Information sheet



#### making a difference to the lives of people with severe learning disabilities

# Mental health problems in people with a learning disability

## This information sheet may be useful for families who are:

- Looking for information about mental health problems in people with a learning disability.
- Looking for examples of common mental health problems and how they are treated.



All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

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#### Introduction

Mental health problems are very common, with one in four people experiencing a mental health problem of some kind each year in England.

People with learning disabilities are just as likely to have mental health problems as the rest of society, with a lot of research suggesting that they are in fact more likely to suffer from a mental health condition. Yet mental health problems can go unnoticed in people with learning disabilities because the symptoms can be lost amongst other behaviours which they may display. It is essential to be aware of potential mental health problems, and to get them assessed and treated without delay.

#### What is a mental illness?



A mental illness is a condition that significantly interferes with an individual's mood, thinking or behaviour.

The symptoms of mental illnesses usually follow a specific pattern, but this can be difficult to spot if you're not sure what to look for. Being clear on what the symptoms are and noticing these patterns in behaviour can help doctors make a diagnosis.

## Is there a link between mental health problems and challenging behaviour?

Mental illness can lead to changes in a person's behaviour and sometimes cause an increase in challenging behaviour. Research has found that when challenging behaviour becomes more severe it can be connected to an increase in the symptoms of a mental health problem. It has even been suggested that challenging behaviour can sometimes be another symptom of depression, although it's important to remember that other factors can cause challenging behaviour. For more information about the causes of challenging behaviour please see our information sheet: <u>'Understanding Challenging Behaviour</u>'

There are three main ideas around the link between challenging behaviour and mental illness:

- Primary: where the behaviour is a direct result of the mental illness, e.g. Jon displays aggression in response to hearing voices
- Secondary: where a behavioural response to a symptom of the illness creates challenging behaviour, e.g. Greg screams in response to a flashback, Tony, his carer, responds negatively and Greg then displays aggression towards Tony
- Consequential: where the behaviour begins as in primary but is reinforced by others and becomes learned behaviour, e.g. Shaun had become aggressive as part of his mental illness, and noticed that he got a lot more attention when he did so. Despite the medication helping his mental illness, he continued to use aggression as a way of attracting the attention he needed from others.

#### Is challenging behaviour itself a mental health problem?

Behaviours are described as "challenging" mainly because they break social rules, i.e. 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 display these kinds of behaviours. The fact that a person shows challenging behaviour does not mean that they have a mental health problem. This is probably true for most individuals with a learning disability. However, some people *do* have both a mental health problem and display behaviour that challenges. It is important to consider if behaviour is communicating an emotion or a sign of a mental health problem. A major barrier in recognising the symptoms of mental health in people with learning disabilities has been the readiness to label people as 'challenging' or put everything down to a person's learning disability. This is known as "*diagnostic overshadowing*".

When a person has mental health problems and displays challenging behaviour, the picture becomes very complicated. It is often difficult to know whether the challenging behaviour is happening partly because of the mental health problem, or

whether the challenging behaviour has completely different causes, perhaps relating to a physical health problem or the way they are supported at school for example.

### Can having a learning disability affect the development of a mental health problem?



A wide range of factors influence a person's mental health. Having friends and family, money, being in good physical health and included within society are all factors which can help protect our mental health. If we do not have these things in our life e.g. live in poverty we are more vulnerable to mental health problems.

In addition, the *level* of learning disability can be an important factor when assessing the individual's mental health. In people with severe or profound learning disabilities, mental health problems are more likely to relate to complex brain, nervous system, genetic and other biological abnormalities.

People with mild or moderate learning disabilities are more likely to be affected by social risk factors like parental rejection, long-term institutionalisation, poor social networks, lack of self-esteem etc. It is also important to remember that many people with learning disabilities, even if they have a good quality of life now, may continue to suffer from the effects of their past life. Long periods in an institution and/or early parental rejection may affect the rest of the person's life.

#### **Examples of common mental health problems**

### Depression

What is it?



In the general population, depression is the most common mental health problem in adults, occurring in about 13% of all people at some time in their lives.

The main symptoms of depression are:

- low mood
- loss of interest or pleasure in almost all activities
- loss of energy

Other symptoms can include:

- weight loss or gain
- changes in sleep pattern
- agitation
- loss of ability to concentrate
- suicidal thoughts

#### Why does it happen?

There is no single cause of depression. It can be a combination of many different factors including:

- an imbalance in brain chemistry
- illness
- life experiences such as bereavement and losing a job
- genetics

It occurs most often in people who have no close relationships. People with learning disabilities who have no family or friends are therefore at high risk.

#### Treatment

- talking therapies such as cognitive behavioural therapy (which can be adapted for people with learning disabilities)
- antidepressants

#### Further Info\*

#### **Depression and Learning Disability**

Feeling Down: Looking after my mental health by the Foundation for People with Learning Disabilities

Books Beyond Words: 'Ron's feeling blue' and 'Sonia's feeling sad'

#### **Bipolar Disorder**

*What is it?* Symptoms of bipolar disorder include:

- periods of depression, followed by a highly elated mood
- extreme mood swings along with changes in thinking and behaviour
- symptoms of depressive periods include feeling low, feeling tired all the time, crying for no reason and waking up too early in the morning
- symptoms of 'elated' periods include excessive 'high' or euphoric feelings, talking too much and too fast and sleeping less than usual

#### Why does it happen?

The exact cause is unknown but factors include:

- a chemical imbalance in the brain
- genetics
- social influences

#### Treatment

- medication including mood stabilisers and antidepressants
- talking therapy
- lifestyle changes (exercise, diet changes and sleep)
- Learning relaxation techniques



#### Further Info\*

Bipolar disorder. Easy read guide by MindEd Biploar Affective Disorder by Royal College of Psychiatrists

#### Anxiety disorders

#### What is it?

Anxiety can be seen as a mental health problem when the feelings of anxiety or dread last a long time or are very severe and can stop the person doing the things they would like to be able to do.

Types of anxiety disorder include:

- Agoraphobia
- Panic disorder
- Generalised anxiety disorder
- Phobias
- Obsessive-compulsive disorder (OCD)
- Post-traumatic stress disorder (PTSD)

All anxiety disorders are usually associated with physical symptoms such as increased heart rate, shortness of breath, sweating, trembling, shaking, feeling tense and having difficulty sleeping.

#### Why does it happen?

The exact cause of anxiety disorders is not understood although factors include:

- brain over activity
- chemical imbalances in the brain
- genetics
- history of stressful and traumatic experiences
- long term health conditions
- Using street drugs such as Amphetamines
- Financial difficulties



- Talking therapies such as Cognitive Behavioural Therapy (CBT)
- applied relaxation



- medication
- Exercise

#### Further Info\*

#### Anxiety disorder. Easy read guide by the Royal College of Psychiatrists An easy read guide to Anxiety by the Foundation for People with Learning Disabilities

#### **Post-Traumatic Stress Disorder**

#### What is it?

Post-traumatic stress disorder (PTSD) is an anxiety disorder caused by very stressful, frightening or traumatic events.

PTSD can develop immediately after someone experiences a disturbing event or it can occur weeks, months or even years later.

Someone with PTSD will often relive the traumatic event through nightmares and flashbacks.

They may also have problems sleeping.

#### Why does it happen?

A number of possible reasons have been suggested:

- due to abnormal level of the stress hormone
- changes in the brain and emotional processing
- as a survival mechanism (so you're more prepared if it happens again)

#### **Treatment**

- psychotherapy such as cognitive behavioural therapy or 'eye movement desensitisation and processing'
- antidepressants are sometimes used if psychotherapy has been unsuccessful

#### Further Info\*

Post Traumatic Stress Disorder- Easy read guide, by MindEd

#### **Psychosis**

#### What is it?

Psychosis is not a mental illness but a symptom of some mental health problems such as schizophrenia and mania in which the person partly or totally loses contact with reality. Core symptoms are:

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- Delusions (a belief in something which is untrue)
- Hallucinations (false perceptions e.g. the person seeing, hearing, feeling, smelling or tasting something that is not actually there)

#### Why does it happen?

Psychosis can occur for a variety of reasons:

- use of or withdrawal from alcohol and drugs
- as part of a head injury or a physical illness that disrupts brain functioning from a major stress in a person's life (e.g. death or change of living circumstance)

#### Treatment

- antipsychotic medication
- talking therapy
- Exercise

#### Further Info\*

<u>Recognizing psychosis in persons with intellectual disabilities who do not use</u> <u>speech</u> by the University of Hertfordshire

#### Psychosis. Easy read guide by the Royal College of Psychiatrists

#### Schizophrenia

#### What is it?

Schizophrenia usually starts when a person is 18-30 years old.

Around 3% of people with a learning disability have schizophrenia (though many think this is an underestimate). This is 3 times higher than the prevalence in the general population.

The main symptoms are delusions, hallucinations and not being able to think or talk clearly.

#### Why does it happen?

It is unclear what the cause is, possible causes are:

- a link to brain dysfunction
- family history (genetic predisposition)
- Life stresses
- Illegal drug use

#### Treatment

A combination of:

- medication
- talking therapy
- activities such as art or music

Further Info\* Schizophrenia – Easy guide by Norfolk Living Well

#### Dementia

#### What is it?

Dementia is not a mental illness but it can lead to behaviour change and mental health problems such as depression. There are a number of different types of dementia the most common are Alzheimer's disease and vascular dementia.

Dementia involves loss of memory, problems with language and communication and behavioural and mood changes. People with a learning disability are at greater risk of developing dementia than the general population.

#### Why does it happen?

- linked to a number of changes happening throughout the brain
- genetics (people with Down syndrome are particularly prone to Alzheimer's disease)

#### Treatment

There is currently no cure for dementia or Alzheimer's, though *medication is available for Alzheimer's that can temporarily reduce some symptoms or slow down the progression of the condition in some people.* 

#### Further Info\*

- Learning disabilities and dementia Alzheimer's Society
- Dementia Foundation for people with learning disabilities
- Dementia. Easy read guide by the Royal College of Psychiatrists
- <u>Ann has Dementia</u>. Books Beyond Words

\*The CBF cannot guarantee accuracy of external websites; links are provided for further reading. Professional advice should be sought if there are concerns about the mental health of an individual. Giving psychotropic medication to people with severe learning disabilities should only be done under the supervision of a suitably qualified and experienced professional.

#### What can be done to improve mental health?

#### **Recognise the problem**

The first step to mental health care is for the problem to be *recognised*. This can be difficult in people with learning disabilities as they may find it hard to recognise that they have poor mental health, or to find treatment on their own. *This means that often someone else has to recognise that the person is showing signs of mental health problems.* 

If the symptoms are very severe, the mental health problem is more likely to be identified. In many cases however, the signs may be so mixed up with other behaviours related to the person's learning disabilities or challenging behaviour that the mental health problem remains unrecognised. Studies have confirmed that this is the case, many people with depression and anxiety are not diagnosed or treated for their condition.

Families, support workers and direct care staff working with people with learning disabilities have a crucial role in recognising potential symptoms. They are in the best position to identify significant behaviour change and to make appropriate referrals if needed.



There are some special assessment tools to help people recognise mental health problems as early as possible. A widely used tool is the *PAS-ADD Checklist (Revised)*: a mental health questionnaire, written in everyday language, designed for use specifically by care staff of people with learning disabilities. It helps record a range of problems which may be part of a mental health illness.

#### Get the best possible assessment

For people with a mental health problem who do not have a learning disability, the first assessment is usually an interview with a mental health professional. Lack of, or limited verbal communication makes it hard for people with severe learning disabilities to answer questions about their mental health so reports from other people such as family members and care staff are very important in the process of diagnosis.



The clinical picture can be very complicated, especially when there is a mental health problem and challenging behaviour. Many assessments may be needed over time, including direct observations and evaluation of biological, psychological, social, family and environmental factors.

To start the process a carer should initially contact the person's key worker, social worker or GP, and ask how to get an initial assessment of potential mental health problems within the local Health Service. There are different services available in different parts of the country, Some areas of the UK offer instant access to psychological therapies as part of the Improving Access to Psychological Therapies

(IAPT) programme and work has been done to make these services accessible for people with learning disabilities.

#### Treatment

It is often not known the exact reason why a person develops a mental health problem, and it is also not possible to know how they might respond to any particular treatment. This can make treatment complicated and several treatment options may be recommended. As the person's progress is monitored, the treatment plan may be changed in the light of new evidence. For people with learning disabilities treatments should be watched closely and adapted to suit their needs.

#### **Examples of treatments:**

 Medication: There are a number of sets of guidance about the use of medications specifically for people with learning disabilities. Recommendations include: multi-disciplinary assessment, use of the minimum about of medication to be effective, regular attempts to reduce dosage, monitoring of side effects and integration with other treatments. Please see the CBF's information sheet 'Use of Medication' and "Medication pathway" for more information.

Although medications can be highly effective, it is important to remember that most mental health problems probably have multiple causes. Medication cannot change the environment, or cure problems arising from early life trauma. In most cases additional forms of intervention are necessary as well.

- **Psychological therapies:** People with a learning disability who are able to link their behaviour with how they think and feel can access Cognitive Behaviour Therapy (CBT). CBT works by helping people manage problems by changing the way they think and behave. Anger management has been found to work well with individuals with mild to moderate learning disabilities. Using relaxation training to treat anxiety disorders has also had good results, including in people who have severe learning disabilities.
- Psychotherapy: The term psychotherapy can mean a variety of therapies including psychodynamic psychotherapy and counselling. People with a learning disability are highly likely to have experienced early-life emotional trauma, and it has been recognised that individuals with learning disabilities who have relatively well-developed verbal communication skills can benefit from psychodynamic psychotherapy, as long as the language and content is adapted to suit their needs.
- *Educational interventions*: Providing information and education about mental health problems is important, both for the individual and for his/her support network.

#### **Further information**

Here's how to support the mental health of people with learning disabilities by Learning Disability Today

Mental health by Mencap

Feeling down. Improving the mental health of people with learning disabilities by the Foundation for People with Learning Disabilities



Learning disability and mental health by Skills for Care

Medication Pathway by the Challenging Behaviour Foundation

Understanding Challenging Behaviour by the Challenging Behaviour Foundation

Use of Medication by the Challenging Behaviour Foundation

Health and Challenging Behaviour by the Challenging Behaviour Foundation

#### Reference

Moss, S.C (2002) The PAS-ADD Checklist (Revised). Brighton: Pavilion Press

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#### **The Challenging Behaviour Foundation**

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: www.challengingbehaviour.org.uk

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