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Psychopathology in Children and Adolescents with Intellectual Disability: Measurement, Prevalence, Course, and Risk

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Children, including adolescents, with intellectual disability (ID) are at higher risk than children without ID for developing psychopathology, a term we use to subsume similar terms such as mental illness or health problems, psychiatric or behavior disorders, and behavior and emotional problems. Psychopathology in children with ID is also more likely to go unrecognized and untreated. Psychopathology may have a major effect on their general well-being, personal independence, school and social functioning, and quality of life, as well as on family and other caregivers. The combination of ID and psychopathology can also give rise to further stigmatization, prejudices, and misunderstandings, which may decrease the likelihood of full integration.

However, evidence-based knowledge on these problems in children is lacking, although developing in the past decade. Few systematic studies on the relationship between ID and psychopathology exist. The development of valid and effective tools for the assessment, diagnosis, and management of these problems is recent for the most part. Evidence on risk factors for their onset and persistence is still weak. Consequently, more information on the detection of associated psychopathology, the maintenance of mental health, and the prevention and management of problems is needed.

This chapter considers evidence mainly on the association between ID generally and overall psychopathology. We will discuss in turn (1) definition and assessment of psychopathology in children with ID; (2) the instruments available for assessment and diagnosis; and findings regarding (3) prevalence, (4) course and development, and (5) associated risk factors of psychopathology. We will end with (6) conclusions and recommendations for research, practice, and policy.

We refer, for example, to [Dykens \(2000\)](#) and [Reiss and Aman \(1997\)](#) for discussions of the emerging literature on specific psychopathologies associated with specific syndromes or diagnoses. This chapter does not review interventions to reduce psychopathology in children with ID, but we refer to several general sources on psychopathology and ID for discussions of this (e.g., [Bouras, 1994](#); [Dosen & Day, 2001](#); [Fletcher & Dosen, 1993](#); [Jacobson & Mulick, 1996](#); [Nezu, Nezu, & Gill-Weiss, 1992](#)).

We use the term intellectual disability in this chapter for two reasons. This is currently the term most accepted internationally. Second, we do this to be consistent with the majority of the research that is cited. That is, 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.

I. DEFINITION AND ASSESSMENT OF PSYCHOPATHOLOGY

Psychopathology is discussed under various terms, as noted, but regardless of terminology, these problems need to be defined operationally 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 ([Verhulst & Koot, 1992](#); [Achenbach, 1995](#)). 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: clinical–medical and psychometric–empirical approaches.

A. Clinical–Medical Approach

The clinical–medical assessment tradition seeks syndromes of signs and symptoms to distinguish between and among disorders expected to have distinctive organic etiologies and course. The principles of this tradition 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, 1995) 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 that are 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 by definition experience a different developmental course from the norm and a course that varies considerably among individuals with ID.

The application of DSM and ICD systems is further complicated with children with ID due to several factors. 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., stereotyping, 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 designed specifically for children with ID rather than instruments used with 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, Prendergast, Cox, Harrington, Siminoff, & Rutter, 1995; Reich, 2000; Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000), their applicability with even mild ID may be complicated. Persons with ID have a limited ability to express abstract thoughts and feelings or to answer questions about the onset, duration, frequency, and severity of symptoms, and in addition show acquiescence bias to interview questions (Moss, 1999). 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, Prosser, & Goldberg, 1996; Moss, Ibbotson, Prosser, Goldberg, Patel, & Simpson, 1997). Moss et al. (1996) showed that direct interviews with both respondents and caregiver informants using these schedules with adults with ID reduces missed diagnoses. However, we are not aware of an adapted interview schedule for children with ID.

B. Psychometric–Empirical Approach

Some of the just-described issues are addressed in the alternative approach to the assessment of psychopathology, i.e., the psychometric–empirical approach. However, this approach has its own concerns. This

approach is characterized by the use of rating scales comprising a broad range of problem behaviors, 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, for example, 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 (for an earlier review, see [Aman, 1991](#)), including the Reiss Scales for Children's Dual Diagnosis ([Reiss & Valenti-Hein, 1994](#)), the Aberrant Behavior Checklist ([Aman, Singh, Stewart, & Field, 1985](#); [Freund & Reiss, 1991](#)), the Developmental Behavior Checklist ([Einfeld & Tonge, 1992, 1995](#)), and the Nisonger Child Behavior Rating Form ([Aman, Tasse, Rojahn, & Hammer, 1996](#); [Tasse, Aman, Hammer, & Rojahn, 1996](#)). These 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, norms have been set. In addition, instruments developed for typically developing children, such as the Child Behavior Checklist and Teacher's Report Form ([Achenbach, 1991a,b](#)), can be of value with children with mild and moderate ID ([Dekker, Koot, van der Ende, & Verhulst, 2001](#); [Frison, Wallander, & Browne, 1998](#)). Children in this range of ID display, for the most part, behavior and function like typically developing children.

Psychometric instruments have enhanced the understanding of psychopathology in children with ID. However, they differ widely in item composition and syndrome scales and they are not attuned to DSM-IV or ICD-10 diagnostic categories. Therefore, the relations of the instruments to these classification systems and to each other will need to be tested carefully in future studies. We need to avoid the situation where the identification of psychopathology becomes instrument specific, making comparisons across studies difficult ([Borthwick-Duffy, 1994](#)).

C. Multi-Informant Assessment of Psychopathology

An issue when assessing lower-functioning and less verbal children is that they may not be able to reflect on their own behaviors due, for example, to 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 clinical–medical and psychometric–empirical approaches. However, 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 children with ID (Aman et al., 1996; Dekker et al., 2001; 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 the case in community-residing populations, in which 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, may 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, whereas parents are perhaps more likely to compare their child with his/her non-ID siblings or other children in the neighborhood.

II. INSTRUMENTS FOR ASSESSING PSYCHOPATHOLOGY

Aman (1991) completed a thorough review of instruments for assessing psychopathology in persons 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 did identify some “promising” instruments that assess a broad range of problem behaviors in children with mental retardation (MR): the Developmentally Delayed Child Behavior Checklist (Einfeld & Tonge, 1990, 1992, 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 developed originally for use with children in the general population was adapted for use with children with ID. We have selected

instruments for this review that (a) assess a broad range of psychopathology for at least five different syndromes or clusters; (b) have scales derived empirically with factor analytic techniques; (c) are designed for use with children up to age 18; (d) who live in the community; (e) can be completed by lay informants (parents, teachers); and (f) have available information on reliability or validity post-1980. Four instruments meet these criteria.

Our criteria excluded instruments that only incorporate one general scale that does not differentiate among domains of psychopathology (e.g., the maladaptive behavior section of the Vineland Scales; Sparrow, Balla, & Cicchetti, 1984); does not contain empirically derived psychopathology domains (e.g., part II of the AAMD Adaptive Behavior Scale–School Edition; Lambert, Windmiller, Tharinger, & Cole, 1981); were not developed or adapted for use in children with a broad range of levels of ID (e.g., the Rutter scales; Rutter, Tizard, & Whitmore, 1970; the Child Behavior Checklist, Achenbach, 1991a); 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); cannot be completed by lay informants (e.g., the maladaptive behavior section of the Vineland Scales; Sparrow et al., 1984); and 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 I provides descriptive and psychometric information pertaining to the four instruments retained for this review.

A. The Aberrant Behavior Checklist (ABC)

The original ABC (Aman et al., 1985) 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 and young adults. After item modification, a five-factor structure (irritability/agitation, lethargy/social withdrawal, stereotypic, hyperactive/noncompliance, inappropriate speech) was found explaining 55% of the common variance in the parent version for both the parent and the teacher version with good cross-informant congruence in structures. Internal consistency estimates (Cronbach's alpha) were good, ranging from .83 to .93 for the parent ratings and from .79 to .94 for the teacher ratings. Good test–retest reliabilities were found for the parent ratings, ranging from .80 to .95, but were somewhat lower for the teacher ratings, ranging from .50 to .67. Parent–teacher agreement was moderate, with correlation coefficients ranging from .18 to .49. Unfortunately, no information was reported on

TABLE I
RECENT (>1980) LAY INFORMANT (PARENTS, TEACHERS) INSTRUMENTS ASSESSING A BROAD RANGE
OF PSYCHOPATHOLOGY IN CHILDREN WITH MR IN THE COMMUNITY

| Instrument (reference and country of sample) | Description Sample | Derivation items/scales | Description scales (No. of items) | α | Test-retest reliability ^a | Similar role informant agreement | Parent-teacher agreement | Convergent validity | Criterion-related validity |
|--|---|---|-------------------------------------|----------|--------------------------------------|----------------------------------|--------------------------|---------------------|----------------------------|
| Aberrant Behavior Checklist—parent rating (ABC) (Freund & Reiss, 1991; USA) | <i>N</i> = 110 Borderline to severe ID 3-25 years old 72% outpatients of neuropsychiatric unit | Originally developed to measure pharmacological effects in residential children and adults by third-party raters/adjustments in wording/PCA similar to original | 1. Irritability/agitation (15) | .90 | .95 | Not available (N.A.) | .49 | N.A. | N.A. |
| | | | 2. Lethargy, social withdrawal (14) | .93 | .92 | | | | |
| | | | 3. Stereotypic (5) | .88 | .88 | | | | |
| | | | 4. Hyperactivity/noncompliance (15) | .90 | .88 | | | | |
| | | | 5. Inappropriate speech (5) | .83 | .80 | | | | |
| Aberrant Behavior Checklist—teacher rating (ABC) (Freund & Reiss, 1991; USA) | <i>N</i> = 94 Borderline to severe ID 3-26 years old 72% outpatients of neuropsychiatric unit | See parent rating (ABC)/PCA similar to original | 1. Irritability/agitation (16) | .88 | .61 | N.A. | See parent rating (ABC) | N.A. | N.A. |
| | | | 2. Lethargy, social withdrawal (18) | .94 | .50 | | | | |
| | | | 3. Stereotypies/Self-injury (8) | .90 | .67 | | | | |
| | | | 4. Hyperactivity/noncompliance (13) | .89 | .61 | | | | |
| | | | 5. Inappropriate speech (2) | .79 | .59 | | | | |

| | | | | | | | | | |
|---|--|---|--|---|---|---|------|------------------|---|
| Aberrant Behavior Checklist—teacher rating (ABC) (Marsburn & Aman, 1992; USA) | <i>N</i> = 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/noncompliance (16) 5. Inappropriate speech (4) | .93 .90 .89 .96 .76 | N.A. | N.A. | N.A. | N.A. | N.A. |
| Developmental Behavior Checklist—primary carer (DBC-P) (Einfeld & Tonge, 1995; Australia) | PCA <i>N</i> = 1093 Norms <i>N</i> = 454 (split by level of ID) Mild to profound 4–18 years old Multicenter/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. Antisocial (4) Total problems (96) | .91 .86 .81 .76 .73 .67 .94 | .84 .87 .76 .77 .70 .51 .83 | .78 .79 .75 .80 .78 .79 .80 | .05 | (<i>N</i> = 40) | (<i>N</i> = 70) Total problems—maladaptive behavior section of AAMD ABC ^b ; <i>r</i> = .86 Total problems—total score problem behavior section of the SIB ^c <i>r</i> = .72 Significant mean difference in total problems between cases and noncases as rated by child psychiatrists ROC = 92% |
| Developmental Behavior Checklist—teacher version (DBC-T) (Einfeld, Tonge, & Parmenter, 1998; Australia) | <i>N</i> = 640 (norms split by level of ID) Mild to profound 4–18 years old Multicenter/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. Antisocial (4) Total problems (94) | .68 .74 .62 .66 .48 .30 .94 | .68 .74 .62 .66 .48 .30 .76 | .60 .60 .60 .60 .60 .60 .60 | 0.5 | N.A. | N.A. |

(continued)

TABLE I (Continued)

| Instrument (reference and country of sample) | Description Sample | Derivation items/scales | Description scales (No. of items) | α | Similar role | | | Criterion-related validity |
|---|---|--|---|--|--|---|---|--|
| | | | | | Test-retest reliability ^d | informant agreement | Parent-teacher agreement | |
| Developmental Behavior Checklist/ <i>revised</i> subscales—primary carer (DBC-P) (New DBC Manual; Dekker <i>et al.</i> , 2000; Australia) | See original DBC-P scales | Items original DBC/PCA combined Dutch-Australian sample (services ID and schools educable and trainable) | 1. Disruptive/antisocial (27) 2. Self-absorbed (31) 3. Communication disturbance (13) 4. Anxiety (9) 5. Social relating (10) Total problems (96) | .91 .89 .73 .66 .71 .94 | .66 .88 .76 .82 .73 .83 | See original DBC-P | See original DBC-P | See original DBC-P |
| Developmental Behavior Checklist/ <i>revised</i> subscales—teacher version (DBC-T) (New DBC Manual; Dekker <i>et al.</i> , 2000; Australia) | See original DBC-T scales | Case records ID service/empirical (PCA)/similar to DBC-P revised | 1. Disruptive/antisocial (27) 2. Self-absorbed (31) 3. Communication disturbance (13) 4. Anxiety (8) 5. Social relating (7) Total problems (94) | .90 .91 .73 .62 .76 .94 | .63 .79 .61 .46 .65 .76 | See revised DBC-P scales (Australia) | N.A. | N.A. |
| Developmental Behavior Checklist/ <i>revised</i> subscales—teacher version (DBC-T) (Dekker <i>et al.</i> , submitted 2000; Dekker, Nunn, & Koot, 2001; The Netherlands) | <i>N</i> = 930 (norms split by sex and age) Children at schools for trainable and educable, or daycare centers for ID (borderline to profound) 6–18 years old Multispecial school and daycare sample | Case records ID service/empirical (PCA)/similar to DBC-P revised | 1. Disruptive/antisocial (27) 2. Self-absorbed (31) 3. Communication disturbance (13) 4. Anxiety (8) 5. Social relating (7) Total problems (94) | .91 .88 .74 .67 .75 .94 | .87 .91 .73 .69 .75 .85 | See revised subscales DBC-P in Dutch sample | (<i>N</i> = 1040) Total problems TRF ^d : <i>r</i> = .85 Corresponding TRF scales Range: <i>r</i> = .43 to .87 | (<i>N</i> = 869) Significant mean difference DBC-T scales between referred and nonreferred children |

| | | | | | | | | | |
|---|---|---|------------------------------------|-----|------|------|-------------------------------------|--|---|
| Developmental Behavior Checklist/ revised subscales— primary carer (DBC-P) (Dekker <i>et al.</i> , 2001; Dekker, Nunn, & Koot, 2000; The Netherlands) | <i>N</i> = 1057 (norms split by sex and age) Children at schools for trainable and educable, or day-care centers for ID (borderline to profound) 6–18 years old Multispecial school and day-care sample | Dutch translation of DBC items PCA combined Dutch– Australian sample | 1. Disruptive/ antisocial (27) | .91 | .85 | .64 | .37 | <i>(N</i> = 1040) Total problems CBCL: <i>r</i> = .85 Corresponding CBCL scales Range: <i>r</i> = .47 to .85 | <i>(N</i> = 460) Significant mean difference DBC scales with corresponding DSM-IV) diagnoses (DISC-IV) ^f (<i>N</i> = 1057) Significant mean difference DBC-P scales between referred and nonreferred children |
| | | | 2. Self-absorbed (31) | .88 | .86 | .67 | .57 | | |
| | | | 3. Communication disturbance (13) | .74 | .82 | .52 | .27 | | |
| | | | 4. Anxiety (9) | .66 | .89 | .65 | .39 | | |
| | | | 5. Social relating (10) | .72 | .76 | .55 | .42 | | |
| | | | Total problems (96) | .95 | .86 | | | | |
| Nisonger Child Behavior Rating form—parent version (CBRF) (Aman <i>et al.</i> , 1996; Tassé <i>et al.</i> , 1996; USA) | <i>N</i> = 326 (norms split by age) Mild to profound 3–16 years old Outpatients referred for evaluation at center for MR and DD | Adaptation of CBRF/case records psychiatric inpatients/ PCA + extra items | 1. Conduct problem (16) | .93 | N.A. | N.A. | .37 | <i>(N</i> = 58) Corresponding ABC ^g scales Range: <i>r</i> = .49 to .80 | N.A. |
| | | | 2. Insecure/anxious (15) | .89 | | | .53 | | |
| | | | 3. Hyperactive (9) | .90 | | | .42 | | |
| | | | 4. Self-injury/ stereotypic (7) | .81 | | | .54 | | |
| | | | 5. Self-isolated/ ritualistic (8) | .77 | | | .51 | | |
| | | | 6. Overly sensitive (5) | .80 | | | .22 | | |
| Nisonger Child Behavior Rating form—teacher version (CBRF) (Aman <i>et al.</i> , 1996; Tassé <i>et al.</i> , 1996; USA) | <i>N</i> = 260 (norms split by age) Mild to profound 3–16 years old Outpatients referred for evaluation at center for MR and DD | Adaptation of CBRF/case records Psychiatric inpatients/ separate PCA solution | 1. Conduct problem (13) | .91 | N.A. | N.A. | See parent version of Nisonger CBRF | <i>(N</i> = 58) Corresponding ABC ^g scales Range: <i>r</i> = .49 to .85 | N.A. |
| | | | 2. Insecure/anxious (15) | .88 | | | | | |
| | | | 3. Hyperactive (8) | .87 | | | | | |
| | | | 4. Self-injury/ stereotypic (9) | .83 | | | | | |
| | | | 5. Self-isolated/ ritualistic (11) | .81 | | | | | |
| | | | 6. Irritable (6) | .88 | | | | | |

(continued)

TABLE I (Continued)

| Instrument (reference and country of sample) | Description Sample | Derivation items/scales | Description scales (No. of items) | α | Similar role | | | Convergent validity | Criterion-related validity |
|--|---|---|-----------------------------------|----------|--------------------------------------|---------------------|--|---------------------|--|
| | | | | | Test-retest reliability ^a | informant agreement | Parent-teacher agreement | | |
| Nisonger Child Behavior Rating Form—French parent and teacher version (Tassé & Lecavalier, 2000; Tassé, Morin, & Girouard, 2000; Girouard, Morin, & Tassé, 1998) | <i>N</i> = 383 parents Mild to profound 5–18 years old Schools (with services) for intellectually disabled | French translation of Nisonger CBRF/ separate PCA solution (congruence with Nisonger CBRF .61 to .98) | 1. Conduct problem | .92 | .93 | .86 | .63 | N.A. | N.A. |
| | | | 2. Insecure/anxious | .89 | .89 | .80 | .57 | | |
| | | | 3. Hyperactive | .88 | .88 | .79 | .54 | | |
| | | | 4. Self-injury/ stereotypic | .74 | .86 | .68 | .49 | | |
| | | | 5. Self-isolated/ ritualistic | .74 | .76 | .68 | .42 | | |
| | | | 6. Overly sensitive | .75 | .76 | .66 | (Only similar items used) | | |
| Nisonger Child Behavior Rating Form—French parent and teacher version (Tassé & Lecavalier, 2000; Tassé, Morin, & Girouard, 2000; Girouard, Morin, & Tassé, 1998) | <i>N</i> = 328 teachers Mild to profound 5–18 years old Schools (with services) for intellectually disabled | French translation of Nisonger CBRF/separate PCA solution (congruence with Nisonger CBRF .30 and 74 to .98) | 1. Conduct problem | .90 | .88 | .74 | See French parent version of Nisonger CBRF | N.A. | N.A. |
| | | | 2. Insecure/anxious | .86 | .84 | .60 | | | |
| | | | 3. Hyperactive | .84 | .82 | .44 | | | |
| | | | 4. Self-injury/stereotypic | .82 | .89 | .79 | | | |
| | | | 5. Self-isolated/ ritualistic | .78 | .74 | .47 | | | |
| | | | 6. Irritable | .90 | .87 | .67 | | | |
| Reiss Scales for Children's Dual Diagnosis (RSC- DD) (Reiss & Valenti-Hein, 1994; USA) | <i>N</i> = 583 Mild to profound 4–21 years old Referred to community/ residential-based agencies and special schools | Item selection DSM-III-R/ PCA + extra items | 1. Anger/self-control (5) | .86 | 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 Relation-specific diagnosis and scale scores |
| | | | 2. Anxiety disorder (5) | .75 | | | | | |
| | | | 3. Attention deficit (5) | .69 | | | | | |
| | | | 4. Autism (3) | .63 | | | | | |
| | | | 5. Conduct disorder (5) | .80 | | | | | |
| | | | 6. Depression (5) | .57 | | | | | |
| | | | 7. Poor self-esteem (3) | .80 | | | | | |
| | | | 8. Psychosis (3) | .66 | | | | | |
| | | | 9. Somatoform (5) | .79 | | | | | |
| | | | 10. Withdrawn/isolated (5) | .83 | | | | | |
| | | | Total score | .92 | | | | | |

^a r = Pearson product-moment correlation; ICC, intraclass correlation.

^bAAMD ABC, American Association of Mental Deficiency Adaptive Behavior Scales School Edition (Lambert & Windmiller, 1981).

^cSIB, Scale of Independent Behavior (Bruininks, Woodcock, & Weatherma, 1984).

^dTeacher's Report Form (Achenbach, 1991b; Verhulst *et al.*, 1997).

^eChild Behavior Checklist (Achenbach, 1991a; Verhulst *et al.*, 1996).

^fDiagnostic Interview Schedule for children IV parent version (Shaffer *et al.*, 2000).

^gAberrant Behavior Checklist (Aman *et al.*, 1985a,b).

agreement among people in similar roles or 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., 1985) was still used. Good estimates of internal consistency, ranging from .76 to .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.

B. The Developmental Behavior 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 (see Table I) were derived empirically (accounting for 33% of the total variance) with Cronbach's alphas for the DBC-P scales ranging from .67 to .91 and test-retest reliabilities from .51 to .87, and the interparent agreement for the total problems scale was .80. The DBC-P proved to have good convergent validity, shown by a .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., 1985). The DBC-P has known sensitivity and specificity with regard to expert clinician judgment of the subject as a psychiatric case versus a noncase, with the area under the ROC curve of 92% (Einfeld & Tonge, 1992). 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 ($r = .05$; Einfeld et al., 1998).

The DBC-P and DBC-T have been translated into Dutch (Koot & Dekker, 1997). When Dutch data were combined with the original Australian data, analyses could be completed on 1536 children representative of all levels of ID (all IQ scores < 70; Dekker, Nunn, Einfeld, Tonge, & Koot, 2000). The following results were largely consistent across parents and teachers. Five well-interpretable scales were obtained: labeled disruptive/antisocial, self-absorbed, communication disturbance, anxiety, and social relating (explaining 44% of the total variance). The reliability of the revised scales in both Australian and Dutch samples was good and similar to those found for the original DBC scales (see Table I). A correlation of .85 with the total problems scale of the Achenbach scales (Achenbach, 1991a,b; Verhulst, van der Ende, & Koot, 1996, 1997) was obtained in the Dutch sample of children, who were attending schools for educable or trainable

students or a day-care center for children with moderate to severe ID. Significantly higher mean scores for children referred for mental health services versus those who had never been referred support the criterion-related validity of the DBC scales. In addition, the mean DBC scale scores were significantly higher for children with a related DSM-IV diagnosis, as assessed with the DISC-IV parent version (Shaffer et al., 2000), compared to children without a diagnosis (Dekker et al., 2001). Unfortunately, no interteacher agreement reliability estimates were available in the Dutch study. Australian and Dutch norms for the revised DBC scales (all split by level of ID or educational exceptionality) are forthcoming for both DBC-P and DBC-T.

C. 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 a 71-item parent as well as a teacher version. The six-factor solution (conduct problem, insecure/anxious, hyperactive, self-injury/stereotypic, self-isolated/ritualistic, irritable), explaining about 50% of the variance, showed good internal consistencies for both the parent (alphas ranging from .77 to .93) and the teacher (alphas ranging from .81 to .91) version. 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 (cf. Achenbach et al., 1987). Unfortunately, no information was found on criterion-related validity. Norms for different age groups (and split by sex for the conduct problem and insecure/anxious scale on the parent version) are based on a sample of outpatient children referred for evaluation for ID and developmental disorders.

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

The RSC-DD has mostly good internal consistency, ranging from .57 to .86, for most of its 10 scales (see Table I), 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 the detailed assessment of specific disorders because the various scales contain only three to five items

each. Unfortunately, no reliability or convergent validity information could be found for the RSC-DD.

E. 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. The DBC-P and DBC-T currently have the most comprehensive psychometric information available, with satisfactory reliability, validity, and norms based on adequate samples. The NCBRF also shows good reliability and validity for both the parent and the teacher version. More information on criterion-related validity is needed for this instrument. 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 needs more information on validity and on reliability in nonpatient 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.

III. PREVALENCE OF PSYCHOPATHOLOGY

Our goal here is to summarize the findings on the 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 of 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 II provides more information about the studies meeting these criteria and the prevalence estimates each has produced.

A. Summary of Prevalence Findings

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, then, the reported overall prevalence of psychopathology ranges from 4 to 65%.

These differences in methods make it hard to compare studies or to reach a “best” estimate of prevalence. Therefore, the next section discusses differences between these studies and the effect these may have on the resulting prevalence estimates.

In the absence of a specific point prevalence estimate and the lack 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.

Only five studies used a comparison group of children in the general population as a point of reference. Rutter et al. (1970) reported a four-fold risk of psychopathology for the ID group; Koller, Stephen, Richardson, Katz, and McLaren (1982) a seven-fold; Linna et al. (1999) a three-fold; Dekker et al. (2001) a three- to four-fold; and Wallander, Browne, and Stankovic (2002) a three- to six-fold risk. As an example, Wallander and colleagues (2002) used the Youth Self-Report (Achenbach, 1991c) with a criterion for self-reported psychopathology that produces a 10% prevalence in the general population. In comparison, African-American adolescents placed in a special education program due to mild ID met this same criterion in 32% of the cases.

Thus, the observation that children with ID are at a substantially increased risk for psychopathology relative to children from the general population is robust across studies conducted in England, Scotland, Finland, The Netherlands, and the United States. In fact, three out of five studies that used standardized parent (and in Rutter et al.’s case, also teacher) rating scales and an empirically determined criterion for disorder consistently reported psychopathology to be three to four times more prevalent in children with ID compared to children in the general population (Linna et al., 1999; Dekker et al., 2001; Rutter et al., 1970). Koller et al. (1982) obtained a larger differential prevalence, but classified disorder based on the investigators’ judgment incorporating multiple sources of information. Wallander et al. (2002) produced a six-fold increased risk based on parent report and studied a low socioeconomic status (SES), urban sample, which may experience more psychopathology due to environmental stress. Moreover, consistent with the majority of the parent-report findings, teacher- and self-reports yielded a three-fold risk for psychopathology in four samples of children with mild ID (Dekker et al., 2001; Linna et al., 1999; Rutter et al., 1970; Wallander et al., 2002).

It is important to note that primarily those with *mild* levels of ID constituted the samples of children with ID in these five studies. 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 (APA, 1995; Szymanski, 1977), display types of psychopathology similar to that in the general population (Borthwick-Duffy, Lane, & Widaman, 1997; Dykens, 2000; Einfeld & Tonge, 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 assessed in instruments used with the general population and comparison with the whole spectrum of children with ID therefore becomes impossible.

B. Methodological Issues and Their Influence on Prevalence

As noted, epidemiological studies of psychopathology in children with ID have differed greatly in their methods, producing a wide range of prevalence estimates. We will discuss several of these methodological issues and how they affect the reported prevalence estimates.

1. DEFINITION OF DISORDER

Because there is no consensus in the general psychopathology literature, studies of prevalence have employed different criteria for what constitutes a sufficient degree of psychopathology to classify as a disorder. As discussed earlier, there is the basic distinction between the clinical–medical and psychometric–empirical approaches. A number of prevalence studies have used an empirical criterion to define disorder (Cormack, Brown, & Hastings, 2000; Dekker et al., 2001; Einfeld & Tonge, 1996; Linna et al., 1999; Rutter et al., 1970; Tonge & Einfeld, 2000; Wallander et al., 2002). These cutoff scores are based on or are related to some external criterion, e.g., judgments by clinicians (Einfeld & Tonge, 1992, 1995) or optimal prediction of referral to mental health care (Achenbach, 1991a,b,c; Verhulst et al., 1996, 1997; Rutter et al., 1970). 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 & Menolascina, 1982; Jacobson, 1982; Rojahn et al., 1993). The range of 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 (Chess, 1970, 1977; Koller et al., 1982; Kushlick, 1975; McQueen, Spence, Garner, Pereira, & Winsor, 1987; Gillberg, Persson, Grufman, & Themner, 1986; Reiss, 1985; Szymanski, 1977) have reported prevalence estimates ranging from 9 to 60%. A fourth set of studies used global and unstandardized methods to assess global levels of problem behaviors (Eaton & Menolascina, 1982; Jacobson, 1982; McQueen et al., 1987; Rojahn et al., 1993). These studies have 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, the 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.

2. 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 & Menolascina, 1982; Einfeld & Tonge, 1996; 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 with mild ID being underrepresented. The main reason for this is the greater likelihood of children with mild ID being fully integrated and not found in the services systems providing the sampling frame for these studies.

A set of other studies included children attending education programs for children with ID (Chess, 1970, 1977; Dekker et al., 2001; Linna et al., 1999; Wallander et al., 2002; Reiss, 1985). In these studies, children with severe and profound levels of ID are under represented, 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 The Netherlands (Dekker et al., 2001) and Finland (Linna et al., 1999).

Some studies reported the prevalence of psychopathology split by the level of ID or IQ (Borthwick-Duffy & Eyman, 1990; Dekker et al., 2001; Einfeld & Tonge, 1996; Gillberg et al., 1986; Jacobson, 1982; Koller et al., 1982; Kushlick, 1975; Reiss, 1985). 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, there is no discernible association between prevalence and ID level.

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, whereas psychotic, self-absorbed, and autistic behaviors are more likely to be found in children with lower IQs (Einfeld & Tonge, 1996b; Dekker et al., 2001; Gillberg et al., 1986; Koller et al., 1982). Significant effects of level of ID or IQ or educational placement were reported in five studies (Borthwick-Duffy & Eyman, 1990; Dekker et al., 2001; Einfeld & Tonge, 1996; Jacobson, 1982; Koller et al., 1982). However, differences were not always found on overall levels of psychopathology, but rather for syndrome or scale scores (Dekker et al., 2001; Jacobson, 1982; Einfeld & Tonge, 1996).

3. 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 & Koot, 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 (Eaton & Menolascina, 1982; Gillberg et al., 1986; Tonge & Einfeld, 2000), this option is not time- and cost-efficient because a large sample is required for producing reliable prevalence estimates. The only example of a general population study that did not preselect 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), then, all research on the 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 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 overrepresented in service-based samples, which can influence the prevalence estimates (Einfeld & Tonge, 1996). 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 young people with ID are reached through these systems differ considerably by country or region. For example, in 1996, about 2% of all 6- to 18-year-old Dutch children attended a school for the educable or trainable (Dekker et al., 2001). Therefore, almost all children with mild to moderate levels of ID are reached through this sampling frame.

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 review studies herein with samples of children who are *not* selected through mental health agencies. This strategy protects against an accumulation of selection by referral bias.

4. MULTIPLE INFORMANTS

Because of the moderate cross-informant agreement in reports on children's behaviors and emotions, discussed previously, it is important to know which informant is used to report on psychopathology when comparing different prevalence estimates. Dekker et al. (2001), Linna et al. (1999), Rutter et al. (1970), and Wallander et al. (2002) were the only studies that used different informants but standardized cross-informant instruments to estimate prevalence. Dekker et al. (2001) and Wallander et al. (2002) used the Achenbach scales (1991a,b,c), 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 also seems to be an interaction effect of instrument by informant when estimating prevalence.

5. AGE RANGE

There are several age-related issues in this 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 [Rojahn et al., 1993](#); [Borthwick-Duffy & Eyman, 1990](#); [Eaton & Menolascino, 1982](#)) 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. \(1970\)](#) 10–11 year olds, [McQueen et al. \(1987\)](#) and [Koller et al. \(1982\)](#) 7–10 year olds, and [Gillberg et al. \(1986\)](#) and [Wallander et al. \(2002\)](#) adolescents. Because age has been found to affect the level of psychopathology in children with ID ([Dekker et al., 2001](#); [Einfeld & Tonge, 1996](#); [Koller et al., 1982](#); [Jacobson, 1982](#); [Cormack et al., 2000](#)), restricting the age range of a study sample may affect the prevalence estimates obtained.

6. SAMPLING ISSUES

Sample size also differs across studies. Other things being equal, a larger sample size will produce more accurate (less standard error in the) estimates. Some studies have enrolled fewer than 100 children with ID ([Chess, 1977](#); [Chess, 1970](#); [Linna et al., 1999](#); [Kushlick, 1975](#); [Rutter et al., 1970](#)), whereas other studies have samples of more than 500 children ([Dekker et al., 2001](#); [Eaton & Menolascina, 1982](#); [Jacobson, 1982](#); [Reiss, 1985](#); [Tonge & Einfeld, 2000](#)). Two studies examining existing 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, sample composition and how well the sample represents the population of interest are critical considerations. It is important to know whether all or a random sample of recruitment sources (e.g., agencies, schools serving children with MR) was 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 et al. \(2002\)](#), the majority of participants came from one public school system, with the result that almost the whole sample was low SES, urban African-Americans. [Chess and Hassibi \(1970\)](#); [Chess, 1977](#)) reported on children only from middle-class families. Both [Eaton and Menolascina \(1982\)](#) 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 the level of ID, age, sex, and SES conforms to expectations. Information on the response rate and distribution of nonresponse is necessary to draw conclusions about response bias, representativeness, and generalizability. Unfortunately, only a portion of the studies report about nonresponse and the bias that this can potentially create ([Dekker et al., 2001](#); [Wallander et al., 2002](#); [Einfeld & Tonge, 1996](#); [Tonge & Einfeld, 2000](#); [Rutter et al., 1970](#)).

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.

IV. COURSE AND DEVELOPMENT

Several questions pertain to the course and development of psychopathology in children with ID. To answer these questions requires a longitudinal prospective cohort design. Most of the studies on the prevalence of psychopathology reviewed previously were one-time assessments. However, a few recent studies have followed a sample across at least 1 year in, respectively, The Netherlands, Australia, and Alabama. We will use these studies to inform about the course and development of psychopathology in this population. Because two of these are also important for our discussion of risk factors for psychopathology in the next section, we will first summarize these three studies briefly (see also Table II).

The Dutch (Netherlands) study (Dekker et al., 2001; Dekker & Koot, 2001; Koot, Dekker, & Wallander, 2001) enrolled a random population sample of 968 children, ages 6–18 with a mild to moderate level of ID, who were attending special schools for the intellectually disabled and living in a southwest region of the county. Parent and teacher reports of psychopathology were obtained with the *Achenbach scales* (1991a,b), and the DBC (Einfeld & Tonge, 1992, 1995; Dekker et al., 2001) at two time points thus far, 1 year apart.

The Australia study (Tonge & Einfeld 2000; Tonge, Einfeld, & Parmenter, 2001) enrolled a combined epidemiological and clinical sample of 592 children at the first assessment. Children were ages 3–19, living in the south and central eastern regions of the country, and represented the entire range of ID and also several specific syndromes. The parent report was obtained on the DBC thus far on three occasions, at enrollment and 5 and 8 years later.

The Alabama study (Wallander et al., 2002; Wallander, Frison, & Rydvalova, 2001) enrolled a sample of 237 children, ages 13–16 with mild ID participating in special education for educable mental retardation and living in a metropolitan area. This sample is predominantly African-Americans living in urban, low SES families. Parent and self-report were obtained with the *Achenbach scales* (1991a,c) on three occasions each 1 year apart. Trained interviewers completed a structured mental status exam and

TABLE II
PREVALENCE STUDIES (1970–2001) USING STATISTICAL OR GLOBAL CLINICAL CRITERIA FOR DISORDER

| Study | Country | Sample | | | | | Definition of disorder | Assessment method(s) | Prevalence of psychiatric disorder ^a | | |
|--------------------------------|----------|----------|----------------------|------------------|----------------------------------|--|---|---|---|---|---|
| | | Size ID | Size reference | Age ^b | IQ or educational level | Method | | | Overall | Specific syndromes | Associated factors |
| Borthwick-Duffy & Eyman (1990) | USA (CA) | 78,603 | Not available (N.A.) | 0–86 | Mild to profound | 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 psychiatric diagnosis: 10.0% Mild: 15.9% Moderate: 9.1% Severe: 5.0% Profound: 6.0% | N.A. | Relation: Level of ID; living conditions; 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, and observation child; clinical psychiatric evaluation | Overall After 3 years: 58.3% After 6 years: 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, and observation child; clinical psychiatric evaluation | Overall: 59.6% | Reactive behavior disorder; neurotic disorder; cerebral dysfunction; psychosis; behavior patterns | N.A. |

(continued)

TABLE II (Continued)

| Study | Country | Sample | | | | | | Prevalence of psychiatric disorder ^d | | | | |
|-----------------------------------|-------------------------------------|---------|--|-----------------------|---|--|--|---|---|---|---|--|
| | | Size ID | Size reference | Age ^b | IQ or educational level | Method | Definition of disorder | Assessment method(s) | Overall | Specific syndromes | Associated factors | |
| Cormack, Brown, & Hastings (2000) | UK (Southampton and the New Forest) | 123 | N.A. | 4-18 | Moderate to severe/attending schools for children with severe learning difficulties | Administratively defined population of parents of children attending one of four SLD schools | Statistical: Cutoff based on ROC of judgements clinicians in ID sample | DBC-P | Total: 50.4% | Disruptive; self-absorbed; communication disturbance; anxiety; autistic relating; antisocial | Relation: Down's syndrome; age; physical disability index No relation: sex; epilepsy | |
| Dekker <i>et al.</i> (2001) | The Netherlands (Z-Holland) | 968 | 1855 GP ^c ; children at regular schools | 6-18 | Educable and trainable (borderline to moderate) | Random sample schools for educable and trainable | Statistical: Borderline/clinical cutoff based on prediction referral status in GP sample | CBCL (parent) TRF (teacher) | ID (cbcl): 49.1% Educable: 48.1% Trainable: 51.3% GP: 18.0% ID (trf): 46.1% Educable: 44.9% Trainable: 48.3% GP: 19.0% | Withdrawn; somatic complaints; anxious/depressed; social Problems; thought Problems; attention problems; delinquent behavior; aggressive behavior | Relation: Level of education; sex; age | |
| Eaton & Menolascino (1982) | USA (Nebraska) | 798 | N.A. | 6-76 (49% 6-20 years) | Borderline to severe | Participants in community-based ID program | Clinical: Psychiatric disorder (DSM-III) | Psychiatric consult | Referred: 21% Diagnosis: 14.3% | Schizophrenia; personality disorder; anxiety disorder; organic brain disorder | N.A. (only descriptive) | |
| Einfeld & Tonge (1996) | Australia (NSW) | 454 | N.A. | 4-18 | Mild to profound | Random sample from services ID (NSW) | Statistical: Cutoff based on ROC of judgments clinicians in ID sample | DBC-P (parent) | Total 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 <i>et al.</i> (1986) | Sweden (Göteborg) | 149 | N.A. | 13–17 | Mild to severe | ID subjects from all children Göteborg (born 1966–1970) | Clinical: Global psychiatric diagnostic categories | Child seen by doctor; structured interview parent | Total: 59.7% Mild: 56.6% IQ < 50: 63.6% | Psychotic; depressive; conduct; emotional; psychosomatic; hyperkinetic | Relation: Level of ID; sex; epilepsy; Down syndrome |
| Jacobson (1982) | USA (NY) | 8784 | N.A. | 0–21 (also adults) | Mild to profound | All children receiving services for the ID | Clinical: Global psychiatric disability (DSM-III-R); problem behaviors | Developmental Disabilities Information Survey (DDIS) | Psychiatric disorder: 9.8% Problem behaviors: 54% Mild: 48% Moderate: 55% Severe: 61% Profound: 51% | Cognitive problems; affective problems; major behaviors; minor behaviors | Relation: Level of ID; age; living conditions |
| Koller <i>et al.</i> (1982, 1983) | Great Britain (Aberdeen) | 173 | 173 (IQ > 75; matched for age, sex, SES) | 7–10 (and post-school) | Mild to severe | ID subjects from random GP ^e sample Aberdeen (born 1951–1955) | Clinical: Global behavior disturbance (moderate–severe) classification | Interview with parent; records | 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 | 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 <i>et al.</i> (1999) | Finland | 90 | 5804 GP; children at regular schools | 8 | Educational subnormal and trainable | ID subjects attending special schools from random GP sample (born 1981) | Statistical: Cutoff based on prediction referral status in GP sample | Rutter A2 (parent); Rutter B2 (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 <i>et al.</i> (1987) | Canada (three maritime provinces) | 307 | N.A. | 7–10 | IQ < 55; Moderate to profound | Children born 1969–1972 from schools, service agencies, and institutions | Clinical: Global behavior disorders; psychiatric disorder | Record data | Behavior disorders: 31.7% Psychiatric disorders: 9% | N.A. | N.A. |

(continued)

TABLE II (Continued)

| Study | Country | Sample | | | | | Method | Definition of disorder | Assessment method(s) | Prevalence of psychiatric disorder ^d | | |
|--|-------------------------|-----------------------|---------------------------------|--------------------|-------------------------|---|---|--|---|--|-------------------------|--|
| | | Size ID | Size reference | Age ^b | IQ or educational level | Overall | | | | Specific syndromes | Associated factors | |
| Reiss (1985) | USA (IL) | 5,639 | N.A. | School aged | Educable and trainable | Data from Illinois State Board of Education of children enrolled in special education classes (1980–1981) | Clinical: Global evaluation of behavioral disturbance by school psychologist | N.A. | Overall: 10.2% Educable: 16.8% Trainable: 8.6% | N.A. | Relation: Level of ID | |
| Rojahn, Borthwick-Duffy, & Jacobson (1993) | USA (CA and NY) | 135, 102 (40.9% 0–20) | 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); DDIS | Psychiatric disorder CA: 5.4% NY: 3.9% Problem behaviors CA: 21.1% NY: 40.1% | AD/HD; conduct disorder; PDD; adjustment disorder; anxiety disorders; organic brain disorder; schizophrenic; affective disorders; personality disorders; behavior problems | Relation: Sample | |
| Rutter, Tizard, & Whitmore (1970) | England (Isle of Wight) | 56 | 147 GP; random sample (IQ > 70) | 10–11 ^b | IQ < 70 | All children with IQ < 70 from total sample | Statistical: Cutoff based on prediction referral status in GP sample Clinical: Overall judgment psychiatric disorder | Rutter A2 (parent); Rutter B2 (teacher); Psychiatric interview (child) | ID (RA2): 30.4% GP: 7.7% ID (RB2): 41.8% GP: 9.5% Interview ID: 23.6% GP: 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: 30% Severe emotional difficulty: 24% In need of care: 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 | Four-year follow-up of random sample from services ID (NSW: 1995–1996) | Statistical: Cutoff based on ROC of judgments of clinicians in ID sample | DBC-P (parent) | Time 1 Total: 43.3 Time 2 Total: 38.6% | Disruptive; self-absorbed; communication disturbance; anxiety; autistic relating; antisocial | In time no significant changes in scale scores and no interaction age and time |
| Wallander, Stankovic, & Browne (2002) | USA (Alabama) | 211 African-American | N.A. | 13–16 | Mild ID; all in EMR schools | Volunteers out of EMR schools in four school districts | Statistical: Clinical cutoff 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 two informants: 35% | Achenbach scales (see Dekker <i>et al.</i>); psychiatric symptoms; e.g. somatic; anxiety; depression; suicide/self-mutilation; social isolation; suspicion; grandiosity; antisocial; negativism; agitation; memory problems | No relation: Demograph risk index; IQ |

^aPrevalence of children with ID and at least one psychiatric disorder.

^bAge at the time of assessing the level of psychopathology.

^cGeneral population sample.

psychopathology ratings as well, and standardized clinical criteria were employed to define a case with psychopathology.

A. Stability

The first question is whether the level of psychopathology remains stable over time. The overall 1-year stability of the parent version of the DBC in the Dutch study was $r = .75$ and on the CBCL it was $.72$ in boys and $.81$ in girls. The Alabama study found a highly similar $.74$ for parent-reported psychopathology for their sample, which decreased only to $.69$ over 2 years. The corresponding coefficients for self-reported psychopathology were $.62$ and $.50$ in the Alabama study. The stability coefficients for interviewer-reported psychopathology were somewhat lower: $.35$ for 1 year and $.30$ for 2 years. Consequently, there is considerable stability over time in how people who are closely involved with the child with ID perceive the degree of psychopathology.

B. Persistence

The second question is whether psychopathology meeting criteria for a disorder persists in children with MR? Another way of putting this question is how chronic is significant psychopathology? The Dutch study reported that 71% of the children meeting standardized case criteria applied to the parent report at the first assessment also did so 1 year later. The Australian study has reported that 70% persisted in meeting standardized case criteria for the parent report 4 years later. This study also found that about 74 to 85% of the children showed no clinical change across time on the DBC subscales (Tonge & Einfeld, 2000). This high persistence in the epidemiological sample of children with ID was also seen in the syndromes included in this study (i.e., autism, Down, Williams, fragile X, Prader–Willi).

C. Developmental Effects

The third question is whether the size of the group with psychopathology changes as children mature. One general approach to answering this question involves comparing the prevalence for the total sample on each assessment, representing the developmental passage for each participant. Individual participants, however, span the age range of interest in the given study. This method therefore only provides a gross indication of effect of maturation.

In the Dutch study, overall psychopathology, as measured with the CBCL, was found for 49% of the children at the first assessment, which decreased slightly to 42% about 1 year later. The Alabama study found that

the prevalence based on parent and self-reports decreased more noticeably over the two follow-up assessments, especially by the first follow-up (63 to 52% for parent report, 33 to 18% for self-report). In contrast, the interview-reported prevalence increased slightly from 23 to 26% over 2 years. The Australian study found that the parent-reported prevalence decreased slightly over 4 years, from 42 to 39%. A consistent picture thus does not emerge from these findings, with reporting source, time periods, and developmental span varying inconsistently among studies.

A more refined approach is to compare age cohorts as each develops over time. This requires a sufficient number of participants at each age. The Alabama study enrolled about 50 at each of the ages 13 through 16, following them until ages 15 through 18. Figure 1 presents the case prevalence based on parent reports, showing general trends toward a decreased level of psychopathology with development in adolescence. However, this trend cannot be separated from an interaction with assessment occasion, such that parents also report less psychopathology on each subsequent assessment regardless of the age of their child.

Whereas the just-described findings have pertained to overall psychopathology, a final developmental question for now is whether different syndromes or symptom clusters change with development? The Australian study found notable changes in parent reports of depressed and hyperactive behaviors as their sample matured from an average age of 11 at the first to 15 at the second and 18 at the third assessment. Depressed behavior increased between the first and the second assessment, but remained stable between the second and the third assessment. In contrast, hyperactive behaviors decreased on each assessment. Both trends are consistent with

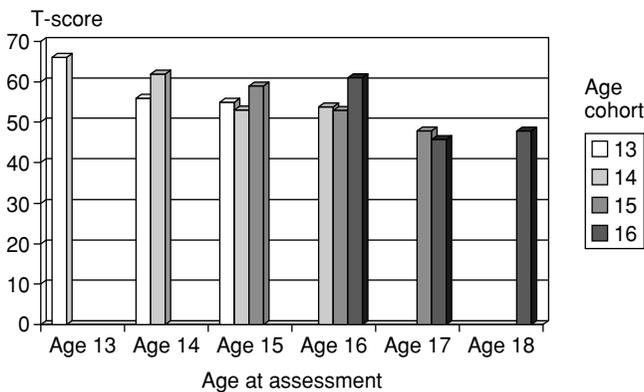


FIG. 1. Parent report (CBCL) of psychopathology by age of assessment and cohort in the Alabama study.

expectations for the general population of children (cf. Mash & Barkley, 1996). Other symptom clusters assessed with the DBC did not evidence gross developmental changes such as these. Thus it is likely that there are developmental trends in psychopathology in children with ID, but few developmental analyses have yet been conducted. This needs to be addressed in future work.

V. FACTORS ASSOCIATED WITH PSYCHOPATHOLOGY

Few studies reporting on the prevalence of psychopathology in children with ID have examined associated factors beyond gross demographic and disability-related ones (see Table II). These limitations are unfortunate because research into a broader range of factors that may increase or decrease risk can illuminate the etiology of psychopathology as well as targets for intervention. However, the three contemporary longitudinal studies discussed in the previous section, conducted in The Netherlands, Australia, and Alabama, have an explicit aim to discern such factors. Consequently, they have investigated a broad range of factors, informed by *a priori* theoretical formulations, which may explain individual differences in the development of psychopathology in children with ID.

The study of the development of psychopathology requires a longitudinal design to enable explanation of the variance in change of psychopathology from one time point to another, based on factors measured at the first time point. As discussed in the previous section, psychopathology is highly stable over 1 (and 2)-year periods. In addition to determining that previous psychopathology is the most salient risk factor for later psychopathology, this stability also challenges the detection of other factors associated with its development. There simply is not much variance in the change of psychopathology over 1- and 2-year periods.

Findings from the Australian study are detailed in the chapter by Tonge and Einfeld in this volume. Therefore, we will focus on the Dutch and Alabama studies here, which established conceptual frameworks for their examination of factors associated with the development of psychopathology. Both studies ordered factors on a proximal-to-distal continuum in relation to psychopathology. That is, factors were grouped into those of the individual child, his or her family, and the broader social ecology. While the specific conceptual organization and factors considered in these two studies are distinct, as outlined in Table III, numerous similarities can be noted.

The Dutch study controlled for age and sex in their analysis in the first step of a hierarchical multiple regression analysis, then entered Time 1 psychopathology (as measured with the CBCL), followed in order by the

set of factors in the developmental, biological, family, and environmental risk domains (see Table III). The development of total psychopathology over 1 year, by a parent report, was significantly predicted (but accounting for small portions of the variance) by the child having more physical symptoms and a history of parental psychopathology reported at the beginning of this period (Koot et al., 2001; Wallander, Dekker, & Koot, 2002). It is noteworthy that differences in child educational placement, an indication of IQ range per se, was not a significant predictor. Preliminary data on the 1-year prediction of any anxiety, mood, or disruptive disorder as measured with the DISC-IV (Shaffer et al., 2000) suggested that the best predictors were overall psychopathology, more physical problems of the child, low social competence of the child, and more life events within the family environment (Dekker & Koot, 2001).

TABLE III
RISK AND RESILIENCE FACTORS STUDIED IN THE NETHERLANDS
AND ALABAMA STUDIES

| <i>The Netherlands study</i> | | |
|--|---|--|
| Developmental risk domain Social disability Daily living skills disability Communication disability Intellectual disability Social competence | | Biological risk domain Physical symptoms Chronic disease history or lengthy hospitalization |
| Family risk domain Parental distress Family dysfunction Parental psychopathology history | | Environmental risk domain Life events exposure Low SES Single parent household Ethnic minority |
| | <i>The Alabama study</i> | |
| Personal risk domain Life events exposure | Family risk domain Parental dysfunction Family changes Family arguments Family violence | Community risk domain Neighborhood distress |
| Personal resilience domain Ethnic identity Global self-worth Internal control Calm demeanor Independent minded Tender minded | Family resilience domain Child acceptance focus Family harmony focus | Community resilience domain Extended family support Peer support Church involvement Family community integration |

The Alabama study first investigated associations between various demographic characteristics and both parent- and self-reported psychopathology. No relations were found. This may be explained in part by the predominance of low SES families in the sample, but even a demographic risk composite formed by all demographic variables and on which cases varied did not relate to psychopathology. The development of psychopathology over a 1-year period by adolescent report was significantly predicted (but accounting for a small portion of the variance) by more family dysfunction and less ethnic identity (recall that this was predominantly an African-American sample and, in fact, these analyses were conducted only on that portion of the sample) (Wallander et al., 2001). The parent-reported development of psychopathology was predicted only by less child acceptance focus in the family.

Obviously, as illustrated in these studies, when different factors that may explain the development of psychopathology are studied, different results will be produced. However, the two studies show that family factors and child factors are associated with increased levels of psychopathology in children with ID 1 year later, whereas broader social-ecological factors appear less informative. This is consistent with much research on psychopathology in the general child population (cf. Koot, Crijnen, & Ferdinand, 1999; Burack, Cicchetti, & Weisz, 1997). This finding notwithstanding, these studies have primarily initiated a direction that must be pursued in future research.

VI. CONCLUSIONS AND RECOMMENDATIONS

A. Knowledge and Research

Significant psychopathology affects at least one-third of all children with ID and is about three times more common than in children in the general population. Given that ID is estimated to be present in 10–30 per 1000 in the population, this translates into that *3–10 per 1000 of all children experience both ID and psychopathology*. This is a sizable number of children. In comparison, children affected with acute lymphocytic leukemia equal 0.1 per 1000, insulin-dependent diabetes equal 2 per 1000, and moderate to severe asthma equal 10 per 1000 (Newacheck & Taylor, 1992). Yet, the attention given this problem is minuscule in comparison.

While research has been ongoing for quite some time (i.e., the Isle of Wight study published in 1970 marking the beginning of a scientific approach to this topic), it has lacked breadth at any time and consistency in the degree of effort over time. In the last decade there have been only a

handful of studies addressing psychopathology in children with ID in general in a substantial manner. Consequently, the most important implication to take away from the work completed thus far is that we need more of it. Importantly, also, we believe it should develop in specific directions.

1. MEASUREMENT

Scientific knowledge cannot advance without high-quality measurement of the phenomena under study. Both mental retardation and psychopathology are challenging to measure. We believe that quicker progress can be made if we adopt a common set of measures of psychopathology in children with ID. Witness the impact on the knowledge of psychopathology in the general population of children resulting from the widespread use of the [Achenbach scales \(1991a,b,c\)](#).

Based on the available evidence thus far, we recommend that future research employ the DBC ([Einfeld & Tonge, 1992, 1995](#); [Einfeld et al., 1998](#)) to assess psychopathology for all levels of ID in children. The DBC-P and DBC-T currently have the most comprehensive psychometric information available among instruments for assessing psychopathology in children with ID. It has satisfactory reliability, validity, and norms based on adequate samples. When studying mild and probably moderate ID in children, the Achenbach scales need to be added to allow comparison to the general population. Indeed, it would be beneficial to determine more exactly below for which level of IQ the Achenbach scales appear not to yield useful information.

We do not intend for these recommendations to imply that we advocate solely for the psychometric–empirical assessment approach. Rather, we also encourage research into the use of diagnostic interview schedules with children with ID. Again, we need to learn for which children with ID this is an appropriate assessment approach. The Dutch longitudinal study used a structured diagnostic interview with mild and moderate ID levels ([Dekker & Koot, 2001](#)), and the Alabama longitudinal study used a structured symptom interview approach with its sample of adolescents with mild ID ([Wallander et al., 2002](#)), providing an ample precedent for its feasibility.

Informant source is an important component of any assessment of psychopathology in children, probably even more so for those with ID. Therefore, we need research into the convergence and influences on divergence among sources, such as parent, teacher, professional, and child. Given the attributions that people tend to make about ID, we cannot assume that findings regarding cross-informant issues in the general psychopathology research apply here.

2. METHODS

Numerous methodological issues influencing findings on psychopathology in children with ID were discussed in a previous section. That discussion provides implications for advancing the methods used in this research. However, we would like to highlight a few recommendations. We recommend that efforts be made to sample children with ID as much as possible in the community. This would include the schools in those countries where this is a universal service. Community sampling will minimize selection biases inherent in institutional or service agency samples.

One of the few things that is well established in the research conducted thus far is the three- to four-fold increased relative risk of psychopathology for children with ID. While the exact prevalence of psychopathology is dependent on the measurement and criteria used, we have considerable convergence in the estimated prevalence as well, in the range of 30–40%. Therefore, we feel that basic general descriptive prevalence studies will provide limited additional information in the future. However, we need more information about specific segments of the ID population, e.g., as defined by etiology or syndrome. While there is growing knowledge about patterns of psychopathology associated with specific syndromes, such as fragile X, Prader–Willi, Williams, and Down (cf. [Reiss & Aman, 1997](#); see previous chapter by Tonge and Einfeld, pp. 61–92), more focused research in this manner is needed.

Moreover, psychopathology and ID are developmental phenomena, which are accentuated in childhood with rapid changes over time. Most questions facing us today regarding the onset, course, and change in psychopathology would benefit from longitudinal studies. More longitudinal studies are needed than the three highlighted here where developmental changes can be captured.

Related to this methodological encouragement is that research into the development of psychopathology in children with ID could benefit from modeling the methods and questions present in developmental psychopathology more generally. For example, there has been no research into the interplay over time between cognitive processes in children with ID and psychopathology. For example, one useful approach for understanding conduct problems in the general child population has been to focus on deficits in social information processing (e.g., [Dodge & Coie, 1987](#)). As another example, attention deficits in children in general have been illuminated by research into self-regulation (e.g., [Barkley, 1997](#)). We argue that the general developmental psychopathology literature has much to offer the study of psychopathology in children with ID.

As well, we need to encourage the general developmental psychopathology research lines to include children with ID. As it stands now, most studies of psychopathology in the general child population specifically exclude those with ID. Much is lost due to this strategy, certainly for our understanding of psychopathology in children with ID, but also in children in general. That is, findings on one of these populations likely will advance understanding of the other. It is particularly distressing to see the exclusion of children with ID from the large-scale, long-term hallmark longitudinal studies that have been conducted, providing such a wealth of information but neglecting an important and sizable segment of the population (cf. [Verhulst & Koot, 1992, 1995](#)). To be certain, there will be measurement challenges when pursuing this recommendation.

3. SALIENT RESEARCH QUESTIONS

Given the sparse knowledge base, many important questions about psychopathology in children with ID warrant attention. We can only highlight a small number here. The nature of psychopathology in children with ID needs further explication. For example, what are the salient subtypes? The developmental nature of psychopathology in this population is largely unknown. For example, what different developmental processes influence the expression of different psychopathologies? The role of level of ID in the display of different types of psychopathology is poorly understood as yet. For example, do we see the same pattern of psychopathology over age in children with ID as in those without? Very little is known about the etiology of psychopathology in those with ID where there is no organic basis identified. Recent research has focused on intrapersonal and family factors, finding similarities with the general psychopathology literature ([Koot et al., 2001](#); [Wallander et al., 2001](#)).

To be able to understand etiological processes to establish an empirical basis for intervention planning, more research must follow. In addition to the need to replicate initial findings, different conceptual structures should also be explored, identifying other factors and processes. Again, the general developmental psychopathology literature should be of substantial help in moving this work forward. At the same time, we have essentially no information about the role of the core deficits of ID in the development of psychopathology. Knowledge about ID thus needs to be incorporated in the research to follow.

B. Practice and Policy

This chapter focused on scientific issues and findings rather than on practice and policy issues. Even so, research into psychopathology in

children with ID conducted thus far has implications for practice and policy. Foremost in our mind is that there is now a strong indication that all service systems serving children with ID must screen routinely for psychopathology. Again, at least one-third of children in this group display or experience significantly disordered behavior. However, this large portion is not being identified and referred to mental health care. Rather, there is a huge gap between expressed and treated psychopathology in this population.

There are likely numerous reasons for this, a primary one being diagnostic overshadowing. This refers to when the attribution is made that the pathological behavior is another expression of the underlying impairment causing the ID. However, whether this is the case is irrelevant at the point of identification and referral. Because the behavior in question is causing problems for the child and/or those caring for him/her, it warrants a referral for intervention.

Consequently, screening is imperative in all service systems caring for children with ID, most especially the schools. Fortunately, there are useful instruments for screening. Again, we recommended the DBC and the Achenbach scales, as described earlier. A teacher, for example, can complete either in less than 10 minutes. U.S. law mandates that all children with ID be evaluated at least every 3 years. Screening for psychopathology, to identify it before it becomes severe, needs to be conducted more often than that. At a minimum, screening needs to occur in conjunction with the formulation of the educational plan occurring at least yearly.

Psychopathology is a problem for which the primary system put into place to serve children with ID, the education system, is not well suited. There is the legal mandate in the United States that most needs of the child with ID are to be identified in the education process and the indicated services are to be supplied as part of an individualized educational program. Services provided through the educational system can include, for example, physical therapy and vision correction. In our experience, this rarely includes mental health services. Admittedly, providing mental health services for about one-third of all children with ID would be prohibitively expensive for the education systems in most countries. It is often said that the mental health needs of those with ID fall between the cracks. In the case of children, these are the cracks between the education and mental health systems: Typically, the education system does not have expertise in mental health issues and the mental health system does not have expertise in ID.

There is little empirical basis for deciding how to treat different psychopathologies in children with ID. One common approach is extrapolating from the ID adult intervention research, which is somewhat more advanced (Bouras, 1994; Dosen & Day, 2001; Fletcher & Dosen, 1993; Jacobson & Mulick, 1996; Nezu et al., 1992). Alternatively, research into

intervention effectiveness with the general child population may be informative. Either approach obviously can be problematic for ignoring the developmental comparability between the original population and children with ID.

Rather, we need to develop a specific empirical base for intervention with children with ID. Gordon Paul's (1967) oft-cited question bears repeating here: "What treatment, by whom, is most effective for this individual with that specific problem, under which set of circumstances?" (p. 111). We at least need to begin now to answer this question for children with ID. This work needs to be inclusive of both behavioral and pharmacological interventions and their interactions.

To conclude, the empirical knowledge base regarding psychopathology in children with ID is in its infancy. The research reviewed in this chapter, however, points to the importance of rapidly expanding this work on all fronts. Psychopathology hinders all other development. Certainly, all who work with or are otherwise concerned with children with ID hold as one of their most important goals: that of ensuring that all these children can develop optimally to experience a life of quality.

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