function in the borderline to mild ID ranges, this approach might still be somewhat questionable. For example, a greater degree of inference on the part of the parent may be needed as symptoms and signs of psychiatric disorders are more likely to be expressed in a somewhat altered fashion. However, we agree with Sturmey (1995) when he emphasizes the importance of initially using these classification systems in an unmodified way, because to date many modifications are still quite ad hoc, not always clearly operationalized, and make it harder to compare across studies. We believe that it is important to start investigating psychopathology in children with ID by using a common and well-known vocabulary to describe these phenomena which ensures clarity and comparability across studies.

Psychometric-empirical approach to psychopathology

The alternative approach to the assessment of psychopathology is the psychometric-empirical approach, and it does address some of the issues just discussed regarding the clinical-medical approach. However, this approach has its own concerns. The psychometric-empirical approach is characterized by the use of rating scales comprising a broad range of problem behaviors that can be completed by parents, caregivers, teachers, clinicians, or the children themselves. Continuous syndrome scales derived through multivariate statistical analysis allow comparisons of an individual child's scores to those of normative groups in different problem areas and of sex- and age-mates. Scale scores are typically more useful in scientific research because they retain more statistical information than present versus absent categories. This enables their application as more sensitive outcome measures in treatment studies. In addition, they enhance the empirical search for valid diagnostic constructs without the premature closure that is inherent in the diagnostic classification systems.

Several instruments for children with ID have been developed during the last decade (see Aman (1991) for an earlier review) including the Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1994), the Aberrant Behavior Checklist (Aman, Singh, Stewart, &

Field, 1985a; Freund & Reiss, 1991) the Developmental Behaviour Checklist (Einfeld & Tonge, 1992; Einfeld & Tonge, 1995), and the Nisonger Child Behavior Rating form (Aman, Tasse, Rojahn, & Hammer, 1996; Tassé, Aman, Hammer, & Rojahn, 1996). These instruments will be reviewed in detail in a later section. They include behavioral and emotional symptoms typically seen in children with ID that are organized into syndrome scales based on empirical analyses. Good reliability and validity have been demonstrated for several of these instruments, and for some, norm-scores have been determined. In addition, instruments developed for typically-developing children, such as the Child Behavior Checklist and Teacher's Report Form (Achenbach, 1991a, 1991b), can be of value in asessing children with mild and moderate ID (Frison, Wallander, & Browne, 1998; Linna et al., 1999). Children in this range of ID display, for the most part, behavior and function like typically developing children.

Psychometric instruments have enhanced our understanding of psychopathology in children with ID. Several factors tend to recur with considerable consistency across the five aforementioned empirically-derived instruments assessing emotional and behavioral problems in children and adults with ID: (a) Aggressive, Antisocial, Self-Injurious behavior, (b) Withdrawn behavior, (c) Stereotypic behavior, and (d) Hyperactivity. In addition, (e) Repetitive verbalizations, (f) Anxious, Tense, Fearful behavior, and (g) Self-Injurious behavior tended to emerge also, but with less consistency (Aman, 1991). However, these psychometric instruments still tend to differ in item composition and syndrome scales and they are not attuned to DSM-IV or ICD-10 diagnostic categories. Therefore, the relationship of the instruments to these classification systems and to each other needs to be carefully tested. We need to avoid the situation where identification of psychopathology becomes instrument-specific, making comparisons across studies difficult (Borthwick-Duffy, 1994).

As none of the approaches mentioned above can be regarded as the "gold standard" in the assessment of psychopathology in children in general, and in children with ID in particular, this study incorporated instruments from both the clinical-medical approach (i.e. DSM-IV parental interview) and the psychometric approach. Being able to study the relationship between the various instruments is a clear advantage of this approach. In addition, we used instruments to assess psychopathology of which one was developed for children from the general population, and one was specifically designed for children with ID, and then we studied their applicability (see Chapter 2 to 5).

Confounding factors of ID and psychopathology

The identification of ID and psychopathology can be confounded by the characteristics of each condition. For example, psychopathology can suppress a child's score on an intelligence test, and might consequently cause false classification of ID.

Another problem is that of 'diagnostic overshadowing', that is, problem behaviors are viewed as part of the ID. For example, communication deficits can make it harder to decide whether abnormal behavior is due to psychiatric disorder, because of brain damage with associated ID or because of other factors (Borthwick-Duffy, 1994). It can be difficult to judge whether highly frequent problem behaviors in the ID, such as concentration problems, impulsiveness, are part of normal development or not (Holland & Koot, 1998). Reiss, Levitan, and Szyszko (1982) found that individuals with ID were less likely to receive a psychiatric diagnosis then those without ID, while experiencing identical behavioral symptoms. This

underscores the importance of studying non-referred children with ID, and using standardized instruments to prevent for the under-estimation of the prevalence of psychopathology in children with ID.

In this study we choose to follow the more pragmatic approach to psychopathology, based on the definition of Graham and Rutter (1970). This definition assumes no underlying cause, and views behaviors and emotions as abnormal by virtue of their qualitative or quantitative deviancy and when they cannot be explained on the basis of ID alone. In addition, significant added impairment in everyday functioning is taken into account when addressing DSM-IV disorders.

Multi-informant assessment of psychopathology in children with ID

A final issue when assessing children with ID is that they may not be able to reflect on their own behaviors as well as non-ID children can. This could result, for example, from introspective and verbal limitations. Therefore, the assessment of psychopathology in children with ID in comparison to those without ID may rely even more on the use of multiple informants, such as parents and teachers, to improve diagnostic precision (Dykens, 2000). This issue applies across both the clinical-medical and psychometric-empirical approaches. Further, moderate cross-informant agreement between parents and teachers has been reported for many instruments assessing psychopathology in typically developing children (Achenbach, McConaughy, & Howell, 1987), as well as in children with ID (Aman et al., 1996; Einfeld, Tonge, & Parmenter, 1998; Freund & Reiss, 1991; Tassé & Lecavalier, 2000). Several factors influence this outcome.

Situation-specificity of problem behaviors likely contributes to the moderate cross-informant correlation coefficients. This would be especially true in community residing populations, where children tend to show less pervasive problems across situations. Furthermore, the structured environment at school, and in the case of children with ID, the availability of teachers trained to teach children with ID might result in fewer problem behaviors being displayed at school. Observer-specificity can also play an important role, such as when different observers have different perspectives, tolerance levels, or thresholds for reporting behavior (van der Ende, 1999). Differences in parent and teacher ratings of children with ID might to some extent be a result of teachers comparing a student with his/her ID classmates, while parents are perhaps more likely to compare their child with his/her non-ID siblings or other children in the neighborhood.

Therefore, in this study we collected information on psychopathology from multiple informants, specifially parents and teachers, using both general population instruments and instruments for the ID.

Psychopathology in children with ID: Major previous findings

Restating, the main goals of this study were to determine the value of different ways to assess psychopathology in children with ID, to estimate the prevalence of psychopathology in children with ID, and to address consequences and risk factors.

In the next part of this chapter we will present major findings on these topics from previous research studies. First, we will examine some of the promising instruments developed to assess a broad range of problem behaviors in children with ID that were available when we started the present research project. Second, we will discuss prevalence rates found in previous studies in relation to various methodological issues. Third, we will

summarize some of the major correlates and risk factors of psychopathology that seem to reoccur in general population research, since very little empirical and epidemiological data is available about risk factors of psychopathology in children with ID.

Instruments for assessing psychopathology in children with ID

Aman (1991) completed a thorough review of instruments for assessing psychopathology in people with ID. However, he refrained from recommending any instruments for general use in children with ID, mostly because of the lack of satisfactory standardization and inadequate field testing of the instruments then available. He identified some "promising" instruments that assess a broad range of problem behaviors in children with ID, namely the Developmentally Delayed Child Behaviour Checklist (Einfeld & Tonge, 1990; Einfeld & Tonge, 1992; Einfeld & Tonge, 1995), the Aberrant Behavior Checklist (Freund & Reiss, 1991; Marshburn & Aman, 1992), and the Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1994).

The development of these promising instruments progressed after Aman's review. Applications in community samples were tested, new factor structures were suggested, additional norms were collected, and one instrument originally developed for use with children in the general population was adapted for use with children with ID, i.e. the Nisonger Child Behavior Rating Form (Aman et al., 1996; Tassé et al. 1996). We selected instruments for this review that: (a) assess a broad range of psychopathology for at least five different syndromes or clusters; (b) have scales empirically derived with factor analytic techniques; (c) are designed for use with children up to age 18; (d) can be completed by lay-informants (parents, teachers); and (e) have available information on reliability or validity post-1980. Four instruments meet these criteria.

Our criteria excluded instruments that: (a) only incorporate one general scale which does not differentiate among domains of psychopathology (e.g. the Maladaptive behavior section of the Vineland Scales; Sparrow, Balla, & Cicchetti, 1984); (b) does not contain empirically derived psychopathology domains (e.g. Part II of the AAMD Adaptive Behavior Scale-School Edition; Lambert, Windmiller, Tharinger, & Cole, 1981); (c) were not developed or adapted for use in children with a broad range of levels of ID (e.g. the Rutter scales (Rutter et al., 1970) or the Child Behavior Checklist, (Achenbach, 1991a)); (d) were not developed or adjusted for school-aged children (e.g. Psychopathology Instrument for Mentally Retarded Adults; Matson, Kazdin, & Senatore, 1984; Watson, Aman, & Singh, 1988); (e) cannot be completed by lay-informants (e.g. the Maladaptive behavior section of the Vineland Scales; Sparrow et al., 1984); and (f) focus only on specific domains of psychopathology (e.g. the Emotional Disorders Ratings Scale for Children with MR; Feinstein, Kaminer, Barrett, & Tylenda, 1988). We refer to Aman (1991) for an overview of excluded instruments. Table 1.1 provides descriptive and psychometric information pertaining to the four instruments we retained for this review.

The Aberrant Behavior Checklist (ABC)

The original ABC (Aman, Singh, Stewart, & Field, 1985b) is a 58-item questionnaire developed to measure the effects of pharmacological intervention in individuals living in residential facilities. Freund and Reiss (1991) adapted this for use by parents and teachers and tested it in an outpatient sample of children a five-factor structure (Irritability/Agitation, Lethargy/Social Withdrawal, Stereotypic, Hyperactive/Non-compliance, Inappropriate Speech) was found to explain 55% of the common variance in the parent version, and good

congruence in structure between the parent and teacher version of the ABC was found. Internal consistency estimates (Cronbach's alpha) were good, ranging from 0.83 to 0.93 for the parent ratings, and from 0.79 to 0.94 for the teacher ratings. Good test-retest reliabilities were found for the parent ratings, ranging from 0.80 to 0.95, but were somewhat lower for the teacher ratings, ranging from 0.50 to 0.67. Parent-teacher agreement was moderate, with correlation coefficients ranging from 0.18 to 0.49. Unfortunately no information was reported on agreement among people in similar roles or for either convergent or criterion-related validity.

The ABC was also evaluated in a community sample rated by teachers (Marshburn & Aman, 1992). Although a four-factor solution (accounting for 52% of the variance) fit the data best, the original five-factor solution (Aman et al., 1985a) was still used. Good estimates of internal consistency, ranging from 0.76 to 0.93, were found. No information is available on other indices of reliability and validity, and no psychometric properties are available for the ABC in community samples of children with ID using parents instead of teachers as informants.

The Developmental Behaviour Checklist (DBC)

The DBC (originally called the Developmentally Delayed Child Behavior Checklist, DD-CBC) consists of a 96-item parent-version (DBC-P) and a 94-item teacher version (DBC-T) (Einfeld & Tonge, 1992; 1995; Einfeld et al., 1998). Originally, six scales were empirically derived (accounting for 33% of the total variance). Cronbach's alphas for the DBC-P scales ranged from 0.67 to 0.91 and test-retest reliabilities from 0.51 to 0.87 (see Table 1.1). The inter-parent agreement for the Total Problems scale was 0.80. The DBC-P proved to have good convergent validity, shown by a 0.86 correlation between the Total Problems scores of the DBC-P and the Maladaptive Behavior section of the Adaptive Behavior Scales (ABC; Aman et al., 1985a). The DBC-P has known sensitivity and specificity with regard to expert clinician judgment of the subject as a psychiatric case versus a non-case, with the area under the ROC curve of 92% (Einfeld & Tonge, 1992). Norm scores are available for all levels of ID. The original DBC-T Total Problems scale likewise showed good internal consistency and test-retest reliability. However, the correlation between the DBC-P and the DBC-T Total Problems score was low ($r = 0.05$; Einfeld et al., 1998).

The Nisonger Child Behavior Rating Form (NCBRF)

The current NCBRF is an adaptation of the original version, to which 16 items related to self-injury, stereotypic, and shy behavior were added (Aman et al., 1996; Tassé et al., 1996). The NCBRF has both a 71-item parent and teacher version. The six-factor solution (Conduct problem, Insecure/Anxious, Hyperactive, Self-Injury/Stereotypic, Self-Isolated/Ritualistic, Irritable), explaining about 50% of the variance, and showed good internal consistencies for both the parent (alphas ranging from 0.77 to 0.93) and teacher version (alphas ranging from 0.81 to 0.91). Good correspondence with the ABC was found. The factor solution of the French version showed good congruence with the U.S. version (Tassé, Morin, & Girouard, 2000). Good to excellent test-retest reliability, and similar-role informant agreement were found in a Canadian sample of school children with ID. Furthermore, cross-informant reliability was relatively high when compared to other studies (Achenbach et al., 1987). Unfortunately, no information was found on criterion-related validity. Norms for different age groups, and split by sex for the parent version are based on a sample of outpatient children referred for evaluation for ID and developmental disorders.

Table 1.1 Review of recent (>1970) lay informant (parents, teachers) instruments assessing a broad range of emotional and behavioral problems in children and adolescents with ID living in the community

Instrument (reference & country of sample)	Description Sample	Derivation items/scales	Description scales (# items)	α	Test-retest reliability[b]	Similar role informant agreement	Parent-teacher agreement	Convergent validity	Criterion related validity
Aberrant Behavior Checklist – Parent Rating (ABC) (Freund & Reiss, 1991; USA)	n=110 Borderline to severe ID 3-25 years old 72% out-patients of neuro-psychiatric unit	Originally developed to measure pharmacological effects in residential children & adults by third party raters/adjustments in wording/ PCA[a] similar to original	1. Irritability/Agitation (15) 2. Lethargy, Social Withdrawal (14) 3. Stereotypic (5) 4. Hyperactivity/Non-Compliance (15) 5. Inappropriate Speech (5)	(n=110) 0.90 0.93 0.88 0.90 0.83	r (n=30) 0.95 0.92 0.88 0.88 0.80	N.A.	r (n=94) 0.49 0.18 0.45 0.47 0.39	N.A.	N.A.
Aberrant Behavior Checklist – Teacher Rating (ABC) (Freund & Reiss, 1991; USA)	n=94 Borderline to severe ID 3-26 years old 72% out-patients of neuro-psychiatric unit	See Parent Rating (ABC)/ PCA similar to original	1. Irritability/Agitation (16) 2. Lethargy, Social Withdrawal (18) 3. Stereotypies/Self-Injury (8) 4. Hyperactivity/Non-Compliance (13) 5. Inappropriate Speech (2)	(n=94) 0.88 0.94 0.90 0.89 0.79	r(n=25) 0.61 0.50 0.67 0.61 0.59	N.A.	See Parent Rating (ABC)	N.A.	N.A.
Aberrant Behavior Checklist – Teacher Rating (ABC) (Marsburn & Aman, 1992; USA)	n=666 Children in special education classes (majority IQ< 80) 6-21 years old	See Teacher Rating (ABC)/ PCA similar to original	1. Irritability/Agitation (15) 2. Lethargy, Social Withdrawal (16) 3. Stereotypic (7) 4. Hyperactivity/Non-Compliance (16) 5. Inappropriate Speech (4)	(n=666) 0.93 0.90 0.89 0.96 0.76	N.A.	N.A.	N.A.	N.A.	N.A.

Table 1.1 continued

Instrument (reference & country of sample)	Description Sample	Derivation items/scales	Description scales (# items)	α	Test-retest reliability[1]	Similar role informant agreement	Parent-teacher agreement	Convergent validity	Criterion related validity
Developmental Behavior Checklist- Primary Carer (DBC-P) (Einfeld & Tonge, 1992; 1995; Australia)	PCA n=1,093 Norms n=454 (split by level of ID) Mild to profound ID 4-18 years old Multi-center/area community sample	Records ID service/ empirical (PCA)	1. Disruptive (20) 2. Self-absorbed (19) 3. Communication Disturbance (9) 4. Anxiety (11) 5. Social Relating (8) 6. Anti-social (4) Total Problems (96)	(n=1,093) 0.91 0.86 0.81 0.76 0.73 0.67 0.94	ICC (n=63) 0.84 0.87 0.76 0.77 0.70 0.51 0.83	ICC (n=42) 0.78 0.79 0.75 0.80 0.78 0.79 0.80	ICC (n=51) 0.05	(n=40) Total Problems with Maladaptive Behaviour Section of AAMD ABC[c]: r=0.86 Total Problems with Total score Problem Behaviour Section of the SIB[d] r=0.72	(n=70) Significant mean difference in Total Problems between cases and non-cases as rated by child psychiatrists ROC= 92%
Developmental Behavior Checklist- Teacher Version (DBC-T) (Einfeld, Tonge, & Parmenter, 1998; Australia)	n=640 (norms split by level of ID) Mild to profound ID 4-18 years old Multi-center/area community sample	Records ID service/ empirical (PCA)/ similar to DBC-P	1. Disruptive (20) 2. Self-absorbed (19) 3. Communication Disturbance (9) 4. Anxiety (10) 5. Social Relating (8) 6. Anti-social (4) Total Problems (94)	(n=640) 0.94	ICC (n=16) 0.76	ICC (n=56) 0.68 0.74 0.62 0.66 0.48 0.30 0.60	ICC (n=51) 0.05	N.A.	N.A.
Nisonger Child Behavior Rating Form -Parent version (CBRF) (Aman et al. 1996; Tassé et al. 1996; USA)	n=326 (norms split by age) Mild to profound ID 3-16 years old Outpatients referred for evaluation at center for MR & DD	Adaptation of CBRF/ Case records psychiatric inpatients/ PCA + extra items	1. Conduct Problem (16) 2. Insecure/Anxious (15) 3. Hyperactive (9) 4. Self-Injury/ Stereotypic (7) 5. Self-Isolated/ Ritualistic (8) 6. Overly sensitive (5)	(n=326) 0.93 0.89 0.90 0.81 0.77 0.80	N.A.	N.A.	r (n=189) 0.37 0.53 0.42 0.54 0.51 0.22	(n=58) Corresponding ABC[d] scales Range: r=0.49 to 0.80	N.A.

Table 1.1 continued

Instrument (reference & country of sample)	Description Sample	Derivation items/scales	Description scales (# items)	α	Test-retest reliability[1]	Similar role informant agreement	Parent-teacher agreement	Convergent validity	Criterion related validity
Nisonger Child Behavior Rating Form - Teacher version (CBRF) (Aman et al. 1996; Tassé et al. 1996; USA)	n=260 (norms split by age) Mild to profound ID 3-16 years old Outpatients referred for evaluation at center for MR & DD	Adaptation of CBRF/ Case records psychiatric inpatients/ separate PCA solution	1. Conduct Problem (13) 2. Insecure/Anxious (15) 3. Hyperactive (8) 4. Self-Injury/ Stereotypic (9) 5. Self-Isolated/ Ritualistic (11) 6. Irritable (6)	(n=260) 0.91 0.88 0.87 0.83 0.81 0.88	N.A.	N.A.	See parent version of Nisonger CBRF	(n=58) Corresponding ABC[d] scales Range: r=0.49 to 0.85	N.A.
Nisonger Child Behavior Rating Form – French Parent Version (Tassé & Lecavalier 2000; Tassé, Morin, & Girouard 2000; Girouard, Morin, Tassé, 1998)	n=383 parents Mild to profound ID 5-18 years old Schools (with services) for ID	French translation of Nisonger CBRF/ separate PCA solution (congruence with Nison-ger CBRF 0.61 to 0.95)	1. Conduct Problem 2. Insecure/Anxious 3. Hyperactive 4. Self-Injury/ Stereotypic 5. Self-Isolated/ Ritualistic 6. Overly sensitive	(n=383) 0.92 0.89 0.88 0.74 0.74 0.75	ICC (n=57) 0.93 0.89 0.88 0.86 0.76 0.76	ICC (n=55) 0.86 0.80 0.79 0.68 0.68 0.66	ICC (n=109) 0.63 0.57 0.54 0.49 0.42 -- (Only similar items used)	N.A.	N.A.
Nisonger Child Behavior Rating Form – French Teacher Version (Tassé & Lecavalier 2000; Tassé, Morin, & Girouard 2000; Girouard, Morin, Tassé, 1998)	n=328 teachers Mild to profound ID 5-18 years old Schools (with services) for intellectually disabled	French translation of Nisonger CBRF/ separate PCA solution (congruence with Nisonger CBRF 0.30 0.91)	1. Conduct Problem 2. Insecure/Anxious 3. Hyperactive 4. Self-Injury/ Stereotypic 5. Self-Isolated/ Ritualistic 6. Irritable	(n=328) 0.90 0.86 0.84 0.82 0.78 0.90	ICC (n=56) 0.88 0.84 0.82 0.89 0.74 0.87	ICC (n=54) 0.74 0.60 0.44 0.79 0.47 0.67	See French parent version of Nisonger CBRF	N.A.	N.A.

Table 1.1 continued

Instrument (reference & country of sample)	Description Sample	Derivation items/scales	Description scales (# items)	α	Test-retest reliability[1]	Similar role informant agreement	Parent-teacher agreement	Convergent validity	Criterion related validity
Reiss Scales for Children's Dual Diagnosis (RSC-DD) (Reiss & Valenti-Hein, 1994; USA)	n= 583 Mild to profound ID 4-21 years old Referred to community/ residential based agencies & special schools	Item selection DSM-III-R /PCA + extra items		(n=270)	N.A.	N.A.	N.A.	N.A.	Children with dual diagnosis score about 1 SD higher on total score than children without dual diagnosis
			1. Anger/Self-Control (5)	0.86					
			2. Anxiety Disord. (5)	0.75					
			3. Attention Deficit (5)	0.69					
			4. Autism (3)	0.63					
			5. Conduct Disord.(5)	0.80					
			6. Depression (5)	0.57					
			7. Poor Self-Esteem (3)	0.80					Relation specific diagnosis and scale scores
			8. Psychosis (3)	0.66					
			9. Somatoform (5)	0.79					
			10. Withdrawn/ Isolated (5)	0.83					
			Total Score	0.92					

[a]PCA=Principal Components Analysis

[b]r=Pearson product-moment correlation; ICC=Intra Class Correlation

[c] AAMD ABC= American Association of Mental Deficiency Adaptive Behaviour Scales School Edition (Lambert, Windmiller, Tharinger, & Cole 1981).

[d]SIB=Scale of independent Behaviour (Bruininks, Woodcock, Weatherman, & Hill 1984).

[e]Aberrant Behavior Checklist (Aman et al. 1985a, 1985b).

The Reiss Screen for Children's Dual Diagnosis (RSC-DD)

The 60-item RSC-DD shows good internal consistency for most of its ten scales, ranging from 0.57 to 0.86, for most of its ten scales (see Table 1.1), especially when considering the small number of items in each scale. Criterion-related validity was shown by the strong relation between the Total Problems score and the presence versus absence of psychiatric diagnosis in the child's case file (Reiss & Valenti-Hein, 1994). The RSC-DD is less suited for detailed assessment of specific disorders because each scale only contains only three to five items each. Unfortunately, no further information on the reliability or convergent validity was available for the RSC-DD.

Overall instrument evaluation

We conclude that progress has been made since 1991 in the empirical development of instruments to assess psychopathology in children with ID living in the community. When we started the present study, the DBC-P and DBC-T currently had the most comprehensive psychometric information available, with satisfactory reliability, validity, and norms based on adequate samples. The NCBRF also showed good reliability and validity for both the parent and teacher version, but more information is needed on criterion-related validity. Furthermore, the available norms for the NCBRF (English version) are based on a sample limited to outpatients referred to one mental retardation center. The ABC lacks data regarding the validity and reliability in non-patient samples, especially for the parent version. Finally, the RSC-DD needs considerably more field-testing on reliability and convergent validity, and should be evaluated with teachers.

Based, on the information available, we concluded that the DBC was at the time the most broadly studied instrument and had proved to be very promising. Therefore, the DBC was translated into Dutch, and after a successful back translation validation procedure, was used in the present study (Koot & Dekker, 2001). Chapters 3 and 4 will report on the psychometric properties of the Dutch translation of the DBC.

Prevalence of psychopathology in children with ID and methodological issues

Next, we summarize the findings on prevalence of psychopathology from community-based studies and discuss their strengths and limitations. We do not include studies of children with ID who are selected through mental health agencies. We focus on published, or recently submitted studies regarding school-aged children that use standardized statistical or clinical criteria for psychopathology. The focus, moreover, is on overall psychopathology rather than specific psychiatric disorders or syndromes, and on children with ID in general rather than children with specific genetic disorders or children with ID who have specific behavioral phenotypes. The reviewed studies collected information on the child's psychopathology as reported by professionals, parents, and teachers as well as children themselves. Table 1.2 provides more information about the studies meeting these criteria and the prevalence estimates found.

The studies vary considerably in methods used for selecting and sampling the subjects, definition of psychopathology, instruments and informants, and age range and level of ID of the participants. Not surprisingly, the reported overall prevalence of psychopathology ranges from 4% to 65%. The differences in methods make it hard to compare studies or to reach a

"best" estimate of prevalence. Therefore, in the next section we will discuss differences between these studies and the effects these differences may have on the resulting prevalence estimates.

Comparing prevalence of psychopathology in children with and without ID

In the absence of a "gold" standard for the assessment of psychopathology, it is informative to estimate the *relative* risk of developing psychopathology in children with ID compared to children in the general population. By applying the same standardized instrument for both groups, the risk can be estimated in reference to the prevalence obtained in the general population. This is especially valuable when studying children in the mild ID range because they are typically well integrated in society, if not completely so, and face similar expectations for an adult life style as those in the general population. To date, only four studies used a comparison group of children in the general population as a point of reference.

Rutter et al. (1970) reported a 4-fold risk of psychopathology for the ID group, Koller et al. (1982) a 7-fold, Linna et al. (1999) a 3-fold, and Wallander, Browne, and Stankovic (submitted) a 3- to 6-fold risk. Thus, the observation that children with ID are at a substantially increased risk for psychopathology relative to children from the general population seems consistent across studies conducted in England, Scotland, Finland, and the U.S.

It is important to note the samples of children with ID in these four studies included primarily those with *mild* levels. This makes it feasible to apply the same assessment of psychopathology across the target and reference group. That is, a general agreement has grown that individuals with mild ID, who make up 75%-85% of the ID population (American Psychiatric Association, 1994), display types of psychopathology similar to those in the general population (Borthwick-Duffy, Lane, & Widaman, 1997; Dykens, 2000; Einfeld & Aman, 1995; Reiss, 1985). In contrast, children with more severe ID more commonly also display symptoms of psychopathology that are rarely seen in the general population (e.g. self-injurious behavior, echolalia, mouthing objects, staring at lights, laughing for no reason, standing too close to others). These behaviors are typically not represented in assessment instruments used with the general population, and comparison with the whole spectrum of children with ID therefore becomes impossible.

Definition of psychopathology in children with ID

As discussed earlier in this chapter, there is no consensus about the definition of psychopathology. Therefore, studies examining the prevalence of psychopathology have employed different criteria for what constitutes a sufficient degree of psychopathology to classify a disorder. Further, there is the basic distinction between the clinical-medical and psychometric-empirical approaches, also discussed earlier. A number of prevalence studies have used an empirical criterion to define disorder (Cormack, Brown, & Hastings, 2000; Einfeld & Tonge, 1996b; Linna et al., 1999; Rutter et al., 1970; Tonge & Einfeld, 2000; Wallander, Browne, & Stankovic, submitted). These cut-off scores are based on or related to some external criterion, for example judgments by clinicians (Einfeld & Aman, 1995; Einfeld & Tonge, 1992) or optimal prediction of referral to mental health care (Achenbach, 1991a, 1991b; Rutter et al., 1970; Tonge & Einfeld, 2000; Verhulst, van der Ende, & Koot, 1996, 1997). The prevalence of empirically defined psychopathology in children with ID reported by parents ranges from 30% to 65% and by teachers from 28% to 46%.

Other studies have relied on clinical judgments to define and describe psychopathology. Some of those judgments are based on standardized diagnostic criteria specified in the DSM or ICD taxonomic systems, mainly gathered through clinical file records (Borthwick-Duffy & Eyman, 1990; Eaton & Menolascino, 1982; Jacobson, 1982; Rojahn, Borthwick-Duffy, & Jacobson, 1993). The prevalence of disorder in these studies ranges from 4% to 14%.

In contrast, a third set of studies that have used more global and less standardized methods to define clinical levels of psychopathology (Cadman, Boyle, Szatmari, & Offord, 1987; Chess, 1977; Chess & Hassibi, 1970; Gillberg, Persson, Grufman, & Themner, 1986; Koller et al., 1982; Kushlick, 1975; McQueen, Spence, Garner, Pereira, & Winsor, 1987; Reiss, 1985; Szymanski, 1977) have reported prevalence estimates ranging from 9% to 60%.

And a fourth set of studies, which also used global and unstandardized methods to assess global levels of problem behaviors (Eaton & Menolascino, 1982; Jacobson, 1982; McQueen et al., 1987; Rojahn et al., 1993), reported prevalence estimates ranging from 21% to 61% (note that Jacobson, 1982, and Rojahn et al., 1993 applied both diagnostic and global problem behavior level criteria).

Consequently, the lowest prevalence as well as the smallest range was found in the second set of studies that used standardized diagnostic criteria. However, this smaller range in this set of studies may be due to the fact that three of the five studies (Jacobson, 1982; Rojahn et al., 1993; Borthwick-Duffy, & Eyman, 1990) were based on the same database, although different cross-sections were used. Furthermore, the information on DSM diagnoses in these studies is gathered through clinical records. The Reiss (1990) study showed that when studying psychopathology in the same people using data from case files, screening surveys, and clinical evaluations, prevalence rates were smallest when using case files and highest for individual evaluations.

ID and IQ range

The range of ID in the samples differs among the studies. Numerous studies covered the whole range of ID (Borthwick-Duffy & Eyman, 1990; Eaton & Menolascino, 1982; Einfeld & Tonge, 1996b; Gillberg et al., 1986; Jacobson, 1982; Koller et al., 1982; Kushlick, 1975; Rojahn et al., 1993). Nonetheless, the distribution in these studies was still often skewed, with children having mild ID being underrepresented. The main reason for this is the greater likelihood of children with mild ID being fully integrated, and therefore, not found in the services systems providing the sampling frame for these studies.

Another group of studies included children attending education programs for children with ID (Chess, 1977; Chess & Hassibi, 1970; Linna et al., 1999; Wallander, Browne, & Stankovic, submitted; Reiss, 1985). In these studies, children with severe and profound levels of ID are underrepresented, whereas children with mild ID are better represented. This is especially the case in countries where few children with ID attend regular schools and many children with borderline to moderate levels of ID go to special schools or classes, such as in Finland (Linna et al., 1999).

Some studies reported prevalence rates of psychopathology split by level of ID or IQ (Borthwick-Duffy, & Eyman, 1990; Einfeld & Tonge, 1996b; Gillberg et al., 1986; Jacobson, 1982; Koller et al., 1982; Kushlick, 1975; Reiss, 1985). The prevalence estimates of psychopathology for children with mild ID range from 16% to 57% across studies, moderate ID from 9% to 64%, severe ID from 5% to 61%, and profound levels of ID from 6% to 51%.

Thus, within each ID level, a range of prevalence estimates has been reported that is as broad as that reported for the children with ID overall. Therefore, a discernable association between prevalence of overall psychopathology and ID level does not seem to exist.

Considering these studies in more detail suggests that the relation between ID level and psychopathology differs for different types of psychopathology. The manifestation of some behaviors and emotions may require a certain level of development being achieved (Borthwick-Duffy, 1994, Jacobson, 1982). The general trends are that depressed mood, anxiety, and antisocial behaviors seem more common among those with relatively higher levels of IQ, while psychotic, self-absorbed, and autistic behaviors are more likely to be found in children with lower IQs (Einfeld & Tonge, 1996b; Gillberg et al., 1986; Koller et al., 1982). Significant effects across level of ID, IQ or educational placement were reported in four studies (Borthwick-Duffy, & Eyman, 1990; Einfeld & Tonge, 1996b; Jacobson, 1982; Koller et al., 1982). However, differences were not always found on overall levels of psychopathology, but rather for syndrome or scale scores (Einfeld & Tonge, 1996b; Jacobson, 1982).

Selection of children with ID

An ideal design for studying psychopathology in children with ID is to enroll a random sample of unselected humans from the general population among whom will be a portion with ID (Verhulst, 1995). This enables the researcher to study the whole spectrum of symptoms, syndromes, or disorders indicative of psychopathology, without selection biases inherent in referral to mental health care, attending schools for special education, or using services for ID. However, because ID is a relatively rare disability, with estimates ranging from 1% to 3% in the general population (Hodapp et al., 1998), this option is not time- and cost-efficient, or even practical, because such a large sample is required for producing reliable prevalence estimates. The only example of a general population study that did not pre-select children with ID, but instead assessed the presence of ID independently, is the Isle of Wight Study (Rutter et al., 1970). A few studies have recruited children with ID from the general population, such as Koller et al (1982), Gillberg et al. (1986), and Linna et al. (1999), but defined children as having ID based on external information, such as placements in special schools, training centers, day-care facilities for children with ID, or through register searches.

Except for the Isle of Wight study (Rutter et al., 1970), all research on prevalence of psychopathology in children with ID is based on samples that were present in a service or special school program for children with ID. Because children with mild ID and borderline intellectual functioning, and without severe physical or behavioral problems are more commonly fully integrated and not necessarily found in ID service programs, they are more likely to be missed with this sampling procedure. Consequently, children with more severe ID and/or severe physical or behavioral problems will be over-represented in service-based samples, which can influence the prevalence estimates (Einfeld & Tonge, 1996a). Moreover, the effect of selection bias depends on the country, state, or region of sampling. The way services and special education are organized and what percentage of children with ID is reached through these systems differ considerably by country or region.

Obviously, the selection bias effect on the prevalence of psychopathology would be compounded if sampling occurred in mental health service programs. However, recall that we only reviewed studies herein with samples of children who were *not* selected through mental health agencies. This strategy protects against an accumulation of selection by referral bias.

Table 1.2 Prevalence studies (1970-2001) using statistical or global clinical criteria for psychopathology

Study	Country	Sample					Definition of disorder	Assessment Method(s)	Prevalence of psychopathology[a]			
		Size ID	Size Reference	Age[3]	ID or educational level	Method			Overall		Specific syndromes	Associated factors
Borthwick-Duffy, Eyman (1990)	USA (CA)	78,603	N.A.	0-86	Mild to profound ID	Clients of Department of Developmental Services 1986	Clinical: Psychiatric diagnosis (DSM-III-R);	Client Development Evaluation Report CDER; Psychiatric diagnosis from case file (DSM-III-R)	Overall ID Mild ID Moderate Severe Profound	10.0% 15.9% 9.1% 5.0% 6.0%	N.A.	Relation: Level of ID Living conditons Impact dual diagnosis Extrapunitive behavior
Chess (1977)	USA (NY)	48 44	N.A.	8-14 11-19	IQ 50-75 all in special classes	3 and 6 year follow-up of Chess, Hassibi (1970)	Clinical: Global Psychiatric diagnosis	Interviews with parent, teacher, & observation child; clinical psychiatric evaluation	Overall After 3 y After 6 y	58.3% 41.9%	Reactive Behavior disorder Neurotic Behavior disorder Behavior disorder due to neurological damage Psychosis	Relation: Temperament
Chess, Hassibi (1970)	USA (NY)	52	N.A.	5-11	IQ 50-75 all in special classes	Recruited from special classes	Clinical: Global Psychiatric diagnosis	Interviews with parent, teacher, & observation child; clinical psychiatric evaluation	Overall	59.6%	Reactive behavior disorder Neurotic disorder Cerebral dysfunction Psychosis Behavior patterns	N.A.
Cormack, Brown, Hastings (2000)	UK (Southampton and the New Forest)	123	N.A.	4-18	Moderate to severe ID/ Attending schools for children with severe learning difficulties	Administratively defined population of parents of children attending one of 4 SLD schools	Statistical: Cut-off based on ROC of judgements clinicians in ID sample	DBC-P	Overall	50.4%	Disruptive Self-absorbed Communication disturbance Anxiety Autistic relating Antisocial	Relation: Down's syndrome Age Physical disability index No relation: Sex Epilepsy

Table 1.2 continued

Study	Sample								Prevalence of psychopahtology		
	Country	Size ID	Size Reference	Age	ID or educational level	Method	Definition of disorder	Assessment Method(s)	Overall	Specific syndromes	Associated factors
Eaton, Menolas-cino (1982)	USA (Nebras ka)	798	N.A.	6–76 49%= 6–20	Borderline to severe ID	Partcipants in community-based ID program	Clinical: Pyschiatric disorder (DSM-III)	Psychiatric consult	Referred Diagnosis — 21% 14.3%	Schizophrenia Personality disorder Anxiety disorder Organic brain disorder	N.A. (only descriptive)
Einfeld and Tonge (1996a, 1996b)	Austra-lia (NSW)	454	N.A.	4–18	Mild to profound ID	Random sample from services ID (NSW)	Statistical: cut-off based on ROC of judgements clinicians in ID sample	DBC-P (parent)	Overall ID 40.7% Mild 46.4% Moderate 39.9% Severe 44.7% Profound 5.0%	Disruptive Self-absorbed Communication disturbance Anxiety Autistic relating Antisocial	Relation: Level of ID Age No relation: Sex
Gillberg, Persson, Grufman, et al. (1986)	Sweden (Göte-burg)	149	N.A.	13–17	Mild to severe ID	ID subjects from all children Göteburg (born 1966-1970)	Clinical: global psychiatric diagnostic categories	Child seen by doctor; Structured interview parent	Overall ID 59.7% Mild 56.6% IQ < 50 63.6%	Psychotic disorder Depressive disorder Conduct disorder Emotional disorder Psychosomatic & Hyperkinetic disorder	Relation: Level of ID Sex Epilepsy Down's syndrome
Jacobson (1982)	USA (NY)	8,784	N.A.	0–21 also adults	Mild to profound ID	All children receiving services for the ID	Clinical: Global psychiatric disability (DSM-III-R); Problem behaviors	Developmental Disabilities Information Survey (DDIS)	Overall ID Psych. dis. 9.8% Problem behaviors: Mild 54% Moderate 48% Severe 55% Profound 61% 51%	Cognitive problems Affective problems Major & minor behavior problems	Relation: Level of ID Age Living conditions

Table 1.2 continued

	Sample								Prevalence of psychopathology		
Study	Country	Size ID	Size Reference	Age	ID or educational level	Method	Definition of disorder	Assessment Method(s)	Overall	Specific syndromes	Associated factors
Koller, Richarson Katz, et al. (1982, 1983)	Great-Britain (Aberdeen)	173	173 (IQ > 75; matched for age, sex, SES)	7-10 & post-school	Mild to severe ID	ID subjects from random GP[b] sample Aberdeen (born 1951-1955)	Clinical: Global behavior disturbance (moderate-severe)	Interview with parent; records	Overall ID 35.3%; IQ<50 38%; 50-59 34%; 60-69 30%; 70-75 48%; GP 4.6%	Emotional Hyperactive Aggressive conduct Antisocial	Relation: IQ Sex Age
Kushlick (1975)	South of England	59	N.A.	<16 also adults	Mild to severe ID	All children receiving health and social services for the ID	Global severe disruptive behavior disorders	Global survey questions	IQ > 50 18.8%; IQ < 50 18.2%	N.A.	Relation: Physical capacity Epilepsy
Linna, Moilanen, Ebeling et al. (1999)	Finland	90	5,804 GP[b], Children at regular schools	8	educational subnormal & trainables	ID subjects attending special schools from random GP sample (born 1981)	Statistical: Cut-off based on prediction referral status in GP sample	RutterA2 (parent); RutterB2 (teacher); CDI (child)	ID (RA2) 32.2%; GP 10.8%; ID (RB2) 34.9%; GP 13.5%; ID (CDI) 11.0%; GP 6.6%	Emotional Mixed Behavioral	N.A.
McQueen, Spence, Garner, et al. (1987)	Canada (3 provinces)	307	N.A.	7-10	IQ < 55; Moderate to profound	Children born '69-'72 from schools, service agencies, and institutions.	Clinical: Global behavior disorders; Psychiatric disorder	Record data	Behavior disorders 31.7%; Psychiatric disorders 9.0%	N.A.	N.A.
Reiss (1985)	USA (IL)	5,639	N.A.	School aged	Educable and trainable	Illinois State Board of Education of children in special education classes '80-'81	Clinical: Global evaluation of behavioral disturbance psychologist school	N.A.	Overall 10.2%; Educable 16.8%; Trainable 8.6%	N.A.	Relation: Level of ID

Table 1.2 continued

Study	Country	Size ID	Size Reference	Age	IQ or educational level	Method	Definition of disorder	Assessment Method(s)	Overall	Specific syndromes		Associated factors
Rojahn, Borthwick-Duffy, Jacobson (1993)	USA (CA & NY)	135,102	N.A.	0-45; 40.9% =0-20	Mild to profound	All persons receiving services for the ID	Clinical: Psychiatric diagnosis (DSM-III-R); Problem behaviors	Client Development Evaluation Report (CDER); Developmental Disabilities Information Survey (DDIS)	Psychiatric disorder:: CA NY Problem behaviors: CA NY	5.4% 3.9% 21.1% 40.1%	AD/HD; CD; PDD; Adjustment, Anxiety, Affective, Organic brain, Personality disorders; Schizophrenic; Behavior problems	Relation: Sample
Rutter, Tizard, Whitmore (1970)	England (Isle of Wight)	56	147; GP; Random sample IQ > 70	10-11[c]	IQ < 70	All children with IQ < 70 from total sample	Statistical: cut-off based on prediction referral status in GP sample; Clinical; Overall judgement psychiatric disorder	RutterA2 (parent); RutterB2 (teacher); Psychiatric interview (child)	ID (RA2) GP ID (RB2) GP Interview ID GP	30.4% 7.7% 41.8% 9.5% 23.6% 1.4%	Neurotic disorder Antisocial disorder Mixed	Relation: Brain damage?
Szymanski (1977)	USA (Boston, MA)	107	N.A.	Children	Mentally Retarded	Children from Developmental Evaluation Clinic	Clinical: Global (Severe) emotional difficulties	Seen by psychiatrist	Emotional difficulty Severe emotional difficulty In need of care	30% 24% 54%	N.A.	
Tonge, & Einfeld (2000)	Australia (NSW)	Time 1: 582 Time 2: 467	N.A.	Time 1: 3-19 Time 2: 7-23	Mild to profound ID	Four-year follow-up of random sample from services ID (NSW: 1995-1996)	Statistical: Cut-off based on ROC of judgements clinicians in ID sample	DBC-P (parent)	Time 1 Total: Time 2 Total:	43.3% 38.6%	Disruptive Self-absorbed Communication disturbance Anxiety Autistic relating Antisocial	In time no significant changes in scale scores; no interaction age & time

Table 1.2 continued

Study	Sample						Definition of disorder	Assessment Method(s)	Prevalence of psychopathology		
	Country	Size ID	Size Reference	Age	IQ or educational level	Method			Overall	Specific syndromes	Associated factors
Wallander Stankovic (submitted)	USA (Alabama)	211 Afro-Am.	N.A.	13-16	Mild ID; All in EMR Schools	Volunteers out of EMR schools in 4 School districts	Statistical: clinical cut-off based on prediction referral status in GP sample; Global psychiatric symptoms	CBCL (parent); TRF (teacher); YSR (youth); Interview: Psychiatric Evaluation Form (PEF) (youth)	Parent(s) 55-65% Teacher 28% Youth 32% Youth (PEF) 23% At least 2 informants 35%	Achenbach scales; Psychiatric symptoms: e.g.: Somatic; Anxiety Depression; Suicide/ Self-mutulation; Social isolation; Suspision; Grandiosity; Anti-social; Negativism; Agitation; Memory problems	No relation: demografic risk index; IQ;

[a]Prevalence of children with ID and at least one psychiatric disorder.

[b]GP = General Population sample.

[c]Age at the time of assessing the level of psychopathology

Multiple informants

Because of the moderate cross-informant agreement in reports on children's behaviors and emotions, as discussed previously, it is important to know which informant is used to report on psychopathology when comparing different prevalence estimates. Linna et al. (1999), Rutter et al. (1970), and Wallander, Browne, and Stankovic (submitted) were the only studies that used different informants but standardized cross-informant instruments to estimate prevalence. Wallander, Browne, and Stankovic (submitted) used the Achenbach scales (1991a, 1991b, 1991c), showing higher prevalence rates reported by parents than by teachers. Linna et al. (1999), and Rutter et al. (1970) used the Rutter scales (1970) and found higher prevalence rates for teachers than for parents. These findings suggest that, in addition to low informant agreement, there might also be an interaction effect of the instrument by informant when estimating prevalence.

Age range

There are several age-related issues in this field of research. Although all studies being reviewed herein included school-age children in their sample, not all were designed to address psychopathology solely in children. Mixing adults with children in the sample is confusing. In fact, only two (Jacobson, 1982; Kushlick, 1975) of the five studies that also included adults (the remaining being: Borthwick-Duffy, & Eyman, 1990; Eaton & Menolascina, 1982, and Rojahn et al., 1993) reported separate prevalence rates for children.

Most studies have focused on a rather limited age range. For example, Linna et al. (1999) studied 8-year-olds, Rutter et al. (1970) 10- to 11-year-olds, McQueen et al. (1987) and Koller et al. (1982) 7- to 10-year-olds, and Gillberg et al. (1986) and Wallander, Browne, & Stankovic (submitted) adolescents. Because age has been found to affect the level of psychopathology in children with ID (Cormack et al., 2000; Einfeld & Tonge, 1996b; Jacobson, 1982; Koller et al., 1982), restricting the age range of a study sample may affect the prevalence estimates obtained.

Sampling issues

Sample size also differs across studies. Other things being equal, a larger sample size will produce more accurate (i.e. less standard error in) the estimates. Some studies have enrolled fewer than 100 children with ID (Chess, 1977; Chess & Hassibi, 1970; Linna et al., 1999; Kushlick, 1975; Rutter et al., 1970), while other studies have samples of more than 500 children (Eaton & Menolascina, 1982; Jacobson, 1982; Reiss, 1985; Tonge & Einfeld, 2000). Two studies examining existing case records rather than collecting new data have sampled more than 10,000 children (Borthwick-Duffy, & Eyman, 1990; Rojahn et al., 1993).

However, apart from sample size, other critical considerations are the sample composition and how well the sample represents the population. It is important to know whether all or at least a random sample of recruitment sources (e.g. agencies, schools serving children with MR) were used to enroll children with ID or whether more select or convenience samples were used. For example, Cormack et al. (2000) used an administratively defined population of only four special schools, including one school for autistic children. In Wallander, Browne, and Stankovic (submitted), the majority of the participants came from one public school system, with the result that almost the whole sample consisted of urban African-American families of low socio-economic status, urban African-Americans. Chess and Hassibi (1970) reported on children only from middle-class families. Both Eaton and Menolascino (1982)

and Szymanski (1977) included only children attending one specific community-based program for children with ID.

Even when studies sample their subjects from multiple centers or schools in a random fashion, we still need to know whether the distribution in level of ID, age, sex, and SES conforms to demographic expectations. Information on the response rate and distribution of non-response is necessary to draw conclusions about response bias, representativeness, and generalizability. Unfortunately, only a portion of the studies report about non-response and the bias this can potentially create (Einfeld & Tonge, 1996b; Tonge & Einfeld, 2000; Rutter et al., 1970; Wallander, Browne, & Stankovic, submitted). Additional studies discuss the limitations of their sample (Cormack et al., 2000; Gillberg et al., 1986; Jacobson, 1982; Rojahn et al., 1993). In conclusion, restrictions in age and level of ID range, the geographic region covered, the type of agencies or schools used, and the representativeness of the sample all influence the generalizability of the study results, and information on these issues should be well documented.

In this study we used, as mentioned before, both the clinical-medical and the psychometric-empirical approach to define psychopathology, ensuring that prevalence estimates from both approaches can be compared within the same sample. We included a large sample of children with a limited ID range, but who constitute over 90% of all ID (no severe or profound ID). Children were randomly selected from all schools for the educable and trainable in the province of Zuid-Holland, the Netherlands. At the time of selection, few children with ID, attended regular schools, so the negative effect often associated with selection is limited relative to many other countries (see Chapter 2 for description of this study's sample and procedure). Finally, a wide age-range (6 to 18 years) was incorporated in the study.

Risk factors of psychopathology in ID

Several theoretical considerations lead to the expectation of an increased risk for psychopathology in children with ID relative to their typically developing peers (Matson & Sevin, 1994). For example, children with ID have, compared to non-ID children, an increased risk for organic disorders, which are known to be related to both ID and psychopathology (e.g. epilepsy, brain damage, specific genetic disorders). Children with ID are also more likely to encounter negative social experiences, like rejection by peers, infantilization, social prejudices, they are much more likely to encounter failure experiences (e.g. due to over-demanding), and they more often grow up in low socio-economic environments.

This expected increased risk of psychopathology in children with ID has been supported by only a few representative epidemiological studies so far. These studies showed that children with ID are at least 3 times more likely to develop psychopathology than children without ID (Koller et al., 1982; Linna et al., 1999; Rutter et al., 1970).

However, little research has been conducted to address factors associated with psychopathology in children with ID. Such epidemiological research, to this point, has been limited to factors like IQ, age and gender. Findings suggest that depressive feelings, anxiety, and antisocial behaviors are more common among those with higher levels of intellectual functioning, while psychotic, self-absorbed, and autistic behaviors are more likely to be found in children with lower IQs, and few or contradicting gender and age differences are found (Borthwick-Duffy et al., 1997; Einfeld & Tonge, 1996a, 1996b; Gillberg et al., 1986; Koller et al., 1982)

In research on non-ID children, a number of child and family variables seem to reoccur as significant predictors of general psychopathology, and some seem to be more specifically associated with internalizing or externalizing problems:

(1) *previous psychopathology of the child*, with relatively stronger homotypic externalizing pathways (i.e. externalizing problems predicting externalizing problems) than internalizing pathways (Beardslee et al., 1996; Esser, Schmidt, & Woerner, 1990; Ferdinand & Verhulst, 1995; Lavigne et al., 1998; Lewinsohn, Gotlib, & Seeley, 1995; Offord et al., 1992; Stanger, McConaughy, & Achenbach, 1992);

(2) *(chronic) physical condition* (Bird, Gould, Yager, Staghezza, & Canino, 1989; Breslau, 1985; Lavigne & Faier-Routman, 1992, 1993; Offord et al., 1992; Wallander & Varni, 1998);

(3) *school/learning problems*, most often related to externalizing problems (Beardslee et al., 1996; Bird et al., 1989; Costello, 1989; Esser et al., 1990; Farrington, 1993; Lewinsohn et al., 1995; Offord, Boyle, & Racine, 1989; Velez, Johnson, & Cohen, 1989; Williams, Anderson, McGee, & Silva, 1990);

(4) *stressful life events* (Bird et al., 1989; Costello, 1989; Esser et al., 1990; Jensen, Bloedau, DeGroot, Ussery, & Davis, 1990; Jensen, Richters, Ussery, Bloedau, & Davis, 1991; Lewinsohn et al., 1995; Stanger et al., 1992; Velez et al., 1989);

(5) *gender*, with boys being more at risk for disruptive behavior and girls for emotional problems (Bird et al., 1989; Costello, 1989; Farrington, 1993; Lewinsohn et al., 1995; Velez et al., 1989; Williams et al., 1990);

(6) *maternal psychopathology* (Biederman et al., 1995; Farrington, 1993; Jensen et al., 1990; Lavigne et al., 1998; Offord et al., 1989; Rae-Grant, Thomas, Offord, & Boyle, 1989; Velez et al., 1989; Williams et al., 1990);

(7) *paternal sociopathy* in relation to externalizing disorders (Farrington, 1993; Offord et al., 1989; Velez et al., 1989);

(8) *family dysfunction* (Biederman et al., 1995; Bird et al., 1989; Lavigne & Faier-Routman, 1993; Offord et al., 1989; Offord et al., 1992; Rae-Grant et al., 1989);

(9) *single parenthood/history of divorce* (Biederman et al., 1995; Bird et al., 1989; Costello, 1989; Jensen et al., 1990; Lavigne et al., 1998; Offord et al., 1989; Rae-Grant et al., 1989; Stanger et al., 1992; Velez et al., 1989);

(10) *low socio-economic status/low income/low parental education*, most often in relation to externalizing problems (Biederman et al., 1995; Bird et al., 1989; Costello, 1989; Jensen et al., 1990; Lavigne et al., 1998; Offord et al., 1989; Stanger et al., 1992; Velez et al., 1989).

Other variables often taken into consideration, like age and ethnicity, give somewhat more contradictory results. In the present study we assessed similar child and family risk factors, as well as more ID-specific variables.

We can conclude that several issues need further clarification in the study of psychopathology in children with ID. First of all, the issue of defining and operationalizing psychopathology in children with ID, and the development of reliable and valid instruments. More research is needed to study the psychometric properties of various instruments to assess psychopathology in children with ID. Second, the need for more differentiated estimates of prevalence of psychopathology in children with ID, by using large, representative and clearly defined samples, various definitions of psychopathology, and standardized assessment methods. Third, there is still very little evidence-based information on the assumed increased

risk of psychopathology in children with ID compared to children without ID. And fourth, there is a need for epidemiological studies identifying correlates and risk factors of psychopathology in children with ID to enhance the identification of those most at risk. In this study, we aim to produce a unique body of research that, to a significant extent, addresses each of these major issues.

Study aims

The present study focuses on three main topics, addressing the following series of questions:

1. *The assessment of psychopathology in children with ID*
    1.1. What is the reliability and validity for both the parent and teacher version of a standardized questionnaire developed for the assessment of emotional and behavioral problems in children with ID, namely the Developmental Behavior Checklist?
    1.2. What is the applicability, in the realm of ID, of standardized questionnaires developed for the assessment of emotional and behavioral problems in typically developed children, namely the Child Behavior Checklist and the Teacher's Report Form?
    1.3. What is the applicability of a standardized parental interview to assess DSM-IV disorders in children with ID, namely the Diagnostic Interview Schedule for Children?
2. *The prevalence and impact of psychopathology in children with ID*
    2.1. What is the prevalence of emotional and behavioral problems in children with ID, and to what extent are these problems related to mental health care referral?
    2.2. What is the prevalence and comorbidity of DSM-IV disorders in children with ID, and to what extent are these disorders associated with significant impairment in everyday life functioning and referral to mental health care services?
    2.3. What is the increased risk of emotional and behavioral problems in children with ID compared to children without ID?
3. *Correlates and predictors of psychopathology in children with ID*
    3.1. What is the influence of educational level on the prevalence of emotional and behavioral problems and DSM-IV disorders?
    3.2. What is the stability of emotional and behavioral problems in children with ID?
    3.3. What are the prospective associations of emotional and behavioral problems with DSM-IV disorders in children with ID, and how specific are these relations?
    3.4. What other child and family factors predict DSM-IV disorders in children with ID?

Structure of this thesis

The methods of data collection, the samples and instruments used in the present study are described in Chapter 2. In Chapter 3 we will examine the factor structure of the Developmental Behaviour Checklist in a large combined Australian/Dutch sample. In Chapter 4 we will assess the internal consistency, test-retest and cross-informant reliabilities of the Dutch translation of the DBC. In this chapter we will also report on the inter-parent agreement, the one-year stability, and measures of convergent, discriminant, and criterion-related validity of the DBC scales. The relationship between the DBC (parent and teacher version), and the CBCL, the TRF, and DSM-IV disorders will also be reported. In Chapter 5 our main focus will be on the prevalence of emotional and behavioral problems as measured

with the CBCL and the TRF, and on comparing the risk for deviant problems in children with ID to that of children without ID. This chapter will also discuss the applicability of the CBCL and the TRF in children with ID. We continue to look at prevalence of psychopathology in Chapter 6. In this Chapter we will look at the prevalence and comorbidity of three main groupings of DSM-IV disorders, namely anxiety disorder, disruptive disorder, and mood disorder. In addition, teacher information on the prevalence of pervasive developmental disorders will be presented. The impact of meeting the criteria for a DSM-IV disorder is studied in relation to experienced impairment in everyday functioning, and mental health care referral. In Chapter 7 we will examine the importance and specificity of various child, and family variables in predicting DSM-IV disorders assessed one-year later. In Chapter 8, conclusions and implications of the study's results will be discussed.

2 | Method

Introduction

This study consists of two data collection phases that examine members of the same sample at two different times. The first phase was initiated in 1997, and about one year later a second data collection phase began. In this chapter we will present the sampling procedures and response rates, some basic sample characteristics, and the instruments and variables used.

The first phase involved selecting a representative sample of children with ID and qualifying them for inclusion in the study. The main caregiver of each participating child was then asked to fill out, among other instruments, two well-regarded instruments to assess psychopathology. The teacher of each participating child was also asked to complete the teacher's version of these instruments. Finally, general practitioners were asked to fill out a questionnaire on the child's health and conditions related to ID to complete the data collection.

During the second phase, a random subset of the parents whose children were included in the first phase study group was contacted again, and each child's mental health was evaluated again using the same instruments as in phase one, and this time also including a comprehensive and standardized interview to asses DSM-IV disorders in children.

Sample and procedure during phase one

Sampling children through schools and day-care centers for the ID

In the summer of 1997, all Dutch schools for the educable (inclusion IQ range about 60 to 80) and trainable (inclusion IQ range about 30 to 60), and all day-care centers for the ID in the province of Zuid-Holland, the Netherlands, were asked to participate in the present study. The province of Zuid-Holland encompasses approximately 20% of all Dutch inhabitants, and includes urban, rural, as well as semi-rural areas.

In 1996, about 2% of all Dutch school-aged children attended a school for the educable or the trainable and about 19% of these children went to school in the province of Zuid-Holland (Central Bureau of Statistics, 2001). In October 1996, 7,607 6- to 18-year-olds attended a school for the educable, 2,092 a school for the trainable (Ministry of Education, 1996), and about 890 children were estimated to visit a day-care center for children with ID (Guidebook for Social Services for Childcare, 1995) in Zuid-Holland.

Every one of these schools and day-care centers were invited to participate in the study. Each school or day-care center was sent sampling instructions and a table of random numbers (based on the number of students of each school or day-care center in 1996), and was requested to randomly select 20% of their students.

Of the 87 schools for the educable 71 schools participated (81.6%), all but one school for the trainable cooperated (*n*=44; 97.8%), and 23 out of 24 day-care centers for the ID (95.8%). These participation rates significantly differed by type of school or day-care center (χ^2=10.0, df=2, *p*<0.01). The reasons for non-participation of schools for the educable were mostly reorganizations (new laws required schools for the ID to merge with other types of special schools and with regular schools) and already being involved in other studies or projects. The resulting sample included 1,204 out of 6,095 educable children (19.8% of students of participating schools, 15.8% of all students attending a school for the educable in the province of Zuid-Holland), 411 out of 2,064 trainable children (19.9% of participating schools, and 18.3% of all students attending a school for the trainable in the province of Zuid-Holland),

and 132 out of 867 children visiting a day-care center (15.1% of participating centers; 14.8% of all children visiting a day-care center for the ID in the province of Zuid-Holland).

Qualifying the sample for inclusion

In order to be included in the study, the sampled students and their families were required to meet certain criteria. Specifically, children were included in the study sample if they were 6 to 18 years old, lived at home for 4 or more days per week, and at least one parent had enough comprehension of the Dutch language to be interviewed. Furthermore, the child was required to attend the school he or she was sampled from at the time the research team could make the first contact.

Each participating school sent us a list of the sampled students, including only anonymous information (date of birth, gender, and school type). The schools themselves provided the initial age, home-care, and attendance qualification through the sampling procedures they followed. Then, because the research team could not initiate direct contact with the parent due to privacy regulations, parents and caregivers of the 1,747 sampled children were sent an invitation letter through the schools. After receiving written consent, parents were contacted by phone or visited at home by the research team, which qualified the parents or caregivers in terms of their proficiency with the Dutch language.

To ensure the highest level of participation possible, after two months, we sent each school a list with anonymous identifiers of children whose parents did not respond to the initial letter. The schools were asked to identify the corresponding children, to send a reminder letter to their parents, and if possible, to phone non-responding parents.

Response of parents or caregivers

We were able to personally contact the parents of 1,497 of the sampled children. Unfortunately, 250 parents (14.3%) did not respond to the letters send through the schools.

We excluded 229 children from the study: 145 children because of parental language problems (assessed through a personal conversation with the parent) and 84 children were excluded after sampling, because they exceeded the age range, had left school in the meantime or because they were no longer living at home.

Finally, 188 parents explicitly refused to participate. Children whose parents did not want to participate personally, but who gave permission for the child's teacher to participate, were included in the study. The sample structure and response rates are illustrated in Figure 2.1

Response of parents during phase one

Nineteen interviewers carried out interviews at home with the parents between November 1997 and July 1998. Of the 1,518 eligible children, a Developmental Behaviour Checklist (Einfeld & Tonge, 2002) and/or a Child Behavior Checklist (Achenbach, 1991a) – the two core instruments of the first phase – was filled out for 680 out of 1,028 educable children (response=66.1%), for 302 out of 368 trainable children (response=82.1%), and for 77 out of 122 children visiting a day-care center (response=63.1%). Response rates of parents were significantly different by type of school or day-care center (χ^2=35.4, df=2, p<0.001). Information on psychopathology was collected for a total of 1,059 children (total response=69.8%; a full 83.5% of those contacted in person by the research team). Results from non-response analyses can be found in Chapters 3 to 7.

In addition, a test-retest, and an inter-parent agreement sample were drawn (see Chapter 4).
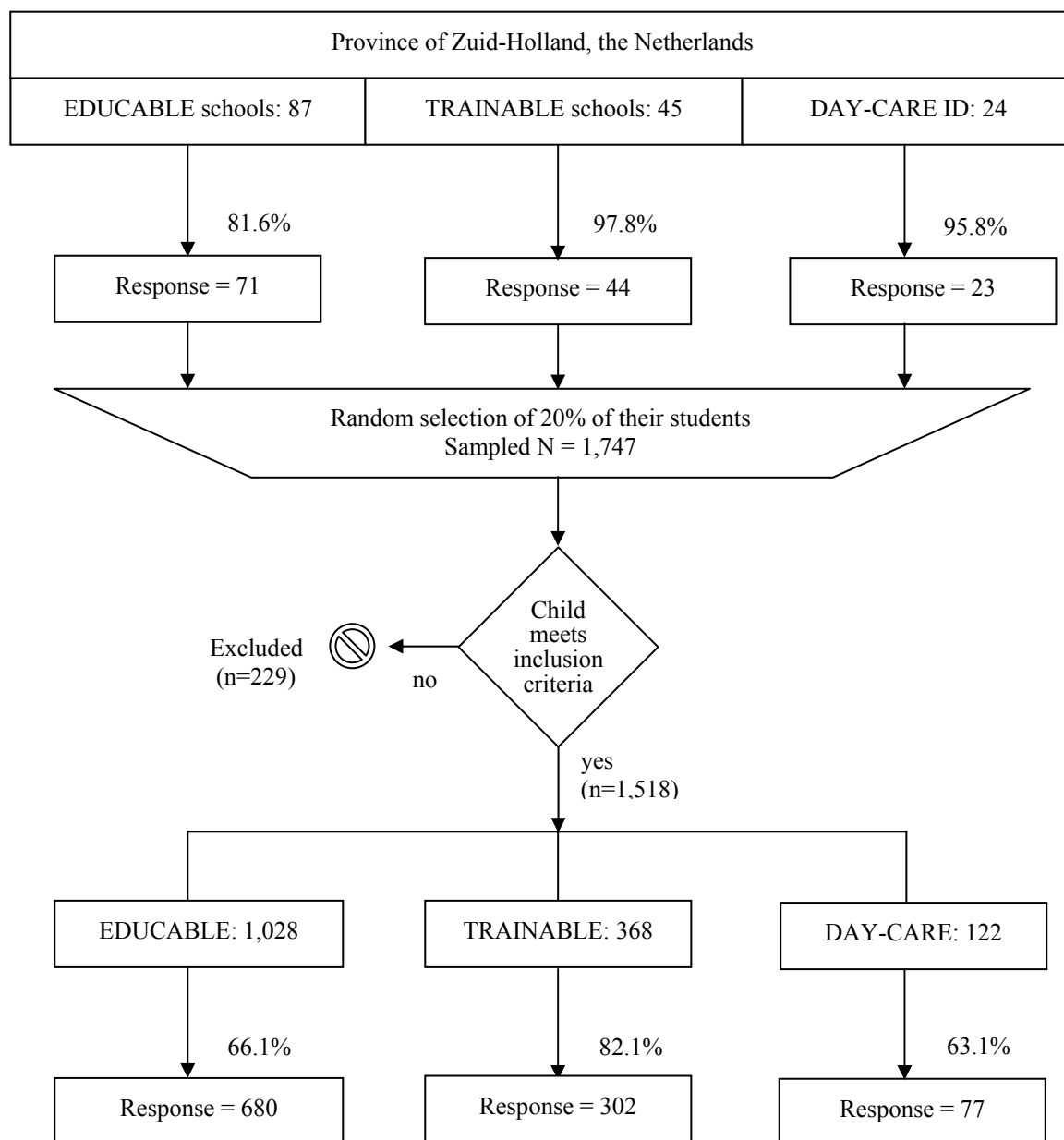
```
┌─────────────────────────────────────────────────────────────────────┐
│                   Province of Zuid-Holland, the Netherlands           │
├───────────────────────┬───────────────────────┬──────────────────────┤
│  EDUCABLE schools: 87  │  TRAINABLE schools: 45 │   DAY-CARE ID: 24    │
└───────────────────────┴───────────────────────┴──────────────────────┘
          │ 81.6%                  │ 97.8%                 │ 95.8%
          ▼                        ▼                       ▼
┌──────────────────┐     ┌──────────────────┐    ┌──────────────────┐
│  Response = 71   │     │  Response = 44   │    │  Response = 23   │
└──────────────────┘     └──────────────────┘    └──────────────────┘
```

Random selection of 20% of their students
Sampled N = 1,747

Child meets inclusion criteria

Excluded (n=229) — no

yes (n=1,518)

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┌──────────────────┐     ┌──────────────────┐    ┌──────────────────┐
│ EDUCABLE: 1,028  │     │  TRAINABLE: 368  │    │  DAY-CARE: 122   │
└──────────────────┘     └──────────────────┘    └──────────────────┘
          │ 66.1%                  │ 82.1%                 │ 63.1%
          ▼                        ▼                       ▼
┌──────────────────┐     ┌──────────────────┐    ┌──────────────────┐
│ Response = 680   │     │ Response = 302   │    │  Response = 77   │
└──────────────────┘     └──────────────────┘    └──────────────────┘
```

Figure 2.1 Sampling and response of schools/day-care centers for the ID and of parents of children with ID

Contacting and response of teachers or group workers during phase one

After receiving written consent from the parents, teachers and group workers were sent a Developmental Behaviour Checklist (DBC-T; Einfeld & Tonge, 2002). Teachers were also sent a Teacher's Report Form (Achenbach, 1991b) by mail.

A Developmental Behaviour Checklist (teacher version) and/or a Teacher's Report Form – the two core instruments of the first phase – was completed for 579 out of 729 educable children (response=79.4%), for 290 out of 322 trainable children (response=90.1%), and for 71 out of 83 children visiting a day-care center (response=85.6%). Response rates were significantly different by type of school or day-care center (χ^2=13.7, df=2, p=0.001). Of the total of 1,134 questionnaire packages sent, 940 were completed and returned (response=82.9%). In addition, a DBC-T test-retest sample was drawn (see Chapter 4).

Contacting and response of general practitioners during phase one

After receiving written consent from the parents, general practitioners were asked to fill out a questionnaire on the child's health and conditions related to ID. Out of the 1,129 questionnaires sent, 864 were filled out and returned (response=76.5%).

Sample characteristics from phase one

Demographic sample characteristics

Table 2.1 presents some demographic characteristics of the first phase sample of children for whom information on psychopathology is available. In addition, prevalence rates regarding the four most common genetic syndromes associated with ID in this sample, which tend to receive most attention in international research (Dykens, 2000), are given. Sample characteristics are presented for the total group and separately for each type of school or day-care center. In the first phase, 64.2% of the children attended a school for the educable, 28.5% a school for the trainable, and 7.3% a day-care center for the ID. Additional information on motor and sensory impairments and epilepsy can be found in Chapter 6.

Table 2.1 Sample characteristics phase one[a]

	ID sample	Educable	Trainable	Day-care	
	% (n=1,059)	% (n=680)	% (n=302)	% (n=77)	p^b
Male	60.0	59.4	59.3	67.5	ns
Low socio-economic status	54.3	61.0	43.7	37.7	.000
Low parental education	69.0	74.5	60.1	56.0	.000
Single parent	15.8	16.4	15.6	11.7	ns
≥ 1 non-Dutch parent	22.7	24.4	21.3	14.3	ns
Down's syndrome	7.6	2.5	22.5	14.3	.000
Fragile-X syndrome	1.1	0.1	3.3	1.3	.000
Prader-Willi syndrome	0.4	0.1	1.0	0.0	ns
Williams syndrome	0.4	0.0	1.3	0.0	.007
Mean age (sd)	11.6 (3.1)	11.6 (2.8)	12.0 (3.3)	9.9 (3.6)	.000
Mean IQ (sd)	67.0 (11.8)	71.6 (8.9)	55.5 (10.1)	N.A[c].	.000

[a]Information on ID related syndromes are based on reports from parents, general practitioners, or teachers.
[b]Differences between groups were tested with χ^2-tests, except for mean age and IQ differences, which were tested with univariate analysis of variance; ns=not significant at p<0.05.
[c]N.A. =not available, but estimated IQ is below 50.

Level of ID

Each teacher was also asked to report the child's IQ score. When no, or insufficient information was reported (e.g. name of IQ test or date of assessment was missing), we personally contacted the schools for further information.

As mentioned in Chapter 1, we were only partly able to recover reliable and recent full IQ scores of the children from school records. In general, IQ scores were missing because an

incomplete IQ test or an unofficial short form was administered to the child. In some cases, only mental age information was available or the information was lost (e.g. due to school changes).

In the end, we were able to recover a full IQ score or subtest scores that could be reliably transformed to a full IQ score (using algorithms from the various IQ test manuals) for 508 out of 680 *educable* children (74.7%), and for 198 out of the 302 *trainable* children (65.6%). This relatively lower percentage for trainable children was primarily due to the fact that for 29 of these children, only their mental age was reported and no, or not enough, (sub)test information was available to compute a full IQ.

Another problem was that some test scores were from a rather early date. Recent IQ scores, defined as less than 5 years old, were available for 462 out of the 508 educable children, and for 184 out of the 198 trainable children. Based on these more recent IQ scores, *educable* children had a mean IQ score of 71.6 (SD=8.9; mode=71; median=72) and *trainable* children had a mean IQ score of 55.5 (SD=10.1; mode=55; median=55). Because of 'floor-effects' in many IQ tests, and because some trainable children miss full IQ scores because they could not be completely tested, this latter score might be an overestimation of their true mean IQ. In addition, we were able to approximate the level of intelligence of 25 trainable children for whom only a mental age was reported by dividing their mental age by their calendar age at the time of assessment (less than 5 years ago) times 100. For these children, a mean of 45.1 (SD=14.8) was found using this rough estimate of IQ.

Another concern is the wide range of IQ tests and IQ-related tests used, especially in the trainable group. Seven major tests were used to assess the level of intelligence in *educable* children, with (any version of) the Wechsler Intelligence Scale for Children (WISC) being most often used (61% of all tests). Fourteen different tests were used to assess level of intelligence or mental age in *trainable* children. Again (any version) the WISC was most commonly used (38% of all tests), followed by (any version of) the Dutch Snijders-Oomen Non-verbal intelligence test (SON; 24.5%).

Including only tests that are originally designed to measure intelligence (WISC, SON, Revision of the Amsterdam Intelligence test for children (RAKIT), the Leiden Diagnostic Test (LDT), and the Stanford-Binet test), we found a mean IQ of 71.9 (SD=8.5; *n*=387) for *educable* children, and a mean IQ of 56.2 (SD=9.7; *n*=149) for *trainable* children. An IQ score below or equal to 70 was found for 43.4% of the educable children, and an IQ score below or equal to 75 for 64.9% of the educable group.

No reliable IQ information was available through the day-care centers for the ID, mostly because for these children it is much more difficult to complete a full test, or because their estimated IQ level was below a measurable score on an IQ test. Mental ages from tests were reported for 25 children, and for 12 children the day-care center made an estimate of the child's mental age. For 33 children we were able to approximate their level of intelligence by dividing their mental age by their calendar age at the time of the assessment and multiplying this number by 100. A mean of 27.1 (SD=13.2) was found using this rough estimate of IQ. In general, children visiting a day-care center for the ID are expected to have an IQ below 50.

Practical and financial limitations kept us from assessing IQ tests ourselves. Therefore, only in Chapter 3 we used information from intelligence tests. To avoid problems regarding imperfect IQ data, we chose to use educational level as a proxy for intelligence level in all other chapters.

Sampling and procedure during phase two

About one year after the first data collection phase (mean interval 409.6 days, SD=79.9), a random sample of 58% of the parents whose children were included in the first phase study sample (*n*=557) were contacted a second time. In the first phase, schools for the educable were less likely to participate than schools for the trainable. Therefore, we sampled in such a way that the distribution of educable and trainable children in the second phase sample represented the original distribution of these educational levels in the Zuid-Holland population (75% educable and 25% trainable). Parents of children who visited day-care centers were excluded from the second phase, as we expected the assessment of DSM-IV disorders – the main focus of the second phase – to be questionable in this small and heterogeneous group of children with more severe levels of ID.

Six families were excluded because they did not meet the language requirements for the more complicated diagnostic interview and 5 children were no longer living at home (eligible *n*=546). Eleven parents could not be contacted, 53 chose not to participate, and 8 did not want to participate in the diagnostic interview. Finally, between October 1998 and June 1999, thirteen trained interviewers carried out 474 home interviews with the parents (response 86.8%).

Sample characteristics from phase two

Table 2.2 presents some sample characteristics for the second phase sample of children for whom information on psychopathology is available. Sample characteristics are presented for the total group and separately for each type of school. In the second phase, 77.4% of the studied children visited a school for the educable, and 22.6% a school for the trainable.

General population sample

In the present study we also made use of a general population sample to compare the prevalence of emotional and behavioral problems in children with or without ID. The original general population sample consisted of 4- to 18-year-old children of Dutch nationality, living in The Netherlands, selected in 1993 by a stratified, multistage cluster and random sampling design (Verhulst et al., 1997). Of the 2,709 eligible children, parent interviews were completed for 2,227 children (82.2%). In addition, for 1,720 of these children a teacher completed a TRF (76.3%). For the present study, only data from children attending regular schools and who were between 6 and 18 years of age were used for comparison, resulting in 1,855 CBCLs and 1,417 TRFs (see also Chapter 5).

Table 2.2 Sample characteristics phase two[a]

	ID sample	Educable	Trainable	
	% (*n*=474)	% (*n*=367)	% (*n*=107)	p^b
Male	61.8	61.6	62.6	ns
Low socio-economic status	49.9	53.3	38.3	.006
Low parental education	66.7	69.6	57.0	.015
Single parent	15.2	15.0	15.9	ns
≥ 1 non-Dutch parent	11.8	12.3	9.0	ns
Down's syndrome	5.3	0.3	22.4	.000
Fragile-X syndrome	0.8	0.0	3.7	.000
Prader-Willi syndrome	0.2	0.3	0.0	ns
Williams syndrome	0.0	0.0	0.0	--
Mean age (sd)	12.9 (3.0)	12.8 (2.8)	13.4 (3.5)	ns

[a]Information on ID related syndromes are based on reports from parents, general practitioners, or teachers.
[b]Differences between groups were tested with χ^2-tests, except for mean age differences, which were tested with univariate analysis of variance; ns=not significant at p<.05.

Study design

The first phase of the present study can be described as a population-based case-control study (Hennekens & Buring, 1987). This type of study allows for both the description of psychopathology in that population (i.e. prevalence survey) and the direct computation of rates of psychopathology in exposed versus non-exposed individuals (e.g. children with or without ID, children with or without parents with a history of mental illness). A limitation of this study's design is the use of prevalent instead of newly diagnosed cases. This makes it hard to decide to what extent a certain factor is a determinant of etiology or/and of prognosis (i.e. cause or/and consequence). The clarification of the temporal sequence between exposure and psychopathology is however not complicated when exposure variables are studied that are more or less stable over time (e.g. gender, level of ID).

In the second phase, a random sample of the first phase responders were contacted again, transforming our study into a follow-up study. Consequently, exposure factors measured in the first phase could be tested for their predictive value (i.e. predictors, predicting the outcome). In addition, temporal relationships of exposure factors with the outcome could be studied, as we were able to control for the level of psychopathology at first assessment (i.e. risk factors, preceding the outcome).

Instruments and measurements

In the first phase, parent, teacher, and general practitioner information was collected and in the second phase only parent information. The core variables and instruments used within each phase can be found in Table 2.3. Further information on these variables and instruments will be presented in Chapters 3 to 7.

Table 2.3 Variables and instruments used during each phase of assessment

	Phase of assessment	
Variables	Phase one	Phase two
Parent report		
Emotional & behavioral problems	DBC-P & CBCL/4-18	DBC-P & CBCL/4-18
Social Competence	CBCL/4-18	CBCL/4-18
Psychiatric disorders	--	DISC-IV-P
Impairment due to psychopathology		DISC-IV-P & CIS
Adaptive behavior	Vineland screener	--
Physical symptoms	WPSI	WPSI
Chronic physical condition	Interview	Interview
Life events	LEQ	LEQ
Psychopathology primary caregiver	YASR-29	YASR-29
Family dysfunction	FAD-GF	FAD-GF
Mental health care referral child/parents/siblings		DISC-IV-P
Parental educational level	Interview	Interview
Socio-economic status		
Other demographic variables		
Teacher report		
Emotional & behavioral problems	DBC-T & TRF	--
Pervasive developmental disorder	PDD-MRS	--
General practitioner report		--
Physical conditions & ID related conditions	Questionnaire	

Note: DBC-P=Developmental Behaviour Checklist-Primary Caregiver; CBCL/4-18=Child Behavior Checklist for 4-18-year-olds; DISC-IV-P=Diagnostic Interview Schedule for Children-Parent interview; CIS=Colombia Impairment Scale; WPSI=Wahler Physical Symptoms Inventory; LEQ=Life Events Questionnaire; YASR-29=short version of Young Adult Self-Report-Form; FAD-GF=Family Assessment Device-General Functioning scale; DBC-T=Developmental Behaviour Checklist-Teacher version; TRF=Teacher's Report Form; PDD-MRS=Scale of Pervasive Developmental Disorder in Mentally Retarded Persons.

3 | Assessing emotional and behavioral problems in children with intellectual disability: Revisiting the factor structure of the Developmental Behaviour Checklist

Marielle C. Dekker
Russell J. Nunn
Stewart E. Einfeld
Bruce J.Tonge
Hans M. Koot

Abstract

The objective of the reported study was to reassess the factor structure of the Developmental Behaviour Checklist (DBC) in a large cross-cultural sample representing all levels of intellectual disability. Parent and teacher DBC ratings on a combined sample of 1,536 Dutch and Australian children and adolescents (ages 3-22) with mild to profound intellectual disability were used. Principal components analyses produced five subscales: Disruptive/Antisocial, Self-absorbed, Communication Disturbance, Anxiety, and Social Relating, explaining 43.7% of the total variance. Internal consistencies of these subscales ranged from 0.66 to 0.91. The revised factor structure of the DBC appears to be an improved and useful tool for assessing emotional and behavioral problems in children with intellectual disabilities.

Introduction

The assessment of emotional and behavioral problems in children and adolescents with intellectual disability (ID) is a complicated matter, and continuous efforts to develop reliable and valid instruments are urgently needed. In 1991, Aman refrained from recommending any instruments for assessing emotional and behavioral problems for general use in children and adolescents with ID, mainly, because of the lack of decent standardization and the inadequate field-testing of the available instruments. However, he mentioned some promising instruments developed or adjusted for use in children and adolescents with all levels of ID residing in institutions as well as living in the community, assessing a wide range of emotional and behavioral problems, and using untrained lay informants. The instruments mentioned by Aman (1991) included the Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1994), the Aberrant Behavior Checklist (ABC; Aman et al. 1985a; Freund & Reiss, 1991), and the Developmentally Delayed Child Behaviour Checklist (DD-CBC; Einfeld & Tonge, 1992). Following Aman's (1991) review, the development of these instruments progressed. Of these, the DD-CBC, now called the Developmental Behaviour Checklist (DBC), has proved to be a useful questionnaire for the description and measurement of behavioral and emotional disturbance in children and adolescents with ID. Emotions and behaviors represented in the DBC are regarded as problems by virtue of their qualitative or quantitative deviance and that they cannot be explained on the basis of ID alone, and that they cause significant distress to the child, the caregivers or the community, as well as the fact that they result in significant added impairment (Einfeld & Tonge, 1992; Rutter et al., 1970). They do not intend to measure or reflect a priori defined (classifications of) diagnostic constructs or categories of aberrant behavior. Both a primary caregiver and a teacher version are available for the DBC. Good reliability has been reported for the original six scales of the DBC, as well as good content, concurrent, and criterion group validity (Einfeld & Tonge, 1992, 1995). Because of these promising properties, the DBC was translated into Dutch to be validated in a large group of children with intellectual disabilities in the Netherlands. The development of a Dutch language version offered the opportunity to re-examine the factor structure of the DBC using a combined Australian-Dutch sample of young people with ID.

Three compelling reasons existed for this re-evaluation. First, the original scales were based on data obtained in Australian samples only. An internal structure based on samples from different countries is more likely to be valid across different cultures. Second, in the sample from which the original DBC scales were derived (Einfeld & Tonge, 1992, 1995),

children with mild ID were underrepresented. Therefore, to enhance its generalizability, the internal structure of the DBC was reassessed using a large Australian-Dutch sample, including children with profound, severe, moderate, and mild ID. A final issue concerned the data analytic techniques employed in the original principal components analysis of the DBC (Einfeld & Tonge, 1995; Tonge et al., 1996), involving exploratory principal components analyses with varimax rotation on a matrix of Pearson product-moment correlations. However, because the DBC uses a 3-point (0,1, 2) or ordinal item rating scale, the calculation of Pearson product-moment correlations, which assume variables measured at interval level, produces an under-estimation of the "true" inter-item correlations and subsequent factor loadings (Jöreskog & Sörbom, 1996; Rowe & Rowe, 1997). Instead it is better to use polychoric correlation coefficients, which assume an ordinal level of measurement. Another problem concerns the use of an orthogonal rotation (varimax) in the original DBC principal components analysis. Given that we may expect considerable overlap and comorbidity of dimensions of childhood emotional and behavioral problems (Angold, Costello, & Erkanli, 1999), it may be preferable to employ an oblique rotation that allows the factors to correlate (Floyd & Widaman, 1995; Rowe & Rowe, 1997). In summary, the goal of this study was to employ appropriate analytic techniques to reassess the most appropriate way to summarize the information contained in the raw DBC data in a cross-cultural sample of children and adolescents representative of the entire range of ID.

Method

Sample and procedure

The Australian sample

The Australian sample (*n*=937) comprised 538 children with ID recruited in 1991 and 1992 from a community epidemiological prevalence study and 399 children included in the original validation studies of the DBC. The sampling procedure for the Australian sample is described in more detail elsewhere (Einfeld & Tonge, 1992; Tonge & Einfeld, 1991). All IQ levels are represented in the Australian sample although it is acknowledged by the original authors of the DBC that there is an under-representation of children in the mild IQ range (Eaton & Menolascino, 1982; Einfeld & Tonge, 1995, 1996b).

The Dutch sample

In 1997, a 20% random sample (*n*=1,747) was selected from all students visiting one of 115 (87.1%) out of all 132 non-residential school settings for the educable (IQ range about 60 to 80) and the trainable (IQ range about 30 to 60), and children from 23 (95.8%) out of 24 day-care centers for children with ID (IQ below 50 and many having additional physical or sensory handicaps) in the province of Zuid-Holland. Children were only included in the sample if (a) they were 6-18 years old, (b) lived at home for 4 or more days per week, and (c) at least one parent had enough comprehension of the Dutch language to be interviewed. Parents and caregivers of the sampled children were sent a letter through the schools, because the research team could not initiate direct contact with the parent due to privacy regulations. The schools sent a reminder to those parents who did not respond to the initial letter, and, if possible, non-responding parents were phoned. Of the final number of 1,518 eligible students 188 parents refused to participate, 23 did not fill out the DBC-P, although they consented to participate in the study, and in 250 cases the non-responding parents could not be contacted

by telephone (final response 69.6%; *n*=1,057). After written consent of the parents, 1,134 teachers and group workers were sent a DBC-T by mail of which 930 were returned (82.0%). A differential dropout by educational level and SES was found. A lower response rate was found for parents of children attending schools for the educable and daycare centers (χ^2=30.2, df=2, *p*<0.001), and a larger (χ^2=11.1, df=2, *p*<0.01) proportion of children from low SES families were in the non-participating group. No differential dropout by age or sex was found. A more detailed description of the Dutch sampling procedure is given elsewhere (Dekker, Nunn, & Koot, 2002).

The combined Australian-Dutch sample

To assess the internal structure of the DBC, data on Australian and Dutch ID subjects were combined (*n*=1,536), representing the whole range of ID (Table 3.1). After excluding borderline functioning children (*n*=296) and children attending schools for the educable for whom no reliable information on their intellectual functioning was available (*n*=162), 599 Dutch subjects remained for this analysis. No significant differences in sex (χ^2=0.06, df=1, ns), or total level of DBC-P emotional and behavioral problems (*t*=-0.87, df=676, ns) were found between educable children with or without reliable information on their IQ. However, the mean age of the educable children with reliable information was significantly lower (11.4 years) compared to those without reliable information (12.3 years; *t*=3.8, df=676, *p*<0.001).

The age and gender distributions of the Dutch and Australian samples were not significantly different from each other (*t*=0.93, df=1514, ns; χ^2=0.07, df=1, ns). However, the Dutch sample contained a higher proportion of children in the mild IQ range compared to the Australian sample (see Table 3.1). A further difference between the samples was that the Australian sample included children living outside the family home in institutional or residential care (approximately 15% to 20%) whereas all children in the Dutch sample lived predominantly at home.

Table 3.1 Combined Australian-Dutch sample characteristics

	Sample		
	Australian (*n* = 937)	Dutch (*n* = 599)	Total (*n* = 1,536)
Age	Mean=12.0 years SD=4.4 Range=3-22	Mean=12.2 years SD=3.3 Range=6-18	Mean=12.1 years SD=4.0 Range=3-22
Sex (% male)	58.3%	58.9%	58.5%
Level if ID:			
Mild	31.7%	62.1%	43.6%
Moderate	40.8%	14.7%	30.6%
Severe	23.6%	4.2%	16.0%
Profound	3.9%	1.8%	3.1%
Mild to Moderate[a]	---	10.2%	4.0%
Moderate to Profound[b]	---	7.0%	2.7%

[a]level of ID estimated from placement in school for the trainable.

[b]level of ID estimated from day-care center placement.

Instruments

DBC-P

The DBC-P (Einfeld & Tonge, 1992, 1995, 2002) is a 96-item checklist completed by parents or caregivers to assess a broad range of behavioral and emotional problems in children with ID aged 4-18 years (Dutch manual: Koot & Dekker, 2001. Most respondents can complete the DBC in 15-20 minutes. The items were derived from 664 clinical records with detailed descriptions of behavioral concerns. The six original empirically derived subscales, Disruptive, Self-absorbed, Communication Disturbance, Anxiety, Social Relating, and Antisocial, showed good internal consistency, and inter-rater and test-retest reliability. Furthermore, the DBC's criterion and concurrent validity are satisfactory and the instrument is specific and sensitive in distinguishing psychiatric disorder cases from non-cases (Einfeld & Tonge, 1992). About 40% of the Australian sample was distinguished as a clinical case, which is within the 30% to 60% range of prevalence estimates of emotional and behavioral problems found in representative population-based studies of school-aged children and adolescents with ID (Chess, 1977; Chess & Hassibi, 1970; Cormack et al., 2000; Gillberg et al., 1986; Jacobson, 1982; Koller et al., 1982; Linna et al., 1999; McQueen et al., 1987; Rojahn et al., 1993; Rutter et al., 1970).

DBC-T

The DBC-T (Einfeld et al., 1998; Parmenter, Einfeld, Tonge, & Dempster, 1998, Einfeld & Tonge, 2002) is a 93-item checklist completed by teachers or teacher's aids designed to assess a broad range of behavioral and emotional problems in children with ID (Dutch manual: Koot & Dekker, 2001). All items have a counterpart on the DBC-P, except for three items related to sleep disturbance that have been deleted and one item that has been added, "Unpopular with other children". The DBC-T has good test-retest and inter-rater reliability (Einfeld et al., 1998). The correlation between parent and teacher ratings on a small subsample (*n*=51) of the Australian sample was non-significant (ICC=0.05; Einfeld et al., 1998). Other studies also find relatively low agreement between parent's and teacher's ratings of emotional and behavioral problems, even though similar internal factor structures are found for both informants (e.g. Achenbach et al., 1987).

Data analysis

The internal structure of the DBC was ascertained by principal components analysis on a matrix of polychoric correlations. An oblique rotation (promax) was performed on four-, five- and six-factor solutions. In total, 90 of 96 items from the parent/primary caregiver version of the DBC were included in the analysis. Item #36 (inappropriate sexual activity) and item #80 (talks about suicide) were removed because of low observed frequencies (4.5% and 4.4%). Also deleted were three items symptomatic of psychotic illness: item #15 (delusions), item #79 (hallucinations) and item #84 (unconnected thoughts) which are acknowledged by the authors of the DBC to be rated unreliably by parents/primary caregivers (Einfeld & Tonge, 1992). The analysis was performed using NOVAX (Waller, 1994), a stand-alone factor analysis program for ordinal polytomous data. In accordance with guidelines proposed by Achenbach (1991a), it was decided that factors must contain at least six items with a loading of 0.30 or greater. To reduce the number of cross-loadings, only items loading 0.40 or greater on a secondary factor were retained.

Results

The analysis produced 21 factors with an Eigenvalue greater than 1. However, examination of the scree plot suggested that a four-, five- or six-factor solution was most appropriate. The four-factor solution accounted for 40.8% of the total variance. Examination of the unrotated variance components indicated that the Self-Absorbed factor accounted for most of the variance (24.1%) followed by the Disruptive/Antisocial factor (8.6%), Social Relating factor (4.5%) and the Communication Disturbance factor (3.6%). The five-factor solution accounted for 43.7% of the total variance and included the four previous factors plus an additional factor pertaining to anxiety problems (accounting for 2.9% of the variance) (Table 3.2). After promax rotation, four items from the original 90 failed to load significantly on any of the factors: item #12 (distressed when hearing particular sounds), item #19 (easily distracted), item # 65 (scratches or picks skin), and item #67 (sleeps too little). Four items loaded significantly on more than one factor: item #14 (deliberately runs away), item #50 (overactive) and item #86 (throws or breaks objects) cross-loaded on the Disruptive/Antisocial and Self-Absorbed factors, and item #3 (aloof) loaded on both the Self-Absorbed and Social Relating factors. Inter-factor correlations after promax rotation ranged from -0.12 (Communication Disturbance with Social Relating) to -0.34 (Disruptive/Antisocial with Anxiety). The internal consistency of the Disruptive/Antisocial and Self-Absorbed factors was high (α=0.91 and α=0.89) and satisfactory for the Communication Disturbance and Social Relating factors (α=0.73 and α=0.71). The internal consistency of the Anxiety factor was marginally less than satisfactory (α=0.66). Of the 96 items of the DBC-P, 86 are represented in this five-factor solution. The six-factor solution (accounting for 46.2% of the total variance) included the previous five factors plus a sixth factor containing six items mostly relating to over-activity and distractibility that had been included in the Disruptive/Antisocial factor from the five-factor solution. However, it also included the item 'stands too close to others', which did not appear to fit very well with the rest of the items. Furthermore, the forced six-factor solution had a negative impact on the item compositions of some of the other subscales. It was therefore decided that the five-factor solution provided the best overall summary of the dimensionality of the DBC.

A principal components analysis of items in the teacher version of the DBC (*n*=1,155) produced a solution that was similar but not identical to that found for the parent checklist. Similar to the procedure with the DBC-P, three items that were symptomatic of psychotic illness were removed (#15 delusions, #79 hallucinations, and #84 unconnected thoughts), and item #21 (eats non-food), item #42 (lights fires), and item #77 (talks about suicide) were removed because of low observed frequencies. The four-factor solution included Disruptive/Antisocial, Self-Absorbed, Communication Disturbance, and Social Relating subscales that were similar in item composition to that found in the DBC-P five-factor solution. It was found that 81.5% of the DBC-T items on the Disruptive/Antisocial subscale corresponded with the Disruptive/Antisocial subscale of the DBC-P. The same was true for 77.4% of the items of the Self-Absorbed subscale, 70% of the items of the Social Relating subscale, and 53.8% of the items of the Communication Disturbance subscale. The DBC-T Communication Disturbance subscale did not incorporate the stereotypic behaviors represented in the corresponding DBC-P subscale. Three items of the Social Relating subscale, and two items of the Communication Disturbance subscale of the DBC-T

Table 3.2 Item loadings of the revised subscales of the Developmental Behaviour Checklist

SCALE		SCALE	
Number of items; $\alpha_{DBC-P}/\alpha_{DBC-T}$		*Number of items; $\alpha_{DBC-P}/\alpha_{DBC-T}$*	
Item[a] (original DBC scale[b])	Loading	Item[a] (original DBC scale[b])	Loading
I. DISRUPTIVE/ANTISOCIAL		**II. SELF-ABSORBED**	
27 items; 0.91/0.90		*31 items; 0.89/0.91*	
Abusive, swears (D)	0.86	Eats non food (S-A)	0.85
Lies (D/AS)	0.81	Hums, grunts (S-A)	0.78
Stubborn, disobedient (D)	0.78	Mouths objects (S-A)	0.75
Manipulates others (D)	0.73	Bites others (--)	0.67
Steals (AS)	0.73	Soils though trained (S-A)	0.66
Very bossy (D)	0.71	Poor sense of danger (S-A)	0.65
Impulsive (D)	0.68	Hits or bites self (S-A)	0.65
Kicks, hits others (D)	0.67	Plays with unusual objects (S-A)	0.63
Impatient (D)	0.64	Smells, tastes, licks objects (S-A)	0.62
Temper tantrums (D)	0.64	Repetitive activity (S-A)	0.60
Irritable (D)	0.62	Stares at lights (S-A)	0.59
Jealous (D)	0.61	Repeated movements (SR)	0.59
Whines a lot (D)	0.59	Wanders aimlessly (S-A)	0.56
Hides things (AS)	0.57	Flicks objects (S-A)	0.55
Overly attention seeking (D)	0.56	Throws or breaks objects[cross-I] (S-A)	0.54
Lights fires (AS)	0.56	Bangs head (S-A)	0.54
Says things not capable of (D)	0.54	Gorges food (--)	0.52
Easily led by others (--)	0.53	Urinates outside toilet (S-A)	0.52
Talks too much (CD)	0.53	Masturbates in public (S-A)	0.46
Rapid mood changes (D)	0.51	Laughs for no reason (SR)	0.46
Throws or breaks objects[cross-II] (D/S-A)	0.50	Over-active[cross-I] (S-A)	0.46
Refuses to go to school (AS)	0.45	Over-exited (D)	0.46
Noisy or boisterous (D)	0.45	Deliberately runs away[cross-I] (S-A)	0.46
Deliberately runs away[cross-II] (S-A)	0.42	Strips off clothes (S-A)	0.44
Over-active[cross-II] (S-A)	0.41	Aloof, in own world[cross −V] (SR)	0.43
Tense (D)	0.39	Grinds teeth (--)	0.43
Lacks self-confidence (--)	0.37	Under-reacts to pain (CD)	0.42
		Screams a lot (S-A)	0.41
		Poor attention span (--)	0.39
		Unusual body movements (--)	0.36
		Facial twitches (SR)	0.33

Table 3.2 (Continued)

SCALE *Number of items; $\alpha_{DBC-P}/\alpha_{DBC-T}$* Item[a] (original DBC scale[b])	Loading	SCALE *Number of items; $\alpha_{DBC-P}/\alpha_{DBC-T}$* Item[a] (original DBC scale[b])	Loading
III. COMMUNICATION DISTURBANCE		**IV. ANXIETY**	
13 items; 0.73/0.73		*9 items; 0 .66/0.62*	
Arranges objects (--)	0.61	Distressed when separated (A)	0.60
Echolalia (CD)	0.51	Distressed being alone (A)	0.60
Talks to self or imaginary others (CD)	0.49	Nightmares, sleep walks[dbc-p] (A)	0.52
Confuses pronouns (CD)	0.49	Fears things, situations (A)	0.49
Repeats words or phrases (CD)	0.46	Cries for no reason (A)	0.42
Unusual tone or rhythm (CD)	0.44	Shy (A)	0.37
Unrealistically elated (CD)	0.42	Loss of appetite (--)	0.35
Obsessed idea or activity (--)	0.41	Upset over small changes (A)	0.32
Interested in mechanical things (--)	0.41	Fussy eater, food fads (A)	0.30
Doesn't mix with own age group (--)	0.38	**V. SOCIAL RELATING**	
Preoccupied with 1 or 2 interests (--)	0.35	*10 items; 0.71/0.76*	
Over-affectionate (--)	0.33	Under-active (SR)	0.59
Stands too close to others (--)	0.31	Doesn't show affection (SR)	0.55
		Depressed, unhappy (SR)	0.55
		Sleeps too much[dbc-p] (SR)	0.50
		Resists being cuddled (SR)	0.49
		Aloof, in own world[cross-II] (SR)	0.45
		Avoids eye contact (SR)	0.41
		Over-breathes, other complaints (--)	0.38
		No response to others (SR)	0.38
		Prefers to be on his/her own (S-A)	0.36

[a]The terms used are summary terms, not the actual wording of the items in the checklist;

[cross-I]=cross loading of scale I; [cross-II]=cross loading of scale II; [cross-V]=cross loading of scale V; [dbc-p]=item only listed in DBC-P

[b]Original DBC scales: D=Disruptive; S-A=Self-absorbed; CD=Communication Disturbance; A=Anxiety; SR=Social Relating; AS=Antisocial; -- = not on an original DBC scale

corresponded to the items of the Anxiety subscale of the DBC-P. Unlike the DBC-P five-factor solution, the DBC-T five-factor solution was unable to clearly separate anxiety symptoms into a distinct and meaningful subscale.

The results indicate that the item composition of the Disruptive/Antisocial, Self-Absorbed, and Social Relating subscales are similar across the parent and teacher versions of the DBC. The composition of the Communication Disturbance subscale is less similar and, as indicated earlier, the principal components analysis of the DBC-T failed to identify a separate Anxiety factor. Application of the DBC-P five-factor solution to the teacher sample data produces subscales with good internal consistency for the Disruptive/Antisocial and Self-Absorbed subscales and satisfactory consistency for the Communication and Social Relating subscales. The Anxiety factor in the teacher sample is marginally less than satisfactory (see Table 3.2). Given the broad similarities between the factor structures of the parent and teacher versions of the DBC and to facilitate comparison of parent and teacher ratings, it was decided to apply the parent five-factor solution to both the parent and teacher checklists.

Finally, we examined the correlations between the original and the revised DBC subscales (based on unit-weighted summation of the items within each scale) (see Table 3.3). Correlation coefficients exceeding 0.90 were found between the corresponding subscales, except for the Communication Disturbance subscales which correlated 0.81. The revised Communication Disturbance scale included additional items related to stereotypical behaviors, for example 'arranges objects in strict order', 'gets obsessed with idea or activity', 'overly interested in mechanical things', 'preoccupied with one or two interests'. The original sixth subscale 'Antisocial' correlated 0.66 with the revised Disruptive/Antisocial subscale, which incorporated all the five items of the original Antisocial scale. Similar results were obtained for the original and revised subscales of the DBC-T.

Table 3.3 Pearson product-moment correlation coefficients[a] between corresponding revised and original DBC-P and DBC-T subscales

Revised DBC subscales	Original DBC subscales	DBC-P (n=1,536)	DBC-T (n=1,155)
Disruptive/Antisocial	Disruptive	0.97	0.97
	Antisocial	0.66	0.53
Self-Absorbed	Self-absorbed	0.96	0.96
Communication Disturbance	Communication Disturbance	0.81	0.82
Anxiety	Anxiety	0.91	0.89
Social Relating	Social Relating	0.92	0.92

[a]All $p<0.05$.

Conclusion

This study aimed to establish a good summarization of the patterns of correlation coefficients among the observed variables of the DBC. Five interpretable and clinically relevant subscales for the DBC-P were derived, explaining 44% of the variance in a combined Australian/Dutch sample. This revised scale structure constitutes an improvement over the original structure given that it is based on a larger sample and one that better represents all levels of ID. Furthermore, the revised component structure explains a larger proportion of the item variance compared to the proportion accounted for by the original principal component analysis of the DBC (44% versus 33%) (Einfeld & Tonge, 1995). Overall, the percentage of variance explained in this study is similar to that found for other instruments assessing emotional and behavioral problems in children with intellectually disability. For example, a percentage of explained variance of 51% was found for both the English and the French version of the Nisonger Child Behavior Rating Form (Aman et al., 1996; Girouard, Morin, & Tassé, 1998; Tassé et al., 1996; Tassé et al., 2000), and for the Aberrant Behavior Checklist a percentage of explained variance of 52% was found in a sample of children attending special classes (Marshburn & Aman, 1992).

Furthermore, the revised scale structure incorporates 86 of the 96 items of the DBC and has four cross-loadings, compared to 81 items and five cross-loadings in the original DBC structure. The 10 items that do not have component loadings above 0.30 on any of the subscales (four items) or that were excluded in the analyses because of low frequency (three items) or because the symptoms were psychotic in nature (three items), were retained in the DBC, because of their clinical relevance in relation to the inventorial purpose of the DBC, and

are used in the calculation of the Total Behavior Problem Score, but are not included in the calculation of the subscales.

The reliability of the scales was satisfactory as shown by the good to high internal consistency of the subscales Self-Absorbed, Disruptive/Antisocial, Communication Disturbance, and Social Relating. A moderate internal consistency was found for the Anxiety subscale. However, we decided to incorporate this scale in the final solution because anxiety problems are seen as clinically relevant indicators of internalizing problems. Furthermore, anxious, tense, fearful behavior is one of the factors that tend to reoccur in empirically derived instruments for children with ID (Aman, 1991). Future revisions of the DBC should consider adding or revising the items in the Anxiety scale to improve its psychometric properties.

The internal structure of the DBC-T was similar to the Disruptive/Antisocial, Self-Absorbed, and Social Relating scales found for the DBC-P. A four-factor structure without a separate Anxiety scale fitted the DBC-T data best. This structure may suggest that teachers generally provide less differentiated ratings of internalizing problems than parents do. Although, the DBC-P and DBC-T internal structure did not fit perfectly, it was decided to use the same items and scales for both the DBC-P and DBC-T to enhance cross-informant comparisons. The internal structure of the DBC-P was chosen, because it differentiated best between internalizing behaviors, and because the internal consistency measures of the DBC-T, using the DBC-P five-factor solution, were very similar to those found for the DBC-P. A similar level of consistency in factor structure across rater types has been found for the Nisonger Child Behavior Rating Form (Aman et al., 1996; Tassé et al., 2000), and the Aberrant Behavior Checklist in a community sample of children attending special classes (Marshburn & Aman, 1992).

The correlation between parent and teacher revised DBC subscale scores varied from 0.27 for the Anxiety scale to 0.57 for the Self-absorbed scale in a large (*n*=851) representative Dutch sample (Dekker, Nunn et al., 2002). This moderate cross-informant agreement between parent and teachers is similar or even somewhat higher to those reported in many other studies assessing emotional and behavioral problems in both children with and without intellectual disability (Achenbach et al., 1987; Aman et al., 1996; Freund & Reiss, 1991). Situation specificity of problem behaviors, together with observer-specificity may account for the modest agreement between parents and teachers (Van der Ende, 1999).

The correlations between similar original and revised subscales of the DBC-P and the DBC-T showed that the basic structure of the DBC is stable. However, we did not find any reason for including a separate scale incorporating only antisocial behavior, as was found in the original 1995 analyses. Furthermore, the revised Communication Disturbance scale incorporated four items reflecting stereotypical behaviors. None of these clinically significant behaviors were represented in the original scale structure of the DBC. Adding stereotypical behaviors to the communication disturbance items might suggest the use of another name for this factor, for example 'Communication disturbances & stereotypical behaviors'. However, because changing the name does not mean that the factor is any better understood, we preferred to keep the original DBC factor name. The observation that both communication disturbances and stereotypical behavior tend to co-occur is in correspondence with the behavioral pattern seen in children with pervasive developmental disorders (American Psychiatric Association, 1994).

Aman (1991) concluded that the following factors tend to recur with considerable consistency across five empirically derived instruments assessing emotional and behavioral problems in children and adults with ID: (a) Aggressive, Antisocial, Self-Injurious behavior,

(b) Withdrawn behavior, (c) Stereotypic behavior, and (d) Hyperactivity. In addition, (e) Repetitive verbalizations, (f) Anxious, Tense, Fearful behavior, and (g) Self-Injurious behavior tended to emerge also, but with less consistency. The DBC scale structure shows similarities with these reoccurring structures. The DBC Disruptive/Antisocial scale corresponds to (a), Self-absorbed to (c) and (g), Social Relating to (b), Communication Disturbance is related to both (c) and (e), and Anxiety to (f).

It could be argued that Confirmatory Factor Analysis (CFA) would be a better way to evaluate the internal structure of the DBC. However, at this point, and even more when the DBC items were selected, there is not sufficient theory regarding the dimensionality of emotional and behavioral problems in children and adolescents with intellectual disability. The DBC items were not selected based on a theory which related them to some underlying construct, but purely by the fact that those behaviors and emotions were seen in this particular population and considered to reflect more than just ID. The CFA approach to construct validation is too restrictive, given the fact that no sufficient theory on dimensionality of emotional and behavioral problems is available, that the principal component solution found in this and other studies explains only about 50% of all the variance, and the large amount of variables involved. Finally, regardless of these objections, we have tried to fit the original six-factor DBC solution on the Dutch sample, and both the original six-factor and the revised five-factor DBC solution on an independent large Dutch-Friesian sample (n=838) representative of all levels of ID, using both polychoric and Pearson correlations as an input matrix. Unfortunately, all correlation matrices were not positive definite, and the output could not to be trusted.

Study strengths and limitations

The combined Australian-Dutch sample was large, with much more than five subjects per observed variable, as suggested by Tabachnick and Fidell (1989). Furthermore, the sample was representative of the full range of ID. The empirically derived DBC scales in this study are based on the most comprehensive sample of intellectually disabled children and adolescents currently available. Because principal component and internal consistency analyses are descriptions of relationships between items, and not descriptions of populations, we expect differential non-response of subjects within the samples, for example, children from families with low SES being underrepresented, not to be problematic.

The scale structure of the DBC may need further refinement when future samples of clinically referred children with ID become available, although one can wonder whether the expected high co-occurrence of problem behaviors in referred samples will actually enhance the internal structure of the DBC and its discriminative validity. On the other hand, combinations of rare problem behaviors, which are more common in referred populations of children with ID, might be important indicators of emotional and behavioral problems. In addition to our preliminary psychometric studies (Dekker, Nunn et al., 2002), the validity of the DBC subscales may be further tested using consensus-based clinical syndromes (e.g. DSM-IV) as well as biological and observation-based behavioral data as a criterion.

Because the DBC was designed to assess emotional and behavioral problems in the intellectually disabled, children in the borderline IQ range were excluded from the Principal Component Analysis. However, a post-hoc analysis showed that the structure of the DBC based on the Australian-Dutch sample with these children included in the analysis was similar to the structure presented in this paper. The question remains whether emotional and behavioral problems of children with borderline intellectual functioning are most similar to

problems of children from the general population or to those of children with ID. In other words, are these children best served by using instruments designed for the general population, such as the Child Behavior Checklist (Achenbach, 1991a), or by instruments like the DBC, especially developed for children with ID.

Although the revised factor structure reported here is a significant improvement on the original factor analysis of the DBC, only a modest amount of the total item variance has been accounted for (44%). Although this is not surprising given the length and complexity of the DBC, and comparable with the amount of variance explained in similar instruments, it suggests that a significant amount of item redundancy remains in the checklist. Floyd and Widaman (1995) suggest that a good factor solution should explain approximately 80% of the estimated common variance. Although there is little doubt that the 96-item DBC-P provides a comprehensive listing of relevant individual symptoms in young people with ID, and therefore has many benefits in terms of its ability to provide a detailed assessment of an individual's mental health status, this investigation suggests that it may be possible to capture the main dimensions of emotional and behavioral problems with a smaller number of key items loading on each factor. The development of a shortened version of the DBC, including a revision of some of the content of the factors Communication Disturbance, Anxiety, and Social Relating for research purposes to enhance the psychometric properties of the DBC, is a task that should be pursued in the future.

Clinical and research implications

As the prevalence of emotional and behavioral problems in children with ID is estimated to be much larger than in the general population (Koller et al., 1982; Linna et al., 1999; Rutter et al., 1970), and given the problems in defining emotional and behavioral problems in children with ID, the use of standardized, reliable and valid instruments to assess and record emotional and behavioral problems, and to evaluate interventions is recommended in this under-diagnosed and under-treated group.

In clinical applications, the improved factor structure will allow for meaningful comparisons of an individual's percentile score against norms. Standardized norms for the DBC for both the Australian and the Dutch population of the intellectually disabled will enable clinicians to relate subscale scores obtained for individual clients with those of a representative group of children with a similar level of ID. The revised subscales also promise to provide enhanced screening properties for clinical syndromes such as anxiety and autistic spectrum disorders (Brereton, 2000; Gray & Tonge, 2000).

Good test-retest reliability, a moderate inter-parent and parent-teacher agreement was found in a large representative sample of Dutch children with ID and borderline intellectual functioning. In addition good criterion-related validity was shown by significant mean DBC scale differences between referred and non-referred children, and between children with or without a corresponding DSM-IV diagnosis (Dekker, Nunn et al., 2002). Further research is needed to assess the reliability and validity of the revised DBC-P and DBC-T subscales in both clinical and community samples. In the Australian sample a clinical cut-off score of 46 or larger for the Total Behavior Problem Score was found to discriminate best between psychiatric cases and non-cases (Einfeld & Tonge, 1992, 1995). However, more research is needed to try to replicate these findings in other samples and to establish valid scale cut-off scores that discriminate best between children and adolescents in need of professional mental health care versus those who are not. Finally, research is needed to test whether the present internal structure will replicate across different samples.

4

Psychometric properties of the revised Developmental Behaviour Checklist scales in Dutch children with intellectual disability

Marielle C. Dekker
Russell J. Nunn
Hans M. Koot

Abstract

The present study assessed the reliability and validity of the revised scales of the Developmental Behaviour Checklist (DBC) in a Dutch sample of children with intellectual disability (ID). The psychometric properties of the parent and teacher version of the DBC were assessed in various subsamples derived from a sample of 1,057 Dutch children (age range = 6-18 years) with ID or borderline intellectual functioning. Good test-retest reliability was shown both for the parent and teacher versions. Moderate inter-parent agreement and a high one-year stability was found for the scale scores. Construct validity was satisfactory, although limited by high informant variance. The DBC scales showed good criterion-related validity, as indicated by significant mean differences between referred and non-referred children, and between children with and without a corresponding DSM-IV diagnosis. The reliability and validity of the revised DBC scales are satisfactory, and the DBC is recommended for clinical and research purposes.

Introduction

Many children (henceforward also denoting adolescents) with intellectual disability (ID) have considerable emotional and behavioral problems, which can be an additional source of burden to the child's and parents' life. Prevalence estimates of psychopathology in children with ID range from 14% to more than 80% (Borthwick-Duffy, 1994; Bregman & Hodapp, 1991). Compared to children from the general population, children with ID are about four to eight times more likely to show deviant levels of emotional and behavioral problems (Koller et al., 1982; Linna et al., 1999; Rutter et al., 1970). The large differences in prevalence are mainly attributable to the use of different samples, (e.g. referred and community samples), variance in definitions of psychopathology, and the lack of use of standardized instruments to assess psychopathology (Borthwick-Duffy, 1994; Singh, Sood, Sonenklar, & Ellis, 1991).

Assessment of emotional and behavioral problems among children with ID is complicated. First of all, these children are less likely to be able to report on their own experiences and feelings, making it desirable to use parents and teachers as important sources of information (Dykens, 2000). Secondly, confounding factors of both conditions can make it difficult to decide whether certain behaviors are caused by mental disturbance or ID (Borthwick-Duffy, 1994; Lovell & Reiss, 1993), emphasizing the importance of establishing separate norms for children with ID. Furthermore, these children are likely to show deviant behaviors that are seldom reported for children without ID, such as self-absorbed behaviors (e.g. eating non-food, humming and grunting), communication disturbances (e.g. echolalia and confusing pronouns), and social relating problems (e.g. avoiding eye contact and not showing affection) (Einfeld & Aman, 1995; Einfeld & Tonge, 1995). This suggests that there is a surplus value in using instruments specifically designed for children with ID to assess emotional and behavioral problems over instruments used in general child mental health care, such as the Child Behavior Checklist (CBCL; Achenbach, 1991a).

Given the problems in defining psychopathology in children with ID and the need to improve the assessment of mental health problems in this under-diagnosed and under-treated group, reliable standardized instruments assessing a broad range of emotional and behavioral problems are necessary.

Aman (1991) refrained from recommending any instruments for general use in children with ID, mostly because of the lack of decent standardization and inadequate field-testing of

the available instruments. However, the above author mentioned some promising instruments, including the Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1994), the Aberrant Behavior Checklist (ABC; Aman et al., 1985a; Freund & Reiss, 1991), and the Developmentally Delayed Child Behaviour Checklist (DD-CBCL; Einfeld & Tonge, 1992). After Aman's (1991) review the development of these instruments progressed. Of these, the DD-CBC, now called the Developmental Behaviour Checklist (DBC), has attractive properties. Both a primary caregiver (DBC-P) and a teacher version (DBC-T) are available. Most of the original six scales of the DBC (i.e. Disruptive, Self-Absorbed, Communication Disturbance, Anxiety, Social Relating, and Antisocial) had satisfactory internal consistency, as well as good test-retest reliability. Furthermore, the DBC has been shown to have good content, and convergent validity, and good specificity and sensitivity with regard to expert clinician judgement of the subject as a psychiatric case or non-case (Einfeld & Tonge, 1992, 1995; Einfeld et al., 1998). Because it had demonstrated good psychometric properties in an Australian sample, both the parent and teacher versions looked very promising for use in the Netherlands.

The DBC scales were recently revised. The use of a large Australian-Dutch sample, representative of the entire spectrum of ID, resulted in five scales, i.e. Disruptive/Antisocial, Self-Absorbed, Communication Disturbance, Anxiety, and Social Relating, which differed from the original scales in item composition, and were easily interpretable and internally consistent (Dekker, Nunn, Einfeld, Tonge, & Koot, 2002). The present study investigated the reliability and validity of these new DBC scales.

The first goal of this study was to assess the reliability of the revised DBC scales in children aged between 6 and 18 years attending schools for the educable and trainable or visiting a day-care center for children with ID in the Netherlands. To this end, the internal consistencies, the test-retest reliabilities, and the inter-rater agreements of the DBC filled out by parents (DBC-P) and teachers (DBC-T), were determined.

Second, the present authors aimed to assess the validity of the DBC scales. In the absence of an objective or definite standard criterion they addressed the convergence of the measured DBC constructs with similar constructs from other instruments assessing psychopathology. In several studies the CBCL (Achenbach, 1991a; Verhulst et al., 1996), and the TRF (Achenbach, 1991b; Verhulst et al., 1997), originally developed for the non-ID population, were used in samples of children with ID, and showed promise (Borthwick-Duffy et al., 1997; Curfs, Verhulst, & Fryns, 1991; Floyd & Phillippe, 1993; Floyd & Saitzyk, 1992; Floyd & Zmich, 1991; Pueschel, Bernier, & Pezzullo, 1991; Van Lieshout, de Meyer, Curfs, Koot, & Fryns, 1998). The present authors expected a high positive correlation between DBC-P/DBC-T and CBCL/TRF scales representing similar syndromes of psychopathology. The discriminant validity of the DBC was addressed by examining the divergence between scales supposed to tap different dimensions of psychopathology, and between DBC scales and measures of adaptive functioning assessed with the Vineland Screener (Sparrow, Carter, & Cicchetti, no date).

To examine criterion-related validity, comparisons were made between scale scores of children referred for emotional and behavioral problems versus non-referred children, as reported by their parents. However, referral to mental health care is not a perfect criterion for the presence and severity of the emotional and behavior problems of thea child. Apart from behavioral and emotional problems other factors, such as motivation and knowledge of parents to search for help, parents' own mental well-being, resilience of the family, and availability of care, also influence referral status (Verhulst et al., 1996). Therefore, the present

authors also examined the power of several DBC-P scales to discriminate between children with a corresponding DSM-IV diagnosis (Axis I, including Anxiety Disorder, Mood Disorder, and Disruptive Disorder).

Materials and methods

Sample and procedure

Initial sample

In 1997, a 20% random sample was selected of all students from 115 (87.1%) out of all 132 non-residential school settings for the educable (inclusion IQ range about 60 to 80) and the trainable (inclusion IQ range about 30 to 60) in the province of Zuid-Holland (*n*=1,615). Additionally, 20% of the children from 23 (95.8%) out of 24 day-care centers for children with ID (IQs below 50 and many having additional physical or sensory handicaps) were randomly recruited (*n*=132). Children were only included in the sample if (1) they were between 6 and 18 years old; (2) they lived at home for ≥ 4 days a week; and (3) at least one parent had enough comprehension of the Dutch language to be interviewed. The parents and caregivers of the sampled children were sent a letter through the schools, because the research team could not initiate direct contact with the parent due to privacy regulation. After receiving written consent, parents were contacted by phone or visited at home. The schools sent a reminder to those parents who did not respond to the initial letter, and if possible, non-responding parents were telephoned. Parents were interviewed at home between November 1997 and July 1998.

Of the selected subjects, 145 were excluded because of parental language problems, eight because of exceeding the age range, and 76 because they had left their school or daycare center, or moved during the period of data collection. Out off the final number of 1,518 eligible subjects, 188 parents refused to participate, 23 did not fill out the DBC-P, although they consented to participate in the study, and in 250 cases the non-responding parents could not be contacted by telephone. The final response rate for the DBC-P, based on all eligible subjects, was 69.6% (*n*=1,057; 83.4% of those contacted in person by the research team). After the written consent of the parents was received, teachers and group workers were sent a DBC-T by mail and 930 out of 1,134 questionnaires were returned (82.0%). DBC-T information was available for 82.2% of the children for whom also a DBC-P was completed. In all, a DBC-P or a DBC-T was completed for 1,118 children (74.3%), of whom 64.1% attended a school for the educable, 28.6% a school for the trainable, and 7.2% a daycare center for children with ID. The mean age of the subjects was 12.1 years (SD=3.1), 60.1% of the children were male, and 56.1%, 28.8% and 15.2% of the children came from families with low, medium and high socio-economic status (SES), respectively.

In addition, parents filled out the CBCL (Achenbach, 1991a), and teachers filled out the TRF (Achenbach, 1991b). Parents were interviewed with the Vineland screener (Sparrow et al., no date), and gave information about their child's contacts with mental health care services.

No significant differences were found in the distribution of sex (χ^2=3.4, df=1, *p*=0.07) and year of birth (*t*=-1.1, df=1477, *p*=0.29) between children for whom a DBC was completed, and for those for whom this was not the case. There was a differential dropout by educational level and SES, with fewer schools for the educable agreeing to participate (χ^2=8.5, df=2,

$p<0.05$), a lower response rate for both these schools and daycare centers ($\chi^2=30.2$, df=2, $p<0.001$), and a larger proportion of children from low SES-families in the non-participating group ($\chi^2=11.1$, df=2, $p<0.01$).

DBC-P test-retest sample

The test-retest reliability of the DBC-P scales was assessed by having a random sample of 88 parents complete the DBC-P twice, with a mean interval of 17 days (SD=7.7 days). Out of the 114 eligible parents, 26 refused to fill out the DBC–P a second time.

DBC-T test-retest sample

The test-retest reliability of the DBC-T scales was addressed by having a random sample of 69 teachers complete the DBC-T twice, with a mean interval of 18.9 days (SD=7.4 days). Out of the 87 eligible teachers, 18 did not return the second DBC–T.

Inter-parent agreement sample

The inter-parent agreement was addressed by having a random sample of 96 spouses complete the DBC-P, with a mean interval of 10.9 days (SD=8.0 days). Out of the 118 eligible families, 22 spouses refused to participate.

Follow-up sample

About one year later (Time 2), the present authors contacted a random sample of about 55% of Time 1 respondents ($n=557$) for a second time. Six families were excluded because they did not meet the language requirements for the more complicated diagnostic interview to be held this time, and five children were no longer living at home (eligible $n=546$). At time 2, the present authors were not able to get in contact with 11 parents, 51 parents refused to participate, and eight parents did not fill out the DBC-P. A DBC-P was filled out by 474 parents (86.8%) for whom a valid Time 1 DBC-P was available, with a mean time interval of 409.6 days (SD=79.9 days). These parents also completed the Diagnostic Interview Schedule for Children (DISC-P; Shaffer, Fisher, Lucas, Dulcan, Schwab-Stone, 2000; Dutch translation by Ferdinand, van der Ende, and Mesman). In addition the parents were interviewed with the Columbia Impairment Scale (CIS; Bird et al., 1993, 1996).

No significant differences between children from responders and non-responders were found for any of the Time 1 DBC-P scale scores (all p>0.05), their Time 1 age ($t=1.5$, df=544, $p=0.13$), or type of school ($\chi^2=0.1$, df=1, $p=0.74$). Time 2 non-responders were more likely to be the parents of girls ($\chi^2=6.6$, df=1, $p=0.01$), and to have a low SES ($\chi^2=15.9$, df=2, $p<0.001$) than Time 2 responders.

At Time 2 the sample consisted of 77.4% of children originally attending a school for the educable and 22.6% a school for the trainable, which is as expected. The mean age was 12.9 years (SD=3.0), and 61.8% of the subjects were male. Almost 50%, 32.8% and 16.3% of the children came from families with low, medium and high SES, respectively.

Instruments

DBC-P

The DBC-P (Einfeld & Tonge, 1992, 1995; Dutch translation: Koot and Dekker) is a 96-item checklist to be completed by parents or caregivers and designed to assess a broad range of behavioral and emotional problems in children and adolescents with ID. Most respondents

can complete the DBC in 15-20 minutes. The six original empirically derived subscales showed good reliability. The Cronbach's alphas of the DBC-P range from 0.67 to 0.91. Test-retest reliabilities, using intra-class correlations (ICC) range from 0.51 to 0.87, and the inter-parent agreement ICC was 0.80. Furthermore, the DBC-P has been proven to have good convergent validity, as was shown by a 0.86 correlation between the Total Problems scores of the DBC-P and the Maladaptive Behaviour section of the Adaptive Behaviour Scales (ABC; Nihira, Foster, Shellhaas, & Leland, 1975). Finally, the DBC-P has known sensitivity and specificity with regard to expert clinician judgement of the subject as a psychiatric case or non-case, with an area under the Receiver Operating Characteristics (ROC) curve of 92% (Einfeld & Tonge, 1992, 1995).

DBC-T

The DBC-T (Einfeld et al., 1998; Parmenter et al., 1998; Dutch translation: Koot and Dekker) is the 94-item teacher version of the DBC-P to be completed by teachers or teacher's aids and designed to assess a broad range of behavioral and emotional problems in children and adolescents with ID. All items have a counterpart on the DBC-P, except for three items related to sleep disturbance that have been deleted and one item that has been added, i.e. Unpopular with other children. Factor analysis using DBC-T data alone has yielded a factor structure similar to that of the factor structure from combined DBC-P and DBC-T data (Einfeld et al., 1998). No published data is available on internal consistency or test-retest reliability of the DBC-T scales. The inter-rater reliability (intra-class correlation teacher-aide) of the DBC-T Total Problems score was found to be 0.60 (Einfeld et al., 1998). The correlation between the DBC-P and the DBC-T Total Problems score is low (r=0.05). However, this is consistent with other studies that have found low agreement between parents' and teachers' ratings of psychopathology (e.g. Rutter et al., 1970; Achenbach et al., 1987).

The present study uses the DBC-P and DBC-T scales that were recently re-evaluated in a combined sample of 1,536 Dutch and Australian children (age = 3-22 years) representative of all levels of ID (Dekker, Nunn, Einfeld et al., 2002). The results were largely consistent across both parents and teachers. Five well-interpretable scales were obtained and consisted of the Disruptive/Antisocial, Self-Absorbed, Communication Disturbance, Anxiety, and Social Relating scales These scales explained 43.7% of the total variance. The Disruptive/Antisocial scale (27 items) includes a variety of acting-out problems, such as being abusive, swearing, lying, being disobedient, being manipulative, and stealing. The Self-Absorbed scale (31 items) includes items like eating non-food, humming, mouthing objects, and biting others. The Communication Disturbance scale (13 items) includes behaviors such as echolalia, talking to self or imaginary people or objects, confusing pronouns, and repeating words or phrases. The Anxiety scale (9 items DBC-P; 8 items DBC-T) includes items related to elevated anxiety, such as distressed when separated, distressed when being alone, nightmares, and fearing things or situations. Finally, the Social Relating scale (10 items DBC-P; 9 items DBC-T) includes items like being under-active, not showing affection, being depressed or unhappy, and sleeping too much. In the combined Dutch-Australian sample, the Cronbach's alphas of these five scales ranged from 0.66 to 0.91 for the DBC-P, and from 0.62 to 0.91 for the DBC-T.

CBCL and TRF

The CBCL and TRF (Achenbach, 1991a, 1991b) are standardized reports on children's emotional and behavioral problems over the preceding 6 months, as reported by parents, and teachers. Good reliability and validity have been demonstrated for the Dutch CBCL and TRF (De Groot, Koot, & Verhulst, 1994, 1996; Verhulst, Akkerhuis, & Althaus, 1985; Verhulst, Berden et al., 1985; Verhulst et al., 1996, 1997). In the present sample, a mean Cronbach's alpha of 0.73 for the CBCL scales and of 0.77 for the TRF scales was found for children attending schools for the educable and trainable. The Cronbach's alphas for the CBCL and TRF scales were highly comparable to those reported for the Dutch general population and referred samples (Verhulst et al., 1996, 1997).

Vineland Screener

The Vineland Screener was designed as a measure of the personal and social sufficiency of individuals from birth to 19 years of age for the purpose of screening large groups, and can be administered to the parent or caregiver of the child by a trained interviewer. From a pool of 261 items from the Vineland Adaptive Behavior Scales (VABS; Sparrow et al., 1984), 45 items were selected on the basis of ease of administration, reliability, domain coverage, and strength of correlation with the total scales (Sparrow et al., no date). In the 6- to 18-year-old age range, the Vineland Screener addresses the domains Communication, Daily Living Skills, and Socialization. The Vineland Screener has been standardized on a large representative American sample and is compatible with the normative tables in the Vineland Survey Form Manual. Correlations between the equated Vineland Screener domain raw scores and the Vineland full-scale domain standard scores range from 0.92 to 0.95 for the 6- to 18-year-olds (Sparrow et al., no date).

Referral status

During a home interview parents were asked if their child was ever referred, examined, treated, or admitted to hospital for emotional or behavioral problems.

Diagnostic Interview Schedule for Children - Parent Version (DISC-IV-P)

The Diagnostic Interview Schedule for Children - Parent Version (DISC-IV-P) is designed to obtain DSM-IV diagnoses, and to be administered by well-trained interviewers who need not have formal clinical training. The preliminary results of the National Institute of Mental Health DISC-IV showed that this version has moderate to good test-retest reliability, and moderate to good agreement with clinicians' ratings (Shaffer, Fisher, Lucas, Dulcan et al., 2000). With the permission of the authors, the DISC-IV was translated into Dutch (by Ferdinand, van der Ende, & Mesman) following the original text as closely as possible. Parents were interviewed by one of 13 trained lay interviewers. In this study the present authors administered questions addressing Anxiety Disorders (i.e. separation anxiety disorder, panic disorder, agoraphobia, specific phobia, social phobia, obsessive-compulsive disorder, posttraumatic stress disorder, generalized anxiety, and selective mutism), Mood Disorders (major depressive disorder, dysthymic disorder, manic disorder, and hypomanic Disorder), and Behavior Disorders (attention-deficit/hyperactivity disorder, conduct disorder, and oppositional defiant disorder). The DSM-IV diagnoses were derived from DISC-IV-P scores by applying algorithms provided by the authors of the DISC-IV.

Columbia Impairment Scale (CIS).

The Columbia Impairment Scale (CIS) is a 13-item scale covering four major areas of functioning: (1) interpersonal relations; (2) broad areas of psychopathology; (3) functioning at school or work; and (4) use of leisure time. Items are scored from 0 ("no problem) to 4 ("a very bad problem") (Bird et al., 1993). The CIS can be administered to the parent of the child by a trained lay interviewer. Good reliability was found, as well as good construct, discriminant, and concurrent validity (Bird et al., 1993, 1996). The optimal threshold ≥16 recommended by Bird et al. (1996) was used to distinguish between those with definite impairment and all others.

Results

Reliability of the DBC

The reliabilities of the DBC-P and the DBC-T are given in Table 4.1. The Cronbach's alphas of the revised DBC scales in the Dutch sample ranged from 0.66 to 0.91 (mean α=0.78) for the DBC-P, and from 0.67 to 0.91 (mean α=0.79) for the DBC-T. The test-retest reliabilities, assessed by the intraclass correlation (ICC) (Shrout & Fleiss, 1979), ranged from 0.76 to 0.89 (mean ICC=0.84) for the DBC-P, and from 0.69 to 0.91 (mean ICC=0.79) for the DBC-T. Inter-parent intraclass correlation coefficients ranged from 0.52 to 0.67 (mean ICC=0.61).

Stability of the DBC-P

As shown in Table 4.1, Pearson product-moment correlation coefficients between DBC-P scale scores over a one-year period, ranged from 0.66 to 0.75 (mean *r*=0.70).

Construct validity of the DBC

First, convergent validity was assessed by correlating the corresponding DBC-P and DBC-T scales (see Table 4.1). All Pearson correlation coefficients were significantly different from zero (all *p*<0.001), and were predominantly in the medium range according to Cohen's (1988) criteria. The Total Problems scales of both instruments showed a correlation of 0.42. The correlation coefficients ranged from 0.29 for the Anxiety scales to 0.57 for the Self-Absorbed scales. The mean correlation between similar scales of the DBC-P and DBC-T was 0.39. All correlation coefficients between dissimilar scales were smaller than their convergent validities, except for one: the Self-Absorbed scale of the DBC-P showed a correlation of 0.41 with the Communication Disturbance scale of the DBC-T, while the correlation between both Communication Disturbance scales was 0.35. Finally, 82% of the correlation coefficients between dissimilar scales of the DBC within the same informant exceeded the correlation coefficients between similar scales of the DBC across informants, suggesting high informant variance.

Next, convergent validity between corresponding scales of the DBC-P and the CBCL (n=1,040), and the DBC-T and the TRF (*n*=850) was assessed (see Table 4.2). The correlation between the Total Problem scales of both instruments was 0.85 and the average correlation between similar scales was 0.63 for both parents and teachers. The correlation between the Disruptive/Antisocial scale of the DBC-P and the Aggressive Behavior scale of the CBCL, and between the Social Relating scale of the DBC-P, and the Withdrawn scale of the CBCL exceeded 0.70. Similar results were found for the teacher versions of both instruments.

Table 4.1 Cronbach's alpha, test-retest reliability, inter-parent agreement, one-year stability, and parent-teacher agreement of the Developmental Behaviour Checklist Parent (DBC-P) and Teacher (DBC-T) versions

	DBC-P				DBC-T		
DBC Scale	Cronbach's α (n=1,057)	Test-retest ICC (99%CI)[a][b] (n=88)	Inter-parent ICC (99%CI) (n=80)	One-year Stability[c] (n=474)	Cronbach's α (n=930)	Test-retest ICC (99%CI) (n=69)	Parent-Teacher Agreement[c] (n=851)
Disruptive/Antisocial	0.91	0.85 (0.75-0.91)	0.64 (0.43-0.78)	0.74	0.91	0.87 (0.76-0.93)	0.37
Self-Absorbed	0.88	0.86 (0.77-0.92)	0.67 (0.47-0.80)	0.75	0.88	0.91 (0.83-0.95)	0.57
Communication Disturbance	0.74	0.82 (0.71-0.90)	0.57 (0.34-0.73)	0.67	0.74	0.73 (0.54-0.84)	0.35
Anxiety	0.66	0.89 (0.82-0.94)	0.52 (0.28-0.70)	0.66	0.67	0.69 (0.48-0.82)	0.27
Social Relating	0.72	0.76 (0.62-0.86)	0.65 (0.45-0.79)	0.67	0.75	0.75 (0.57-0.86)	0.39
Total Problems	0.95	0.86 (0.77-0.92)	0.55 (0.31-0.72)	0.75	0.94	0.85 (0.74-0.92)	0.42

[a]ICC=Intra Class Correlation Coefficients, all ICC coefficients $p<.001$.

[b]99%CI = 99% Confidence Interval.

[c]All Pearson product-moment correlation coefficients $p<.001$

Table 4.2 Pearson correlation coefficients[a] between corresponding Developmental Behaviour Checklist Parents Version (DBC-P) and Child Behavior Checklist (CBCL) scales, and DBC Teacher Version (DBC-T) and Teacher's Report Form (TRF) scales

Corresponding DBC – CBCL/TRF scales	DBC-P – CBCL (n=1,040)	DBC-T – TRF (n=850)
Disruptive/Antisocial – Aggressive Behavior	0.85	0.87
Disruptive/Antisocial – Delinquent Behavior	0.62	0.64
Disruptive/Antisocial – Attention Problems	0.62	0.60
Anxiety – Anxious/Depressed	0.51	0.50
Social Relating – Withdrawn	0.71	0.73
Social Relating – Anxious/Depressed	0.47	0.43
Total Problems – Total Problem Score	0.85	0.85

[a]All Pearson product-moment correlation coefficients p<.001.

Moderate to high correlations (cf. Cohen, 1988) were also found between the DBC Disruptive/Antisocial scale and the CBCL/TRF Attention Problems scale and Delinquent Behavior scale, as well as between the DBC Anxiety and Social Relating scale and the CBCL/TRF Anxious/Depressed scale.

Out of the 132 comparisons between dissimilar constructs of DBC and the CBCL/TRF, 17 exceeded their corresponding convergent validity coefficients (12.9%). Some high correlation coefficients were found between constructs that were not a priori hypothesized to be similar; for example, for parents a correlation of 0.67 was found between the Self-Absorbed scale and the Attention Problems scale, and a correlation of 0.60 between the Disruptive/Antisocial scale and the Anxious/Depressed scale. A high correlation between the Self-Absorbed scale and the Attention Problems scale was also found for teachers (r=0.71).

Finally, discriminant validity was assessed by relating the DBC scales to three domains of adaptive behavior, i.e. Communication, Daily Living Skills, and Socialization, as assessed with the Vineland Screener. The correlation between the DBC scales Self-Absorbed, Communication Disturbances and Social Relating and the three domains of the Vineland screener ranged from -0.20 to -0.41 (see Table 4.3). The correlation between the Total Problems scale of the DBC-P and DBC-T and the Total Adaptive Functioning scale of the Vineland Screener was -0.32 and -0.31, respectively.

Criterion-related validities of the DBC-P and DBC-T

Criterion-related validity was assessed by comparing scale scores of all children who had ever been referred to mental health services with those of children who never have been referred, and by comparing scale scores of children with a DSM-IV diagnosis versus those without one. The mean scores of children who at least once in their life were referred for professional help for emotional and behavioral problems, and children who were never referred for this type of help are shown in Table 4.4 for both the DBC-P and DBC-T. Children who had ever been referred showed the highest mean scores on all DBC scales. Mean DBC Total Problem scores for referred children were about one standard deviation above the mean of children who were never referred. Percentages of explained variance in DBC scores accounted for by referral status obtained from analyses of variance (ANOVAs) accounting for

sex, age, and SES differences, ranged from 1.9% to 12.0%, indicating small to moderate effects (Cohen, 1988). Few, and small effects were found for the demographic variables (see Table 4.4).

Next, ANOVAs showed that, after adjustment for sex, age, and SES differences, the mean DBC-P scales at Time 2 varied significantly with meeting the criteria for a corresponding DSM-IV diagnosis (see Table 4.5). Children could meet the criteria for any of the following DSM-IV diagnoses: Anxiety Disorder, Disruptive Disorder, or Mood Disorder (defined by a dysthymic disorder or major depression). Any Disorder was defined by meeting the criteria for at least one of these disorders. In addition, children differed in whether or not they showed definite signs of impairment, as indicated by a CIS score of ≥16. Post-hoc Bonferroni pairwise comparisons showed that children who met DSM-IV criteria for Any Disorder, Anxiety Disorder, or Disruptive Disorder and who showed signs of definite impairment scored significantly higher on the corresponding DBC-P scales than children without signs of definite impairment. In turn these children, scored significantly higher on the corresponding DBC-P scales than those who did not meet the criteria for a DSM-IV disorder. A significant mean difference on the Social Relating scale of the DBC-P was only found between children who met the DSM-IV criteria for Mood Disorder and who showed definite signs of impairment versus children who did not meet the criteria for a DSM-IV diagnosis. Moderate to large effect sizes were found for Any Disorder, Disruptive Disorder, and Anxiety Disorder (cf. Cohen, 1988).

No significant main effects for the demographic variables sex, age, and SES were found.

Discussion

The reliability of the scales was satisfactory for both the DBC-P and DBC-T, as shown by the high internal consistency of the scales Self-Absorbed and Disruptive/Antisocial, and the moderate to high internal consistency for Communication Disturbance and Social Relating. The Anxiety scale showed somewhat lower internal consistency. Reliability was further confirmed by the good test-retest reliability for both the DBC-P and the DBC-T. The test-retest reliability of the DBC-P of 0.86 was similar to the test-retest reliability of 0.83 found in the Australian sample on which the DBC was developed (Einfeld & Tonge, 1992).

Even though the mean interval between inter-parent ratings of the DBC-P was 11 days, the present authors found a mean correlation of 0.61 between spouses, which is similar to the 0.59 correlation between similar role informants found in a large meta-analysis on cross-informant agreement on psychopathology (Achenbach et al., 1987). The inter-parent intra-class correlation for the Total Problems Score (0.55) was lower than the 0.80 correlation found in the original Australian sample (Einfeld & Tonge, 1992). This might be explained by the time interval between the two ratings in our present study. In addition, it should be noted that intra-class correlations are not directly comparable with Pearson correlations.

Considerable one-year stability was found for the DBC-P, suggesting the absence of extreme changes in the ranking of problem behavior over a one-year period. This was also found for problem behaviors in children in the general population (Verhulst & Koot, 1995). Parent-teacher agreement was only moderate. A moderate cross-informant agreement between parents and teachers on similar scales of psychopathology has been reported for many other instruments assessing psychopathology across samples of non-ID children (Achenbach et al., 1987). In the original Australian study a parent-teacher intra-class correlation for the Total Problem Score of 0.05 was found (Einfeld & Tonge, 1995), which is lower than the 0.42

Table 4.3 Significant[a] Pearson correlation coefficients between Developmental Behaviour Checklist Paren (DBC-P) and Teacher (DBC-T) versions scales and the domains of adaptive functioning of the Vineland Screener

DBC scales	DBC-P (n=1,032)				DBC-T (n=863)			
	Communication	Daily Living Skills	Socialization	Total Adaptive Functioning	Communication	Daily Living Skills	Socialization	Total Adaptive Functioning
Disruptive/Antisocial	ns	ns	-0.20	-0.11	-0.11	ns	-0.14	-0.12
Self-Absorbed	-0.33	-0.41	-0.40	-0.43	-0.30	-0.36	-0.30	-0.37
Communication Disturbance	-0.29	-0.33	-0.33	-0.37	-0.26	-0.29	-0.25	-0.31
Anxiety	-0.06	-0.11	-0.12	-0.11	-0.17	-0.25	-0.21	-0.24
Social Relating	-0.23	-0.23	-0.37	-0.31	-0.20	-0.20	-0.27	-0.26
Total Problems	-0.22	-0.27	-0.35	-0.32	-0.25	-0.26	-0.28	-0.31

[a]All reported Pearson Product-Moment correlation coefficients p<0.05; ns = not significant.

Table 4.4 Percentage of variance[a] explained by referral status (i.e. ever received help for emotional and behavioral problems, as reported by parents) and demographic variables [i.e. sex, age (6-12 and 13-18 years) and socio-economic status; i.e. low, medium or high)] in the Developmental Behaviour Checklist Parent (DBC-P) and Teacher (DBC-T) version scales[a]

	DBC-P (n=1,057)						DBC-T (n=869)					
	Referral status						Referral status					
	Help ever (n=470)	No help (n=587)	Referral				Help ever (n=388)	No help (n=481)	Referral			
DBC scale	Mean (SD)	Mean (SD)	Status[b]	Sex[c]	Age[d]	SES[e]	Mean (SD)	Mean (SD)	Status	Sex	Age	SES
Disruptive/Antisocial	16.9 (10.1)	9.3 (7.3)	12.0^R	--	--	2.2^L	10.9 (8.7)	7.1 (7.1)	4.4^R	2.5^M	2.6^Y	--
Self-absorbed	11.1 (8.6)	5.4 (5.5)	10.6^R	1.5^M	1.8^Y	--	7.4 (7.4)	4.1 (5.2)	3.7^R	0.6^M	0.7^Y	--
Communication												
Disturbance	5.3 (4.2)	3.0 (3.2)	6.9^R	--	--	0.1^H	2.7 (3.4)	1.6 (2.3)	3.8^R	--	--	--
Anxiety	4.3 (3.1)	2.8 (2.6)	5.9^R	0.8^F	1.3^Y	--	2.2 (2.4)	1.6 (2.0)	1.9^R	0.5^F	--	--
Social Relating	4.4 (3.3)	2.2 (2.6)	9.1^R	--	1.9^O	--	3.6 (3.1)	2.3 (2.6)	4.7^R	--	--	--
Total Problems	42.9 (22.9)	23.7 (17.3)	14.4^R	--	--	--	27.5 (19.4)	17.2 (15.2)	6.1^R	0.9^M	1.0^Y	--

[a]Only significant (p<0.05) main effects are reported.

[b]R: referred children scored higher.

[c]M: Male participants scores higher; F: Female participants scores higher.

[d]Y: Younger children (6-12 years) scored higher; O: older children (13-18 years) scored higher.

[e]L:Low SES scored higher; H: High SES scored higher.

Table 4.5 Means and percentages of explained variance (PEV) of Developmental Behaviour Checklist Parent Version (DBC-P) scales by corresponding DSM-IV diagnosis with or without definite impairment[a]

Corresponding DBC scales – DSM-IV disorders[a]	DBC-P[b]						
	DSM-IV criteria met + CIS ≥16		DSM-IV criteria met		DSM-IV criteria not met		
	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	PEV
Total Problems – Any Disorder	53.4 (21.2)	72	34.3 (20.7)	110	18.6 (13.8)	278	26.3
Anxiety – Anxiety Disorder	5.7 (3.2)	47	4.2 (3.0)	61	2.2 (2.1)	352	11.2
Disruptive/Antisocial – Disruptive Disorder	25.0 (9.5)	52	18.2 (9.5)	63	8.8 (7.0)	346	24.9
Social Relating – Mood Disorder[c]	6.2 (2.7)	17	3.0 (4.2)	2	2.8 (2.8)	454	4.9

[a]DSM-IV diagnosis (last year) based on standardized interview with DISC-IV Parent Version. Definite impairment is defined by a CIS score ≥16.

[b]*Post Hoc* Bonferroni tests for pairwise comparisons of the observed means were all significant (p<0.01), except for the pairwise comparison of the mean of the Social Relating scale between children who met the DSM-IV criteria for Mood Disorder compared to children with No Mood Disorder, and between children who met the DSM-IV criteria for Mood Disorder versus children with a Mood Disorder plus definite signs of impairment.

[c]Mood Disorder is defined by Dysthymic Disorder or Major Depression.

correlation found in the present study. Again, these two measures are not directly comparable. Situation-specificity of problem behaviors is likely to contribute to the relatively low cross-informant correlation coefficients, especially in community populations, in which children may tend to show less situation-pervasive problems. Observer-specificity can also play an important role, for example, different observers can have different perspectives, tolerance levels, or thresholds for reporting behavior (Van der Ende, 1999). A clearer picture of the meaning of this disparity between parent and teacher ratings may be obtained from future studies that employ structured behavioral observations in both the home and school environment, as well as parent and teacher reports.

Large informant effects for the DBC scales were suggested by the fact that the vast majority of the correlation coefficients between dissimilar scales of the DBC within the same informant exceeded the correlation coefficients between similar scales of the DBC across informants. Results from other studies using multi-trait, multi-method analyses (Fergusson & Horwood, 1987; Greenbaum, Dedrick, Prange, & Friedman, 1994) have shown similar large informant effects. These analyses also indicate high co-occurrence of different behavioral/emotional problems. The high co-occurrence of different problem behaviors is a well-known phenomenon in child psychiatry. It is likely that apparent co-morbidity results from a higher order pattern of co-occurring problems, or that two or more problem behaviors result from the same underlying cause (Verhulst & Koot, 1992).

Results suggested a moderate to high degree of convergent validity between corresponding scales of the DBC-P/DBC-T and the CBCL/TRF. Furthermore, the DBC-P Total Problems score correlated 0.85 with the CBCL Total Problem Score. The same high correlation was found between the DBC-T and the TRF. These correlation coefficients are similar to the correlation of 0.86 found between the DBC-P and the ABC (Aman et al., 1985a) in the Australian study (Einfeld & Tonge, 1992).

Finally, supportive evidence for discriminant construct validity was found in the present study. The Disruptive/Antisocial scale and the Anxiety scale of the DBC had small correlation coefficients with domains of adaptive functioning, indicating discriminant validity. The DBC Total Problems, Self-Absorbed, Communication Disturbance and Social Relating scales showed moderate correlation coefficients with domains of adaptive functioning, suggesting that the level of adaptive functioning affected the scores on these scales. However, none of the correlation coefficients exceeded -0.41, indicating that the DBC and the Vineland Screener tap related but different concepts.

Evidence for criterion-related validity of the DBC scales was demonstrated by significantly higher mean scores for children who had ever been referred for mental health services versus those who had never been referred. A more narrow definition of referral status, such as being referred to mental health care in the past year, might have resulted in even larger mean differences. In addition, the mean DBC scale scores were significantly higher for children with a related DSM-IV diagnosis compared to children without a diagnosis. The mean DBC-P scale scores also differed significantly between children with or without definite signs of impairment in addition to a related DSM-IV diagnosis, except for Mood Disorder. These results indicate that the DBC-P scale scores reflect both presence and experienced severity of a related DSM-IV disorder.

It should be noted that all measures of psychopathology used in this study to validate the DBC do not make a perfect standard. The CBCL, the TRF, and the DSM-IV taxonomy are not specifically designed and validated for children with ID. However, because there is a lack

of any definite criteria to define psychopathology, the simultaneous use of multiple methods is viewed as an appropriate and useful way to validate instruments, as well as to come to a better understanding of psychopathology in children with ID (Aman, 1991).

Clinical and research implications

Because the prevalence of psychopathology in children with ID is estimated to be much larger than in the general population (Koller et al., 1982; Linna et al., 1999; Rutter et al., 1970), the use of standardized, reliable and valid instruments to assess and record psychopathology, and to evaluate interventions is needed in this under-diagnosed and under-treated group. The present study shows that the DBC-P and DBC-T can be valuable tools, as indicated by their good reliability and satisfactory validity. Other assets are their ease of administration and the broad range of emotional and behavioral problems that can be assessed, making the DBC a useful structured information-gathering tool for clinical practice and research. The availability of Dutch (and Australian) standardized norm scores enables users to relate scale scores obtained for individual clients with those of a representative group of children with a similar level of ID. Distinction between probable cases and non-cases may be based on a well-chosen cut-point of scores. In the Australian study a cut-off score for Total Problems at the sixtieth percentile was shown to be best for discriminating between cases and non-cases, ascertained by child psychiatrists' ratings (Einfeld & Tonge, 1992). However, more research is needed to decide on which cut-off scores are optimal in discriminating cases from non-cases in groups with different levels of ID in different samples. Finally, the DBC or specific scales of the DBC can be used to measure effects of interventions in a standardized way. Where individual items may not have enough variance to be sensitive to small changes, scale scores and the Total Problem score may give adequate measures of change (Einfeld & Tonge, 1992).

Although, significant differences in DBC mean scores were found for children with and without a DSM-IV diagnosis in the present study, more research is needed to see whether the DBC is successful as a screening tool for specific disorders, such as anxiety and autistic spectrum disorders (Brereton, 2000; Gray & Tonge, 2000). Furthermore, additional research is needed to clarify the issue to what extent the behavioral/emotional problems tapped by the DBC are primarily linked to psychopathology in the individual or to contextual or environmental variables. This is an important issue, since treatment for behavior problems resulting from environmental influences may be vastly different from treatment for individual psychopathology. As for now, the DBC is well-suited to tap behavioral and emotional problems that can be reliably reported by parents and teachers independent of the origin of the problems.

A limitation of the present study is that no direct observations of the child's behavior by mental health professionals or researchers were available. Assessing the relation between the DBC scores and direct observations and evaluation by professionals should be an important focus in the continuing validation process of the DBC. The use of the DBC in referred samples will give important additional information on the discriminative power of the DBC regarding the cut-off points on DBC scales which distinguish best between psychiatric cases and non-cases. Therefore, the application of the DBC in non-selective samples of referred children with ID should be a major focus in future research.

Another issue to be addressed regards the question of which kind of instruments are best suited to the assessment of behavioral and emotional problems in children with borderline intellectual functioning, or children with developmental disabilities and normal IQ such as Asperger's Syndrome. In addressing these issues, the incremental value of the DBC over ratings scales developed for children from the average population needs to be assessed.

5 | Emotional and behavioral problems in children and adolescents with and without intellectual disability

Marielle C. Dekker
Hans M. Koot
Jan van der Ende
Frank C. Verhulst

Abstract

The main objective of this study was to assess and compare the prevalence of a wide range of emotional and behavioral problems in children with and without intellectual disability (ID). We studied 1,041 non-residential children randomly selected from special schools for educable (IQ 60 to 80) and trainable children (IQ 30 to 60) without severe additional physical or sensory impairments, and compared them to 1,855 children randomly selected from the general population (both ages 6 to 18). Parents completed the Child Behavior Checklist (CBCL), and teachers the Teacher's Report Form (TRF). Controlling for sex, age, and socioeconomic status, we found that both educable and trainable children had significantly higher mean scores on all CBCL and TRF scales than children without ID, except for trainable children on the scales Anxious/Depressed and Somatic Complaints. Almost 50% of children with ID had a Total Problem score in the deviant range compared to about 18% in children without ID. Compared to children without ID, the most prominent problem behaviors of educable children were Social Problems, Attention Problems, and Aggressive Behavior, and trainable children had an increased risk for Social Problems, Attention Problems, Withdrawn and Thought Problems. Elevated scale scores reflected differences between children with and without ID over a broad range of items, and not solely on items more likely to be related to developmental delay. Therefore, problem areas covered by the items in these scales deserve special attention in the mental health care of children with ID.

Introduction

Several theoretical considerations and empirical findings lead to the expectation of an increased risk of co-occurrence of psychopathology and ID (Matson & Sevin, 1994). Estimates of the prevalence of psychopathology in children (henceforward children includes adolescents) with ID, gathered from studies addressing representative community samples including school-aged children, range from 30% to 60% (Chess, 1977; Chess & Hassibi, 1970; Einfeld & Tonge, 1996b; Gillberg et al., 1986; Jacobson, 1982; Koller et al., 1982; Linna et al., 1999; Rojahn et al., 1993; Rutter et al., 1970). This wide prevalence range may be accounted for by problems in the definition of both ID and psychopathology, the use of different instruments to assess psychopathology, the use of different samples (e.g. referred to services for children with ID versus general population studies), and including different ranges of levels of ID (Borthwick-Duffy, 1994; Bregman, 1991; Einfeld & Tonge, 1995). These issues hamper the comparability of studies addressing the prevalence of different types of psychopathology.

Attempting to further address comparability of psychopathology in children with ID to children without ID is even more challenging. Only three studies used a comparison group of children without ID as a point of reference to test the relative increased risk for co-occurrence of psychopathology and ID. Rutter et al. (1970) found a fourfold risk of parent- and teacher-reported psychopathology for the ID group compared to the general population. Koller et al. (1982) reported a prevalence rate of psychopathology in children with ID that was about seven times higher than in the non-ID comparison group. Linna et al. (1999) found that children with ID were about three times more often reported to score above the cutoff of the Rutter Parent and Teacher Questionnaires compared to children without ID. Based on these studies we may conclude that the risk of significant psychopathology in the population of

children with ID increases at least threefold in comparison to children without ID. What is notably lacking is a detailed picture of the type of problems that are most deviant in children with ID. Unfortunately, the informational value of previous epidemiological studies is limited on this point. The Isle of Wight study (Rutter et al., 1970), and the Linna et al. study (1999) only reported on Neurotic and Antisocial psychopathology, lacking a more comprehensive and detailed picture of important problem areas. Koller et al. (1982) provided only parent-reported information and made use of more idiosyncratic classification procedures, which hampers comparability. Moreover, all three studies used relatively small samples of children with ID (*N* ranges from 55 to 173).

This study aims to confirm the estimates of increased risk of general psychopathology in a sizeable sample of children and adolescents with borderline to moderate ID and few additional handicaps. In addition, it aims to specify the types of problems that are typically elevated according to parent and teacher reports. Finally, the size of the sample allows the comparison of the prevalence of behavioral/emotional problems in children with different educational levels. Available results suggest that the relation between intellectual functioning and psychopathology depends to some extent on the type of psychopathology measured, because the manifestation of some behaviors and emotions may require a certain level of intelligence (Borthwick-Duffy, 1994). Previous studies found trends for depressive feelings, anxiety, and antisocial behaviors to be more common among those with higher levels of intellectual functioning, while psychotic, self-absorbed, and autistic behaviors are more likely to be found in children with lower IQs (Einfeld & Tonge, 1996b; Gillberg et al., 1986; Koller et al., 1982).

This study relies on the use of standardized rating scales developed for the general population to assess behavioral and emotional problems, which is not uncommon for studies in this area (e.g. Rutter et al., 1970; Linna et al., 1999). In recent years, a general agreement has grown that individuals with mild ID develop types of psychopathology similar to those present in the general population (Borthwick-Duffy et al., 1997; Dykens, 2000; Einfeld & Tonge, 1995). This general agreement, and the fact that there is no general population data available from questionnaires developed for children with ID, forms the basis for comparing problem behaviors between children with and without ID using standardized instruments developed in the general population.

It is acknowledged that to allow for comparisons between the level of psychopathology in children with and without ID, compromises have to be made. First, it is likely that problem behaviors that are uncommon in typically developing children, e.g. autistic and self-absorbed behaviors, are less well represented in instruments designed to assess emotions and behaviors typically seen in disturbed children from the general population (Einfeld & Tonge, 1992). Therefore, comparisons between children with and without ID should not be restricted to overall level of problem behavior, because this might result in an underestimation of problem behaviors in children with ID. Instead, measures should allow for comparison on differentiated problem scales. Second, the assessment of emotional and behavioral problems in children with ID depends to a greater extent on the use of multiple informants to improve diagnostic precision, because of more difficulties with self-reflection and the verbal expression of problems compared to non-ID age-mates (Dykens, 2000). Therefore, instruments should be employed that provide information that is comparable across informants.

Although, they were not specifically designed for the assessment of psychopathology in children with ID, and therefore may be less applicable to children with severe levels of ID

(Einfeld & Tonge, 1995), there is evidence that the Child Behavior Checklist (CBCL) and the Teacher's Report Form (TRF) are sensitive to detect behavioral and emotional problems in children with ID. Both the CBCL and TRF are well-validated and normed instruments used to obtain parent and teacher reports on a wide range of psychopathology in children from the general population (Achenbach, 1991a, 1991b). Several studies of children with ID, mostly based on small samples of selected groups (e.g. children with Prader-Willi or Down syndrome), used the CBCL to assess psychopathology (Curfs et al., 1991; Floyd & Phillippe, 1993; Floyd & Saitzyk, 1992; Floyd & Zmich, 1991; Pueschel et al., 1991; Van Lieshout et al., 1998). Furthermore, Pueshel et al. (1991) concluded that the CBCL was applicable to children with Down syndrome, and van Lieshout et al. (1998) found acceptable Cronbach alphas in a sample of children with Prader-Willi syndrome. The study of Borthwick-Duffy et al. (1997) supported the factor validity of the CBCL Internalizing and Externalizing broad-band factors in children with moderate to severe ID. In addition, the use of the CBCL and TRF was supported by a moderate to high degree of convergence found between corresponding scales of the CBCL/TRF and the parent and teacher version of the Developmental Behaviour Checklist (Dekker, Nunn et al., 2002), which is an instrument designed to assess psychopathology in children with all levels of ID (Einfeld & Tonge, 1995; Einfeld et al., 1998). Unfortunately, no scores on instruments designed to measure psychopathology in children with ID are available for children without ID. Acknowledging the limitations of the CBCL and TRF in the assessment of typical behaviors seen in children with ID, these instruments may be regarded as the best option currently available for comparing psychopathology in children with borderline, mild to moderate ID to children without ID.

In sum, the present study aimed to assess and compare the prevalence of a wide range of parent- and teacher-reported emotional and behavioral problems in children with borderline to moderate levels of ID to that found in a general population sample in order to obtain a differentiated picture of the relative risk for psychopathology.

Method

Samples and procedure

Intellectually disabled

The intellectually disabled sample was obtained from schools for educable and trainable children in the Dutch province of Zuid-Holland. There are about four schools for the educable to each school for the trainable. At the time of sampling (1996), almost all children with ID in the Netherlands who went to school and who did not have severe additional physical or sensory disabilities, attended one of these two special school types, which are located separately from the regular schools. In 1996, the main criterion in the Netherlands to enter a school for the trainable was to have an IQ between 30 and 60 (moderate to mild ID), and to enter a school for the educable to have an IQ of about 60 to 80 (mild to borderline ID). Educable and trainable children with physical or sensory disabilities are likely to visit a special school for sensory disabled children, a school for children with multiple handicaps, or for children with chronic illness. Children with severe additional physical or sensory disabilities and an IQ below 50 are likely to visit a day-care facility. Although no exact numbers were available on how many children with ID attended a regular school, a school for

the sensory disabled, or a school for children with multiple handicaps or chronic illness, estimations are that this is true for less than 0.1% of all Dutch school-aged children (Central Bureau of Statistics, 1999; Scheepstra et al., 1992).

In 1996, 39,100 of all Dutch 6- to 18-year-olds attended a school for the educable (1.6%), and 9,700 (0.4%) visited a school for the trainable (Central Bureau of Statistics, 1999). In the same year, 19.3% of all school-aged children lived in the province of Zuid- Holland. In September 1997, all 132 schools for the educable and trainable in this province were approached and 115 schools agreed to participate (87.1%). A random sample of 20% of the students ($n=1,615$) was drawn from each participating school. Each school was sent sampling instructions and a table of random numbers, based on the number of students in the previous school year. Parents and caregivers of these children were informed about the research project through the schools, and were contacted by the researchers only after they agreed to it. All parents who participated in the study signed an informed consent form. The Committee for Medical Ethics of the Erasmus MC-Sophia Children's Hospital approved all procedures.

Children were included in the study if (1) they were between 6 and 18 years old, (2) lived at home for 4 or more days per week, and (3) at least one parent had enough comprehension of the Dutch language to be interviewed. The first two criteria were applied by the schools, and the third criterion after a personal conversation between an interviewer and the parent. Parents were interviewed at home between November 1997 and July 1998. Of the selected students, 141 were excluded because of parental language problems, 7 because they exceeded the age range, and 71 because they had left school or moved. Of the 1,396 remaining eligible parents of students, 231 could not be contacted in person (because the parents did not respond to the letters sent by the school), 164 refused to participate, and 33 parents who participated did not fill out the CBCL. The final response rate was 69.3% ($n=968$; 83.1% of the parents who could be contacted in person by the research group). After parents gave their written consent, 1,058 teachers were sent a TRF by mail, which they filled out and returned for 863 of their students (81.6%). TRF information was available for 81.8% of the children for whom a CBCL was also completed.

Non-response analysis

There were no significant differences in the distribution of sex ($\chi^2=3.0$, df=1, $p=0.08$) and year of birth ($t=-1.8$, df=1384, $p=0.07$) between participants and non-participants. However, fewer ($\chi^2=10.2$, df=1, $p<0.01$) schools for educable than for trainable children agreed to participate (80.5% vs. 97.8%). Also, fewer parents of children attending schools for the educable than for the trainable responded (65.3% vs. 80.4%; $\chi^2=29.4$, df=1, $p<0.01$). Of all the included children, 68.8% attended a school for the educable and 31.2% a school for the trainable. Furthermore, a significantly larger ($\chi^2=11.0$, df=2, $p<0.01$) percentage of parents who did not participate, but who gave us some information by telephone ($n=122$), had a low SES compared to the participating parents (68.9% vs. 55.4%). These results are related to the differential dropout by educational level, with educable children being more likely to come from low SES families than trainable children (62.3% vs. 44.7%). After correcting for age, sex, and SES differences, no significant differences (all $p>0.05$) in mean CBCL scale scores were found between children for whom TRFs were or were not completed.

Both parents and teachers were asked to report whether the child was not, or hardly, able to use arms or legs, whether the child was deaf or had problems hearing, whether the child was blind or had a visual disorder, and whether the child was not, or hardly, able to speak. In addition, general practitioners were asked to provide information on any physical problems of

the child. Motor, sensory or speech impairments were reported for 19 (1.8%), 71 (6.8%), and 53 (5.1%) of the children, respectively. Of those children with motor impairments, 7 children were spastic or had (hemi)plegia, 4 had other neurological impairments (e.g. related to spina bifida, a history of coma), and 8 children had unspecified motor impairments (e.g. psycho-motor delay, motor problems). The sample did not contain any totally blind or deaf children. Three children were found to be deaf in one ear. Most other problems with hearing were related to specific disorders (e.g. eardrum problems, tubes in the ears) or more mild hearing loss. Most visual problems, as reported for 37 children, were related to milder problems, like needing glasses, or to more specific disorders (e.g. cataract, problems with seeing depth). Finally, 53 children were reported to have speech or language problems. Four children were mute, and 8 children only used a few words or used sounds or gestures to communicate (5 of these children were also diagnosed with autism). The other children showed milder problems (e.g. hard to understand, poor articulation, using only short sentences). Over 50% of the children with speech problems were diagnosed with Down syndrome. Overall, it can be concluded that our sample included few children with additional motor, sensory, or speech disabilities, and that the more severe problems were only found in the motor (n=19: 9 educable and 10 trainable) and speech domain (n=12: all trainable). For the majority of the children with ID, the parent, the general practitioner or the teacher reported no particular cause of the ID. Down syndrome, Epilepsy, Fragile-X syndrome, Pervasive Developmental Disorder, and Williams syndrome were significantly more often observed in trainable children than in educable children (see Table 5.1).

General population

The general population sample consisted of 4- to 18-year-old children of Dutch nationality, living in The Netherlands, selected in 1993 by a stratified multistage cluster and random sampling design (Verhulst et al., 1997). Of the 2,709 eligible children, parent interviews were completed for 2,227 children (82.2%). In addition, for 1,720 of these children a teacher completed a TRF (76.3%). For the present analyses, only data from children attending regular schools and who were between 6 and 18 years of age were used for comparison, resulting in 1,855 CBCLs and 1,417 TRFs. Significantly (p<0.05) lower mean CBCL scale scores were found for children for whom a TRF was filled out compared to children for whom this was not the case, except for Somatic Problems, Anxious/Depressed, and Thought Problems.

Comparison of samples

Compared to the general population sample, the ID sample included significantly (p<0.001) more boys, more children from low SES families, more single-parent families, and more children with at least one non-Dutch parent (see Table 5.1). Within the ID sample educable children were more likely to come from lower SES families (p<0.001) than trainable children (see Table 5.1).

Measures

Psychopathology

The Child Behavior Checklist (CBCL) and the Teacher's Report Form (TRF) (Achenbach, 1991a, 1991b) are standardized parent and teacher evaluations of children's emotional and behavioral problems for the preceding 6 months. Good reliability and validity have been

Table 5.1 Sample characteristics[a][b] and comparisons[c]

	ID Sample				Total Sample		
	EDU	TRA			GP	ID	
	% (n=716)	% (n=325)	p		% (n=1,855)	% (n=1,041)	p
Male	59.2	60.3	ns	Male	49.4	59.6	0.000
SES: Low	62.5	45.5		SES: Low	27.4	57.2	
Medium	26.6	32.0	0.000	Medium	37.9	28.3	
High	10.9	22.5		High	34.7	14.5	0.000
Single parent	17.0	15.4	ns	Single parent	7.8	16.5	0.000
≥ 1 Non-Dutch parent	20.3	19.1	ns	≥ 1 Non-Dutch parent	8.7	19.9	0.000
Down syndrome	0.3	21.8	0.000				
Epilepsy	3.5	8.0	0.003				
Fragile-X syndrome	0.1	3.4	0.000				
Pervasive Developmental Disorder	3.4	12.3	0.000				
Prader-Willi syndrome	0.3	0.9	ns				
Williams syndrome	0.0	1.2	0.009				
Mean age (SD)	11.7 (2.8)	12.1 (3.5)	ns	Mean age (SD)	11.6 (3.7)	11.8 (3.0)	ns

[a]ID=Intellectually Disabled; EDU=Educable children; TRA=Trainable children; GP=General Population sample (CBCL or TRF information available).

[b]Information on all disorders and syndromes (reported by parents, general practioners or teachers) only available for ID sample.

[c]Mean age differences were tested with t-tests; other differences with χ^2-tests; ns=not significant at $p<0.05$.

demonstrated for the Dutch CBCL and TRF (De Groot et al., 1994, 1996; Verhulst, Akkerhuis et al., 1985; Verhulst, Berden et al., 1985; Verhulst et al., 1996, 1997). Children with a T score $\geq$ 67 on the problem scales, and with a T score $\geq$ 60 on Total Problems, Internalizing, and Externalizing of the CBCL and the TRF are classified as scoring in the borderline/clinical range (Verhulst et al., 1996, 1997).

Applicability of the CBCL and TRF to this sample is supported by data on scale reliability and stability, and convergence with scales designed specifically for children with ID. In the present ID sample, Cronbach's alphas ranging from 0.58 to 0.90 for the CBCL syndrome scales were found for educable children, and from 0.52 to 0.91 for trainable children, compared to 0.54 to 0.85 in the general population sample. Cronbach's alphas ranging from 0.59 to 0.95 for the TRF scales were found for educable children, and from 0.49 to 0.94 for trainable children, compared to 0.47 to 0.94 in the general population. Most CBCL scales showed higher alphas for children with ID than for children from the general population sample. Relatively low internal consistency was found within the trainable group on the TRF scales Somatic Complaints, Social Problems, and Attention Problems compared to the general population sample. Overall, the Cronbach's alphas for the CBCL and TRF scales, the broadband scales, and the Total Problem score were similar to those reported for the Dutch general population and referred samples (Verhulst et al., 1996, 1997). The one-year stability (n=471; randomly selected from the total sample) of the Total Problems scale of the CBCL in children with ID was 0.77 (0.79 in educable children, and 0.72 in trainable children).

All parents and teachers of children with ID also completed the Developmental Behaviour Checklist (DBC-P for parents; DBC-T for teachers). The DBC is a 96-item questionnaire specifically designed to assess emotional and behavior problems in children with ID (Einfeld & Tonge, 1995; Einfeld et al., 1998). Although the DBC results cannot be directly used in this study, since there is no non-ID comparison group, they can be used to support the validity of the CBCL and the TRF. Both CBCL and TRF scales showed convergent validity with similar scales of the DBC-P and the DBC-T (Dekker, Nunn et al., 2002). In the current sample, the correlation between the CBCL Total Problems scale and the DBC-P Total Problems scale was 0.87 for educable children, and 0.85 for trainable children. The correlation between the TRF Total Problems scale and the DBC-T Total Problem scale was 0.88 in educable and 0.83 in trainable children.

The Pearson cross-informant correlation coefficients between the eight CBCL and TRF scales were all significant at $p<0.001$, and ranged in the general population sample from 0.17 to 0.43 (mean r=0.30), in the sample of educable children from 0.19 to 0.40 (mean r=0.34), and in the sample of trainable children from 0.17 to 0.50 (mean r=0.31). Using Fisher r-to-Z transformations, no significant (all $p<0.05$) differences in the cross-informant correlation coefficients between the three samples were found (Hays, 1988, formula [14.21.11]).

Socio-economic status

Socio-economic status (SES) was assessed by considering both educational and occupational level of the highest scoring parent. SES was recoded into three categories: 'low SES', including the unemployed, unskilled workers and workers with lower vocational training; 'medium SES', including jobs requiring middle vocational training; and 'high SES' with jobs requiring higher vocational training (Central Bureau of Statistics, 1993; Van Westerlaak, Kropman, & Collaris, 1975).

Educational level. Two educational levels, educable versus trainable, were used as a proxy of level of intelligence in the sample of children with ID.

Data analysis

To assess differences in raw CBCL and TRF scale scores between children with and without ID, univariate analyses of variance were performed (all $p<0.001$). The main factor in the model was group (three levels, i.e. children from the general population (GP), educable children (EDU), and trainable children (TRA)). In addition sex and SES were entered as factors, and age as a covariate to adjust for group differences. According to Cohen's criteria, effect sizes were considered small when the percentage of explained variance (PEV) was smaller than 5.9%, medium when the PEV was between 5.9% and 13.0%, and large when the PEV exceeded 13.0% (Cohen, 1988). Each significant group effect was followed by Bonferroni post-hoc tests, comparing each group pair wise (adjusting for multiple comparisons).

Univariate logistic regression analyses, controlling for sex, age, and SES differences, were performed to compare the distribution of the dichotomized CBCL and TRF scale scores (normal versus borderline/clinical range) and the dichotomized item scores (items scored 0 versus 1 or 2) across the three groups. The risks of educable and trainable children scoring in the deviant range of the CBCL and TRF scales were compared to the risk of children from the general population. The significance level of the odds ratios for the scales are reported at $p<0.001$, $p<0.01$, and $p<0.05$, and for the items, to adjust for multiple comparisons, at $p<0.0001$.

Results

Scale scores

Comparing the CBCL and the TRF scales scores in the general population sample with those in the sample of educable children showed that educable children had significantly higher mean scores on all scales (see Table 5.2). The same was true when comparing children from the general population with trainable children, except that no significant differences were found on the Anxious/Depressed scale of the CBCL, nor on the Somatic Complaints scale of the TRF. The mean Total Problems score in both ID samples was almost one standard deviation above the mean found in the general population sample. Because of the presence of 31 children in the ID sample with a severe motor or speech handicap, which might limit their ability to perform certain behaviors or to express problems, we repeated the analyses without these children. No significant differences between both analyses were found. All mean scores for the restricted sample were within one standard error of the original mean.

Across scales, different effect sizes were found, and educational level effects were in different directions. Medium to large effect sizes (Cohen, 1988) were found on both instruments for Total Problems, Social Problems, and Attention Problems, and on the CBCL for Withdrawn. Some mean scale scores increased with decreasing educational level, namely the Withdrawn and the Thought Problems scale on both instruments, and the Social Problems and the Attention Problems scale of the CBCL. The average Anxious/Depressed scale scores on both instruments, and the Delinquent Behavior scale score on the CBCL were significantly higher for educable children compared to both trainable children and children without ID. The other scales showed similar mean scores for educable and trainable children.

Table 5.2 Means[a,b,c] and standard deviations for CBCL and TRF scale scores in the general population (GP), the educable (EDU), and the trainable (TRA) sample

	CBCL				TRF			
	GP	EDU	TRA	PEV	GP	EDU	TRA	PEV
	Mean (SD)	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	Mean (SD)	
	(n=1,855)	(n=668)	(n=300)		(n=1,417)	(n=577)	(n=286)	
Withdrawn	1.9 (2.2)	3.2 (3.1)	4.0 (3.2)	6.6	2.1 (2.6)	3.1 (3.1)	3.8 (3.1)	4.4
Somatic Complaints	1.0 (1.6)	1.5 (2.0)	1.3 (1.9)[nsID]	1.2	0.4 (1.0)	0.8 (1.6)	0.6 (1.2)[nsGP, nsID]	1.1
Anxious/ Depressed	2.8 (3.3)	4.4 (4.5)	3.2 (3.6)[nsGP]	2.6	3.5 (4.1)	5.1 (5.1)	4.5 (4.9)	2.2
Social Problems	1.3 (1.8)	4.0 (3.1)	5.1 (2.6)	29.4	1.9 (3.0)	4.3 (4.0)	3.9 (2.9)[nsID]	8.0
Thought Problems	0.5 (1.0)	0.7 (1.4)	1.1 (1.6)	2.8	0.4 (0.9)	0.7 (1.4)	1.2 (1.9)	4.7
Attention Problems	3.1 (2.9)	6.1 (4.1)	7.2 (3.8)	17.7	6.3 (6.5)	11.6 (7.5)	12.1 (7.6)[nsID]	9.7
Delinquent Behavior	1.3 (1.8)	2.2 (2.6)	1.7 (2.1)	2.4	0.8 (1.5)	1.6 (2.2)	1.2 (1.7)[nsID]	1.3
Aggressive Behavior	5.2 (5.0)	9.0 (7.3)	8.8 (7.3)[nsID]	5.7	4.3 (6.9)	8.6 (9.8)	8.8 (9.4)[nsID]	4.5
Internalizing	5.6 (5.6)	8.8 (7.8)	8.3 (6.7)[nsID]	4.2	5.8 (6.2)	8.6 (7.7)	8.7 (6.8)[nsID]	3.4
Externalizing	6.5 (6.2)	11.2 (9.3)	10.6 (8.8)[nsID]	5.3	5.0 (8.0)	10.2 (11.5)	10.0 (10.6)[nsID]	4.1
Total Problem Score	19.7 (15.4)	33.7 (23.4)	35.5 (20.6)[nsID]	10.4	18.9 (18.9)	34.1 (24.4)	35.3 (22.0)[nsID]	8.8

[a] All educational level main effects $p<0.001$; PEV=Percentage Explained Variance from ANCOVA corrected for age, sex, and SES differences between samples.

[b] All Bonferroni post-hoc tests comparing GP with EDU or TRA are significant at $p <0.05$, except for [nsGP], which indicates a non-significant effect.

[c] All Bonferroni post-hoc tests comparing EDU with TRA are significant at $p<0.05$, except for [nsID], which indicates a non-significant effect.

Deviant scores

Table 5.3 shows the percentages of children from the general population sample, the educable sample, and the trainable sample scoring in the deviant range of the CBCL and the TRF scales. Educable and trainable children scored significantly more often in the deviant range on all CBCL and TRF scales than children without ID, except for trainable children who had a similar risk of scoring in the deviant range on the Somatic Complaints scale of the TRF as children from the general population.

Table 5.3 also shows the odds ratios of deviant CBCL and TRF scale scores in children without ID compared to educable and trainable children (GP versus EDU, and GP versus TRA), corrected for sex, age, and SES differences, and their corresponding 95% confidence intervals. The relative risk of educable or trainable children to show deviant problems compared to children without ID differed across the scales. The odds ratios for the GP versus EDU comparison ranged from 1.5 to 12.0, with the largest odds ratios (all *p*<0.001) for Social Problems, Attention Problems, and Aggressive Behavior. The odds ratios for the GP versus TRA comparison ranged from 1.5 to 20.0, with the largest odds ratios (all *p*<0.001) for Social Problems, Attention Problems, Withdrawn (CBCL), and Thought Problems (TRF). The odds ratios for teacher-reported problems were all smaller than those for parent-reported problems, except for Thought Problems.

Item scores

The Pearson product-moment correlation between the mean item scores of children without ID and the mean item scores of children with ID was for CBCL items 0.82 and for TRF items 0.85 (both *p*<0.001).

Dichotomized item scores were compared to investigate which items were most likely to cause elevated problem scale scores of children with ID relative to children without ID (i.e. scales with the largest effect sizes or largest odds ratios), and of educable versus trainable children. In discussing which items contributed most, items were included when the odds ratio for at least one comparison (GP versus EDU or GP versus TRA) was 3.0 or higher for at least one informant. The odds ratios of these selected items and their corresponding 95% confidence intervals are shown in detail in Table 5.4.

In educable children the elevated risk to have Social Problems was most notably caused by items (abbreviated) such as [1] Acts too young, [25] Does not get along with peers, [38] Is teased, [62] Clumsy, and [64] Prefers younger kids. In trainable children similar items caused elevated risk, and to a larger extent. The relatively higher risk for educable children to show Withdrawn behavior was most likely caused by the higher prevalence of items like: [42] Would rather be alone, [80] Stares blankly, [102] Lacks energy, and [111] Withdrawn. Again, similar items were elevated for the trainable group, but with a higher relative risk compared to educable children. The elevated risk for Attention Problems in both educable and trainable children was reflected in relatively high odds ratios for items like [1] Acts too young, [8] Can't concentrate, [13] Confused, [22] Difficulty with directions, [46] Nervous movements, [49] Difficulty learning, [62] Clumsy, and [80] Stares blankly. A wide range of items making up the Aggressive Behavior scale of the CBCL or the TRF were elevated in both the educable and trainable group (e.g. [16] Mean to others, [20] Destroys own things [21] Destroys others' things, [57] Attacks people). The Thought Problem scale scores were most elevated by items such as [66] Repeats actions, [84] Strange behavior, and [80] Stares blankly, and most notably in the trainable group.

Table 5.3 Percentages and odds ratios[a] of children and adolescents scoring in the borderline/clinical range of CBCL and TRF scales in the general population (GP) sample versus the educable (EDU), and the trainable (TRA) sample

Scales:	CBCL					TRF				
	% GP	% EDU	% TRA	OR[d](95% CI) GP vs. EDU	OR (95% CI) GP vs. TRA	% GP	% EDU	% TRA	OR (95% CI) GP vs. EDU	OR (95% CI) GP vs. TRA
Withdrawn	5.4	17.5	22.3	3.4 (2.5-4.7)	4.8 (3.4-6.7)	5.2	9.2	12.9	1.5c (1.0-2.3)	2.7 (1.7-4.1)
Somatic Complaints	5.0	12.0	8.3	2.4 (1.7-3.4)	1.7c (1.1-2.7)	4.5	10.4	5.2	2.2 (1.5-3.3)	1.1ns (0.6-2.1)
Anxious/ Depressed	6.6	16.8	10.3	2.7 (2.0-3.6)	1.5c (1.0-2.3)	5.8	12.1	14.0	2.2 (1.6-3.2)	2.4 (1.6-3.6)
Social Problems	5.1	35.5	51.7	12.0 (9.0-16.0)	20.0 (14.6-27.4)	6.1	18.2	13.3	3.2 (2.3-4.5)	2.1 (1.4-3.2)
Thought Problems	3.8	8.8	12.3	2.3 (1.6-3.4)	3.3 (2.2-5.1)	5.7	12.1	23.4	2.4 (1.7-3.5)	4.8 (3.3-6.9)
Attention Problems	6.0	30.7	38.0	7.1 (5.4-9.3)	9.1 (6.7-12.4)	5.4	14.0	17.1	2.7 (1.9-3.9)	3.8 (2.5-5.7)
Delinquent Behavior	5.5	18.0	11.0	3.5 (2.6-4.8)	2.0b (1.3-3.1)	4.9	13.2	8.4	2.5 (1.8-3.7)	1.8c (1.1-2.9)
Aggressive Behavior	5.2	21.0	19.7	4.5 (3.3-6.1)	4.2 (2.9-6.1)	5.7	17.2	19.2	3.1 (2.2-4.4)	3.7 (2.6-5.5)
Internalizing	18.7	39.4	37.0	2.6 (2.1-3.1)	2.4 (1.8-3.1)	19.5	34.1	36.4	1.9 (1.5-2.5)	2.2 (1.7-2.9)
Externalizing	16.8	38.8	37.0	2.9 (2.4-3.6)	2.8 (2.1-3.7)	18.1	39.3	37.8	2.7 (2.1-3.4)	2.7 (2.0-3.5)
Total Problem Score	18.0	48.1	51.3	3.8 (3.1-4.6)	4.5 (3.4-5.8)	19.0	44.9	48.3	3.2 (2.5-4.0)	4.0 (3.0-5.2)

[a]All odds ratios: $p<0.001$ (adjusted for multiple comparisons), except for [b]OR: $p<0.01$; [c]OR: $p<0.05$; ns not significant at $p<0.05$.

[d]OR=Odds Ratio (corrected for age, sex, and SES differences between samples); 95%CI=95% Confidence Interval.

Finally, differences between educable and trainable children were most notable on the Anxious/Depressed scale for the items [35] Feels worthless and [89] Suspicious, and on the Delinquent Behavior scale for the items [67] Runs away from home, [72] Sets fires, [81] Steals at home, [82] Steals outside the home, and [106] Vandalism.

Discussion and Conclusions

The aim of the present study was to compare the prevalence of a broad range of parent- and teacher-reported emotional and behavioral problems in children with different levels of ID to those found in a general population sample. The overall prevalence rate of emotional and behavioral problems in children with ID of about 50% found in this study is within the expected range of 30% to 60% found in other population based studies (Einfeld & Tonge, 1996b, Gath & Gumley, 1986, Gillberg et al., (1986), Koller et al., 1982, Linna et al., 1999, Rutter et al., 1970). A three- to fourfold risk was found for overall level of problem behavior, with about 50% of the ID samples scoring in the deviant range of the Total Problem Score scale compared to about 18% of the children without ID. This heightened risk for psychopathology is comparable to the relative risk found in the studies of Rutter et al. (1970), and Linna et al. (1999), but is smaller than the one found in the study of Koller et al. (1982). The use of interview and record data in Koller's study compared to information reported on highly structured questionnaires like the Rutter scales and the CBCL/TRF, might explain this discrepancy.

This study shows that the relative risk for problem behaviors differs largely across the problem behaviors themselves, suggesting that overall problem behavior measures are less informative. Comparisons with other studies are difficult, because they did not incorporate a wide range of behavior problem scales. Emotional and behavioral scales like Withdrawn, Somatic Complaints, Social Problems, and Thought Problems do not have a clear counterpart on the instruments used in Rutter's (1970), Koller's (1982), or Linna's (1999) study.

Both educable and trainable children are reported to have significantly higher mean scores and an increased risk of scoring in the deviant range on all CBCL and TRF scales compared to children without ID, except for trainable children on the Anxious/Depressed and on the Somatic Complaints scale. The size of these effects was for some scales larger in the educable group and for others larger in the trainable group. This underscores the importance of evaluating a wide range of problem behaviors to address prevalence and relative risk. The percentage of children in both ID groups scoring in the deviant range on the CBCL scales Social Problems and Attention Problems, and that of trainable children on Thought Problems, was similar to that of children from the general population who are referred to mental health care (Verhulst et al., 1996, 1997), suggesting that these areas of problem behavior should be a major point of focus in the care for these children.

One might get the impression that the increased risk of emotional or behavioral problems in children with ID compared to children without ID is caused by problem items associated with their developmental delays that are not necessarily signs of behavior deviance, including items like (abbreviated): [1] Acts too young, [8] Can't concentrate, [11] Too dependent, [49] Difficulty learning, [62] Clumsy, [79] Speech problem, and [107] Wets during day. However, this study showed that various items responsible for elevated problem scale scores in children with ID were considered deviant irrespective of developmental delay, including for example (abbreviated): [16] Mean to others, [20] Destroys own things, [25] Doesn't get along with peers, [35] Feels worthless, [67] Runs away from home, [80] Stares blankly, [82] Steals

Table 5.4 Odds ratios[abc] of CBCL and TRF item scores for children from the general population (GP) sample versus educable children (EDU), and versus trainable (TRA) children

Items[d]		CBCL		TRF	
		OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
		GP vs. EDU	GP vs. TRA	GP vs. EDU	GP vs. TRA
1.	Acts too young	7.1 (5.7-8.7)	32.0 (21.9-47.0)	4.9 (3.9-6.2)	9.6 (7.1-13.0)
6.	BM outside toilet[cbcl]	ns	7.6 (4.5-12.8)	---	---
8.	Can't concentrate	4.8 (3.9-5.9)	6.1 (4.5-8.3)	2.0 (1.6-2.5)	2.3 (1.8-3.1)
11.	Too dependent	3.5 (2.8-4.2)	5.3 (4.1-6.9)	2.2 (1.7-2.8)	2.4 (1.8-3.2)
13.	Confused	3.1 (2.3-4.3)	2.9 (2.0-4.3)	2.0 (1.5-2.6)	ns
15.	Cruel to animals[cbcl]	5.1 (2.9-9.1)	5.5 (3.0-10.2)	---	---
16.	Mean to others	3.1 (2.4-4.1)	2.6 (1.8-3.7)	2.3 (1.7-3.0)	2.2 (1.6-3.2)
18.	Harms self	ns	8.5 (3.3-21.8)	ns	ns
19.	Demands attention	2.7 (2.2-3.2)	3.8 (2.9-5.0)	2.4 (1.9-3.0)	2.5 (1.9-3.3)
20.	Destroys own things	3.0 (2.2-4.0)	4.1 (2.9-5.9)	ns	ns
21.	Destroys others' things	2.5 (1.7-3.5)	5.1 (3.5-7.4)	ns	ns
22.	Difficulty with directions[trf]	---	---	3.1 (2.5-3.9)	4.6 (3.5-6.0)
23.	Disobeys at school	2.3 (1.8-2.9)	3.3 (2.4-4.3)	2.5 (2.0-3.2)	2.9 (2.2-3.9)
25.	Doesn't get along	5.1 (3.9-6.7)	6.5 (4.8-8.9)	1.8 (1.5-2.3)	ns
28.	Eats non-food	ns	ns	ns	7.8 (3.1-19.7)
29.	Fears	ns	3.8 (2.9-5.0)	2.5 (1.7-3.7)	5.9 (4.1-8.7)
35.	Feels worthless	3.1 (2.4-3.9)	ns	3.1 (2.4-4.0)	ns
38.	Is teased	4.6 (3.7-5.7)	4.0 (3.1-5.2)	2.3 (1.7-2.9)	ns
42.	Would rather be alone	1.8 (1.5-2.2)	3.0 (2.3-3.8)	ns	2.1 (1.6-2.8)
46.	Nervous movements	2.3 (1.7-3.0)	3.1 (2.2-4.2)	2.2 (1.6-3.0)	2.9 (2.0-4.0)
48.	Not liked	3.6 (2.8-4.6)	2.8 (2.0-3.8)	ns	ns
49.	Difficulty learning[trf]	---	---	16.2 (12.0-21.9)	11.3 (8.0-16.1)
50.	Fearful, anxious	3.6 (2.8-4.6)	5.2 (3.9-6.9)	2.1 (1.6-2.7)	2.6 (1.9-3.4)
53.	Eats too much	2.4 (1.8-3.0)	3.6 (2.7-4.8)	2.2 (1.7-2.7)	2.1 (1.6-2.8)
55.	Overweight	2.4 (1.8-3.2)	3.9 (2.8-5.4)	ns	3.2 (2.2-4.5)
56e.	Skin Problems	ns	ns	ns	ns
56h.	Other physical problem	3.8 (2.0-7.3)	ns	ns	ns
57.	Attacks people	3.5 (2.4-4.9)	4.5 (3.0-6.7)	ns	2.8 (2.0-4.1)
58.	Picking	ns	2.0 (1.5-2.7)	ns	3.8 (2.5-5.8)
59.	Plays with sex parts in public	ns	4.3 (2.3-7.8)	ns	ns
60.	Plays with sex parts too much[cbcl]	ns	6.7 (3.9-11.6)	---	---
62.	Clumsy	5.4 (4.3-6.8)	7.1 (5.4-9.3)	3.7 (2.9-4.8)	4.7 (3.5-6.3)
64.	Prefers younger kids	4.4 (3.5-5.4)	4.5 (3.4-5.9)	2.4 (1.8-3.2)	ns
66.	Repeats actions	ns	9.2 (5.5-15.3)	7.3 (3.1-17.5)	25.5 (11.3-57.5)
67.	Runs away from home[cbcl]	5.5 (3.0-9.9)	ns	---	---
68.	Screams a lot	2.0 (1.6-2.5)	2.6 (2.0-3.4)	2.1 (1.5-3.0)	3.1 (2.2-4.6)
72.	Sets fires[cbcl]	3.2 (1.9-5.4)	ns	---	---
73.	Irresponsible[trf]	---	---	4.0 (2.7-5.8)	3.5 (2.3-5.4)
76.	Explosive[trf]	---	---	2.8 (2.1-3.7)	3.2 (2.3-4.5)
77.	Easily frustrated	ns	ns	2.5 (1.9-3.3)	3.2 (2.3-4.4)
79.	Speech problem	5.2 (3.9-6.8)	23.4 (17.1-32.0)	4.0 (3.0-5.4)	15.9 (11.3-22.3)

Table 5.4 continued

Items[d]	CBCL		TRF	
	OR (95% CI) GP vs. EDU	OR (95% CI) GP vs. TRA	OR (95% CI) GP vs. EDU	OR (95% CI) GP vs. TRA
80. Stares blankly	4.2 (3.0-5.9)	6.7 (4.7-9.5)	2.0 (1.5-2.5)	2.4 (1.7-3.2)
81. Steals at home	3.5 (2.2-5.8)	ns	---	---
82. Steals outside the home	5.3 (3.0-9.3)	ns	3.8 (2.0-7.1)	ns
84. Strange behavior	5.6 (3.6-8.6)	11.1 (7.1-17.1)	ns	3.2 (2.2-4.7)
85. Strange thoughts	ns	ns	3.4 (1.9-6.2)	ns
86. Stubborn	1.7 (1.4-2.0)	2.2 (1.7-2.9)	2.3 (1.8-2.9)	3.1 (2.4-4.0)
88. Sulks a lot	ns	ns	2.3 (1.8-3.0)	3.1 (2.3-4.1)
89. Suspicious	3.0 (2.3-3.9)	ns	2.6 (1.9-3.5)	ns
91. Suicidal thoughts	3.2 (1.9-5.2)	ns	ns	ns
94. Teases a lot	1.7 (1.4-2.1)	ns	3.1 (2.3-4.0)	3.2 (2.2-4.4)
95. Hot temper	2.3 (1.9-2.8)	2.0 (1.5-2.6)	2.3 (1.7-3.1)	3.0 (2.1-4.3)
97. Threatens people	7.1 (3.4-14.9)	10.0 (4.6-21.6)	4.3 (2.5-7.4)	4.3 (2.3-8.1)
102. Lacks energy	2.9 (2.2-3.9)	4.9 (3.6-6.7)	ns	2.0 (1.5-2.8)
106. Vandalism[cbcl]	4.4 (2.4-8.1)	ns	---	---
107. Wets during day[cbcl]	4.8 (2.3-10.1)	4.0 (2.0-7.8)	---	---
108. Wets bed[cbcl]	3.5 (2.4-4.9)	4.8 (3.2-7.1)	---	---
111. Withdrawn	3.3 (2.5-4.3)	6.0 (4.4-8.2)	ns	2.1 (1.6-2.9)

[a]OR=Odds Ratio; 95% CI= 95% Confidence Interval.

[b]Only items with significant (all $p<0.0001$) ORs ≥3.0 (EDU or TRA scoring more often 1 or 2) on at least one instrument are shown; ns=not significant at $p<0.0001$.

[c]Odds ratios are corrected for sex, age, and SES differences between samples.

[d]Items are abbreviated.

[cbcl]=Item unique for CBCL; [trf]=Item unique for TRF.

outside the home, and [106] Vandalism. These findings suggest that the elevated problem scale scores of children with ID compared to children without ID reflect true differences, but that there might be a need for the use of separate norm scores for educable and trainable children to correct for items sensitive to developmental delays.

Although the direction of effects was similar for parents and teachers, the prevalence rates of teacher-reported emotional and behavioral problems in children with ID were below those reported by parents, the same was true for the odds ratios of item scores when comparing children with or without ID. One explanation might be that teachers compare pupils with their classmates, who are all about the same level of intellectual functioning, while parents compare a child with his or her normally developed siblings, or other children in the neighborhood. Another explanation might be situation specificity of emotional and behavioral problems. The structured environment at school, and the presence of teachers specifically trained to teach children with ID, may result in actually less problem behaviors at school. Similar effects of rating bias or situation specificity of behavior problems were, however, also found in the general population as shown by the lack of significant differences in cross-informant correlation coefficients between children with and without ID.

Overall, significant differences between educable and trainable children were found for behavioral problems, similar to the trends found in comparable studies (Einfeld & Tonge,

1996b; Gillberg et al., 1986; Koller et al., 1982). Our study showed that educable children, i.e. with relatively higher levels of intellectual functioning, were reported to have more depressive feelings, anxiety, and antisocial behaviors, compared to trainable children. This finding might be explained by the fact that some of the related symptoms are more difficult to express by, or to recognize in, children with lower levels of ID, because of shortcomings in their self-reflecting skills (e.g. expressing suicidal thoughts and feeling worthless) or because of the lack of opportunity to display certain behaviors due to closer supervision (e.g. setting fires).

Our study also showed that compared to educable children, trainable children were considered to be more withdrawn and to have more thought problems, as was reflected by the higher prevalence of behaviors frequently seen in children with pervasive developmental disorder (PDD; e.g. 'stares blankly', 'withdrawn', 'would like to be alone', 'repeats acts', 'strange behaviors', and 'strange thoughts'). Children with PDD are also more likely to go to schools for the trainable, as discussed in the sample description. It should be noted that instruments designed to assess emotional and behavioral problems in children with ID are likely to be even more sensitive for picking up differences in behaviors associated with PDD across educational levels than the CBCL and the TRF.

We did not find differences between educable and trainable children on CBCL and TRF measures of overall problem behavior, internalizing, and externalizing problems, which stresses the importance of including more differentiated measures when evaluating the effect of intellectual functioning on psychopathology. However, an alternative explanation for the lack of difference in overall problem behavior between educable and trainable children in this study might be the use of measures not specifically targeting ID-specific behaviors. Incorporating more items addressing behaviors related to, for example, PDD and self-injurious behaviors, might make global measures of problem behavior more sensitive to educational level effects.

In sum, we can conclude that children with ID have an increased risk of showing a broad range of emotional and behavioral problems compared to children without ID, that the size of the relative risks differs across problem behaviors, and across educational level, and that these elevated risks are found for problem behaviors that are considered to reflect deviancy irrespective of developmental delay, as well as for problem behaviors that may be mainly caused by the intellectual disability itself, e.g. reflecting cognitive or academic deficits.

Study strengths and limitations

The major strengths of the present study are its sample size, the random sampling procedure, and the representative sample used compared to other studies in this field. The use of well-known and reliable standardized instruments, which allowed us to assess a broad range of emotional and behavior problems, gave us the opportunity to compare our sample with a general population sample of children without ID. Although it is generally believed that emotional and behavioral problems seen in typically developing children are also seen in children with mild and moderate ID, it should be noted that the use of instruments that are not specifically designed to assess problem behaviors in children with ID might result in under-reporting of behaviors that are typically seen in children with ID.

By including children with borderline to moderate levels of ID, this study is likely to be representative of over 90% of all children with ID (e.g. Roeleveld, Zielhuis, & Gabreëls, 1997). This study captured a large, school-based sample of children with ID living at home, including children who never had any contact with mental health care but who show deviant

CBCL and TRF scores. Referral bias is unlikely to be an issue in this study. Our sample is representative of children attending special schools for the educable and trainable, who represent 2% of all the 6- to 18-year-olds attending schools in the Netherlands. These children generally have IQs in the borderline, mild, and moderate range, and no severe additional physical or sensory impairments. The exclusion of the relatively few children with ID visiting a regular school or a school for complex handicapped children is unlikely to have had a major effect on our study results. It is most reliable to generalize the present study's results to children with borderline, mild, and moderate ID without severe motor, sensory, or speech impairments. We do not know whether these findings apply to those with severe or profound ID. Furthermore, these results can only be generalized to non-institutionalized children.

Clinical implications and directions for future research

Our results suggest that in mental health care for intellectually disabled children special interest should be focused on social problems, attention problems, and aggressive behavior. These areas of problem behavior showed the largest sample differences between children with and without ID, and were highly prevalent among the intellectually disabled. Although high scores on the Attention Problems and Social Problems scale may be mainly caused by cognitive and academic impairments, these problems deserve attention from the clinician just like they would when present in children without ID. Focusing on these emotional and behavioral problems should not result in overlooking low prevalent behaviors of concern, such as eating non-food, hallucinations, and suicidal thoughts.

The advantage of using CBCL and TRF norm scores, which are now available for children with ID as a result of this study, is that it will allow clinicians and researchers to make comparisons to children with similar levels of ID, with non-ID children from the general population, as well as to referred, non-ID children. Future research should focus on reference data for institutionalized children with ID, and for children with ID referred to mental health care.

The use of the CBCL and the TRF in this group was supported by the internal consistency of their scales, which was comparable to that in the general population, by the high one-year stability of CBCL problem scores, and by the relatively high inter-informant agreement, both at the item and scale level. In addition, CBCL/TRF scales showed high correlations with similar DBC-P and DBC-T scales (Dekker, Nunn et al., 2002). However, more research is needed on the construct validity of the CBCL and TRF in this population. Because of the lack of a gold standard, the future focus should be on the relation of the CBCL and the TRF with DSM-IV diagnoses and with instruments designed for children with ID, like the DBC. Relating the problem scales of all these instruments to an external criterion, for example referral to mental health care, in a longitudinal design, might shed more light on which scales or instruments best predict future problems for children of particular educational level.

Future research should also focus on differences between children with and without ID in the distribution and the effect size of potential risk factors associated with psychopathology, like parents' mental health, child's chronic illness, and family functioning. In addition, factors more unique for children with ID, e.g. cause of retardation, level of adaptive functioning, and level of intellectual functioning should be addressed (Dykens, 2000).

6 | The prevalence and impact of DSM-IV disorders in children with borderline to moderate intellectual disability

Marielle C. Dekker
Hans M. Koot

Abstract

The objective of this study was to assess the prevalence, comorbidity, and impact of DSM-IV disorders in 7- to 20-year-olds with intellectual disability. 474 children (response 86.8%) were randomly selected from a sample of students from Dutch schools for the intellectually disabled. Parents completed the anxiety, mood, and disruptive disorder modules of the Diagnostic Interview Schedule for Children. 21.9% of the children met the DSM-IV symptom criteria for anxiety disorder, 4.4% for mood disorder, and 25.1% for disruptive disorder. Similar prevalence rates were found for children who screened positive or negative for pervasive developmental disorder. Over half of the children meeting the criteria for a DSM-IV disorder were severely impaired in everyday functioning, and about 37% of the diagnosed children had a comorbid disorder. Children with multiple disorders were more likely to be impaired across various areas of everyday functioning. Almost 27% of the diagnosed children received mental health care in the last year. Comorbidity and impairment in everyday functioning increased the likelihood of referral. Concluding, most disorders can be observed in intellectually disabled children. Impairment and comorbidity are high. The finding that less than a third of the children with a psychiatric disorder receive mental health care deserves attention.

Introduction

Psychopathology in children and adolescents with intellectual disability (ID) receives increasing attention from researchers and mental health practitioners alike. However, basic information on prevalence and impact of psychiatric disorders from well-designed epidemiological studies is scarce.

In the limited number of studies conducted thus far, prevalence estimates of DSM-III(-R) disorders in community-based samples of children with ID vary from 4% to 18% (Borthwick-Duffy and Eyman, 1990; Eaton and Menolascino, 1982; Jacobson, 1982; Rojahn et al., 1993). Even fewer studies present estimates of specific disorders. Prevalence estimates for attention-deficit hyperactivity disorder (ADHD) range from about 0.5% to 11%, for conduct disorder (CD) and oppositional defiant disorder (ODD) from 0.5% to 12%, for anxiety disorders from 0.5% to 10%, and for mood disorders from 0.5% to 4% (Gillberg et al., 1986; Myers and Pueschel, 1991; Rojahn et al., 1993). Surprisingly, these estimates are in the same range or even lower than those reported in many general population studies of children without ID (Anderson et al., 1987; Bird et al., 1988; Cohen et al., 1993; Costello, Angold, Burns, Stangl et al., 1996; McGee et al., 1990; Offord et al., 1987; Verhulst et al., 1997), which contrasts with the three- to fourfold increased risk of deviant emotional and behavioral problems found in children with ID compared to non-ID children in studies using standardized rating scales (Dekker, Koot, van der Ende, & Verhulst, 2002; Koller et al., 1982; Linna et al., 1999; Rutter et al., 1970). A possible explanation for this discrepancy, apart from differences in defining and operationalizing psychopathology, might lay in the methods of data collection employed.

To this day, almost all information on DSM diagnoses in community-based studies of children with ID is gathered through clinical records, while studies focused on non-ID children make regular use of standardized instruments (e.g. Anderson, Williams, McGee, & Silva, 1987; Bird et al., 1988). Clinical files often record a clinician's diagnosis without stating how and what kind of information was gathered. Furthermore, the presenting problems and cognitive disabilities of subjects are known to differentially influence referral for

psychiatric evaluation (Jacobson, 1982; Rojahn et al., 1993). Therefore, case file studies of persons known to ID services are likely to underestimate the true prevalence of psychopathology (Reiss, 1990).

The first aim of this study was to estimate the one-year prevalence of anxiety disorders, mood disorders, and disruptive disorders (including ADHD) according to DSM-IV symptom criteria, and to assess demographic differences in prevalence in a community-based sample of children with borderline to moderate ID, using a standardized instrument, i.e. the DISC-IV-P (Shaffer, Fisher, Lucas, Comer, 2000; Shaffer, Fisher, Lucas, Dulcan et al., 2000).

In characterizing psychiatric disorders in children with ID it is important to address their impact on everyday functioning. General population studies of non-ID children show that about one-third to half of the children who met the DSM-IV symptom criteria are significantly impaired in their everyday functioning (Anderson et al., 1987; Bird et al., 1988; Cohen et al., 1993; Costello, Angold, Burns, Stangl et al., 1996; McGee et al., 1990; Offord et al., 1987; Verhulst et al., 1997). This study assessed whether the same is true for children with ID.

A factor that might aggravate impairment in everyday functioning is the presence of a comorbid disorder. To this date no information on comorbidity of psychiatric disorders in community-based studies of children with ID is available. Community-based studies of non-ID children show that the overall co-occurrence of disorders in those diagnosed ranges from about 25% to 55% (Anderson et al., 1987; Bird et al., 1988; Cohen et al., 1993; McGee et al., 1990; Verhulst et al., 1997), with the highest comorbidities between ADHD and CD, and between depressive disorder and anxiety disorder (Angold et al., 1999). The third goal of this study was to address comorbidity among children with ID. We also examined whether children who screened positive for pervasive developmental disorder (PDD) were more likely to have a comorbid anxiety, mood or disruptive disorder than children who were screened negative.

A final objective was to evaluate mental health care utilization in children with ID. This paper details the proportion of children who received mental health care in the last year, and addresses the effect of impairment and comorbidity on the probability of referral.

Method

This study consists of two data collection phases. The first one was initiated in 1997, and about one year later a second phase began. In the second phase, a random sample of the first phase responders were contacted again to be interviewed at home. The study was approved by the Medical Ethical Committee of Erasmus MC Rotterdam.

Subjects

In the first phase, a random sample of 20% of all students (*n*=1,615) was drawn from 115 participating schools for the ID (87.1% of all schools for ID) in the province of Zuid-Holland, the Netherlands. Each school was sent sampling instructions and a table of random numbers, based on the number of students in the previous school year. This sampling frame is largely representative of all children and adolescents with ID without major additional physical and sensory disabilities who went to school at that time (about 2% of all 6- to 18-year-olds

attended a school for ID (Central Bureau of Statistics, 1999)). About three-fourths of these children attend a school for the educable (IQ between 60 and 80) and one-fourth a school for the trainable (IQ between 30 and 60).

Parents and caregivers of these children were informed about the research project through the schools, and were contacted by the researchers after agreeing to it. All parents who participated in the study signed an informed consent form. Children were included in the first phase of the study if they were 6 to 18 years old, lived at home for at least 4 days per week, and at least one parent had enough comprehension of the Dutch language to be interviewed.

Of the 1,396 eligible students, 968 parents participated (69.3%). A more detailed description of this first data collection phase can be found in Dekker, Koot et al. (2002).

About one year later (mean interval 409.6 days, SD=79.9), a random sample of 58% of the first phase participants (n=557) were contacted for a second time. Six families were excluded because they did not meet the language requirements for the more complicated diagnostic interview and five children were no longer living at home (eligible n=546). Eleven parents could not be contacted, 53 chose not to participate, and eight did not want to participate in the diagnostic interview. Finally, thirteen trained interviewers carried out 474 home interviews with the parents (86.8%). Details on the present sample can be found in Table 6.1.

Tabel 6.1 Sample characteristics

	%		%
Educational level		Family	
Educable	77.4	Single parent	15.2
Trainable	22.6	Complete	84.8
Sex		Ethnicity	
Male	61.8	≥ 1 parent non-Dutch	11.5
Female	38.2	Single or both parent(s) Dutch	88.5
SES		Down syndrome	5.3
Low	49.9	Epilepsy	5.5
Medium to high	50.1	Motor impairment	1.3
Mean age (SD)	12.9 (3.0)	Sensory impairment (partially deaf/blind)	0.4

No significant (p>0.05) differences were found between the original eligible first phase sample and the second phase sample in the distribution of sex (χ^2=3.1, df=1), educational level (χ^2=4.1, df=1), and year of birth (χ^2=7.5, df=14). Seventy-eight percent of the parents of all eligible children gave us information on their socio-economic status (SES). No significant difference in SES was found between the sample of eligible children and the second phase sample (χ^2=2.2, df=1). However, those parents who did not participate in any phase and who gave us information on SES (n=122) were more likely to have low SES (68.9%) compared to the first phase participants (55.4%; χ^2=11.0, df=1).

Comparing children whose parents participated in both phases to those who participated only in the first phase, no significant (p>0.05) difference was found in the percentage of children scoring in the deviant range of the Total Problems scale (χ^2=0.8, df=1), the Externalizing scale (χ^2=0.32, df=1), and the Internalizing scale (χ^2=2.4, df=1) of the CBCL, nor in the percentage of children scoring above the 75th percentile of the Total Problems scale (χ^2=0.2, df=1) of the DBC-P.

Measures

The Diagnostic Interview Schedule for Children - Parent Version (DISC-IV-P)

The DISC-IV-P (Shaffer, Fisher, Lucas, Dulcan et al., 2000) is designed to obtain DSM-IV diagnoses, and to be administered by trained interviewers who need not have formal clinical training. Preliminary results on the DISC-IV showed that it has moderate to good test-retest reliability, and moderate to good agreement with clinicians' ratings (Shaffer, Fisher, Lucas, Comer, 2000). With the permission of the authors, the DISC-IV was translated into Dutch (by Ferdinand, van der Ende and Mesman) following the original text as closely as possible. Interviewers were graduating or graduated university students from psychology (related) programs. They received a 4-day training at the DISC training center of Erasmus MC-Sophia Children's Hospital, the Netherlands. Both DISC-IV trainers are officially trained as trainers for the DISC-IV administration at the Columbia University New York by P. Fisher.

This highly structured and reliable DISC-IV interview was chosen over a semi-structured interview, like the Diagnostic Interview for Children and Adolescents (DICA; Reich, 2000), because of this study's sample size, time constraints and the use of trained lay-interviewers. However, it is acknowledged that a structured interview lacks the possibility to seek clarification through follow-up questions to ensure understanding and accuracy.

No direct assessment components with the children were included in this study. Time and budget constraints, as well as a lack of any proven direct assessment method available to generate psychiatric diagnoses in children with ID without needing formal training, limited us to parents as informants.

This study focused on three major DISC-IV groupings of DSM-IV disorders, namely anxiety disorders, mood disorders, and disruptive disorders (including ADHD, ODD, and CD; see Table 6.2 for a listing of the specific disorders). The DSM-IV diagnoses were derived from DISC-IV-P scores by applying algorithms provided by the authors of the DISC-IV (Shaffer, Fisher, Lucas, Comer, 2000). It should be noted that a DISC-IV diagnosis is made when a child meets the symptom criteria of a DSM-IV disorders, and that this does not include significant impairment. With regard to differential diagnosis, medical and substance abuse rule-outs (e.g. hyperthyroidism, drug abuse) were not applied and mental disorder rule-outs (e.g. PDD, CD) were only applied when assessed in one of the DISC-IV modules.

Impairment due to psychiatric disorder

In addition to meeting DSM-IV symptom criteria, the impairment C algorithm of the DISC-IV (child is reported to be severely impaired in at least one area of everyday functioning in the past year) was used to assess the effect of each disorder on everyday functioning (Shaffer, Fisher, Lucas, Comer, 2000), as it corresponds best to the criterion mentioned for most psychiatric disorders in the DSM-IV manual (American Psychiatric Association, 1994). This disorder specific impairment criterion has the advantage over a global impairment measure that it is less likely to be inflated by the level of impairment due to other psychiatric disorders.

Mental health care utilization

Whenever a child experienced enough key symptoms of a specific disorder, the parent was asked whether the child had received professional mental health care in the past year for these symptoms, or whether an appointment was made to see a professional in the near future.

The Scale of Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-MRS).

The PDD-MRS is a 12-item questionnaire to screen for PDD (DSM-III-R) in people with ID. It addresses communication, social behavior and stereotyped behavior, and has good sensitivity and specificity (Kraijer, 1997). In this study, teachers or school psychologists completed the PDD-MRS in the first phase of the study. Children with scores of 10 or more were categorized as PDD screen positives. For 76% of the children in phase two a PDD-MRS score was available (n=360). No significant differences (all p(χ^2)>0.05) were found in the prevalence of DSM-IV disorders between children with or without a PDD-MRS score.

Socio-economic status.

Socio-economic status was assessed by evaluating both educational and occupational level of each parent and assigning a score to the highest rated parent. SES was recoded into two categories: 'low SES', including the unemployed, unskilled workers and workers with lower vocational training; and 'medium to high SES', including jobs requiring middle or higher vocational training or a university degree (Central Bureau of Statistics, 1993).

Educational level.

The two educational levels were used as an indication of the child's level of intellectual disability: educable (IQ between 60-80) and trainable (IQ between 30- 60).

Data analysis

Power analysis showed that the present sample size was large enough to detect the more common disorders (>1% prevalence) with sufficient power (1-β>.85; Cohen, 1988). The relationship between diagnosis and demographic variables, and the assessment of the impact of comorbidity (absent versus present) and impairment (absent versus present) on mental health care utilization, was examined by multivariate logistic regression. When the overall model χ^2 was significant (p<0.05), significant odds ratios (two tailed Wald statistic, p<0.05), adjusted for the other correlates in the model, were reported.

Results

One-year prevalence of DSM-IV disorders

Table 6.2 shows the one-year prevalence of the DSM-IV disorders in children with ID. Almost 39% of the children met the symptom criteria for at least one DSM-IV disorder. The three most prevalent disorders were specific phobia (17.5%), ADHD (14.8%), and ODD (13.9%). None of the children met the symptom criteria for generalized anxiety disorder (GAD) or posttraumatic stress disorder (PTSD).

No significant sex, age, educational level or SES differences in the prevalence of DSM-IV disorders were found, except for obsessive compulsive disorder (OCD; χ^2=12.3, df=4, $R^2_{Nagelkerke}$=0.115, p<0.05). Trainable children were 3.9 times (95% CI=1.2-12.2), and 13- to 20-year-olds were 5.0 times (95% CI=1.1-22.9) more likely to have OCD compared to educable and 7- to 12-year-olds, respectively.

Table 6.2 Prevalence of children meeting DSM-IV criteria with and without severe impairment in everyday life functioning, and percentage of received mental health care

DSM-IV disorders	DSM-IV criteria		DSM-IV + impairment	
	% (±SE[a])	% help	% (±SE)	% help
Any DSM-IV disorder	38.6 (±2.4)	26.8	21.7 (±1.9)	40.8
Any anxiety disorder	21.9 (±1.9)	16.3	10.5 (±1.4)	28.0
Social phobia	2.5 (±0.7)	33.3	1.9 (±0.6)	44.4
Separation anxiety disorder	2.1 (±0.7)	30.0	1.9 (±0.6)	33.3
Specific phobia	17.5 (±1.7)	2.4	6.8 (±1.2)	6.3
Panic disorder without agoraphobia	0.2 (±0.2)	0.0	0.2 (±0.2)	0.0
Panic disorder with agoraphobia	0.4 (±0.3)	50.0	0.2 (±0.7)	100.0
Agoraphobia without panic disorder	1.3 (±0.5)	0.0	1.1 (±0.5)	0.0
Generalized anxiety disorder	0.0	---	0.0	---
Obsessive-compulsive disorder	2.7 (±0.8)	23.1	1.5 (±0.6)	28.6
Posttraumatic stress disorder	0.0	---	0.0	---

DSM-IV disorders	DSM-Ivcriteria		DSM-IV + impairment	
	% (±SE)	% help	% (±SE)	% help
Any mood disorder	4.4 (±0.9)	33.3	2.3 (±0.7)	36.4
Major depressive disorder	1.7 (±0.6)	50.0	1.5 (±0.6)	42.9
Dysthymic disorder	2.3 (±0.7)	9.1	0.4 (±0.3)	50.0
Manic disorder	0.2 (±0.2)	0.0	0.2 (±0.2)	0.0
Hypomanic disorder[b]	0.4 (±0.3)	50.0	---	---
Any disruptive disorder	25.1 (±1.6)	27.7	14.8 (±1.2)	40.0
Any ADHD[c]	14.8 (±1.1)	30.0	6.8 (±0.8)	43.8
ADHD combined	5.9 (±1.1)	35.7	3.0 (±0.8)	50.0
Inattentive type	7.2 (±1.2)	20.6	3.2 (±0.8)	33.3
Hyperactive-impulsive type	1.7 (±0.6)	50.0	0.6 (±0.4)	66.7
Oppositional defiant disorder	13.9 (±1.6)	24.2	9.7 (±1.4)	34.8
Conduct disorder	3.0 (±0.8)	21.4	1.7 (±0.6)	25.0

[a] SE=Standard Error.

[b] There are no DISC-P impairment algorithms for hypomanic disorder.

[c] ADHD=attention-deficit hyperactivity disorder.

Impairment in everyday functioning

Meeting the symptom criteria for a DSM-IV disorder did not always coincide with significant impairment with respect to everyday functioning. About 56% of the diagnosed children were significantly impaired in at least one area of everyday functioning (see Table 6.2). Children with dysthymic disorder, ADHD or specific phobia were least often impaired.

Comorbidity

Multiple disorders were observed in 14.2% of all children (36.8% of those who met DSM-IV symptom criteria). Of these children, 52.8% were significantly impaired in everyday functioning, which is similar to children with a single disorder. However, children with more than one DSM-IV disorder were 2.9 times more likely to be impaired in two or more areas of everyday functioning than children with a single disorder (χ^2=8.3, df=1, $p<0.01$). About half of the children with anxiety disorder (10.7% of all children) or disruptive disorder (12.6%), and four-fifths of the children with mood disorder (3.6%), had a comorbid disorder.

Overall, comorbidity within the same major DISC-IV grouping of disorders (i.e. anxiety disorder, mood disorder, or disruptive disorder) was seen in 3.7% of all children (2.7% when impairment was included). Only one child (0.2%) met the criteria for both major depressive disorder and hypomanic disorder. A comorbid anxiety disorder was found in 1% (0.8% impaired), and multiple disruptive disorders in 2.5% (1.7% impaired) of all children. Almost 44% of the children with ADHD (any type) also met the criteria for ODD (highest within group comorbidity).

Figure 6.1 presents two Venn diagrams showing the overlap between the DISC-IV groupings, with and without including the impairment criterion. Comorbidity between different DISC-IV groupings of DSM-IV disorders was seen in 10.5% of all the children with ID (5% impaired). The largest degree of comorbidity was found for mood disorders: 79.5% of the children with a mood disorder had a coexisting disorder in another major grouping (78.3% impaired), most likely a DISC-IV disruptive disorder.

Comparing children with or without PDD

In this study 7.5% (±1.4%) of the children were screened positive for PDD. No sex, age or SES differences were found, only a significant educational level effect (χ^2=15.9, df=4, $R^2_{Nagelkerke}$=0.105, $p<0.01$). Trainable children were 4.7 times (95% CI=2.1-10.6) more likely to screen positive for PDD (17.9% ±4.2%) than educable children (4.3% ±1.2%). A comorbid impairing DSM-IV disorder was found in 40.7% of the children screened positive for PDD. Screen positives were 3.7 times more likely (95% CI=1.4-9.4; $p<0.01$) to have an impairing anxiety disorder (χ^2=8.2, df=1, $p<0.01$) than screen negatives. Within the anxiety disorders, only an increased risk was found for OCD (OR=13.8; 95% CI=2.6-71.8; $p<0.001$), which in turn could be explained by an increased risk on the key symptoms: 'other thoughts that kept coming back into the child's mind over and over again that the child could not get rid of' (χ^2=10.3, df=1, $p<0.01$) with an odds ratio of 4.7 (95% CI=1.7-113.0) and 'any other things that the child did over and over again without being able to stop' (χ^2=10.3, df=1, $p<0.01$) with an odds ratio of 10.3 (95% CI=3.8-27.9). No significant difference between children with or without PDD was found for the presence of an impairing mood or disruptive disorder, or the occurrence of two or more comorbid disorders (all $p>0.05$).
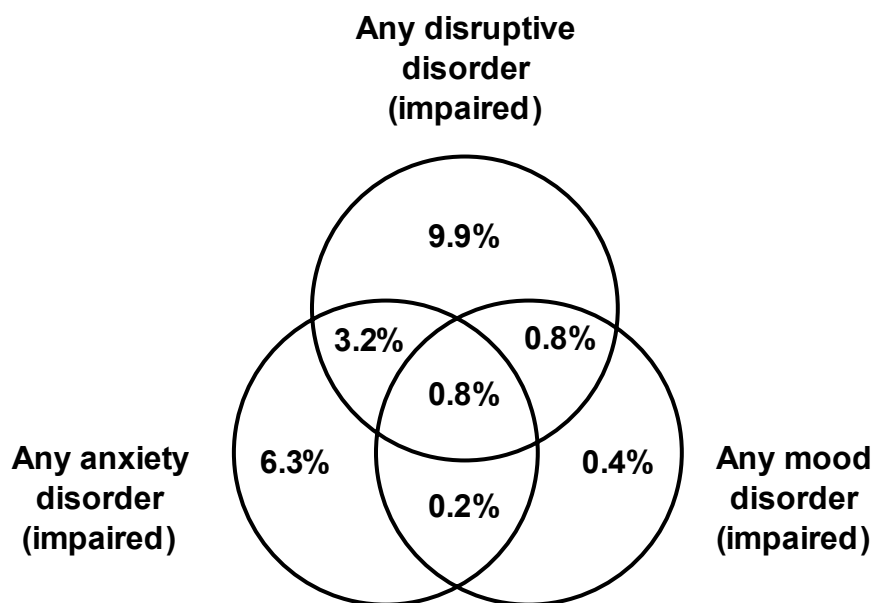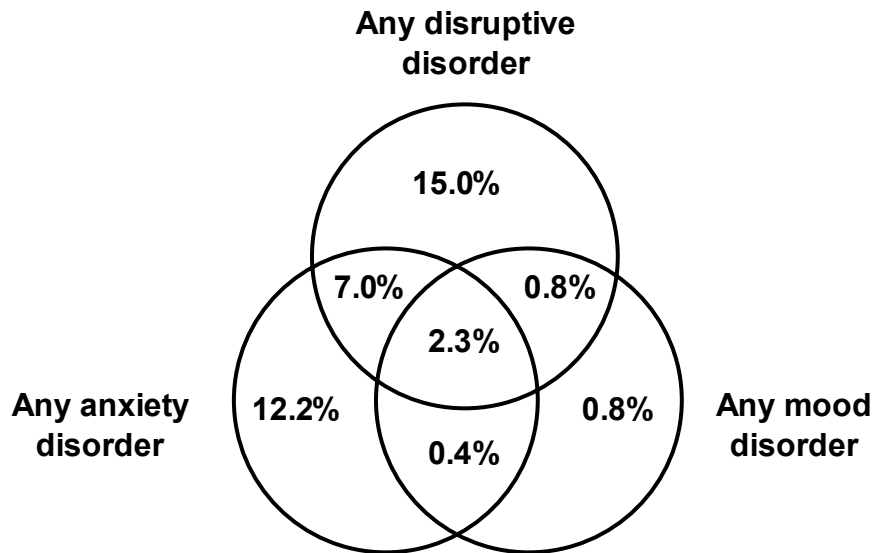
Figure 6.1 Comorbidiy (% prevalence) between major groupings of DSM-IV disorders with and without severe impairment in everyday functioning

Impact on mental health care utilization

Table 6.2 shows the percentage of children who received mental health care for each specific disorder. About 27% of the children who met DSM-IV symptom criteria received professional help. Almost 41% of those impaired received mental health care compared to 8.8% of those not impaired, and this was true for 50.7% of the children with a comorbid disorder versus 12.9% of those with a single disorder. Multivariate logistic regression analysis showed that referral to mental health care (χ^2=39.5, df=2; $R^2_{Nagelkerke}$=0.28, $p<0.001$) was 4.2 times more likely in children with a comorbid disorder (Wald statistic=12.9, df=1, 95%CI OR=1.9-9.2, $p=<0.001$), and independent of comorbidity, 3.9 times more likely in children who were impaired in everyday functioning (Wald statistic=8.2, df=1, 95%CI OR=1.5-10.1, $p<0.01$). PDD status did not significantly add to the prediction of referral ($p>0.05$).

Discussion

Most psychiatric disorders that can be identified in the general population were observed in this sample, except for GAD and PTSD, which are also rarely observed in general population samples of non-ID children (Costello, Angold, Burns, Stangl et al., 1996; Verhulst et al., 1997). Results showed that prevalence estimates of DSM-IV disorders, defined as meeting the DSM-IV symptom criteria, exceeded those found in community-based case file studies of children with ID (Gillberg et al., 1986; Myers and Pueschel; 1991; Rojahn et al., 1993), and this was also true for most disorders after including the impairment criterion. This finding supports our assumption that case file studies underestimate prevalence of psychiatric disorders. Furthermore, prevalence estimates of most disorders exceeded those found in general population studies (e.g. Anderson et al., 1987; Costello, Angold, Burns, Stangl et al., 1996; Verhulst et al., 1997), which confirmed our expectations based on studies assessing behavioral problems in children with and without ID.

Demographic differences were only found for OCD, with older and trainable children being more likely to meet DSM-IV criteria. However, this educational level difference was related to PDD screening status, and to key symptoms that included stereotypic behavior, also seen in children with PDD, suggesting overlapping symptoms or a limited ability of the DISC-IV to validly assees symptoms of OCD in the presence of PDD or ID. It should be noted however, neither PDD nor mental retardation is part of the DSM-IV exclusion criteria for OCD.

The lack of age differences in the prevalenc of DSM-IV disorders contrasts with findings from general population studies of psychopathology (e.g. Bird et al., 1988; Cohen et al., 1993; Verhulst et al., 1997). A possible explanation apart from power issues related to sample size, might be that it is their younger mental age that to some extent explains the lack of (chronological) age differences. For example, problem behaviors that are often found to be less prevalent at older age in non-ID samples, like ADHD and ODD, are far more prevalent in children with ID of all ages. In these children, the development of behavioral regulation might mature at a slower pace. In addition, possible causes of impulsive behavior and attention problems in children with ID are perhaps more likely to be based in the more common neurological and genetic deficits (Bregman, 1991), which are less likely to change over time.

We found that over half of the children with ID are impaired in everyday functioning by their symptoms compared to a third to half of the non-ID children (Bird et al., 1988; Costello, Angold, Burns, Erkanli et al., 1996; Verhulst et al., 1997), suggesting that psychopathology is more likely to cause impairment in everyday life in children with ID than in non-ID children.

Although it was shown that the majority of children with specific phobia had neither severe signs of impairment nor a comorbid anxiety disorder, still a relatively high percentage of children met DSM-IV criteria compared to prevalence estimates from non-ID studies (e.g. Anderson et al., 1987, Bird et al., 1988). A less developed reality testing, and lower self-confidence in children with ID, might make it harder for them to cope with frightening situations.

The majority of the children had a single DSM-IV disorder. However, 37% had a comorbid disorder, which is within the range of comorbidity found in general population studies of non-ID children (e.g. Anderson et al., 1987; Cohen et al., 1993). Children with more than one DSM-IV disorder were more likely to experience significant impairment in different areas of everyday functioning, suggesting more pervasive impairment, compared to children with a single disorder.

Comorbidity within a major grouping of disorders was highest between ADHD and ODD. Comorbidity between major groupings of disorders was most common between disruptive disorder and mood disorder, followed by disruptive disorder with anxiety disorder. In contrast to general population findings, the strongest associations were not found between CD and ADHD or between mood disorder and anxiety disorder (Angold et al., 1999). The first difference might be explained by the observation that ODD is often seen as a developmental precursor of CD (Angold et al., 1999). Because children with ID have significant developmental delays, and because they are perhaps less able to act upon antisocial tendencies because of closer supervision, they might make the transition from ODD to CD at a later age or they might be less likely to make the transition at all. The difference in comorbidity between major DSM-IV grouping might also be explained by their younger mental age (e.g. irritable mood instead of depressed mood, because of limitations in the expression of feelings). Future longitudinal studies should focus on disentangling questions related to timing of disorder onset and development of comorbidity in relation to both age and mental age. Information is needed on developmental tracks of psychopathology in children with ID, the effects of major life transitions, and associated risk and protective factors.

This study also assessed the effect of diagnosis, comorbidity and impairment on receiving mental health care. Less than a third of the children who met the symptom criteria for a DSM-IV disorder received mental health care, which is similar to rates in non-ID children (Anderson et al., 1987; Koot & Verhulst, 1992; Offord et al., 1987). Although the most vulnerable children (those with multiple or impairing disorders) were most likely to receive mental health care, still about half of these children were not served. Only a moderate strength of association was found between service utilization and comorbidity and impairment factors, suggesting the importance of other factors related to mental health care utilization. These might include the recognition of a problem by the parent(s), knowledge of the availability and accessibility of professional care, the availability of alternative resources of support, expectations about effectiveness of mental health services available, parental psychopathology, family composition, family functioning, and life stresses (Borthwick-Duffy, 1994; Offord et al., 1987; Verhulst & van der Ende, 1997).

Clinical implications

The results from this study make us aware that most studied disorders can be observed in children with borderline to moderate ID, that procedures for identifying these disorders are available, and that most estimates of prevalence of DSM-IV disorders exceed those found in non-ID children. Although many children with ID who meet the symptom criteria for a DSM-

IV disorder seem to function rather well, still about half of them are severely impaired in everyday functioning. These children might require special attention, especially when knowing that less than half of these children actually received mental health care in the past year. Just like in non-ID children, the presence of a comorbid disorder and severe impairment in everyday functioning in children with ID are important indicators of need for mental health care in this special population.

Methodological limitations

The study captured a large sample of children with ID living at home and attending a school for the ID. Since few children with mild to moderate ID visit a regular or another type of school in the Netherlands (<0.1%), this sample is thought to be representative of the large majority of students with borderline to moderate ID. Children from low SES families were somewhat under-represented, although half of the children came from families with low SES.

It is generally assumed that people with ID, and especially those with borderline to moderate levels of ID, present the full range of psychiatric disorders in roughly the same manner as non-ID people (Borthwick-Duffy, 1994; Sturmey, 1993, 1995), which is supported by findings that indicate a considerable overlap between psychopathology assessed with instruments developed for the general population and instruments developed specifically for the ID population (Dekker, Nunn et al., 2002). However, the applicability of a broadly accepted classification system like the DSM (American Psychiatric Association, 1994) to this population is still somewhat questionable (Einfeld and Tonge, 1999). Some have modified the existing criteria for diagnosing people with ID (Deb, Matthews, Holt, & Bouras, 2001). However, we agree with Sturmey (1995) when he emphasizes the importance of initially using these classification systems in an unmodified way, because to date many modifications are still quite ad hoc, not always clearly operationalized, and make it harder to compare across studies. In spite of this, we acknowledge that a greater degree of inference on the part of the parent may be needed as symptoms and signs of psychiatric disorders are more likely to be expressed in a somewhat altered fashion.

Not applying medical or substance abuse rule-outs, and mental disorder rule-outs only when assessed in the DISC-interview might have caused an overestimation of the true prevalence of specific psychiatric disorders. However, the conceptual and empirical basis for these decision rules are not explicit (Sturmey, 1995) and more research is needed on the effect of including and excluding these rule-outs. Unfortunately, no child, teacher or clinician information on DSM-IV disorders was available to provide a broader perspective ant to allow for inter-informant comparisons. Since we used a PDD screen, no PDD diagnoses were available.

7 | Child and family factors predicting DSM-IV disorders in children with intellectual disability

Marielle C. Dekker
Hans M. Koot

Abstract

The objective of this study was to identify child and family factors that predict DSM-IV disorders in children with intellectual disability (ID). In 1997, 968 6- to 18-year-olds were randomly selected from Dutch schools for the ID (response 69.3%). Parents completed the Child Behavior Checklist, the Developmental Behaviour Checklist, the Vineland Screener, and instruments addressing their child's physical health, family functioning, and parental mental health. One year later, parents of 474 children, randomly selected from the 1997 participants (response 86.8%), completed the anxiety, mood, and disruptive disorder modules of the Diagnostic Interview Schedule for Children-IV. Both child and family factors were significantly related to DSM-IV outcome one year later. Emotional and behavioral problems, social incompetence, inadequate daily living skills, child health problems, parental mental health problems, and negative life events were the strongest predictors of DSM-IV disorders one year later. The child's educational level, gender, age, and socioeconomic status were not directly associated with DSM-IV outcome, but proved to be significant moderators. These factors can improve the identification of children at risk, and point to topics that need attention in diagnostic and intervention procedures.

Introduction

Several theoretical considerations lead to the expectation of increased risk for psychopathology in children with ID relative to their typically developing peers (Matson and Sevin, 1994), and epidemiological studies show that children with ID are 3 to 7 times more likely to develop psychopathology than children without ID (Dekker, Koot et al., 2002; Koller et al., 1982; Linna et al., 1999; Rutter et al., 1970). Henceforward children also denotes adolescents. However, little research has been conducted to address factors associated with psychopathology in children with ID. Such epidemiological research, to this point, has been limited to factors like IQ, age and gender. Findings suggest that depressive feelings, anxiety, and antisocial behaviors are more common among those with higher levels of intellectual functioning, while psychotic, self-absorbed, and autistic behaviors are more likely to be found in children with lower IQs. (Borthwick-Duffy et al., 1997; Dekker, Koot et al., 2002; Einfeld and Tonge, 1996a, 1996b; Gillberg et al., 1986; Koller et al., 1982). Few or contradicting gender and age differences are found

The goal of this study is to address the relative importance of various child and family factors in their ability to predict psychiatric disorders. Information from this study may enhance the identification of children at risk for psychopathology (cf. Dykens, 2000).

In research on non-ID children a number of child and family variables seem to reoccur as significant predictors of general psychopathology, and some seem to be specifically associated with internalizing or externalizing problems. Findings from general population studies (e.g. Bird et al., 1989; Breslau, 1985; Costello, 1989; Esser et al., 1990; Farrington, 1993; Ferdinand, & Verhulst, 1995; Lavigne et al., 1998; Lavigne and Faier-Routman, 1992, 1993; Mesman, Bongers, & Koot, 2001; Offord et al., 1989, 1992; Rae-Grant et al., 1989; Stanger et al., 1992; Velez et al., 1989; Williams et al., 1990) suggest that the following factors are related to or

predictive of psychopathology: (1) *previous psychopathology of the child*, with relatively stronger homotypic externalizing pathways than internalizing pathways; (2) *(chronic) physical condition*; (3) *school/learning problems*, most often related to externalizing problems; (4) *stressful live events*; (5) *gender*, with boys more at risk for disruptive behavior and girls for emotional problems; (6) *maternal psychopathology*; (7) *paternal sociopathy* in relation to externalizing disorders; (8) *family dysfunction;* (9) *single parenthood/history of divorce*; and (10) *low SES/low income/low parental education*, most often in relation to externalizing problems. Other variables often taken into consideration, like age and ethnicity, give somewhat more contradictory results.

In a previous study based on the same sample as this study, we found no significant sex, age, educational level, and socioeconomic (SES) differences in prevalence of DSM-IV disorders (Dekker & Koot (provisionally accepted; see Chapter 6). However, these variables might be significant moderators. This study will address both main and moderating effects of predictors of psychopathology. We hypothesized that all factors associated with psychopathology in non-ID children would predict psychopathology in children with ID in a similar way. Considering previously mentioned results from general population studies of non-ID children, we expected that most predictors of psychopathology would be non-specific. We expected previous externalizing problems, parental imprisonment, and low parental education to be specific predictors of disruptive disorders, and previous internalizing problems to be specific predictors of anxiety and mood disorders. In addition, we included ID-related variables (i.e. domains of adaptive functioning, self-absorbed behavior, communication disturbance, level of special education), but without specifying disorder-specific relationships.

Method

Sample and procedure

This study was approved by the Medical Ethical Committee of Erasmus MC Rotterdam, and consisted of two data collection phases. The first phase (T1) was initiated in 1997, and about one year later a second phase (T2) began.

The target population consisted of all 6- to 18-year-olds who attended a school for ID in the province of Zuid Holland, the Netherlands. In September 1997, a 20% random sample of students (n=1,615) was drawn from each of the 115 participating schools for ID (out of 132 schools for ID in this province; response=87.1%). Each school was sent sampling instructions and a table of random numbers, based on the number of students in the previous school year. When we established our sampling frame in 1996, about 2% (n=48,800) of all 6- to 18-year-old Dutch children attended a school for ID (about one-fifth of them in Zuid Holland), and because children with ID were unlikely to attend regular schools (Central Bureau of Statistics, 1999). About three-fourth attended a school for the educable (IQ between 60 and 80) and one-fourth a school for the trainable (IQ below 60). Both groups were unlikely to have any severe additional physical or sensory handicaps.

Parents and caregivers of these children were sent a letter and a brochure about the research project through the schools, and were contacted by the researchers, only after giving consent. All parents who participated in the study signed an informed consent form. To be included in this study, the children had to live at home for at least four days per week, and at least one parent had

to have enough comprehension of the Dutch language to be interviewed (assessed by the interviewer after a personal conversation).

Of the first phase students, 141 were excluded from this study because of parental language problems, seven because they exceeded the age range, and 71 because they had left school by the time the first data collection phase started. Of the 1,396 remaining eligible students, the research group could not contact the parents of 231 students, 164 parents refused to participate, and 33 of the participating parents did not fill out all included instruments. The final number of participants with valid scores was 968 (69.3% of all eligible, and 83.1% of all parents who could be contacted in person).

About one year later (T2), we contacted a random sample of 58% of T1 respondents (*n*=557) for a second time. The mean interval between the two phases was 409.6 days (SD=79.9). Six families were excluded because they did not meet the language requirements for the more complicated diagnostic interview and five children were no longer living at home (eligible *n*=546). We were not able to contact 11 parents a second time, 53 parents refused to participate, and eight parents did not want to participate in the diagnostic interview. At T2, 474 home interviews were carried out (response 86.8%).

Measures

Impairing child psychiatric disorders

The presence of a psychiatric disorder in the preceding year was assessed at T2 during an interview with the main caregiver of the child (86% mothers) using the Diagnostic Interview Schedule for Children - Parent Version (DISC-IV-P). This interview schedule is designed to obtain DSM-IV diagnoses and to be administered by well-trained interviewers who need not have formal clinical training. Preliminary results from the National Institute of Mental Health DISC-IV showed that it has moderate to good test-retest reliability, and moderate to good agreement with clinicians' ratings (Shaffer, Fisher, Lucas, Dulcan et al., 2000). With the permission of the authors, the DISC-IV was translated into Dutch (by Ferdinand, van der Ende, and Mesman), following the original text as closely as possible.

We focused on three major groupings of disorders, namely anxiety disorders, disruptive disorders, and mood disorders. The DSM-IV diagnoses were derived from DISC-IV scores by applying algorithms provided by the authors of the DISC-IV (Shaffer, Fisher, Lucas, Comer, 2000). With regard to differential diagnosis, medical and substance abuse rule-outs were not applied (e.g. hyperthyroidism, drug abuse) and mental disorder rule-outs (e.g. PDD, CD) were only applied when assessed in one of the DISC-IV modules.

In addition to whether or not a child met the symptom criteria for a DSM-IV disorder, we used the impairment C algorithm of the DISC-IV interview (child is reported to be severely impaired in at least one area of everyday life functioning in the past year) to assess the effect of disorder specific impairment (Shaffer, Fisher, Lucas, Comer, 2000; Shaffer, Fisher, Lucas, Dulcan et al., 2000). Prevalence estimates of the specific disorders and information on impairment, comorbidity, and impact on mental health care will be published elsewhere (Dekker & Koot (provisionally accepted); See Chapter 6).

Child and family factors

All predictor variables were assessed at T1. Descriptions of the variables and instruments used can be found in Table 7.1.

Data analysis

Univariate logistic regression analysis was performed for each predictor with each DSM-IV outcome, while controlling for age and gender (Table 7.2 shows age and gender adjusted odds ratios). Moderating effects of age, gender, child educational level and SES were tested separately by adding each variable and its interaction term with the main variable to the model (Holmbeck, 1997). If the model χ^2 significantly improved ($p<0.05$), post-hoc probing was performed to determine the significance and strength of the association between the main variable and DSM-IV outcome within each level of the moderator (Holmbeck, 2002). Table 7.2 reports the significant odds ratios (Wald statistic, $p<0.05$) within each level of the moderator whenever a significant interaction effect was present.

Results concerning predictors of mood disorder should be interpreted cautiously, as the low prevalence of this disorder reduced power to evaluate predictive associations.

Next, multivariate stepwise logistic regression analysis was used to see which factors were the strongest predictors of DSM-IV disorders, while controlling for possible confounding effects from other predictors. In order to asses whether child and family predictors could be considered risk factors, i.e. preceding the DSM-IV outcome (see Kraemer et al., 1997), we used T1 deviant emotional/behavioral problems as proxies for T1 DSM-IV status. Dichotomized CBCL and DBC scores were included in the analysis after including the significant child and family factors from the first step (see Table 7.3). Table 7.3 also shows the unique contribution of each factor to the prediction of DSM-IV outcome, corrected for the presence of deviant problems at T1.

Results

Predicting any DSM-IV disorder

Most child factors predicted the presence of a DSM-IV disorder, except for the child's educational level, gender, and age. Parental psychopathology, referral to mental health care, and single parent family were the only family factors predicting DSM-IV disorder one year later. Age and gender moderated some associations (see Table 7.2).

Children with problem behaviors, especially externalizing behaviors and self-absorbed behaviors, had the highest relative risk for DSM-IV disorder one year later. Almost 63% of the children with a deviant DBC Total Problems score and 36.4% of those with a deviant CBCL Total Problems score had a DSM-IV disorder one year later.

When controlling for the effect of other child and family factors, many child and several family factors maintained their strong and significant association with DSM-IV disorders (Table 7.3, upper part). However, when T1 behavioral/ emotional problems were included in the model some child and all family factors no longer predicted DSM-IV outcome (Table 7.3, lower part).

Table 7.1 Description of child and family predictor variables measured at Time one

Predictors	Description of instruments and variables	Risk group (coded 1)	Cronbach's α present sample
Child:			
Emotional/behavioral problems	Children's emotional and behavioral problems (past 6 months) were assessed using the Child Behavior Checklist (CBCL; Achenbach, 1991a; Dekker, Koot, van der Ende, & Verhulst, 2002; Verhulst et al. 1996) and the Developmental Behaviour Checklist – Primary Carer version (DBC-P; Einfeld and Tonge, 2002; Koot and Dekker, 2001, Dekker, Nunn et al., 2002)	CBCL T scores: Syndrome scales ≥67 Internalizing, Externalizing, Total Problem score ≥60 DBC scales: ≥75th percentile of Dutch normative ID sample (Koot and Dekker, 2001)	0.64 to 0.91 0.88 to 0.95 0.65 to 0.95
Inadequate adaptive behavior	Vineland Screener (Sparrow, Carter, & Cicchetti, no date). 45 item short version of the Vineland Adaptive Behaviors Scales (Sparrow, Balla, & Cicchetti, 1984)	Standard score <85	
Inadequate Socialization			0.71
Inadequate Communication			0.87
Inadequate Daily Living Skills			0.84
Social Incompetence	CBCL social competence scale	T score <33	0.62
Chronic physical condition[a]	Child is troubled by physical condition/handicap ≥3 months a year or condition causes hospitalization ≥1 month a year	Present	
High physical symptoms	Wahler Physical Symtom Checklist (WPSI; Wahler, 1968). Six-point scale (almost never to almost every day) assessing 42 physical symptoms (e.g. pains, paralysis, nausea)	1 standard deviation above mean	0.78
Negative life events	Child negatively effected by ≥1 life event in the past 2 years (e.g. parent leaving the house, 20% decline in income) using 16-item adjusted version of the Life Events Questionnaire (Berden, Althaus, & Verhulst, 1990)	Present	
Educational level	Attended school for the educable (IQ 60-80) or trainable (IQ <60)	Trainable	
Gender		Boys	
Age	Mean age 11.8 years (SD=3.0). Two groups: 6-12-year-olds and 13-18-year-olds	13- to 18-year-olds	

Table 7.1 continued

Predictors	Description of instruments and variables	Risk group (coded 1)	Cronbach's α present sample
Family:			
Psychopathology primary caregiver	29-item version of the Young Adult Self-Report-Form (YASR; Achenbach, 1997; Wiznitzer, unpublished PhD-thesis) representing internalizing problems (past 6 months) of primary caregiver (86% mothers)	1 sd above mean of normative Dutch sample (Verhulst & van der Ende, 1997)	0.90
Parental referral to mental health care	≥1 parent referred to mental health care ever	Present	
Sibling referral to mental health care	≥1 sibling referred to mental health care ever	Present	
Parental imprisonment	≥1 parent imprisoned in the past two years	Present	
Family dysfunction	12-item General Functioning subscale of the McMaster Family Assessment Device (Byles, Byrne, Boyle, Offord, 1988)	Mean item score >2.17	0.85
Parental educational level	Highest completed education of highest scoring parent. Low educational level is lower voacational level or lower, and medium/high educational level is high school or higher	Low educational level	
Ethnicity	≥1 parent born outside the Netherlands versus both (or single) parents Dutch	Non-Dutch parent	
Single parent	Not married/cohabiting at T1 versus non-single parent	Single parent	
Socioeconomic status	Occupational level of highest rated parent (Central Bureau of Statistics, 1993). Low socioeconomic status (SES) includes unemployed, unskilled workers, workers with lower vocational training; and medium/high SES includes jobs at higher levels	Low SES	

[a]musculoskeletal disease (*n*=32; e.g. growth retardation, scoliosis, motor problems); neurological problems (*n*=31; e.g. epilepsy, brain damage, muscular tension problems); respiratory problems (*n*=29); sensory problems (*n*=19); skin problems (*n*=6); cardiac problems (*n*=5); intestinal problems (*n*=5); other chronic physical conditions (*n*=9).

Table 7.2 Prevalence (%) and odds ratios of Time one predictors of impairing DSM-IV disorder, anxiety disorder, disruptive disorder or mood disorder one year later

Predictors	% (n=474)	DSM-IV (21.7%)[bc] OR (95% CI)	Anxiety (10.5%) OR (95% CI)	Disruptive (14.8%) OR (95% CI)	Mood (2.3%) OR (95% CI)
Child:					
CBCL problem scales (deviant score):					
Total Problem Score	48.6	7.1 (4.1-12.4)	6.6 (3.0-14.4)	8.1 (4.0-16.3)	ns
Internalizing	41.2	3.4 (2.1-5.3)	3.1 (1.7-5.8)	L=7.7 (3.1-19.4); M-H=ns	12.2 (1.5-98.8)*
Externalizing	37.3	Y=4.3 (2.3-8.1); O=13.2 (5.7-30.4)*	3.8 (2.0-7.0)	Y=5.2 (2.4-11.1); O=81.4 (10.9-610.5) E=18.9 (7.8-45.8); T=3.8 (1.2-11.6)*	14.3 (1.8-115.5)*
Withdrawn	19.6	3.0 (1.8-4.9)	2.9 (1.6-5.4)**	2.6 (1.5-4.6)**	8.7 (2.1-35.6)**
Somatic Complaints	10.4	3.2 (1.7-5.9)	2.9 (1.4-6.1)**	3.0 (1.5-5.9)**	4.8 (1.1-20.3)*
Anxious/Depressed	17.3	4.3 (2.6-7.3)	3.5 (1.9-6.6)	3.8 (2.2-6.7)	4.0 (1.0-15.4)*
Social Problems	40.7	3.7 (2.3-5.9)	3.3 (1.8-6.3)	E=5.9 (3.1-11.5); T=ns	5.1 (1.0-25.2)*
Thought Problems	11.7	4.1 (2.3-7.4)	5.3 (2.7-10.3)	2.8 (1.5-5.4)**	ns
Attention Problems	35.2	4.3 (2.7-6.9)	2.6 (1.4-4.7)**	6.5 (3.7-11.5)	ns
Delinquent Behavior	17.1	Y=3.1 (1.6-6.0)**; O=15.5 (6.5-37.2)	O=5.7 (2.2-14.8)*d, L=5.7 (2.2-14.6)*e	E=11.2 (5.8-21.6); T=ns	4.5 (1.1-7.8)*
Aggressive Behavior	20.3	6.2 (3.8-10.3)	L=7.7 (3.0-19.4); M-H=ns	E=10.9 (5.7-20.9);T=ns	8.5 (2.1-34.8)**
DBC-P problem scales (deviant score):					
Total Problems	25.7	9.4 (5.7-15.4)	7.4 (3.9-13.8)	8.8 (5.0-15.4)	12.3 (2.6-59.1)**
Disruptive/antisocial	32.1	6.7 (4.0-11.2)	4.8 (2.5-9.0)	E=10.2 (5.2-20.7); T=ns	9.2 (1.8-45.9)**
Self-absorbed	25.1	6.1 (3.8-9.9)	4.7 (2.6-8.6)	7.9 (4.5-13.7)	7.3 (1.9-28.9)**
Communication Disturbance	27.9	3.2 (2.0-5.1)	4.0 (2.2-7.4)	B=6.4 (2.6-15.8); G=ns	ns
Anxiety	28.3	3.4 (2.1-5.4)	4.3 (2.3-8.0)	2.5 (1.5-4.2)**	3.8 (1.0-13.8)*
Social Relating	29.6	B=4.7 (2.1-10.3); G=ns	3.7 (2.0-6.7)	2.3 (1.4-4.0)**	5.6 (1.4-22.0)*
Adaptive behavior					
Inadequate Socialization	70.7	2.5 (1.4-4.4)**	2.3 (1.0-5.0)*	2.5 (1.3-4.9)**	ns
Inadequate Communication	86.4	ns	ns	ns	ns
Inadequate Daily Living Skills	69.9	2.6 (1.5-4.6)**	ns	Y=9.4 (2.2-40.3); O=ns	ns

Table 7.2 continued

Predictors	%	DSM-IV (21.7%)[a]	Anxiety (10.5%)	Disruptive (14.8%)	Mood (2.3%)
	(n=474)	OR (95% CI)[bc]	OR (95% CI)	OR (95% CI)	OR (95% CI)
Social Incompetence	37.9	2.3 (1.4-3.6)	L=ns; M-H=3.9 (1.5-10.4)**	3.1 (1.8-5.3)	ns
Chronic physical condition	22.8	B=ns; G=3.7 (2.1-6.8)	3.2 (1.7-5.8)	ns	ns
High physical symptoms	13.8	4.2 (2.4-7.4)	Y=ns; O=9.9 (3.9-25.3)	3.2 (1.7-6.0)	3.9 (1.0-14.6)*
Negative life events	25.3	2.5 (1.5-4.0)	3.1(1.7-5.7)	Y=ns; O=4.3 (2.0-9.4)**	4.7 (1.3-17.2)*
Educational level trainable	22.6	ns	ns	ns	ns
Gender male	61.8	ns	ns	ns	ns
Age 12–18 years	50.2	ns	ns	ns	ns
Family:					
Psychopathology primary caregiver	15.7	2.7 (1.6-4.7)	B=4.6 (2.0-10.7)*; G=ns	2.3 (1.3-4.3)**	ns
Parental referral to mental health care	12.1	2.0 (1.1-3.7)*	2.4 (1.1-4.9)	B=4.6 (1.7-11.9)**; G=ns	ns
Sibling referral to mental heath care	3.6	ns	ns	ns	ns
Parental imprisonment	0.6	ns	ns	ns	ns
Family dysfunction	12.0	ns	ns	2.4 (1.2-4.6)**	ns
Low parental educational level	66.7	ns	ns	2.0 (1.1-3.6)*	ns
Non-Dutch parent	11.5	ns	ns	ns	ns
Single parent	15.2	B=ns; G=2.0 (1.0-4.0)*	B=ns; G=2.9 (1.2-6.6)*	ns	L=ns; M-H=8.9 (1.7-46.6)**
Low socioeconomic status	49.9	ns	ns	ns	ns

[a]Prevalence of impairing DSM-IV disorder between brackets.

[b]OR=Odds Ratio; 95% CI=95% Confidence interval; all *p*<0.001, except for ***p*<0.01; **p*<0.05; ns=not significant at *p*<.05.

[c]Odds ratios resulting from post-hoc probing of significant interaction effects ($p(\chi^2)$<0.05) of predictor with age (Y=6-11 years; O=12-18 years), gender (B=boys; G=girls), educational level (E=educable; T=trainable) or SES (L=low SES; M-H=medium/high SES) are reported within each level of the moderator.

[d]Y=ns.

[e]M-H=ns.

Predicting specific DSM-IV disorders

The majority of child and family factors did not have a unique association with a specific DSM-IV outcome (see Table 7.2), with a few exceptions.

Having a chronic physical condition was uniquely associated with anxiety disorder. Relatively smaller odds ratios were found for externalizing behaviors and relatively larger odds ratios for thought problems compared to those found for DISC-IV disruptive and mood disorder. Multivariate logistic regression showed that the presence of a chronic physical condition, deviant anxiety and self-absorbed behaviors were the strongest predictors of anxiety disorder.

Inadequate daily living skills, family dysfunction, and low parental educational level specifically predicted DISC-IV disruptive disorder. Deviant attention problems and delinquent behavior showed relatively larger odds ratios for this disorder compared to those found for anxiety and mood disorder. Only social incompetence remained a significant predictor of disruptive disorder after correcting for T1 problem behaviors. CBCL attention problems, and delinquent behavior, and DBC-P self-absorbed behavior independently predicted disruptive disorder one year later, while deviant social relating was negatively related to DISC-IV disruptive disorder.

Relatively higher odds ratios were found for children with deviant withdrawn behavior, and deviant social relating in relation to having mood disorder compared to DISC-IV disruptive and anxiety disorder. Negative life events proved to be the strongest and only significant predictor of mood disorder while controlling for all other factors.

Specific moderating effects were found for gender, age, educational level, and SES. Living in a single parent family predicted anxiety (in girls) and mood disorder (in children from medium/high SES families). Educational level moderated the relation between externalizing behaviors and disruptive disorder.

Discussion

The results from this study showed that most included child factors and some family factors predicted impairing psychiatric disorders in children with ID one year later. Inadequate daily living skills, chronic physical condition, social incompetence, negative life events, high physical complaints, parental psychopathology, and parental referral to mental health care were the strongest predictors of DSM-IV disorders. After correcting for T1 emotional/behavioral problems the first four predictors proved to be significant risk factors for DSM-IV outcome, i.e. factors related to psychopathology, but also preceding outcome.

Most variables were non-specific predictors of DSM-IV disorder. However, some predictors were outcome-specific or had odds ratios that were relatively larger in relation to a specific disorder. As comorbidity is high, and because of the influence of subclinical levels of symptoms for other disorders that blur the distinction (Williams et al., 1990), it was not surprising that only a few predictors clearly distinguished between disorders, as discussed below.

Table 7.3 Odds ratios of Time one variables independently predicting[a] (from multivariate logistic regression) DSM-IV disorder, anxiety disorder, disruptive disorder and mood disorder one year later

Variables	Any DSM-IV OR (95% CI)	Anxiety OR (95% CI)	Disruptive OR (95% CI)	Mood OR (95% CI)
Child and family:				
Inadequate. Daily Living Skills	2.6 (1.4-5.0)		2.3 (1.1-4.8)*	
Social Incompetence	2.3 (1.4-3.8)	2.1 (1.1-4.1)*	2.9 (1.6-5.1)	
Chronic physical condition	2.5 (1.4-4.2)	2.1 (1.0-4.3)*		
High physical symptoms		2.5 (1.1-5.5)*	2.2 (1.1-4.3)*	
Negative life events	1.9 (1.1-3.4)*			5.4 (1.3-23.0)*
Psychopathology caregiver	2.0 (1.1-3.9)*			
Parental referral mental health care		2.6 (1.1-5.7)*	2.2 (1.0-4.5)*	
$R^2_{Nagelkerke}$	0.18	0.13	0.16	0.07
Child and family, and emotional/behavioral problems:				
Inadequate Daily Living Skills	2.5 (1.3-4.8)			
Social Incompetence			2.5 (1.4-4.7)	
Chronic physical condition	2.5 (1.5-4.4)	2.7 (1.4-5.3)		
Negative life events				5.9 (1.4-24.9)*
Thought Problems (CBCL)		ns		
Attention Problems (CBCL)			2.5 (1.3-5.1)	ns
Delinquent Behavior (CBCL)	2.5 (1.3-4.7)		3.7 (1.9-7.3)	
Aggressive Behavior (CBCL)	2.4 (1.3-4.6)			
Self-absorbed (DBC-P)	2.6 (1.4-4.7)	2.5 (1.2-5.0)*	4.4 (2.0-9.4)	
Anxiety (DBC-P)		2.6 (1.3-5.3)		
Social Relating (DBC-P)			0.5 (0.2-1.0)*	
$R^2_{Nagelkerke}$	0.29	0.21	0.33	0.31

[a] All $p<0.01$, except for * $p<0.05$, ns=not significant (although factor included in overall significant model).

Emotional/behavioral problems

We hypothesized that T1 externalizing problems would relate most to disruptive disorder, and T1 internalizing problems to anxiety and mood disorder. The first hypothesis was confirmed as both univariate and multivariate analyses showed that children with deviant externalizing problems and attention problems, in addition to children with self-absorbed behaviors, were most likely have disruptive disorder one year later. After controlling for all other T1 predictors, including social incompetence (e.g. problems getting along with others, not actively involved in a club, no/few real friends to do things with), children with deviant social relating (e.g. underactive, not showing affection, depressed, resisting being cuddled, aloof), proved to be less likely to show

disruptive disorder one year later than children scoring in the normal range. Socially withdrawn children were also found to be less likely to have disruptive disorder in a study by Farrington (1993). In contrast to others (Mesman et al., 2001; Farrington, 1993), we did not find anxiety to be a protective factor.

Both T1 internalizing and externalizing problems were related to anxiety and mood disorder one year later. In the multivariate model, however, only internalizing problems remained as significant predictors of anxiety disorder. Most at risk for anxiety disorder were children with deviant anxiety and self-absorbed behavior.

None of the CBCL or DBC scales predicted mood disorder, above and beyond negative life events. This is might result from reduced power due to the rarity of the disorder. However, univariate logistic regression showed that mood disorder was related to both internalizing (withdrawn, self-absorbed) and externalizing problems (aggressive and disruptive/antisocial behavior). This latter finding was expected due to the high comorbidity found between mood and disruptive disorder in this sample (78.3% of those with mood disorder also have disruptive disorder; Dekker and Koot (provisionally accepted); see Chapter 6).

Both CBCL and DBC scales independently predicted DSM-IV outcome, suggesting that each scale has its own unique predictive value, and that behaviors typically seen in children with ID are also related to DSM-IV outcome. Any DSM-IV outcome was predicted better by the presence of a deviant DBC Total problems score than a deviant CBCL Total Problem score, suggesting that a different, more strict, CBCL cutoff-point for this group might be needed in order to improve predictability.

Child and family factors
The presence of a chronic physical condition was, unlike hypothesized, only related to anxiety disorder. A high level of physical symptoms was also strongly associated with anxiety disorder, but had significant relationships with DISC-IV disruptive and mood disorder as well. A meta-analytic study of Lavigne and Faier-Routman (1992) showed that teachers were more likely to report internalizing rather than externalizing symptoms in children with physical disorders, although this effect was not found for parent reports. Possible explanations for the strong relation with anxiety disorder might be that children with psychical conditions are more likely to worry, and perhaps that some motor conditions result in fewer possibilities of acting out.

Single parenthood proved only to be associated with anxiety disorder and mood disorder. Non-ID studies found relationships with both internalizing and externalizing problems (e.g. Velez et al, 1989; Mesman et al., 2001; Williams et al., 1990).

Disruptive disorder was predicted by most family factors, including the hypothesized low parental educational level, which was, together with family dysfunction, uniquely associated with disruptive disorder. However, parental imprisonment was not predictive of DISC-IV disruptive (or any other) disorder. This was likely a result of infrequent parental imprisonment. In future studies it might be more fruitful to focus on broader concepts of parental sociopathy (e.g. level of antisocial behaviors regardless of police contact).

In addition to educational level being an important moderator, it was shown that more ID-specific variables, like inadequate levels of daily living skills, and self-absorbed behavior, are also important predictors of DSM-IV outcome. These factors might, to a certain extent, explain the increased risk of psychopathology in children with ID.

Parental psychopathology and referral to mental health care were the strongest family predictors of non-specific DSM-IV outcome. However, in the full multivariate model they no longer predicted DSM-IV outcome above and beyond the other variables. These family factors were apparently already associated with T1 emotional/behavioral problems, whether as cause or consequence, and did not add predictive power to T2 DSM-IV outcome.

Limitations

Although half of the participating families had low SES, children from low SES families were somewhat underrepresented in this sample. Apart from SES, this sample is regarded to be representative of Dutch school children with ID who live at home.

It should be noted that no causal direction could be inferred from the present findings, as it was not shown that changes in the predictors caused changes in the outcome variable.

The present sample size was not large enough to accurately evaluate predictors of mood disorder. Consequently, studies with larger sample sizes are needed.

Although a moderate strength of association between predictor and outcome variables was found (see 'pseudo' $R^2_{Nagelkerke}$ in Table 7.3), inclusion of other possible risk factors of later DSM-IV outcome (e.g. early life and life time risk factors, family dynamics, parental stress, peer rejection, genetic deficiencies related to ID) might be able to improve predictive power. However, it is difficult to prospectively assess early life risk factors in large samples of children with borderline to mild ID, as the non-typical development is often not recognized until these children start school. Furthermore, it is unlikely that many genetic syndromes related to ID would have been detected in the present sample, as most children had borderline to mild ID, while two-third of the parents had low educational level, suggesting a strong familial component (e.g. only 5.3% of the children had Down syndrome).

No information is available on the psychometric properties of the DISC-IV in children with ID. However, as modifications are still quite ad hoc and not yet clearly operationalized (Sturmey, 1995), we believe it is important to initially use the DSM criteria in an unmodified standardized way. We acknowledge however, that a greater degree of inference on the part of the parent might have been needed, especially in respect to internalizing problems, since communication problems are more common in children with ID.

Future (longitudinal) studies are needed to examine factors predicting onset and prognosis of psychiatric disorders in children with ID.

Clinical implications

Clinicians should realize that children with ID are at increased risk for psychopathology, and that within this group some are more at risk than others. The most important predictors are emotional/behavioral problems, both of general and of ID-specific nature. As with non-ID children, problem behaviors are highly stable (Dekker, Nunn et al., 2002), and as it now appears, predictive of impairing DSM-IV disorder. Efforts are needed to stimulate the prevention of and

early intervention with problem behaviors. The use of both general and ID-specific (screening) instruments can help to improve early detection of problem behaviors in both educable and trainable children.

Regarding the other predictors, both child and family factors seem important (social competence, daily living skills, child health, negative life events, and parental mental health). Some of these can be used to invoke preventive interventions, including competence-based programs, dealing with social and everyday life competence for children at risk. However, adequate and continuous support to families with members having (a history of) mental health problems, regardless of whether cause or consequence of the child's own mental health problems, seems important too.

8 | General discussion and conclusions

General discussion and conclusions

The main aims of this study were to (1) examine the psychometric characteristics of instruments to assess psychopathology in children with intellectual disability (ID); (2) to characterize the prevalence and impact of psychopathology in children with ID, and (3) to identify correlates and predictors of psychopathology. In this chapter the main results and conclusions from the study and some research and clinical implications are discussed.

Psychometric characteristics of instruments assessing psychopathology in children with ID

In this study we used three kind of instruments to assess psychopathology in our study group. The main focus was to examine the psychometric properties of an instrument specifically developed for use in children with ID, i.e. the Developmental Behaviour Checklist (DBC-P/DBC-T). The major conclusions regarding the DBC will be addressed first. The applicability of the two other instruments, that is the Achenbach scales (CBCL/TRF) and the Diagnostic Interview Schedule for Children (DISC-IV parent interview), both originally developed for use in children without ID, are also discussed.

The Developmental Behaviour Checklist

As far as instruments are concerned, the main focus of this study was to verify the reliability and validity of the Dutch translation of both the parent and teacher versions of the Developmental Behaviour Checklist (DBC-P and DBC-T, respectively). These are standardized questionnaires to assess emotional and behavioral problems in children with ID.

We started our assessment of the psychometric properties of the DBC-P in Chapter 3 by re-visiting the internal structure of the DBC. In contrast to the original Australian DBC study, we used a larger, combined Australian-Dutch sample that was representative of all levels of ID, and employed a more appropriate data analysis technique. Our goal was to come up with a good characterization of the correlation patterns between the observed emotions and behaviors in children with all levels of ID. We preferred the five factor solution because it included factors that tended to replicate across various factor solutions, that were not too narrow in scope, that had few cross-loadings, and that were well interpretable and clinically relevant. The five syndrome-scales derived from this solution were labeled Disruptive/Antisocial, Self-Absorbed, Communication Disturbance, Anxiety, and Social Relating. Together, these factors explained 44% of the total variance in the data set, which is comparable to similar instruments in this field (see Chapter 1), and they also incorporated 86 of the 96 DBC-P items. Inclusion of borderline intellectual functioning children resulted in a similar internal structure.

The DBC-T factor solution was comparable to the one found for the DBC-P, although no 'Anxiety' factor was extracted. Similar levels of consistency in factor structure across rater types has been found for the Nisonger Child Behavior Rating Form (Nisonger CBRF; (Aman et al., 1996; Tassé et al., 2000) and the Aberrant Behavior Checklist (ABC; Marshburn & Aman, 1992). Imposing the DBC-P factor solution on the DBC-T, which will facilitate cross-informant comparison, showed that the internal consistency of all DBC-P and DBC-T scales were both comparable and in the moderate to high range, with the exception of the Anxiety scale. The lack of a clear Anxiety scale in factor solutions of the DBC-T may suggest that teachers are less able to provide differentiated ratings on anxious behaviors in children with ID. As shown in the Dutch DBC manual (appendix C & D; Koot & Dekker, 2001) most items

making up the Anxiety scale are about two times less often observed by teachers than by parents. Although this might also be due to situation specificity of the anxiety, the lower rate of reported anxiety symptoms suggests that the lack of a separate anxiety factor in the DBC-T may have resulted from a lack of observable anxiety in the school.

In Chapter 4 we examined the internal consistency and test-retest reliability of the DBC-P and DBC-T scale scores in our large and representative sample of Dutch children attending schools for the educable or the trainable, i.e. who have borderline to moderate ID. High internal consistencies for the Total Problems scale, the Disruptive/Antisocial scale and the Self-Absorbed scale of both the parent and teacher versions were found. The other scales had moderate to good internal consistencies, except for the Anxiety scale which had relatively low internal consistency, which was also found in the combined Australian-Dutch sample in Chapter 3. For both the DBC-P and the DBC-T good test-retest reliabilities were found, which were highly comparable to those found in the original Australian DBC study (Einfeld & Tonge, 1992), as well as in other studies assessing psychopathology in children with ID (Freund & Reiss, 1991; Girouard et al., 1998; Tassé & Lecavalier, 2000; Tassé et al., 2000).

Next, in Chapter 4 and Chapter 7 we studied the cross-informant agreement, the construct validity, the criterion-related validity and the predictive validity of the DBC-P/DBC-T.

Even though the mean interval between inter-parent ratings of the DBC-P was 11 days, suggesting an additional test-retest effect, a moderate level of agreement was found. Although the inter-parent agreement was lower than the one found in the original Australian study, it corresponded very well to the agreement found between similar role informants in a large meta-analysis on cross-informant agreement on psychopathology (Achenbach et al., 1987).

As expected, the parent-teacher agreement was lower than the inter-parent agreement, but similar to that found for many other instruments assessing psychopathology across samples of typically developing children (Achenbach et al., 1987), and higher than the parent-teacher agreement found in the original Australian study. Both situation and observer specificity might explain the moderate agreement found between parent and teacher ratings.

Because of the lack of any definite criteria to define psychopathology (see Chapter 1) the simultaneous use of multiple methods is viewed as an appropriate and useful way to assess the construct validity of instruments (Campbell & Fiske, 1959). However, we acknowledge that this approach has a bit of a 'pulling yourself up by your bootstraps' quality to it.

Overall the construct validity of both the DBC-P and the DBC-T was supported by evidence of convergent validity and discriminant validity, but limited by high informant effects. A moderate to high degree of convergent validity between corresponding scales of the DBC-P and the CBCL and between the DBC-T and the TRF was found. Discriminant validity was somewhat limited due to the high convergence of constructs that were, not *'a priori'* hypothesized to be similar, i.e Disruptive/Antisocial with Anxious/Depressed, and Self-absorbed behaviors with Attention Problems. The convergence of the first two scales is probably a result of the high co-occurrence of disruptive disorders in children with mood disorders (see Chapter 6). The convergence of the latter two scales might, apart from correspondence in content (e.g. problems concentrating, impulsive, nervous movements), at least be partly explained by their higher sensitivity to educational level. Behaviors in both scales are more likely to be observed in trainable than in educable children (see Koot & Dekker, 2001; Chapters 4 and 5). Discriminant validity of the DBC scales was moderately supported by the fact that across informants, a vast majority of the correlation coefficients between dissimilar scales were smaller than their corresponding convergent validities. However, large informant effects were found, which might be caused by halo effects, e.g.

each informants' general impression of a child's problems distorts his or her perception of the presence or absence of specific problems. To some extent, high informant effects might also be a result of a higher-order pattern of co-occurring problems, e.g. the often distinguished higher order groupings of internalizing and externalizing behaviors, or a result of problems that share the same cause. Results form other studies using multi-trait, multi-method analyses (Fergusson & Horwood, 1987; Greenbaum et al., 1994) have shown similar large informant effects.

Discriminant validity of the DBC scales with the three domains of adaptive functioning was supported for the Disruptive/Antisocial and the Anxiety scale. The other DBC scales were more affected by level of adaptive functioning, suggesting that these emotional and behavioral problems are related to adaptive behavior (regardless whether cause or consequence).

Finally, supportive evidence of criterion-related validity of the DBC was found (see Chapters 4 and 7). Children who have ever been referred to mental health care had significantly higher DBC-P and DBC-T mean scores than children who had never been referred. Moderate effect sizes were found for the DBC-P scales, but only small effect sizes for the DBC-T scales. Possible explanations might be that the problems, for which the children were referred to mental health care, were situation specific, or that teachers knew the child less well or for a shorter period of time. Furthermore, in contrast to the parents, teachers were more likely to be blind to the child's referral status, which in the case of the parents can bias the way the child's behavior is evaluated (e.g. recall bias, halo effect). Once referred to mental health care, parents are also more likely to become more aware of and to learn more about their child's behaviors and emotions, which might result in more reported problem behaviors on the DBC-P

Further evidence for the criterion-related and predictive validity of the DBC was shown by the following results. The mean DBC-P scale scores were found to be significantly higher for children who met the DSM-IV criteria for a corresponding anxiety disorder, disruptive disorder, and/or mood disorder, showing moderate to large effect sizes (Cohen, 1988). The DBC-P scale scores were even higher for children who were severely impaired by their anxiety disorder or mood disorder compared to children who met the DSM-IV criteria without experiencing significant impairment in everyday functioning, suggesting that the DBC scale scores reflect both presence and severity of problem behaviors. In Chapter 7 it was also shown that children with deviant DBC scale scores were about 3 to 9 times more likely to have an impairing DSM-IV disorder one-year later than children without deviant DBC scale scores. Almost 63% of the children with a deviant DBC Total Problems score had an impairing DSM-IV disorder one year later.

Finally, DBC data from this study together with DBC data from the Dutch-Frisian study (Groningen University, Department of Child and Adolescent Psychiatry; drs. A. de Bildt, dr. S. Sytema, dr. D. Kraijer, dr. C. Ketelaars, and prof. dr. R. Minderaa), resulted in the development of Dutch norms for the DBC-P and DBC-T. Separate Dutch norms, based on a combined sample of 1,867 children with ID, are now available for each educational level, gender, and age group (6- to 11-years-old and 12- to 18-years-old), and are reported in the Dutch DBC manual (Koot & Dekker, 2001).

Summarizing, we can conclude that this study added important information to the field-testing of the DBC, including a wide variety of reliability and validity measures for both the

parent and teacher version. Results regarding the psychometric properties of the DBC were quite satisfactory, especially when taking into account the limitations imposed by and expectations from this relatively unexplored field of research.

The Child Behavior Checklist/Teacher's Report Form

The use of general population instruments to assess psychopathology in children with ID is not uncommon (e.g. Linna et al., 1999; Pueschel et al.,, 1991; Rutter et al., 1970). Although not specifically developed for use in children with ID, and therefore maybe less applicable to children with severe levels of ID, evidence already existed that the CBCL and TRF were sufficiently sensitive to detect behavioral and emotional problems in children with ID (see Chapter 5).

In this study we were interested in the applicability of the CBCL and the TRF in children with ID. Indicators of the applicability, reliability and validity of these instruments in children with ID will be discussed here.

The internal consistency estimates of the CBCL and the TRF scales in children with ID were comparable to or even higher than those found in Dutch general population and referred samples (e.g. satisfactory to high internal consistency for Total Problems, Internalizing, Externalizing, Aggressive Behavior, and Anxious/Depressed). Just like in the Dutch general population, the least internally consistent scales were Thought Problems and Somatic Complaints (Verhulst et al., 1996).

Moderate cross-informant correlations between the CBCL and the TRF were found, which were not significantly different from those found in the Dutch general population sample. Convergent validity was already shown by the moderate to high correspondence with similar DBC scales. And just as with the DBC scales, high informant effects were found.

In Chapter 5 it was shown that some of the items that were responsible for the increased risk of psychopathology in children with ID compared to children without ID might be related to the developmental delays of the former (e.g. like 'acting too young', 'difficulty learning', and 'problems concentrating'). At the same time, increased risks were also found for items, that can be considered deviant irrespective of developmental delay (e.g. 'mean to others', 'destroying own things'). In Chapter 7 it was shown that children scoring in the deviant range of the CBCL scales (defined by general population norms) had an about 3 to 7 times increased risk of meeting the criteria for an impairing DSM-IV disorder one year later than children without a deviant CBCL scale score, suggesting predictive validity. However, only 36.4% of those with a deviant CBCL Total Problems score met the criteria for an impairing DSM-IV disorder one year later. These findings suggest that for the use in the ID population, adjusted norms, and newly established cut-off scores to define deviant behavior, are needed.

Although, more research is needed to assess the reliability and validity of the CBCL/TRF in children with ID, we can conclude that the use of the CBCL and the TRF in the group of educable and trainable children is supported by this study's results.

The Diagnostic Interview Schedule for Children with ID (parent interview)

The third instrument used to assess psychopathology in children with ID, was the DISC-IV. In this study we were able to directly interview the parents of most children in the study group. On average it took us about 2 to 3 hours to complete the DISC-IV modules on anxiety disorder, mood disorder, and disruptive disorder. Standardized assessment of DSM-IV disorders with parents of children with ID proved to be possible, even though the majority of the parents had a low educational level.

The use of a structured interview excludes the possibility to seek clarification through follow-up questions to ensure understanding and accuracy, which might have resulted in some unreliable answers. However, the strict standardization increases general reliability and comparability across interviewers and across studies, and it is really the best practical option when one wants to assess psychiatric disorders in large samples by interviewers who do not have formal clinical training.

Almost all assessed DSM-IV disorders were observed in our sample of children with ID, and those that were not observed, are also known to have low prevalence rates in the general population. Furthermore, as discussed in Chapter 4 and Chapter 7, DSM-IV disorders were significantly related to emotions and behaviors that are observed in children with ID, as assessed with the DBC scales, as well as to emotions and behaviors assessed with a general population instrument, i.e. the CBCL. DISC-IV disruptive disorders were most strongly predicted by externalizing problem behaviors as measured with the CBCL/DBC-P, while anxiety and mood disorders were predicted by both internalizing and externalizing problems, although the DBC-P anxiety scale proved to be the strongest predictor of anxiety problems.

Unfortunately, we did not have clinician's ratings to validate our results. We do know however, that for more than half of the children their problems were serious enough to cause significant impairment in everyday functioning and that over 40% of these children received mental health care in the past year, which supports the criterion-related validity of the DISC-IV.

Prevalence of psychopathology in children with ID

The second goal of this study was to assess the prevalence of emotional and behavioral problems (psychometric-empirical approach), and psychiatric disorders (clinical-medical approach) in educable and trainable children. We were also interested in the relative risk of psychopathology in children with ID compared to children without ID.

Emotional and behavioral problems in children with ID

In Chapter 5 we reported the prevalence of a wide range of emotional and behavioral problems in children with ID, assessed with standardized questionnaires developed for typically developing children, i.e. the CBCL, and the TRF. The overall prevalence rate of emotional and behavioral problems in children with ID as reported by their parents was 49%, and 46% as reported by their teachers. These prevalence estimates were within the range of comparable studies in this field (see Chapter 1). The most prevalent emotional and behavioral problems in children with ID were social problems, attention problems, aggressive behavior, and withdrawn behavior

This study showed that compared to non-ID children, both educable and trainable children had significantly higher mean CBCL and TRF scores, and an increased risk of scoring in the deviant range of these instruments on a broad range of emotional and behavior problems. Overall, children with ID were about three to four times more likely to show deviant emotional and behavioral problems. These findings confirm our expectations of an overall increased risk of psychopathology in children with ID based on theoretical considerations and scarce previous empirical findings (see Chapter 1).

Thus far, no study incorporated (or reported about) a wide range of problem behaviors. However, this study demonstrated the value of a more differentiated approach, as effect sizes expressing the difference between children with or without ID differed largely across CBCL

and TRF scales. Children with ID differed most from children without ID on social problems, attention problems, aggressive behavior, withdrawn behavior, and thought problems.

Elevated scale scores reflected differences between children with and without ID over a broad range of items, and not solely on items more likely to be related to developmental delay. However, the high relative risk found for children with ID compared to non-ID children on the CBCL and TRF scales Social Problems and Attention Problems is probably an overestimation. Both scales include items that are expected to be more overlapping with general characteristics of children with ID, and were also found to be highly prevalent in our study group (e.g. 'acting too young', 'difficulty learning', 'problems concentrating').

The prevalence rates of teacher-reported emotional and behavioral problems in children with ID were below those reported by parents. Similar effects are also observed in the general population (e.g. Verhulst et al., 1996), suggesting non-ID specific processes involved in cross-informant differences. However, teacher reported relative risks of children with ID versus children without ID, also tended to be lower than parent reported relative risks for most problem scales. One explanation might be that teachers are more likely to use the child's classmates behaviors as a standard to evaluate the intensity or frequency of the child's behavior, while parents are perhaps more likely to compare their child with his or her normally developing siblings. On the other hand, situation specificity might also play a role in this sample. The structured environment of the school, and the presence of teachers specifically trained to teach children with ID, may actually result in fewer problem behaviors at school.

As we have not yet developed an optimal cut-off point to define deviant behavior on the DBC scales, we were not able to estimate the prevalence of emotional and behavioral problems typically seen in children with ID.

Psychiatric disorders and comorbidity in children with ID

In Chapter 6 we demonstrated that most psychiatric disorders assessed in this study were actually observed in the past year in both educable and trainable children, except for GAD and PTSD, which are also uncommon in non-ID children. The three most prevalent disorders were specific phobia (17.5%), ADHD (14.8%), and ODD (13.9%). Overall, almost 40% of the children had a psychiatric disorder according to DSM-IV criteria. Almost 22% of the children met the DSM-IV criteria for anxiety disorder, 4.4% for mood disorder, and about 25% for disruptive disorder. As expected, based upon findings regarding prevalence of psychopathology in studies using the psychometric-empirical approach, these estimates exceeded DSM estimates found in community-based case file studies of children with ID. Although different assessment methods (standardized DISC-IV interview instead of a professional's judgment) and different DSM versions (DSM-IV instead of DSM-III(-R)) were used in our study, this difference in prevalence is most likely due to referral bias in the case file studies. Since children with ID are less likely to be referred for mental health care (Jacobson, 1982; Rojahn et al., 1993), studies that base their prevalence estimates on case files of referred children may miss a proportion of the children in the community who do indeed have psychiatric problems. In our study, a relatively high percentage of children met the criteria for specific phobia, which might be caused by less developed reality-testing and problem-solving skills in children with ID.

As expected, and confirming our findings using rating scales, prevalence estimates of most disorders exceeded those found in general populations samples (e.g. Anderson et al., 1987; Costello, Angold, Burns, Stangl et al., 1996; Verhulst et al., 1997).

Over 14% of all children with ID met the criteria for more than one DSM-IV disorder, and this was the case for 37% of those diagnosed. Comorbidity within the same major DSM-IV grouping was highest between ADHD and ODD, while comorbidity between different DSM-IV groupings was highest between mood disorder and disruptive disorder. These findings are in contrast to findings in non-ID children, where the highest comorbidity is found between ADHD and CD, and between mood disorder and anxiety disorder (Angold et al., 1999). The first difference might be explained by the observation that ODD is often seen as a precursor of CD. Since children with ID have significant developmental delays, and because they are perhaps less able to act upon antisocial tendencies because of closer supervision, they might make the transition from ODD to CD at a later age or they might be less likely to make the transition at all. On the other hand, still 3% of the children with ID met the DSM-IV criteria for CD. Therefore, an alternative explanation, might be that ODD related problems in children with ID outnumber the CD related problems relative to children without ID, and therefore are more likely to show major overlap with ADHD. The high comorbidity between mood disorder and disruptive disorder might also be an expression of their younger mental age. Younger children in the general population are also known to be more likely to show symptoms of an irritable mood instead of a depressed mood, because of limitations in the expression of feelings (American Psychiatric Association, 1994).

Additional analyses, performed to find out whether children with PDD were more likely to have a comorbid disorder compared to children without PDD, showed that about 41% of the children who screened positive for PDD also met the DSM-IV criteria for anxiety disorder, mood disorder, or disruptive disorder. Compared to children without PDD, children with PDD only had an increased risk of meeting the criteria for OCD. This finding seemed likely to be caused by overlapping symptoms of stereotypic behavior between PDD and OCD diagnoses.

Impact of psychopathology in children with ID

In characterizing psychopathology in children with ID, it is also important to address its impact on everyday life. Impairment and mental health care referral, are important indicators of the severity of the reported problems, although it is acknowledged that impairment and mental health care referral are also influenced by other factors (e.g. presence of additional physical conditions or handicaps, parental psychopathology, parental stress, coping, family support, availability of mental health services for children with ID).

Findings in Chapter 4 suggested that higher levels of emotional and behavioral problems typically seen in children with ID were related to indicators of negative impact. Children with higher scores on the DBC-P/DBC-T were more likely to have been referred to mental health care at some point (especially in the case of disruptive/antisocial, self-absorbed, and social relating problems), or to experience significant impairment in everyday life functioning due to the presence of a DSM-IV disorder.

In Chapter 6 it was shown that over half of the children with ID who met the criteria for at least one DSM-IV disorder were severely impaired in everyday functioning by their symptoms, compared to about a third to half of the children without ID (e.g. (Bird et al., 1988; Costello, Angold, Burns, Erkanli et al., 1996; Verhulst et al., 1997). This finding suggests that psychopathology might be more likely to cause impairment in everyday life functioning in children with ID than in non-ID children. It was also shown that children with a comorbid DSM-IV disorder were more likely to be severely impaired in more than one area of everyday functioning (e.g. family life, school, peers).

Less than a third of the children who met the criteria for a DSM-IV disorder, received mental health care for that specific disorder in the past year. Although the percentage of families that received mental health care for their child's problems is rather low, it is similar to findings in non-ID children (Anderson et al., 1987; Koot & Verhulst, 1992; Offord et al., 1987). Furthermore, results in chapter 6 showed that the seemingly most vulnerable children, i.e. those with multiple or impairing disorders, were most likely to receive mental health care. Still about half of the children, who can be regarded as having serious problems, were not served.

Correlates and predictive factors of psychopathology in children with ID

The final aim of this study was to look at the influence of educational level, and some basic demographic variables on the prevalence of psychopathology, to examine the stability of emotional and behavioral problems, and to see what child and family factors were predictive of psychopathology in children with ID, and the specificity of these relationships.

Educational level differences in psychopathology in children with ID

Educational differences in mean DBC-P and DBC-T scale scores were not directly addressed in Chapter 4, and sex, age, and socio-economic differences in mean scale scores were only addressed after correcting for referral status. However, results regarding these analyses were reported in the Dutch manual for the DBC-P and the DBC-T (Koot & Dekker, 2001). In the Dutch manual it was concluded that trainable children had, according to parents and teachers, a significantly higher mean score on the Self-absorbed, Communication Disturbance, Anxiety, Social Relating, and Total Problems scales. Effect sizes were in the moderate (Self-absorbed and Total Problems, explaining 6.9% to 18.1% of the variance) to small range (explaining less than 5% of the variance). These differences were less clear in the Australian study, where children with mild and moderate ID had similar scores. This might be explained by sample differences (e.g. our study including borderline functioning children and the Australian study only partially representing children with mild ID).

In Chapter 5 we showed that the mean scores of some CBCL and TRF scales significantly differed by educational level, while controlling for gender, age, and socio-economic status. Although not reported in Chapter 5, effect sizes were small, ranging from 0.5% to 2.0% explained variance. Some emotional and behavioral problems were reported more often by parents and teachers for educable children, i.e. Anxious/Depressed and Delinquent Behavior (only by teachers), while other problems were reported more often for trainable children, i.e. Withdrawn, Thought Problems, Social Problems (only by parents), and Attention Problems (only by parents). These results are comparable to results from previous studies that found trends for depressive feelings, anxiety, and antisocial behaviors to be more common among those with higher levels of intellectual functioning, while psychotic, self-absorbed, and autistic behaviors were more likely to be found in children with lower IQ (Einfeld & Tonge, 1996b; Gillberg et al., 1986; Koller et al., 1982).

The importance of differentiating between various emotional and behavioral problems was shown by the fact that no significant educational level difference was found for either the overall level of problem behavior, or for externalizing, and internalizing problems on the CBCL and the TRF.

Education level differences found for the Achenbach scales and the DBC, as well as the relationship found with adaptive functioning (see Chapter 4) support the idea that the DBC is more sensitive in picking up emotions and behaviors more typically seen in children with

(lower levels of) ID. On the other hand, the CBCL and the TRF seem, at least to some extent, more sensitive in picking up emotions and behaviors that require a higher level of intellectual functioning. Some of the symptoms associated with the CBCL-TRF Anxious/Depressed and Delinquent Behavior scale are, for example, more difficult to express by, or to recognize in children with lower levels of ID, because of shortcomings in there self-reflecting skills (e.g. expressing suicidal thoughts and feelings of worthlessness), or because of the lack of opportunity to display certain behaviors due to closer supervision (e.g. setting fires). However, behaviors seen in children with PDD, who are most likely to attend a school for the trainable (see Chapter 2), are represented in the CBCL/TRF (e.g. 'stares blankly', 'withdrawn', 'would like to be alone', 'repeats acts', and 'strange behaviors'). Overall, the presented results seem to suggest the use of the DBC-P/DBC-T in children with moderate (and lower levels of) ID, and the use of the CBCL/TRF in children with borderline intellectual functioning. However, it is still unclear which instrument is best for assessing psychopathology in children with mild ID since they attend both schools types.

Finally, no education level difference was found for any of the DSM-IV disorders, except for OCD. Trainable children were more likely to meet the criteria for OCD compared to educable children. Additional analyses showed that children who screened positive for PDD were also more likely to attend a school for the trainable, and children who screened positive for PDD were also more likely to have OCD. This increased risk for OCD could be explained by an increased risk for key symptoms related to thr PDD symptoms regarding stereotypic behaviors (e.g. 'other thoughts that kept coming back in the child's mind over and over again that the child could not get rid of', and 'other things that the child did over and over again without being able to stop').

Gender, age, and socio-economic status differences in psychopathology in children with ID

In the Dutch DBC manual we were able to report and comment on gender, age, and socio-economic status differences in DBC scale scores (Koot & Dekker, 2001). We will address some of these findings, because due to word limitations, we were not able to report on these issues in the published papers included in this dissertation.

Small effect sizes of gender, age, and socio-economic status differences in DBC-P and DBC-T scales (all explaining less than 4.5% of the variance) were found. The gender and age effects were highly similar to those found in the Australian study (Einfeld & Tonge, 2002). Boys had a higher mean score on Self-Absorbed, Social Relating, Disruptive/Antisocial, while girls had a higher mean score on the Anxiety scale. Also small effects were found for age group (explaining less than 1.5% of the variance), with younger children (aged 6 to 11 years) having a higher mean score on Self-absorbed and Anxiety, and older children (12 to 18 years old) having a higher mean score on Social Relating. Finally, children from families with high socio-economic status were more likely to have a higher mean score on the Self-absorbed scale (explaining 1.1% of the variance). Based on these differences it was decided to provide separate norm scores for each educational level, gender, and age group in the Dutch DBC manual.

Due to word limitations we were also not able to report on the effects of gender, age, and socio-economic status differences in CBCL and TRF scale scores, even though we controlled for these effects in the analysis of educational levels effects of CBCL and TRF problem behaviors (see Chapter 5). However, only small effects were found for these demographic variables, ranging from 0.5% to 1.9% explained variance. The direction of the effects was

highly similar across informants, and also similar to effects found in children without ID in the Netherlands (Verhulst et al., 1996; 1997). Boys had a significantly higher mean score on Attention Problems, Aggressive Behavior, Delinquent Behavior, and Thought Problems, while this was true for girls on the Somatic Problems scale. Older children had a higher mean score on Withdrawn, Somatic Complaints, and Anxious/Depressed, while younger children had a higher mean score on Aggressive Behavior and Attention Problems. Finally, children from families with a low socio-economic status had a higher mean score on Delinquent Behavior and Aggressive Behavior, while children from families with a high socio-economic status had a higher mean score on Social Problems. Based on these differences we would suggest that future CBCL/TRF norm scores should be reported separately for each educational level, gender, and age group in the Dutch DBC manual.

No significant age, gender, or socio-economic status differences were found for any of the DSM-IV disorders, except for OCD. Older children were more likely to meet the criteria for OCD. The lack of more age differences contrasted with findings from studies of non-ID children. Possible explanations, apart from power issues related to sample size, might be linked to developmental issues. For example, problem behaviors that are often found to be less prevalent at older age in non-ID children, like ADHD and ODD, are far more prevalent in children with ID of all ages. Perhaps in children with ID, the development of behavioral regulation might mature at a slower pace. In addition, the possible related causes of impulsive behavior and attention problems in children with ID are perhaps more likely to be based in the more common neurological and genetic deficits that are more common in this group (Bregman, 1991), and which are less likely to change over time.

Although almost no educational level, gender, age, and socio-economic status differences were found in the prevalence of DSM-IV disorders, it was shown in Chapter 7 that these variables proved to be significant moderators in the prediction of DSM-IV disorders by various child and family factors.

One-year stability of psychopathology

In Chapter 4 we described the one-year stability of emotional and behavioral problems as reported by parents on the DBC. A high stability of problem behaviors was found, with correlation coefficients ranging from 0.66 to 0.75.

A correlation coefficient of 0.77 was reported in Chapter 5 for the one-year stability of Total problems as reported by parents on the CBCL. Although, not reported in the published paper included in this dissertation (Chapter 5), the correlation coefficients ranged from 0.55 to 0.74 across the eight CBCL/TRF syndrome scales.

The considerable one-year stability of emotional and behavioral problems suggests that previous problem behaviors are, just as in children without ID, important predictors of later problem behaviors, and that it is unjustified to assume that most problems will just disappear over time.

Child and family predictors of psychopathology

In Chapter 7 it was shown that most included child factors and some family factors predicted impairing psychiatric disorders in children with ID one year later. Inadequate daily living skills, chronic physical condition, high levels of physical complaints, social incompetence, negative life events, parental psychopathology, and parental referral to mental

health care were the strongest predictors of DSM-IV disorders. After correcting for emotional/behavioral problems that were already present the year before, the first five predictors proved to be significant risk factors for DSM-IV outcome.

Results also showed that most child and family factors were non-specific predictors of DSM-IV disorder. Since comorbidity is high (see Chapter 6), and because of the influence of sub-clinical levels of symptoms for other disorders blur the distinction, it was not surprising that few predictors clearly distinguished between disorders (Williams et al., 1990). Despite this, some predictors actually were outcome-specific or had at least odds ratios that were relatively larger in relation to a specific disorder.

Specificity of emotional and behavioral problems predicting DSM-IV disorders

In Chapter 7 we confirmed that externalizing problems measured one year earlier, as assessed with the CBCL and the DBC-P, related most strongly to DISC-IV disruptive disorder. Both univariate and multivariate analyses showed that children with deviant externalizing problems and attention problems, in addition to children displaying elevated levels of self-absorbed behavior, were most likely have a disruptive disorder one year later. After controlling for all other problem behaviors, deviant social relating proved to be negatively related to disruptive disorder one year later. Socially withdrawn children were less likely to have a disruptive disorder the next year, which was also found in a study by Farrington (1993). However, we did not find anxiety to be a protective factor for externalizing disorders, as was found in other studies (e.g. Mesman et al., 2001; Farrington, 1993).

Both internalizing and externalizing problems present in the first phase were related to anxiety and mood disorder one year later, suggesting a non-specific relation. In the multivariate model, however, internalizing problems remained a significant predictor of anxiety disorder. Most at risk for anxiety disorder, were children with deviant anxiety and self-absorbed behavior. None of the CBCL or DBC scales predicted mood disorder, above and beyond negative life events. This is most likely caused by reduced power due to the rarity of the disorder in this sample. However, univariate logistic regression showed that mood disorder was non-specifically predicted by both internalizing (withdrawn, self-absorbed) and externalizing problems (aggressive and disruptive/antisocial behavior), as expected due to the high comorbidity found between mood disorder and disruptive disorder in this sample (discussed in Chapter 6).

Specificity of child and family factors predicting DSM-IV disorders

The presence of a chronic physical condition was, unlike hypothesized, specifically related to anxiety disorder. High levels of physical symptoms were strongly associated with anxiety disorder, but also had significant relationships with DISC-IV disruptive and mood disorders. A meta-analytic study by Lavigne and Faier-Routman (1992) also showed that teachers were more likely to report internalizing rather than externalizing symptoms in children with physical disorders, although this effect was not found for parent reports. Possible explanations for the strong relation with anxiety disorder might be that children with psychical conditions are more likely to worry (partly because they just have more to worry about). Another explanation might be that possible motor disabilities result in fewer possibilities for acting out, although severe motor problems were not very common in the present study's sample (see Chapter 7).

Single parenthood proved to be specifically associated with internalizing DSM-IV disorders, i.e. anxiety disorder and mood disorder. Studies on non-ID samples found relationships with internalizing and/or externalizing problems (e.g. Velez et al, 1989; Mesman et al., 2001; Williams et al., 1990).

DISC-IV disruptive disorder was predicted by the most family factors, including the hypothesized low parental educational level, which was, together with family dysfunction, uniquely associated with disruptive disorder. However, parental imprisonment was not predictive of disruptive (or any other disorder). This was likely a result of infrequent parental imprisonment.

In addition to educational level being an important moderator, it was shown that more ID-specific variables, like inadequate levels of socialization, daily living skills, and self-absorbed behavior, are also important predictors of DSM-IV outcome. These factors might, to a certain extent, explain the increased risk of psychopathology in children with ID.

Parental psychopathology and parental referral to mental health care were the strongest family predictors of non-specific DSM-IV outcome. However, in the full multivariate model they no longer predicted DSM-IV outcome above and beyond the other variables. The association between these family factors and emotional/behavioral problems were apparently already present in the first assessment, either as cause or consequence, and did not add to the prediction of DSM-IV outcome one year later.

In sum, the strongest overall predictors of psychiatric disorder were earlier high level of behavioral and emotional problems, limited child social and daily living skills, elevated (chronic) physical problems, as well as additional stressful life-events. Furthermore, single parenthood and chronic physical conditions specifically predicted internalizing DSM-IV disorders, while low parental education and family dysfunction specifically predicted externalizing DSM-IV disorders.

Strengths and limitations, and implications for future research

As discussed in Chapter 1, the reliability and the generalizibility of prevalence and risk estimates of psychopathology in children with ID depends on the way ID and psychopathology are operationalized (reliability and validity), the level of standardization used in the assessments, and on the sampling frame and representativeness of the sample used.

In this section we will discuss the limitations and research implications concerning the assessment tools we used to assess psychopathology in the presents sample. We will also address the effects of the sample composition and the reliability of the used assessment instruments on the reported prevalence estimates for psychopathology in children with ID. And thirdly, we address the limitations and research implications of the findings on correlates and predictors of psychopathology in children with ID.

Assessment of psychopathology in children with ID

Compared to the original Australian DBC study, this study used a larger, combined Australian-Dutch sample that was representative of all levels of ID, and employed a more appropriate data analysis technique. Although overall the DBC factor structure seemed rather stable, future studies are needed to determine whether similar factors replicate across different samples (e.g. different cultures, referred to mental health care). Samples of children with ID referred to mental care, for example, might give us the opportunity to observe more rare

combinations of problem behaviors. On the other hand, the relatively high co-occurrence of problem behaviors in clinical samples might make it at the same time harder to differentiate among factors.

At the moment we are conducting a research project on a sample of children with ID who have recently been referred to mental health care in the Netherlands (Erasmus MC, Department of child and adolescent psychiatry; drs. M.C. Dekker, prof. dr. J. M. Koot, and prof. dr. F.C. Verhulst). This study will allow us to assess the DBC factor structure and corresponding internal consistencies. This study also gives us the opportunity to further validate the DBC and the CBCL/TRF, by relating their scale scores to DSM-IV diagnoses made by clinicians, which was missing validation method in the present study.

The present study was not designed to assess the reliability and validity of DISC-IV derived DSM-IV disorders, and is therefore limited in that respect. At the very least, more research is needed to examine to what extent the moderate to good agreement of the DISC-IV interview with clinicians' ratings in the general population (Shaffer, Fisher, Lucas, Dulcan et al., 2000) can be replicated in an ID sample.

In addition, so far, no cut-off point sensitive and specific enough to correctly identify children with ID in need of mental health care, has been developed for the Dutch translation of the DBC or adjusted for the CBCL. The present study has some possibilities to examine the screening qualities of these instruments. Our current research project on children with ID who have recently been referred to mental health care might give us an even better opportunity to determine a cut-off point that discriminates best between children referred to mental health care and never-referred children. This latter group will be sampled from the present study.

Although this study showed satisfactory measures of reliability and validity for the DBC-P/DBC-T and the CBCL/TRF in children with ID, more research on the (long-term) predictive power of these instruments is needed. At the moment a follow-up study, 5 years after the first data collection phase of the present study, is being conducted (Erasmus MC, Department of child and adolescent psychiatry; drs. J.C.H. Douma, drs. K.P. de Ruiter, drs. M.C. Dekker, prof. dr. J.M. Koot, and prof. dr. F.C. Verhulst). This study will allow for the further examination of the predictive power of the DBC-P/DBC-T, the CBCL/TRF, as well as the DISC-IV. This information might also help us to decide on which instrument is best in predicting outcomes for specific groups.

One of the limitations of the DBC is the somewhat unreliable Anxiety scale, even though this scale was one of the strongest predictors of anxiety disorder one year later. Future addition or revision of anxiety related items in the DBC, as well as some revisions in content for some of the other scales, are tasks that should be pursued in cooperation with the Australian designers of the DBC.

Prevalence and impact of psychopathology in children with ID

The accuracy and generalizibilty of the prevalence estimates of psychopathology depend on the representativeness of the sample. Further, it is acknowledged that all presented prevalence estimates are a function of the reliability of the assessment methods used, as is the case in all prevalence studies. As no "gold" standard is available in the field of child psychiatry, and especially in the sub-field of children with ID, and because no perfect reliability measures were found for the DBC-P/DBC-T or the CBCL/TRF, prevalence estimates are only approximations of the true prevalence. Finally, prevalence estimates are also a function of the reliability, and the sensitivity and specificity of the decision rules used to define 'normal' and 'deviant' emotions and behaviors, which can be somewhat arbitrary.

The present study is, compared to most other studies in this field (discussed in Chapter 1), unique because it includes a large sample of 6- to 18-year-old children randomly selected from many different schools of the ID. The high response rate of the participating schools is also unique in this field (e.g. Cormack et al., 2000; Wallander & Stankovic, submitted). Furthermore, unlike many other countries, most children with ID in the Netherlands were very unlikely to be enrolled in regular schools in 1996. Therefore, referral (to special education) bias is unlikely to be an issue in children with mild to moderate ID. We believe that the present sample represents students with mild to moderate ID very well. These levels of ID are known to be representative of over 90% of all children with ID.

It is expected that borderline functioning children, i.e. those with an expected IQ score between 70 and 80, are only partly represented in the present sample, as they are more likely to be integrated in regular schools. At the same time, we assume that children with borderline functioning and additional social and emotional problems (e.g. fear of failure, attention problems) are more likely to enter a school for the educable than borderline functioning children without additional problems, although no empirical data is available on this matter. This referral (to special education) bias could have resulted in an overestimation of the true prevalence of psychopathology in borderline functioning children.

Unlike some other studies in children with ID (e.g Borthwick-Duffy & Eyman, 1990; Eaton & Menolascino, 1982; Einfeld & Tonge, 1996b), bias caused by including only children who are referred to services for the ID (e.g. families in need of some kind of help, including advice or support with managing emotional and behavioral problems of the child), is unlikely to be an issue in this study.

It was shown in Chapter 5 that the gender and age distribution in our phase one sample represented the gender and age distributions found in schools for the educable and trainable in the province of Zuid-Holland.

This finding also strengthens our confidence in the randomization process performed by the schools. Our confidence in the randomization process was also supported by the finding that in the Dutch-Frisian study (Groningen University, Department of child and adolescent psychiatry; drs. A. de Bildt, dr. S. Sytema, dr. D. Kraijer, dr. C. Ketelaars, and prof. dr. R. Minderaa), similar DBC-P and DBC-T mean scale scores were found for educable and trainable children, while this study approached *all* children with ID, instead of a random sample (Koot & Dekker, 2001).

The overall response rate is comparable to other studies including children with mild to moderate ID (Einfeld & Tonge, 1996b, Dutch-Frisian study (personal correspondence), although few other studies actually report their response rates. We believe that the response rate could have been higher if the research team had been able to directly contact the parents in person, instead of indirectly through the schools. Thanks to the professionalism and sensitivity of our interviewers and research-assistants in contacting and interviewing subject families, almost 84% of the directly contacted parents were willing to participate.

In the first phase of this study, a differential higher dropout of schools for the educable and of parents of educable children was reported (see Chapter 2, 4, and 5). Educable children were underrepresented in this study. This finding was not surprising when taking into account that more than half of the families of educable children were expected to have low socio-economic status, which is a factor known to be related to lower participation rates in general population studies (e.g. McGee et al., 1990; Offord et al., 1987; Verhulst, Akkerhuis et al., 1985).

Because of the consequent unequal representation of the two educational levels, prevalence estimates of emotional and behavioral problems were presented separately for educable and trainable children, and relative risks were corrected for socio-economic status in Chapter 5.

As we only had complete information on gender, age, educational level, and partial data on socio-economic status of the non-participating children and their families, we were limited in our assessment of whether or not non-participation was differential in regard to level of emotional and behavioral problems. Families with low socio-economic status were found to be more likely to refuse to participate. In general population studies (e.g. Verhulst et al., 1996, see also Chapter 7), and in the present study (Koot & Dekker, 2001), small effects (explaining less than 2% of the variance) for socio-economic status were found in relation to emotional and behavioral problems. Most often, children from families with low socio-economic status were reported to have more problem behaviors. However, we do not know whether these effects would have been larger if all eligible subjects would have participated.

In the second phase of our study, a stratified sampling method was used to make sure that the distribution of educable and trainable children represented the original distribution of these educational levels in the Zuid-Holland population (75% educable and 25% trainable). It was shown in Chapter 6 that no significant differences were found in the distribution of educational level, gender, year of birth, and socio-economic status between the original first phase sample of eligible children and the second phase sample. In addition, no significant differences were found between first and second phase participants in the prevalence of deviant internalizing, externalizing, and total problem scores as measured with the CBCL and the DBC.

The response rate in the second phase was high (87%). Apart from the fact that the least interested parents of eligible children already dropped out in the first data collection phase, we believe that this high response was also a result of the fact that in this phase the research team was able to personally contact all parents. Furthermore, it reflects the professionalism and sensitivity in contacting and interviewing subject families shown by our interviewers and research-assistants in both phases.

Unfortunately, practical and financial constraints prevented us to design special procedures to make it possible to include children from parents whose comprehension of the Dutch language was limited (n=145), e.g. by translating the major instruments of this study, and by interviewing parents in their own native language. The exclusion of parents who did not have enough comprehension of the Dutch language, resulted in an under-representation of children from immigrant families attending schools for the ID (although the percentage of children from immigrant families is still above the Dutch average of 19.5% of all Dutch 0-to19-year old children coming from first or second generation immigrant families). If we could have included these children in the present sample, we might have found higher prevalence rates of psychopathology. For example, a study comparing Dutch and Turkish immigrant children living in the Netherlands showed that immigrant children scored significantly higher on six of the 11 CBCL scales (Bengi-Arslan, Verhulst, van der Ende, & Erol, 1997).

The results of this study can only be generalized to children living at home. Children residing in group homes or institutions were excluded from the present study because our main interest was to collect parent reported information on emotions and behaviors of their

child. Some children with ID reside outside their parents' home due to additional emotional and behavioral problems. If we had included these children in the present study, this might have resulted in higher prevalence estimates of problem behaviors.

In addition, the present study's findings can also not be generalized to children with severe to profound ID, and to children who have severe additional sensory or physical conditions or handicaps. If we had included these children we might have found different prevalence estimates of psychopathology. For example, we might expect lower prevalence estimates of anxious/depressed behaviors because children with severe to profound ID are less able to reflect on and express their own feelings (e.g. 'feels worthless', 'suspicious'). In addition, children with severe motor limitations (also more common in children with severe to profound ID) are less likely to perform behaviors related to disruptive behaviors (e.g. 'deliberately running away', 'hiding things', 'stealing'). On the other hand, sensory disabled children are known to show more signs of emotional and behavioral problems (Teare, 1984; Van Eldik, 1994; Vostanis, Hayes, Du Feu, & Warren, 1997).

Another issue is the reliability of the cut-off scores from the CBCL/TRF when reporting on prevalence estimates. In relation to the CBCL/TRF, a question was raised regarding the need to develop adjusted cut-off scores. Due to the presence of some behavioral items in the CBCL/TRF that are sensitive to developmental delays (e.g. 'acts too young', 'difficulty learning'), the reported prevalence based on these questionnaires is likely to be a slight over-estimation of the true prevalence of deviant behavior. At the same time, as the CBCL and the TRF are not designed to assess problem behaviors in children with ID, there might also be an under-reporting of behaviors that are typically seen in children with ID.

This study assessed a limited number of DSM-IV disorders. For example, we did not assess eating disorders, tic disorders, psychotic disorders, and we only used a screen for PDD. Consequently, the estimate of overall prevalence of psychiatric disorders is an under-estimation of the true overall prevalence of DSM-IV disorders, although the estimates on anxiety, mood, and disruptive disorders are fairly reliable.

No information on the reliability of the DISC-IV in children with ID was available. Furthermore, medical or substance abuse rule-outs were not applied, and mental disorder rule-outs only partly. This might have caused an over-estimation of the true prevalence of specific psychiatric disorders. However, the conceptual and empirical basis for these decision rules are often not explicit (Sturmey, 1995), and more research is needed on the effect of including and excluding these rule-outs.

The prevalence of PDD was limited to a teacher-based screen during the first phase, as PDD could not be assessed with the DISC-IV interview. For specific information on PDD in Dutch children with ID we to refer to the Dutch-Frisian study on 'Pervasive developmental disorders in children and adolescents with mental retardation' from the department of child and adolescent psychiatry of the University of Groningen (drs. A. de Bildt, dr. S. Sytema, dr. D. Kraijer, dr. C. Ketelaars, and Prof. Dr. R. Minderaa). This study started in 1997, and included all school-aged children with ID in the province of Friesland, the Netherlands. This study also uses the DBC-P/DBC-T, the CBCL/TRF, and the PDD-MRS, as well as other instruments to assess PDD.

The present study was limited by the lack of complete data on IQ scores, which prevented us from presenting prevalence rates by level of ID, which would have improved comparability across studies. Fortunately, we will be able to administer 4 subtests of the Dutch WISC-III (NIP Service-center & Boom, 2002) in our 5-year follow-up to the present study's phase one sample. This information will allow us to differentiate our sample according to ID level

(borderline, mild, moderate), and we are considering using this information retrospectively for reanalysis of the present study's results. Information on IQ scores will also make it possible to present accurate prevalence estimates separately for children with mild ID, as these children are, in contrast to borderline functioning children, believed to be well-represented in the present study.

In chapter 6 we argued that the high comorbidity between ADHD and ODD and between mood disorder and disruptive disorder, might be caused by the slower transition of ODD related behaviors into CD related behaviors in children with ID. Future longitudinal studies should focus on disentangling questions related to timing of disorder onset and development of comorbidity in relation to both age and mental age in children with ID. The ongoing 5-year follow-up of our first phase sample is a first step in that direction.

Finally, as only a moderate effect size was found for comorbidity and impairment factors explaining mental health care utilization, it was suggested in Chapter 6 that more research is needed to identify other factors related to mental health care utilization. In our ongoing 5-year follow-up of the present study special attention will also be paid to other factors that can help identify both the need and the reception of mental health care (e.g. the perception of availability and accessibility of professional care, the availability of alternative sources of support, expectations about the effectiveness of mental health care services, parental stress, parental psychopathology, family composition and functioning, and life stresses).

Correlates and predictors of psychopathology in ID

It should be noted that no causal direction could be inferred from the present study findings on the relation between predictor variables and DSM-IV disorders, as it was not shown that changes in the predictors caused changes in the outcome variable.

The present sample size was not large enough to accurately evaluate predictors of mood disorder. Consequently, studies with larger sample sizes are needed. Fortunately, our ongoing 5-year-follow-up study will allow for the assessment of the same DSM-IV disorders (and in addition tic disorders, and schizophrenia) in all phase one participants of the present study (expected sample size is about 800 to 900 11- to 23-year-olds).

Although a moderate strength of association between predictor and outcome variables was found, other possible risk factors of later DSM-IV outcome (e.g. early life and life time risk factors, family dynamics, parental stress, peer rejection, genetic deficiencies related to ID) might be able to improve predictive power. However, it is difficult to prospectively assess early life risk factors in large samples of children with borderline to mild ID, as the non-typical development is often not recognized until these children start school. Furthermore, it is unlikely that many genetic syndromes related to ID would have been detected in the present sample, as most children had borderline to mild ID, while two-third of the parents had low educational level, suggesting a strong familial component (e.g. only 5.3% of the children had Down syndrome). In future studies it might be more fruitful to focus on broader concepts of parental sociopathy (e.g. level of antisocial behaviors regardless of police contact) as predictor of disruptive disorder in children with ID, since parental imprisonment seemed a limited marker, due to its low probability.

Future (longitudinal) studies are needed to examine factors predicting onset and prognosis of psychiatric disorders in children with ID. Information is needed about developmental tracks of psychopathology in children with ID (and how they relate to developmental tracks in non-

ID children), the effects of major life transitions, and their associated risk and protective factors. These questions will be addressed in our 5-year follow-up study of the present sample.

Clinical implications

Given the problems in defining emotional and behavioral problems in children with ID, the use of standardized, reliable, and valid instruments to assess and record emotional and behavioral problems and to evaluate interventions is recommended in this under-diagnosed and under-treated group. Both the DBC and the CBCL are good candidates, as satisfactory indicators of reliability and validity were found for both instruments. Although, each questionnaire also showed its own unique contribution to the prediction of DSM-IV disorders (see Chapter 7), the use of both instruments in clinical practice seems a bit redundant. However, more research is needed to evaluate whether instruments developed for children with ID, (e.g. the DBC), or instruments developed for the general population (e.g. the CBCL) are best in describing their problem behaviors (e.g. practical usefulness of instruments as judged by clinicians). We also need to examine which instrument is best for various levels of ID in predicting future psychopathology (e.g. impairing psychiatric disorders) or predicting other external criteria poor outcome (e.g. referral to mental health care, police contact, school dropout, poor everyday life functioning, alcohol and drug use). The ongoing 5-year follow-up of the present study (Erasmus MC, Department of child and adolescent psychiatry; drs. J.C.H. Douma, drs. K.P. de Ruiter, drs. M.C. Dekker, prof. dr. J.M. Koot, and prof. dr. F.C. Verhulst) will provide interesting data on this matter that will help make an evidenced-based decision about which questionnaire to use for whom. At the same time, our ongoing study in children with ID referred to mental health care (Erasmus MC, Department of child and adolescent psychiatry; drs. M.C. Dekker, prof. dr. J.M. Koot, and prof. dr. F.C. Verhulst) will also add important information about the practical applicability of DBC and CBCL information, as evaluated by clinicians in various mental health care settings.

In clinical applications, the DBC will allow for meaningful comparisons of an individual's score against representative Dutch norms, which can be found in the Dutch DBC Manual (Koot & Dekker, 2001). Norms for the Dutch DBC-P and the DBC-T (split by educational level/day-care, age group, and gender) are based on the present study's sample, as well as on the Dutch-Frisian population of 6- to 18-year-old children with ID (n=810; Groningen University, Department of Child and Adolescent Psychiatry; drs. A. de Bildt, dr. S. Sytema, dr. D. Kraijer, dr. C. Ketelaars, and prof.dr. R. Minderaa). Ongoing research in children referred to mental health care will add useful information on the practical applicability of the information available from the DBC, and will provide information to establish an optimal cut-off point that will support the identification of children with ID who are most at risk.

Furthermore, the DBC is likely to become even more interesting to Dutch clinicians by means of other possible applications, e.g. the use of some items from the DBC as a screen for autism, e.g. the DBC-ASA (Brereton, 2000).

When we translate the prevalence findings from the present study to all 6- to 18-year-old children attending a school for the educable or trainable in the Netherlands in 1996 (neglecting possible differences in prevalence estimates of psychopathology due to differences in, for example, urbanisation and the distribution of immigrant families across the Dutch provinces), about 25,000 children are estimated to have a level of emotional and behavioral problems that would be considered serious enough for referral to mental health

care in children without ID. Furthermore, if we translate the prevalence estimates of DSM-IV disorders to the whole Dutch population of 6- to 18-year-old children attending a school for the educable or the trainable, we can project that about 19,500 children would meet the criteria for DSM-IV anxiety disorder, mood disorder, or disruptive disorder. However, only 27% of these children would have received professional mental health care in the past year. About 11,000 of the diagnosed children would be expected to be severely impaired in everyday functioning because of these problems. Although, significantly more of those children would have received mental health care, the majority (59%) would still not. Finally, about 7,000 children would meet the criteria for 2 or more DSM-IV disorders, which is also likely to be an indicator of more serious problems. Again, only about half of these children would have received mental health care for these problems.

Although the percentage of children with ID actually receiving mental health care is comparable to non-ID children, it might also be sign of diagnostic overshadowing, e.g. attributing the problem behaviors as being part of the ID. We believe that the question about what is causing the problems is not relevant at the point of identification and referral, and should not keep the child and/or those caring for him or her from possible interventions that might reduce the problems or help the child and/or his or her significant others to better deal with the situation. Mental health care workers should be aware of the high prevalence of emotional and behavioral problems, and psychiatric problems in children with ID, and the risks of diagnostic overshadowing.

The high percentage of children with ID that might be in need of some kind of mental health care (ranging from about 25% to 50%) is, in our opinion, also suggestive of the need for service systems serving children with ID (e.g. indication committees for special education, school-psychologists within special schools, social-pedagogical services for the ID) to screen routinely for psychopathology. The DBC-P/DBC-T and the Achenbach scales are viewed as good candidates, as they only take about 10-15 minutes to complete by parents and teachers, and because of their promising psychometric qualities as discussed in this report.

These findings also have implications regarding the policy of stimulating children with ID to attend regular schools. It is likely that additional emotional and behavioral problems will decrease the likelihood of full integration in the schools. Early identification and increasing possibilities for treatment of psychopathology, as well as the coaching of teachers in dealing with emotional and behavioral problems, should be part of the policy of helping children with ID to live as normal lives as is possible.

The present study results also suggest that in mental health care for children with ID, special interest should be focused on social problems, attention problems, and aggressive behaviors, as these areas of problem behavior were most prevalent, and also showed the largest difference with non-ID children. Although some of these problems are likely to be (also) caused by their cognitive and academic impairments, these problems deserve attention form the clinician just like they would when present in children without ID. Assuming that the child's skills or the skills of significant others surrounding the child can be improved in order to deal with these kinds of problem behaviors in a more efficient way, this will increase the child's possibilities in life. Of course, focusing on these highly prevalent behaviors should not result in overlooking low prevalent behaviors of concern, such as eating non-food, suicidal thoughts, and possible hallucinations.

Furthermore, clinicians should be aware of, just as in non-ID children, the presence of comorbid disorders in children with ID, as over a third of the children who met the criteria for one DSM-IV disorder also met the criteria for a second DSM-IV disorder, which is likely to

be an under-estimation since only a limited number of disorders were assessed. Special interest should be paid to the co-occurrence of mood and disruptive disorder, and ODD and ADHD, as these were the most common co-occurring disorders.

Clinicians should realize that some children with ID are more at risk for psychopathology than other children with ID. The most important predictors are emotional/behavioral problems, both of general and of ID-specific nature. As with non-ID children, problem behaviors are highly stable, and predictive of an impairing DSM-IV disorder. Efforts are needed to stimulate the prevention of, and early intervention against, problem behaviors. The use of both general and ID-specific (screening) instruments can help to improve early detection of problem behaviors in both educable and trainable children.

Regarding the other predictors, both child and family factors seem important (social competence, daily living skills, child health, negative life events, and parental mental health). Some of these invoke preventive interventions, including competence-based programs, dealing with social and everyday life competence in children at risk. However, adequate and continuous support to families with members with (a history of) mental health problems, regardless whether these problems are a cause or consequence of the child problems, appears important too.

Concluding, we can state that the present study's findings laid an important foundation for future research on psychopathology in children with ID. Three well-regarded instruments to assess emotional and behavioral problems were evaluated for use in children with ID in a large and representative sample. Each proved to be satisfactory for further use in the field. Based on the psychometric data gathered using the DBC, the Dutch manual for the DBC was composed, and is now available for clinical use and screening practices. Furthermore, prevalence estimates for a wide range of emotional and behavioral problems and psychiatric disorders, and their impacts on everyday life functioning and mental health care referral were reported. These results underscore the need for mental health care for children with ID, and direct us to which problems behaviors are most common and most impairing. Data from this study can help policy makers to plan services and allocate financial resources more valuably for these children. And finally, we were able to point out some of the major correlates and predictors of psychopathology in children with ID. This information helps establish a starting point for prevention and intervention projects, and forms a springboard for etiologically oriented and theoretically focused research on risk factors of psychopathology in children with ID

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Summary

Summary

Several theoretical considerations and some empirical findings lead to the expectation of an increased risk for psychopathology in children with ID. Psychopathology in children with intellectual disability (ID) may have a major effect on their personal independence, academic functioning, social functioning, and on their well-being, as well as that of their family and other caregivers. And it may decrease the likelihood of full integration in society. However, useful epidemiological findings on prevalence and relative risk of psychopathology in children with ID compared to typically developing children are limited due to the use of various definitions of psychopathology, the lack of use of standardized instruments and representative community samples, and general scarcity of research in this field. Findings from previous studies were discussed in Chapter 1, and showed that prevalence estimates of psychopathology in children with ID range from 4% to 60%, varying due to study design, instruments used, and sample composition. Although very few studies were able to directly assess the increased risk of psychopathology in children with ID compared to those without ID, those who did showed that children with ID had at least a 3-to 4-fold increased risk. Research issues related to the paucity of information on factors associated with psychopathology in children with ID was also discussed in the first chapter.

The lack of reliable and valid instruments developed to assess psychopathology in children with ID is another important issue. In this under-diagnosed and under-treated group, reliable standardized instruments are needed. Efforts to develop instruments to assess a broad range of emotional and behavioral problems in children with ID are increasing. These developments were discussed in the first chapter. Few promising instruments were available at the time of the study, none of which were in the Dutch language. The Australian Developmental Behaviour Checklist (DBC) was one of the most broadly studied instruments, showing promising psychometric qualities, and we therefore translated it into Dutch (the Dutch translation of the DBC is called: Vragenlijst over Ontwikkeling en Gedrag).

The aim of this study, was to address the following three main questions:
1. What is the reliability and validity of the Dutch translation of the DBC, and what is the applicability to the population of intellectually disabled children of standardized instruments originally designed to assess psychopathology in non-ID children?
2. What is the prevalence and impact of psychopathology in children with ID?
3. What are significant correlates and predictors of psychopathology in children with ID?

Six- to 18-year-old children were randomly sampled from all schools for the educable and trainable, and from all day-care centers for the ID in the province of Zuid-Holland, The Netherlands (response 88%). During the first phase of this study, parents of 1,059 children participated (response 70%). They filled out questionnaires and were interviewed at their home by trained interviewers regarding their child's emotional and behavioral problems, their child's social and physical well-being, and about their own well-being and family functioning. For 940 children, teachers or group workers completed questionnaires about their student's emotional and behavioral problems (response 83%).

In the second phase of this study, about one year later, we randomly selected 58% of the first phase responders and we asked the parents to fill out questionnaires similar to those filled out in the first phase, and additionally to participate in an standardized interview to assess psychiatric disorders (response 87%).

The objective of the study reported in Chapter 3 was to reassess the factor structure of the DBC in a large cross-cultural sample representing all levels of intellectual disability. Parent and teacher DBC ratings on a combined sample of 1,536 Dutch and Australian children and adolescents (ages 3-22) with mild to profound intellectual disability were used. Principal components analyses produced five interpretable and clinically relevant subscales: Disruptive/Antisocial, Self-absorbed, Communication Disturbance, Anxiety, and Social Relating, explaining 44% of the total variance and incorporating 86 of the 96 items of the DBC. The Teacher version of the DBC showed a similar factor structure. The reliability of the scales was satisfactory, as shown by good to high internal consistencies for the Disruptive/Antisocial, Self-absorbed, and Social Relating scales (Cronbach's alpha ranged from 0.76 to 0.91), and moderate internal consistencies for the Communication Disturbance and Anxiety scales (Cronbach's alpha ranged from 0.62 to 0.73).

The revised factor structure of the DBC appeared to be an improved and useful tool for assessing emotional and behavioral problems in children with intellectual disabilities. It incorporates factors that tend to recur with considerable consistency across other empirically derived instruments for assessing emotional and behavioral problems. Future research is needed to define sensitive and specific cut-off scores for the Dutch DBC, and refinements to the Anxiety and the Communication Disturbance scale, and a shortened DBC version, were suggested.

In Chapter 4 we assessed the reliability and validity of the revised DBC scales in our Dutch sample of children with ID. The psychometric properties of the parent and teacher version of the DBC were assessed in various subsamples derived from a sample of 1,057 Dutch children with ID or borderline intellectual functioning. Good test-retest reliability was shown both for the parent and teacher version of the DBC. Moderate inter-parent and parent-teacher agreement was found, which has also been reported for many other instruments assessing psychopathology across samples of non-ID children. The high one-year stability found for the DBC scale scores has also been commonly found for problem behaviors in children without ID, and suggests the absence of extreme changes in problem behaviors. The construct validity of the DBC was satisfactory, although limited by high informant variance. Again, this is also a common finding in other instruments developed for non-ID children. The DBC scales converged with corresponding scales of the Child Behavior Checklist (CBCL) and the Teacher's Report Form (TRF). Adaptive behavior was only moderately related with the Self-absorbed, Communication Disturbance, and the Social Relating scales indicating satisfactory divergent validity. The DBC scales showed good criterion-related validity, as indicated by significant mean differences between referred and non-referred children, and between children with and without a corresponding DSM-IV diagnosis. The use of this standardized, reliable, and valid tool is recommended for use in clinical practice to assess and record emotional and behavioral problems, and to evaluate interventions. The availability of Dutch norm scores (combining scores from this study and scores from a Dutch-Frisian study) allows for a meaningful comparison of an individual's score against his or her norm group. Future research was suggested to assess the relation between DBC scores and clinician judgements, and to find out to what level of ID or borderline intellectual functioning, the DBC or an instrument developed for children without ID is best suited to assess psychopathology.

Chapter 5 assessed and compared the prevalence of a wide range of emotional and behavioral problems in children with and without ID. We compared 1,041 children with ID to 1,855 non-ID children randomly selected from the general population. Parents completed the

CBCL, and teachers the TRF. The use of general population instruments to assess psychopathology in children with ID was shown not to be uncommon in children with mild ID. Present study results showed that the internal consistency estimates of the CBCL and the TRF scales were comparable to or even higher than those found in Dutch general populations and referred samples. Satisfactory to high internal consistency was found for the scales: Total Problems, Internalizing, Externalizing, Aggressive Behavior, and Anxious/Depressed. Moderate agreement between parents and teachers was found in children with ID, which was not significantly different from that found in the Dutch general population sample. In Chapter 4 we had already discussed the satisfactory convergent validity of the DBC scales with corresponding CBCL/TRF scales.

Controlling for sex, age, and socio-economic status, we found that both educable and trainable children had significantly higher mean scores on all CBCL and TRF scales than children without ID, except for trainable children on the scales Anxious/Depressed and Somatic Complaints. Almost 50% of children with ID had a Total Problem score in the deviant range compared to about 18% in children without ID. Similar to the few previous studies, an overall 3- to 4-fold increased risk of psychopathology in children with ID was found. In contrast to previous studies, we were able to look at a broad range of problem behaviors, which showed to have quite different levels of increased risk. Compared to children without ID, the most prominent problem behaviors for educable children were Social Problems, Attention Problems, and Aggressive Behavior, and trainable children had an increased risk for Social Problems, Attention Problems, Withdrawn and Thought Problems. Elevated scale scores reflected differences between children with and without ID over a broad range of items, and not solely on items more likely to be related to developmental delay. Therefore, problem areas covered by the items in these scales deserve special attention in the mental health care of children with ID. Although more research is needed to assess the reliability and validity of the CBCL and the TRF in children with ID, and the use of adapted norms is suggested, the use of these instruments in children with borderline to moderate ID is supported by this study.

In Chapter 6 we assessed the prevalence, comorbidity, and impact of DSM-IV disorders in 7- to 20-year-olds with intellectual disability. About one year after phase one parents of 474 randomly selected children from the first phase participated in phase two. Parents completed the anxiety, mood, and disruptive disorder modules of the Diagnostic Interview Schedule for Children (DISC-IV). Of the included children, 21.9% met the DSM-IV symptom criteria for anxiety disorder, 4.4% for mood disorder, and 25.1% for disruptive disorder. Similar prevalence rates of DSM-IV disorders were found for children who screened positive or negative for pervasive developmental disorder. Most of the prevalence estimates exceeded the DSM prevalence estimates found so far from case-file studies in children with ID. Over half of the children meeting the symptom criteria for a DSM-IV disorder were severely impaired in everyday functioning, and about 37% of the diagnosed children had a comorbid disorder. The highest comorbidity was found between ADHD and ODD, and between disruptive disorders and mood disorders. These findings differ from findings in general population research, and might be linked to the younger mental age of children with ID. Children with multiple disorders were found to be more likely to be impaired across various areas of everyday functioning.

The finding that less than a third of the children with a psychiatric disorder received mental health care in the past year deserves attention. Although comorbidity and impairment in everyday functioning increased the likelihood of referral, still about half of the children

with multiple or impairing disorders did not receive mental health treatment. Other factors, like the availability and accessibility of professional care, alternative support resources, family functioning, and parental stress, need to be examined in future research, as these factors may help explain why so many children are not served. A 5-year follow-up of the present study will address these and other possible factors related to the need of and referral to mental health care. No clinical ratings were available to validate the DISC-IV diagnoses in children with ID. However, this study's findings on convergent validity of the DISC-IV major groupings of disorders with the DBC scales, and on the criterion-related validity of the DISC-IV (i.e mental health care referral, impairment), showed that the DISC-IV can be used to assess DSM-IV disorders in children with borderline to moderate ID.

The objective of Chapter 7 was to identify child and family factors that predict DSM-IV disorders in children with ID. In the first phase of this study parents completed the CBCL, the the DBC, the Vineland Screener, and questionnaires addressing their child's physical health, family functioning, and parental mental health. In phase two, parents completed the anxiety, mood, and disruptive disorder modules of the DISC-IV. Both child and family factors were significantly related to DSM-IV outcome one year later. Emotional and behavioral problems, social incompetence, inadequate daily living skills, child health problems, parental mental health problems, and negative life events were the strongest predictors of DSM-IV disorders, one year later. The child's educational level, gender, age, and socio-economic status were not directly associated with DSM-IV outcome, but proved to be significant moderators. The majority of the child and family factors did not have a unique association with a specific DSM-IV outcome. However, externalizing behavior problems, inadequate daily living skills, low parental educational level, and family dysfunction had an outcome-specific relationship with DISC-IV disruptive disorder, and the presence of a chronic physical condition, and single parent family status were uniquely related to internalizing DSM-IV disorder. After correcting for each child's level of emotional and behavioral problems at first assessment, the strongest predictor of anxiety disorder was the presence of a chronic physical condition. The strongest predictor of disruptive disorder was social incompetence, and mood disorders showed the strongest relationship with the experience of a negative life event. Some of the factors found to be related to DSM-IV diagnosis can help improve the identification of children at risk, point to topics that need attention in diagnostic and intervention procedures, and invoke possible (preventive) interventions, including competence-based programs for the children.

A number of additional findings are of importance. In Chapter 8 we also reported on educational level, gender, age, and socio-economic status differences in psychopathology in children with ID. Most effect sizes were in the small range. It was shown, for example, that children attending schools for the educable scored significantly higher on the Anxious/Depressed and the Delinquent Behavior scale of the CBCL or TRF. Children attending schools for the trainable had higher mean scores on Withdrawn, Thought Problems, Social Problems, and Attention Problems of the CBCL or TRF, and on all DBC scales, except on the Disruptive/Antisocial scale. These results made us decide to provide separate norm scores for each educational level, gender, and age group for the Dutch DBC scales, and for the CBCL and TRF. High stability of emotional and behavioral problems was reported for both the DBC-P and the CBCL. Finally, general conclusions, research limitations, clinical implications, and directions for future research were discussed in Chapter 8. Concluding, we can state that the present study's findings laid an important foundation for future research on psychopathology in children with ID. Three well-regarded instruments to assess emotional

and behavioral problems, and psychiatric disorders were evaluated for use in children with ID in a large and representative sample. Each proved to be satisfactory for further use in this field. Based on the psychometric data gathered on the DBC in this study, the Dutch manual for the DBC was composed and is now available for clinical use and screening practices. This study also provided CBCL and TRF norm scores for educable and trainable children. Furthermore, prevalence estimates for a wide range of emotional and behavioral problems and psychiatric disorders, and their impact on everyday life functioning and mental health care referral were reported. The results underscore the importance of good mental health care for children with ID, and show us which problem behaviors are most common and most impairing in this population. Data from this study can help policy makers to plan services and allocate financial resources more valuably for these children. And finally, we were able to point out some of the major correlates and predictors of psychopathology in children with ID. This information helps establish a starting point for prevention and intervention projects, and forms a springboard for etiologically oriented and theoretically focused research on risk factors of psychopathology in children with ID.

The present study is, compared to most other studies in this field, unique because it includes a large sample of randomly selected children from many different schools of the ID. Furthermore, unlike in many other countries, almost all children with ID in the Netherlands at the time were unlikely to be enrolled in regular schools.

Three ongoing studies, two of which are a follow-up of the present study, and one that is related to the present study, will help to further assess important research questions in this field, and will also address some of the limitations of this study. These studies have the following main topics:

• Continuity, change, and determinants of psychopathology in children with ID (5-year follow-up).

• Determinants of objective and subjective need for mental health care services for children with ID, and discrepancies between need for help and help obtained (5-year follow-up).

• Practical applicability and further validation of the DBC in mental health care settings, and the prevalence and associated factors of psychopathology in a sample of children with borderline intellectual functioning or ID who are referred to mental health care.

The five-year follow-up of the present study includes the assessment of IQ tests by the research group, as the present study showed that information on IQ through school records resulted in incomplete data. This new IQ information which will make it possible to (retrospectively) classify children as borderline, mild, and moderate ID, which is internationally regarded as a meaningful classification. Furthermore, in the follow-up study a larger group of children will be assessed with the DISC-IV to improve the power to detect more rare DSM-IV disorders. This time, the youths will also provide information about their own well-being, and much more elaborate information on help needs will be collected. In the third study, DBC and CBCL scores will be related to clinicians' judgements, as this information was not available for the present study. This study will also give information on the practical applicability of the DBC, and will provide information that will help us to determine an optimal cut-off point to define deviant behavior on the DBC scales. Future research is needed to improve the factor structure of the DBC, to further assess the validity of the DISC-IV in children with ID, and to decide which instruments are best to assess emotional and behavioral problems for specific levels of ID. In addition, future studies should consider incorporating procedures that allow for the inclusion of children from non-Dutch speaking parents.

Samenvatting

Op grond van verscheidene theoretische overwegingen en enkele empirische bevindingen kan verwacht kan worden dat kinderen met verstandelijke beperkingen (VB) een verhoogd risico op psychopathologie hebben. Psychopathologie bij kinderen met VB kan een groot effect hebben op hun persoonlijke onafhankelijkheid, hun functioneren op school, hun sociale functioneren, en op hun persoonlijk welzijn, evenals op het functioneren van het gezin en de overige verzorgers. En het zou ook hun mogelijkheden tot volledige integratie in de samenleving kunnen verminderen.

Echter, bruikbare epidemiologische bevindingen tot nu toe ten aanzien van de prevalentie van psychopathologie bij kinderen met VB en de relatieve risico's in vergelijking tot verstandelijk normaal ontwikkelende kinderen zijn beperkt vanwege het gebruik van verschillende definities van psychopathologie, het beperkte gebruik van gestandaardiseerde instrumenten en representatieve steekproeven, en het algemene tekort aan onderzoek in dit veld. Bevindingen uit eerdere onderzoeken werden in Hoofdstuk 1 besproken en lieten zien dat prevalentie schattingen van psychopathologie bij kinderen met VB varieerden van 4% tot 60%, afhankelijk van het gebruikte onderzoeksontwerp, de instrumentkeuze en de samenstelling van de steekproef. Alhoewel slechts enkele studies in staat waren om op directe wijze het verhoogde risico op psychopathologie van kinderen met VB in vergelijking met kinderen zonder VB vast te stellen, bleken kinderen met VB een drie- tot viervoudig verhoogd risico op psychopathologie te hebben. Het probleem van het gebrek aan informatie over factoren die geassocieerd zijn met psychopathologie bij kinderen met VB werd ook besproken in het eerste hoofdstuk.

Het tekort aan betrouwbare en valide instrumenten die speciaal ontwikkeld zijn voor het vaststellen van psychopathologie bij kinderen met VB is een ander belangrijk punt. Betrouwbare en gestandaardiseerde instrumenten zijn nodig in deze onder-gediagnostiseerde en onderbehandelde groep. Er wordt in toenemende mate inspanningen verricht om instrumenten te ontwikkelen waarmee een breed scala aan emotionele problemen en gedragsproblemen bij kinderen met VB kan worden vastgesteld. Deze ontwikkelingen werden in het eerste hoofdstuk besproken. Slechts enkele instrumenten waren beschikbaar toen we met deze studie begonnen, en niet één was beschikbaar in de Nederlandse taal. De Australische Developmental Behaviour Checklist (DBC) was op dat moment één van de meest onderzochte instrumenten met veelbelovende psychometrische kwaliteiten. Er werd besloten om de DBC in het Nederlands te vertalen (de Nederlandse vertaling van de DBC is Vragenlijst over Ontwikkeling en Gedrag).

Het doel van deze studie was om de volgende drie hoofdvragen te behandelen:
1. Wat is de betrouwbaarheid en de validiteit van de Nederlandse vertaling van de DBC, en hoe bruikbaar voor de groep van kinderen met VB zijn gestandaardiseerde instrumenten die oorspronkelijk ontwikkeld zijn voor verstandelijk normaal ontwikkelde kinderen?
2. Wat is de prevalentie en de impact van psychopathologie bij kinderen met VB?
3. Welke factoren hangen samen met of voorspellen psychopathologie bij kinderen met VB?

Er is een willekeurige steekproef van 6 tot 18 jarigen getrokken uit alle scholen voor moeilijke lerende kinderen (MLK) en zeer moeilijk lerende kinderen (ZMLK) en alle kinderdagcentra voor kinderen met verstandelijke handicaps in de provincie Zuid-Holland (respons 88%). Tijdens de eerste fase van dit onderzoek werkten 1.059 ouders mee aan het onderzoek (respons 70%). Ze vulden vragenlijsten in en werden thuis vragen gesteld door

getrainde interviewers aangaande de emotionele problemen en gedragsproblemen van hun kind, over het sociale en lichamelijke functioneren van hun kind, en over hun eigen welzijn en het functioneren van het gezin. Leerkrachten en groepsleiders vulden voor 940 kinderen vragenlijsten over de emotionele problemen en gedragsproblemen van hun leerlingen in (respons 83%).

Voor de tweede fase van dit onderzoek, ongeveer 1 jaar later, werd een willekeurige steekproef getrokken uit 58% van de respondenten uit de eerste fase en vroegen we de ouders om vergelijkbare vragenlijsten als die uit eerste fase in te vullen, en werden ouders tevens gevraagd om mee te werken aan een gestandaardiseerd interview om psychiatrische stoornissen vast te stellen (respons 87%).

Het doel van de studie, zoals gerapporteerd in Hoofdstuk 3, was om de factorstructuur van de DBC opnieuw te bepalen op basis van een gecombineerde streekproef van 1.536 Nederlandse en Australische kinderen en adolescenten (leeftijd 3 –22 jaar) met lichte tot diepe verstandelijke beperkingen. Principale componenten analyse produceerde vijf interpreteerbare and klinisch relevante subschalen: Storend en Anti-Sociaal, In zichzelf Gekeerd, Communicatie Stoornissen, Angst, en Sociale Beperkingen, welke 44% van de totale variantie verklaarden en opgebouwd zijn uit 86 van de in totaal 96 items van de DBC. De leerkrachtversie van de DBC liet een vergelijkbare factorstructuur zien. De betrouwbaarheid van de verschillende schalen was bevredigend, hetgeen blijkt uit de goede tot hoge interne consistentie van de schalen Storend en Anti-sociaal, In Zichzelf Gekeerd, en Sociale Beperkingen (Cronbach's alfa varieerde van 0.76 tot 0.91), en de matig tot redelijke interne consistentie van de schalen Communicatie Stoornissen en Angst (Cronbach's alfa varieerde van 0.62 tot 0.73).

De herziene factorstructuur van de DBC bleek een verbeterd en bruikbaar instrument voor het vaststellen van emotionele problemen en gedragsproblemen bij kinderen met verstandelijke beperkingen. Het omvat factoren die vrij consistent lijken terug te keren over verschillende empirisch ontwikkelde instrumenten om emotionele problemen en gedragsproblemen. Toekomstig onderzoek is nodig om afkappunten met hoge sensitiviteit en specificiteit te bepalen voor de Nederlandse DBC, om de schalen Angst en Communicatiestoornissen verder te verfijnen, en om een verkorte DBC versie te ontwikkelen.

In Hoofdstuk 4 bepaalden we de betrouwbaarheid en de validiteit van de herziene DBC schalen in onze Nederlandse steekproef van zwakbegaafde tot matige verstandelijk beperkte kinderen. De psychometrische eigenschappen van de ouder- en leerkrachtversie van de DBC werden vastgesteld in verschillende deelsteekproeven afkomstig uit een steekproef van 1.057 Nederlandse kinderen met verstandelijke beperkingen. Goede test-hertest betrouwbaarheid werd gevonden voor zowel de ouder- als de leerkrachtversie. Een matig tot redelijke overeenstemming tussen ouders en tussen ouders en leerkrachten werd gevonden, hetgeen overeenstemt met resultaten op basis van andere instrumenten die psychopathologie vaststellen in steekproeven van kinderen zonder verstandelijke beperkingen. De hoge 1-jaars stabiliteit van de DBC schaalscores is ook een gebruikelijke bevinding voor probleemgedragingen bij kinderen zonder VB, en suggereert een afwezigheid van extreme veranderingen in probleem gedrag. De construct validiteit van de DBC was voldoende, alhoewel enigszins beperkt door de hoge informanten variantie. Ook dit is een gebruikelijke bevinding bij instrumenten ontwikkeld voor kinderen zonder VB. De DBC schalen convergeerden met overeenkomstige schalen van de Child Behavior Checklist (CBCL) en de Teacher's Report Form (TRF). Adaptief gedrag hing alleen matig tot redelijk samen met de schalen In Zichzelf Gekeerd, Communicatie Stoornissen, en Sociale Beperkingen wat wijst op

redelijke divergente validiteit van de DBC. De DBC schalen lieten ook een goede criteriumgerelateerde validiteit zien, hetgeen bleek uit de significante verschillen in gemiddelde tussen al dan niet in verband met emotionele problemen of gedragsproblemen verwezen kinderen, en tussen kinderen met die al dan niet voldeden aan de criteria voor een DSM-IV diagnose. Het gebruik van dit gestandaardiseerde, betrouwbare en valide instrument wordt aangeraden voor de klinische praktijk om zo emotionele problemen en gedragsproblemen vast te stellen, te registreren, en om interventies te evalueren. De beschikbaarheid van Nederlandse normen (combinatie van scores uit deze studie als ook uit een Friese studie) maakt een betekenisvolle vergelijking tussen een individuele score van een kind ten opzichte van zijn of haar normgroep mogelijk. Toekomstig onderzoek werd voorgesteld om de relatie tussen DBC schaalscores en het oordeel van professionals vast te stellen, en om te bekijken tot welk niveau van VB de DBC, of juist een instrument ontwikkeld voor kinderen zonder VB, het beste geschikt is voor het vaststellen van psychopathologie.

In Hoofdstuk 5 werd de prevalentie van een breed scala van emotionele problemen en gedragsproblemen in kinderen met VB vastgesteld en vergeleken met kinderen zonder VB. We vergeleken 1.041 kinderen met verstandelijke beperkingen met een willekeurige steekproef van 1.855 kinderen zonder VB uit de algemene bevolking. De ouders vulden een CBCL in en de leerkrachten een TRF. Het gebruik van instrumenten ontwikkeld voor kinderen uit de algemene bevolking om psychopathologie bij kinderen met VB vast te stellen is niet ongebruikelijk bij kinderen met lichte VB. De resultaten uit de huidige studie lieten zien dat de interne consistentie van de CBCL en TRF schalen vergelijkbaar met of zelfs hoger was dan de interne consistentie zoals gevonden in een steekproef uit de Nederlandse algemene bevolking of in een naar de geestelijke gezondheidszorg verwezen steekproef van kinderen zonder VB. Voldoende tot hoge interne consistentie werd gevonden voor de schalen: Totale Problemen, Internaliseren, Externaliseren, Agressief gedrag, en Angstig/Depressief. Een matige tot redelijke overstemming tussen ouders en leerkrachten werd gevonden voor kinderen met VB, hetgeen niet significant afwijkt van bevindingen uit de Nederlandse algemene bevolkingssteekproef. In Hoofdstuk 4 hadden we reeds de bevredigende convergente validiteit van de DBC schalen met overeenkomstige CBCL/TRF schalen besproken.

Controlerend voor geslacht, leeftijd, en socio-economische status, vonden we dat zowel MLK als ZMLK leerlingen significant hogere gemiddelde scores hadden op alle CBCL en TRF schalen dan kinderen zonder VB, met uitzondering van ZMLK leerlingen op de schalen Angstig/Depressief en Somatische Klachten. Bijna 50% van de kinderen met VB hadden een deviante Totale Probleemscore in vergelijking tot 18% van de kinderen zonder VB. Het gevonden drie- tot viervoudig verhoogde risico op psychopathologie bij kinderen met VB was vergelijkbaar met het beperkte aantal bevindingen uit voorgaande studies. In tegenstelling tot de vorige studies, waren wij in staat om naar een breed scala van probleemgedragingen te kijken, welke een verschillend beeld lieten zien wat betreft verhoogd risico. In vergelijking tot kinderen zonder VB, waren Sociale Problemen, Aandachtsproblemen, en Agressief Gedrag de meest prominent aanwezige probleemgedragingen bij MLK leerlingen, terwijl de scores op de schalen Sociale Problemen, Aandachtsproblemen, Teruggetrokken, en Denkproblemen het meest verhoogd waren bij ZMLK leerlingen. De verhoogde schaalscores reflecteerden verschillen tussen kinderen met en zonder VB over een groot aantal items, en hadden niet slechts betrekking op items die gerelateerd waren aan achterstanden in de ontwikkeling. Om die reden, denken we dat de probleemgebieden die door de items van deze schalen gedekt worden speciale aandacht behoeven binnen de geestelijke gezondheidszorg voor kinderen met

VB. Alhoewel meer onderzoek nodig is naar de betrouwbaarheid en de validiteit van de CBCL en de TRF bij kinderen met VB, en het gebruik van aanpaste normen wordt voorgesteld, wordt het gebruik van deze instrumenten bij zwakbegaafde tot matig verstandelijk beperkte kinderen door deze studie ondersteund.

In Hoofdstuk 6 keken we naar de prevalentie, co-morbiditeit en de impact van DSM-IV stoornissen bij 7 tot 20 jarigen met VB. Ongeveer 1 jaar na de eerste fase werkten de ouders van 474 willekeurige geselecteerde kinderen uit de eerste fase weer mee in de tweede fase van het onderzoek. Ouders beantwoorden de vragen uit de angst, stemming, en gedragsstoornissen modules van de DISC-IV. Van de geïncludeerde kinderen voldeed 21.9% aan de DSM-IV symptoomcriteria voor een angststoornis, 4.4% voor een stemmingstoornis, en 25.1% voor een gedragsstoornis. Vergelijkbare prevalenties voor DSM-IV stoornissen werden gevonden voor kinderen die of positief of negatief scoorden op een screen voor pervasieve ontwikkelingsstoornis. De meeste prevalentie schattingen overtroffen de prevalentie schattingen die tot nu werden gevonden in onderzoeken op basis van informatie uit statussen. Meer dan de helft van de kinderen die voldeden aan de DSM-IV symptoom criteria, werden hierdoor ernstig in hun dagelijkse functioneren beperkt, en ongeveer 37% van gediagnosticeerde kinderen had een co-morbide stoornis. De hoogste co-morbiditeit werd gevonden tussen Aandachtstekort-/Hyperactivititeitsstoornis en Oppositioneel-opstandige gedragsstoornis, en tussen gedragsstoornissen en stemmingsstoornissen. Deze bevindingen verschillen van resultaten uit algemeen bevolkingsonderzoek, en zijn mogelijk gerelateerd aan de jongere mentale leeftijd van kinderen met VB. Kinderen met meerdere stoornissen bleken meer risico te lopen om op meerdere gebieden in hun dagelijkse leven beperkt te worden.

De bevinding dat minder dan eenderde van de kinderen met een psychiatrische stoornis in het afgelopen jaar hiervoor geestelijke gezondheidszorg heeft ontvangen, behoeft de nodige aandacht. Alhoewel het hebben van meerdere of ernstig beperkend stoornissen de kans op verwijzing vergroot, blijkt dat toch nog ongeveer de helft van de kinderen met meerdere of beperkende stoornissen geen geestelijke gezondheidszorg ontving in het afgelopen jaar. Andere factoren, zoals de beschikbaarheid en de toegankelijkheid van de professionele hulpverlening, de beschikbaarheid van alternatieve bronnen van steun, gezinsfunctioneren, en ervaren ouderlijke stress, dienen in toekomstig onderzoek verder bekeken te worden, omdat ze wellicht kunnen helpen verklaren waarom zoveel kinderen niet bereikt worden. Een vervolgstudie 5 jaar na de huidige studie zal deze en andere factoren die mogelijke gerelateerd zijn aan hulpbehoefte en het werkelijk ontvangen van geestelijke gezondheidszorg verder onderzoeken. Helaas waren er geen oordelen van clinici beschikbaar om de DISC-IV diagnoses bij kinderen met VB te valideren. Echter, de bevindingen uit dit onderzoek lieten wel zien dat er sprake was van convergente validiteit van de DISC-IV hoofdgroepen met de DBC schalen, en samen met de aangetoonde criteriumgerelateerde validiteit (significante relatie met verwijzing naar geestelijke gezondheidszorg, beperkingen in het dagelijkse functioneren), wijzen deze bevindingen erop dat de DISC-IV gebruikt kan worden om DSM-IV stoornissen vast te stellen bij zwakbegaafde tot licht verstandelijk beperkte kinderen.

Het doel van hoofdstuk 7 was het identificeren van kind- en gezinsfactoren welke DSM-IV stoornissen in kinderen met VB konden voorspellen. In de eerste fase van het onderzoek vulden de ouders de CBCL, de DBC, de Vineland screener, en vragenlijsten waarin gevraagd werd naar de lichamelijke gezondheid van het kind, gezinsfunctioneren, en de geestelijke gezondheid van de ouders. In de tweede fase beantwoordden de ouders vragen uit de angst-, stemmings-, en gedragsstoornissen modules van de DISC-IV. Zowel kind- als gezinsfactoren waren significant gerelateerd aan DSM-IV uitkomsten 1 jaar later. Emotionele problemen en

gedragsproblemen, sociale incompetentie, inadequate dagelijkse vaardigheden, gezondheidsproblemen van het kind, ouderlijke geestelijke gezondheidsproblemen, en negatieve levensgebeurtenissen waren de sterkste voorspellers van DSM-IV stoornissen een jaar later. Het niveau van schoolse functioneren, geslacht, leeftijd, en sociaal-economische status bleken niet direct gerelateerd aan DSM-IV uitkomsten, maar bleken wel significante modererende effecten te hebben. De meerderheid van de kind- en gezinsfactoren bleken niet uniek gerelateerd aan een specifieke DSM-IV uitkomst. Externaliserende gedragsproblemen, inadequate dagelijkse vaardigheden, laag opleidingsniveau van de ouders, en het disfunctioneren van het gezin bleken specifiek gerelateerd aan DISC-IV gedragsstoornissen, en de aanwezigheid van een chronische lichamelijke aandoening en behoren tot een eenoudergezin bleek specifiek gerelateerd aan het hebben van een internaliserende DSM-IV stoornis. Nadat er gecorrigeerd was voor het niveau van emotionele problemen en gedragsproblemen tijdens de eerste fase, bleek dat de sterkste voorspeller van een angststoornis de aanwezigheid van een chronisch lichamelijke aandoening was. De sterkste voorspeller van een gedragsstoornis was sociale incompetentie, en de aanwezigheid van een stemmingsstoornis was het sterkste gerelateerd aan het ervaren van een negatieve levensgebeurtenis. Sommige van de factoren die een relatie vertoonden met een DSM-IV diagnose kunnen helpen bij het verbeteren van de identificatie van risicokinderen, kunnen wijzen op belangrijke aandachtspunten binnen diagnostische en interventieprocedures, en geven aanknopingspunten voor mogelijke (preventieve) interventies, zoals programma's gericht op het versterken van de persoonlijke competentie van de kinderen.

Een aantal aanvullende resultaten zijn van belang. In Hoofdstuk 8 rapporteerden we ook over verschillen in psychopathologie veroorzaakt door verschillen in het schoolniveau, geslacht, leeftijd, en sociaal-economische status bij kinderen met VB. De meeste effecten waren klein. Er werd bijvoorbeeld aangetoond dat MLK leerlingen significant hoger scoorden op de schalen Angstig/Depressief en Delinquent Gedrag van de CBCL/TRF. ZMLK leerlingen hadden een hogere gemiddelde score op schalen Teruggetrokken, Denkproblemen, Sociale Problemen, en Aandachtsproblemen van de CBCL/TRF, en op alle DBC schalen, met uitzondering van de schaal Storend en Anti-sociaal. Deze resultaten waren aanleiding om te kiezen voor aparte normen voor elk schoolniveau, geslacht, en leeftijdsgroep te ontwikkelen voor de Nederlandse handleiding voor de DBC, en voor de CBCL/TRF schalen bij gebruik bij kinderen met VB. Tenslotte bespraken we in Hoofdstuk 8 de algemene conclusies, de onderzoeksbeperkingen, de klinische implicaties, en de aanwijzingen voor toekomstig onderzoek. Concluderend kunnen we stellen dat de bevindingen uit dit onderzoek een belangrijke basis hebben gelegd voor verder onderzoek naar psychopathologie bij kinderen met VB. Drie goed bekendstaande instrumenten voor het vaststellen van emotionele problemen, gedragsproblemen, en psychiatrische stoornissen werden geëvalueerd voor gebruik bij kinderen met VB in een grote en representatieve steekproef. Elk instrument bleek voldoende bevredigend voor verder gebruik binnen dit veld. Op basis van de verzamelde psychometrische gegevens over de DBC is er een Nederlandse handleiding voor de DBC samengesteld en beschikbaar voor gebruik in de klinische praktijk en voor het screenen van kinderen. Dit onderzoek heeft ook normscores voor de CBCL en de TRF opgeleverd voor MLK en ZMLK leerlingen. Daarnaast zijn er prevalentie schattingen van een breed scala aan emotionele problemen, gedragsproblemen en psychiatrische stoornissen beschikbaar, alsook gegevens over de impact van deze stoornissen op het dagelijkse leven en op de geestelijke gezondheidszorg. De resultaten benadrukken het belang van een goede geestelijke gezondheidszorg voor kinderen met VB, en wijzen ook op de meest voorkomende en de

meeste beperkende problemen in deze groep kinderen. Gegevens uit deze studie kunnen door beleidsmakers gebruikt worden voor de verbetering van de planning van verschillende vormen van hulpverlening en het toekennen van financiële middelen voor deze kinderen. En als laatste waren we in staat om een aantal belangrijke geassocieerde factoren en voorspellers van psychopathologie aan te wijzen bij kinderen met VB. Deze informatie vormt een belangrijk aangrijpingspunt voor preventieve en interventieprojecten, en een startpunt voor meer etiologisch en theoretisch georiënteerd onderzoek naar risicofactoren van psychopathologie bij kinderen met VB.

De huidige studie is uniek in vergelijking met de meeste andere studies in dit veld, aangezien hij een grote steekproef omvat van willekeurig geselecteerde kinderen afkomstig van een groot aantal verschillende school voor kinderen met VB. Tevens, in tegenstelling tot vele andere landen, was het in die tijd onwaarschijnlijk dat kinderen met VB een school voor regulier onderwijs bezochten.

Drie lopende onderzoeken, waarvan er twee een vervolg op de huidige studie zijn, en waarvan de derde gerelateerd is aan de huidige studie, zullen een verdere bijdrage leveren aan belangrijke onderzoeksvragen binnen dit veld, en ze zullen ook tegemoetkomen aan een aantal tekortkomingen van deze studie. Deze onderzoeken hebben de volgende hoofdonderwerpen:

- Continuïteit, verandering en determinanten van psychopathologie bij kinderen met VB (vervolgstudie 5 jaar later)
- Determinanten van objectieve en subjectieve behoefte aan geestelijke gezondheidszorg voor kinderen met VB, en van discrepanties tussen behoefte aan hulp en de uiteindelijk ontvangen hulp (vervolgstudie 5 jaar later)
- De praktische toepasbaarheid en verdere validering van de DBC binnen instellingen voor de geestelijke gezondheidszorg, en de vaststelling van prevalentie van psychopathologie en geassocieerde factoren in een steekproef van zwakbegaafde tot matig verstandelijk beperkte kinderen die recent verwezen zijn naar instellingen voor de geestelijke gezondheidszorg

De vervolgstudie, 5 jaar na de start van de huidige studie, omvat onder andere het afnemen van een IQ-test, daar de huidige studie ons heeft geleerd dat informatie over IQ via de scholen incomplete gegevens oplevert. Deze nieuwe informatie over IQ zal het mogelijk maken om (retrospectief) kinderen te classificeren als zwakbegaafd, licht en matig VB, hetgeen internationaal gezien een zinvolle manier van classificeren is. Tevens zullen in de vervolgstudie voor een grotere groep kinderen de ouders geïnterviewd worden met de DISC-IV, om zo de kans op het ontdekken van weinig voorkomende stoornissen te vergroten. Deze keer zullen ook de jongeren zelf informatie geven over hun eigen welbevinden, en zal veel meer uitgebreide informatie over hulpbehoefte verzameld worden. In de derde studie zullen DBC en CBCL scores gerelateerd worden aan oordelen van behandelaars, hetgeen niet mogelijk was in de huidige studie. Dat onderzoek zal ook informatie opleveren over de praktische bruikbaarheid van de DBC, en maakt het ons mogelijk om een optimaal afkappunt te bepalen voor het definiëren van afwijkend gedrag op de DBC schalen. Toekomstig onderzoek is nodig voor het verbeteren van de factorstructuur van de DBC, het verder bepalen van de validiteit van de DISC-IV bij kinderen met VB, en om te bepalen met welk instrument het beste emotionele problemen en gedragsproblemen vastgesteld kan worden voor welk specifieke niveau van VB. Daarnaast zullen toekomstige studies moeten overwegen om procedures toe te voegen die het mogelijk maken om ook kinderen van niet-Nederlands sprekende ouders te kunnen includeren.

Dankwoord
Curriculum Vitae

Dankwoord

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Ik wil mijn vrienden en familie bedanken voor hun getoonde interesse en steun in de afgelopen jaren. Nu kunnen jullie eindelijk eens lezen wat Jel zo al heeft uitgevoerd in die tijd.

Last but not least! Allerliefste Scott, zonder jouw liefde, je motiverende steun, je geduld, en je enorme hulp bij het redigeren van mijn teksten was ik nooit zover gekomen. Ik beloof je dat we vanaf nu alleen nog maar leuke dingen gaan doen in de weekenden!

Zo, het zit er bijna op. Ik kijk uit naar mijn post-promotie tijd!

Curriculum Vitae

Marielle Cornelia Dekker werd geboren op 9 augustus 1969 te Dordrecht. In 1987 behaalde zij het V.W.O. diploma aan de Scholengemeenschap Noordendijk te Dordrecht. In de periode 1987 tot en met 1991 behaalde ze haar diploma Sociaal-Cultureel Werk aan de Hogeschool Rotterdam & Omstreken. In 1991 startte ze haar opleiding Psychologie aan de Rijksuniversiteit Leiden. In 1994/1995 was zij werkzaam als student-assistent van dr. Gerda J. Methorst bij de vakgroep Klinische- en Gezondheidspsychologie van de Rijksuniversiteit Leiden. In 1996 legde zij het doctoraal examen cum laude af met als afstudeerrichting praktijkgericht onderzoeker bij de vakgroep Methoden & Technieken onder begeleiding van Prof.dr. Leo J.Th. van der Kamp.

Van 1996 tot en met 2000 was ze als assistent in opleiding (AIO) verbonden aan de Erasmus Universiteit Rotterdam en was ze werkzaam op de afdeling kinder- en jeugdpsychiatrie van het Erasmus MC-Sophia kinderziekenhuis te Rotterdam (hoofd: Prof.dr. Frank C. Verhulst). In 2000/2001 werd deze aanstelling gedeeltelijk verlengd door een detacheringsovereenkomst met Stichting de Wendel te Venlo. Daarnaast was ze in die tijd aangesteld bij het SCO-Kohnstamm Instituut/Universiteit van Amsterdam voor het opzetten van een onderzoek gericht op het ontwikkelen van een schooldifferentiatietest voor nieuwkomers (algemeen programmaleider Prof.dr. Willem van Hoorn).

Sinds maart 2001 is ze als wetenschappelijk onderzoeker aangesteld op de afdeling kinder-en jeugdpsychiatrie van het Erasmus MC-Sophia Kinderziekenhuis te Rotterdam. Zij is momenteel betrokken bij drie onderzoeken die een vervolg zijn op of gerelateerd zijn aan het onderzoek zoals beschreven in dit proefschrift.