INFORMATION SHEET

making a difference
to the lives of people with
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Psychiatric disorders in people with learning disability

Dr Steve Moss BSc MSc Phd, Consultant Research Psychologist attached to the Estia Centre, Guys Hospital, London.

In the whole population it has been estimated that there are more people in hospital for mental illness than for all other diseases combined - including heart disease, cancer, tuberculosis or alcoholism. Mental illness places enormous burdens on carers, social and medical services. It reduces the person's quality of life, and their ability to cope.

People with learning disability (LD) are at least as susceptible to mental illness as the rest of society, yet their problems often remain undetected because the symptoms can be lost amongst the various other behaviours which they may exhibit. It is thus essential to be as aware as possible of potential mental health problems, and to get them assessed and treated with the minimum of delay.

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What is a mental illness?

The essential feature of any mental illness is a *clinically recognisable set of symptoms or behaviours, usually associated with distress and interference in personal functioning*. The reference to a "*set* of symptoms" is a key part of the definition, because mental illnesses tend to have characteristic patterns of symptoms. Identifying the particular pattern exhibited by an individual is a central part of making a diagnosis. For clarity, we use the term "psychiatric disorder" when talking about these types of disorder in the remainder of this information sheet.

The following are some of the major classes of psychiatric disorder:

Depression

In the general population, depression is the most common psychiatric disorder of adults, occurring in about 13% of all people at some time in their lives. It occurs most often in people who have no close interpersonal relationships or who are divorced or separated. People with LD who live alone are therefore at considerable risk. The core features of depression are: low mood, loss of interest or pleasure in almost all activities, and loss of energy. Other symptoms can include: weight loss or gain when not dieting, change in sleep pattern, agitation, feelings of worthlessness or guilt, loss of ability to concentrate and suicidal thoughts.

Manic-depression

This is a disturbance of mood characterised by sustained periods of depression, followed by highly elated mood. Individuals experience extreme mood swings accompanied by changes in thinking and behaviour. Generally, there are periods of normal moods in between the two extremes. Symptoms of mania include excessive 'high' or euphoric feelings, extreme over-confidence, reckless behaviour with no perception of risk, very rapid speech leaping from topic to topic and decreased need for sleep.

Anxiety disorders

Anxiety is a feeling that everyone experiences from time to time, and is an entirely appropriate response to many situations. It becomes a disorder only if the severity of anxiety and feelings of dread are so out of proportion to the circumstances, that normal daily routines are disrupted. There are various kinds of anxiety disorder which can be diagnosed, depending on the acuteness of the symptoms, and the circumstances under which they occur. These conditions include panic disorder, phobias and obsessive-compulsive disorder. All anxiety disorders are typically associated with physical symptoms such as increased heart rate, shortness of breath, sweating, trembling, shaking, chest pain, discomfort and nausea.

Psychoses

Psychoses are very serious conditions in which the person partly or totally loses contact with reality. The symptoms are typically bizarre, core symptoms being delusions and hallucinations. A delusion is a false and unshakeable belief in something which is untrue. Delusions most often centre around the person themselves and may be very bizarre in content, for instance, that the person is being spied on, or that people on the television are talking to them personally. The person is so convinced of their delusions, that the most logical argument cannot make them change their mind. Hallucinations are false perceptions. The person will report that they can see, or hear, feel, smell or taste something that is not actually there. Psychotic conditions can occur for a variety of reasons. Use of or withdrawal from alcohol and drugs can be associated with the appearance of psychotic symptoms. Sometimes psychotic symptoms may appear as part of a head injury or a physical illness that disrupts brain functioning such as encephalitis, AIDS or a tumour. Psychotic symptoms can also arise suddenly from a major stress in a person's life (e.g. death or change of living circumstance). In this case the person normally makes a good recovery. Schizophrenia is a long term psychotic condition in which the initial onset is typically in early adulthood, with bouts occurring throughout life.

Organic disorders

Serious mental health problems can sometimes arise because of brain injury. Depending on the nature of the injury or damage, a wide variety of different symptoms can occur including disturbances of consciousness, attention and perception. Hallucination can sometimes occur. One of the most commonly occurring classes of organic conditions is dementia. There are a number of different types, of which Alzheimer dementia is the most frequent. Alzheimer disease is associated with a number of characteristic cellular changes, which are widely distributed throughout the brain. The other most commonly occurring type is multi-infarct dementia, in which the brain is damaged in a number of localised sites by burst blood vessels (infarcts). The dementia syndrome involves deterioration in many aspects of mental functioning including memory cognitive functioning and emotional state. People with Down's syndrome are particularly prone to Alzheimer's disease.

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Is challenging behaviour a mental disorder?

Behaviours are described as “challenging” primarily because they break fundamental social rules, ie that it is wrong to hurt others, hurt one’s self, destroy property or otherwise disrupt other people’s lives. There are many reasons why someone might exhibit these kinds of behaviours including frustration, conflict with others, lack of significant relationships or a history of inappropriately learned behaviours.

The fact that a person shows challenging behaviour carries no implication that they have a psychiatric disorder. Indeed this is probably the case for the majority of these individuals. However, some people *do* have both types of problem. Anxiety disorders, depression and mania are all more prevalent in people with severe challenging behaviour.

When a person has both types of disorder, ie a challenging behaviour and psychiatric disorder, the clinical picture becomes very complex. It is often difficult to know whether the challenging behaviour is occurring partly *because* of the psychiatric disorder, or whether the challenging behaviour has completely different causes, perhaps relating to problems in the person’s current environment.

Why do psychiatric disorders occur?

Organic mental health problems such as dementia, resulting directly from brain damage, have a clear physical cause. In the case of schizophrenia, the evidence for a direct physical cause is less clear. There appears to be some genetic link because there is a greater chance of getting schizophrenia if there is a family history of the condition. However, many people develop schizophrenia when there is no family history. Although it seems likely that this severe mental disorder is in some way linked to brain dysfunction, it is not yet clear what the mechanism is.

In the case of most common psychiatric disorders there is usually no clear physical cause. However, there is a wide range of social and psychological risk factors, which need to be considered when assessing the person’s mental health needs. Mental health is closely associated with the quality of physical and social environment.

Having good social supports, esteem within society and an interesting and stimulating environment are all factors which can help protect our mental health. Conversely, if we do not have these strong supports we are more vulnerable to mental illness. The fact that many elderly people in the wider community have lost these supports is partly responsible for the high rates of depression and anxiety disorders in this sector of the population.

Similarly, many people with LD also have impoverished supports. Many do not have a partner or children, most have low esteem within society and have relatively little control over their lives. Most importantly, people with LD tend to have poorer coping mechanisms and insight than those in the general population. This makes them very vulnerable to the impact of life events such as bereavement, which for people with LD can have serious consequences for mental health.

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It is also important to remember that many people with LD, even if they have a good quality of life now, may continue to suffer from the effects of their past life. Early parental rejection and/or long periods within an institution, may have had effects on personality development and adjustment for the rest of the persons life

We must also bear in mind that the *level* of LD can be an important factor when assessing the individual's mental health needs. In people with severe or profound LD, mental health problems are likely to relate primarily to complex neurological, genetic and other biological abnormalities.

People with mild or moderate LD, on the other hand, are likely to demonstrate to a greater extent the impact of social risk factors – e.g. parental rejection, long-term institutionalisation, impoverished social networks, lack of self esteem etc.

What can be done to improve mental health?

1. Recognise the potential problem

The first step to mental health care is to have one's problem *recognised*, and in this respect people with LD are at a major disadvantage compared to the general population. Most people with LD are unable either to recognise that a problem exists, or to seek treatment on their own behalf. **This means that someone else first has to recognise that the person is showing signs of mental illness**.

If the symptoms are very severe, the mental health problem is likely to be recognised. In many cases however, the signs may be so mixed up with other behaviours related to the person's LD or challenging behaviour that the disorder remains unrecognised. Studies have confirmed that this is indeed the case, many cases of depression and anxiety disorders remaining unrecognised and untreated

Support workers and direct care staff working with people who have LD have a crucial role in recognising potential symptoms. These are the people who are in the best position to identify significant behaviour change and potentially, to make appropriate referrals. Most services for people with LD in the UK now train staff in the detection, management and treatment of mental illness in people with LD, and in the use of special assessment tools to help them recognise potential cases as soon as possible.

Amongst the most widely used on these tools i*s the PAS-ADD Checklist (Revised)*: a mental health questionnaire, couched in everyday language, designed for use specifically by care staff and families of people with LD. The Checklist aims to help staff and carers collect information on symptoms of mental illness, and to decide whether further assessment of an individual's mental health may be helpful. It can be used to screen whole groups of individuals, or as part of a regular monitoring of people who are considered to be at risk of mental illness. It is designed to record the presence of a range of problems, all of which may be part of a psychiatric condition. The scoring system includes threshold scores which, if exceeded, indicate the presence of a potential psychiatric problem which should be referred for further assessment.

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2. Get the best possible assessment

In the general population, psychiatric disorders are usually assessed primarily by a clinical interview where the psychiatrist asks the patient first about current symptoms and difficulties and then about an ever-widening circle of other experiences and events, past and present. The poor verbal ability of many people with LD makes it difficult for them to be interviewed, so a much stronger emphasis is placed on reports from other people such as family members and care staff. Collecting detailed information from these informants is thus essential.

The clinical picture can sometimes be very complicated, especially if a psychiatric disorder coexists with a challenging behaviour. Evaluating the relative contributions of biological, psychological, social, family and environmental factors to the observed signs and symptoms may thus require repeated assessments over a period of time, and in some cases the use of direct observational techniques.

The process to get an assessment cannot be universally specified, and will depend on what services are in place in the particular catchment area. To start the process a carer should initially contact the

person's key worker, and ask how to get an initial assessment of a potential psychiatric disorder, within the local Health Service.

3. Treatment

It is often not precisely known why a person develops a mental health problem, and it is also not possible to know exactly how they will respond to any particular treatment. This can make treatment a complex process, in which several treatment components may be recommended. As the person's progress is monitored, the treatment plan may be modified in the light of the new evidence. The following are the principal types of treatment approach.

Medication
A range of medications is available for treating psychiatric disorders including schizophrenia, manic depression, attention deficit hyperactivity disorder and various forms of anxiety. In general, individuals with LD respond in a similar way to the general population. However, individuals with LD sometimes exhibit unusual side effects that are not always outlined in the clinical profile of the medication. It is common practice to provide a comprehensive assessment of the problem, start medication on lower doses and slowly increase to achieve maximum benefit with minimal side effects. There are a number of published standards for the use of medications in the psychiatry of individuals with LD. Recommendations include: multi-disciplinary assessment of need for medications, informed consent, use of minimal effective dose, periodic attempts to reduce dosage, monitoring of side effects and integration with other treatments. Although medications can be highly effective, it is important to remember that most mental health problems probably have multiple causes, including psychological and social factors. Medication cannot change an impoverished social environment, or cure problems arising from early life trauma. In most cases additional forms of intervention are necessary to augment the treatment.

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Cognitive Therapy

Cognitive therapy is based on the fact that people's mood is influenced by the way in which they view and structure their experiences. Beliefs, expectancies, plans and values are seen as having a large contribution to the maintenance of abnormal behaviour, so changing them can have a beneficial effect. The application of cognitive therapy in individuals with LD is relatively new, but there are some promising findings. Anger management has been found to be effective with individuals with mild to moderate LD. The aim is to teach methods of controlling anger as well as socially acceptable ways to express anger. Training includes recognition and identification of emotions, self monitoring of mood, relaxation training, self-instructional training and problem solving. The use of relaxation training to treat anxiety disorders has also been shown to be effective, even with people who have severe or profound LD and multiple disabilities.

Psychotherapy

The term psychotherapy encompasses a variety of therapeutic approaches including psychodynamic psychotherapy and counselling. Counselling seeks to help people understand and work out their day-to-day problems. They are often seen as therapists who listen, encourage and offer support and advice. Counsellors can also teach the individual to distinguish between behaviours that are socially inappropriate and those that are appropriate. Psychodynamic psychotherapy is applicable to people whose problems stem from emotional conflicts which have arisen in early life. The basic concept is that lifelong problems can arise if the person has attempted to escape from these conflicts by repressing

the memory into their unconscious mind. Through therapy, the person is encouraged to unearth these memories and to learn to deal with them in the relationship with the therapist. People with LD are highly likely to have experienced early-life emotional trauma, yet for many decades the common view was that their limited developmental level prevented the use of psychotherapy. Nowadays there is an awareness that some of the more able individuals with LD can benefit from psychodynamic psychotherapy, provided the language and content is appropriately adapted.

Educational Interventions

Providing information and education about mental health problems can be valuable, both for the individual and for his/her support network. For the individuals it can help them gain some insight into their difficulties, enhance their understanding of why they behave in a certain manner and why particular treatments are indicated. This can help facilitate compliance with treatment. Education also helps to dispel myths and outdated beliefs that may be held in the individual and/or the support network. The education can cover a wide range of topics but it is important to tailor it to individuals and their particular circumstances. Topics can include: psychiatric disorders, specific symptoms, the rationale of use of different therapies, medication profiles and side effects and monitoring of changes in symptoms.

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Dr Steve Moss has worked for over 25 years in disability research, initially in the field of visual handicap, and subsequently in the area of learning disability. From 1985 to 1990, he directed an extensive programme of research and service development relating to the needs, characteristics and provision of services to older individuals with learning disability. From 1990 to 1997, he directed a Department of Health funded programme of research on the detection and diagnosis of mental disorders in this population. He has an international reputation for his work in both these fields.

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