Chapter 3

Structured Assessment Of Mental Health Problems On Children And Adolescents With Intellectual Disabilities

Louise A. Ellis and Stewart L. Einfeld

Over the past decade, there has been an emergence of structured assessment tools developed specifically to assess psychopathology in children and adolescents with intellectual disabilities (ID). This chapter highlights the importance of incorporating structured instruments into clinical practice when working with young people with ID, and describes a number of the most widely used and psychometrically sound measures currently available for this population. Although limitations are identified with many of the existing instruments, the routine use of structured assessment tools may significantly improve the diagnosis of, and quality of care for, people with ID. A comprehensive multi-method approach to assessing psychopathology in individuals with ID is advocated, as well as the routine use of structured tools to monitor progress and treatment response over time.

Introduction

The identification and correct diagnosis of psychopathology in young people with intellectual disabilities (ID) is complex and can be highly challenging for even the most experienced clinician. Atypical presentations, maladaptive behaviours, communication and cognitive limitations, differential developmental trajectories and limitations in lifestyle, as well as reliance on diagnostic criteria developed for intellectually normal individuals can lead to under- and mis-diagnosis (see Costello & Bouras, 2006, for review). The deficiency of adequate assessment measures has also contributed to the under- and mis-diagnosis of psychopathology in young people with ID (Rush, Bowman, Eidman, Toole, & Mortenson, 2004). However, over the past decade there has been an emergence of structured assessment tools specifically developed to screen for psychopathology, thus improving the ability to conduct adequate assessments.

Why Structured Psychometric Assessment Is Important

The unstructured traditional diagnostic assessment has been the standard practice for making initial psychiatric diagnoses. To increase diagnostic validity and reliability, clinicians have expanded the Mental Status Examination (MSE) and the history of present and past illnesses, and are using more structured formats (Miller, Dasher, Collins, Griffiths, & Brown, 2001). As asserted by Frances, First, and Pincus (1995),

> ‘most clinicians are now imbued not only with the content of the DSM-IV sets but also with a different method of interviewing patients and eliciting psychopathology. Compared to pre-DSM-III days, clinical evaluations are now much more likely to be more semi-structured and less open-ended’ (p. 66).

These changes have largely reflected concerns raised in the 1980s that unstructured clinical assessments may lead to inconsistency, biases and inaccuracies in diagnosis. Much of the discussion focused upon the dichotomy of *clinical* versus *actuarial* assessment (Dawes, Faust, & Meehl, 1989). In the clinical method, the assessor, in this case the diagnostician, ‘combines or processes information in his or her head’ (Dawes et al., 1989, p. 1668). The questions that the clinician asks will often be subjective, inconsistent, and perhaps even only tangentially related to the problem under consideration. On the other hand, ‘in the actuarial or statistical method, the human judge is eliminated and conclusions rest solely on relations between data and the condition or event of interest’ (Dawes et al., 1989, p. 1668). An actuarial assessment tool asks the same set of questions of each individual, asks them in the same way, and interprets the answers consistently.

The idea that actuarial judgement is superior to clinical judgement is not new and was championed by Meehl and his colleagues almost 50 years ago (Meehl, 1954; 1957; 1959). Since that time, others have joined in and research has consistently shown that actuarial methods are more accurate or, at minimum, equally as accurate as clinical predictions (e.g., Ægisdóttir et al., 2006; Dawes et al., 1989; Garb, 1994; Grove, Zald, Lebow, Snitz, & Nelson,

2000; Russell, 1995; Wiggins, 1981). The most comprehensive meta-analytic investigation conducted to date (Grove et al., 2000) compared the accuracy of actuarial versus clinical predictions in 136 studies of human health and behaviour. Actuarial procedures were, on average, 10% more accurate than clinical predictions and substantially more accurate in 33 to 47% of the studies examined.

Due to past concerns about the suitability and accuracy of unstructured clinical assessments, considerable effort has gone into improving psychiatric assessment procedures. The development of structured and semi-structured interviews for individuals with ID has followed the development of such interviewing schedules for intellectually normal individuals (Harris, 2006). A number of problem checklists and rating scales have also been developed to improve the reliability and validity of psychiatric evaluation for young people with ID.

Structured Assessment Tools For Children And Adolescents With Intellectual Disability

Several standardised assessment tools have been developed to assist in the identification of mental health problems in children and adolescents with ID. Some of these measures focus on making a specific diagnosis, whereas others are used to assess the range and severity of behavioural and emotional problems. The most widely used and psychometrically sound tools for this population, including interview schedules, behaviour checklists and rating scales, are described below.

Interview Schedules

A small number of structured and semi-structured psychiatric interview schedules have been developed specifically for children and adolescents with ID. The schedule of Handicaps and Behavior and Skills (HBS-Revised, Wing, 1982) is a semi-structured interview schedule based on parents' ratings of the abilities and behaviours of their child. The HBS can be used

to assess children and adolescents with mild through to profound ID. Although the stated purpose of the HBS is to provide all information that is necessary to arrive at a diagnosis and develop a prognosis, the schedule places a very heavy emphasis on questions related to autism behaviours rather than a wide range of psychiatric disorders (Aman, 1991a). Additionally, while there is some psychometric data available for the HBS, this schedule appears to have received little attention by researchers and clinicians in the field (Handen, 2007).

The Structured Clinical Interview (SCI; Spragg, 1988) is another interview schedule designed specifically for individuals with ID. It comprises approximately 130 questions and is intended to complement other types of clinical data by providing information in the cognitive and affective domains. However, there is limited available data on the SCI's psychometric properties and there is little evidence of its use for either clinical or research purposes (Aman, 1991a; Handen, 2007).

A small number of interview schedules have also been designed to assess specific disorders in young people with ID. For example, the Autism Diagnosis Interview – Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) is a structured interview used with the child's primary caregiver and is designed to accompany the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999). The ADI-R consists of ninety-three items applicable to any person with a mental age of 2 years and above. However, administration time for the ADI-R is long (up to three hours), and clinicians need extensive training in order for it to be administered reliably.

Behaviour Checklists And Rating Scales

Behaviour checklists and rating scales have been used extensively to augment the diagnosis of psychopathology in children and adolescents with ID. Most rating scales are informant-based measures, which are particularly relevant to the assessment of young people with moderate to

profound ID, where self-reporting is not possible. Some of the advantages of rating scales are: they are easy to administer; they capture perceptions of low-frequency behaviours; they provide structure for informants; and, they typically have better psychometric properties than other subjective measures such as interviews (Rush et al., 2004).

These tools allow the professional to obtain information from multiple informants (e.g., teachers, parents), who might otherwise not be available during the assessment (Handen, 2007). If administered routinely they also provide a history of behaviour, which is valuable for monitoring progress and treatment response (Einfeld & Tonge, 1995). In general, there are three categories of behaviour checklists and rating scales available for the assessment of psychopathology in individuals with ID. These include, (1) instruments designed to assess a broad range of psychopathology specifically for individuals with ID; (2) instruments designed originally to assess psychopathology in typically developing individuals which have been extended to individuals with ID; and, (3) instruments designed to assess specific disorders in individuals with ID.

Instruments Assessing A Broad Spectrum Of Psychopathology In Young People With Intellectual Disabilities

Aberrant Behavior Checklist

The Aberrant Behavior Checklist (ABC; Aman & Singh, 1986) is an informant-based problem behaviour rating scale that was originally developed for institutionalised intellectually disabled individuals (aged 5 years and above) with moderate, severe, and profound ID. The ABC has since been revised for community use and there are now two versions available: the original ABC, now renamed ABC–Residential (ABC-R), and the newer ABC–Community version (ABC-C; Aman & Singh, 1994). Both versions consist of fifty-eight items, each scored on a 4-point rating scale (0 = not a problem to 3 = problem is

severe in degree). The instruments consist of five subscales: (1) Irritability, Agitation, Crying (15 items); (2) Lethargy, Social Withdrawal (16 items); (3) Stereotypic Behaviour (7 items); (4) Hyperactivity, Non-Compliance (16 items); and, (5) Inappropriate Speech (4 items).

A number of psychometric studies have shown that the ABC-R and ABC-C are reliable and valid behaviour rating scales for adolescents and adults (see Brown, Aman, & Havercamp, 2002, for review). Research has also shown that these instruments may be suitable for children, though there are some potential limitations with the use of the both ABC-R and ABC-C for this population (see Rojahn & Heisel, 1991; Brown et al., 2002).

Developmental Behaviour Checklist

The Developmental Behavior Checklist (Einfeld & Tonge, 1995) was specifically developed to screen for behavioural and emotional disturbances in children and adolescents (aged 4-18 years) with all levels of ID. Two versions are available: a Primary Carer Version (DBC-P) consisting of ninety-six items; and a Teacher Version (DBC-T) consisting of ninety-four items. Each item is rated from zero to two (i.e., 0 = not true as far as you know; 2 = very true or often true). The DBC consists of five subscales: Disruptive/Antisocial, Self-Absorbed, Communication Disturbance, Anxiety, and Social Relating (Einfeld & Tonge, 2002). The instrument has strong psychometric properties, with high test-retest internal consistency, adequate inter-rater reliability and good predictive validity of clinically significant behaviour and emotional disturbance (Einfeld & Tonge, 1995, 2002).

The DBC has also been used widely in research on children and adolescents with ID, and the DBC-P has been translated into various languages. The DBC-M (Evans, Taffe, Einfeld, Tonge, & Grey, 2003) is an additional tool that has been developed for monitoring specific behaviours. This allows for up to five behaviours to be scored daily. Using the DBC-M requires far less time than completing the full DBC versions. Thus, while the DBC-P or

DBC-T is recommended for assessment purposes, the DBC-M can be used in clinical interventions with young people to map progress.

Nisonger Child Behavior Rating Form

The Nisonger Child Behavior Rating Form (NCBRF; Aman, Tasse, Rojahn, & Hammer, 1996) was designed for use with children (aged 3-16 years). The NCBRF has a parent version and a teacher version, with identical content and similar factor structures. Both versions contain ten social competence items and sixty-six problem behaviour items, which are rated on four-point scales. The social competence items are distributed on two subscales: Compliant/Calm; and Adaptive/Social. The problem behaviour items are distributed on six subscales: Conduct Problem; Insecure/Anxious; Hyperactive; Self-injury/Stereotypic, Self-isolated/Ritualistic, and Overly Sensitive (parent)/Irritable (teacher). The NCBRF has good psychometric properties (Aman et al., 1996; Lecavalier & Aman, 2005) and has been translated into several languages.

Reiss Scales For Children's Dual Diagnosis

The Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1994) is a sixty item measure for children (aged 4 years and over). The instrument is completed by informants (e.g., teachers and parents) and items are rated on a three-point scale from zero to two (i.e., 0 = no problem; 2 = major problem). The instrument consists of ten subscales (Anger/Self-Control, Anxiety Disorder, Attention Deficit, Autism, Conduct Disorder, Depression, Poor Self-Esteem, Psychosis, Somatoform Behaviour, and Withdrawn/Isolated), and, ten specific behaviour problems (e.g., crying spells, hallucinations). Although research suggests that the total score produced by the instrument is a highly reliable and an accurate indicator of the

presence or absence of psychopathology in children with ID, the results appear to be less favourable for the individual subscale scores (Reiss & Valenti-Hein, 1994).

Instruments Designed For Assessing Psychopathology In Typically Developing Individuals

Structured behaviour checklists and rating scales developed for typically developing individuals have also been used to evaluate psychopathology among children and adolescents with ID. Although these instruments generally have good test-retest reliability, they vary in terms of their inter-rater reliability, internal consistency and validity (Harris, 2006). Examples include the Child Behaviour Checklist, the Beck Depression Inventory, the Rutter Behavioural Scales, the Zung Self-Rating Anxiety Scale, and the Zung Self-Rating Depression Scale. While these tools have been used with young people with mild to moderate ID, they are less likely to be used in the assessment of young people with severe or profound ID. As a general rule, the use of appropriately designed tools for young people with ID is recommended.

Instruments Designed For Assessing Specific Disorders In Individuals With Intellectual Disabilities

Only a few rating scales have been developed to assess specific disorders in young people with ID. For example, the Self-Report Depression Questionnaire (SRDQ; Reynolds & Baker, 1988) has been designed to assess depressive symptomatology in adolescents and adults with mild ID. The Anxiety, Depression, and Mood Scale (ADAMS; Esbensen, Rojahn, Aman, & Ruedrich, 2003) is an informant-based rating scale used to measure symptoms related to anxiety, depression, and mania in individuals with ID (aged 10 years and over). The Social Communication Questionnaire (SCQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999) is a

parent questionnaire that can be used to help evaluate communication skills and social functioning in children (aged 4 years and over) who may have autism or autism spectrum disorders.

Instruments Designed For Assessing Adaptive Functioning In Individuals With Intellectual Disabilities

Information that is most useful when assessing psychopathology in young people with ID includes not only information about the presence of psychiatric problems, but also information regarding the young person's adaptive functioning (Rojahn & Tasse, 1996). The Vineland Adaptive Behaviour Scales (VABS-II; Sparrow, Cicchettii, & Balla, 2005) is a widely used measure of adaptive behaviour for children and adolescents with ID. The VABS assesses four domain areas: communication, daily living skills, socialisation, and motor skills. There is also a maladaptive behaviour domain that can be used to assess problem behaviours. Another popular measure of adaptive functioning is the American Association on Mental Retardation (AAMR) Adaptive Behavior Scales (ABS), which consists of two versions: School and Community (ABS-S2; Lambert, Nihira, & Leland, 1993) and Residential and Community (ABS-RC2; Nihira, Leland, & Lambert, 1993). Norms are provided for young people with and without ID (aged 3-21 years).

Conclusions

When working with young people with ID, clinicians are recommended to use a comprehensive multi-method approach to assess psychopathology, with a combination of structured and unstructured techniques and information from several sources (e.g., the young person with ID, professionals, parents, carers and teachers). The unstructured aspect allows the development of adequate rapport, and the expression and evaluation of feeling. The

structured component utilises systematic questioning to ascertain the presence and severity of a range of important psychiatric symptoms. Specifically, when assessing psychopathology in young people with ID, the assessment should include: (1) clinical assessments, which include history, individual and family clinical interviews, and mental status examination of the child or adolescent; as well as (2) structured interviews, questionnaires, behaviour checklists and rating scales (Harris, 2006). If behaviour checklists and rating scales are administered routinely, they also provide a valuable history that can be used in monitoring progress and treatment response over time (Einfeld & Tonge, 1995).