Chapter 3
Depressive disorders in people with intellectual disabilities

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Overview
This chapter presents an overview of the presentation and manifestation of depressive disorders in people with ID. It explores the challenges facing practitioners in diagnosing and assessing depressive disorder across the range of cognitive abilities, and reviews risk factors for people with ID.

Learning objectives
- To understand the phenomenology of depressive disorders.
- To understand the presentation of depressive disorders in people with ID.
- To understand the various classification categories and the determinants and risk factors in people with ID.
- To review the assessment instruments for depressive disorders in people with ID.

Introduction
The occurrence of depressive disorders in persons with ID was described as early as the 19th century, and Wilber (1877) described melancholia and mania separate from mental retardation. Hurd (1888), meanwhile, described a range of depressive phenomenon including suicidal behaviours...
in persons with ID, and ID was acknowledged as a possible risk factor for the development of depression by Clouston (1883).

However, there were continuing conceptual doubts concerning the occurrence of syndromal affective disorders, especially in persons with severe ID (Earl, 1961; Sovner & Hurley, 1983). The 1980s saw a resurgence of interest in affective disorders in people with ID, when Reiss et al (1982) identified untreated emotional disorders as a significant unmet need in this population and Sovner and Hurley (1983) reviewed the existing studies and concluded that persons with ID experience the full range of affective disorders.

It has become increasingly acknowledged that depressive disorders significantly impair functioning and compromise community living (Jacobson & Schwartz, 1983). They also have a significant impact on families and carers (Bryne & Cunningham, 1985) and in increased costs of care.

**Nature of depression**

The basic affects, or emotions, such as joy, sadness, anger and fear, serve a communicative function and are expressed through facial expressions, vocal inflections, gestures and posture. Importantly, they tend to be short-lived in contrast to moods, which has been defined by the American Psychiatric Association as ‘a pervasive and sustained emotion that, in the extreme, markedly colours one’s perception of the world’ (APA, 2000). They are of a more enduring nature, conveying sustained emotions experienced long enough to be felt inwardly.

The normal everyday emotions of sadness should be differentiated from major depressive disorder. Sadness is a universal human response to defeat, disappointment or other adversities, and it may be adaptive in attempting to elicit support from significant others. Transient depressive periods also occur as reactions to specific stressors and loss. The expression of mood and affect may also be mediated by a person’s affective temperament, which are inherent patterns or traits that develop in early life and determine a person’s responses to events. These tend to vary in a relatively minor fashion in response and do not interfere with functioning. Temperaments tend to cluster into basic types and the depressive temperament, in which the person easily swings in the direction of sadness, occurs in three to six per cent of the general population.
Mood disorders, on the other hand, are characterised by predominant and persistent disturbances in mood, and they cover a variety of conditions of varying severity. These mood disturbances in turn lead to changes in cognitive appraisal of the self, the other and the future. They are also accompanied by changes in behaviours and biological functions, such as sleep, appetite and psychomotor functions. Mood disorders represent abnormal or extreme variations of mood that is out of proportion to any concurrent situation, or they arise without apparent life stress, are sustained for weeks or months, and have a pervasive effect on the person’s judgement and functioning.

The ICD-10 (WHO, 2010) and the DSM-IV (APA, 2000) both categorise mood disorders into bipolar disorders (with manic or hypomanic, depressive, or mixed episodes) and major depressive disorders and their respective attenuated variants known as cyclothymic and dysthymic disorders.

**Clinical features of depressive disorders in persons with ID**

The symptoms of depression are many and varied, and they include:

- early morning waking
- sleeping too much
- losing or gaining weight
- loss of appetite
- low mood with or without diurnal variation
- anxiety
- social withdrawal
- loss of sexual interest
- loss of confidence
- self-blame and inappropriate guilt
- inability to make decisions
- difficulty concentrating
- slowed down thinking
- loss of functional or self-care skills
- thoughts of death
- suicidal thoughts/actions or other self-harming behaviour
depressive delusions
aggression
irritability.

**Low mood:** many people who have experienced severe forms of depression would express feeling overwhelmed by their black moods, while others suggest that depression is like having an intense physical pain. It is much more than just feeling a bit low.

**Loss of interest:** people with ID who are depressed lose their zest for life and for their favourite pastimes. Everything seems an enormous effort, with lack of energy and constant tiredness being quite frequent features. These symptoms are more difficult to identify in people with greater degrees of ID, but there is no reason to suppose that the subjective sense of fatigue and loss of interest are not felt too.

**Lowered energy:** a common symptom in depression is fatigue, which may lead to visits to the GP. There may be a tendency to complain of physical aches and pains, as people with ID may have under-diagnosed physical health problems, and it is therefore important that the GP excludes physical health causes for any lack of energy first. Carers and family may find their lack of enjoyment difficult to understand or be sympathetic about, particularly when there is no obvious cause for depression.

Other features of depression may include anxiety and repetitive behaviours, obsessional thoughts, cognitive features and somatic features. It is not uncommon to find that depression triggers or increases certain kinds of challenging behaviours.

When a depressed person cannot communicate their feelings, it is important to be able to describe and monitor any behaviours that may suggest underlying depression. In two studies of depressed adults with Down’s syndrome, the commonest symptoms were sadness, loss of interest, social withdrawal, reduced energy and slowed activity. However, in this group there are many more symptoms that have been described (Cooper & Collacott, 1994).

A lowered mood varies little from day to day and is often unresponsive to circumstances, yet may show a characteristic diurnal variation as the day goes on. As with manic episodes, the clinical presentation shows marked individual variations, and atypical presentations are particularly common
in adolescents and in adults with ID. In some cases, anxiety, distress and motor agitation may at certain times be more prominent than features such as irritability, excessive consumption of alcohol and histrionic behaviour, while an increase in pre-existing phobic or obsessional symptoms or hypochondriacal preoccupations may also mask the depression, and the mood change. For depressive episodes, a duration of at least two weeks is usually required for diagnosis, but shorter periods may be reasonable if symptoms are unusually severe and of rapid onset.

Some of the above symptoms may be marked, and may develop characteristic features that are widely regarded as having special clinical significance. The most typical examples of these physical symptoms are:

- loss of interest or pleasure in activities that are normally enjoyable
- lack of emotional reactivity to normally pleasurable surroundings and events
- waking in the morning two or more hours before the usual time
- being particularly depressed in the morning
- objective evidence of definite psychomotor retardation or agitation (remarked on or reported by other people)
- marked loss of appetite
- weight loss (often defined as 5% or more of body weight in the past month)
- marked loss of libido.

In very severe depression, delusions, hallucinations or depressive stupor may sometimes be present. The delusions usually involve ideas of sin, poverty or imminent disasters, responsibility for which may be assumed by the patient. Auditory hallucinations are usually of defamatory or accusatory voices, while olfactory hallucinations are often of rotting filth or decomposing flesh.

Marston et al (1997) identified core features of depression, as described by diagnostic criteria, that were present in those with mild ID but, with increasing cognitive disabilities, only depressed mood and sleep disturbances retained their significance whereas screaming, self-injury and aggression were more frequently displayed. They described a checklist of symptoms commonly present in persons with ID that last two weeks or more:

- depressed effect
- tearfulness
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- loss of interest
- lack of emotional response
- sleep disturbance (state type)
- diurnal variation of mood
- psychomotor agitation
- loss of appetite
- weight loss (5% body mass in one month)
- loss of libido
- loss of confidence
- unreasonable self-reproach
- suicidal ideation
- self-injurious behaviour
- delusion (mood congruents)
- loss of energy
- constipation
- anxiety
- obsessional/compulsive behaviour
- aggression
- irritability
- changeable mood
- reduced communication
- social liaison
- running away
- screaming
- anti-social behaviour
- stereotyped behaviour
- poor concentration.
Case study: Peter

Peter, a 20-year-old with severe ID and some autistic features, was causing himself serious injury. When he was first seen he had two black eyes from punching himself in the face, and lacerations on his chin from banging his head on the table.

He had a number of lacerations on the scalp stapled together as a result of constantly hitting his head. He was described by his carer as looking ‘quite a pitiful sight’. He could only be restrained with 24 hour, one-to-one nursing support. He would not say a word to the clinician who saw him, or even make eye contact. However, there was some other important information: while he was trying to hurt himself he was wailing miserably all the time, obviously greatly distressed. This was unusual as many self-injurious patients appear rather disassociated while hitting their heads or picking at their skin.

Further examination revealed that Peter was eating and sleeping poorly, and losing weight. The clinician was told that this behaviour began about six months earlier when his grandmother died. She was the only person to whom he related at all. He would run up to her when she visited him, while totally ignoring his parents.

A major depression was diagnosed, precipitated by bereavement. He was given antidepressants, which had a dramatic effect and his self-injurious behaviour stopped completely.

Epidemiology

Depression has been acknowledged as a major public health challenge with the World Health Organization (WHO) predicting that it will become the second leading contributor to the global burden of disease by 2020 (WHO, 2001). Ormel et al (2008) and Spijker et al (2004) suggested that depressive and anxiety disorders have a great impact on public health due to their negative effects on well-being, functioning and productivity. Both disorders often present a chronic intermittent cause, imposing a high disease burden throughout life. Most prognostic studies have found that basic clinical factors, such as early age of onset, severity and duration of the index episode, and co-morbidity of anxiety and depression, are among the most consistent and strong predictors (Spijker et al, 2004).
Since the 1980s, case reports have been replaced by large scale epidemiological studies of affective disorders in persons with ID. There has also been an attempt to delineate their presentation across the range of abilities. It is now acknowledged that depressed mood is among the most common of psychiatric symptoms experienced by adults with ID (Nezu et al., 1995). Major depression has, in fact, been reported in between one and five per cent of ID population (Cooper & Collacott, 1996; Lowry, 1998), and it may be that as many as one in 10 will experience clinical depression at some stage.

It is important to note that the risk of depression in persons with ID may be greater than that in the general population. Richards et al. (2001) demonstrated that mild ID at the age of 15 was associated with a four-fold increase in affective disorders in midlife. It is also expected that, as in the general population, the risk of depression will increase with age (Thorpe, 1998).

An epidemiological investigation of affective disorders with a population based cohort study of 1,023 adults with ID was conducted by Cooper et al. (2007). They found that the age-specific prevalence of depression as defined by the DC-LD was 4.9%. However, the point prevalence of depression, also defined by DC-LD, was:

- 3.8% for the group with mild ID
- 4.4% for the group with moderate ID
- 4.6% for the group with severe ID
- 2.2% for the group with profound ID.

The results show that the point prevalence was higher than previously reported for the general population, with DC-LD yielding 3.8% for depression and 0.6% for mania. Similar to the findings for the general population, depression was more associated with women and smoking, and rates were affected by preceding life events and the number of preceding family physician appointments. However, unlike the findings in the general population, obesity and unemployment were not independently associated with depression, nor was sensory impairment or a previous long stay in hospital residence. They therefore concluded that there is a high point prevalence of affective disorders in adults with ID.
Aetiology and risk factors of depressive disorders

A variety of genetic, biochemical, physical and psychosocial factors have been linked to affective disorders in the general population. However, people with ID are particularly vulnerable in some of these areas and for this reason they may be at increased risk of presenting with depressive features.

Biological factors

Many studies have reported biological abnormalities in people with mood disorders who have ID, and until recently the mono-immune neurotransmitters such as norepinephrine, dopamine, serotonin and histamine have been the main the focus of research as a possible cause. However, a progressive shift has now occurred towards studying neurobehavioural systems, neurocircuits and more intricate neuroregulatory systems.

Genetic factors

Numerous family, adoption and twin studies have long documented the heritability of mood disorders. Recently, however, the primary focus of genetic studies has been to identify specific genes that can make an individual susceptible by using molecular genetic methods. Feroz-Nainer (2005) made the point that epilepsy, FXS (see p30) and Down’s syndrome are among the biological/genetic causes and correlates of ID, and he raised the question as to whether these factors also contribute to the higher rates of depression in people with mild ID.

Given the high prevalence of brain damage in the ID population, particularly in more severe ID, it is surprising that the role of organic factors such as epilepsy in the causation of depression has not been the subject of major reviews.

In his annual review of mental retardation, Rutter (1971) noted that children with ID accompanied by neurological abnormalities were more likely to have psychiatric diagnoses than those without such abnormalities. Lund (1985), meanwhile, in a study of 300 persons with ID, reported that
52% of people with both ID and epilepsy have a psychiatric diagnosis, compared to just 26% of those without epilepsy. Although this study did not examine a specific link with depressive disorder, Cornelius et al (1991) looked at the features of organic mood syndrome as presented by 130 patients with a variety of neurological disorders including epilepsy, cerebrovascular accidents and Parkinson’s disease, and found a link between these organic syndromes and depression. Mendez et al (1994) further investigated the association between epilepsy and depression and found that the association may be particularly prominent with a left hemisphere lesion, especially those whose seizures originated from a structural brain lesion other than the mesial temporal sclerosis.

Psychosocial factors

It is a long-standing clinical observation that stressful life events more often precede the first episode of mood disorder than subsequent episodes. This association has been reported in both patients with major depressive disorder, and patients with bipolar disorder.

However, when it comes to ID, relatively few studies have examined the impact of life events on mental health, despite the possibility that people with ID might be particularly vulnerable to such events. McGillivray and McCabe (2007) maintained that disruptive life events, such as going into hospital, moving house, experiencing loss or separation from significant others, changes in family relationships or life-changing events, such as deaths in the family, are what can put persons with ID at risk of developing depression. Tsakanikos et al (2007) examined the impact of multiple life events on the mental health of people with ID and found that a single exposure to life events, both traumatic and non-traumatic, was significantly associated with schizophrenia, personality disorders and depression. Multiple exposures to life events were associated with personality disorder, depression and adjustment reaction, and these results suggest an increased vulnerability to life events in people with ID.

Day (1985), for example, explored the relationship between grief and depression in the psychoanalytic literature, and emphasised the difficulties facing people with ID in working through the grief process. Bereavement for an individual with ID may therefore be a particularly threatening life event resulting in a terrifying and rapid change in circumstances if someone close to them dies, especially if they were the individual’s main carer (Harper & Wadsworth, 1993).
This view was also supported by Brown and Harris in their book, *The Social Origins of Depression* (1978), emphasising the importance of threatening life events in the genesis of depression, and the protective effects of intimate relationships and social support. People with ID often lack the skills to establish intimate relationships that could otherwise give some degree of protection, and they may be very isolated with poor systems of social support, particularly in community settings, thereby increasing their vulnerability to depression.

**Personality factors**

There is no single personality trait or type that uniquely predisposes a person to depression. All humans of whatever personality pattern can or do become depressed under certain circumstances. In the general population, however, people with certain personality disorders such as obsessive compulsive, histrionic and borderline, may be at greater risk of depression than people with antisocial or paranoid personality disorders.

John Bowlby (1973) believed that damaged early attachments and traumatic separation in childhood predispose the individual to depression. A loss that then occurs in adulthood will revive the memory of the traumatic childhood experience and so precipitate a depressive episode.

Lewinsohn (1974), meanwhile, proposed a model of depression that suggests that interactions between the individual and the environment lead to an increased vulnerability to depression. As many people with ID are relatively less competent in all areas than people in the normal IQ range, they experience negative reactions from family, peers, education and work settings, which may well lower self-esteem and lead to an increased vulnerability to depression.

**Cognitive theory**

According to cognitive theory, depression results from specific cognitive distortions that are present in people susceptible to depression, which are referred to as depressogenic schemata, and are a person's cognitive ‘templates’ that affect how they perceive both internal and external data, and which are altered by early experiences. Beck *et al* (1979) postulated a cognitive triad of depression that centres on a person’s views of:
the self i.e. a negative self-perception
the environment i.e. a tendency to view the world as hostile and demanding
the future i.e. the expectation of suffering and failure.

In therapy, modifying these distortions is crucial.

**Learned helplessness**

The learned helplessness theory of depression connects depressive episodes to the experience of uncontrollable events where a person has both cognitive motivational deficit (they would not attempt to escape the event) and emotional deficit (indicating decreased reactivity to the event). This concept was introduced by Seligman (1981) who suggested that when an individual is faced with repeated failure they may begin to feel that they cannot change the situation for the better, and therefore assume a helpless response leading to a further deterioration in problem-solving behaviour and an increased vulnerability to depression. People with ID are particularly prone to failure because of basic deficits in understanding and problem-solving abilities, and are therefore more likely to assume a position of learned helplessness.

In their research on the early detection of depression and associated risk factors in adults with mild to moderate ID, McGillivray and McCabe (2007) described a number of cognitive factors that have been related to depression. They found, for example, links between depression and negative social comparison, poor self-concept and low self-esteem in this population. There is also evidence that severely depressed students with ID demonstrate a higher level of dysfunctional cognitive self-statements when compared to those who are not severely depressed, which suggests a need for further examination of the impact of cognitive factors on the development of depression in individuals with ID.

**Diagnostic aspects**

Recognising depressive disorders is not always easy, even in people without ID in primary care settings, with 50% of depressive illness being missed at first contact (Paykel & Priest, 1992), and this may well also be the true of persons with ID (Reynolds & Baker, 1988). In fact, recognising mental illness, including depression, in people with ID presents additional difficulties.
Not only might symptoms of an internalising non-disruptive nature not be recognised as a problem by carers (Marston et al., 1997), but the mediating effects of organic brain injury and additional genetic syndromes (Yappa & Roy, 1990) might further hamper recognition of an additional mental health concern. The reporting of symptoms may also be dependent upon the training and skills of care staff (Charlot et al., 1993), and may be confounded by the side effects of medication (Sovner & Hurley, 1983). In people with ID, depressive disorder may be difficult to diagnose because of impaired communication, and with this reduced ability to disclose their own moods, the psychiatrist is thereby denied access to the cardinal symptoms of affective illness (Einfeld, 1992). Furthermore, while people with mild ID may often be able to report their thoughts, feelings and emotions to another person, in the case of people with severe ID the psychiatrist must often rely on non-verbal cues from the client and behavioural observations from carers. In their report of five cases of bipolar illness in adolescents with a learning disability, McCraken and Diamond (1988) suggest that bipolar illness is commonly misdiagnosed in this population because of difficulties in eliciting histories of mood change and an overemphasis on psychotic and pseudo-organic symptoms. In many cases, symptoms such as reduced psychomotor activity, weight loss and sad facial expressions may be seen as non-disruptive, which lessens the likelihood that these clinical signs are regarded as a problem by carers.

Einfeld (1992) argues that mania tends to be over-diagnosed, as over-activity and excitement are common symptoms in this population. However, Charlot et al. (1993) suggest that, as clinicians become more sensitive to the concern of the over diagnosis of mania, a downward trend in its occurrence might be expected.

Another major issue is the lack of diagnostic criteria for depression in people with ID. Standard general population diagnostic criteria such as ICD-10 or DSM-IV-TR are difficult to apply fully to people with severe and profound ID (see below). For example, a full understanding of complex concepts such as guilt and worthlessness require a developmental level of about seven years, and those without verbal communication skills would be unable to report recurrent thoughts of death, suicidal ideation or diminished ability to think, therefore limiting the usefulness of such items (Smiley & Cooper, 2003).

However, it is reported that the pragmatic application of standardised diagnostic criteria could, to an extent, overcome this problem. Indeed, studies by Meins (1995) and Marston et al. (1997) suggest that standardised diagnostic criteria, such as DSM-IV and ICD-10, can be effectively used to
detect depression associated with mild ID, but this criteria may be less useful for people with more severe disabilities.

Sovner and Hurley (1982) were the first to postulate that mood disorders may present atypically in persons with ID, and they proposed the term ‘behavioural equivalents’ to describe these alternative behavioural manifestations. Lowry and Sovner (1992) further delineated these ‘symptomatic behaviours’ based on a review of case notes as well as clinical experience. It was postulated that these observable behaviours would complement both self and informant reports. In this model, behavioural equivalents elaborated on symptoms of depression found in the non-disabled population but did not replace them.

Langlois and Martin (2008) looked at the relationship between diagnostic criteria, depressive equivalents and diagnosis of depression among older adults with ID. They looked at the criteria in the interRAI-ID assessment instrument that are representative of the DSM-IV criteria, and depressive equivalents were examined among persons with ID in an institution and in community based residential settings. They found that the DSM-IV diagnostic criteria and depressive equivalents were significantly related to a diagnosis of depression among older and younger adults with ID. The results show that a non-trivial proportion of persons in the study exhibited both DSM-IV criteria related to sad mood and somatic symptoms, and that the depressive equivalents were also common where aggression and self-injurious behaviour were the most prevalent. They also found that adults without a diagnosis of depression tended to exhibit self-injurious behaviour less frequently than younger adults, although rates for all other indicators were unaffected by age.

Tsiouris et al (2004) used the Bayesian analysis of the Clinical Behaviour Checklist for Persons with Intellectual Disabilities (CBCPID) (Marston et al, 1997) to predict depression in people with ID. This checklist was administered to 92 adults with ID who had been referred for psychiatric assessment, and compared the presence or absence of each criterion to the presence or absence of a diagnosis of depression by a psychiatrist. The study found only one item with adequate sensitivity (anxiety) and a few items with adequate specificity (suicidality, self-reproach, weight loss, constipation, loss of appetite, antisocial behaviour, loss of confidence, running away and psychomotor agitation). Although ideally the items should have both high sensitivity and specificity, unfortunately no items in this analysis had that property.
Adaptation to diagnostic systems

The use of structured interviews in conjunction with fully operationalised criteria has had a major impact on the overall reliability of the psychiatric diagnosis process.

There is, however, some debate about the use of such diagnostic tools when they are applied to people with ID. Some argue that the existing psychiatric nosological systems fall short when they are applied to this population, and several reviews over the last three decades (Cooper & Collacott, 1996; Davis et al., 1997; Janowsky & Davis, 2005) have found that the use of unmodified ICD-10 and DSM diagnostic systems is inappropriate, especially for those with severe ID. It has been stated, on the other hand, that standard diagnostic criteria may be appropriate for mild to moderate ID (Pawlarczyk & Beckwith, 1987; Tsiouris, 2001; McBrien, 2003).

Authors have highlighted the risks of both false negatives due to under recognition (McBrien, 2003) and false positives with increased rates observed when using symptoms equivalents (Davis et al., 1997; Holden & Gitelsen, 2004). McBrien (2003) has presented a comprehensive review of the various historical alternatives and modifications to DSM and ICD criteria.

The National Association for the Dually Diagnosed, in collaboration with the APA, adapted the DSM-IV-TR for use with individuals with ID. It has been recognised that the Diagnostic Manual – Intellectual Disability (DM-ID) is easy to use, accurate and can reduce residual categories (Fletcher et al., 2009). It provides clear examples of how criteria should be interpreted when used on people with ID, addressing the pathoplastic effects of ID on psychopathology.

Following a review of current literature, it was agreed that DSM-IV-TR mood disorder criteria did not need to be changed in significant ways, and the effort should aim at improving reliability and validity in eliciting existing criteria for this population (Charlot et al., 2007). The report recommended that some symptoms should be given differential emphasis, for instance irritability may present frequently as sadness (Charlot, 1997; Davis et al., 1997). It also suggests stipulating four or more symptoms (instead of five) required by DSM-IV-TR.

The DM-ID emphasises the need for a ‘change from what is usually observed for the individual’. This can include an onset of, or an increase in, ‘agitated behaviours’ (assaults, self-injury, disruptive or destructive behaviours) as
well as stereotypes and ritualistic behaviours. It also provides guidance on the manner in which these symptoms may present to observers, for example weight loss may present as refusing meals, or exhibiting agitated behaviours at meal times such as throwing food and screaming when meals arrive. It has been suggested that psychomotor agitation may present more commonly in persons with ID, but Charlot et al (1997) has described a combination of withdrawn, underactive behaviours alternating with agitated, restless behaviours in response to demands. It also emphasises ruling out physical problems causing pain or distress such as infections, constipation or medication-induced side effects.

The DC-LD represents the consensus of current professional opinion and suggests modifications that are appropriate for people with moderate to profound ID and uses the hierarchical approach in order to place problem behaviours within the diagnostic framework with clear instructions regarding organic disorders and behavioural phenotypes. It also has items within categories that accommodate the pathoplastic effect of more severe ID and replaces some of the self-report items with observable items (Smiley & Cooper, 2003).

The DC-LD suggests eliminating the requirement for more cognitively based symptoms, such as excessive feelings of guilt and unworthiness, pessimistic views about the future and ideas of self-harm, and instead includes other symptoms such as an increase in specific maladaptive behaviours concurrent with episodes of mood disorder or the recent onset of, or increase in, physical health symptoms. Other examples include anhedonia (loss of ability to experience pleasure), which may manifest in an apparent loss of skills and non-compliance with care, and loss of confidence, which may manifest as an increase in fearfulness and reassurance seeking.

The DM-ID was also designed to consider the developmental perspective in order to aid the clinician in recognising symptom profiles in children with ID as well.
Assessment tools

Several scales are needed, both as screening tools to evaluate the need for further assessment, and to evaluate the trajectory of a particular episode. Some of the scales are derived from those designed for use with the general population, however more recently several instruments have been designed and validated specifically for people with ID.

As has already been discussed, there are various challenges to be faced when assessing depressive disorders in people with ID, and Reynolds and Baker (1988) highlighted the particular problems with using self-report questionnaires, which are reliant on both expressive and receptive language abilities. They also expressed their concerns regarding the lack of psychometric data available for scales modified for use with ID. Feinstein et al (1988), meanwhile, highlighted the mediating effects of immaturity in children and adolescents with ID.

Feinstein et al (1988) suggested that a scale should ideally be able to assess a broad range of different moods, and the emphasis should be on behavioural descriptions using verbal information as supplementary data. It also eschewed brief interview formats, instead encouraging extended informant observations in naturalised settings, including measuring both frequency and severity of depressive episodes.

Table 3.1 summarises some of the instruments used in the assessment of mood disorders in persons with ID.
### Table 3.1: Summary of assessment instruments

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<thead>
<tr>
<th>Name</th>
<th>Description</th>
<th>Advantages</th>
<th>Disadvantages</th>
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<tbody>
<tr>
<td>The Mini PAS-ADD Interview (Prasser et al., 1998)</td>
<td>86 items. Covers a range of psychiatric disorders. Informant rated.</td>
<td>Complements psychiatric assessment but does not replace it as it does not provide a diagnosis.</td>
<td>Training required. Psychometric data is limited to the overall scale rather than affective subscale in particular, hence validity statistics is limited.</td>
</tr>
<tr>
<td>PAS-ADD checklist revised (Moss et al., 1998)</td>
<td>25 items covering a range of disorders. Informant rated. Screening and monitoring affective disorder items.</td>
<td>Can be used with severe ID. No training needed. Uses ‘everyday’ language.</td>
<td>Needs two raters. Some concerns about untrained raters to use the checklist.</td>
</tr>
<tr>
<td>Children’s Depression Inventory [CDI] (Kovacs, 1985)</td>
<td>27 items based on Beck Depression Inventory. Both self and informant formats. All levels of ID.</td>
<td>Pictorial response scales. Probes to check understanding. Reasonable psychometric properties.</td>
<td>Depends on level of cognitive and linguistic abilities. Some doubts have been raised about informants rating complex internal states.</td>
</tr>
</tbody>
</table>
### Table 3.1: Summary of assessment instruments (continued)

<table>
<thead>
<tr>
<th>Assessment Instrument</th>
<th>Description</th>
<th>Notes</th>
</tr>
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<tbody>
<tr>
<td>Glasgow Depression Scale for People with Learning Disability (GDS-LD) (Cuthill et al., 2003)</td>
<td>Self report. Screening Instrument. 20 items for use with mild to moderate ID. Based on DC-LD criteria. Uses symbols anchoring events and alternative phasing. Informant version with good psychometric properties and good interaction correlations with self-rating scales.</td>
<td>New scale, more research needed reading the psychometric properties of the instrument.</td>
</tr>
<tr>
<td>Psychopathology Inventory for Mentally Retarded Adults (PIWRA) (Senatore et al., 1985)</td>
<td>56 item broadband scale. Screening tool. 7 item affective disorder. Section for persons with mild ID. Not specific to depression. From DSM-III. Simplified descriptions. Psychometrics for individual scales are not as robust.</td>
<td>Adapted assessment to co-morbid disorders.</td>
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</table>
Case study

A 34-year-old man with moderate ID and FXS (based upon chromosomal analysis) presented with a one-year history of increasing aggression and loss of functioning. Three of his four brothers also had chromosomal evidence of FXS. The patient was in good health, living in a community residence, and had been in care between the ages of 11 and 31. As a child he had been treated with stimulant therapy for hyperactivity. He was admitted to a psychiatric hospital at the age of 32 to control his aggressive behaviour and treatment has predominantly used neuroleptics, which has been largely ineffective.

At the time of his initial assessment he was taking chlorpromazine (200mg), trifluoperazine (10mg x 2 per day) and benzatropine (2mg). His behavioural problems included agitation and aggressiveness and he was easily frustrated and distractible, while he also said unusual things such as claiming that he was his brother. He also had orofacial dyskinesia, which was observed as the trifluoperazine was tapered off.

A diagnosis of organic personality disorder was considered and over an 18-month period the chlorpromazine was slowly withdrawn. During this period his aggressive behaviour began to increase and beta blocker therapy was tried, but this proved unsuccessful and was stopped due to hypertension. His clinical status was reassessed and a diagnosis of depressive disorder was given. He was therefore treated with antidepressants, which proved effective after eight weeks as his features reduced to a manageable level, he was a lot happier and the activities in his daily life were improved.

Conclusion

Depressive disorders are increasingly recognised as among the most common source of distress for people with ID. Diagnosis in those with ID entails a flexible approach that responds to the communication and cognitive styles of the person, a sound knowledge of the varied presentations across a range of skills, and a good understanding of the constitutional and environmental factors that may impact on presentations.

The particular challenges to accurate recognition include the lack of availability of valid diagnostic systems and the mediating effects of the developmental disabilities. Hopefully, diagnostic systems specifically adapted to persons with ID will mitigate some of these difficulties.
Summary

- The risk of depression in persons with ID may be greater than that in the general population.
- Depressive disorders significantly impair functioning, compromise community living and lead to significant morbidity in the form of self-injury and other maladaptive behaviours. They also have a significant impact on families and carers and increased costs of care.
- The recognition of depressive disorders in persons with ID poses additional challenges.
- Diagnostic systems and assessment instruments specifically adapted to people with ID will improve the recognition of this potentially treatable condition.

References


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