Assessment of Mental Health Problems in People with Intellectual Disabilities

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Abstract: Although it is widely accepted that individuals with intellectual disabilities face an increased vulnerability to developing mental health problems, there is currently a lack of agreement about the most appropriate form of assessment. When applied to people with intellectual disabilities, there is no consensus about which problems should be included in the term “mental health problem,” and identifying mental illness is far from straightforward. The adoption of standardized classification systems assumes that individuals with intellectual disabilities have adequate linguistic skills and they present mental health problems in the same way as members of the general population. Yet, individuals with intellectual disabilities are less likely to fulfill verbal expectations that are the basis of current classification systems and many exhibit problem behaviors incompatible with existing criteria. Nevertheless, accurate diagnosis provides a clear direction for interventions. Although there is currently a lack of consensus about which instruments are most effective, the routine use of valid and reliable assessment and monitoring tools may significantly improve the quality of research and care. The complexity of factors influencing the mental health of individuals with intellectual disabilities has implications for how these needs can be effectively met. Clearly, diagnostic classification provides only partial guidance to morbidity and the quality of life experienced and mental health services increasingly adopt a problem-based, “biopsychosocial” approach to assessment and treatment delivered by multidisciplinary teams. The most basic and vital role of carers within this context is the awareness that a person with intellectual disabilities may suffer from a mental illness. Carers play a central role in recognising possible mental illness, making referrals for further psychiatric assessment and providing diagnostic information and treatment feedback. In the absence of information about the manifestation of mental health problems in individuals with intellectual disabilities, it is likely that the signs of mental illness will be overlooked. Training initiatives, aimed at increasing the ability of care staff to recognise the signs of mental illness and to make informed referral decisions, are vital in ensuring adequate access to mental health services by individuals with intellectual disabilities.

Introduction

Assessing the presence of mental health problems in individuals with intellectual disabilities is a complex process, which raises distinct theoretical questions and methodological dilemmas. These relate to the definition of mental health problems, the nature of psychiatric assessment and the classification of problem behaviors. This article describes the prevalence of mental health problems, highlights key assumptions underlying the assessment process and considers the implications for community services in meeting the mental health needs of individuals with intellectual disabilities.

Prevalence of Mental Health Problems in Persons with Intellectual Disability

Although substantially increased in recent years, research evidence about the prevalence of mental health problems in individuals with intellectual disabilities and the risk factors for developing specific psychiatric disorders is limited and often conflicting. Most estimates of the prevalence of psychiatric illness in people with intellectual disabilities range from 10–39% (1–5). Predictably, a relatively high prevalence is reported by studies using screening instruments to detect the presence of mental health problems. For example, in a small sample (n=127) based in a single GP (general practitioner) practice of an urban city, Roy et al. (2) reported an overall prevalence of 33% using the PAS-ADD checklist (6).
Using the same screening instrument, a larger study of 1,155 adults with intellectual disabilities in a county district of North East England reported an overall prevalence of 20.1% (7). In contrast, Deb et al. (1) measured the prevalence of functional psychiatric illness in an administratively defined random sample of 101 adults with intellectual disabilities living in the community (n=246). Enhancing comparison with studies of the general population, a blind two-stage diagnostic procedure including standardized, valid and reliable assessment instruments and ICD-10 criteria (8), was used. Information was collected through clinical interview with informants and 89% of the individuals with intellectual disabilities. Deb et al. (1) report an overall prevalence of 14.4% for this. This compares to 16% found for the general population using the same criteria (9). The authors concluded that the prevalence of functional psychiatric illness in people with intellectual disabilities was similar to that found in the general population, although rates of schizophrenic illness and phobic disorder were significantly higher in the study cohort than in general population.

Moss (10) measured the one-month period prevalence of psychiatric disorders in a cross-sectional descriptive study (n=146) comprising a randomized sample drawn from a health and social service register in North West England (1996–1998) (n=710). Data were collected through the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) (11), completed with respondents and informants in conjunction with ICD-10 (8) and DSM-IV clinical diagnoses (12). As in the Deb et al. study (1), behavior disorders, personality disorders and Pervasive Developmental Disorders were excluded. The results were compared with an OPCS study (13) of the general population also using ICD-10 (8) (n=10108). This study found an overall 12.3% prevalence compared to 14.7% reported by OPCS (13). Moss (10) concluded that using ICD-10 (8), the prevalence of psychiatric disorders in adults with intellectual disabilities was similar to that found in the general population. However, he cautions that ICD-10 (8) may under-diagnose certain disorders such as psychotic disorders. Indeed, using DSM-IV clinical diagnosis (12), a prevalence of 26.0% was found in the same sample.

Although most categories of mental illness have been reported in this population (14-16), the pattern of prevalence in people with intellectual disabilities may well differ from that found in the general population (17). For example, in the studies described above, Deb (1) and Moss (10) reported a point prevalence of 3% (range 1.3% to 3.7%) and 2.7% respectively for schizophrenia. This compares to 0.4% in the general population (9). Consensus about the reasons for increased prevalence of schizophrenia has yet to be reached (18). Explanations include the presence of underlying brain damage, the difficulty in detecting complex subjective symptoms (19) and a persistent clinical bias to “think schizophrenia first” in the presence of psychotic symptoms (20, 21). In contrast, diagnoses of disorders such as depression, which occur the most frequently in the general population, appear less common in people with intellectual disabilities (14). The point prevalence of depressive disorder ranges from 1.3% to 3.7% in individuals with intellectual disabilities (1, 5, 22) and is 15% for the general population (9).

There is limited evidence currently regarding the factors predicting the presence of mental health problems in individuals with intellectual disabilities. As for the general population (e.g., 23), gender and age have been identified as risk factors for developing certain psychiatric disorders. For example, Cooper (3) reports a higher prevalence of psychiatric disorders in older individuals with intellectual disabilities, particularly for depression and anxiety. There is also growing evidence to suggest that certain genetic syndromes may predispose individuals to developing particular mental disorders. Therefore, the aetiology of intellectual disabilities may affect the rate of psychiatric disorder. For example, Collacott et al. (24) showed that individuals with Down syndrome had higher rates for depression and dementia. In contrast, after controlling for the level of intellectual disabilities, Haveman et al. (25) demonstrated much lower prevalence rates for psychiatric disorder in people with Down syndrome. Opinion varies about how the severity of intellectual disabilities affects an individual’s vulnerability to developing different psychiatric disorders (18). The respective rates of psychopathology in people with mild or moderate intellectual disabilities and people with severe and profound intellectual disabilities vary across studies. Gostason (26) and Lund (27)
showed higher rates of psychiatric illness in people with severe intellectual disabilities, whereas Iverson and Fox (28), Jacobson (29) and Borthwick-Duffy and Eyman (30) all showed a higher prevalence in adults with mild intellectual disabilities. Corbett (31) found no evidence either way.

To summarize, research suggests that the prevalence of mental health problems in individuals with intellectual disabilities is at least as high, although probably higher, than in the general population. As discussed in the following sections, individuals with intellectual disabilities form a heterogeneous population and the application of measurement techniques developed for the general population is problematic. As such, studies comparing the presence of mental health problems in individuals with and without intellectual disabilities using common assessment criteria are yet to be conducted and may be inappropriate.

Assessment
Hampered by a lack of validated diagnostic instruments (32), studies have adopted a broad range of approaches to measuring psychopathology with many failing to report operational definitions adequately (4). As yet, the equivalence of measurement techniques is uncertain (33), although prevalence estimates reliant upon routine clinical assessment for diagnosis generate higher estimates than those studies using standardized methods or case notes (1, 34). Prevalence estimates are also heavily influenced by sample selection (4, 34) and until recently many studies relied upon institutional or administrative samples. This may lead to sampling bias and to the inflation of prevalence because each of these groups is more likely to have mental health problems compared to the population at risk (30). Furthermore, studies examining the complete spectrum of psychiatric disorders are rare and the focus of diagnostic enquiry often varies from one study to another. Apparent differences in morbidity between the general population and individuals with intellectual disabilities may therefore partly reflect uneven diagnostic enquiry.

Therefore, in interpreting evidence about the presence of mental health problems in individuals with intellectual disabilities it is necessary to consider the methodology employed and the assumptions underlying the assessment process. Key issues relate to the definition of mental health problems and the nature of psychiatric assessment.

The definition of mental health problems
Estimates of prevalence depend greatly on the definition of a mental health problem and the definition of a case. When applied to people with intellectual disabilities, there is no consensus about which problems should be included in the term “mental health problem” (35). Diverse conceptualizations of both intellectual disabilities and mental health are evident in the research literature (35). A variety of terms are used including mental illness, mental disorders, psychiatric disorder, emotional disorder and behavioral disorder. These labels are used interchangeably and the range of terms reflects the theoretical backgrounds of the assessor rather than a specific category (36). One solution has been to use the overarching term “mental health problem” to indicate the presence of psychopathology (symptoms, signs or abnormal traits). This approach encompasses both single significant behaviors and clusters of symptoms occurring as part of a psychiatric illness such as schizophrenia and acknowledges that, as described subsequently, many behavioral problems are a complex mix of difficult to classify symptoms.

Therefore, the definition and identification of “mental illness” is far from straightforward (35). Mental health problems are socially defined and, as a result, they are highly interactive with the context in which the person lives and the social expectations placed upon him/her. In defining mental health, a whole range of factors needs to be taken into consideration, encompassing not just the individual, but also the wider ecology within which the person lives (37). Both personal and external social factors determine whether a given set of symptoms results in presentation to a doctor and a person becomes a “case” (38). Indeed, most mental health problems do not come to the attention of mental health services. Falloon and Fadden (39) estimated that support networks such as family and friends are able to manage 90–95% of all cases of mental disorder in the community. Inevitably, psychiatric assistance is more likely to be sought when conditions cause a high degree of debilitation. In the general population, iden-
Identification of a mental health problem is often prompted by the failure to maintain social roles such as employment and parenting. In contrast, individuals with intellectual disabilities generally have fewer role expectations and the severity of symptoms does not necessarily relate to the degree of impairment in daily life. As a result, the impact of mental health problems on the individual's life and upon those of others, such as carers, may be less visible. This reduces the likelihood that mental health problems will be recognised by carers. As a result, conditions such as anxiety and depression may be clearly manifested and may cause significant distress to an individual, yet remain unrecognised.

**The nature of psychiatric assessment**

Standardized classification systems of psychiatric disorders such as DSM-IV (12) and ICD-10 (8) are often adopted in studies of mental health problems in people with intellectual disabilities. Such systems provide a common discourse among researchers and clinicians and are an important clinical tool in medication and other forms of treatment. They can also be used as a basis for designing assessment and screening instruments. Adopting standardized criteria to measure prevalence increases comparison with findings for the general population. However, its equivalence in individuals with and without intellectual disabilities is not known. Also, interpreting the study findings within the context of other prevalence studies of intellectually disabled populations becomes more problematic. This is because it often entails making assumptions about the methods used to identify disorder in such studies.

Psychiatric assessment is concerned with identifying and matching patterns of symptoms with those of previously defined disorders, such as depression and schizophrenia, which in turn have a predictive value with respect to prognosis and treatment (35). Diagnosis is determined by the interaction of a variety of factors: what the person says they are experiencing; what others say about them; how they are seen to behave; and the history of their complaint. Psychiatric disorders have a period of onset and represent deterioration in behavior from the pre-morbid state (40). Therefore, establishing a baseline and recording clinical history are central to the diagnostic process. The problem is regarded as being “within the individual” and treatment focuses on the diagnosed disorder rather than on specific symptoms (10). Two factors influence the applicability of standardized assessment criteria to individuals with intellectual disabilities — linguistic skills and the presentation of mental health problems.

**Linguistic skills**

Diagnostic systems such as ICD-10 (8) rely upon verbal accounts of symptoms. A reduced ability to conceptualize and to express emotions places people with intellectual disabilities at a disadvantage in respect of this form of assessment. The applicability of standardized classification systems to members of this population is therefore influenced by the linguistic skills of the individual being assessed. Although people with intellectual disabilities can often provide reliable and valid information about symptoms, parallel interviewing of both the patient and a key informant is essential for effective case detection (41). Some features of mental illness are very complex and require a high level of verbal fluency to describe them. In people of average ability, a high degree of symptom differentiation is possible, but in individuals with limited or no verbal skills fine discrimination between symptoms is often impossible. Even in verbally competent individuals with intellectual disabilities, Moss et al. (41) found that the only first-rank symptom that could be detected with any frequency in psychiatric interviews was auditory hallucinations.

Hence, within this context, information about how the individuals themselves regard their current experiences is limited and is often totally absent. As a result non-verbal behavior, historical information and observations from informants such as family members or staff carers play a more prominent role. Reliance upon third party reports for assessment and diagnosis increases with the severity of an individual’s intellectual disabilities. This has serious implications for the quality of information yielded and, as a consequence, the validity of diagnoses, especially in non-verbal people, is uncertain (17). Indeed, the application of standardized criteria across the whole spectrum of intellectual disabilities and in particular the difficulties in diagnosing psychiatric disorders in individuals with severe levels of disabilities may partly account for reported discrepancies in the re-
spective morbidity in individuals with and without intellectual disabilities.

A variety of factors may influence the quality of informant observations including the nature of the relationship between the informant and the person being assessed and the prior existence of a label such as “challenging behavior.” Little is known about the comparability of ratings made by different types of informant (42), and there is uncertainty about how conflicting informant information should be reconciled. The validity of the informant interview is also dependent on the condition in question. Inevitably, informants are more aware of symptoms with clear behavioral manifestations than of subjectively experienced phenomena such as thought disorder or anxiety. Informants are more likely to report worry, loss of interest, social withdrawal and irritability, whereas individuals with intellectual disabilities more frequently report autonomic symptoms and psychotic phenomena whose impact on behavior is often hard for informants to evaluate (41). Such differences in perspective may have a crucial impact on diagnostic conclusions.

The presentation of mental health problems

The application of standardized classification systems to individuals with intellectual disabilities assumes that they express mental health problems in the same way as individuals in the general population. Yet, a variety of factors, common to both populations, determine manifestation. These include: the person’s usual level of cognitive, communicative, physical and social functioning; the individual’s usual behavioral repertoire together with past and present interpersonal, cultural and environmental influences (43). Some studies suggest that psychiatric symptoms are essentially the same in this population as they are in the general population. For example, Sovner and Hurley (14) found that while impaired social functioning influenced clinical presentation, it did not affect symptomatology. However, important differences are also evident. In diagnosing mental illness, it is necessary to differentiate between symptoms that are part of an illness and signs and symptoms that are an expression of underlying brain damage (1). For example, it is important to distinguish between intellectual disabilities and the negative symptoms of schizophrenia such as slowness of thought and poverty of speech (44). In some cases, the presence of intellectual disabilities may overshadow problem behaviors usually considered indicative of psychopathology. As a result, the signs of mental health problems are incorrectly ascribed to an intellectual disability and “diagnostic overshadowing” occurs (45). As yet, it is unclear how such diagnostic overshadowing varies by clinical context, professional discipline or service user characteristics (46).

Generally, adults with mild intellectual disabilities and reasonable verbal skills exhibit symptoms that are similar, although possibly less complex, than those witnessed in the general population. “Psychosocial masking” (47), such as impoverished social skills and life experiences typical of this population, may lead to symptoms which may not seem as “rich” as in the general population. For example, aggressive acting out, withdrawal and/or somatic complaints may be observed instead of more typical depressive symptoms such as feelings of hopelessness (48). “Cognitive disintegration” may also imply that many people with intellectual disabilities have lower thresholds for anxiety to become overwhelming and to impair cognitive function (47). Also, disturbed or regressed behaviors, physical signs and complaints such as headaches and abdominal pains are more common in individuals with moderate and severe intellectual disabilities (49). Further differences in presentation include the common occurrence of some symptoms that are “atypical” and unusual in the general population. Examples include the onset or increases in specific maladaptive behaviors such as screaming, aggression and self-injury (50–53).

Mental Health Problems Versus Challenging Behavior

While it may be more valid to apply standardized criteria to individuals with mild intellectual disabilities (54), people with severe intellectual disabilities display many behaviors which are incompatible with existing criteria. As such, they pose a special challenge to current mental health classification systems. Moss (10) argues that this does not imply that such behaviors are not the signs of mental health problems and that current classification systems are of
limited value to this particular population. The inclusion or exclusion of behavioral problems as a psychiatric disorder has a huge impact on the estimated prevalence of mental health problems. Where behavioral disorders are included, prevalence is significantly higher and includes a large proportion of personality disorders (32). Deb et al. (1) suggest that if behavioral disorders, personality disorders, autism and ADHD are excluded, then the overall rate of psychiatric illness does not differ significantly from the general population. Yet, 16.7% of people with intellectual disabilities in the UK have challenging behavior (21), and it is the most common reason for referral to psychiatric services and accounts for a third of the admissions to psychiatric units from the community (55). Examples include aggressive, destructive, attention seeking, sexually inappropriate, self-injurious, noisy, hyperactive and socially inappropriate behaviors.

Emerson (56) defined challenging behavior as “culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.” Hence, challenging behavior is not a diagnostic category. Rather it is used to quantify the needs of individuals with intellectual disabilities in community services. Whether behavior is judged to be “challenging” or not is determined by a combination of what the person does, the setting in which they do it and how their behavior is interpreted (1). As a result, challenging behaviors are likely to vary in their form and in the psychological and/or biological processes that underlie them (21). Such behavioral problems are often long-term behavior patterns without a predictable time course, and there is confusion regarding the conditions under which a challenging behavior meets the formal diagnostic criteria for a psychiatric diagnosis. A number of possible links between challenging behaviors and psychiatric disorders have been suggested (57). Hypotheses include: a) Challenging behavior and mental illness have the same biological basis and, in some cases, the biological basis that normally produces a challenging behavior may be expressed as a psychiatric disorder; b) challenging behavior may be an expression of mental illness; and c) challenging behavior and mental illness may be linked on an operant basis, whereby challenging behavior may occur in order to terminate aversive events during periods of mental illness.

Few studies address the relationship between challenging behaviors and mental illness, but it is likely that some challenging behavior is caused or exacerbated by a co-existing psychiatric disorder (57). Some studies demonstrate a positive relationship between the severity of challenging behavior and the prevalence of psychiatric symptoms. For example, Moss and colleagues (34) found that depression was four times as prevalent in people with more demanding challenging behavior compared to people without challenging behavior. However, other studies such as Tsiouris et al. (58) found no evidence that challenging behaviors were depressive equivalents in individuals with intellectual disabilities. Ultimately, behavioral disturbances in people with intellectual disabilities are a complex mix of symptoms of multiple origins. Determining whether behaviors are the result of organic conditions, psychiatric disorders, environmental influences, or a combination of these, is often very difficult. For example, in some cases, behavioral problems may affect a person’s interpersonal skills without underlying psychopathology, but in others, the same behaviors and stunted social development may be symptoms of underlying mental illness (59). Evaluating the relative contributions of these factors to the observed signs and symptoms is a core element of the assessment process.

To summarize, the terms challenging behavior and mental health problems represent two distinct approaches to understanding problem behaviors in individuals with mental health problems. Challenging behavior is not a disorder, but recognition of the extent to which behavior has some adverse effect on the individual or others concerned with supporting that individual. As such its definition and identification refers not to the form of the behavior, but to its impact. While in some cases, each of these terms may be used to describe the same behavior, the status of challenging behaviors within psychiatry is uncertain and its relationship to mental health problems is unclear. For example, research is yet to establish under what circumstances a challenging behavior represents a separate entity, when it is an idiosyncratic expression of a mental health problem and
when it is a contributory factor. Ultimately, the distin-
tinction between challenging behavior and mental
health problems may be artificial and too simplistic.
In virtually every psychiatric disorder there may be
behavioral manifestations that are learned, condi-
tioned by environmental factors or under voluntary
control. Nevertheless, identifying those individuals
with challenging behavior resulting from a psychiat-
ric disorder is crucial in improving that individual’s
quality of life and in ensuring that adequate care
plans and appropriate support and training for
carers is in place. For example, having a formal diag-
nosis of a psychiatric disorder rather than a non-spe-
cific description of challenging behavior is very
important because a diagnosis may lead to specific
treatment.

Implications for Community Services in
Meeting Mental Health Needs

Large numbers of individuals with intellectual dis-
abilities living in the community exhibit psychiatric
or behavioral problems arising from mental health
problems. Together the joint contributions of mental
illness and intellectual disabilities indicate a group of
individuals whose needs are considerable, and
whose quality of life will be seriously impaired if the
illness is not effectively identified and treated (22,
60). Following de-institutionalization, there was a
need to identify, treat and manage the mental health
problems of people with intellectual disabilities in
the community (54). Behavioral and psychiatric dis-
orders are crucial determinants of the level and costs
of specialist support an individual requires to live in-
dependently in the community (32). Yet the com-
plexity of factors influencing the mental health of
individuals with intellectual disabilities has implica-
tions for how these needs can be effectively met.

In terms of assessment, the accurate diagnosis of
mental illness provides a clear direction for biomed-
ic interventions (34). Clearly, diagnostic classifica-
tion provides only partial guidance to morbidity and
the quality of life experienced by individuals with
mental illness (39). Increased clinical and research
attention in recent years has resulted in the develop-
ment of a range of assessment instruments aimed at
improving the identification and diagnosis of psy-
chiatric and behavioral disorders in this population.
The routine use of valid and reliable assessment and
monitoring tools may make a significant contribu-
tion to improving the quality of care. Yet currently
there is no consensus about which assessment in-
struments should be used. Research has begun to
focus on the adaptation of existing classification sys-
tems for use with people with intellectual disabilities.
For example, Moss and colleagues (11) developed
the “PAS-ADD” (Psychiatric Assessment Schedule
for Adults with Developmental Disabilities), a psy-
chiatric interview based on ICD-10 criteria (8)
which combines information from self-reports of in-
dividuals with intellectual disabilities and from key
informants.

The application of standard psychiatric diagno-
sic criteria to adults with severe and profound levels
of intellectual disabilities is not supported at this
time by many experienced researchers (61). For peo-
ple with a moderate or greater degree of intellectual
disabilities, specially developed carer or clinician-
completed instruments are probably required. An al-
ternative solution may be to devise a separate diag-
nostic framework specifically for adults with
intellectual disabilities or to modify existing catego-
ries of disorder to take account of the differences due
to intellectual disabilities. The DC-LD (diagnostic
criteria for use with adults with intellectual disabili-
ities) (62) is one example of a new set of diagnostic
categories specifically designed for individuals with
moderate to profound intellectual disabilities. These
criteria are based on the ICD framework and were
developed on the basis of expert clinical consensus.
Assessment and monitoring tools based on these cri-
teria are awaited. See Mohr and Costello (63), Rush
et al. (64) and Hatton (65) for reviews of assessment
and monitoring tools designed for measuring mental
health problems in individuals with intellectual dis-
abilities.

Today, mental health services increasingly adopt
a problem-based, rather than a strictly diagnostic ap-
proach. Emphasis is placed upon multidisciplinary
teams, providing a coordinated and comprehensive
“biopsychosocial” approach to assessment and treat-
ment (66). Assessment must therefore extend be-
ond the clinical interview and incorporate the
wider aspects of a person’s life, such as ability to cope
with life transitions and the adequacy of support net-
works. This broad approach implies that a range of
agencies, including carers and individuals with intellectual disabilities, work together in order to maximize the gathering of developmental, background, functional, behavioral and observational data (43). This has implications for residential service responses, both in terms of staffing ratios and the range of necessary staff skills.

The role of carers
Limited communication skills imply that many people with intellectual disabilities experience difficulties in articulating their mental health problems. In contrast to members of the general population, the decision to seek help is not made by the person with intellectual disabilities him or herself (67). Access to appropriate treatment is therefore dependent upon family and staff carers recognising the signs of mental illness, understanding their significance and taking appropriate action (21). Frequent contact with individuals with intellectual disabilities across a range of settings enables carers to build up a comprehensive knowledge of the behavioral repertoires of the individuals they support. Carers therefore have a unique insight into the behaviors of individuals, and they are ideally placed to detect any changes, which may signify the onset of mental illness. Furthermore, they are often the sole source of information, and they form an essential bridge between individuals with intellectual disabilities, their family, other staff and the mental health team.

The most basic and vital role of carers within this context is the awareness that a person with intellectual disabilities may suffer from a mental illness. They must also know what changes in behavior and emotional state indicate mental illness, and they need to look for patterns of change because a single feature can have several causes. Awareness of the vulnerability factors predisposing individuals with intellectual disabilities to developing mental illness is also necessary. This enables carers to be proactive and to be alert to particular behavior changes before problems become chronic (68). They must also know when and how to access appropriate external opinion and support. Carers play a central role in the diagnostic process, especially for people with more severe intellectual disabilities, where assessment is heavily reliant upon third party reports and observations. They must accurately describe the changes observed and provide information about the person’s life such as where they live and their current relationships. Carers also play an important role in treatment implementation and monitoring. Again, they must have an understanding of which behaviors are pertinent to mental health assessment, so that they can provide feedback to mental health professionals about the effectiveness of any treatments implemented. However, many of the difficulties relating to the assessment of mental health problems in individuals with intellectual disabilities also confound the process of identification and referral.

To summarize, carers play a central role in recognising possible mental illness, making referrals for further psychiatric assessment and providing diagnostic information and treatment feedback. Research suggests that carers lack the necessary skills to perform this role and unless conspicuous, the signs of mental health problems are likely to be overlooked by carers (10, 11). Training initiatives aimed at increasing the ability of carers to recognise the signs of mental illness and to make informed referral decisions are therefore paramount in ensuring adequate access to mental health services by individuals with intellectual disabilities (69).

Conclusions
Methodological diversity, along with complexities in defining mental illness and the nature of psychiatric assessment make conclusions about the prevalence and manifestations of mental health problems in this population are problematic and probably premature (32). Until we are able to examine more representative samples, are able to assume that diagnostic disorders are valid and that all individuals with mental health problems have been identified, then prevalence estimates reflect the characteristics of the service-delivery systems as much as those of individuals with intellectual disabilities and mental health problems (30).

Nevertheless, the presence of mental health problems in a high proportion of individuals with intellectual disabilities indicates the importance of providing effective support and treatment strategies for addressing mental health needs. This has implications for the characteristics of residential, day and mental health services if mental health problems are
to be adequately met. Application of standard psychiatric diagnostic criteria across the spectrum of intellectual disability is problematic, and a comprehensive, problem-based approach conducted by multidisciplinary teams is required. Ensuring that carers have adequate skills in relation to recognising and referring individuals with mental health problems is essential in determining access to mental health services and in maximizing the quality of care for individuals with intellectual disabilities.

References